A case of social pressure versus asthma pressure?
Initial examination of a model portraying exertion as a context for conflict amongst adolescents with asthma

by

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DEDICATIONS

I would like to dedicate this volume of the portfolio to my family, who have all been through so much in these last three years.

To Rijk, my husband and my best friend, who has supported me and kept me grounded and positive throughout the challenges of training – and endured my episodes of non-stop talking about clinical psychology with such patience and good humour. You are my world.

To my parents, Marion and Alan, for giving me the freedom to follow my own path and for being there; to my Granny and Grandad, Beryl and Ted, for your encouragement and pride in me; to my sister Philippa, blossoming now; and to my father-in-law Roy, for having so much courage and for all the “Keep going”s.

In memory of

Peggy
My mum-in-law, who is missed so very much

And

Grandma and Grandpa
Devoted to each other in life, and now reunited.

My love and thanks to you all.
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INTRODUCTION TO THE PORTFOLIO – VOLUME I

This portfolio contains work completed toward a degree of Doctor of Psychology in Clinical Psychology. Volume I comprises three dossiers of work: academic, clinical and research. These dossiers are intended to reflect a range of client groups, presenting concerns, psychological approaches to understanding and treating psychological distress, and methodological approaches to psychological research.

- The academic dossier consists of essays relating to the four core placements.

- The clinical dossier contains summaries of all six placements and case reports from five (four core and one specialist). Other clinical placement documentation including the five case reports, logbooks and placement evaluation forms for all six placements, and anonymised examples of professional correspondence can be found in a confidential appendix to the clinical dossier located in Volume 2 of this portfolio.

- The research dossier includes a research log and summary of research experience gained during training, together with the Service Related Research Project and the Major Research Project. The Qualitative Research Project has been included as an informal addition to reflect better the range of methodologies covered during training.

- Evidence of teaching conducted on placement and feedback of the Service-Related Research Project to the host Trust is contained in the Appendix to Volume I.
Academic dossier
INTRODUCTION TO THE ACADEMIC DOSSIER

This dossier contains four essays representing academic experience gained during study towards the degree of Doctor of Psychology in Clinical Psychology. The essays reflect the core clinical placements: Adult Mental Health and People with Learning Disabilities (completed during the first year), Children and Young People (conducted during the second year) and Older People (completed during the third year). The essays aim to demonstrate critical understanding and examination of a range of psychological approaches to concerns presenting across the lifespan and in different client groups. These essays have been completed alongside passing informally-assessed clinical vignettes for the Adult Mental Health, People with Learning Disabilities and Children and Young People placements.
ESSAYS

- **Adult Mental Health**
  "Would there ever be a scenario in which a psychodynamic rather than a cognitive-behavioural approach might be more appropriate in the treatment of obsessive compulsive disorder?"

- **People with Learning Disabilities**
  "Critically review the current status of the assessment and treatment of dementia in adults with learning disabilities."

- **Children and Young People**
  "Is cognitive behavioural therapy appropriate or effective for children? If not, can it be made so?"

- **Older People**
  "Race and ethnicity are relatively unimportant variables in both the incidence and treatment of mental health difficulties in older people. Critically discuss this statement."
Would there ever be a scenario in which a psychodynamic rather than a cognitive-behavioural approach might be more appropriate in the treatment of obsessive-compulsive disorder?
Introduction

Obsessive Compulsive Disorder (OCD) is thought to affect up to 3.2 per cent of the population (Salkovskis & Kirk, 1997). Its definition in the fourth Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994) includes two main components. The first is obsessions — persistent, intrusive thoughts that cause distress, are recognised as products of the person's own mind, that the person attempts to suppress and which "are not simply excessive worries about real-life problems" (p.422). The second component is compulsions, which could include repetitive overt behaviours or covert mental processes performed rigidly and excessively with the aim of alleviating discomfort and preventing feared outcomes.

Cognitive Behavioural Therapy (CBT) has performed well in outcome studies and has been widely taken up as the evidence-based treatment for OCD in the NHS (Salkovskis, 1999). However, Gabbard (2001) points out that more complicated cases of psychological disorders can be omitted from controlled outcome studies as they may not meet strict selection criteria for such studies. This essay focuses on scenarios that may appear the proverbial exception to the (CBT) norm. What factors might make a psychodynamic approach to treatment appropriate, even though outcome studies suggest CBT is more promising?

Thinking about a scenario requires more thinking about the person (and the idiosyncratic processes underlying their condition) and slightly less thinking about general theories of disorder than might be usual for psychological debates that affect wider service provision. Psychodynamic arguments have often suffered in debates due to frequent reliance on case-example, which raises concern about generalisability of findings. While this concern still exists, it is less problematic in thinking about individual scenarios. What is most interesting here is how theories and research findings illuminate the processes relevant to an individual case and thereby influence formulation.

The evidence for or against a formulation (and the applicability of a general theory to a specific scenario) would ultimately come from information gathered from the client in therapy. This information would include and influence predictions about the
processes maintaining the client's symptoms, the client's experience of and response to therapy, and the client's own therapeutic goals. In this essay, these factors are assumed to determine whether an approach to treatment is appropriate.

The emphasis in this question on a scenario may initially appear to move the discussion away from debate relevant to the evidence-based NHS. Nevertheless, clinicians are essentially faced with scenarios in their day-to-day work, and this question is especially relevant to clinicians whose training spans cognitive-behavioural and psychodynamic approaches, who make choices regarding the balance of principles from each approach in therapeutic work with individual clients.

This essay will firstly outline what is meant by a “psychodynamic” or “cognitive-behavioural” approach, and explore how these perspectives have been applied to understanding and treating OCD. It will then discuss in greater depth the contribution of the two approaches to the issues of responsibility, compliance and concordance, shame and concealment, and the role of insight in change. It argues that psychodynamic concepts — particularly those from psychoanalytic self-psychology (McCarter, 1997) — may offer useful perspectives on the roles and functions of responsibility, efficacy and influence, as well as the therapeutic relationship. However, the essay concludes this case is much undermined by lack of evidence and highlights issues where further research and discussion is needed.

Overlapping territories — defining the psychodynamic and cognitive-behavioural approaches

Should an “approach” be conceptualised as a discrete, homogenous discipline to be applied “purely”, exclusively and in its entirety; or should it be viewed as a framework of principles that can each be drawn upon as viewed necessary? This essay assumes the latter definition of “approach”. There is, of course, a danger of reductionism by focusing on the component principles of an approach rather than attending to the gestalt whole that may be greater than the sum of its parts. However, both the psychodynamic and cognitive-behavioural approaches have fostered diverse theories and techniques (Brown & Pedder, 1991; Clark & Fairburn,
This is particularly true of the psychodynamic approach; Brown & Pedder (1991) have acknowledged the difficulty of summarising an approach which, in its history has spawned numerous and heterogeneous ideas. Nevertheless, they have highlighted a set of principles that have become hallmarks of the approach. These include a focus on conflict between competing, sometimes incompatible drives which may reflect dual or multiple levels of the person – some biological, primitive and possibly unconscious, and some social, moral, more sophisticated and perhaps more conscious. A growing child has to learn to cope with such conflict, which causes anxiety and "psychic pain". It is helped in this process by its caregivers (with particular focus on the mother) who act to contain and re-process the child's projected anguish. The child develops "defence mechanisms" to cope with conflict, and its experiences of conflict and coping in one stage of its life will be carried through to later stages, into adulthood. A person's behaviour, thought and emotion will therefore reflect an attempt to cope with conflicting needs or drives. Problems or pathology in these realms will emerge when the defence mechanisms employed to cope with conflict are inappropriate or maladaptive. Symptoms may take on a symbolic flavour hinting at the underlying unconscious processes. Psychodynamic psychotherapy aims to facilitate clients' insight into their own conflicts and defences – a process that is enriched and furthered by the patterns of transference and counter-transference in the client-therapist relationship. These ideas are viewed by this essay as the principles of the psychodynamic approach.

The cognitive-behavioural approach focuses on the links between thoughts or beliefs, emotions and behaviours. Theorists including Judith Beck (1995) have tended to attribute particular causal influence to beliefs in the production of emotions and behaviours, although there is a development towards viewing these factors as more inter-causal (Teasdale & Barnard, 1993). Cognitive-behavioural therapy (CBT) therefore aims to identify and modify dysfunctional thoughts and beliefs.
Cognitive-behavioural and psychodynamic approaches need not necessarily be regarded as mutually exclusive. Through the increased emphasis on core-beliefs (Beck, 1995), CBT has continued to incorporate attention to the impacts of childhood experience which might once have been regarded as more psychodynamic territory. The role of the therapeutic relationship has also received attention in CBT — though the emphasis may be more on collaboration (Beck, 1995) than on containment (Brown & Pedder, 1991). This nevertheless highlights the potential for psychodynamic principles to be incorporated into CBT if they prove valuable in understanding a condition.

The cognitive-behavioural approach to OCD

Experimental and clinical research findings have formed the basis of the cognitive-behavioural approach to understanding and treating OCD proposed by Salkovskis (1999). Rachman, de Silva & Roper (1976, cited by Salkovskis, 1999) found that “obsessional checkers” placed in situations designed to elicit checking urges experienced an immediate reduction in anxiety if allowed to check. However, those prevented from checking experienced a more gradual decline in anxiety over one hour — a process termed “spontaneous decay”. This phenomenon underlined the behavioural approach to treating OCD through exposure and response-prevention (ERP) aimed at preventing avoidance (i.e. compulsive) behaviours from blocking the natural, spontaneous decay and extinction of anxiety (Salkovskis & Kirk, 1997).

This approach was said to be successful in about 75 per cent of OCD cases, but was difficult to apply to obsessive rumination where there is no overt avoidance behaviour (Salkovskis & Kirk, 1997). This clinical observation has been coupled with findings that intrusive thoughts occur in at least 90 per cent of the population and are similar in content to obsessional intrusions (Rachman & de Silva, 1978, cited by Salkovskis, 1999). Salkovskis (1999) has proposed that a key process that maintains OCD symptoms is the misinterpretation of normal, intrusive thoughts as signs that the person may be responsible for causing or preventing harm — particularly harm to others. This catastrophic appraisal causes discomfort which the person attempts to alleviate through ultimately counter-productive, neutralising behaviours including overt rituals (e.g. washing or checking) or covert strategies, particularly thought
suppression – which have been demonstrated to have paradoxical effects of increasing the frequency and salience of intrusions (Salkovskis & Kirk, 1997).

CBT for OCD therefore aims to provide, through “guided discovery”, alternative, less catastrophic interpretations for intrusive thoughts, involving behavioural experiments which utilise ERP procedures but are aimed at providing evidence for these new interpretations (Salkovskis, 1999). Outcome studies have suggested this CBT approach is at least as effective as behavioural therapy in treating OCD and that, unlike behavioural therapy, is also a useful treatment for obsessional rumination (Van Oppen, de Haan, Van Balkom, Spinhoven, Hoogduin et al., 1995; and Freeston, Ladouceur, Gagnon, Thibodeau, Rhéaume, et al., 1997, both cited by Salkovskis, 1999).

Further attention is now being paid to the deeper cognitions that may underlie such catastrophic misinterpretations – particularly beliefs about responsibility. This has followed findings including Roper & Rachman’s observations (1975, cited by Salkovskis & Kirk, 1997) that normally anxiety-provoking situations for people who obsessively check produced little discomfort in the presence of a (responsible) therapist. Identifying and challenging dysfunctional responsibility beliefs is therefore being explored as a means of further improving CBT treatments. This issue – and its implications for the psychodynamic approach – will be examined later in this essay.

**Psychodynamic perspectives on OCD**

Bristol (2001) is not alone in highlighting the dearth of recent psychodynamic theory and research into OCD. This seriously undermines the case for providing psychodynamic treatment for OCD in NHS settings, but the ideas are still worth examining for their potential value in understanding specific scenarios – potential that could be further investigated by future research.

Freud’s psychosexual theory (1905, cited by Jakes, 1996) viewed OCD as an outcome of regression to the anal-sadistic stage of development in response to insurmountable conflict in the Oedipal stage. Reaction formations including submissiveness, gentleness, cleanliness and order are said to occur as defence
mechanisms against their counterpart impulses towards aggression, cruelty, dirtiness
and disorder – accounting for the preoccupation of many OCD clients with hygiene,
prediction that the denial of persecutory and sadistic feelings could "split off"
emotional meanings from their associated thoughts, leading to the stereotypical and
repetitive quality of rituals and ruminations. This is an interesting contrast to
cognitive-behavioural theory – what CBT might regard as the intrusive thought
(Salkovskis, 1999), is viewed by Cooper (2000) as akin to a conscious neutralisation
of a subconscious, potentially-intrusive thought.

Cooper (2000) describes one of her own clinical cases, of Jim, who had experienced
a "breakdown" manifesting in the repetition of two words associated with a recently
ended relationship. Cooper views the point of acknowledgement of loss and
abandonment fears as a "turning point" in this client's fears – but her assumption that
Jim's condition is OCD – or "obsessional thought disorder" is questionable. Indeed,
Cooper states that many of her clients with obsessional thinking were previously
diagnosed with "Personality Disorder", so Jim's dwelling upon two words may
represent a different phenomenon from the obsessive rumination described by
Salkovskis (1999). The applicability of this case study to understanding OCD is
therefore unclear.

Jakes (1996) reminds readers of the lack of evidence supporting Freud's psychosexual
theory of development but discusses Malan's (1979, cited by Jakes, 1996) account and
rationale. This theory also views OCD symptoms as defences against painful conflict
(not necessarily aggressive) and again draws symbolic parallels between the nature of
OCD preoccupations with hygiene and orderliness and the "freedom versus restraint"
issues (Jakes, 1996, p.98) associated with toilet training. Malan (1979, ibid) links the
elimination of body products with the expression of emotion – particularly anger –
both of which come from inside the body. Disgust or anxiety about body products
such as faeces and urine could therefore reflect concern about the outburst of
emotion which could also "make a mess" of a situation – for instance by damaging a
precious attachment relationship. Jakes (1996) however, points out the ease with
which any two concepts can be symbolically linked, undermining the value of the
“intuitive appeal” of such interpretations. Furthermore, he highlights how disgust about body products is not limited to those with OCD and is likely to have a strong evolutionary value. Almost every body product – including blood, saliva, phlegm and vomit – is aversive (with the apparent exception of tears), whereas not all emotions are aversive – undermining the causal link between feared emotional expression and fears about eliminated body products in OCD (Jakes, 1996). Indeed, tears might be particularly linked with emotional outburst so their lack of aversiveness sharply contradicts Malan’s (1979, ibid) explanation.

Nevertheless, the concept of conflict between different drives or needs – and importantly, its resolution – is echoed in the principles of mutual adaptation and reciprocity drawn from “psychoanalytic self-psychology” by McCarter (1997). McCarter cites the observations of parent-child interactions described by Stechler and Kaplan (1980, cited by McCarter 1997) where the infant’s seeking of compromise between one drive and another helps foster self-regulation and mastery over psychic conflict. The example given is of a child, “Nancy”, observed throwing objects (presumably meeting a need to develop a sense of agency over the object) and requested to stop by her mother (provoking a conflict with the need to maintain the attachment-relationship by responding to the request). Nancy responded by maintaining eye contact with her mother while gently letting the object drop from her fingers – a compromise between the two drives, achieved through mutual adaptation (the mother also had to compromise). This process is argued to develop the sense of mastery both over the outside world and the inner drives and the “possibility of being true to herself and maintaining connection with others at the same time” (McCarter, 1997, p.79). A child exposed to rigid rules and criticism might therefore learn that to maintain its attachments, it must direct all its effort towards responding to others’ needs and suppressing its own drives. The symptoms of OCD might therefore reflect a desperate attempt to control these drives and maintain the rigid order demanded by attachment figures. This theory will be returned to in the discussion that follows about the role of responsibility in OCD.
Responsibility, efficacy and influence in OCD – a crossroads for psychodynamic and CBT approaches?

Cognitive-behavioural theories of OCD have suggested an "influence=responsibility" bias (Salkovskis, Shaffran, Rachman & Freeston, 1999) may be contributory to OCD. Interestingly, an attempt to define responsibility by Salkovskis, Rachman, Ladouceur, Freeston, Taylor, et al. (1996, cited by Salkovskis, 1999) reflects the difficulty of distinguishing influence and responsibility. Responsibility in the context of OCD is defined as:

"The belief that one has power which is pivotal to bring about or prevent subjectively crucial negative outcomes. These outcomes are perceived as essential to prevent. They may be actual, that is having consequences in the real world, and/or at a moral level." (Salkovskis et al., 1996, ibid, p332)

Does “power” mean “influence”? And would having “pivotal influence” be the same as “being responsible”? It is possible to envisage situations where it might not. The issue of drivers who fall asleep at the wheel causing fatal road accidents is an example. They have certainly had pivotal influence in bringing about tragically negative consequences. Yet whether they are perceived responsible may depend on a number of factors. Take the example of a junior doctor, who has just had to complete a 72-hour shift and has no other means of transport home. Is s/he, or the system s/he serves responsible? In contrast, a driver who has spent 72-hours playing computer games might be judged very differently. What mediates the relationship between influence and responsibility? One possibility is that “efficacy” – or a person’s ability to actually utilise their influence effectively – has a role to play. In the doctor’s case, their lack of efficacy might be attributed to external causes, where internal causes might be said to underlie the lacking efficacy of the person playing computer games. Of course, this issue will reflect personal, religious and cultural perspectives on the philosophical issue of free-will and determinism (for example, Tarnas, 1996) – and indeed the very fundamental nature of this issue may add to the weight of meaning the person with exaggerated responsibility beliefs carries. However, if these processes are at work, it would mean the responsibility has something to do with causing (rather than pivotally influencing) a situation. The therapeutic technique of
using pie charts to identify alternative sources of influence in an outcome (Salkovskis, 1999) might therefore have something to do with highlighting that a person might not be the causal agent in a situation they have either intentionally or unwittingly influenced.

However, the Salkovskis et al. (1996, ibid) definition of responsibility seems to be supported by an experiment by Ladouceur, Rhéaume & Aublet (1997) which examined the behaviour and subjective experiences of non-clinical participants. Participants were randomly distributed into conditions of apparent heightened influence, negative consequences, a combination of the two, or a control condition. Ladouceur et al. (1997) found that participants' subjective experiences of responsibility were greater in the Influence condition than the Negative Consequences condition, but that the Combined condition produced greatest responsibility perceptions of all. They concluded that both constructs contributed to responsibility perceptions but that influence had a greater role than potential negative consequences. This conclusion contradicts the model outlined above where the attribution of causality would be predicted to determine responsibility perceptions, not the outcome of that causal role (although that might determine affective response). But there may be some problems with Ladouceur et al.'s (1997) conclusions. The experimenters may, in their attempt to increase perceived potential negative consequences, have inadvertently increased perceptions of influence in the Combined condition. Participants in this condition were told their responses would “directly influence the making of drugs and thus prevent serious consequence from taking place” (Ladouceur et al., 1997, p.425): this direct influence might have been interpreted as causal influence. Furthermore, Influence condition participants were told they were one of only three participants (to heighten personal influence). No such statement was given in the Combined condition: the role of others in the decision-making process may therefore have remained unconsidered by these participants. So it is possible the Combined condition reflects greater influence perceptions than the Influence condition – bringing the role of perceived negative consequences into question. Ladouceur et al. (1997) did attempt to verify their experimental manipulations, but unfortunately, they do not report comparisons
between the Influence and Combined conditions. The role of negative consequences in perceived responsibility therefore remains an unanswered research issue.

If efficacy does have a mediating role between influence perceptions and responsibility attributions, could this tie in with the emphasis in psychoanalytic self-psychology (McCarter, 1997) on the development of "efficacy and mastery"? Perhaps there might be a cognitive bias in OCD towards internal attribution of lacking efficacy, and, if so, perhaps these cognitive ideas might be unified with those described by McCarter (1997) to explain the origins of these biases.

Interestingly, Salkovskis et al. (1999) propose possible "pathways to inflated responsibility beliefs" (p.1055), based mainly on clinical observation and cognitive theory, that may overlap with some of the processes McCarter (1997) cites as potential sources of psychopathology in the self. Salkovskis et al. (1999) argue that "Rigid and extreme codes of conduct and duty" (p.1061) may lead to the development of inflexible standards of conduct and thinking. McCarter (1997) would argue they undermine the process of mutual adaptation that fosters the child's development of mastery over its internal and external worlds. Salkovskis et al. (1999) also suggest "An early developed and broad sense of responsibility that is deliberately or implicitly encouraged or promoted during childhood" (p.1060) could occur if a child is "scapegoated" or required to assume responsibilities at an early age. In McCarter's (1997) terms, the normal balance of compromise between a child's internal and social drives would be altered, and once again its sense of mastery over its internal and external worlds would be undermined. Bristol (2001) cites arguments that a mother's inability to respond to the developing needs of her child would force the child to accommodate its mother's needs and begin a pattern of "pathological attachment" (p.142) — the attachment the child so needs becomes contingent on taking responsibility for both the mother's and its own needs. Could these processes also underpin a bias in attributing lacking efficacy internally? For instance, if the child fails to meet the needs of its attachment figures for whom it has become "responsible", could this lack of efficacy be assumed, by the child, to be its own fault in the absence of contextual information about the abnormality of the situation (i.e. that inability to exert influence efficaciously may have more to do with being a child
than being a failed child?) The value of such ideas, that integrate both cognitive and psychodynamic concepts, is worthy of research, not least since Salkovskis et al. (1999) predict these two sources of inflated responsibility would have a “below average” response to CBT.

Could the role of inflated responsibility beliefs contra-indicate psychodynamic treatment of OCD? Could the possibility of transferring responsibility to the therapist (Roper & Rachman, 1975, ibid) make the containing psychodynamic therapeutic relationship (Brown & Pedder, 1991) less helpful than the collaborative therapeutic alliance of CBT (Beck, 1995)? Cooper’s (2000) case suggests there are dangers for therapist and client. Cooper felt frightened by, and responsible for, her client’s “projected feelings” and “threats of suicide”, felt “drawn into reassuring him in a way which seemed most unanalytic” and “unable to answer the phone because he would hold me captive by his threats and demands” (all quotes, Cooper, 2000, p.420). Nevertheless, the doubts raised above about the validity of this as a case of “obsessional thinking” also relate to the implications for therapeutic relationships. Not all OCD cases would necessarily demonstrate such a response, but this issue needs to be borne in mind, though, conversely, McCarter (1997) suggests the CBT approach may be too “directive” and therefore prevent the client from having desired influence in the therapeutic process.

Salkovskis & Kirk (1997) acknowledge the need to spend time building rapport early on, in order to facilitate engagement with therapy. This raises the issue of compliance and concordance, which will be considered next.

**Compliance, concordance and function**

Salkovskis (1999) acknowledges that, at the outset of CBT, the client’s and therapist’s goals are likely to differ – the client will probably view their compulsions as solutions and seek help to be rid of their unwanted thoughts. The therapist will view their appraisals and compulsions as the problem. Furthermore, ERP tasks are likely to seem very daunting and clients may consequently refuse them (McCarter, 1997).
In the field of physical medicine, "compliance" (or lack of it) has long been viewed as a problem that interferes with treatment (Mullen, 1997). However, Mullen (1997) proposes the term "compliance" should be replaced with "concordance" and incorporate recognition of the real barriers to following treatment regimens that clients face. McCarter (1997) describes a case where a client refused ERP strategies, and believes that pushing this issue would have worked against the process of "mutual adaptation", a principle which was utilised in building the therapeutic alliance so the ERP strategies were eventually negotiated. Here, the barrier to concordance appeared to be fear, but Gabbard (2001) suggests OCD symptoms are also likely to have unconscious meanings and "secondary gain" which "may lead the patient to be highly invested in maintaining their symptoms" (p.208). Gabbard (2001) proposes that symptoms, although not necessarily originated in psychic conflicts, may act as "vehicles" for their expression and thereby become resistant to treatment. He focuses on conflicts involving aggressive impulses, but the idea might also be applied to the aforementioned issues surrounding responsibility. The "core beliefs" or "assumptions" (Beck, 1995) a person holds about responsibility, could be functional — especially, for example, if attachments have previously been contingent on the child taking responsibility (Bristol, 2001). Inflated responsibility beliefs might even have a function in increasing a person's sense of influence or control over their internal or external worlds. This process might help explain some of the patterns seen in the cases of OCD following trauma (often with comorbid symptoms of Post-Traumatic Stress Disorder) described by de Silva & Marks (1999). For instance, "Mr K"'s obsessional checking following a disabling physical attack and "Mrs Y"'s compulsive washing and tidying rituals after being tied up, threatened and raped, could both be viewed as desperate attempts to control one's external world after incidents of profound loss of influence over it. In McCarter's terms (1997), they are attempts to regain a sense of mastery. Gabbard (2001) suggests that psychodynamic work enabling clients to understand the functions of their own symptoms may help to alleviate resistance to (or lack of concordance with) treatment.

Shame, concealment and the dilemma of casting a "shadow"

Could there be risks in highlighting potential (possibly unconscious) functions of symptoms? One concern is that this idea might feed the worry of some clients that
their intrusive thoughts somehow represent a shadowy aspect of themselves of which they are terribly afraid. Compulsive symptoms might even reflect attempts to stave off a “feared-for self” and try to become one’s “hoped-for self” (Markus & Ruvolo, 1989, cited by Pervin, 1996).

Newth & Rachman (2001) have drawn attention to the concealment of obsessions which they argue is motivated by clients’ catastrophic appraisals of intrusive thoughts (for example, thoughts of harming children might be misinterpreted by a client as signs that s/he is a real threat to children and therefore an outcast of society). Newth & Rachman (2001) go on to argue that disclosure of such obsessions can be therapeutic by exposing clients to alternative, less threatening interpretations. This suggests any attempts to identify functions and meanings of symptoms to increase concordance (Gabbard, 2001) should carefully avoid the implication that intrusive thoughts reveal dangerous aspects to a client’s character. The client’s beliefs around this would ideally be elicited during psychological assessment, but Newth & Rachman’s arguments suggest concealment could prevent this.

Insight is not enough – so can psychodynamic treatment make any difference?

Malan (1979, ibid), suggests that making a client aware of the unconscious conflicts underlying their symptoms should result in the disappearance of those symptoms. However, there seems to be little evidence to support this idea, and Jakes (1996) points out other psychodynamic thinkers would place far less emphasis on insight.

Salkovskis (1999) observes that understanding the role of beliefs in OCD may be helpful for clients, but is not sufficient to bring about the desired change – a principle that seems likely to apply to any unconscious contributors as well. Cases described by McCarter (1997) and Gabbard (2001) also suggest insight was insufficient to provoke change. McCarter (1997) utilised psychodynamic principles to develop the therapeutic relationship and explore underlying issues – but ultimately relied on ERP procedures to enable change for his client. Gabbard (2001) used a psychodynamic approach with someone who disliked CBT (“Mr B”). Mr B’s symptoms persisted,
although Gabbard believes his relationships have improved as a result of the insights gained through therapy.

Gabbard's argument (2001), although highly subjective, does raise the question of whether client-work aimed, in line with the "Recovery Model", at helping a person achieve valued social roles and relationships despite continuing symptoms (Perkins & Repper, 1999) is a worthwhile focus of therapy. If this is accepted, the value of psychodynamic therapy in promoting better interpersonal relationships for clients is also worth examining. Unfortunately, there is not room to discuss this here.

Conclusions
This essay has discussed some aspects of the cognitive-behavioural and psychodynamic approaches to understanding and treating OCD, with particular reference to the issues of responsibility, concordance, concealment and insight. The case for psychodynamic treatment of OCD is undermined by lack of research evidence, and CBT must, at present, be regarded as the more evidence-based, appropriate treatment in the NHS.

Nevertheless, psychodynamic principles, particularly those from psychoanalytic self-psychology highlighted by McCarter (1997), may help to explain the origins of inflated responsibility beliefs that are proposed to be important in OCD by cognitive-behavioural theorists (e.g. Salkovskis, 1999). The explanatory value and therapeutic implications of the psychoanalytic self-psychology model is worthy of further exploration since these might usefully be integrated with current CBT methods, and possibly further prevent relapse if they yield more successful strategies for helping clients deal with deeper-level cognitions. McCarter's (1997) case study also suggests the principles might be applied beneficially to the development of the therapeutic relationship in scenarios where clients may experience a loss of perceived influence during CBT or fear carrying out ERP or behavioural experiment procedures.

The issue of whether identifying functions of symptoms (Gabbard, 2001) or beliefs would enhance concordance (Mullen, 1997) or feed catastrophic interpretations of normal intrusive thoughts and further motivate concealment (Newth & Rachman,
1999) needs considerable thought and research to elucidate the scenarios where a psychodynamic approach is appropriate or contra-indicated.

Psychodynamic therapy may be appropriate where other approaches including CBT have already proved fruitless or aversive. Although current evidence suggests psychodynamic therapy is unlikely to “cure” symptoms, it may prove helpful in enabling a client achieve and improve wanted relationships despite their symptoms – thereby enhancing quality of life. How helpful psychodynamic therapy would be in achieving this again requires further research. Also in need of considerable thought and discussion is the question of whether, and in what contexts, this is a valid aim of service provision in the NHS.
References


Critically review the current status of the assessment and treatment of dementia in adults with learning disabilities

October 2002
Year 1
Introduction

Increases in life-expectancy have meant more people living in developed countries, including those with learning disabilities, are surviving into older-age (Janicki & Dalton, 1999). The “ageing” of the population is likely to increase the prevalence of older-age-associated health problems – including dementia (Janicki & Dalton, 1999). This essay considers concerns about the readiness of services to assess and treat dementia in people with learning disabilities as prevalence increases. “Learning disability” (LD) is here understood according to the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV) (American Psychiatric Association (APA), 1994) criteria of impaired intellectual functioning reflected in an IQ score of ≤70, deficits in adaptive or social functioning, and onset in childhood (before 18 years of age).

The essay will first discuss the basis for current prevalence estimates of dementia in people with LDs – including evidence of increased propensity for Dementia of the Alzheimer’s Type (DAT) in people with Down’s Syndrome. Such investigations have been undermined by lack of agreement about the definition of and diagnostic-criteria for dementia (Janicki & Dalton, 1999). Differing approaches to definition will therefore be discussed with particular reference to the need for differential diagnosis of dementias with different assumed aetiologies (Burt & Aylward, 1999). Possible links between current causal models of dementia and trends in defining dementia will be examined, as will the reciprocal barriers created by lack of clear definition and lack of understanding of dementia. This situation is argued to undermine current approaches to both assessment and treatment of dementia in adults with LDs.

This essay views the theoretical understanding of dementia as a foundation to both assessment and treatment. Assessment is assumed to include the processes leading to initial referral as well as those precipitating diagnosis. Attempts to develop standardised measurement instruments (such as the Dementia Questionnaire for Persons with Mental Retardation (DMR) (Prasher, 1997) for screening, diagnostic and research purposes are also considered. The term “treatment” is interpreted broadly as referring to intervention approaches, of which this essay will focus predominantly
upon psychosocial, rather than pharmaco-medical interventions. It is argued there is a dearth of specific guidelines for carers and care-workers (Janicki & Dalton, 1999). This perhaps reflects the current status of relevant research and theory, and necessitates dependence of care management upon a somewhat anecdotal evidence-base emerging from clinicians’ creative responses to care dilemmas and observations. The essay concludes that the current drive to standardise dementia-assessment, although crucial to unifying investigation into dementia, risks neglecting clinically important concerns and undermining evidence-based practice in this field.

**Why does dementia matter? Prevalence patterns and the Down’s Syndrome link**

Demographic patterns are important to understanding the scale of concern about dementia. In developed countries, rising life-expectancy and the demographic structure of the population – with a high proportion of people reaching their 50’s and 60’s following the post-World War II “baby-boom” – is producing an “ageing” population with “ageing” health and social-care needs (Janicki & Dalton, 1999). The 12-20 per cent of the population currently accounted for by older-adults is expected to rise to 30 per cent within the next two decades (Janicki & Dalton, 1999).

The demographic changes are perhaps even more striking for people with LDs, particularly those with Down’s Syndrome (DS). At the beginning of the 20th Century, people with DS had a life-expectancy of around ten years. By the turn of the millennium, that had increased to nearly 50 years, and people with DS now form the biggest group among those with LD (Holland, 1999). This “ageing” of the population of those with LDs might alone be expected to increase the rate of age-associated dementia. However, there are several factors thought to increase the susceptibility of people with LDs in general, and those with DS in particular, to dementia.

As mentioned, there have been large discrepancies in prevalence estimates of dementia in people with LDs for reasons discussed in more detail later. However, for those people with LDs not related to DS, the prevalence of dementia is currently thought to be slightly below that of the general population due to lower life-expectancy (Janicki & Dalton, 1999). If, as expected, life-expectancy among this group
continues to rise, it is expected the prevalence of dementia will soon equal the rate in the general population (Janicki & Dalton, 1999). However, it is possible that higher rates of psychological distress, and the use of poly-pharmaceutical treatments in people with LDs could create additional vulnerability to dementia (Janicki & Dalton, 1999).

People with DS are thought to be at further risk of developing dementia, specifically Dementia of the Alzheimer’s Type (DAT) (Holland, 1999). The majority of people with Down’s Syndrome have an additional chromosome 21, which appears to cause premature ageing – leading to the hypothesis that people with DS are more susceptible to age-associated health problems (Holland, 1999). Holland (1999) describes research suggesting that the genetic factors underlying DS also heighten risk for DAT. Post-mortems of people with DS have found that the neuropathological signs characteristic of Alzheimer’s Disease (including plaques and neurofibrillary tangles), are present in people with DS as young as 30 years-old. Excessive production of amyloid proteins has been linked to DAT and the genetic coding for amyloid precursor protein (APP) has been found on chromosome 21 (Goldgaber, Lerman, MacBride, Saffioti & Gajdusecek, 1987, cited by Holland, 1999). It is therefore hypothesised that the extra “copy” of the APP-related genetic coding held by people with DS may predispose them to developing DAT following neuronal damage brought about by excessive amyloid levels.

However, there appears to be a substantial delay between heightening amyloid deposition levels (reported in childhood by Mann & Esiri, 1989, cited by Holland, 1999), the neuropathological signs of Alzheimer’s disease (found in early adulthood), and the onset of dementia symptoms – the reported mean age of which is in the early 50s in people with DS (Holland, 1999). This fascinating finding has led to proposals that levels of amyloid or amyloid-associated neuronal damage may have to reach some “critical level” before the onset of dementia symptoms (Holland, 1999). It also leaves open the possibility that some “critical event” (Holland, 1999), which interacts with these pre-existing biological vulnerabilities, could be involved.
There are further possible risk-factors for dementia in people with DS. For example, Holland (1999) reports that thyroid disorder, which is more common in people with DS, may be a risk-factor for DAT. However, the potential for thyroid disorder to "mimic dementia" has led to this factor being viewed differently by other commentators (Thase, 1982, cited by Holland, 1999), discussed later. Nevertheless, there are clearly many concerns about the vulnerability of people with DS to dementia. Holland, Hon, Stevens & Huppert (1996, cited by Holland, 1999) carried out a population-based study of rates of dementia meeting the criteria of DSM-IV and the International Classification of Diseases, 10th Edition (ICD-10) (World Health Organisation (WHO), 1992, cited by Holland, 1999) in people with DS according to age group. Prevalence rates of 0 per cent in 30-39 year-olds, 3.4 per cent in 40-49 year-olds and 26 per cent in 50-59 year-olds were found and juxtaposed with similar prevalence rates in the general population 40 years-of-age later (Holland, 1999).

The expected increase of dementia-prevalence in the general population has profound implications for social policy as a whole (Janicki & Dalton, 1999), and the potential to touch many families and every community. The potential for a sharper increase in those with LDs, especially related to DS, is also of huge significance to general social policy but also to services providing care to people with LDs. It creates a pressing need to identify effective care-management strategies. Many of these are likely to rely on improved understanding of dementias, making research a priority. It is possible that further investigation of the patterns of signs and symptoms of DAT in people with DS could yield scientific insights relevant to understanding of DAT in the general population as a whole – increasing still further the potential value of such research. Research will rely on the identification of dementia syndromes.

**Definitions and classification of dementia**

Implicit in both the ICD-10 (WHO, 1992, cited by Burt & Aylward, 1999) and DSM-IV-TR (Text Revision) (APA, 2000, cited by BehaveNet, 2002) classificatory criteria for dementia is the assumption that dementia is a syndrome resulting from multiple potential-pathologies. ICD-10 (WHO, 1992, ibid) categorises dementia as a decline in memory, accompanied by a decline in some other cognitive ability (such as judgement or planning) which occurs independently of any "clouding of
consciousness”, also manifests a decline in emotional control, motivation or social functioning and has been present for at least six months. For a diagnosis of Alzheimer’s disease, these criteria, together with exclusionary criteria ruling out other causes such as substance-misuse or a "systemic disorder”, and a pattern of gradual onset with continuing cognitive decline must be met.

The DSM-IV-TR (APA, 2000, ibid) dementia criteria also require demonstration of memory impairment alongside at least two of a list of other cognitive disturbances including aphasia, apraxia, agnosia, and dysexecutive problems. Again, the problems must not occur exclusively during reduced consciousness (“delirium”), and the cognitive deficits must cause significant social or occupational functioning problems. For a diagnosis of DAT, a gradual onset and continued cognitive decline must also be shown, and several other pathologies excluded including central nervous system conditions, systemic conditions such as hypothyroidism or B-vitamin deficiency, and Axis I disorders such as depression and schizophrenia.

Burt & Aylward (1999) highlight that these definitions of dementia do not imply any determined prognosis. The dementia-syndrome could be progressive (as in the case or DAT), or static (for example, the result of brain injury). The dementia could be irreversible (as DAT continues to be in the absence of a “cure”) or reversible (for instance, if underlying infections or depression can be successfully treated). Thus, dementia could have any number of causes and outcomes. Nevertheless, DSM-IV-TR (APA, 2000, ibid) does classify different dementias by suspected aetiologies, most of which are related to biological factors including microbiological agents (for example the Creutzfeldt-Jakob Disease prion and Human Immuno-Deficiency Virus), pharmaceutical toxicity or injury (BehaveNet, 2002).

However, commentators have found problems with applying these criteria to people with LDs. Many of these relate to problems of assessment and will be discussed in more detail later in this essay. Burt & Aylward (1999) argue the ICD-10 criterion of a six-month duration is potentially-problematic, as higher-than-average variation in performance would be expected over a six-month time-frame in people with LDs. The more recent DSM-IV-TR (APA, 2000, ibid) criteria may avoid this difficulty.
However, difficulties establishing the necessary range of cognitive disturbance when people with LDs are likely to have pre-existing impairment in some cognitive domains also hamper the utility of the diagnostic criteria to the LD field (Burt & Aylward, 1999). Burt & Aylward (1999) instead suggest less specific criteria of lowered performance on cognitive tests accompanied by documented changes in everyday functioning which are more apparent in more demanding contexts, and are greater than those associated with normal ageing. As will be discussed, these criteria require baseline measures in order to establish cognitive and functional change (Burt & Aylward, 1999). They do, however, remain close to the concepts outlined in ICD-10 and DSM-IV-TR while avoiding the problems of requiring more specific demonstrations of cognitive decline. They also acknowledge the need to understand normal age-associated cognitive change in LDs rather than assuming all decline is dementia-related or that any decline is the result of LD alone.

Despite the importance of definitions of dementia to the development of understanding of dementia in adults with LDs, many papers are not explicit about the definitions adopted. Indeed, many appear to make implicit assumptions that are rather incongruous with the DSM-IV-TR, ICD-10 and Burt & Aylward (1999) criteria. For example, Janicki, Heller, Seltzer & Hogg (1996) in their report of practice guidelines issued by an international workgroup of the American Association on Mental Retardation and International Association for the Scientific Study of Intellectual Disability, assume that progressive, currently irreversible dementias such as DAT do qualify as “dementia”. However, in their urge to differentiate (and dismiss) other pathologies which could produce the symptomatology of dementia (such as depression and thyroid problems) they imply that these do not qualify as dementias. Holland (1999) highlights a potential role for thyroid problems in triggering DAT yet later advocates screening out such cases.

These assumptions appear out of line with the model of dementia as a syndrome with multiple potential pathologies (including depression and thyroid disorder). Implicit definitions based upon the irreversibility and progressive nature of dementia symptoms are problematic as they reflect the current status of treatment approaches, which is subject to change. It is possible that the emerging evidence of a
genetic predisposition in aetiologies of dementias like DAT is fuelling an implicit, "discretist" (Rayner, 1997), genetic-determinist model of dementia – leading to the dismissal of other possible aetiologies from understanding of dementia. This "discretism" (Rayner, 1997) – the view that a (single) impermeable agent (in this case "genetic code") is the cause of dementia – while tempting in its simplicity at a time when scientists have a mountainous question to scale – is risky. Indeed, it seems slightly ironic that this model seems to have influenced thinking in the LDs field when it is people with DS who have so clearly demonstrated a discrepancy between genetic-predisposition and onset of symptoms. This discrepancy has highlighted the need to consider “critical events” (Holland, 1999) which may interact with such predisposition.

Karen Dodd (2002) has queried whether life stresses could trigger DAT onset in people with underlying vulnerability – an idea more in line with the biopsychosocial, stress-diathesis models which have become common in understanding many physical and mental disorders (Hall, Irish, Roter, Ehrlich & Miller, 1994). Yet differential-diagnosis models such as that proposed by Holland (1999) exclude people who have experienced recent life stress from dementia diagnoses. While, as Holland (1999) argues, the effects of stress need to be considered, by overlooking a possible role of stress in triggering pathology, early symptoms of dementia could be dismissed and opportunities for early interventions (such as medical treatments (Alzheimer’s Society, 2002) could be lost.

It may be important to remain alert to the adoption of such implicit assumptions about dementia, since these may blur the adoption of definitions which guide research into and assessment of dementia, and, in the case of genetic-determinist models, convey a sense of hopelessness which could shape care-management strategies.

**Assessment of dementia in adults with learning disabilities**

Assessment is important in identification both of clients who would benefit from dementia-related intervention strategies, and of people who are manifesting dementia symptoms who could participate in research to enhance understanding of dementia.
The current status of assessment of dementia in adults with LDs is now discussed in terms of insights made so far and remaining barriers and challenges to assessment.

**Onset, recognition and referral**

Before a client with suspected dementia can be assessed, they have to be referred. For this to happen, there has to be a recognition of the possible symptoms and signs of dementia onset, and Valios (2001) has highlighted concerns that care-staff may overlook these. Lack of understanding that people with DS may be particularly vulnerable to DAT is cited as one concern. Other barriers include high staff-turnover or use of agency staff — so care-workers do not know clients long-enough or well-enough to notice signs of decline. Burt & Aylward (1999) have expressed concerns that dementia symptoms could be misattributed to pre-existing LDs or to normal ageing, and clarify that severe decline in cognitive abilities should not be expected outcomes of these two conditions.

Whitehouse, Chamberlain & Tunna (2000) also voiced these concerns and investigated the staff knowledge of dementia and attributions of dementia-like change. They found that many care-workers had levels of knowledge about ageing similar “to that of college students” (p.148) and were unaware of many symptoms of dementia including sleep-pattern and personality changes. Changes attributed to dementia were likely to be viewed by staff as stable, global and uncontrollable. Although staff reported they would make high efforts to care for clients with dementia, they felt pessimistic about the likelihood of such care yielding positive consequences (Whitehouse et al., 2000). This finding may highlight potential for problems with staff-burnout. The results prompted Whitehouse et al. (2000) to call for staff training about ageing and dementia, as well as effective care strategies. They had also developed and piloted an induction pack with relevant information for care staff.

So, although major concerns exist about staff understanding of dementia and the potential for non-recognition or misattribution of dementia symptoms, interventions to overcome these barriers are being piloted. Further study will be needed to assess the effectiveness of such strategies.
Differential diagnosis
The aforementioned problems defining dementia in a way applicable to people with LDs may underlie the acknowledged lack of standardised assessment instruments or processes (Janicki et al., 1996). Indeed, there is an apparent "Catch 22" where lack of definition undermines the development of standardised assessment techniques, which in turn hampers clear diagnosis and subsequent research into characteristics and aetiologies of dementias, thus reducing opportunity to clarify definitions. Janicki et al. (1996) advocate a three-step approach to dementia care-practice involving 1) recognising changes through enhancing staff knowledge and screening, 2) assessing and evaluating those changes (with the ultimate aim of categorising or diagnosing) and 3) installing appropriate medical or care-management strategies. They highlight the need for baseline data in order to confirm longitudinal change, especially where staff turnover may reduce the reliability to clinical observations (Janicki et al., 1996). Burt & Aylward (1999) also argue the "absolute necessity" (p.144) of baseline data and call for

"...all adults with intellectual disability (to) be evaluated using standardised procedures to assess memory, other cognitive functions, and adaptive/maladaptive behaviour at least once in early adulthood (by the age of 25 years)." (Burt & Aylward, 1999, p.152).

The importance of baseline data arises due to the pre-existing cognitive, functional and behavioural impairments likely in those with LDs. Dementia assessment tools used on the general population are unlikely to have appropriate comparative norms and so it is necessary to confirm decline through longitudinal assessment in people with LDs (Burt & Aylward, 1999). There is also likely to be a higher degree of variability between cognitive abilities than among those without LDs, necessitating assessment of a wider range of skills and abilities (Burt & Aylward, 1999). There is, therefore, a pressing need for standardised assessment instruments to evaluate and screen for decline in cognitive, functional and behavioural domains.
**Standardised assessment instruments**

An extensive review of attempts to devise standardised assessment instruments to measure dementia-associated changes in adults with LDs is not possible here. Instead, this essay will attempt to illustrate some key concerns and approaches to developing standardised measures.

Krinsky-McHale, Devenny & Silverman (2002) report an attempt to develop and pilot a standardised measurement instrument concurrent to developing theory and understanding. They developed a modified version of the Selective Reminding Test (SRT) (Buschke, 1973, cited by Krinsky-McHale et al., 2002) by simplifying the vocabulary used to avoid floor-effects. They compared the performance of 14 participants in a longitudinal study who were later diagnosed with DAT, with participants who did not receive that diagnosis. The results were analysed using hierarchical-linear-modelling and suggested that, three years prior to diagnosis, participants with DAT showed declines in recall scores significantly greater than those for normal age-associated decline. Krinsky-McHale et al. (2002) proposed a criterion whereby scores ≥20 per cent below an individual’s highest previous score were regarded as substantial declines in memory, likely to be symptomatic of dementia. The sensitivity (the probability of identifying a substantial decline where DAT was diagnosed) of this criterion was found to be 78.6 per cent at the time of diagnosis and 92.9 per cent a year later. This led to the suggestion that the SRT criterion was detecting cases of DAT before clinical diagnosis could establish this. Specificity (the probability of concluding DAT is not present when it is indeed diagnosed as absent) of 80.3 per cent was reported (Krinsky-McHale et al., 2002).

The study also yielded theoretically-relevant findings. Matched-pairs comparisons revealed that participants with DAT demonstrated significantly greater longitudinal decline in both long-term storage and retrieval of new verbal information, suggesting declines in verbal explicit memory are symptomatic of early DAT (Krinsky-McHale et al., 2002). This approach seems an efficient way of piloting modifications to established standardised measurement instruments and investigating symptomatology. The modified version of the SRT also appears promising in its specificity and sensitivity – and may even excel clinical diagnosis.
However, the apparently arbitrary nature of modifying assessment instruments—particularly by altering criterion-references—to yield the best balance of sensitivity and specificity within these instruments, is perhaps illustrated by Prasher (1997). This independent assessment of the validity of the DMR found that original criteria yielded unacceptably low specificity, with a “false-positive” rate of 47 per cent. Prasher (1997) investigated the effects of altering the criteria and subsequently achieved sensitivity and specificity rates of 82 per cent. This highlights how discrepant the results of assessment instruments can be, and how far there is to go in developing appropriately sensitive and specific reference-criteria, as well as in establishing reliability and validity of such instruments. Burt & Aylward (2000) report the development of a test battery by the Working Group for the Establishment of Criteria for the Diagnosis of Dementia in Individuals with Intellectual Disability, which has drawn upon the experience of clinicians in the field in identifying the most clinically-useful, reliable and well-validated instruments currently available. This test-battery is aimed at assessing a wide range of cognitive and functional domains through informant-report and direct assessment. Burt & Aylward (2000) acknowledge the challenge posed by the need to evaluate the test-battery. However, in the meantime, it might be viewed as a useful stop-gap to unify clinical and research-based assessment while refinements and new developments are made. Hopefully, cycles of further research, enhanced understanding of dementia in adults with LD, and refinements to assessment instruments will produce continuing advances.

Prasher & Filer (1995) suggest that the behavioural disturbances associated with dementia have been neglected in research involving people with LDs in favour of cognitive and adaptive functioning disturbances. They advocate giving further attention to behavioural disturbance, arguing that this would promote understanding of dementia and the strains upon carers. They carried out research examining the frequency and severity of problematic behaviours in people with LD both with and without DAT. Significantly higher frequencies of low mood, communication difficulties, difficulty understanding commands, walking and gait problems, self-dressing difficulties, orientation difficulties at home, sleep disturbance, wandering and
urinary incontinence were reported among those with DAT. Such comparative research helps elucidate the presentation of DAT in people with LDs and could prove highly useful in developing behaviour-based assessment tools.

**Treatment of dementia in adults with learning disabilities**

As Burt & Aylward (1999) point out, differential diagnosis according to likely aetiology is important, not least to identify treatable and reversible causes of dementia including depression and thyroid disorder. Many forms of dementia, including DAT, remain irreversible, however. Despite advances in pharmaceutical treatments such as the use of donepezil hydrochloride (Aricept) in the early stages of DAT (Mental Health Foundation, 2002) and, very recently, memantine (Ebixa) in moderate-late stage DAT (Alzheimer’s Society, 2002), these do not provide “cures” for DAT, although they have been found to slow the progression of decline. Arshad, Sridharan & Brown (2001) have also highlighted concerns that people with LD may have reduced access to such treatments because guidelines issued by the National Institute for Clinical Excellence (NICE) (2001) suggest eligibility for such prescriptions should be established using the Mini-Mental State Examination – a measure Arshad et al. (2001) report cannot be used reliably with people with LD. Further NICE guidance on pharmaceutical treatments for DAT is not anticipated until 2003 (Alzheimer’s Society, 2002). Effective care management strategies continue to be of major importance.

**Care Management Practice**

Janicki et al. (1996) offer three general principles of care management: helping the client maintain function, offering stage-appropriate care, and multi-disciplinary care-planning. They suggest appropriate foci for early-stage care-management include maintaining routine and familiarity, providing access to and encouraging enjoyment of normal activities and attempting to foster a positive sense of wellbeing and involvement – which should also help to preserve muscle-tone and strength. Mid-stage practices are likely to require increased focus upon safety adaptations as cognitive abilities (including judgement) decline but the person remains ambulant. Respite for carers is also likely to become important. By the late stage of dementia, there is likely to be “total loss of body functions” (p.377) and loss of short- and long-
term memory leading to the inability to recognise others. Primary nursing care following the loss of self-care and the need for preventative practice to reduce infection, dehydration, choking and pressure-sore risks when the person becomes bedridden are necessary (Janicki et al., 1996).

While these guidelines offer some help to carers and care-workers about the likely progression of symptoms and care needs, some of the suggestions, for instance those concerning the maintenance of functions, may seem rather general and vague. Janicki & Dalton (1999) acknowledge the lack of more specific suggestions and admit that

"... the prospects for the future are dim unless wide-ranging discussions and exchanges of ideas are conducted with the aims of developing comprehensive care and management practices" (Janicki & Dalton, 1999, p.395).

While a bank of evidence-based care-management strategies is yet to be established, some examples of effective clinical strategies are beginning to emerge. For instance, Valios (2001) describes specific environmental features of specialist accommodation for adults with LD and dementia being set up in Kent, UK. These include design features such as special lighting to minimise confusing shadow-effects, and avoidance of colour breaks in carpets that can be mistaken for depth-changes. Home décor based on that popular 30 years ago (the era clients are most likely to remember) is intended to make surroundings feel familiar and safe, while circular paths lead people who wander safely through the garden and back to the house again (Valios, 2001).

Meanwhile, the Alzheimer's Society (2000) has produced an advice sheet for carers with specific suggestions to help with maintaining skills. These include providing encouragement to continue with tasks, breaking such tasks down into sections to enable the person to experience the achievement of one or two steps at least, removing distractions such as radios and using memory aids such as labels and calendars.
Public Policy Issues

The increasing prevalence of dementia in people with learning disabilities poses profound public policy and ethical considerations (Janicki & Dalton, 1999). There are bound to be resource implications with the need for environmental modifications and 24-hour care (Janicki & Dalton, 1999). Working lives in the health and social care sectors are likely to change as demand for dementia care rises (Janicki & Dalton, 1999). How these changing staff and resource needs are met is a subject of debate. Janicki & Dalton (1999) particularly highlight the choice to be made between specialised care services for adults with LD and dementia, and allowing people to “age in place” by offering support enabling them to remain in their homes for as long as possible.

There would be expected advantages in preserving a familiar environment and social network to help individuals with dementia feel safe and prevent the requirement for high levels of new learning. The “ageing in place” model also fits more readily with the principles of Valuing People (Department of Health, 2001) – particularly the emphasis upon social inclusion partly through access to more mainstream services. Moving people into highly specialist care environments could be viewed as a form of segregation. There may be a risk of institutionalisation – which Janicki & Dalton warn against (1999) – not least since many people with LD and dementia will have experienced very institutionalised care practices in the past and may recall these experiences more readily than more recently emphasised entitlements to choice.

However, there are concerns about the impact of “ageing in place” models upon co-residents – who may be deprived of adequate levels or quality of staff attention as individuals with dementia require more care and staff may experience “burnout”. Clients and staff may also be exposed to bereavements and distressing situations as they witness the decline of individuals with dementias such as DAT. While there may be an urge to “protect” people with learning disabilities from such harsh realities, it is unclear whether this would actually be helpful. As dementia prevalence rises, more and more families will be touched by dementia and it may come to be viewed as a normal, though nevertheless distressing, fact of life. To shield people with learning disabilities from this could therefore be viewed as contrary to the principles of
“normalisation”. Karen Dodd (2002) has described pilot interventions to explain dementia and ageing to people with learning disabilities to help prepare them for life with someone with dementia – an area worthy of further investigation.

This issue highlights the ethical and moral dimension to policy decisions regarding care for people with dementia – concerns which it is not possible to address here. It seems important though, to appreciate that these ethical concerns will be a facet of the experience of carers and care-workers for people with dementia. Perhaps Janicki et al. (1996) were, on some level, aware of this when they suggested that clergy and spiritual leaders may have a role to play in helping staff and clients to come to terms with the problems and challenges unfolding before them.

Conclusions
This essay has only been able to consider a fraction of evidence and theory relating to the definition, prevalence, assessment and treatment of dementia in adults with learning disabilities. Nevertheless, it has perceived an imbalance in the available literature with a greater emphasis upon the diagnostic criteria and means of assessing dementia – objectives currently hampered by the lack of explicit and shared definitions of dementia. Hopefully, cycles of further research leading to advances in understanding and defining of dementia in adults with LD, and refinements to assessment instruments, will help to erode these barriers. Meanwhile, those providing “frontline” dementia care appear to be learning – from creative clinical experience and anecdote – some specific and apparently helpful strategies. Further research to establish effectiveness may be helpful both to clinical practice and in elucidating possible mechanisms of cognitive, functional and behavioural decline and preservation. Such research, when it happens, may have much to learn from adults with LD who are experiencing dementia, and from their carers.
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CHILDREN AND YOUNG PEOPLE ESSAY

Is Cognitive Behavioural Therapy appropriate or effective for children? If not, can it be made so?

January 2003

Year 2
Introduction

Interest in finding effective and appropriate treatment for childhood psychological disorder reflects both clinicians’ concerns about the vulnerability of children to negative impacts of psychological distress, and the perceived opportunity to intervene when habits may be less ingrained, and children may be more flexible and amenable to change (Barrett, 2000). Barrett (2000) argues there is mounting evidence that childhood psychological disorder can be prolonged, and that untreated, chronic distress may be associated with psychological disorder in later life.

The possibility of adapting Cognitive Behavioural Therapy (CBT) for use with children is drawing attention in part due to its apparent effectiveness at treating adult disorder (e.g. Clark & Fairburn, 1997). There is also promising evidence that CBT may be effective in treating childhood disorders: Stallard (2002a) cites findings suggesting the efficacy of CBT in treating, amongst other conditions, generalised anxiety, depression, school refusal, sexual abuse, phobias and interpersonal problems.

This essay will not attempt a comprehensive review of such effectiveness literature. Instead, it will consider a number of issues relevant to debating the effectiveness and appropriateness of CBT for children. The question of effectiveness is perhaps a narrower one than that of appropriateness – relating to “whether CBT works” in reducing the symptomatology it is aimed to treat. Nevertheless, this essay highlights some current barriers to assessing effectiveness – including the lack of clear definition and consensus about what constitutes CBT, and methodological concerns with implications for the interpretation of randomised controlled trial evidence (Stallard, 2002a). In particular, it notes some of the theoretical and empirical criticisms facing adult CBT literature (e.g. Teasdale & Barnard, 1993) and argues that adult CBT should not be regarded as an evidence-proven panacea in the footsteps of which child CBT should follow. Indeed, several authors including Stallard (2002a) and Barrett (2000) have questioned the appropriateness of “downloading” adult interventions onto children without reference to developmental theory or child-specific models of how psychological disorders are caused and maintained.
The issue of the appropriateness – or suitability – of CBT for children is perhaps a broader one, encompassing concerns about the impacts of such treatment upon the whole child – not just the child's symptoms – and whether there may be unwanted outcomes or "side-effects". Stallard (2002a) is concerned that current CBT models may treat the child in "isolation", and thereby neglect the important roles of families, peers and educational systems. Cobham, Dadds & Spence (1998) have examined the potential benefits of providing parental interventions alongside child CBT in families where both child and parent have anxiety disorders. Their findings have also indicated the need to appreciate the age, gender and cultural background of the child being treated, and an emerging theme is the role of individual formulation in guiding treatment.

This essay concludes that, while the "downloading" of adult CBT interventions onto children as a "stop-gap" may, in some circumstances, yield promising outcomes, the establishment of appropriate (and more-likely effective) CBT interventions will require further theory and research into how child development and the onset and maintenance of psychological disorders interact.

Defining Cognitive Behavioural Therapy
Before examining the appropriateness and effectiveness of CBT for children, it is of course necessary to define and clarify what is meant by "cognitive-behavioural therapy". Yet, even in literature relating to working-age clients, this appears not to be a clear-cut issue. In the preface to Science and Practice of Cognitive Behaviour Therapy (Clark & Fairburn, 1997), Clark resorts to highlighting the emphasis of:

"Most cognitive behavioural treatments... on detailed models of the cognitive and behavioural factors involved in maintaining the disorder in question." (Clark, 1997, p.ix, bold added)

Stallard (2002b) also defines CBT through recourse to its assumptions, emphases and therapeutic remit:

"CBT is based on the underlying assumption that affect and behaviour are largely a product of cognitions and, as such, that cognitive and behavioural interventions can bring about changes in thinking, feeling and behaviour." (Stallard, 2002b, p.1)
Cognitive behavioural interventions might therefore be thought of as those which attempt to alleviate psychological distress and disorder by changing individuals’ thoughts and behavioural (coping) strategies. Stallard (2002a) suggests such “loose” definition has rendered CBT an “umbrella term” (p.301) encompassing diverse interventions and treatment strategies. A review of 64 child-focused CBT intervention studies identified eight “core” components (including task-oriented problem solving, social problem solving, self-instruction, role-play, rewards, social cognition training, social skills training and “other” CBT elements (Stallard, 2002a)), but these were used in 42 different combinations (Durlak, Fuhrman & Lampman, 1991, cited by Stallard, 2002a). In reality then, a “cognitive-behavioural treatment” could mean many different things, and such imprecision leaves the approach open to wide variations in interpretation by therapists and potential for this to confuse outcome study findings (Stallard, 2002a). Stallard (2002a) suspects that CBT interventions with children tend to draw more heavily on behavioural interventions such as graded exposure or relaxation techniques, than on cognitive ones such as positive self-talk or cognitive restructuring.

**Theoretical and empirical concerns surrounding CBT**

Such disparity between CBT treatments has been attributed to the lack of an appropriate evidence base for the principles underlying CBT — particularly CBT with children. It is important to gain an idea of the “state of the evidence base” in CBT literature before interpreting effectiveness studies. One assumption which has drawn attention is that children’s psychological distress is the manifestation of cognitive deficits and distortions (Stallard, 2002a). There is some associative evidence for this. Stallard (2002a) cites studies which have found that children with anxiety disorders tend to demonstrate cognitive distortions such as making more threat-related interpretations of ambiguous stimuli, as well as being “overly self-focused and hypercritical” (p.298) and displaying increased levels of negative self-talk and expectation. This is in line with literature on associations between threat-appraisals and anxiety in the working-age population (e.g. Mathews, 1990). Further examples of cognitive distortions in childhood psychological disorders are the increased perception of aggression in ambiguous situations by aggressive children (Dodge, 1985, cited by Stallard, 2002a) and the more negative attributions and self-appraisals...
made by children with depression (Kendall, Stark & Adam, 1990, cited by Stallard, 2002a). Likewise, some cognitive deficits have been associated with childhood psychological problems. For example, planning and problem-solving ability deficits have been linked to Attention Deficit Hyperactivity Disorder (e.g. Kendall, 1993, cited by Stallard, 2002a), and social skills deficits to social phobia (e.g. Spence, Donovan & Brechman-Toussaint, 1999, cited by Spence, Donovan & Brechman-Toussaint, 2000).

However, Stallard (2002a) points out that there is less evidence of any causal role of cognitive deficits and distortions in the onset and maintenance of childhood psychological disorder. Furthermore, the alleviation of such cognitive deficits and distortions has not been established as a mediating factor in CBT treatment outcome. For example, Kolko, Brent, Baugher, Bridge & Birmaher (2000) failed to find any mediating or moderating effects of cognitive distortion upon the outcome of cognitive behavioural treatment for adolescent depression.

In the working-age literature, the very assumption that it is cognitions which produce affect and lead to behaviours has been brought into question by experimental findings suggesting that affect can influence cognition; for instance, mood appears to influence the encoding and retrieval of memories (Teasdale & Barnard, 1993). Teasdale & Barnard (1993) have suggested that some people may develop a “ruminative” style of thinking which, in the face of negative events and cognitions, “instructs” the retrieval of memories and beliefs of similarly negative valence. This could promote intense self-repeating cycles of negative thought and affect. They propose that the development of such ruminative tendencies occurs in childhood – perhaps as a “defence” against anticipated parental criticism. Unfortunately, despite the clear relevance of such theory to childhood interventions – which could potentially be of enormous preventative value – they cite little experimental or clinical evidence involving children.

Nevertheless, these findings and theories do highlight how working-age CBT interventions should not be regarded as an evidence-proven panacea in the footprints of which childhood interventions should be moulded. Perhaps the diversity
of CBT techniques now advocated may even reflect some of the concerns raised by Teasdale & Barnard (1993). For example, rather than viewing thinking errors as central to psychological disorder as Aaron Beck had done (1976, cited by J. Beck, 1995), the cognitive therapy techniques and conceptualisations advocated by Judith Beck (1995) now incorporate more awareness of their potential compensatory (or "defensive") value in coping with certain "core beliefs". Furthermore, some techniques are "borrowed" (Teasdale & Barnard, 1993) from other psychotherapeutic approaches (for instance, the use of role-play, originally pioneered in Gestalt therapy) in order to engage "special "emotional" or experiential processes in restructuring cognitions" (J. Beck, 1995, p. 184). Judith Beck (1995) does not explicitly link these additions to cognitive therapy to any empirical evidence base, instead seeming to draw on clinical experience of what works with individual clients. The abundant range of techniques now available under the heading of CBT probably lends CBT enormous value in the eyes of clinicians faced with diverse psychological problems in their clients. However, this has led to criticism about the non-specificity of CBT and questions about what the effective components of such disparate approaches actually are (Stallard, 2002a).

**Randomised controlled trials and the search for an “active ingredient”**

Stallard (2002a) is not alone in calling, not only for rigorous research examining the effectiveness of CBT with children, but also for such research to provide an understanding of which components of the approach work (and for whom). Indeed, such concerns are highly relevant to National Health Service (NHS) clinicians following the introduction of Clinical Governance, a key concern of which is the implementation of evidence-based clinical standards as well as effective monitoring of care (Department of Health, 1998). Randomised controlled trials (RCTs) are in particular demand. They have the virtues of enabling treatments carried out in (usually) highly standardised ways to be compared with one another and against "control" conditions. The random assignment of participants to treatment conditions alleviates concerns that any emerging differences in outcome are the products of participant-related rather than treatment-related differences. RCT evidence is therefore of great interest in the debate about the effectiveness of CBT with
children. But this very enthusiasm for such data necessitates the possible limitations of the methodology to be borne in mind.

Owen (1999) has argued that the popularity of RCTs is based upon a commonly accepted but flawed metaphor likening the measurement of psychotherapeutic outcome to pharmaceutical trials, with therapists seeking out the

"... pure doses of the active ingredients that create measurable psychological change in pure illnesses." (Owen, 1999, p.203, underline replaces original italics).

He criticises the view of the client as an "inert" and passive recipient of treatment that such a drug-metaphor invokes, and the ignorance of therapist differences which he argues inevitably make the application of any psychotherapeutic program an "impure" dosage, prone to "placebo effects".

Kolko et al.'s (2000) RCT of three therapies and their effects upon adolescent depression provides an example of where attempts have been made to eliminate therapist differences and placebo effects, in order to establish the comparative efficacy as well as outcome-mediators and -moderators of therapeutic intervention.

The study attempted to compare CBT with systemic-behavioural family therapy (SFBT) using non-directive supportive therapy (NST) as a control or "placebo" condition. NST was assumed to incorporate the therapist contact, listening, empathy and exploration of options common to all psychotherapies without the assumed "active ingredients" such as cognitive-distortion modification and reduction of dysfunctional family interactions associated with CBT and SFBT respectively. Therapists were given six months' intensive training to become "protocol therapists", and their rigid adherence to prescribed techniques was assessed carefully to ensure "treatment integrity" and reduce therapist-effects.

The study produced interesting findings. In the acute post-treatment phase, CBT proved significantly more likely to reduce cognitive distortions. Both CBT and SFBT had a greater impact on measured general functioning than NST, while CBT, to the surprise of the researchers, significantly improved marital satisfaction relative to the NST control (SFBT effects were not significantly different from the control). At 2-year follow-up, both SBFT and the NST control proved more effective than CBT at
improving children's conflict behaviour and parent-child relationships. But on measures of long-term co-morbid anxiety and conduct disorder, CBT and NST were more efficacious than SBFT, both showing steady decline while SBFT produced an increase in co-morbid symptomatology before declining to converge with the other two treatment conditions. However, no significant differences were found between treatment conditions for reducing depression. Unfortunately, it appears no exclusion criteria were put in place to prevent participants receiving medical or alternative psychotherapeutic interventions during the study, and around half of participants in each condition did receive additional psychotherapy – confounding the effects of the treatments provided in each of the conditions and thereby reducing the opportunity to discover between-treatment differences. Nevertheless, Kolko et al. (2000) raise interesting questions regarding the apparent successes of the NST control. If these are regarded as “placebo effects” relating to the therapeutic value of having contact with an empathic therapist this would have

“... implications for the training of therapists in an era of “manualization”, where achievement of technical proficiency seems to take precedence over relationship-building skill.” (Kolko et al., p. 612).

Moreover, cognitive-behavioural approaches often stress the importance of developing individual formulations or conceptualisations about the cognitive and behavioural factors predisposing, precipitating and perpetuating (as well as protecting clients from) psychological problems (e.g. J. Beck 1995). There is an inherent dilemma then between this individualised, client-centred approach as used in clinical settings, and the need for highly standardised, symptom-focused treatments administered in RCTs. There are acknowledged concerns about the generalisability of RCT findings when RCTs usually involve strict inclusion and exclusion criteria – placing a gulf between the participant samples of clinical trials and the clients prioritised by psychological services (e.g. Stallard, 2002a). Co-morbidity is a case in point – co-morbid problems are often regarded as exclusion criteria in RCTs but frequently present in clinical settings (Stallard, 2002a). Co-morbidity may even act as a particular prompt to time-pressured clinicians to develop individualised formulations which somehow incorporate factors “key” to all the presenting concerns and therefore identify priority-areas for intervention.
There is also demand for long-term follow-up studies examining whether treatment effects are maintained. This reasoning prompted Barrett, Duffy, Dadds & Rapee (2001) to carry out a six-year follow-up of an RCT (with 12-month follow-up) involving 7-11 year-olds with anxiety. In the original RCT, which was reported by Barrett, Dadds & Rapee in 1996 (cited by Barrett et al., 2001), children assigned to a CBT-only or CBT+family intervention (FAM) condition showed significantly greater improvement on several anxiety measures than children in a waiting-list control group. Those in the CBT+FAM condition had experienced significant additional improvement to those in the CBT-only group – a finding that will be discussed in more detail later. At the 12-month follow-up (Barrett et al., 1996, ibid) 70 per cent of children in the CBT-only condition and 95 per cent of those in the CBT+FAM condition no longer met diagnostic criteria for anxiety disorder. At six-year follow-up (Barrett et al., 2001) 85.7 per cent of all the participants in the two treatment conditions were diagnosis-free, the gains seen at 12-month follow-up were reported to have been maintained, though CBT-only and CBT+FAM interventions now appeared equally efficacious.

These results were interpreted as evidence of the long-term effectiveness of CBT. However, as the authors themselves acknowledged (Barrett et al., 2001), the absence of a waiting-list control group at six-year follow-up undermined this finding, preventing examination of the effects of maturation on recovery. This seems particularly relevant to the non-replication of the superiority of CBT+FAM intervention since some “children” aged 14 in the original study would currently have been 20 and may well have left home – perhaps reducing the impact of family dynamics upon symptomatology.

While the long-term effects of CBT are of great interest, it seems important to consider how findings from such follow-up studies are to be used and to ensure the acute and medium-term gains of treatment are also considered. It is possible even relatively short-lived psychological distress may have heightened impacts upon children in terms, for instance, of educational disruption (Barrett, 2000), impacts upon siblings and perhaps the formation of assumptions about psychological distress
which may have a continuing role in adult disorder (Teasdale & Barnard, 1993). Such concerns highlight the need to understand the impact of psychological disorders upon child and adolescent development, and the impact of development upon psychological disorders.

**The developmental appropriateness of CBT**

Even though some of the key constructs in CBT – including core beliefs and attitudes – are hypothesised to develop in response to childhood experiences (J. Beck, 1995), research and theory into how children develop such beliefs are lacking in the child CBT literature (Stallard, 2002a; Barrett, 2000). In many ways this seems extraordinary. After all, questions such as “How and when in childhood do core beliefs develop and what influences them?” would be of profound relevance to both child and adult theory and intervention. Barrett (2000), in her review of childhood anxiety treatment, also highlights that the existing developmentally-appropriate theories regarding children’s emotional development have not yielded interventions designed to address their identified mechanisms. Bowlby’s (1973, cited by Barrett, 2000) attachment theory has elucidated the likely role of insecure attachment in the mother-infant relationship in the development of anxiety. Meanwhile, Kagan & Snidman’s behavioural inhibition model (1991, cited by Barrett, 2000) suggests temperamental factors such as a behaviourally-inhibited style may be predisposing of childhood anxiety disorder. Further research might elucidate how interventions could address such predisposing mechanisms.

Barrett (2000) argues the dearth of developmentally-appropriate theory has led to children being regarded as “little adults” onto whom adult CBT interventions can be “downloaded” (p.3). Whether or not this is appropriate ties in with one of the key debates in psychology – whether child psychological development is typified by quantitative change largely promoted by growing experience and knowledge, or by more qualitative, stage-related shifts perhaps involving changes in children’s biological capacities for reasoning, behaviour, or affect (Thornton, 1995). Barrett (2000) claims that present CBT interventions require children to possess metacognition, self-regulatory ability and an understanding of others’ emotional states which might be described as “theory of mind” – capacities which developmental evidence suggests
develop in late childhood. On the other hand, Stallard (2002a) suggests that many CBT techniques would require concrete rather than abstract thinking and so children may be able to benefit once they have reached the “concrete-operational” stage. Indeed, according to Thornton (1995), most adults reason in a more concrete than abstract way, deriving their reasoning ability from experience rather than “logical” principles. Donaldson (1978) has also highlighted how children may be able to understand more logically complex principles if they are presented in an interpersonally-familiar context.

These findings suggest that, while “downloading” CBT onto children presents some hazards, changing the way in which concepts are presented may help make CBT appropriate for children. Barrett's (2000) concern that the use of jargon in CBT would be confusing to children might be relatively easily overcome by simplifying language and using imagery and metaphors of familiarity to children. Stallard (2002b) has developed a wealth of materials designed to present CBT concepts and exercises to children in ways to which they can easily relate. For instance, automatic thoughts are likened to a tape recorder playing a tape round and round in your head. Thinking errors are described as “wearing negative glasses” (negative mental filter) or giving yourself “dustbin labels” (negative labelling). Stallard (2002a) argues that materials and concepts should be presented in a way which is “fun, interesting and engaging” (p.302) and achieves this by turning CBT exercises into games and questionnaires such as filling in thought bubbles or looking for names of feelings in word-searches. Of course, adult CBT interventions may well have something to learn from the development of such user-friendly materials! Stallard (2002a) also suggests that play and puppetry might be used to convey some concepts. Such media might also be useful in overcoming the problems which Barrett (2000) is concerned children may face in voicing their thoughts and feelings with a limited vocabulary. Child-friendly CBT programmes such as the “Coping Cat” CBT-based treatment for childhood anxiety (Kendall, 1994, cited by Stallard, 2002a) have yielded promising results so far (Stallard, 2002a).

As well as recognising the differing needs of children in comparison to adults in order to make treatment appropriate, the needs of children of different ages or
developmental stages also requires attention. Stallard (2002a) has pointed out that many RCTs examining the effectiveness of child-centred CBT programmes have involved child participants from seven to 14 years of age, even though the needs of seven year-olds and 14 year-olds must surely be markedly different. Intervention models still need to differentiate the components and techniques suitable for children of different ages and abilities. This concern is also highly relevant to working with children with learning disabilities, as well as those with specific learning difficulties where selection of therapeutic materials will have to be adjusted to match each child’s areas of strength and need.

The use of developmentally-appropriate intervention techniques is far from the only developmental consideration regarding the appropriateness of CBT for children. Barrett (2000) and Stallard (2002a) have both drawn attention to the need to understanding how development influences psychological disorder and how such disorder affects child development. Both highlight the transient and adaptive appearance of anxiety symptoms in normal child development. Stallard (2002a) asks whether there may be “critical stages” in the development of psychopathology – perhaps linked to the ways in which normal childhood anxieties are coped with. Barrett (2000) similarly asks whether there may be times of particular vulnerability to the development of psychological disorder, and likewise “windows of opportunity” (p.4) for preventative treatment.

Just as issues of qualitative and quantitative difference are relevant to understanding development, so they are to understanding psychopathology (e.g. Barrett, 2000). Questions about norms and variation from such norms therefore emerge. Barrett (2000) describes a developmental sequence of typical childhood anxieties, which may have potential value in providing a framework for identifying normative and dysfunctional symptoms, and highlights how the content of such anxieties may reflect the developmental tasks or themes of developmental stages. For example, very young children demonstrate anxiety about separation from attachment figures, while children in middle childhood may be afraid of the dark, the unfamiliar or the imaginary. Adolescents’ anxieties are likely to reflect their heightening social
awareness and concern about negative evaluation from others – anxiety that may, of course, dramatically influence their disclosure behaviours in therapy settings.

There is also a need to recognise the existence of cultural variations about norms of behaviour in childhood (Barrett, 2000) and the age at which children are expected to cope independently with their fears. Barrett (2000) believes the experience of anxiety and learning to discriminate dangerous and benign situations, use appropriate levels of avoidance and control one’s fears is crucial to normal development. Again cultural variations and expectations could lead to wide variation in what appears normative. It is only necessary to think of how children’s lives have changed through modern UK history – from the performance of dangerous work roles by children to a situation where parents may prevent their children playing outside alone for fear of their abduction – to realise how societal risk aversiveness can vary. Such variation highlights the role of society and culture in the perceptions of child psychopathology and the need to account for such systemic issues in interventions (Stallard, 2002a).

Systemic issues and CBT
Stallard (2002a) provides one of the strongest warnings against treating children in “isolation” from their “unique contexts” which are likely to involve parents, carers, peers and the education system (p.300). There are inherent ethical concerns in many of the papers discussed herein that, by using an essentially intrapsychic treatment such as CBT, there is a risk of pathologising the child and encouraging the attribution of psychopathology to some phenomenon within the child. On the other hand, there may be great value in equipping children with cognitive and behavioural strategies which are “within their reach” and may help them to cope with stresses provoked by events beyond their control – CBT techniques, appropriately used, might give children some level of self-determination, power and control. Furthermore, the application of CBT may, in some circumstances, be experienced as less pathologising than medication or purely behavioural approaches; CBT does, at least, convey an entitlement to self-esteem and confidence rather than the need for children to comply with systemic expectations of them at any cost.
Clearly there is a need to balance the provision of readily applicable strategies for distressed children with an appreciation of the systemic contexts inhabited by a child and the contributions of these contexts to any psychological disorder. To be developmentally-appropriate, cognitive-behavioural models of childhood psychological disorders must therefore incorporate the influence of systemic contexts. These may be as wide as the community-level attitudes held towards children and young people (c.f. the impacts of prejudice, discrimination and stigma upon children’s self-esteem (e.g. Vaughan, 1978, cited by Brown, 1995)), or closer to home involving the role of family belief-systems, behaviours and dynamics (Stallard, 2002a).

Spence et al. (2000) have cited several theoretical reasons why parents may play a contributory role in children’s anxiety problems. They highlight evidence of an association between child and parent anxiety disorder. This association has been linked to parenting styles featuring “over-controlling, over-protective and over-critical behaviour” (Spence et al., 2000, p.715), the increased likelihood amongst parents of anxious children of behaving in ways that draw attention to threat cues, and the modelling, prompting and reinforcement of anxiety-related (rather than coping) behaviours. This theoretical background has driven the pioneering of parent-targeted interventions to be used alongside child-focused CBT, and such parental or family involvement has received attention in several RCTs. However, results regarding the effectiveness of involving parents have been mixed. Spence et al. (2000) found several non-significant trends towards superior outcome for parental involvement plus CBT for social phobia rather than child-focused CBT alone. Barrett et al. (1996, ibid) found significantly higher levels of improvement for CBT+FAM intervention over child-only CBT, but this effect disappeared at six-year follow-up (Barrett et al., 2001).

Nevertheless, Cobham, Dadds & Spence (1998) have highlighted how, precisely because participants have been assigned to conditions randomly, parental involvement or family CBT interventions have been applied indiscriminately. They carried out an effectiveness study where participants were assigned to conditions on the basis of parental anxiety level. Children from within these groups were then randomly assigned to treatment conditions involving either child-focused CBT alone
or CBT and a Parental Anxiety Management component (PAM). Post-treatment results indicated that, in families where only the child presented with anxiety, the outcomes for the CBT and the CBT+PAM conditions were much the same (82 per cent and 80 per cent of child-participants no longer met diagnostic criteria for anxiety disorder respectively). However, where parental anxiety had been identified, children showed significantly less improved outcomes. Furthermore, of those children in the CBT-only condition, 39 per cent were diagnosis-free at post-treatment, while of those in the CBT+PAM condition, 77 per cent were diagnosis-free. This interaction was found to be significant – suggesting that anxious children whose parents are also anxious may be the most likely to benefit from parental intervention alongside child-focused CBT.

Interestingly, age and gender effects were also found at post-treatment (Cobham et al., 1998). In the CBT-only condition, parental anxiety seemed to act as a significant barrier to treatment effectiveness in older (11-14 year-old) children, but not younger children, and in girls but not boys. Furthermore, for families where parental anxiety had been identified, the additional benefits of CBT+PAM over CBT-only were significant for girls but not boys. These findings seem to highlight several themes at once: the importance of identifying systemic factors which may contribute to child psychological disorder, the need for developmentally-appropriate models differentiating the contributory factors at different ages or developmental stages, and the influence of individual differences (including gender). Of course, the complexity of this picture is also a reminder of the importance of individual formulation in guiding treatment, as opposed to a formulaic, symptom-driven and standardised approach to intervention design. While further research is required to replicate such findings, consideration about the ethical and policy issues surrounding parental involvement is also required, regarding, for instance, how child- or parent-led the agenda of therapy should be, and the roles of parents as co-therapists, facilitators or co-clients (Stallard, 2002a).

Conclusions
Before drawing conclusions, it is important to acknowledge that the preponderance of literature discussed herein has focused upon childhood anxiety disorders –
conditions for which, according to Stallard (2002a), there is the strongest evidence in favour of CBT. To base conclusions about the effectiveness of CBT upon this handful of studies would therefore be misleading, and a comprehensive review of outcome studies has not been the aim of this essay. Instead, the literature considered seems to bear up Stallard’s (2002a) view that there is promising evidence that CBT may be effective with children. What this essay’s focus on the (relatively strong) anxiety literature has enabled is a consideration of some of the emerging themes and concerns in the effectiveness and appropriateness debates. While clinicians may feel it is necessary to “download” adult CBT interventions onto children as a “stop-gap”, it is important to note that adult CBT is no panacea and the theory- and evidence-base supporting it suffers some difficulties (Teasdale & Barnard, 1993). The innovation of presentational materials which ground CBT concepts in ideas familiar to children (e.g. Stallard, 2002b) goes some way toward making CBT more developmentally-appropriate. However, in the long-run, theory and research is needed to increase psychological understanding of how children develop (or avoid developing) psychological disorders. Such understanding will not only help to guide the introduction of more appropriate interventions but, if it yields insights into the childhood formation of beliefs and attitudes, may be of enormous relevance to CBT across the lifespan and the very issue of how we become the people we are.
References


"Race and ethnicity are relatively unimportant variables in both the incidence and treatment of mental health difficulties in older people."

Critically discuss this statement

August 2003

Year 2
Introduction
Race equality should now be “central” to NHS policy and service-provision since the introduction of the Race Relations (Amendment) Act (RR(A)A) in 2000 (Commission for Racial Equality (CRE), 2003a). The amended Act gives all public authorities a tripartite duty to eliminate unlawful discrimination and promote both equality of opportunity and good race relations. The duty also requires that race equality issues should be “mainstreamed” – the impact of all healthcare policy and service delivery upon the three strands of the duty should always be considered (CRE, 2003a).

Meanwhile, the National Service Framework (NSF) for Older People published by the Department of Health (DoH) (2001a) acknowledges that older people from ethnic minorities have faced disadvantage and discrimination within health and social care services. Services for older people from black and ethnic minority groups are specifically highlighted within Standard Seven of the NSF (“Mental health in older people”). Here, alongside the need for better and earlier diagnosis and treatment of mental health problems for all older people, is the “key intervention”, or demand that:

“Mental health services for older people should be able to respond effectively to individual needs, and take account of the social and cultural factors affecting recovery and support” (DoH, 2001a, p20).

The number of older people from ethnic minorities living in Britain is rising (Silveira & Allebeck, 2001). The NSF (DoH, 2001a) highlights the general phenomenon of the “ageing” population – more than 20 per cent of the population is now over 60. Due largely to migration in the 1960s and 1970s, an increasing number of older people are from ethnic minorities.

These demographics combined with recently-introduced policy and law might suggest that race and ethnicity would appear highly relevant to service provision for older people with mental health difficulties. However, recent findings suggest a lack of implementation and “mainstreaming” of race equality work in the NHS. The CRE (2003b) concluded from a study of Strategic Health Authorities (Bhatt, 2003) that
attempts to implement the RR(A)A were hampered by knowledge limitations. Furthermore, the CRE has argued that the new Mental Health Bill, published for consultation by the DoH, is lacking in the “embedded” commitment to equality that is required (CRE, 2002).

This raises questions about relative importance of race and ethnicity in service provision for older people with mental health difficulties. This essay will first concentrate on the definition of these concepts – a discussion that will incorporate issues of culture and social construction. These will remain important concerns in examining the question “Do race and ethnicity influence mental health difficulties in older people?” The measurement of occurrence of mental health difficulties will be considered as one approach to tackling this question and difficulties in relying on either incidence (frequency) or prevalence (number of people affected at any one time) data highlighted. The importance of ethnicity and culture in treatment and service provision for older people with mental health difficulties will then be discussed with attention to some of the dilemmas faced by services as they attempt to become more “culturally competent”.

Defining? Race, ethnicity and culture as overlapping constructs
Agreeing what is meant by “race” or “ethnicity” is complicated, not least since the socio-historical associations (O’Hagan, 2001) of such words and concepts are problematic and create wariness of the implications of any particular definitions. Even dictionary definitions do not appear very “definitive”. The Oxford English Dictionary (OED) (1993) definitions of “race” include “A group or set, especially of people, having a common feature or features... A tribe, nation or people regarded as of common stock... The fact or condition of belonging to a particular people, ethnic group etc., the qualities or characteristics of this..., Any of the major divisions of humankind, having in common distinct physical features or ethnic background.”

By these definitions, race is a construction formed out of how people have been divided, categorised or regarded in taxonomical systems. O’Hagan (2001) argues that the concept of race is rooted in “the perceptions of Europeans keen to produce race classifications conducive to the social, political and economic domination which they inflicted
on the peoples they conquered” (p.124-125). Evolutionary theory might suggest that different “races” of people have at some point settled into different geographical regions and continued to evolve in separation from one another. The differences expected to emerge from such discontinuity would presumably be focused upon physical characteristics adapted to regional conditions (such as climate and relative health risks), but ideas of genetic inferiority and superiority emerged – precipitating some of the most horrendous crimes against humanity in history (O’Hagan, 2001).

Against this background, perhaps “ethnicity” might appear a less problematic concept, yet it is also elusively difficult to define. Cornell & Hartman (1998, cited by O’Hagan, 2001) highlight the historical association of “ethnic” with “other”, of being one of “them” and not one of “us”. Indeed, according to the OED (1993), the original meaning of “ethnic” was “heathen, A person who is not a Christian or a Jew; a pagan…”. More contemporary definitions range from the tautological (“A member of an ethnic group or minority…”) to the fluid (“Of a population group) sharing a distinctive cultural and historical tradition, often associated with race, nationality or religion, by which the group identifies itself and others recognise it; belonging to or characteristic of such a group.” (OED, 1993). This leads to the idea that ethnicity is whatever is identified (or perceived) to be ethnic. Cornell & Hartman (1998, ibid) suggest the construction of ethnicity can be of positive value – such identity tending to emerge during struggles for equality in the face of discrimination and disempowerment. This way of understanding ethnicity in turn invokes the concepts of culture and cultural identity, and seems to parallel Newland’s (1998) observation that the theme of social context is inseparable from concepts of race, ethnicity and culture.

O’Hagan (2001) reviews several approaches to understanding culture and views the definition of “culture” as work-in-progress. Nevertheless, many attempts at definition refer to “way of life” and include all things that make that “way of life” distinctive – including belief and value systems, rituals and customs, relationship with landscape, dress, diet, family life and leisure practices, and patterns of work. Culture, like the understanding of it, seems dynamic and ever-changing, and it is assumed that every individual will have their own unique experience of and identity in relationship with culture (O’Hagan, 2001, Hays, 1996).
How important are race and ethnicity to cultural identity? O'Hagan (2001) argues that religion and language are fast overtaking race as the most salient variables in cultural identity and experience of discrimination. Hays (1996), suggests the acronym ADRESSING as a framework for “culturally responsive assessment”, with each letter corresponding to an aspect of a client’s culture. E is for “Ethnicity” – so it is regarded as just one aspect of culture. Interestingly, A is for “Age and generation-specific influence”, and this, coupled with the view of culture as ever-changing, is a reminder that a person’s life-experience will have involved experiences of changing culture and changing relationship with that culture over time. Indeed, Hays (1996) points out that no-one is a member of one “cultural group” because there are so many aspects of culture (she also includes disability, religion, social status, sexual orientation, indigenous heritage, national origin and gender). So any one individual will “belong” to multiple groups, and any one “group” will be heterogeneous in containing individuals belonging to multiple other groups. Furthermore, she argues that the relative importance of these aspects of cultural identity, and the relative importance of cultural identity in general, will be mediated by personal and contextual factors. It follows that, as social constructs, race and ethnicity will have different meaning and importance at different times, in different situations and to different people. If a person is constructed as belonging to a particular “race” or “ethnic group”, and that race or ethnic group is assigned particular meaning or value, then that person’s race or ethnicity could be of life-changing, even life-threatening, importance.

Nevertheless, Hays (1996) suggests that aspects of cultural identity will “more often than not” simply be one element of background information on a client, helping the clinician

“...to more thoroughly understand and more effectively help the client... to make hypotheses and ask questions that are more age-sensitive, culturally relevant, and culturally responsive.” (Hays, 1996, p190).

This would seem to fit well with the NSF’s call for individualised, culturally-appropriate care, yet even this ambition highlights a tension between two approaches to understanding the importance of culture (both in clinical settings and research).
The tension occurs between the "etic" approach which would seek to identify universalities between people (with culture acting as an "extraneous" variable to be "seen beyond") and an "emic" approach regarding culture as fundamental and integral to humanity (Newland, 2002).

Such tension may underlie confusion regarding how to respond to ethnicity and culture amongst clinicians, and seems to be reflected in a Q-sort study by Haworth (1998) examining mental health professionals' responses to working with people from ethnic minorities. The two most popular of the "accounts" identified by the study portrayed race and culture quite differently. The first seemed to correspond somewhat with the "emic" approach: race and culture were regarded as very important in the context of an holistic approach viewing every aspect of a client's life as important to both assessment and treatment provision. This most popular account espoused sensitivity and understanding when working with people from ethnic minorities, and the need to understand how individual clients viewed themselves in relationship with their own cultures. Racism was portrayed as occurring at organisational or service level but professionals saw themselves as separated from that "rather than part of it and taking responsibility for it". (Haworth, 1998, p9). The second account seemed to have more in common with the "etic" approach – viewing every individual as essentially similar regardless of ethnicity or culture, and people from ethnic minorities as having the same underlying problems as white English people – eliminating differences and justifying giving the same treatment to all (Haworth, 1998). O'Hagan (2001) argues such differences reflect concerns about minimising the dangers of "Eurocentrism" on the one hand, and the on the other, avoiding the risk of regarding inequality as "cultural" and therefore being complacent to it.

Halsey & Patel (2003) also conceptualise different approaches to understanding race and ethnicity – each with its own perils and pitfalls. They argue that an "apolitical stance", focusing purely on clients' internal worlds, results in ignorance of environmental factors (including racism) creating distress and the internal attribution of such distress to internal factors within the client. A "colour-blind position" – aimed at treating everyone equally (or "the same") – risks the neglect of fundamental
aspects of experience and identity. The “exotic position” – embracing and celebrating “the other” maintains a Eurocentric view of norms. Meanwhile “missionary” approaches, with their emphasis on “rescuing” people, are liable to become paternalistic in their zeal to replace “primitive” beliefs (Halsey & Patel, 2003).

With all these “pitfalls” and the heavy burden of history, it is perhaps not surprising that healthcare staff might shy away from the issue of cultural competence for fear of unwittingly worsening injustice and inequality. Perhaps this is why Yee (2002) attempts to portray cultural competence as an invitation and opportunity to celebrate, recognise, tolerate, respect, include and learn from cultural diversity. Perhaps questioning the relative importance of race, ethnicity and culture might really reflect a preoccupation with whether attempting to practice in culturally competent ways is “worth” such a “burden”. Which begs the question: “What is there to lose through ignorance of race, ethnicity and culture?”.

Do race and ethnicity matter in understanding mental health difficulties in older people?

An approach to answering questions surrounding the relative importance of race and ethnicity to understanding mental health difficulties in older people would be to find evidence relating to whether the occurrence of mental health conditions differs between different ethnic groups. Several authors suggest that belonging to an ethnic minority would subject a person to particular vulnerability to mental health difficulties. This might occur via the mechanism of social deprivation which may itself be particularly relevant to the cohort of people from ethnic minorities who are now in or approaching old age. This “cohort” is thought to be largely comprised of “first generation” ethnic minority groups who settled in Britain following migration in the 1960s and 1970s. All these first generation minority groups experienced higher rates of unemployment, with Black Caribbean people twice as likely to have been unemployed as their White British counterparts (Cabinet Office Performance and Innovation Unit, 2002).

Rait, Burns & Chew (1996) argue that older people from ethnic minorities who have mental health difficulties suffer a “triple jeopardy” of racism and ageism combined
with such socio-economic deprivation. It is also possible that the stigma surrounding mental health problems may create additional vulnerability in terms of the risk of being rejected by communities. However, there are also authors who subscribe to "buffer" rather than vulnerability theories – suggesting that the resourcefulness associated with migrating and making a new life in a new country and community would act as a protection against developing mental health difficulties (Silveira & Allebeck, 2001).

It might be helpful to have good incidence and prevalence data to draw upon in unravelling the relative vulnerabilities or buffers affecting people from different ethnic groups. Indeed, Silveira & Allebeck (2001) say the need for health status information for groups such as people of Somali origin is “urgent”. Unfortunately, there are serious difficulties in obtaining an accurate picture of the occurrence of mental health difficulties across ethnic groups – partly due to the dearth of such research (Rait et al., 1996) but also due to problems interpreting what findings exist.

For example, McCracken, Boneham, Copeland, Williams, Wilson, et al. (1997) carried out a study to assess prevalence of depression and dementia amongst older people from ethnic minorities in an attempted population-survey in Liverpool. They faced many barriers. Not least of these was accessing the population – despite numerous approaches to identifying members of the community from ethnic minorities, their sample did not achieve the population suggested by Census figures. Secondly, as with any such study, concerns emerge about how the presence of mental health difficulties was screened for and diagnosed. This study used AGECAT as an assessment measure, but this standardised measure had been validated against DSM-III criteria (McCracken et al., 1997) which might not even fit with contemporary Western categories as outlined in DSM-IV. The study’s findings suggested that the prevalence of depression and dementia amongst English-speaking ethnic minority groups was comparable to the White British ethnic majority. However, the small number of cases of depression and dementia (sometimes only one or two cases in an ethnic minority category) prevented potentially-useful comparisons between groups and may therefore have overlooked heterogeneity between as well as within ethnic groups. Non-English-speaking was associated with

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higher levels of dementia — a finding which led the researchers to question the validity of the assessment measure used, and to highlight that basing diagnosis upon items such as knowledge of own birth-date or current Prime Minister might not be appropriate for such groups (McCracken et al., 1997).

Issues of access, recognition and diagnosis can clearly hamper such prevalence studies. Could service-use act as an alternative measure of occurrence? Again, several problems emerge. Abramson, Trejo & Lai (2002) suggest that mental health services and people from ethnic minorities tend to lack awareness of each other — a situation which would self-perpetuate if level of service use was assumed to reflect need. Chaudhry & Au (1994) suggest that language and knowledge barriers may prevent many older people from ethnic minorities from successfully negotiating NHS bureaucracy. In a study of older people of African-Caribbean origin from inner Derby, Greatorex (1998) found that people avoided mental health services because they did not want to be labelled as “mad”, be admitted to hospital or required to take unwanted medication.

Marwaha & Livingston (2002) cite findings that older who are from ethnic minorities have high attendance in primary care settings compared to those from the ethnic majority, but are referred to secondary mental health care less frequently. To investigate this, they carried out semi-structured interviews with older people from Black African-Caribbean and White British backgrounds, including participants who had and who had not experienced “depression”. In response to a vignette about a man presenting with what psychiatrists would categorise as symptoms of depression, few people in either ethnic group regarded the man’s condition as an illness, though many thought he was depressed. Ethnicity did seem to have some relationship with the way depression was conceptualised. White British participants tended to attribute the depression to normal stressors associated with ageing such as loneliness following retirement. Black African-Caribbean participants were more likely to cite spiritual causes such as a lack of faith in God (though this was less common in those who had experienced depression), or to lack of contact with one’s “own” community or people. Marwaha & Livingston (2002) suggested the more spiritual explanations might delay Black African-Caribbean people from seeking specialist help.
from the NHS because they viewed it as irrelevant. They also posited that the stigma created by spiritual explanations of depression might be linked to a “dichotomous split” between physical illness and psychological problems – raising the possibility that mental health difficulties would present as physical symptoms and go unrecognised if health care professionals were not aware of this pattern.

However, Marwaha & Livingston (2002) also raised important research concerns in their appraisal of the study’s limitations. They highlighted that they had taken an “etic” approach, applying their own definitions and understanding of depression and examining the extent to which participants’ understandings adhered to their own in terms of recognition and help-seeking.

Silveira & Allebeck (2001) drew attention to language use in their study of Somali men living in the Tower Hamlets Borough of London. In order to ask participants about “depression”, it was necessary to use several different Somali words that described what the researchers would view as different aspects of the depression syndrome. For instance, this included the words diigad (feeling of being low or sad), murugo (conveying pervasive sadness, wanting to cry, deep sorrow and helplessness), and niyad-jab (dissatisfaction with one’s life, apathy and indifference). The complexity of each of these symptoms raises fascinating questions about whether these might be viewed as syndromes in their own right, whether research might find any double-dissociation, and how language might influence or construct symptom presentation. For instance, do people conform to the “done thing” when feeling particular emotions or kinds of distress?

The study (Silveira & Allebeck, 2001) identified some common themes associated with decreased life satisfaction and perceived to increase vulnerability to depression. These themes included loneliness, lack of family support (for variety of reasons – including lack of contact through migration or separation between Boroughs), physical disability, discrimination including ageism, racial and religious discrimination and harassment, and little control over one’s life. Family support appeared to act as a buffer – but was not available to all. A particular issue was that many of the men had worked as sea-farers and this had meant that many of them had not “settled” in
Britain until retirement, only to find themselves feeling isolated and separated from family in Somalia. Furthermore, the civil war there had created great concern about the welfare of family and friends. These factors highlighted the importance of the history and current affairs of particular cultures, and that individuals within a “cultural group” could have quite different experiences of common concerns.

A further finding of the study (Silveira & Allebeck, 2001) was that the men were less likely to recognise depression as a syndrome compared to other psychological disorders. This lead Silveira & Allebeck (2001) to question whether Western models were appropriate and adequate for this population. The idea of “culturally-specific syndromes” such as the syndromes described in the Somali language or the “depression” recognised by Western diagnostic classifications, is a reminder that medical and healthcare models are themselves influenced by culture and so may be culture-specific. Not only may this prevent recognition (especially early recognition) of psychological difficulties in minority groups, it also provokes concern about whether it is helpful to necessitate compliance to the (Western) medical tradition of labelling such distress as illness or disorder in order to access care.

Gergen & McNamee (2000), in an exploration of the construct “mental disorder”, equate insistence upon the “terminology of mental disorder” with the “desecration of traditions”. They suggest other traditions of understanding symptoms of a syndrome such as depression may result in more positive outcomes – for instance in the folk tradition of “feeling blue”:

“To have the blues” is not an illness; it is an honorific state; it signifies that one truly knows life and has experienced its depths and defeats. It is to elicit sympathy, not because one is ill but because people recognize the condition as a “poor lot”. The afflicted one is not weakened by disease but is strong in his or her resistance.” (Gergen & McNamee, 2000, p.339).

The consequences of misinterpreting culturally-specific syndromes may ultimately affect liberty. The Sainsbury Centre for Mental Health (2002, cited by CRE 2002) has highlighted that, while people from ethnic minorities are under-represented in community-based mental health services and access to “talking therapies”, they are
over-represented in terms of compulsory hospital admissions, in detentions by the Police under Section 136, on secure wards, and in prescriptions of anti-psychotics and high-dose major tranquillisers. This was attributed healthcare staff being more likely to perceive to people from ethnic minorities as dangerous. Clearly, these statistics indicate there is a long way to go not only in terms of promoting equality, but still in eliminating discrimination, both direct and indirect, as required by the RR(A)A (DoH, 2001).

The NSF (DoH, 2001a) recognises that assessments may be culturally biased and calls for them to be improved. However, Hays (1996) makes a sobering argument that there can be no such thing as culture-free or culture-fair psychological test, because psychological constructs such as intelligence and personality are, like medical constructs of disorder, inherently cultural. How then, can more culturally-competent services be offered to all?

**Treatment and service provision – the goal of cultural competence**

Hays (1996) considers aspects of cultural competence from the moment clients walk through the door of a mental health service. She highlights how, for people who have experienced discrimination, self-protective strategies may be employed as they assess for themselves whether the mental health professional may hold the biases of their dominant culture. Clearly, clinicians may find this difficult (for instance if they are asked for personal information) but Hays (1996) calls for respect of such self-protective strategies, and consideration of the messages given to clients about the service's approach to cultural diversity. This might include aspects of the building such as access, artwork and wall hangings, and provision of information in different languages. Culture-specific (including generation-specific) norms and customs need to be considered – for instance in use of titles rather than first names. Hays (1996) recommends that clinicians access cultural liaison advisers to obtain information about cultural norms and relevant (for example socio-historical) issues which may have influenced a client's life experiences.

For psychologists, the model of formulation rather than diagnosis may help to circumvent problems with attempting to classify culturally-influenced presentation
within Western medical models. However, there may be tensions and conflicts about intervening with the factors thought to maintain distress whilst respecting cultural differences. For example, cognitive-behavioural approaches emphasise an active and collaborative role which may not fit with the expectations of some clients (Hays, 1996) (including those from White British backgrounds), and the very basis of cognitive-therapy involves challenging clients’ “dysfunctional” beliefs – what if such beliefs are culturally mediated? Constructivist therapies (Hoyt, 1996) might take the approach of exploring the meaning and effect of particular ideas in a way which empowers the client to make their own decisions about the relationship they wish to have with that idea. Cognitive-behavioural therapies might be able to employ this emphasis with clients from any cultural background.

There are probably ideas and beliefs within any culture that psychologists might regard as unhelpful (even ideas that have been espoused by psychologists!). However, there may also be helpful ideas and beliefs. Morisy (1993) highlights how religious views of older age may help to counteract (presumably unhelpful) beliefs about later life representing a low point or descent in the life-course.

Abramson, Trejo & Lai (2002) recommend that attention is paid to culturally-specific healing practices as well as culturally-specific conditions. They cite findings that amongst Native Americans, a culture-specific syndrome called wacinko (similar to reactive depression) is best treated with Native American interventions. They also suggest that people from Asian backgrounds might favour interventions emphasising mind-and-body harmony. Hays (1996) encourages clinicians to harness the strengths of every client’s culture and the supports available from their community, although caution is required to avoid assumptions that people from ethnic minorities will have family members who can act as carers (Hays, 1996; DoH, 2001a). Chaudhry & Au (1994) highlight how cultures are subject to intergenerational change and conflict, and argue that many ethnic minority communities in Britain are undergoing transition in kinship patterns which may affect availability of care.

Such suggestions highlight just some ways in which ethnicity and culture might be important variables in treating older people with mental health difficulties. But are
race, ethnicity and culture important enough to warrant priority attention in the context of overload amongst NHS staff? This attitude may be particularly common in communities where there is low ethnic and cultural diversity, although the Royal Commission on Long Term Care (1999) argued that, in such communities, the need for cultural sensitivity is enhanced because for those in minorities, their minority status is so striking and potentially isolating. Bhatt's (2003) interviews with senior representatives of Strategic Health Authorities (SHAs) as they approached formal constitution suggested wide variation in the mainstreaming of race equality work and confusion about the priority afforded to such work relative to targets such as waiting times, financial balance, hospital ratings and NSFs. Bhatt (2003) was concerned that, as a result, the RR(A)A "risks becoming a lesser priority in SHA agendas and may not be effectively engaged with by some SHAs" (p.5). The CRE (2003c) responded by highlighting how race equality work could be an aid to meeting other targets, and important in reducing health disparity. The CRE also pointed out the bottom-line: the RR(A)A is law, not a target, and therefore "not optional".

Conclusions
This essay has considered a number of factors that might be viewed as mediating the relative importance of race and ethnicity in the incidence and treatment of older people with mental health difficulties. It has argued that race and ethnicity are social constructs, the impacts of which can only be considered alongside a broader examination of culture (O'Hagan, 2001), and are likely to be mediated by personal and contextual factors (Hays, 1996). The relationships between ethnicity, culture and the occurrence of mental health difficulties in older people are unclear, but attempts to study incidence and prevalence across different ethnic and cultural groups have highlighted the need for humility around the application of Western medical, healthcare and psychological models. Differences in cultural norms and understandings need to be considered sensitively if healthcare provision is to be culturally competent (Hays, 1996). Social constructivist therapies (Hoyt, 1996) may provide a model for ways of working to examine beliefs and ideas without being disrespectful to people from varied cultural backgrounds, upon which cognitive therapists might draw. Amongst the social contextual factors mediating the relative
importance of race and ethnicity in current healthcare provision is the fact that the
duty to promote race equality is now enshrined in law.

This essay has drawn predominantly upon theory and argument relating to issues of
race, culture and ethnicity, rather than empirical research findings. Perhaps the new
duties of the RR(A)A will, through creating a need for more evidence relating to the
impacts of ethnicity and culture, effect change in clinical psychological research as
well as practice, and act to bridge this gap in the literature.
References


Greatorex, B. (1998), Assessment and screening for depression in older adults of african caribbean origin. *PSIGE Newsletter, 64,* 3-5.


Clinical dossier
INTRODUCTION TO THE CLINICAL DOSSIER

The clinical dossier is aimed to reflect clinical experience gained during the course of study for the degree of Doctor of Psychology in Clinical Psychology. It is complemented by materials contained in Volume 2 of the portfolio, which acts as a confidential appendix to the clinical dossier, and contains full versions of case reports and placement documentation. This dossier contains:

- Placement summaries for the first five placements conducted. The placement summary for the final Specialist Placement has been included in the Appendix to Volume I as Appendix F on page 399. These placement summaries are complemented by clinical logbooks, samples of professional correspondence, evaluations of the trainee by placement supervisors and evaluations of the placement by the trainee for each placement, held in Volume 2 of the portfolio.

- Summaries of case reports for the four Core Placements and the first Specialist Placement. The full versions of the case reports are contained in Volume 2 of the portfolio, together with signed statements from placement supervisors confirming the representativeness of these reports.

Some details, including clients’ names and those of family members, have been removed from case reports and case report summaries to preserve anonymity.
OVERVIEW OF CLINICAL EXPERIENCE GAINED DURING TRAINING

- Core Adult Mental Health Placement
- Core People with Learning Disabilities Placement
- Core Children and Young People Placement
- Specialist Adolescence Placement
- Core Older People Placement
- Specialist Clinical Health Psychology Placement
CORE ADULT MENTAL HEALTH PLACEMENT SUMMARY

PLACEMENT DETAILS:

Dates: 10 October 2001 – 22 March 2002
Supervisor: Mary Dobbin, Consultant Clinical Psychologist
NHS Trust: Mid-Sussex NHS Trust
Base: Linwood Community Mental Health Centre, Butlers Green Road, Haywards Heath, West Sussex.

Summary of experience: This placement provided experience of providing therapeutic interventions with individual adults referred by their GPs to the Clinical Psychology Service of a Community Mental Health Team (CMHT) and the Department of Clinical Psychology of a hospital outpatients department. Cognitive-behavioural models informed the majority of formulations and interventions, but were supplemented by systemic and attachment theory. Observational experience of a consultant neuropsychologist conducting neuropsychological assessment and of administering sub-tests during neuropsychological assessment was also gained.

Clinical skills and experience: Experience was gained of working with male and female clients from a wide age-range (17 to 82). The range of presenting problems worked with included depression, anxiety disorders, childhood abuse, sleep disorder, self-harm, relationship problems and chronic fatigue syndrome. Assessment measures administered included the SCL-90-R, BDI-II, BAI, HADS, and sub-tests from the WAIS-III-UK and AMIPB.

Other experience gained

• Liaison with a clinical psychologist specialising in chronic fatigue syndrome.
• Conducting a presentation on narrative approaches to team-work.
• Attending a service-users' consultation conference on proposed Trust reorganisation, and a conference on mental health promotion.
• Shadowing a clinical psychologist in Rehabilitation including formation of new assertive outreach team.
CORE PEOPLE WITH LEARNING DISABILITIES PLACEMENT SUMMARY

PLACEMENT DETAILS

Dates: 3 April 2002 – 20 September 2002

Supervisors: Celia Heneage, Chartered Clinical Psychologist and Hilary Smith, Consultant Clinical Psychologist

NHS Trust: West Sussex Health & Social Care NHS Trust

Base: Worthing Community Team for People with Learning Disabilities, 1 St George’s Road, Worthing, West Sussex

Summary of experience: This placement provided experience of working from behavioural, cognitive-behavioural, psychodynamic and systemic perspectives in assessing, formulating, providing consultation on and treating a range of difficulties presented by people with mild, moderate and severe learning disabilities. Assessment measures administered included the WAIS-III, WMS-III and BPVS.

Clinical skills and experience: The placement took place in a service under resource-strain and operating on a Consultation model. It therefore provided experience of brief (three session) therapeutic interventions with presenting concerns including anger-management problems, epilepsy, depression, anxiety, sexual health and relationship problems, psychosis, and bereavement. Experience was also gained of conducted behavioural observations, psychometric assessment of learning disability, dementia assessment, co-facilitating a “Feelings Group”, facilitating a systems consultation and conducting joint work with an occupational therapist.

Other experience:
- Presentation of “The Mind in Place and Its Implications” to Clinical Psychologists.
- Organisational work surrounding informed consent and carer information for the Feelings Group, and developing a satisfaction measure for the service using the Picture Exchange Communication System.
- Shadowing a Speech & Language Therapist conducting treatment sessions.
PLACEMENT DETAILS:


Supervisor: Željana Stermšek, Chartered Clinical Psychologist

NHS Trust: West Sussex Health & Social Care NHS Trust

Base: Worthing Child & Adolescent Mental Health Team (CAMHS), The Children’s Centre, Worthing Hospital, Lyndhurst Road, Worthing, West Sussex.

Summary of experience: Experience was gained of conducting assessment and intervention with individual children, parents and with family systems incorporating behavioural, systemic, cognitive-behavioural and psychodynamic approaches. Assessment measures administered included the WISC-III-UK, WORD, BYI and Conners Scales. Participation in the reflecting team of the CAMHS Family Therapy Clinic also gave observational experience of Systemic Family Therapy with families with a wide range of circumstances and presenting needs.

Clinical skills and experience: Direct and observational experience was gained of working with children and young people from ages 4 to 17 with a variety of Tier II and III presenting concerns. These included social communication disorder, ADHD, depression, self-harm, learning disability, behavioural problems, separation anxiety, early abuse, encopresis, parental divorce and bereavement. Work with a family in crisis following the school exclusion of their child who had a learning disability provided experience of emergency involvement, and liaison with services including Accident & Emergency, special schools and Tier IV inpatient and outreach services.

Other experience:

- Involvement in planning a Social Skills Training Group for children with social communication disorders and their parents
- Introduction to Webster-Stratton group-based approaches through meeting with CAMHS team social worker.
SPECIALIST ADOLESCENCE PLACEMENT

PLACEMENT DETAILS:

Dates: 9 April 2003 – 26 September 2003
Supervisor: Nick Kirby-Turner, Consultant Clinical Psychologist
NHS Trust: West Sussex Health & Social Care NHS Trust
Base: Child & Adolescent Psychology, Department of Psychology, Princess Royal Hospital, Haywards Heath, West Sussex.

Summary of experience: This placement provided specialist experience of working with adolescents and their families from a predominantly systemic perspective. In particular, narrative approaches to individual work with adolescents and structural and solution-focused approaches to family work were applied. Participation in reflecting teams and as a co-therapist enhanced the breadth and depth of experience of Systemic Family Therapy, including in a Tier IV service. Experience was also gained of consultations to CAMHS and Youth Offending Team professionals. Assessment measures including the CDI, EDI2, WISC-III, WOLD, WORD, BDI-II and Adolescent Coping Scale were administered.

Clinical skills and experience: Individual and family work was conducted with young people aged 12 to 17 with a variety of presenting concerns including depression, self-harm, substance-use, emotional and sexual abuse, anxiety disorders, ADHD, conduct disorder, school refusal and diagnosed personality disorder.

Other experience:
- Several experiences of teaching and skills transmission to other professionals
- Shadowing a Designated Family Judge attending child care case proceedings and hearings and meeting with the Risk Assessment Team
- Shadowing the supervisor on an emotionally-based school refusal working group
- Contributing to a project addressing emerging conduct disorder and a focus group on pre-assessment contact in the Family Therapy Clinics
- Attending child psychology seminars on professional and service developments.
CORE OLDER PEOPLE PLACEMENT

PLACEMENT DETAILS:

Dates: 15 October 2003 – 26 March 2004

Supervisor: Clare Crellin, Consultant Clinical Psychologist

NHS Trust: West Sussex Health & Social Care NHS Trust

Base: Linwood Community Mental Health Team for Older People (CMHTE), Butlers Green Road, Haywards Heath, West Sussex

Summary of experience: This placement provided experience of working with individual clients, client-groups and staff-groups applying generative and neuropsychological approaches to assessment, formulation and intervention. This incorporated psychoanalytic and developmental approaches, especially Jungian and life-review models. Assessment measures administered included the WAIS-R, NART-R, AMIPB, BAI, BDI-II, HADS, BHS, MMCI-II and Hammerberg’s PENN inventory. Peer-supervision alongside another trainee provided vicarious learning opportunities.

Clinical skills and experience: Clinical work was conducted with individual men and women aged 69 to 88 with a wide range of presenting concerns and needs. These included bereavement, depression, anxiety disorders, suicide risk, forensic/offending behaviour, adjustment to disability and illness, severe and enduring mental health problems including bi-polar disorder and psychosis, challenging behaviour, and cognitive problems. Developing new psychological service provision in a day hospital provided experience of working with staff teams, organisational dynamics and brief assessment and intervention. In addition, experience of group-work was gained by running a “Psychology Group” on the day hospital.

Other experience:
- Conducting a psychoanalytic observation on a high-support dementia ward
- Attending a PSIGE training day on Jungian approaches to mid and later life
- Visiting an inpatient ward and day hospital for older people
- Shadowing the supervisor at an NSF Implementation Group meeting
SUMMARY OF CASE REPORTS COMPLETED DURING TRAINING

Case reports are included in full in Volume 2 of the portfolio. Brief summaries of the case reports are included in this dossier, as listed below:

- **Adult Mental Health Case Report**
  “Cognitive-behavioural therapy with a 36 year-old woman presenting with anxiety and low self-esteem”

- **People with Learning Disabilities Case Report**
  “Brief anger-management work with a 37 year-old man with a learning disability”

- **Children and Young People Case Report**
  “Formulation-led work with a nine year-old girl presented with tantrums, separation anxiety and headaches – incorporating family-based intervention to improve child-parent attachment relationships and individual cognitive-behavioural therapy to reduce anxiety and enhance affect self-management”

- **Specialist Adolescence Case Report**
  “Psychological therapy incorporating a narrative approach with a 15 year-old girl presenting with low mood and substance-use”

- **Older People Case Report**
  “An extended assessment with a 69 year-old woman presenting with recurrent depression and unexplained physical and functional symptoms”
ADULT MENTAL HEALTH CASE REPORT SUMMARY

“Cognitive-behavioural therapy with a 36 year-old woman presenting with anxiety and low self-esteem”

Reason for referral
Karen Hewstone, a 36 year-old nursing sister, was referred to the Community Mental Health Team by her GP, who reported anxiety problems following a difficult childbirth and marital problems. At initial assessment, possible symptoms of depression were also identified.

Assessment
A semi-structured assessment interview was conducted across three sessions. Standardised, criterion-referenced measures including the Beck Depression Inventory 2nd Edition (BDI-II) and Beck Anxiety Inventory (BAI) were administered to enable additional assessment of Karen’s symptoms. Karen’s BAI score at initial assessment classified as “moderate anxiety”, and her BDI-II score classified as “moderate depression”. Karen felt her BDI-II score was more reflective of low self-esteem than depression.

Karen described herself as a “worrier” since childhood. She reported problems with separation anxiety throughout her schooling, but said her feelings of anxiety and “insecurity” had worsened since her husband admitted to having an extra-marital relationship the day she began maternity leave, prior to having her second child. She found being unable to meet friends’ requests or having to confront junior staff at work particularly anxiety-provoking situations that provoked thoughts such as “They won’t like me” and “Nobody wants to be with me”.

Formulation
A cognitive-behavioural approach was taken to formulating Karen’s presenting concerns. Early perceptions that her brother gained more parental attention than her, and the experience of feeling “abandoned” when her father had an extra-marital relationship and temporarily separated from the family, appeared to have led to core
beliefs including “I am worthless” and “I am unlovable”. Assumptions such as “People like might me and care for me if I give a lot and care for them” were hypothesised to give rise to compensatory strategies involving “giving too much of myself”, and negative thoughts about others’ reactions if she could not meet their requests.

A further core belief that “the world is unpredictable” was suggested to underlie Karen’s apparent coping strategy of worrying to prepare herself for the worst, but also seemed to be linked with a dilemma between being level-headed, hard but cold or emotional, warm and sensitive but unreliable and therefore “worthless”. Karen perceived herself as “out of control” and “neurotic” for her feelings of insecurity and sadness.

**Intervention**

A cognitive-behavioural approach based on that of Judith Beck (1995) was applied to initial therapeutic work with Karen. A diagrammatic representation of the formulated core beliefs, assumptions and automatic thoughts was shared with Karen. Karen began keeping diaries of automatic thoughts and utilising strategies for evaluating and responding to these thoughts. While Karen found this approach helpful in tackling challenging situations with friends and colleagues, she appeared to find it much harder to apply her new strategies in conversations with her husband, where she felt passive and powerless.

A reformulation viewed this style of response as possibly representative of a passive “mind-in-place” (Teasdale, 1997), which was hypothesised to have been formed in childhood as a response to experiences of unpredictability and discouragement of assertive emotional expression. It was proposed that this mind-in-place was being activated in the context of important family relationships – particularly with her husband – and preventing Karen from discussing her emotional needs more openly. A dilemma about whether she should remain in her marriage was also found to be contributing to Karen’s distress on a daily basis.

A problem-solving approach (Gath & Mynors-Wallis, 1997) was taken to exploring Karen’s dilemma and different options available to her – including the option of being
“different” in her relationship with her husband by being more assertive. Karen’s life-story was reviewed with an emphasis on examples of times when she had felt assertive and strong, in order to promote access to her more “capable” mind-in-place. Imagery was used to strengthen the idea of having choices within relationships.

**Outcome and evaluation**

There were slight declines in Karen’s BAI and BDI-II scores from pre- to post-therapy. Karen’s BAI score remained in the “moderate” category, while her post-therapy BDI-II score had reduced to the “mild depression” classification. Karen felt she had become more assertive during therapy: she had been able to handle challenging work-related interpersonal situations more assertively, and had initiated discussions about important emotional concerns with her husband. However, she continued to have difficulty distinguishing assertive from passive strategies, interpreting her ability to accept a response she was not happy with as a sign of improved emotional control. From the trainee’s perspective, this suggested Karen’s progress to using more assertive strategies and being more self-accepting remained fragile. On reflection, the more directive approach this sometimes drew the trainee into in distinguishing assertive from non-assertive strategies may have undermined Karen’s ability to build on her capabilities and self-determine her application of new strategies. A longer therapeutic intervention might have enabled more supportive follow-up in this respect.
PEOPLE WITH LEARNING DISABILITIES CASE REPORT SUMMARY

“Brief anger-management work with a 37 year-old man with a learning disability”

Reason for referral
Paul Read was a 37 year-old man who was unemployed apparently due to epilepsy, but participated in voluntary pursuits including repairing bikes and gardening. He was referred by his GP, who reported “learning difficulties” and “anger problems”. Paul's case was placed on the waiting list for the Clinical Psychology Service of the local Community Team for People with Learning Disabilities. At the time, the Clinical Psychology Service was experiencing considerable resource-strain, with a waiting list up to 18 months long and a partial service operating, providing consultations and some brief, symptom-focused interventions.

After four-months' wait, Paul's mother contacted the service saying Paul was “threatening suicide” and had broken his finger smashing his fist into a wall during an angry “outburst”. Another three months later, Paul's mother reported that, due to a relationship breakdown, Paul was likely to be made homeless within months and needed urgent support. Social Services then requested formal assessment to clarify Paul's eligibility for help on the grounds of having a learning disability.

Assessment
A psychometric assessment using the Wechsler Adult Intelligence Scale 3rd Edition (WAIS-III) was conducted by the Chartered Clinical Psychologist and observed by the trainee. This was supplemented by other information-sources including questionnaires completed by Paul, his mother, and his ex-partner, which suggested that Paul had long-standing difficulties and was experiencing problems in his current social functioning – particularly in coping with relationships with his ex-partner and her two children.

Paul's performance on the WAIS-III gained him a Full Scale IQ score of 59, a score in the Extremely Low range, suggesting he had an intellectual impairment. Paul's
Performance IQ score (69) and Verbal IQ score (58) were statistically-significantly different, which suggested his Full Scale IQ score was not a valid representation of his difficulties, and was consistent with Paul's own perception that he was stronger at practical than language-based tasks. On the basis of his WAIS-III profile, the reported long-standing nature of his difficulties, and impaired social functioning, the Chartered Clinical Psychologist concluded Paul had a learning disability and referred him for appropriate support.

A joint assessment-for-treatment interview with the trainee and Chartered Clinical Psychologist was arranged. Paul attended this session in a highly angered state following a benefits-related problem. He had shouted at his mother and torn up his benefits book, but already regretted this. This enabled a discussion of how anger was affecting his life and an agreement to work together to find new coping strategies.

**Formulation**

Paul's anger-management difficulties were formulated in terms of the transactional, cognitive-behavioural approach outlined by Novaco (1985, cited by Black, Cullen & Novaco, 1997). Several current stressors affecting Paul were identified including relationship discordance with his ex-partner, complicated family dynamics, and the recent sudden death of his father, whose body had been washed up on a beach, attributed by Paul to suicide. Paul also faced the challenges of having a learning disability and physical problems including epilepsy. Consistent with the Novaco model (1985, ibid), he appeared to appraise these external stressors as threatening and antagonistic. The effects of his anger and subsequent aggression on others appeared to worsen his social situation, adding to the stressfulness of his circumstances – creating a vicious circle.

Paul said his father had been unable to tell other people about difficult feelings and thought the power of these unexpressed feelings had ultimately led to his death. Meanwhile, he felt that anger had distorted his older brother – currently charged with and facing imprisonment for an assault on a train guard – into a “nasty and vicious person”. It was hypothesised this led to a dilemma between two drastically different approaches to emotional expression, and that Paul's current strategy of
suppressing anger until it reached intolerable levels might be a compromise designed to avoid the pitfalls of the two extremes.

**Intervention and outcomes**

On the basis of this formulation a three-step intervention was devised to help Paul identify anger symptoms, understand the precursors of anger and learn alternative coping strategies. Due to resource limitations, a very brief, three-session intervention was conducted by the trainee.

Paul readily identified anger symptoms including muscle tension and also described visual imagery of wanting to hit or throw things. He responded to cartoons depicting passive, aggressive and assertive ways of expressing anger, identifying that his strategies were often aggressive. A key source of motivation for change was Paul's sense of hurt that others saw him as an aggressive person. Paul already employed strategies to make anger-provoking situations safer – such as walking away before he hurt someone – and these were validated as useful strategies when he felt he might "explode". Strategies to prevent the build-up of anger once annoyed were also discussed. Visual imagery was used to depict the strategy of “speaking up” rather than bottling up feelings.

Paul was given a “coping card” with visual reminders of the strategies and training in relaxation techniques to reduce the build up of anger-associated physiological arousal (Zillman, 1983, cited by Black et al., 1997).

A six-week follow-up session was arranged. By this time, Paul's case had been allocated to an Occupational Therapist (OT) and Social Worker, and new accommodation had been secured. However, Paul found this process stressful, and although he had managed to walk out of meetings when angry, had been verbally abusive to staff. The OT attended the follow-up to enable her to provide reminders of anger-management strategies to Paul during her ongoing work with him. Paul recalled ideas about the symptoms and triggers of anger well, but, as suggested by recent events, recalled little about socially acceptable anger-expression.
A multi-professional meeting was held with the OT and social worker to discuss their concerns about managing ongoing professional relationships with him. Paul's liking for winning arguments was highlighted and reformulated. A detailed report to all professionals providing details of this work, the formulation and a list of strategies for improving working relationships with Paul was provided.
CHILDREN AND YOUNG PEOPLE CASE REPORT SUMMARY

"Formulation-led work with a nine year-old girl presented with tantrums, separation anxiety and headaches – incorporating family-based intervention to improve child-parent attachment relationships and individual cognitive-behavioural therapy to reduce anxiety and enhance affect self-management"

Reason for referral

Gemma Shellcroft, a nine year-old girl, was referred by her GP to the Child & Adolescent Mental Health Service (CAMHS) with separation anxiety and “tantrums” manifesting in aggressive behaviour towards her mother, Lorraine. A pre-assessment questionnaire also detailed headaches, and owing to this, Gemma’s case was assigned to the trainee for cognitive assessment in addition to general psychological assessment of her behaviours.

Assessment

The first assessment session was attended both by Gemma, Lorraine and her partner Rob, Gemma’s father Paul and her step-mother Becky. The four adults explained how they maintained a close relationship with one another. Becky accompanied Lorraine to a second session to detail presenting concerns. Lorraine attributed most of the problems to “insecurity”. She said Gemma had not been able to accept her new partner Rob, and this seemed to have “turned into nasty thoughts”. Gemma feared her mother would catch fire from a Bunsen burner at work, and would repeatedly check that Lorraine would collect her from school, or call out “You are still there aren’t you Mummy?” during the evenings at home. In addition, Lorraine found Gemma’s sometimes aggressive behaviours difficult to control: she said that Gemma had hit her, bent her knuckles back, made moves to throw objects at her and had said spiteful things like “I hope your mother dies”. Lorraine perceived the behaviours to be more frequent when Rob was around. Becky said Gemma “never put a foot wrong” during stays at her home to visit Paul.
A further assessment session was held with Lorraine on her own. She reported that Gemma was frequently reluctant to attend visits to see her father and often distressed afterwards. Lorraine thought Gemma felt unloved by Paul and said she had complained that she was given little attention by Paul and Becky compared with her two half-sisters.

A cognitive assessment session was conducted using the Wechsler Intelligence Scale for Children 3rd UK Edition (WISC-III-UK). Gemma’s Full Scale IQ Score of 82 placed her performance in the low-average range. She appeared to find visuo-spatial tasks involving independent problem-solving difficult, but did better at those involving following instructions and performing at speed.

**Formulation**

Gemma’s low-average performance on the WISC-III-UK suggested she was likely to struggle relative to her peers at school. Children’s independent problem-solving skills have been found to be influenced by confidence (Hartley, 1986, cited by Thornton, 1995). There were no discrepancies suggestive of underlying neuropathology and Gemma was referred back to her GP for further assessment of her headaches, including the possibility of migraine.

Attachment, systemic and cognitive-behavioural theories were applied to understanding relationships in the Shellcroft family. It was hypothesised that Paul, Becky and their two children formed a “subsystem” around which Gemma felt peripheral. Lorraine now wanted to form a sub-system including herself, Rob and Gemma, but thought Gemma was frightened of being excluded from this, in part because Rob wanted very little contact with her, perceiving her as rude. It was hypothesised that Gemma’s attachment with her mother was the one upon which she relied most heavily, and that this could underline both her proximity-seeking behaviour and her fear of losing this most valued relationship, manifesting in protest-behaviour when she feared her loss.

Gemma’s ongoing contact with her father was formulated to seem contingent on her good behaviour – explaining her efforts to regulate her behaviour during stays at his
and Becky’s home. However, her disappointing experiences during these visits, which included teasing from her half-sisters that Paul was their Daddy not Gemma’s, were hypothesised to give rise to her yearning for her own mother and father to reunite. This was evidenced in her comments made to Lorraine that she should marry Paul again and Rob should marry Becky.

Inconsistent discipline, and insecurity of attachment were also hypothesised to promote emotional dysregulation in Gemma – particularly in situations involving her mother and any perceived threat of loss.

**Intervention**

A meeting with Lorraine and Paul was arranged to discuss how Paul could build the quality of his interactions with Gemma. While he agreed that this would be helpful, he said he had little time to give her. The idea of “quality time” and turning routine activities into special time by, for instance, working as a “little team” on the washing-up or shopping was suggested, and Paul planned to incorporate these ideas. However, at a four-week follow-up Paul had not put any ideas into practice and had hardly seen Gemma due to his work as a lorry-driver. Problem-solving (Gath & Mynors-Wallis, 1997) was taught as a means of thinking through alternative strategies, and it was agreed that Paul, Lorraine and Becky would meet to apply this technique to think through ways forward.

Psychoeducational work introduced Lorraine to behavioural strategies including the use of praise, ignoring and time-out from the possibility of reinforcement Webster-Stratton (1992). In response to her feedback, Rob determined to reward Gemma’s friendly behaviour with friendly, interested responses, and to respond to rudeness with the natural consequence of ignoring and disengaging.

Three individual sessions were conducted with Gemma to conduct “Feelings Work” – including by identifying appropriate strategies for coping with feelings of sadness and anger. Visual techniques including posters made by Gemma and the trainee in session were used to provide reminders of strategies.
Outcome and evaluation

The short duration of the intervention made it difficult to ascertain its longer-term outcomes. Lorraine perceived some “slight” improvement in Gemma’s behaviour at home and an early but dramatic improvement in the quality of interactions between Gemma and Rob.

On reflection, structural systemic patterns might have benefited from more attention. In particular, Gemma’s behaviours might have been viewed as functional in maintaining a relationship between Lorraine, Paul and Becky, based on Lorraine’s need for support.
SPECIALIST ADOLESCENCE CASE REPORT SUMMARY

“Psychological therapy incorporating a narrative approach with a 15 year-old girl presenting with low mood and substance-use”

Reason for referral
Jade Taylor, 14 years-old, was referred to the local Child & Adolescent Mental Health Service by her GP with “possible anxiety/depressive symptoms”. The GP also reported an episode of “non-specific symptoms” consistent with substance misuse (which Jade had denied). Jade’s presenting concerns were having “Come off the side of the right track” and done some things she regretted. She described herself negatively, and her mother, who attended with her, said Jade had a “lovely nature but can also be incredibly selfish, very dishonest, deceitful and lazy”.

This followed an episode of stealing and illicit drug-taking including cannabis, ecstasy and LSD-use. Jade had experienced frightening effects and had stopped using ecstasy and LSD, but continued cannabis-use costing around £80 per week. Jade reported stealing to fund this, and was concerned about the impacts of her behaviours on those around her – especially her relationship with her mother.

Assessment
An assessment interview spanning three sessions was conducted and emphasised collaborative exploration of concerns around substance-use. Jade was the last-born of four siblings. Her mother had experienced a very complicated pregnancy. She had been unaware she was carrying twins, suffered a miscarriage at three-months but continued to experience morning sickness and so returned to her GP who detected Jade’s heartbeat. Jade’s father, to whom she was reportedly close, had left the family five years previously, and since had very little contact with Jade. A succession of stressful events had affected the family since. Jade’s sister had experienced depression culminating in overdoses and hospitalisation, her oldest brother was involved in a motorbike accident he was lucky to survive, and the younger of the two brothers had been affected by substance-use which led to violence necessitating several calls to the Police. Jade’s sister, then 17, had a baby and was supported by
Jade’s mother in raising her. Jade’s mother believed Jade had consequently “lacked my time” since her father left home.

There was a diffuse presentation of behaviours that could be characterised as risk-taking by Jade. In the preceding year, she had experienced a “pregnancy scare”, and “done a lot of drinking and learnt my lesson about that” in addition to her experiences of substance-use and stealing. She had though, coped in ways to avoid the potentially-negative consequences of these risks she had witnessed affect her siblings.

Jade’s and her mother’s responses to the Strengths and Needs Questionnaire were suggestive of High Need Level. Her scores on the Children’s Depression Inventory suggested “very much above average” levels of depressive symptoms.

**Formulation**
A generative approach was taken to formulation of the complex presentation affecting Jade, where substance-use could be regarded as part of a wider pattern of risk-taking behaviour and psychological distress.

The attachment between Jade and her mother was hypothesised as being characterised by affection but lack of availability. The level of risk-behaviour that had affected Jade’s siblings was hypothesised to have prompted learning about the value of risky behaviour in increasing availability of care. Jade’s risk-behaviour could therefore be viewed as functional in securing care and alliance with her mother, and in communicating distress. However, such behaviour also elicited her mother’s criticism and disappointment, fuelling Jade’s self hatred and low self-esteem, and creating a cycle of further distress and care-seeking in form of risk-behaviour.

**Intervention**
Narrative therapy techniques including externalising conversations were used to explore Jade’s thoughts and motivations surrounding the behaviours of concern. This involved naming the problems and labelling them as external to Jade, then interviewing Jade about their purposes, techniques, gifts, thefts, plans, motives and
eventual destinations. Unique outcomes of “resisting” the problems were sought, enabling identification of successful coping strategies. Jade identified some ambivalence about the role of “the puff” in her life: she valued its relaxing effects but believed it was damaging her physically and mentally, giving her a bad temper, confusing her thoughts, and making her “skinny-bony” by reducing appetite. Relaxation techniques were introduced as an alternative means of “chilling out”. Following a three-week break in therapy, Jade reported to have cut the cannabis-use from £80 per week to £5 per fortnight – a change maintained by end of therapy.

Solution-focused family work was also conducted with Jade and her mother to identify steps towards their hoped-for “miracle” of being closer again. Jade’s mother organised a surprise cinema outing, which they both greatly enjoyed, on the basis of this, but continued to find it hard to find time for such contact.

The wider pattern around risk was explored following a period of not eating, and an episode where Jade’s boyfriend and a mutual friend were arrested (following an armed robbery) during a Police raid on the house where Jade and peers were staying. Jade’s fury at being caught up in such events prompted an externalising conversation where risk was portrayed as taking different forms in an attempt to influence Jade’s life. Jade identified “thinking things through” as an alternative to the risk.

**Outcome and evaluation**

Jade reported that therapy had helped her learn that she could make herself better, be clever and think things through. On reflection, more attention to socio-cultural influences surrounding Jade as individual, young person, member of her family, and young woman might have been helpful. Such influences could provoke pressure to conform to the positive social-identifying behaviours of her peer group, pressure to perform in school, pressure to be thin and pressure to be happy and “well-adjusted”. Cannabis-use could be viewed as functional in responding to these pressures – facilitating a sense of belonging in her peer-group, alleviating academic pressure, stealing Jade’s appetite, and helping Jade feel relaxed. Therapy may not have adequately addressed alternative means of coping with these pressures.
OLDER PEOPLE CASE REPORT SUMMARY

"An extended assessment with a 69 year-old woman presenting with recurrent depression and unexplained physical and functional symptoms"

Reason for referral
Mrs Kathleen Bernard, a 69 year-old retired secretary, was referred by a junior medic (SHO) to the Clinical Psychology Service of the local Community Mental Health Team for Older People. The SHO detailed a 17-year history of recurrent depressive episodes including a current episode which had so-far lasted two years and seemed “resistant” to pharmacological treatment. Mrs Bernard said that she currently found little interest or enjoyment in anything and felt a strong sense of insecurity centred around the welfare of her husband, on whom she depended for care and assistance with activities of daily living. She said she had lost her confidence to do almost everything.

Initial assessment indicated that Mrs Bernard had experienced two previous episodes of depression and had previous involvement with an Occupational Therapist (OT) from the local working-age team. Both Mrs Bernard’s recollections and those of the OT suggested the depression had sudden onset with no obvious precipitants and sudden remission with no obvious cause for resolution. The OT also reported that Mrs Bernard had demonstrated symptoms of apraxia and inexplicable falls without reflexes.

Assessment
A semi-structured assessment interview conducted across three hour-and-a-half-long sessions was conducted. Mrs Bernard reported a generally happy childhood. Born before the outbreak of war, she recalled her family receiving extra rations of groceries because her father was in a reserved occupation as a line-etcher. She recalled feelings of insecurity as he attended to fire duties in central London during the Blitz, and also when he went for walks after occasional rows with her mother. Her father had suffered from bouts of depression but Mrs Bernard said he was always positive, talking about when he would be better. Mrs Bernard had married,
and she and her husband had adopted a son after finding they could not have their own children. Mrs Bernard said she was delighted with her son and had “lived life through him”. This suggested that Mrs Bernard’s early life had been characterised by social participation, marital intimacy, and ability to adjust to restrictions as well as appreciating relative privileges. However, in mid-life, Mrs Bernard said she had felt rather redundant and began to experience depression around this time, culminating in overdoses and a hospitalisation.

Several standardised, criterion-referenced measures were used to assess psychological symptoms and processes including the Beck Depression Inventory 2nd Edition (BDI-II), Beck Hopelessness Scale (BHS), Hospital Anxiety and Depression Inventory (HADS) and the Millon Clinical Multiaxial Inventory 2nd Edition (MCMI-II). Mrs Bernard’s BDI-II profile suggested “severe depression” and greater biological than affect-related symptomatology. The HADS suggested moderate anxiety and depression.

A discussion with Mrs Bernard’s GP revealed his perception of a dissociation between functional and affective symptoms. The GP also reported that Mrs Bernard had long-standing anxieties about her health that preceded an episode of hypertensive encephalopathy. As a result, the GP and Mrs Bernard’s husband had decided against telling Mrs Bernard how seriously ill she had been. The GP said the large number of medications Mrs Bernard now took to control her blood pressure could give rise to “any number” of side-effects.

Staff at the Day Hospital Mrs Bernard attended reported that she had suffered a loss of consciousness while attending the unit but that no cause had been found. They also detailed unusual social behaviour including a strong preference for predictability and an apparent difficulty in appreciating others’ needs.

Such disruption to social functioning together with reported apraxic symptoms and falling were suggestive of possible neuropathology. Literature search surrounding the effects of both chronic hypertension and acute hypertensive encephalopathy found theory and research relating to “vascular depression” – a depression-like condition
presenting with greater functional morbidity than affective distress and with frontal lobe syndrome-like features including executive function problems. This was consistent with Mrs Bernard's clinical history and symptomatology.

The National Adult Reading Test Revised Edition (NART-R) yielded a predicted Full Scale IQ (FSIQ) Score of 113. Mrs Bernard's performance on the Wechsler Adult Intelligence Scale Revised Edition (WAIS-R) gained her a FSIQ of 88 — a discrepancy larger than any found in the NART-R normative sample. Qualitative aspects of Mrs Bernard's WAIS-R performance were suggestive of problems with gestalt reasoning. Previous clinical reports of measures of brain anatomy and functioning including computer-assisted tomography (CAT) and magnetic resonance imaging (MRI) scans were obtained and were consistent with cerebrovascular disease.

**Formulation**

"Vascular depression" resulting from chronic hypertension was accepted as an hypothesis likely to explain the pattern and presentation of Mrs Bernard's episodes of depressive symptoms and functional morbidity. However, other possible contributing factors were also outlined. This included the possibility that, in line with attachment theory, she developed an internal working model of her father as loving, caring but vulnerable, and now projected this onto her caring husband, giving rise to the intangible fears for his wellbeing. The interruption of her mid-life transition by episodes of hypothesised vascular depression was formulated to have deprived Mrs Bernard of opportunity to find protective valued roles. Mrs Bernard's level of inactivity was also likely to perpetuate lack of quality of life. Without satisfactory explanation of her symptoms, Mrs Bernard had attributed her condition to personal weakness — possibly promoting maladaptive ruminative rather than more helpful active coping attempts.

**Outcome and evaluation**

On the basis of the formulation, a detailed report was written for staff involved in Mrs Bernard's care. Feedback was also given to Mrs Bernard, and attention was focused on how she would like the later part of her life to develop in the light of the assessment findings, in line with the principles of Hillman (1999). Mrs Bernard came
to value the principles of accepting the validity of her difficulties and "looking on the bright side". She appreciated the consideration given to different aspects of her presentation in the extended assessment. Her BDI-II score at the end of the assessment had reduced from 35 to 20 – placing her symptoms in the "moderate" classification.
Research dossier
INTRODUCTION TO THE RESEARCH DOSSIER

This dossier contains materials that are intended to represent research experience gained during the course of study towards the degree of Doctor of Psychology (Clinical Psychology).

• The research log is aimed to provide an overview of the skills developed and experiences acquired throughout the three-year course of study, including the application of such research skills to clinical practice

• The Service Related Research Project represents experience of quantitative audit work conducted within an NHS Trust to inform service development

• The Qualitative Research Project has been included as an informal addition to the dossier to represent experience of qualitative research methodologies

• The Major Research Project is aimed to represent an original piece of research, conducted over a two-year period, and utilises a quantitative methodology in examining a topic of clinical relevance.
<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
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<tbody>
<tr>
<td>Conduct a literature search</td>
<td>Extensive experience throughout training in research, clinical and academic contexts. Examples include: 1) Literature search towards two research proposals for the Service-Related Research Project, multi-disciplinary team working and staff stress and support in mental health services. Additional literature search into staff experiences of clinical governance for eventual Service-Related Research Project. 2) Complex literature search into multiple research areas relating to asthma in adolescence, for Major Research Project. 3) Routine use of NHS electronic databases (such as KA24) to research up-to-date clinical evidence while on placement; for example, a recent literature search on psychological approaches to auto-immune disorders.</td>
<td>November 2001, January 2002, June 2002, November 2002 – March 2004</td>
</tr>
<tr>
<td>Date research skill/experience acquired</td>
<td>Description of how research skill/experience acquired</td>
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<tr>
<td>August 2002</td>
<td>Ability to critically examine psychological literature and evidence has been applied to research, academic and clinical contexts throughout training. For example:</td>
<td></td>
</tr>
<tr>
<td>May 2003</td>
<td>1) Prepared a literature review on staff responses to Clinical Governance as part of Service.</td>
<td></td>
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<tr>
<td>May 2004</td>
<td>Related Research Project.</td>
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<tr>
<td>August 2003</td>
<td>2) Prepared a brief literature review on clinical psychologistsceptions of the desirability of personal therapy during training for Qualitative Research Project.</td>
<td></td>
</tr>
<tr>
<td>June 2003</td>
<td>3) Examined literature relating to emerging conduct disorders to guide new service-provision and make a presentation regarding evidence-based approaches to conduct disorders to a group of Child Psychologists while on Specialist Adolescence Placement.</td>
<td></td>
</tr>
<tr>
<td>April 2003</td>
<td>4) Formulated a series of research questions for Major Research Project in response to thorough review of wide-ranging evidence-base and a speculated model attempting to account for various research findings. Formulated a specific research question as part of a research group for the Qualitative Research Project. Specific research question was: &quot;What are Trainee Clinical Psychologists' perceptions of the desirability of personal therapy during clinical training?&quot;</td>
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<tr>
<td>November 2001</td>
<td>1) Prepared a brief research proposal on multi-disciplinary team-working in mental health settings. After discussion with research supervisor, it was decided that the topic might be too contentious at a time of organisational change in the host NHS Trust, and the project was curtailed.</td>
<td></td>
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<tr>
<td>February 2002</td>
<td>2) Prepared a brief research proposal on staff stress and support following discussion with a research supervisor, field supervisor and a Beacons Trust that had conducted work of relevance. However, following discussion with the Head of Psychology and Clinical Governance lead, it was decided the process of obtaining Trust approval was likely to be too lengthy and complicated due to an approaching Trust reorganisation, and the project was abandoned.</td>
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<tr>
<td>February 2003</td>
<td>3) Prepared a brief research proposal for the Major Research Project on psychological approaches to self-management behaviour in adolescents with asthma. This proposal was later developed further and led to a more detailed research protocol.</td>
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</tr>
<tr>
<td>September 2003</td>
<td>Wrote a detailed research proposal which formed part of approval applications to a Local Research Ethics Committee, the University of Surrey Ethics Committee, and the host Trust's Research &amp; Development Management Team.</td>
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<tr>
<td>Obtain appropriate supervision/collaboration for research</td>
<td>June 2002</td>
<td>1) Secured collaborative relationships with staff in a Quality Assurance and Audit team of a newly-formed local NHS Trust to facilitate audit work as part of Service-Related Research Project. Obtained field supervision from a regional clinical psychologist.</td>
</tr>
<tr>
<td></td>
<td>February 2003</td>
<td>2) Obtained field supervision and collaboration with the Professor of Health Psychology at the Centre for Health Care Research at the University of Brighton &amp; Sussex Medical School and with a consultant paediatrician specialising in respiratory medicine. Worked alongside clinical teams in the host Trust to conduct research in clinics.</td>
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<td></td>
<td>January 2004</td>
<td>3) Worked with research supervisors and tutors at the University throughout training to address development of research projects and experience.</td>
</tr>
<tr>
<td></td>
<td>September 2003</td>
<td>1) Wrote information sheets and consent forms for parents of participants aged 11-15.</td>
</tr>
<tr>
<td></td>
<td>July 2004</td>
<td>2) Contributed to writing participant information sheet and consent form for Qualitative Research Project.</td>
</tr>
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</table>
## LOG OF RESEARCH EXPERIENCE

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</thead>
</table>
| Judge ethical issues in research and amend plans accordingly | 1) Considered ethical issues relating to the preservation of anonymity of staff participating in a Staff Clinical Governance Survey for Service-Related Research Project. Adapted questionnaire and analysis of data to avoid jigsaw-identification of staff – e.g. by ensuring staff categorised their job titles in large groups rather than individual posts.  
2) Considered ethical issues involved in interviewing trainee clinical psychologists as part of Qualitative Research Project. Worded letters of invitation to avoid expectation of participation and framed as request for help in finding participants.  
| Obtain approval from a research ethics committee | Obtained approval from a Local Research Ethics Committee, the University of Surrey Ethics Committee and the host Trust's Research & Development Management Team, in addition to obtaining honorary contract. Learned about processes and time-scales involved with submitting such approval applications and the importance of time-managing work to use waiting times productively. | September 2003 to February 2004                                                                                                               |
## LOG OF RESEARCH EXPERIENCE

<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
</table>
| Collect data from research participants | 1) Conducted mailshot of questionnaires to staff and collected data via internal mail system for Service-Related Research Project  
2) Conducted qualitative research interview for Qualitative Research Project  
3) Administered questionnaire procedures with adolescent participants and parents attending a busy paediatric outpatient clinic. Learned to conduct complex procedures efficiently and flexibly to minimise impact of research on clinics – for example by utilising pre-appointment waits. | July 2002  
May 2003  
February – June 2004 |
| Set up a data file | 1) Transferred data file from electronic format used by Trust to SPSS, and transformed data to enable descriptive and inferential analysis for Service-Related Research Project  
2) Transcribed research interview into table format to enable Interpretative Phenomenological Analysis for Qualitative Research Project.  
3) Set up large data file to facilitate data analysis in SPSS and smaller data files to construct bar-charts and scatterplots using Excel for Major Research Project. | August 2002  
May 2003  
June 2004 |
| Analyse quantitative data | 1) Conducted descriptive and inferential analysis of quantitative data for Service-Related Research Project  
2) Carried out in-depth data analysis constructing scales, examining reliability and conducting descriptive and inferential analysis to explore a series of research questions and hypotheses for Major Research Project. | June 2002  
June 2004 |
## LOG OF RESEARCH EXPERIENCE

<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analyse qualitative data</td>
<td>Applied principles of Interpretative Phenomenological Analysis to analysing an interview transcript for themes and constructed a summary table outlining themes and sub-themes. Applied creative approach to overcoming difficulties resulting from missing research group meeting where cases were integrated, comparing own summary with analysis of research group to reflect upon process of Interpretative Phenomenological Analysis itself.</td>
<td>April – May 2003</td>
</tr>
<tr>
<td>Summarise results in figures/graphics</td>
<td>1) Used variety of figures and graphs to depict responses to Staff Clinical Governance Survey and illustrate relationships between constructs. 2) Used tables, bar-charts and scatterplots to present results in Major Research Project. Learned to use Excel to provide clearer figures.</td>
<td>September 2002 July 2004</td>
</tr>
<tr>
<td>Interpret results from data analysis</td>
<td>1) Service-Related Research Project involved interpreting SPSS output to report patterns of results and discuss these in relation to service strengths and development needs. 2) Interpreted own summary of themes and that from research group to reflect upon process of Interpretative Phenomenological Analysis. 3) As part of Major Research Project, interpreted SPSS output to present results, and discussed these in relation to previous research, a speculated model and potential clinical implications.</td>
<td>August 2002 May 2003 June 2004</td>
</tr>
</tbody>
</table>
## LOG OF RESEARCH EXPERIENCE

<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
</table>
| Present research findings/plans to an audience | 1) Gave presentation about Service-Related Research Project to first-year trainees preparing to embark on own projects. Provided reflections on process of research to facilitate shared learning.  
2) Worked with rapidly changing staff team to find useful means of feeding back results of Service-Related Research Project to host Trust. Organisational change and circumstances led to significant delay. Eventually submitted a report written for audience of staff throughout the two specialities involved in the audit, which included a summary of key points. Report was welcomed by new Head of Clinical Governance in the Trust.  
3) Presented plans for Major Research Project to second-year trainees about to begin planning their own projects. | September 2003  
September 2003  
September 2004 |
| Produce a written report on a research project | 1) Produced written report of Service-Related Research project.  
2) Produced written report of Service-Related Research project for Trust staff.  
3) Produced written report of Qualitative Research Project  
4) Produced written report of Major Research Project | September 2002  
September 2003  
May 2003  
July 2004 |
| Defend research project at an oral examination | To be acquired at viva voce examination of Major Research Project following submission of this portfolio | Due September 2004 |
# LOG OF RESEARCH EXPERIENCE

<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Submit research report for publication in a journal/book</td>
<td>Worked as part of a research group to submit for publication a research report on the application of the Staff Clinical Governance Survey as an audit tool. This report has been accepted for publication in a journal but has not yet been published.</td>
<td>December 2003</td>
</tr>
</tbody>
</table>
Informed treatment choice for clients presenting with substance-use, depression and conduct disorder.  
Informed an extended assessment with a woman presenting with depression and functional symptoms, who had a history of chronic hypertension.  
Informed thinking and awareness of organisational processes and needs in the development of psychosocial services for palliative care in the area local to Specialist Clinical Health Psychology placement. | June 2003, November 2003, April 2004 |
SUMMARY OF RESEARCH EXPERIENCE

• **Service-Related Research Project**
  “An exploratory study of staff knowledge about, attitudes towards and implementation of clinical governance, using the Staff Clinical Governance Survey”
  (Part 1)

• **Qualitative Research Project**
  “Trainee clinical psychologists’ perceptions of the desirability of personal therapy during clinical training – An Interpretative Phenomenological Analysis”
  (Part 1)

• **Major Research Project**
  “A case of social pressure versus asthma pressure? Initial examination of a model portraying exertion as a context for conflict amongst adolescents with asthma”
  (Part 2)
SERVICE-RELATED RESEARCH PROJECT

An exploratory study of staff knowledge about, attitudes towards and implementation of clinical governance, using the Staff Clinical Governance Survey

Statement of anonymity: Some details have been removed to preserve the anonymity of the participating NHS Trust.

September 2002
Year I
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Abstract

Background: Clinical Governance was outlined as a linchpin in the Government’s drive to increase the quality of healthcare delivered by the National Health Service. It calls for major cultural change as well as the implementation of standards including the so-called “seven pillars”. Staff knowledge about and attitudes towards Clinical Governance were therefore audited in addition to Implementation of Clinical Governance.

Method: 239 staff-members from an NHS Trust Locality Directorate’s specialties of Working Age Mental Health and 110 staff from Services for People with Learning Disabilities were sent an adapted version of the Staff Clinical Governance Survey, which examines Knowledge, Implementation and Attitudes relating to each of the seven pillars of Clinical Governance.

Results: In general, attitudes towards Clinical Governance were positive. Knowledge and Implementation were patchier with Clinical Audit emerging as a particular service development need despite positive staff attitudes towards this pillar. Significant positive correlations were found between constructs. The strongest of these was between Knowledge and Implementation, with a weaker correlation between Attitude and Implementation.

Conclusions: The results must be interpreted in the light of the self-selected nature of the participant sample. The Staff Clinical Governance Survey appears helpful in highlighting service strengths and development needs, and may help target staff consultation to elucidate particular barriers and supports. However, further investigation is needed into the reliability and validity of the items and constructs, as there was some indication that some constructs may not be unitary.
Acknowledgements

Many thanks are owed to all those who helped bring this audit project to fruition. Particular thanks are owed to Dr James Murray for lending his expertise, support, advice and lots of time. Dr Susan Howard and Dr Victoria Senior offered patience, sympathy and helpful suggestions along the bumpy road to completion. Peter and Adelle from the NHS Trust involved in the audit provided technical and practical backing without which the project could not have gone ahead. Hilary and Jane from Psychology at the Trust have also provided ground level support, while other colleagues made a magnificent effort to help with frantic envelope stuffing to get the questionnaire distributed. Finally, sincere thanks are due to all those staff members who took the time to participate in the survey.
Introduction

Clinical Governance was a linchpin of the Government’s drive to enhance the quality of healthcare provided by the National Health Service (NHS) (Department of Health (DoH), 1997). The 1998 DoH publication *A first class service, quality in the new NHS*, outlined Clinical Governance as a key mechanism aligning local health service provision with new national standards (including the National Service Frameworks) and evidence-based guidelines (for example those of the new National Institute for Clinical Effectiveness).

Clinical Governance (CG) embodies a set of component principles, or “pillars” (Commission for Health Improvement, 2000, cited by Murray, Aguirregabiria & White, 2002) that engage NHS Trusts, professional groups and individual employees in:

- Evidence-based practice – the application of research in finding effective clinical interventions;
- Proper use of clinical information;
- Managing risk;
- Staffing and staff management;
- Education, Training and Lifelong Learning;
- Effective clinical audit and monitoring of clinical care;
- Attention to and involvement of service-user experience in enhancing the quality of delivered care;

(DoH, 1998; Hall & Firth-Cozens, 2000; Murray et al, 2002).

As a central instrument of quality enhancement, it is vital for NHS Trusts to audit implementation and staff awareness of CG principles. But the attitudes of staff towards CG are also crucial. Negative appraisals of CG amongst staff may, along with more practical or informational problems, act as a barrier to implementing CG. For instance, Foy, Walker & Penney (2001) highlight 41 potential barriers to CG, while further authors mention numerous others explicitly or implicitly. Some are largely practical in nature, for instance the financial cost of meeting new standards.
disruption to service delivery as change is implemented (Chambers & Boath, 2001), lack of time for planning and poor information technology (Firth-Cozens, 1999). Others are largely informational. Firth-Cozens (1999) found that, although 69% of staff surveyed had heard of CG, far fewer had any detailed understanding of it, and Foy et al. (2001) suggest research findings and guidelines are not being well disseminated to clinicians at “ground level”. Attitudinal or motivational barriers are, however, also apparent: for example disagreement with, and subsequent “rebellion against” guidelines (Chambers & Boath, 2001), and a tendency for audit to focus on favourable rather than concern-provoking areas of practice due to “a climate of securing contracts” (Hill, Evers, Thomas & Stevenson, 1999, p.24).

Cognitive theories of stress such as Lazarus’ transactional model (cited by Folkman, 1984) suggest contextual and individual dispositional factors influence how situations are appraised – combinations of perceived threat and low coping efficacy being most likely to produce stress and negative affect. This raises the possibility that, with CG, practical and informational barriers could have knock-on effects on staff attitude. Such interactions between practical, informational and motivational barriers are highlighted in the literature. Owen (1999) describes his perception that certain standards are unattainable and argues the fear induced by such standards could spark resistance to the whole CG package. Foy et al. (2001) highlight the demand created by “proliferating quantities of guidelines” (p. 170), the low sense of self-efficacy amongst healthcare workers who feel they do not have the knowledge to cope with such standards, and subsequent distaste for change.

Confusion about what Clinical Governance means could also act as a barrier. Some papers reflect dilemmas surrounding interpretation of CG with questions like “black hole or wormhole?” (Hill et al, 1999) “watchword or buzzword?” and “rhetoric…or substantive change” (Campbell, 2001). There are also contrasting hopes and fears. Some papers highlight clinicians’ hopes that CG will re-emphasise quality of healthcare over cost. Yet Hackett (1999), a Trust Chief Executive, perhaps highlights management-centred views that CG is the last chance for clinicians to prove they can self-regulate, before they are forced to “surrender their clinical control” to executive management (Hackett, 1999, p.213). Such contrasting interpretations and
expectations not only create an “emotionally charged climate” (Huntington et al, 2000, p.681), they may also invoke debate about ownership of CG as a process – which may in turn influence staff perceptions of the attainability and value of CG principles.

Staff knowledge of and attitudes towards CG are therefore important, in part, because they could act as barriers to its implementation. But they are also important in their own right, since the seven pillars of CG have been coupled with a demand for “major cultural change” (DoH, 1998, 5.21, p75). CG is not purely about controlling healthcare delivery by meeting standards, but also fostering a non-blaming culture that values continuous learning and thus facilitates quality improvement.

This study therefore aims, not just to audit the implementation of CG, but also to examine where gaps lie in staff knowledge of CG and attitudes could be improved.

This study took place in a locality of a recently reorganised NHS Trust. The previous Trust (2001) had audited some aspects of CG implementation and staff knowledge, but following organisational upheaval, CG leads were concerned staff attitudes towards CG may have deteriorated. While no previous data on staff attitudes were available for comparative purposes, this background did provide ideal opportunity for the study. The survey targeted staff in two locality specialties – Working Age Mental Health (WAMH) and Services for People with Learning Disabilities (SPLD) – enabling audit of a sufficiently large staff group without comparing staff working with clients from greatly different age ranges.
Aims and Research Questions

This study aimed to explore staff attitudes towards, and knowledge and implementation of, the above-mentioned seven pillars of Clinical Governance. As the study was exploratory, no specific hypotheses were formulated. However, the following research questions informed the audit:

1. What aspects of CG are being implemented, and what are the service development needs?

2. How much do staff members know about the principles of CG? What are their informational needs?

3. What are staff members' attitudes towards CG?

4. Are there relationships between staff knowledge and attitudes, and the implementation of CG?

5. Are there differences in knowledge, attitude and implementation between staff with or without management responsibilities, or between the two specialties?
Method

Design
The study was a questionnaire survey. Exploration of Research Question 4 was of correlational design – with staff knowledge and attitude measures acting as independent variables and CG implementation as the dependent variable. Examination of Research Question 5 utilised an independent-participants design: Specialty and Management Status were the two independent variables here, while staff knowledge, attitude and implementation measures acted as dependent variables.

Participants
All staff listed as working for the WAMH and SPLD specialties (this included nursing, support-worker, administrative and care-assistant staff), together with medics, occupational therapists and psychologists working with these specialties, were invited to participate in the study. 239 staff in WAMH and 110 staff in SPLD were contacted with a letter and questionnaire sent via internal mail.

Materials
An adapted version of the Staff Clinical Governance Survey (SCGS) (Murray et al, 2002) was used (See Appendix 1). This questionnaire contains six dichotomous, forced-choice items to elicit “global” attitudes to CG. Another section contains 36 items exploring staff members’ level of agreement with statements relating to their attitude towards, and knowledge and implementation of the seven pillars of CG (See Appendix 2 for relationships between questionnaire items and each construct). The questionnaire was being piloted current to this audit project (Murray et al, 2002) and so reliability and validity data were not available.

The questionnaire was re-formatted by a Trust Research Officer to enable computer-reading using Teleform software. This requires participants to shade-in circles corresponding to responses, which can then be scanned direct into a database. During re-formating, one item (regarding staff attitudes to Clinical Information (See Appendix 2)) was accidentally omitted.
Procedure

The questionnaire, together with an information letter and return envelope, was distributed to staff via internal mail. A closing date was set one calendar month following questionnaire distribution, although collection, by a Trust research officer, continued one week hence from this date.
Analysis and Results

All data were analysed using SPSS for Windows 10.1.

Response Rate

129 questionnaires were returned – a 37% response rate. Comparisons between specialties are detailed in Table 1 below.

Table 1: Distribution of and Response to the Staff Clinical Governance Survey

<table>
<thead>
<tr>
<th>Specialty</th>
<th>Population size (No. potential participants contacted)</th>
<th>Sample size (No. self-selected participants)</th>
<th>Response rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>WAMH</td>
<td>239</td>
<td>81</td>
<td>33.89</td>
</tr>
<tr>
<td>SPLD</td>
<td>110</td>
<td>48</td>
<td>43.64</td>
</tr>
<tr>
<td>Total</td>
<td>349</td>
<td>129</td>
<td>36.96</td>
</tr>
</tbody>
</table>

General attitudes to Clinical Governance

Responses to Section 2 of the SCGS (Appendix 1) are illustrated in Table 2. The percentage of all valid responses to each item is shown. Chi Square tests revealed no significant specialty-differences in responses to General Attitude Items. However, some significant differences were found between participants with and without management responsibilities, and these results are detailed.
Table 2: General Attitudes to Clinical Governance

<table>
<thead>
<tr>
<th>General Attitude Item No</th>
<th>Clinical Governance is...</th>
<th>Proportion of Responses (%)</th>
<th>All participants</th>
<th>Of those with management responsibilities</th>
<th>Of those without management responsibilities</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>A mystery</td>
<td>51.8</td>
<td></td>
<td>37.2**</td>
<td>63.1**</td>
</tr>
<tr>
<td></td>
<td>Clear</td>
<td>48.2</td>
<td></td>
<td>62.8**</td>
<td>36.9**</td>
</tr>
<tr>
<td>2</td>
<td>Overrated</td>
<td>44.6</td>
<td></td>
<td>40.9</td>
<td>50.0</td>
</tr>
<tr>
<td></td>
<td>Underrated</td>
<td>55.4</td>
<td></td>
<td>59.1</td>
<td>50.0</td>
</tr>
<tr>
<td>3</td>
<td>Useful</td>
<td>80.6</td>
<td></td>
<td>93.2**</td>
<td>73.2**</td>
</tr>
<tr>
<td></td>
<td>Useless</td>
<td>19.4</td>
<td></td>
<td>6.8**</td>
<td>26.8**</td>
</tr>
<tr>
<td>4</td>
<td>Simple</td>
<td>24.0</td>
<td></td>
<td>39.5**</td>
<td>13.0**</td>
</tr>
<tr>
<td></td>
<td>Complex</td>
<td>76.0</td>
<td></td>
<td>60.5**</td>
<td>87.0**</td>
</tr>
<tr>
<td>5</td>
<td>Welcome</td>
<td>68.3</td>
<td></td>
<td>76.7</td>
<td>63.8</td>
</tr>
<tr>
<td></td>
<td>Irritating</td>
<td>31.7</td>
<td></td>
<td>23.3</td>
<td>36.2</td>
</tr>
<tr>
<td>6</td>
<td>Tiresome</td>
<td>55.7</td>
<td></td>
<td>41.5*</td>
<td>66.7*</td>
</tr>
<tr>
<td></td>
<td>Energising</td>
<td>44.3</td>
<td></td>
<td>58.5*</td>
<td>33.3*</td>
</tr>
</tbody>
</table>

* Difference between management and non-management responses is significant to p≤0.05.
** Difference between management and non-management responses is significant to p≤0.01.

Attitudes, Knowledge and Implementation of Clinical Governance and its Seven Pillars

Responses to the Likert-type scales used in Section 3 of the SCGS (Appendix 1) were recoded so that, for all items, the level of agreement with the principles of CG was scored as in Table 3 below. In some Knowledge-items a “Don’t Know” response was assumed to represent disagreement with the statement and so scored as 2 (See Appendix 3 items so-recoded). With all other items, “Don’t Know” or invalid responses were excluded from analysis.

Table 3: Legend for range of scores

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Mean scores from items related to the Knowledge, Implementation and Attitude constructs (See Appendix 2) were calculated for each participant. A mean score of all items was also calculated for each client, to represent overall “Concordance” with CG. Mean scores for the sample are presented in Table 4 below.
Table 4: Mean scores for constructs

<table>
<thead>
<tr>
<th>Pillar</th>
<th>Mean score</th>
<th>SD*</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Knowledge</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk Management</td>
<td>3.66</td>
<td>0.71</td>
<td>1.75-5.00</td>
</tr>
<tr>
<td>Clinical Audit</td>
<td>2.67</td>
<td>1.04</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Staff and Staff Management</td>
<td>3.74</td>
<td>0.85</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Education, Training and Lifelong Learning</td>
<td>3.13</td>
<td>1.24</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Research and Effectiveness</td>
<td>3.64</td>
<td>0.79</td>
<td>2.00-5.00</td>
</tr>
<tr>
<td>Clinical Information</td>
<td>3.43</td>
<td>1.12</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Service-User Experience</td>
<td>3.86</td>
<td>0.91</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Overall Knowledge</td>
<td>3.47</td>
<td>0.50</td>
<td>1.96-4.57</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Implementation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk Management</td>
<td>4.03</td>
<td>0.93</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Clinical Audit</td>
<td>2.70</td>
<td>1.19</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Staff and Staff Management</td>
<td>3.48</td>
<td>1.00</td>
<td>1.33-5.00</td>
</tr>
<tr>
<td>Education, Training and Lifelong Learning</td>
<td>3.77</td>
<td>0.95</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Research and Effectiveness</td>
<td>3.27</td>
<td>1.07</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Clinical Information</td>
<td>3.73</td>
<td>0.56</td>
<td>2.00-5.00</td>
</tr>
<tr>
<td>Service-User Experience</td>
<td>3.26</td>
<td>1.12</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Overall Implementation</td>
<td>3.47</td>
<td>0.59</td>
<td>1.81-4.71</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Attitude</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk Management</td>
<td>4.39</td>
<td>0.62</td>
<td>2.00-5.00</td>
</tr>
<tr>
<td>Clinical Audit</td>
<td>4.05</td>
<td>0.85</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Staff and Staff Management</td>
<td>3.90</td>
<td>1.18</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Education, Training and Lifelong Learning</td>
<td>4.01</td>
<td>0.74</td>
<td>2.00-5.00</td>
</tr>
<tr>
<td>Research and Effectiveness</td>
<td>4.05</td>
<td>0.85</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Clinical Information</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Service-User Experience</td>
<td>3.92</td>
<td>0.95</td>
<td>1.00-5.00</td>
</tr>
<tr>
<td>Overall Attitude</td>
<td>4.05</td>
<td>0.46</td>
<td>2.58-5.00</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Overall Concordance</strong></td>
<td>(Mean of all Section 2 items)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3.61</td>
<td>0.44</td>
<td>2.47-4.63</td>
</tr>
</tbody>
</table>

*Standard Deviation

No significant kurtosis or skewness was found in the Knowledge, Implementation, Attitude or Overall Concordance Scores. Therefore, relationships and differences between these were analysed using parametric tests.

A two-way unrelated Analysis of Variance (ANOVA) revealed no significant differences in Knowledge, Implementation, Attitude or Concordance scores between
staff from different specialties. However, a significant effect \( p<0.05 \) was found for Management Status in the overall Attitude score. The mean Attitude score for participants with management responsibilities was 4.17, while that for those without was 3.98. Two significant \( p<0.05 \) interaction effects were also found. The mean scores associated with this interaction are detailed below in Table 5. Unrelated T-test findings, also detailed in Table 5, suggested the significant difference existed in both Implementation and Concordance scores between those with and without management responsibilities working in SPLD but not WAMH. The difference between mean Implementation scores is equivalent to \( 0.75 \times \text{SD} \), and that for Concordance scores is \( 0.73 \times \text{SD} \).

**Table 5: Comparison of mean scores from interaction suggested to be significant by ANOVA analysis**

<table>
<thead>
<tr>
<th>Management responsibilities?</th>
<th>WAMH</th>
<th>SPLD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3.46</td>
<td>3.68*</td>
</tr>
<tr>
<td>No</td>
<td>3.55</td>
<td>3.24*</td>
</tr>
<tr>
<td>Mean Implementation score</td>
<td>3.62</td>
<td>3.78*</td>
</tr>
<tr>
<td>Mean Concordance Score</td>
<td>3.64</td>
<td>3.46*</td>
</tr>
</tbody>
</table>

* Difference between management and non-management responses is significant to \( p<0.05 \) according to unrelated T-Tests. However, the difference is not significant to the \( p<0.0125 \) level required by a Bonferroni Adjustment.

**Salient Responses to Individual Items**

It is not possible to make a detailed analysis of responses to individual items on Section 3 of the SCGS here. However, the items with the four highest and four lowest mean scores — where strongest agreement and disagreement were assumed — are detailed in Table 6 below.
Table 6: The four most strongly agreed- and disagreed-with items

<table>
<thead>
<tr>
<th>Item No</th>
<th>Statement (and related construct)</th>
<th>Mean score</th>
<th>Percentage Agreement (score ≥4)</th>
<th>Percentage Disagreement (score ≤2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>I feel that personal skills development is an important part of providing a good service to clients (Attitude/Training, Education and Lifelong Learning)</td>
<td>4.46</td>
<td>95.3</td>
<td>0.8</td>
</tr>
<tr>
<td>10</td>
<td>I am clear who my line manager is (Knowledge/Staffing and Staff Management)</td>
<td>4.44</td>
<td>86.6</td>
<td>9.5</td>
</tr>
<tr>
<td>11</td>
<td>I feel it is the responsibility of all staff to engage in effective risk management (Attitude/Risk Management)</td>
<td>4.39</td>
<td>94.5</td>
<td>0.8</td>
</tr>
<tr>
<td>14</td>
<td>When working with a client, I update professionals already involved (Implementation/Clinical Information)</td>
<td>4.31</td>
<td>92.6</td>
<td>0.8</td>
</tr>
<tr>
<td>27</td>
<td>I have recently used &quot;CIMS&quot; or &quot;PIMS&quot; to generate useful clinical information (Implementation/Clinical Audit)</td>
<td>2.17</td>
<td>19.8</td>
<td>67.0</td>
</tr>
<tr>
<td>32</td>
<td>The results of clinical audit are made easily available to me (Knowledge/Clinical Audit)</td>
<td>2.59</td>
<td>22.2</td>
<td>46.3</td>
</tr>
<tr>
<td>19</td>
<td>When updating another professional, the information is always sent on to the client (Implementation/Clinical Information)</td>
<td>2.60</td>
<td>18.9</td>
<td>47.2</td>
</tr>
<tr>
<td>33</td>
<td>There are opportunities to put research into practice regularly (Implementation/Research and Effectiveness)</td>
<td>2.81</td>
<td>29.1</td>
<td>40.0</td>
</tr>
</tbody>
</table>

Correlations between Knowledge, Implementation and Attitude

Pearson’s Correlation Coefficients were used to examine the correlations between the overall Knowledge, Implementation and Attitude mean scores. Simple, bivariate correlation coefficients between these measures are shown in Figure 1 below, inside the triangle. Partial correlation coefficients, controlling for the effects of the third variable on each pair, are shown on the outside of the triangle, to allow examination of possible mediating effects.
Figure 1: Simple and Partial Correlations between Knowledge, Implementation and Attitude

**Significant to p<0.01 level.
Discussion

Strengths and Needs in Implementation of Clinical Governance

The mean rating for overall implementation of 3.47 falls nearest the “neither-agree-nor-disagree” response. Nevertheless, all but one of the seven pillars gained mean scores above three, which might be interpreted as slight agreement overall.

Only one “pillar” achieved a mean score above 4 (indicating agreement). This was Risk Management (mean=4.03), while the other higher-rated pillars were Education, Training and Lifelong Learning (mean=3.77) and Clinical Information (mean=3.73). The Clinical Information pillar was the only construct where component items appeared in both most- and least agreed-with items (see Table 6). This suggests that, for this Trust, Implementation/Clinical Information is not a unitary construct. This discrepancy resulted from high staff agreement (92.6%) that they were updating professionals involved with shared-clients, but low agreement (18.9%) that such information was passed on to the client. Implementation/Clinical Information may be an area of potential strength for the Trust – but one where the passing-on of information to clients represents a specific development need.

Only one Implementation pillar was given a mean score below 3 – Implementation/Clinical Audit (mean=2.70; 1.31*SD lower than overall Implementation mean). The fact that an Implementation/Clinical Audit item was the least agreed-with item from Section 3 of the SCGS (Table 6) also suggests this is a particular service development need. 67% of staff disagreed (mean=2.17) that they had used the Trust’s computer-based CIMS (Client Information Management System) or PIMS (Patient Information Management System) to generate useful clinical information. Service-User Experience and Research and Effectiveness also emerged as service development needs.
Staff Knowledge of Clinical Governance and Informational needs

The overall Knowledge mean score was also 3.47. None of the pillars achieved a score of >4. However, all but one of the pillars had mean scores above 3, which might be interpreted as slight agreement.

The highest mean score for the Knowledge constructs related to the Service-User Experience pillar (mean=3.86). This contrasts with the Implementation/Service-User Experience construct, which had the second lowest mean score of the Implementation pillars, and suggests a gap between knowledge and implementation in this area. Staffing and Staff Management (mean=3.74) and Risk Management (3.66) also appeared to be emerging strengths in terms of knowledge of CG.

The Knowledge/Clinical Audit mean score (2.67) was the lowest of those for all constructs. It was 1.6*SD below the mean score for overall knowledge and 2.12*SD below the mean score for overall “concordance”. A Knowledge/Clinical Audit item regarding the availability of results of clinical audit to staff was also the second least agreed-with item in Section 3 of the SCGS (see Table 6). Particular informational needs as well as implementation needs are therefore apparent with regards to Clinical Audit.

Staff Attitudes to Clinical Governance and Overall Concordance

At 4.05, the mean score for overall Attitude was higher than those for the Knowledge and Implementation domains. Four pillars received mean scores above 4 - indicating agreement - and the lowest mean score was 3.92 (for Attitude/Service-User Experience). Of the Attitude pillars, Risk Management achieved the highest mean score (4.39), and an item regarding the responsibility of all staff for effective risk management was the third most agreed-with item (94.5% agreement). Interestingly, Clinical Audit tied with Research and Effectiveness as the second highest mean score (both 4.05) - in contrast to Implementation and Knowledge results. This suggests informational needs and implementation of the Clinical Audit pillar are lagging behind, despite high motivation surrounding this.
A generally positive attitude towards CG was also reflected in the responses to the Section 2 dichotomies. The majority regarded CG as “Welcome” (68.3%), “Useful” (80.6%) and “Underrated” (55.4%). However, some reservations were apparent: 76% of staff regarded CG as “Complex”, 51.8% saw it as “A Mystery”, and 55.7% viewed it as “Tiresome”. These findings hint that informational needs about what CG means and the perceived demands created by CG could be damaging overall concordance.

The mean score of 3.61 for overall concordance is between ambivalence-agreement. Nevertheless, the generally welcoming attitude for CG from staff is an encouraging sign that cultural support for its principles currently exists.

**Differences Between Staff Groups**

Significant differences in attitude according to management status were apparent. Those with management responsibilities were significantly more likely to view CG as “Clear”, “Useful” and “Energising”, and significantly less likely to say CG is “Complex” (although 60.5% of management staff held this view, compared to 87.0% of non-management staff). Within SPLD, staff with management responsibilities also had significantly higher mean Implementation and Concordance scores than those without. However, T-Tests revealed no significant differences between staff with and without management responsibilities working in WAMH, although here, management staff had slightly lower scores than non-management staff, in an interaction highlighted by an ANOVA.

These results raise questions about why SPLD staff feel less well-informed about and less positively-impressed by CG if they are in non-management positions. The absence of this pattern amongst WAMH staff suggests it is not an inevitable consequence of staffing structures, and a mediating variable may be involved.

**Correlations between Knowledge, Implementation and Attitude**

Simple correlations existed between all three domains. The partialled out correlations may reveal more about the mediating effects of these constructs upon one another. The strongest correlation occurred between Knowledge and Implementation ($r=0.49$, controlling for Attitude). A smaller, but still highly significant
(p<0.01) correlation was found between Attitude and Implementation (r=0.32, controlling for Knowledge). Once Implementation was controlled for, the smaller correlation between Attitude and Knowledge (r=0.17) was no longer significant. The pattern of correlational strength is similar to that reported by Murray et al. (2002).

**Using the Staff Clinical Governance Survey to Audit Staff Knowledge, Attitudes and Implementation of Clinical Governance**

Section 1 of the SCGS (Murray et al, 2002), which sought demographic information from participants, enabled comparisons between staff of different specialties and management status. However, questionnaire items seeking job-title took up a lot of space and were complex to develop, owing to the large range of job titles. The resulting professional groups were eventually too small to make valid comparisons. Thus, unless expected sample size is very large, the inclusion of job-title items does not seem worthwhile.

The requirement, in Section 2, for participants to select polarities yielded easily-understandable figures on proportions of staff who, for example, welcomed or were irritated by CG. However, the dichotomy might also have led to oversimplified views of staff attitudes. The absent or invalid response rate to these questions ranged from 13.2%-24.8% - perhaps reflecting reluctance on the part of some staff to categorise their views so extremely.

Nevertheless, Section 3 of the questionnaire enabled more detailed analysis staff responses, and the constructs appear useful in highlighting service strengths and needs. However, at least one construct (Implementation/Clinical Information) yielded contrasting responses, which calls into question whether the constructs are unitary and valid. Furthermore, it is possible the standards and statements used in these items reflected concerns emphasised in the Trust where the SCGS was developed. Nevertheless, the questionnaire was adapted in consultation with Trust Quality and Clinical Audit staff who appeared satisfied with item content.

A key limitation to the study design was the essential self-selection of participants. It is possible that staff who returned the questionnaire were those most interested and
motivated towards the principles of CG. It is also possible staff were more likely to
disclose lack of information implementation as this may be less personally-threatening
than the disclosure of attitudes dystonic with prevailing NHS maxims.

The SCGS (Murray et al, 2002) does not produce information about specific
supports and barriers to CG, which would probably require more complicated,
qualitative study. However, by identifying particular service strengths and
development needs in a relatively short and user-friendly way, the survey could aid
targeted consultation with staff about the most positive or problematic areas.
References

Anonymised NHS Trust Quality and Audit Department (2001). *Clinical Governance and Clinical Quality Assurance Baseline Audit*, NHS.


## TABLE OF APPENDICES

**Appendix 1**  Staff Clinical Governance Survey Questionnaire  
**Appendix 2**  Relationships between Questionnaire Items and Constructs  
**Appendix 3**  Items where "Don't Know" Responses were Re-coded as Disagreement
Appendix 1: Staff Clinical Governance Survey Questionnaire

STAFF CLINICAL GOVERNANCE SURVEY

SECTION 1
1) Please indicate the number of years that you have worked as part of the NHS:

[ ] Years

2) What is the name of the team you are attached to (e.g. WAMH)?

[ ]

3) Which of the following categories best describes your job? Please indicate by shading the circle corresponding to the most appropriate category.

a) Nurse (please indicate grade):
   ○ A to C  ○ D to E  ● F to I/Nurse Consultant

b) Occupational Therapist (please indicate grade):
   ○ Basic Grade  ○ Assistant  ○ Senior  ○ Head

c) Medical Doctor (please indicate grade):
   ○ SHO  ○ Registrar  ○ Staff Grade/Associate Specialist  ○ Consultant

d) Psychology (please indicate discipline):
   ○ Clinical Psychologist  ○ Counselling Psychologist  ○ Psychotherapist

e) Other (please indicate discipline):
   ○ Support Worker  ○ Administrative Worker  ○ Instructor
   ○ Care/Nursing Assistant  ○ Social Worker  ○ Other

4) Do you have management responsibilities?
   ● Yes  ○ No

5) Do you have responsibility for supervising another member of staff?
   ● Yes  ○ No

PLEASE CONTINUE OVERLEAF
SECTION 2

6) Below is a table containing pairs of statements about Clinical Governance. There are circles at either end. Please shade one circle for each pair of statements to indicate which statement you feel is nearest to your own view.

<table>
<thead>
<tr>
<th>A mystery</th>
<th>Clear</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overrated</td>
<td>Underrated</td>
</tr>
<tr>
<td>Useful</td>
<td>Useless</td>
</tr>
<tr>
<td>Simple</td>
<td>Complex</td>
</tr>
<tr>
<td>Welcome</td>
<td>Irritating</td>
</tr>
<tr>
<td>Tiresome</td>
<td>Energising</td>
</tr>
</tbody>
</table>

SECTION 3

请仔细阅读以下陈述，并考虑你服务的环境，考虑你是否同意或不同意这些陈述。所有答案将被保密。没有“正确”或“错误”答案。请尽可能准确地回答，通过在圆圈中打勾来表示你的答案。

7) All incidents and accidents are reported in a formal and structured way.

8) I believe that it is important to analyse the activity of professionals in the Trust closely.

9) I have the knowledge to help a service user make a complaint.

10) I possess the necessary skills to evaluate with confidence the research that I have read.

11) In the last year I have attended a training course relevant to my professional development.

12) I am able to locate all fire exits, fire extinguishers and fire alarms in my building.

13) It is important for clinical work to be research based.

14) The outcome of a complaint is used to change the relevant aspect of a service.

15) Client complaints are an important way of improving service delivery.

16) I am clear whom my line manager is.

17) I feel that it is the responsibility of all staff to engage in effective risk management.

18) The tasks that I receive as part of my work are appropriate to my role and level of expertise.

19) There is sufficient financial support from management to allow me to attend a training course.

### KEY

1 2 3 4 5 U

7) All incidents and accidents are reported in a formal and structured way.  
8) I believe that it is important to analyse the activity of professionals in the Trust closely.  
9) I have the knowledge to help a service user make a complaint.  
10) I possess the necessary skills to evaluate with confidence the research that I have read.  
11) In the last year I have attended a training course relevant to my professional development.  
12) I am able to locate all fire exits, fire extinguishers and fire alarms in my building.  
13) It is important for clinical work to be research based.  
14) The outcome of a complaint is used to change the relevant aspect of a service.  
15) Client complaints are an important way of improving service delivery.  
16) I am clear whom my line manager is.  
17) I feel that it is the responsibility of all staff to engage in effective risk management.  
18) The tasks that I receive as part of my work are appropriate to my role and level of expertise.  
19) There is sufficient financial support from management to allow me to attend a training course.
20) When working with a client, I update professionals already involved.

21) I feel supported by management to attend a training course because he/she provides the necessary time.

22) I have had the opportunity of feeding back my training to the other members of my team and to implement it in my work.

23) In the past year, I have reviewed my performance with my line manager and set my personal goals.

24) My clinical activity has been recorded in the last month (not applicable to administrative staff).

25) When updating another professional, the information is always sent onto the client.

26) I feel that personal skills development is an important part of providing a good service to clients.

27) I am aware of the steps involved in the event of an Adult Protection issue.

28) I am aware of what to do if a client engages in self-harm.

29) I am clear on the most recent guidelines for confidential information in the Trust.

30) I am reluctant to review my work with my manager.

31) I have had the opportunity to complete a personal development plan.

32) I have read at least one relevant research article in the past six months.

33) I have recently used "CIMS" or "PIMS" to generate useful clinical information.

34) I know who the first aider is in my place of work.

35) Relevant research information is readily available in my place of work e.g. journal articles, on-line databases.

36) Service users are actively offered additional written information on the service such as leaflets.

37) The outcomes of clinical audit are used regularly to improve the practice of colleagues and myself.

38) The results of clinical audit are made easily available to me.

39) There are opportunities to put research into practice regularly.

40) There is the opportunity for regular discussion with my supervisor in accordance with the guidelines of my profession.

41) When I make an appointment I always take into account the special needs of the client and their family.

Thank you for your time in completing this survey, your comments are extremely valued.

Please return it in the enclosed addressed envelope by Wednesday 31st July 2002 to:
### Appendix 2: Relationships between questionnaire items and constructs

<table>
<thead>
<tr>
<th></th>
<th>Knowledge</th>
<th>Implementation</th>
<th>Attitude</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Risk Management</strong></td>
<td>6. I am able to locate all fire exits, fire extinguishers and fire alarms in my building.</td>
<td>1. All incidents and accidents are reported in a formal and structured way.</td>
<td>11. I feel it is the responsibility of all staff to engage in effective risk management</td>
</tr>
<tr>
<td></td>
<td>21. I am aware of the steps involved in the event of an Adult Protection issue</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>22. I am aware of what to do if a client engages in self-harm.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>28. I know who the first aider is in my place of work.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Clinical Audit</strong></td>
<td>31. The outcomes of clinical audit are used regularly to improve the practice of colleagues and myself.</td>
<td>18. My clinical activity has been recorded in the last month (not applicable to administrative staff).</td>
<td>2. I believe that it is important to analyse the activity of professionals in the Trust closely.</td>
</tr>
<tr>
<td></td>
<td>32. The results of clinical audit are made easily available to me.</td>
<td>27. I have recently used &quot;CIMS&quot; or &quot;PIMS&quot; to generate useful clinical information.</td>
<td></td>
</tr>
<tr>
<td><strong>Staffing and Staff Management</strong></td>
<td>10. I am clear who my line manager is.</td>
<td>17. In the past year, I have reviewed my performance with my line manager and set my personal goals.</td>
<td>24. I am reluctant to review my work with my manager.</td>
</tr>
<tr>
<td></td>
<td>25. I have had the opportunity to complete a personal development plan.</td>
<td>12. The tasks that I receive as part of my work are appropriate to my role and level of expertise.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>34. There is the opportunity for regular discussion with my supervisor in accordance with the guidelines of my profession.</td>
<td></td>
</tr>
<tr>
<td>Education, Training and Lifelong Learning</td>
<td>13. There is sufficient financial support from management to allow me to attend a training course</td>
<td>5. In the last year I have attended a training course relevant to my professional development.</td>
<td>15. I feel supported by management to attend a training course because he/she provides the necessary time.</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-------------------------------------------------</td>
<td>------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td>16. I have had the opportunity of feeding back my training to the other members of my team and to implement it in my work.</td>
<td>20. I feel that personal skills development is an important part of providing a good service to clients.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research and Effectiveness</td>
<td>4. I possess the necessary skills to evaluate with confidence the research that I have read.</td>
<td>26. I have read at least one relevant research article in the past six months.</td>
<td>7. It is important for clinical work to be research based.</td>
</tr>
<tr>
<td>29. Relevant research information is readily available in my place of work e.g. journal articles, online databases.</td>
<td>33. There are opportunities to put research into practice regularly.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Information</td>
<td>23. I am clear on the most recent guidelines for confidential information in the Trust.</td>
<td>14. When working with a client, I update professionals already involved.</td>
<td>Missed out item: (36.) I believe that it is important to pass all information on to the client.</td>
</tr>
<tr>
<td>19. When updating another professional, the information is always sent onto the client.</td>
<td>30. Service users are actively offered additional written information on the service such as leaflets.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. When I make an appointment I always take into account the special needs of the client and their family.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Service User Experience</td>
<td>9. I have the knowledge to help a service user make a complaint.</td>
<td>8. The outcome of a complaint is used to change the relevant aspect of a service</td>
<td>9. Client complaints are an important way of improving service delivery.</td>
</tr>
</tbody>
</table>
Appendix 3: Section 2 items where “Don’t Know” responses were assumed to represent disagreement and were therefore coded as “2”

<table>
<thead>
<tr>
<th>Item No.</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>I have the knowledge to help a service use make a complaint</td>
</tr>
<tr>
<td>4</td>
<td>I possess the necessary skills to evaluate with confidence the research that I have read</td>
</tr>
<tr>
<td>6</td>
<td>I am able to locate all fire exits, fire extinguishers and fire alarms in my building</td>
</tr>
<tr>
<td>10</td>
<td>I am clear who my line manager is</td>
</tr>
<tr>
<td>21</td>
<td>I am aware of the steps involved in the event of an Adult Protection issue</td>
</tr>
<tr>
<td>22</td>
<td>I am aware of what to do if a client engages in self-harm</td>
</tr>
<tr>
<td>23</td>
<td>I am clear on the most recent guidelines for confidential information in the Trust</td>
</tr>
<tr>
<td>28</td>
<td>I know who the first aider is in my place of work</td>
</tr>
</tbody>
</table>
QUALITATIVE RESEARCH PROJECT

Trainee clinical psychologists’ perceptions of the desirability of personal therapy during clinical training – An Interpretative Phenomenological Analysis

Statement of anonymity: Some details including participants’ names, have been changed, and some omitted, to preserve the anonymity of participants.

May 2003
Year Two
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<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
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</thead>
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<td>Method</td>
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<tr>
<td><em>Participants, procedures and materials</em></td>
<td>151</td>
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<td><em>Analytic method</em></td>
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<td>References</td>
<td>159</td>
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<tr>
<td>Appendices</td>
<td>160</td>
</tr>
</tbody>
</table>
Introduction
Clinical Psychology doctoral training involves no requirement for Trainees to seek personal therapy. This is in contrast to Counselling Psychology training which, to attain accreditation by the British Psychological Society (BPS), requires candidates to “undertake at least 40 hours of personal counselling psychology/therapy, normally on an individual basis” (BPS, 2003, p.7).

So it is in contrast to their Counselling Psychology colleagues that many Trainee Clinical Psychologists retain a choice about whether to seek personal therapy during their training. This raises questions about what influences Trainee Clinical Psychologists’ decisions about personal therapy, and perceptions of its desirability.

Previous research into the experience of personal therapy during psychological, psychotherapeutic or counselling training has tended to focus upon outcomes of mandatory therapy from the perspective of either therapist or “theraped”. Employing Grounded Theory, Grimmer & Tribe (2001) suggested recently-qualified and trainee counselling psychologists valued personal therapy in their professional development – viewing it as an aid to developing reflexivity thereby enhancing professional self-identity.

Participants also perceived personal therapy as an opportunity to be “socialised” to the therapeutic process through the modelling of the therapist, and reported beneficial effect in distinguishing personal issues and concerns from those of their clients. Meanwhile, Williams, Coyle & Lyons (1999) distinguished three factors from a factor analysis of Counselling Psychologists’ views about their personal therapy (learning about therapy, training-related issues and personal issues) and found 88 per cent of participants were in favour of mandatory personal therapy. However, Sherman (2000) noted more ambivalent views amongst therapists about mandatory therapy for trainees, including concern about the impact of requirement upon the “dynamic” of the therapeutic relationship and the perception that trainees’ motivation and readiness for therapy were “crucial variables”.

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There has been some research highlighting possible influences upon views and choices about personal therapy. In a study of clinical psychology trainees in the United States, Dearing (2001) found significant association between belief that personal therapy enhances training and "help-seeking" behaviour. Williams et al. (1999) found stronger endorsement of the idea that personal therapy contributes to understanding therapeutic relationships was related to having more than 40 therapy sessions. Holzman, Searight & Hughes (1996) found that, among clinical psychology trainees, "personal growth" was the most frequently cited reason for seeking therapy.

These predominantly quantitative research findings are interesting and provide some picture of factors trainees might consider in their choice-making about therapy, but provide few clues about what this choice-making experience is like, or the attitudes trainees hold towards personal therapy. This study aimed to utilise principles of Interpretative Phenomenological Analysis (Smith, 1997, cited by Willig, 2001) in seeking a greater understanding of these experiences.
PsychD Portfolio Volume 1: Hazel Fell-Rayner
Qualitative Research Project

Method

Participants, procedures and materials: Semi-structured interviews with seven third-year Trainee Clinical Psychologists were carried out by individual members of a research group of seven second-year Trainees. It was anticipated that third-year Trainees would be most able to reflect on attitudinal change and influence across the course of their training. Participants were selected by research group members contacting "buddies" (to whom they had been assigned the previous academic year), requesting they invite anyone they thought might be interested to participate in the study. In this respect, the participant group was, partly self-selected but also determined by the selection of third-year buddies.

Prior to the interview, participants were issued with an information sheet about the study and invited to sign a consent form (see Appendices 1 and 2 respectively). Background information was then sought via a questionnaire. At the time of report-writing, background data was available from six of the seven participants. Of these, four were female, two male, mean age = 28.5 years (ranging from 26 to 30), all described themselves as "White British", five were (in legal terms) single, one was married, and none had any children.

An interview schedule (Appendix 4) including optional prompts was used to guide the interview process. Interviews were recorded onto audio-tape and transcribed.

Analytic method: Principles of the developing Interpretative Phenomenological Analysis (IPA) method (Smith, 1997, ibid) were applied to the data. The phenomenological emphasis in IPA upon seeking an awareness of participants' experiences and perspectives (views, beliefs, perceptions and attitudes) (Willig, 2001) fitted with the study's aims of understanding the choice-making and desirability-perceptions. Furthermore, the acknowledgement made in IPA of how researchers' analyses of participants' accounts are unavoidably interpretative and influenced by personal perspectives (Willig, 2001) was of particular relevance to this study. The researchers and participants shared occupations as Trainee Clinical Psychologists who, whether they had experienced, sought, considered, ignored or dismissed personal therapy, ultimately responded to a choice about it (indeed, the choice of the research group to study this may have reflected particular interests in this issue).
was, therefore, crucial to recognise and acknowledge the inevitability that the researching Trainees' analyses and readings of accounts would be shaped by their personal thoughts and feelings on the issue, despite any attempts to "bracket" away (Willig, 2001) or suspend any preconceptions.

The research group initially followed the principles of applying IPA outlined by Willig (2001). Individual group members worked on the transcripts from the interviews they had conducted. Firstly, these transcripts were read and re-read, and any "emerging themes" and impressions were noted (utilising a left-hand margin alongside the transcript in line with the recommendations of Smith (1997, ibid). A right-hand was then used to begin structuring these emerging themes into "clusters" (see Appendix 5). Research group members then formulated "summary tables" or diagrams illustrating their impressions of the structures present in the data from their interview transcripts (see Appendix 6). However, in deviation from the method suggested by Willig (2001), page and line numbers were not noted at this stage — the left- and right-hand margin notes instead being used as a "thumb-nail index" for the emergence of the themes. This potentially enabled the point at which the themes occurred to the researcher to be identified within context and reflected upon.

Having completed these procedures on the transcripts provided by individual participants, Willig (2001) prescribes the "integration of cases", whereby superordinate (master) themes are identified for the group as a whole, as an appropriate next step in IPA. She suggests that, since IPA studies will usually sample an homogenous participant group (in that participants are likely to share an experience of relevance to the studied area), it is useful and appropriate to look for general phenomena rather than focusing purely on individuals' accounts and experiences.

It was anticipated that the whole research group meeting together would perform this integration of cases. However, the author (i.e. this Trainee) was not included at this stage of the analysis. This meant that the author was neither party to the thinking and decision-making at this integrative stage, nor present to act as a "spokesperson" for the emerging themes the author had perceived in the transcript.
of the interview this Trainee conducted. Clearly this situation was far from ideal. Nevertheless, it did provide an opportunity to use the current research experience to reflect on the process of integration of cases from an interesting point of view. Willig (2001) suggests the integration process should be similarly cyclical to the procedures used for identifying themes and clusters in individuals’ accounts – for instance by looking across the summary tables to identify super-ordinate and component themes from the participant group. Without access to these procedures or the margin notes of other group members, the author instead decided to attempt, to an extent, to “retrace the steps” of this process from interview transcripts to the “Table of Themes” (Appendix 7) integrated from different cases. It was hoped that, in seeking points of convergence and divergence between the group and individual analyses, something could be learnt about the data and conclusions generated from the IPA approach itself. Unfortunately, little of this learning process can be conveyed due to word-limit restriction. However, an attempt will be made to illustrate some points at which particular reflections on process and method emerged.
Results and some initial observations of process

The research group identified five super-ordinate themes and drew up a diagram (Appendix 8) illustrating their posited relationships. “Benefits” related to positive outcomes of personal therapy including (component themes of) “Personal Growth”, “Understanding motives for being a psychologist” and “Learning from experienced “pro”” (see Appendix 7 for full summary table). Drawbacks involved component themes combining potential negative outcomes, barriers to uptake and doubts about value (“Stigma”, “Pandora’s Box”, “Practicalities”, “Questionable worth if therapy compulsory”). The super-ordinate theme “Influences” related to factors shaping attitudes to therapy including component themes of “Personal experience of therapy”, “Development through training” and “Specialist training” and was viewed as contributory to both “Benefits” and “Drawbacks”. “Influences” was also viewed as contributory to “Theoretical Orientation”, a super-ordinate theme comprising components including CBT (linked to the view of therapy as problem-specific, useful on need-basis) and Psychodynamic (connected with ideas about personal growth being useful both personally and professionally). All four super-ordinate themes were regarded as contributory to “Individual Choice”, which involved components “Compulsory versus voluntary”, “Choice of model used”, “Knowledge of different models”, and “Using alternative support”. Due to word-limit restrictions, it is not possible to detail in any completeness how these themes related to evidence within transcribed interviews or to compare this with the author’s summary table, but some points will be considered which give rise to reflections upon the IPA approach itself.

Whereas the integrated cases produced a “neat” divide between Benefits and Drawbacks, the individual transcription analysed by the author seemed to show more complex “weighing up” of desirability factors. This weighing up did involve benefits (“Desirable because…””) and drawbacks (“Not desirable because…”)”, but also invoked ideas of indication and contraindication (“Desirable if…”, “Maybe desirable if…” “Not desirable if…”). Exploring these aspects of the individual and integrated analyses may be particularly interesting in terms of the question “Are the transcripts, and the individual participants’ views contained within them, fundamentally different, or are researchers’ “takes” on them divergent?”.
There does seem to be considerable agreement and overlap between transcripts around the benefits of therapy. For instance, "Increase understanding of self" (from integrated cases) and "Knowing true self/self-knowledge and self-understanding" (from author's individual transcript) could be viewed as essentially similar and seemed to be nested in ideas that this is useful as a clinician and as a person:

**Sally:** "I think you need (as a therapist) to be very aware of your own kind of (pause), the issues that have come up in therapy for you and why they're difficult for you and the influence you might have on the therapy process..."

**Betty:** "...There were particular client groups that I would have found raised issues for me that I hadn't thought about and actually talking through some of those (in therapy)... I think that experience has been invaluable in kind of developing me as a clinician as well as a person."

**Naomi** (author's transcript): "... understanding yourself, understanding who you are, what, y'know, where you come from and being sort of grounded in seeing who you are and... being GENUINE as to who you are and I think in therapy and in therapeutic relationship that's very important."

"Increase understanding of patient perspective" and "Enhanced understanding of experience of the client in therapy" again seem readily viewable as overlapping, while "Learning about therapeutic relationships" is harder to qualify as a distinct benefit or "sub-component" of this and differs between analyses:

**John:** "If... (therapy) was more a case of trying to understand power relationships and what it's like for somebody to come and see the therapist and spill out some of their most difficult thoughts and feelings then um I could see how that could be worthwhile and could be of help (pause) be useful."

**Betty:** "It can actually illustrate what it's like to be a client. Um, that it's actually quite strange being the other person... What's it then like to be in that relationship?"

**Naomi:** "... actually being in an individual therapy relationship yourself and actually acknowledging how it can be painful when you have to tell somebody else your difficult things... I suppose you can understand how that might be for your client really... If I think I've learnt a lot about therapeutic relationships from (therapy)."
Clive: “Giving you much more of an appreciation of what it is like to be a client/...you’re relying so much on other people divulging things to you and it would be important to go through that experience yourself”

True to the emphasis in IPA on both the “real” occurrence of phenomena and the inevitable interpretative quality of research into them, these excerpts illustrate how such overlaps and differences might either result from participant responses or from interpretative differences, particularly the level of analytic abstraction or descriptive structure. Moreover, the concept of “indication and contraindication” so central to the author’s summary table on the one hand seems present in some aspects of other transcripts, but, on the other hand, seems less salient or frequent:

Alice: (in response to question about particular times when therapy would be less advantageous) “... I actually think in the beginning, because I just think there is so much to adapt to, and so kind of so many concerns about getting into training... it would just be perhaps far too much”

Sally: “… if you are not ready for it, or it’s something you feel you can’t deal with at the moment, then maybe it’s not appropriate for you because then it could involve a lot of, it could just be really hard for you as a person.”

Naomi: “…I'M REALLY NOT sure that it’s appropriate to do (therapy) on training... the Course is so stressful... perhaps in the third year... when you’re more settled... and I would definitely probably say not the first and second year – I think that would be too much (laughs).”

In Naomi’s account, some “possible indicators” such as personal stress were apparent in the context of being mediated by personal choice. The author regarded Individuality and Choice as a super-ordinate, cluster theme, even though it appeared to be woven through different areas of the transcript – a decision mirrored by the group when integrating cases. Most of the participants seemed to regard choice as important and preferable to mandatory therapy:

Naomi: “I wouldn’t implement any (policy), I think it’s personal choice... I do toy with the idea with personal therapy that is mandatory because in can lead to all sorts, different problems... it could be you are just going round the houses and not getting anywhere... I don’t think you can actually force people to do something like that – explore themselves –
because it's going to be counterproductive... like forcing clients into therapy — we'd never do that because it isn't effective.”

John: “If you were doing it for the sake of doing it as part of say like a course recommendation then I can see it being a real pain. So that's why I think there's an element of personal choice there... I wouldn't make it compulsory. I'd be quite clear on that.”

Anne: “I don't think I would force anyone to do that because it changes what you get out of therapy”

One participant (Sally) initially suggested therapy should be compulsory, but later decided against this and in favour of making it “strongly recommended”. This issue of influencing choice was a sub-cluster theme within the author's summary table but did seem to occur in other transcripts too, with some evidence of a common desire for overt or open dialogue, against a background of therapy being covert and stigmatised:

Alice: “I would certainly be interested in hearing about other people's experiences of personal therapy. Um, yeah, I'd find that very interesting because I think I'm kind of stumbling around in the dark a bit because I don't know what it involves.”

Naomi: “I think we could advocate it and it could be advocated a little bit more strongly on the Course so we could have more seminars on the benefits... it's not a big issue on the agenda and... it could make trainees a little bit more aware of the benefits maybe... if it's just having a sort of DIALOGUE about it really... make people more open to discussing the issue”.

Betty: “It kind of feels there's a culture, a professional culture, it's not something we really talk about a great deal or think about unless it's the severe end of the spectrum... I guess perhaps a more open discussion... and more of an acknowledgement that life events do happen, and that you don't have to be competent all of the time... Or maybe even a more open, being more able to openly discuss psychological issues...”
Discussion
Owing to the author’s absence when integrating cases, reflections upon process will be focused upon, rather than conclusions about findings.

The process of completing this IPA, although not performed ideally or in full accordance with the principles outlined by Smith (1997, ibid) has provided a rich opportunity to reflect upon the analytic process. Two particularly salient issues (in the author’s mind!) are the level of analytic abstraction a researcher adopts and the processes of decision-making around what themes to “leave out”.

The author noted a dilemma which, given the “developing” nature of IPA (Willig, 2001) may be worthy of particular consideration. On the one hand, including more of the emerging themes from a transcript may necessitate a more complex structure to incorporate these, thereby entailing greater analytic abstraction from the original data. On the other hand, the removal of emerging themes because they “seem less important” seems particularly subjective and vulnerable to the influence of researcher preconceptions. “Bracketing” one’s thoughts and feelings sufficient to identify themes has been acknowledged to verge on the impossible by IPA (Willig, 1997). Deciding “what matters” seems even more prone to researcher influence.

Willig’s (2001) concern about the “representational validity” of language in communicating experience is also echoed in the transcripts. Some participants had made efforts to “formulate” their accounts prior to interview, while others noticed themselves grappling with words in the struggle to communicate their views. Interestingly enough, these concerns about language, subjectivity and analytical abstraction may mirror concerns about psychological therapies themselves. Perhaps this can be seen as highlighting an affinity between IPA and the reflective study of therapeutic processes.
References


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Appendix I: Information Sheet for Participants

PSYCHD CLINICAL PSYCHOLOGY
Department of Psychology

INFORMATION SHEET

QUALITATIVE RESEARCH PROJECT
The Desirability Of Personal Therapy During Clinical Training

As part of our clinical training here at the University of Surrey we have been asked to conduct a piece of qualitative research and analysis. We saw this as an opportunity to explore trainees' perceptions of the desirability of having personal therapy during clinical training. By personal therapy, we mean individual therapy of any theoretical orientation. Some people may feel that having personal therapy during clinical training is desirable whereas others may feel that it is not desirable. Some people may not have any strong opinions about this at all. However we are interested in your hearing about your opinions.

We are working in a research team of seven and each of us will interview one trainee in Year 3. The interview is semi-structured and will take approximately 20 minutes of your time. With your consent the interview will be tape-recorded and transcribed. The recording will be securely stored and destroyed after transcription. We will then, as a research team, analyse the interview using Interpretative Phenomenological Analysis (IPA) and individually write up a report for submission to the course research team and possibly submit for publication at a later date. Your interview transcript will be anonymised and all of our conversation will remain confidential within the qualitative research team. If you would like to see a copy of the final report, we will make it available to you once it has been submitted and marked.

If you have any questions that have not been addressed in the information above, we are happy to discuss these with you at any time before, during or after the interview. If you wish to verify information then please feel free to contact Dr Adrian Coyle, our university supervisor (01483 686887).

Thank you very much for your time and help in conducting this research.
PSYCHD CLINICAL PSYCHOLOGY
Department of Psychology

CONSENT FORM

QUALITATIVE RESEARCH PROJECT
The Desirability Of Personal Therapy During Clinical Training

I agree to participate in the research investigating the desirability of personal therapy during clinical training. I understand that participation will mean giving consent for the interview to be tape-recorded, transcribed and analysed by the research team conducting this research. I also understand that this information will remain confidential but will be included in an anonymised form in a written report and may be submitted for publication.

Signature of participant:

Name of participant (CAPITALS)

Signature of interviewer:

Name of interviewer (CAPITALS)

Date:

Thank you very much for your time and help in conducting this research.
Appendix 3: Background Information Sheet

BACKGROUND INFORMATION

To begin, I'd like to get some basic information about you (such as your age, education and occupation). The reason that I'd like this information is so that I can show those who read my research report that I managed to obtain the views of a cross-section of people. The information that you give will never to used to identify you in any way because this research is entirely confidential. However, if you don't want to answer some of these questions, please don't feel that you have to.

1. Are you (tick the appropriate answer)
   Male __  Female __

2. How old are you? [ ] years

3. How would you describe your ethnic origins?¹

   Choose one section from (a) to (e) and then tick the appropriate category to indicate your ethnic background.

   (a) White
      British __
      Irish __
      Any other White background, please write in below

   (b) Mixed
      White and Black Caribbean __
      White and Black African __
      White and Asian __
      Any other mixed background, please write in below

¹ The format of this question is taken from the 2001 UK census.
(c) Asian or Asian British

<table>
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<th>__</th>
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</thead>
<tbody>
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<td>__</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>__</td>
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</tbody>
</table>

Any other Asian background, please write in below

(d) Black or Black British

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<tr>
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<th>__</th>
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<tr>
<td>African</td>
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</table>

Any other Black background, please write in below

(e) Chinese or Other ethnic group

<table>
<thead>
<tr>
<th>Chinese</th>
<th>__</th>
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</table>

Any other, please write below

What is your current legal marital status?
(tick the appropriate answer)

<table>
<thead>
<tr>
<th>Single</th>
<th>__</th>
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</thead>
<tbody>
<tr>
<td>Married</td>
<td>__</td>
</tr>
<tr>
<td>Divorced/separated</td>
<td>__</td>
</tr>
<tr>
<td>Widowed</td>
<td>__</td>
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</tbody>
</table>

5 a) Do you have any children?
(tick the appropriate answer)

Yes ___ (go to part b)  No ___ (end of questionnaire: thank you)

b) How many children do you have?

[ ]
Appendix 4: Interview Schedule

QUALITATIVE RESEARCH PROJECT – Interview Guide

"We are interested in trainees' perceptions of the desirability of having personal therapy during clinical training. By personal therapy, we mean individual therapy of any theoretical orientation. Some people may feel that having personal therapy during clinical training is desirable whereas others may feel that it is not desirable. Some people may not have any strong opinions about this at all ..."

Q1) What are your views around having personal therapy during training?
"I'd like us to discuss some of the things you have mentioned in a little more detail now ...."

Q2) What do you see as the potential advantages of personal therapy during clinical training?
   a) For you personally and professionally
   b) For trainees in general

Prompts

What have you based your decision on?

What makes you say that?

Do you think having personal therapy will have any advantages in terms of your clinical work?

How have, if at all, your views on the advantages of personal therapy for yourself changed (developed) over the course of training?

How have, if at all, your views on the advantages of personal therapy for trainees in general changed (developed) over the course of training?
For you personally, would there be certain times when it is more desirable to have personal therapy? (use above prompts in conjunction with this)

For trainees as a group, would there be certain times when it is more desirable to have personal therapy? (use above prompts in conjunction with this)

For you personally, are there any particular issues for which you might consider personal therapy advantageous?

For trainees as a group, are there any particular issues for which you might consider personal therapy advantageous?

How do your views on personal therapy for trainees in general relate to/differ from your views on personal therapy for yourself?

Q3) What do you see as the potential disadvantages of personal therapy during clinical training?

   a) For you personally and professionally
   b) For trainees in general

Prompts

What have you based your decision on?

What makes you say that?

How have, if at all, your views on the advantages of personal therapy for yourself changed (developed) over the course of training?

How have, if at all, your views on the disadvantages of personal therapy for trainees in general changed (developed) over the course of training?
For you personally, would there be certain times or periods when it is less desirable to have personal therapy? (use above prompts in conjunction with this)

For trainees as a group, would there be certain times or periods when it is less desirable to have personal therapy? (use above prompts in conjunction with this)

For you personally, are there any particular issues for which you might consider personal therapy a disadvantage?

For trainees as a group, are there any particular issues for which you might consider personal therapy a disadvantage?

"I'd like to approach the topic from a slightly different perspective now........."

Q4) If you were the course director, what policies around personal therapy for trainees would you advocate/implement?

Prompts

What makes you say that?

Where have your ideas come from?

Do you think this policy would be helpful to trainees? If so, how? / What would be your aims for advocating this kind of policy? / What would you hope to achieve through advocating this policy?

How does this, if at all, differ from what you would like for yourself?

Can you envisage any difficulties with that sort of policy?

What might be the advantages/disadvantages of your policy?
How would you describe the current culture around personal therapy on the course? How would you like the culture to be?

How does your policy differ from or relate to the current course policy?

How does this, if at all, differ from what you would like for yourself?

Q5) a) Is there anything else that you'd like to add that we haven't already covered?

   b) How do you feel being interviewed about this topic?

   c) How do you feel being interviewed by another trainee?

Thank you so much for taking the time to participate in the research. The information you have given will be kept confidential and will be used for our qualitative research projects. If you would like to see a copy of the final report, I can make it available to you once it has been submitted and marked.
**Appendix 5: Sample transcript with margin notes**

<table>
<thead>
<tr>
<th>Initial comments</th>
<th>Interview Transcript</th>
<th>Emerging theme titles</th>
</tr>
</thead>
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| Research interview 15 April 2003 | **Key:**  
*Interviewer*  
*Participant*  

*OK just to introduce the interview, what we are interested in is trainees’ perceptions of the desirability of having personal therapy during clinical training and by personal therapy we mean individual therapy of any theoretical orientation. Some people may feel that having personal therapy during clinical training is desirable, and others might feel that it is not desirable, and some people might not have any strong feelings about it at all.*  

*Ok*  

*So… be interested to know what your views are around having personal therapy during training…*  

*Yes. OK. So can just, you know, start?*  

*Yes*  

*Um, I personally think it is desirable but I suppose that’s because of where I sort of, my sort of outlook on life. I suppose I see it as an important part of life generally maybe in terms of sort of um (pause) understanding yourself, understanding*  

**Desirable**  
**Because...**  
**Life generally**  

**Desirable**  
**Reasons for...**
<table>
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<th>Self-understanding</th>
<th>Grounded in self-understanding</th>
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<tbody>
<tr>
<td>Knowing true self</td>
<td>And BEING true self?/ Genuineness/ being real</td>
</tr>
<tr>
<td>Importance of genuineness to therapeutic relationships</td>
<td>Humility — acknowledgement of own neediness and imperfections?</td>
</tr>
<tr>
<td>Potential painfulness of this acknowledgement — understanding of normality of this and difficulty also faced by client.</td>
<td>Understanding experience of client in therapy</td>
</tr>
</tbody>
</table>

who you are, what, y’know, where you come from and being sort of grounded in seeing who you are and not sort of y’know (pause) actually KNOWING your true self. So I suppose a personal philosophy of how I try to be a real person and it’s sort of about being GENUINE as to who you are and I think in therapy and in therapeutic relationship that’s very important. HUMILITY as well, so you are sort of sharing your strengths and weaknesses y’know, you are showing that you are not a perfect person or a perfect professional and I think part of realising that is actually being in an individual therapy relationship yourself and actually acknowledging how it can be painful when you have to tell somebody else your difficult things which (pause). Most people have gone through something in their lives that can be difficult and painful and actually, recognising how you cope with it sort of makes you in a similar way, I suppose you can understand how that might be for your client really.

Mmm

Um because you’re understanding where they’re coming from and understanding how it can be to have to tell somebody what it’s like to have a difficult situation and not know how to cope with it yourself, and needing to find help from other people. Because it’s a very – I’ve had personal therapy myself before the course – um not for long but it is a real experience I feel, and it’s a
<table>
<thead>
<tr>
<th>Self-learning</th>
<th>(\text{&quot;Receiving end&quot;?} ) experience/feelings</th>
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<tbody>
<tr>
<td>Importance of self-understanding for work role.</td>
<td>real (pause). You learn a lot about yourself actually how it feels to sit in that chair and have that other person looking at you and interpret what they say, what you say, and thinking &quot;I wonder what they're thinking about me&quot; and y'know, having all those feelings you never ever get as a psychologist or as a therapist. And um, I just see it is important to know about yourself and I think that is important in most jobs but particularly in our job, so I see it as desirable, yes. OK, I'd like to discuss some of the things that you've mentioned in a bit more detail and um, I think you've touched on a lot already and it sounds to me – I just want to check this out with you but – you're saying that personal therapy is an important experience in its own right. Yes And that what that brings to you in terms of genuineness Mmm Humility Mmm Hmm And the empathy you might feel towards your client sounds like a beneficial side-effect of it Yes</td>
</tr>
</tbody>
</table>
But you feel the experience of it is important in its own right.

Yes.

What I would like to ask about in a bit more detail is what you see as (laughs) – it might be a bit of a repetition - what you see as the potential advantages of personal therapy actually during clinical training.

Um, you know, looking back I don’t know whether I would want to do it while I’m in clinical training. I can see the benefits of it but I don’t know – I know how difficult training can be – so I would be (pause) have reservations about doing it alongside it because of the issues that it brings up for you as a person. Um it’s very difficult, I think it’s an individual thing and it’s very hard to actually say it that you have to do it in clinical training – I really don’t know how people would cope with both experiences. So I’m really not, I’M REALLY NOT sure that it’s appropriate to do on training but I think it’s an appropriate experience to have as a psychologist. So I can’t really say – I haven’t made my mind up as to whether it would be appropriate to have it during your training cos to me training drains every little bit of energy out of me and I don’t know how much energy you could have but (ends).

Do you feel there are differences in the potential...
Experience of being person and a trainee as fused?

Benefit: learning about therapeutic relationships

CORE SKILLS/QUALITIES
Genuineness
Empathy
Understanding
Non-judgemental

Therapy as aid to core skills as therapist

Knowing and Being true self.

Necessity of (Core Skills/Knowing and Being true self) for all therapists – SHOULD

Experience of therapy as foundation for attitude

Experience of downsides (pitfalls?) of therapy

**advantages from the point of view of you personally or professionally, and the point of view of trainees in general?**

Um, that's a difficult question. I can only speak for me as a trainee so it's hard to separate those two things out. Um I think for me personally, yes it's beneficial, I think I've learnt a lot about therapeutic relationships from that, but therefore, but in terms of trainees in general I think you have to be - the point of any general counselling skills, whatever area you work in in clinical psychology, you need GENUINENESS you need EMPATHY you need to be y’know (pause) to have a good understanding and be non-judgmental, I think individual therapy does give you that. Um because you learn actually who you are and you don’t have a default persona as such you sort of (pause) most therapy will get you in touch with who you are. I don’t know, I just think that those are the benefits of individual therapy and that (pause) all trainees should have those I think, all therapists should know who they are and be touch with who they are. But that's sort of coming from my experience...

*Yes, I was going to ask you this – what you base that conclusion and thinking on.*

Um, I think it probably is past experiences of therapy, (?) of individual therapy. It wasn’t actually a brilliant therapy. It was gestalt therapy and they had these two chairs and I, it felt alright. I could

Fusion/inseparability of self as person and trainee (contextual)

(Desirable, because) learning about therapeutic relationships

Therapy as aiding the development of essential qualities of therapists

Experience of therapy as informing attitude about therapy during training

Personal experience of benefits and pitfalls of
<table>
<thead>
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<th>Experience of benefits:</th>
<th>Self-understanding as grounded in/originating from experience of personal therapy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Being listened to</td>
<td></td>
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<tr>
<td>Able to talk openly</td>
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<tr>
<td>Confidential space</td>
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<tr>
<td>see the down-sides of it in terms of how I felt, in that it didn’t really match how I felt – what she was doing didn’t often match how I felt, and I felt I was misinterpreted at times. But in another way you learn, I felt I learnt about how it felt to be listened to and to be able to talk openly in a confidential way, which was nice – really good. Um, so I suppose I’m basing that, maybe I think I’ve got a good understanding of myself and I feel that part of that comes from therapy so therefore I think it has been useful in my work.</td>
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<tr>
<td>therapist</td>
<td>Therapy as grounding for self understanding and view as important of therapy</td>
</tr>
<tr>
<td>Misinterpretation</td>
<td></td>
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<tr>
<td>Mismatch</td>
<td></td>
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<tr>
<td>Attitude change during course</td>
<td></td>
</tr>
<tr>
<td>Initially: view as important</td>
<td></td>
</tr>
<tr>
<td>Decline in view as important (unsure of reason)</td>
<td></td>
</tr>
<tr>
<td>Psychodynamic placement – heightened awareness and view as important.</td>
<td></td>
</tr>
<tr>
<td>Mmm. Mmm. I don’t know. I suppose, yeah maybe it has (laughs) actually. At the beginning I suppose, yes I did think it was important and maybe, I don’t know why, I can’t think why, why it’s changed but, um, I think maybe it did tail off a bit but I suppose in my last placement – it was very psychodynamic – and I suppose that that’s made me more aware of these issues. Um and</td>
<td></td>
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<tr>
<td>therapy</td>
<td>Therapy as grounding for self understanding and view as important of therapy</td>
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<tr>
<td>Attitude change across duration of training</td>
<td></td>
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<tr>
<td>Fluctuating view of importance of therapy</td>
<td></td>
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<tr>
<td>Psychodynamic placement as context for heightened view of therapy as important</td>
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</table>
maybe it is more important in a job where you are using psychoanalytical approaches and you're very (pause) there's a lot of emphasis on the therapeutic relationship. But that is the case in any kind of work but more so, it was more highlighted in my last placement to an extent. I am more aware of it from that, so I do see it as important now. But, y'know, my next placement will be dealing a lot with parents and parenting and the basis of that relationship, the basis sorry of that work will be a therapeutic relationship with parents in order to be able to get any interventions to work and I'll be using those skills in that so, it has changed a bit but maybe there's more of an emphasis now because I've got my psychodynamic-type placement (?) up (laughs).

Ok, and do you think there are particular times or situations where personal therapy becomes particularly desirable for trainees?

Pause. Mmm, during the course do you mean?

Mmm hmm (yes).

No, and I'm still, like you say, I was thinking on the way here in the car I'm not sure whether I could do, er, have personal therapy during training because it's so stressful – the Course is so stressful. Um, but I suppose, perhaps in the third year, perhaps when you're more settled, you haven't got those initial anxieties of coursework – you've adjusted to the demands of assignments,
there are less stresses, even though you’ve got your research I mean, from September there were less stresses for us so perhaps something in the third year may be OK. And especially if you’re going, if the course changes as it may and there will be all the specialist placements in the third year, you may get people doing more psychodynamic, psychoanalytic-type placements therefore it may be more helpful. So perhaps, that may be the only time, and I would definitely probably say not the first and second year – I think that would be too much (laughs).

OK, so you are talking about the third year maybe being a more ideal time.

Mmm, MAYBE.

*More in terms of being a bit more settled.*

Yes.

*And a bit less, sort of changeable in terms of so much going on (question intonation).*

Yes.

*Do you think there are any particular benefits to be gained as a third year trainee?*

As opposed to being a first year or second year on training?
Mmm hmm (yes).

I think you have got your identity more and your professional identity. I think you feel more confident in the third year. You definitely feel that you are consolidating your skills, you feel that you’ve got the basic skills and you’re sort of just developing those more really in the third year—that’s what you’re concentrating on. And I think personal therapy can add to that. And you can also do it, but in the context of training so you can take any issues sort of (pause) you can use those in supervision and then take it back, so you can develop your skills within supervision—which I suppose you do after you’ve qualified as well. So yeah, perhaps the third year might be a good time.

OK. Thanks. I think some of the things you’ve said are going to touch on my next question really, which is what you might see as the potential disadvantages of personal therapy during clinical training.

I definitely think the issues that it may bring up for you and how you manage all of that because, (laughs) in my experience of training, although training for me has been OK, it’s been hard, it’s been challenging, it’s been difficult, it’s been stressful. And if you have also other things to mull over—because, when you are in therapy you would spend that hour with that person but the therapy goes on for the whole week—you are

| More established (self?) identity and professional identity in third year | Third year – more established identity, greater confidence |
| Greater confidence | Therapy as aid to consolidating basic skills/essential qualities |
| Time of consolidation of basic skills | Supervision as complement enabling learning in therapy to be reflected upon in professional contexts? |
| Personal therapy as a means to consolidating skills | |
| Context of supervision (complementary to using therapy to consolidate skills) | |
| Disadvantages: Issues raised – how to manage | Reasons against... |
| Training as challenging and stressful | Contraindications within therapy: Issues raised – need to manage/cope (therapy as a stressor?) |
| Therapy as “all-week” experience – requiring psychological | Contraindications within training: Stress and challenge |
|  | Psychological demand (effort/headspace) of therapy |
Training as filling head  
- Competition for psychological resources and time -  juggling

Lack of time

Training as preventing full engagement with therapy

Efforts directed at remaining on course

Lack of ability to reflect and use well

Experience of training, Vicarious experience (peers)

(If) beginning of third year then maybe desirable.

Juggling – difficult

resources

constantly in the car, mulling it over it or trying to work things out trying to, um, understand things and trying to reflect on what’s been said in that session – so it never really goes away (laughs). And I think, on the Course, my head always feels full of all sorts, y’know, trying to juggle placement, assignments, research, all of that so – and personal life and social life, so I don’t – it’s almost as though you couldn’t have the time to be able to fully engage in it (question intonation) – if that makes sense. That’s how I would feel – my head’s just trying to y’know, keep on going on the course so I don’t think I would be able to.

So there would be barriers in terms of time and in terms of (pause) headspace (question intonation).

Mmm – YES. Or ability to reflect, I think, on it – and use it well.

And where do you think that opinion is coming from? What would say you base that decision on?

Um, just on my experience really – of being on the course. And also my, you know, peers and other third years on the Course – even though it can be slightly easier in the third year um, at the beginning, the last few months are busier but I think at the beginning it can be slightly easier. But most people know that it’s difficult to juggle all the demands of the Course. Um and some people – you do have less to worry about in the third year cause you’ve done most of your core

| Competing/cumulative demands |
| Juggling |
| Time demands |
| Training preventing full engagement with or reflection from therapy |

| Experience of training |
| Vicarious experience (peers) |

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<table>
<thead>
<tr>
<th>Assignments so it is possible for some people I think to be able to do it alongside training in the third year.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you think, I suppose this relates to where your feelings are coming from as well, do you think this is something that has changed over the duration of the course as well, in that, does your impression of the potential disadvantages of therapy – has that changed?</td>
</tr>
<tr>
<td>No I don’t so – I don’t think I’ve really considered it in any depth but I think I’ve always thought, y’know, it would be great to go back into that – I’d like to do more therapy I think there’s a lot more to learn about yourself and just understanding myself a little bit more. But in the third year I think “Oh God, I’ve got enough to worry about” – you know IT CAN WAIT, that’s how I’ve viewed it. But I think some people could do it but for my opinion I think it could wait.</td>
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<tr>
<td>Ok, and for you personally would there be certain times or situations which would be particularly potentially advantageous do you think to seek personal therapy?</td>
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<tr>
<td>You mean on during the Course?</td>
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<tr>
<td>Yes.</td>
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<tr>
<td>Um, not, I mean, I can’t think of anything. If you were having a particularly difficult time in your Training as a pressing demand vs therapy as able to wait</td>
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<tr>
<td>Personal therapy as a future aim</td>
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<tr>
<td>Desirable maybe if… (indicated situations)</td>
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</table>

No change in impression of disadvantages of therapy during training
Desire for further therapy – not yet – too much to do
Therapy as able to wait – (training can’t)
Desirable (if)
### Personal Difficulties and Stress

<table>
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<tr>
<th>Choice/dilemma – seek help or keep head down and concentrate on the course</th>
<th>Individual choice</th>
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<tbody>
<tr>
<td>Therapy can wait until after the course</td>
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<table>
<thead>
<tr>
<th>Personal opinion</th>
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<tbody>
<tr>
<td>Not desirable (if) in first or second year</td>
</tr>
<tr>
<td>Trying to adjust</td>
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<tr>
<td>Busy</td>
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</table>

**For trainees in general do you think there are times or situations where it would be particularly disadvantageous to seek...?**

I suppose all I would be thinking of is it may be difficult in the first and second year because you are trying to adjust to the course. That would be my only main thing that I particularly think may be disadvantageous – just because you’re so busy and it’s difficult to take on – but that’s my opinion – I’m sure trainees have done it and it’s fine (laughs).

**Another question is whether you think there are any particular issues where you think personal therapy would be either particularly advantageous or particularly disadvantageous.**

Um, again it’s different for different people. I think if you did have a really personally difficult crisis – in your personal life especially – um you may...
| Marital problems, Doing therapy for yourself – regardless of course (maybe desirable) | Want to seek help. If you had a bereavement or if you are having marital problems then you may just go and do that anyway, and sort of, sod the course really. You know, you needed to do this, it was almost a have-to-do-this, um, or if you had a family member who is very ill and, you may feel that helps you. Um, so I would probably have considered it in all of those occasions but it hasn’t happened to me, so I’ve been lucky. But, what was it, disadvantages, and advantages...

**Around particular issues.**

Advantages, I mean, if you were having really difficulty in therapy relationships and this was being pointed out to you I think you would feel almost obliged to go and have some personal therapy yourself in order to understand where you are coming from. But with the selection process it doesn’t seem to me that you would be somebody who has SUCH difficulty or SUCH difficult experiences in therapeutic relationships.

**So why do you say that about the selection process?**

No, I was thinking, because most people have had clinical experience or they’re (pause) quite capable is what I mean, y’know, they don’t just pick people off the streets to do clinical training, there is quite a process you go through and most people have the basic interpersonal skills that they are able to maintain a therapeutic...

| Desirable/necessary if told having difficulty in therapy relationships – obliged – necessary to increase self-understanding | Personal crisis/stress

Therapy for yourself – not for course requirement – maybe desirable

Desirable if You feel it helps you (Individuality and choice?)

Desirable/essential if told having difficulty in therapy relationships – necessary to increase self-understanding

But unlikely to be necessary (capability in terms of basic interpersonal skills/essential qualities)

But unlikely to be necessary

<p>| Capability of trainees – unlikely to be necessary – in terms of pre-requisite interpersonal skills |</p>
<table>
<thead>
<tr>
<th>Personal choice – would not implement policy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mandatory personal therapy as problematic (Based on discussions with professionals who have performed mandatory counselling)</td>
</tr>
<tr>
<td>“Going round the houses” in therapy (Therapy for therapy’s sake?!)</td>
</tr>
<tr>
<td>Frustration – client and counsellor</td>
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<tr>
<td>Can’t force self-exploration</td>
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<tr>
<td>Counterproductive</td>
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<tr>
<td>Would not force our clients into therapy</td>
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<tr>
<td>Not effective</td>
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<tr>
<td>Advocating therapy more strongly</td>
</tr>
<tr>
<td>Seminars on benefits of personal therapy</td>
</tr>
<tr>
<td>More exploratory work on self and therapeutic relationship</td>
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Relationship but, maybe it's something (pause) (laughs).

*Thanks. I would like to approach the subject from a slightly different perspective now, which is to imagine, if you were the Course Director*

Yes.

**What policies around personal therapy for Trainees would you advocate or implement?**

I wouldn't implement any, I think it's personal choice. I really, I do toy with the idea with personal therapy that is mandatory because that can lead to all sorts, different problems because y’know (pause). Talking to supervisors I’ve had who have counselled counselling trainees or counsellors who have to have personal therapy, it could be you are just going round the houses and not really getting anywhere and it can be quite frustrating for the person involved and the supervisor or counsellor. It’s difficult because it is — I don’t think you can actually force people to do something like that — explore themselves – because it’s going to be counterproductive – it’s like forcing people into therapy – like forcing clients into therapy – we’d never do that, because it isn’t effective. I think we could advocate it and it could be advocated a little bit more strongly on the Course so we could have more seminars on the benefits of personal therapy and a bit more exploratory work on yourself and the therapeutic relationship but, maybe it’s something (pause) (laughs).

<table>
<thead>
<tr>
<th>Individuality and choice – not an issue for policy implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mandatory personal therapy as not desirable</td>
</tr>
<tr>
<td>- ?not full engagement</td>
</tr>
<tr>
<td>- frustration</td>
</tr>
<tr>
<td>- not possible to force self-exploration</td>
</tr>
<tr>
<td>- would not force clients</td>
</tr>
<tr>
<td>- not effective</td>
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<tr>
<td>- ((motivation/readiness – own interps?))</td>
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</table>

<table>
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<tr>
<th>Stronger advocating of personal therapy as desirable</th>
</tr>
</thead>
<tbody>
<tr>
<td>(within context of?)</td>
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<tr>
<td>More exploratory/reflective learning during training as desirable</td>
</tr>
<tr>
<td>Heighten awareness of the issue</td>
</tr>
<tr>
<td>--------------------------------</td>
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<tr>
<td>Advocating more strongly – possibility of opinion change</td>
</tr>
<tr>
<td>Need for dialogue about personal therapy</td>
</tr>
<tr>
<td>Background of trainees – pre-existing narratives/attitudes – need to bring discussion and choice into open (make more rational/conscious decision???)</td>
</tr>
<tr>
<td>(Problematic) attitude of self as not needing therapy – therapy as something for others</td>
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</table>

relationship – but I don’t think I’d change the way the Course is. But it’s not a big issue on the agenda and it could be a little bit more, um, it could make trainees a little bit more aware of the benefits maybe.

Ok, so you’re talking about maybe, if it was advocated a bit more strongly and that would be in seminars and lectures to raise awareness?

Yes.

OK, and what sort of difference do you think that would actually make – would it make any difference to you personally if that was going on?

I think it would have maybe, I mean, I was already aware of something I wanted to do anyway, but if you weren’t, if you were somebody who was quite against maybe personal therapy it may change your opinion slightly, possibly, if you could see somebody discussing the benefits of it – or even the disadvantages of it may lead somebody not to go into personal therapy that might have done – so it’s just having a sort of DIALOGUE about it really. And I think, you know, people come from different backgrounds and some people or families would be “Oh no no, you shouldn’t go near that” – even if their child is a trainee psychologist – you know you can have that in families can’t you? – and people may have come with opinions that y’know, we can treat other people in therapy – clients – but WE don’t need it
<table>
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<tr>
<th>Possibility of opinion change in favour or against</th>
<th>Encouraging greater reflection on how own issues might influence professional practice</th>
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<tbody>
<tr>
<td>Nor admitting to having or needing therapy</td>
<td>Therapy as private</td>
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<tr>
<td>Therapy as private</td>
<td>Changing level of concerns about others’ reactions...</td>
</tr>
<tr>
<td>Less concerned about others’ views by third year</td>
<td>Therapy as hidden/private/ not talked about openly</td>
</tr>
<tr>
<td>Greater self reflexivity</td>
<td>... ? related to increasing self-openness about possibility of needing therapy</td>
</tr>
<tr>
<td>Increasing self openness about possibility of needing therapy</td>
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</table>

- so it may change that and make people more open to discussing the issue.

*And for trainees in general, what difference do you think it would make if it was advocated more strongly.*

Um, it may lead them to go into therapy maybe, or think about it for the future, or maybe reflect more on their practice – how issues they have may influence their practice. It may just make them a bit more aware of that.

*OK. I was wondering as well how you would describe the current culture around personal therapy on the Course. What is the culture like about it?*

Um, in terms of our peer group of trainees, I think nobody in the first year – I think this is the same for most courses – would have really wanted to admit that they needed therapy or were in therapy. And it is a private thing – you don’t have to tell anybody. But I suppose (laughs) when you get to the third year you don’t really care what people think or what, you know, you’re more (pause) reflective on yourself and you realise the impact things are having on you and you are more open to admitting that you might need therapy or are having therapy. Um, so I think, in the third year you are a little bit more open about it, but, are you thinking in terms of the course team?
| Being told needing therapy by course team..... | *I was thinking of the Course in general but you can interpret it how you like really.*  
I mean the course team, is not really, (laughs) (pause), I know people have had experiences where they've been told they need therapy by the clinical tutors but I've never had that experience, no I haven't heard that, um.  

*What do think that experience would be like if that happened to you?*  
I think it would be awful, I think you'd be really kind of, you'd feel quite patronised. Maybe if it's said in a nice way, maybe if they said y'know, “we think you need to talk to someone about this”, but I think most people on this course are over 25 and they do have, are able to make judgements for themselves, um,. And I think they can't force you into therapy so I don't think it is, you know, SO awful but I still wouldn't like them to say that to me (laughs). I think I could make my own decision but it depends how it is taken and it depends how it's said (laughs) really.  

*Ok. Is there anything about the culture on the course that you would like to be different around the issue of personal therapy?*  
Mmm, difficult to say because I haven't had any direct experience of people telling me I need personal therapy but it probably, I think for a lot of |
<table>
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<tr>
<th>(Culture)</th>
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<tr>
<td>Therapy seen in negative way</td>
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<tr>
<td>Therapy = not coping</td>
</tr>
<tr>
<td>Feeling of needing to cope on the Course and demonstrating ability to cope (implic that therapy incompatible with that)</td>
</tr>
<tr>
<td>Hard to show it if not coping/need extra help</td>
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</table>

Training courses you can, things can be seen in a negative way, an I think it is still slightly seen in a slightly negative way – that you aren’t coping – and this is only from other people’s not from my experience, but perhaps you feel on the Course that you have to cope – which I think you do you feel that you have to always be coping and showing that you’re doing very well. Which a lot of people are and that’s the way they are but, if you’re NOT, perhaps it’s difficult to say that you’re not and it’s difficult to go into therapy and show that you’re not (pause) – you need extra help to cope, so but I can’t really comment on that because I haven’t had the experience (laughs).

**OK, I'm coming towards the end of this interview now but I was wondering whether there was anything else that you would like to sort of add that we haven't really already covered in the questions, about the issue of desirability of personal therapy during training.**

Um, just really to reiterate that it’s personal choice – I think there are benefits of it, and you can learn from it and it can be beneficial in the therapeutic relationship, but I don’t think it can be mandatory for everybody because clinical training’s very stressful and I don’t think you should push that onto people. I think it’s something you learn the benefits of in time as do clients, and you would never push your client into seeking help y’know so I don’t think you can actually push trainees into it. But perhaps raising awareness may stimulate...
reflective practice in general

more interest and maybe more awareness not just of personal therapy but of reflective practice, being quite aware of who you are and a bit—we’ve talked before about having more um, more thinking around actual counselling skills and what makes a good relationship with a client so perhaps more a little bit about that and that could be brought in alongside personal therapy really.

OK. And just to reflect a bit on the process of what this is like (laughs) as well, just wondering how you feel about being interviewed about this topic and what that’s like.

Ah, it’s quite good actually—just being interviewed in general because I’ve been, for my major research just interviewing people, um just finished interviewing people and it’s quite nice to be on the other end of it just to see also how it feels—like to have that experience of being interviewed. Um, I think it’s something that we do talk about, we have talked about in informal ways but it’s quite nice for somebody to be interested enough and aware of the importance of that.

And what’s it like to be interviewed by another Trainee?

Um, it’s fine I think (laughs). I just think, yeah, it’s ok it’s quite nice to be able to assist you XXXXXXXXXXXXXXXXXXXXXX but also I don’t know I suppose we’re also quite similar because we’ve had the same training experience so you maybe
understand what where I'm coming from. And I don't know your opinions on it but you'll know how I feel about the course and I suppose you feel (?) in a way.

*OK thanks, thanks for that. I just want to confirm that the information you've given will be kept confidential and will be used for our qualitative research project. Also if you would like to see a copy of the report than I will make it available to you once it has been submitted and marked.*

Yes. (confirmed that would like a copy).

*And apart from that can I give you a very very big "thank you" for participating and helping out (laughs)*

That's alright no problem. Thank you.

*End of recording.*
PsychD Portfolio Volume I : Hazel Fell-Rayner
Qualitative Research Project: Appendix 6

Appendix 6: Summary table based on transcript
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<table>
<thead>
<tr>
<th>Individually and choice</th>
<th>Importance of choice and relationship to desirability</th>
<th>Non-desirability of mandatory therapy</th>
<th>Possible (maybe if...) indicators of desirability mediated by individual differences and personal choice</th>
<th>Being told you have difficulties in therapeutic relationships as an unlikely example creating obligation to seek therapy</th>
<th>Therapy and attitudes towards therapy as overt and reflected upon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Influencing choice</td>
<td>Need for stronger advocating of or dialogue about therapy</td>
<td>• more exploratory and reflective learning</td>
<td>• enabling greater self-openness about possibility of needing therapy</td>
<td>desirability of informed &quot;adult&quot; decision-making about therapy</td>
<td>Therapy and attitudes towards therapy as covert or subject to covert influence</td>
</tr>
<tr>
<td></td>
<td>Background of opinions about/narratives surrounding personal therapy</td>
<td>From individuals' family backgrounds</td>
<td>Prejudice/ingrained opinion: e.g. Therapy as not the done thing</td>
<td>Negative attitudes toward therapy, therapy as signifying inability to cope – (?)synonymous with incompetence</td>
<td></td>
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<tr>
<td></td>
<td>From culture of the Course</td>
<td></td>
<td>Therapy as private, not discussed openly or admitted to</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Appendix 7: Table of themes (integrated cases)**

<table>
<thead>
<tr>
<th>Table of themes</th>
<th>Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefits</td>
<td>Personal Growth</td>
</tr>
<tr>
<td></td>
<td>Specific Problem Solving</td>
</tr>
<tr>
<td></td>
<td>Understanding motives for being a psychologist</td>
</tr>
<tr>
<td></td>
<td>Increase understanding of self</td>
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<tr>
<td></td>
<td>Increase understanding of patient perspective</td>
</tr>
<tr>
<td></td>
<td>Learning from experienced ‘pro’</td>
</tr>
<tr>
<td></td>
<td>Personal benefits leading to professional benefits</td>
</tr>
<tr>
<td>Drawbacks</td>
<td>Practicalities (money/time constraints)</td>
</tr>
<tr>
<td></td>
<td>Stigma (evaluation/judgement from course)</td>
</tr>
<tr>
<td></td>
<td>Pandora’s box (emotional strength needed for therapy at stressful time during training)</td>
</tr>
<tr>
<td></td>
<td>Questionable worth if therapy compulsory</td>
</tr>
<tr>
<td></td>
<td>May contradict the ‘competency model’ of the course</td>
</tr>
<tr>
<td>Individual choice</td>
<td>Compulsory vs. voluntary</td>
</tr>
<tr>
<td></td>
<td>Choice of model used</td>
</tr>
<tr>
<td></td>
<td>Knowledge of different models</td>
</tr>
<tr>
<td></td>
<td>Using alternative support (supervisors/friends)</td>
</tr>
<tr>
<td>Influences</td>
<td>Personal experiences of therapy (individual &amp; RPG)</td>
</tr>
<tr>
<td></td>
<td>Specialist training e.g. if psychodynamic option then individual therapy more useful.</td>
</tr>
<tr>
<td></td>
<td>Development through training</td>
</tr>
</tbody>
</table>
Theoretical Orientation

CBT – problem specific should be offered on 'need' basis and not compulsory
Psychodynamic (personal growth) – some would and have found useful personally & professionally
Appendix 8: Diagram illustrating possible relationships between themes
MAJOR RESEARCH PROJECT

A case of social pressure versus asthma pressure?
Initial examination of a model portraying exertion as a context for conflict amongst adolescents with asthma

Statement of anonymity: Some details have been omitted to preserve the anonymity of the host Trust and the participants.

July 2004
Year 3
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Abstract

Background and objectives: Responding to evidence that young people who have asthma experience difficulties surrounding exercise, a formulation proposed that some adolescents possess beliefs that asthma and exertion are incompatible. It was proposed that such individuals might misinterpret symptoms of exertion or anxiety as symptoms of asthma attack – leading them to curtail or avoid exertion. It was suggested this might create conflict with social pressures to participate in sports, producing oscillations in exertion level.

Method: A cross-sectional questionnaire design, enabling initial descriptive and correlational analysis of the research questions and hypotheses. Forty-one adolescents aged 11 to 16 years with confirmed diagnoses of asthma completed the questionnaire while attending paediatric asthma clinics.

Results: 35% of participants thought exercise was unhelpful in the management of asthma. 73% thought energetic activity could trigger an asthma attack. Most of the hypotheses were supported. For example, a strong positive correlation was found between the belief that asthma and exertion are incompatible and asthma-management strategies involving the avoidance or curtailment of exertion. However, such beliefs were positively associated with the interpretation of asthma rather than non-asthma symptoms as asthma – suggesting such beliefs may be based on accurate recognition of exercise-induced broncho-constriction rather than misinterpretations of symptoms.

Conclusions: The questionnaire generated potentially-useful data, and preliminary support for the hypotheses suggested they would merit further study. Potential implications for clinical interventions aimed at reducing restriction associated with asthma were outlined. However, methodological limitations, particularly in relation to measurement of symptom-perception, would require attention to further the theoretical understanding gained from such research.
Acknowledgements

I would like to thank all those who have given so much help and support — both practical and moral — while I have been conducting this research.

Dr Victoria Senior, my research supervisor at the University of Surrey, has provided invaluable advice and feedback on all aspects of the research for the last two years. Professor Rob Horne at the Centre for Health Care Research (CHCR), and Dr Paul Seddon, Consultant Paediatrician, provided enthusiastic field-supervision, helping me over many hurdles and, when the going got tough, spurring me on with their interest in the clinical implications of the research. Between them, my supervisors have not only enabled me to conduct the research for this project, but have also strengthened my aspirations to remain research active in the future.

Jane Clatworthy, also at CHCR, has been a friendly face and source of sound advice, reflecting on the issues involved in helping adolescents express their views in research. Helen Taylor has provided immense help — I could not have done the research without her. I am also grateful for the support I had from all the staff at the clinics where participants were recruited — especially Edwina, Jason, Yvonne and Cathy — and to those who took part in expert-sampling on the symptom checklist.

Thanks are also due to all the participants and their parents or guardians who gave their time to complete the questionnaire and provide their opinions and feedback.

Last, but by no means least, my husband Rijk has been an unfailing source of support and encouragement, and my sister, Philippa has acted as an “IT Helpdesk”. Both have rescued me from sense-of-humour-failure when I needed it most. Thanks.
Introduction

Research interest in asthma: Asthma is a chronic respiratory condition characterised by inflammation and hypersensitivity of the bronchial tubes which form the airways to the lungs (National Asthma Campaign (NAC), 2000a; British Lung Foundation (BLF), 2002a). During asthma attacks (or exacerbations), the wall or lining of the airways inflames, surrounding muscles contract, and mucous may be secreted – obstructing and narrowing the airways. This may cause symptoms of shortness of breath, wheeze, chest tightness and coughing (NAC, 2000a; BLF, 2002a).

Asthma is one of the most common chronic health problems and the NAC (2000a) has cited findings that 3.4 million people in the United Kingdom (UK) have asthma. This includes 1.5 million children – amounting to a childhood prevalence rate of about one in seven (National Asthma Audit 1997/1998, cited by NAC, 2000a). The number of people affected by asthma is believed to be increasing: the NAC reported that the number of children presenting with asthma symptoms trebled between 1982 and 1992 (NAC, 2000a). The consequences of asthma can range from occasional episodes which respond quickly to treatment with bronchodilators (medications that relax the muscles surrounding the airways to allow more air through), more frequent exacerbations which require prophylactic treatment to reduce the inflammation of the airways (usually with corticosteroids), to episodes which ultimately, although very rarely, can lead to respiratory arrest and fatality (NAC, 2000a; NAC, 2000b).

There is currently no cure for asthma: treatment relies largely on self-management incorporating medication to control the symptoms of asthma and avoidance of triggers such as house dust-mite, traffic fumes and cigarette smoke (NAC, 2000a). Noeker & Petermann (1998) point out that individuals' competence at performing self-management behaviours will consequently determine the level of benefit obtained from treatment. The psychological processes underlining such self-management behaviours are therefore of research interest (Lehrer, Feldman, Giardino, Song & Schmaling, 2002). Adolescence emerges as a time of particular theoretical and clinical interest and concern from this perspective. It is viewed as a pivotal time when responsibility for health-related behaviour transfers from parent to
young person, and the foundations for life-long self-management behaviours are laid down (Williams, Holmbeck & Neff Greenley, 2002). It also appears to mark a time of heightened risk for non-adherence to medical regimens – and therefore particular vulnerability for increased morbidity and mortality risk (as well as healthcare cost) (e.g., Logan, Zelikovsky, Labay & Spergel, 2003).

The factors influencing adolescents’ self-management of asthma therefore formed the initial point of interest for this research. As will be discussed, the available literature on general self-management of physical health conditions has largely focused on medical adherence – taking medications as prescribed, attending clinic appointments and avoiding risks (Lehrer et al., 2002). Models with their foundations in health psychology, such as the self-regulation model (e.g. H. Leventhal, E. Leventhal & Contrada, 1998) have elucidated the role of cognitions in shaping such health-management behaviours among adults. However, as will be outlined, there have been problems applying such theories to adolescent treatment adherence. An examination of studies that attempted to take a broader view of adolescents’ attitudes towards and perceptions of asthma suggested that managing peer-related situations may be of greater importance than medication adherence (e.g. Sugar Consulting, 2002; Yoos & McMullen, 1996). In particular, the management of situations involving pressure to participate in exercise or other forms of exertion emerged as areas of particular concern (Sugar, 2002; Yoos & McMullen, 1996).

As will be discussed, such findings were surprising as it appeared some young people viewed exercise as a potentially-harmful behaviour in which they should avoid participating – an idea in contradiction with current health advice (e.g. NAC, 2000b, BLF, 2002a). A speculative model accounting for such findings was proposed and guided the direction of this research. The model incorporated both clinical psychological models (of panic (e.g. D. Clark, 1989, 1997) and deconditioning (e.g. Sharpe, 1997)) and ideas from health psychology models (e.g. Weinman & Petrie, 1997) which might portray the avoidance of exertion as a response to control beliefs.

As will be outlined below, an examination of currently disparate areas of literature including symptom-perception, the relationships between exertion and asthma, and social influences on coping with asthma, provided some initial backing to the ideas
proposed by the speculative model. The model therefore directed a series of more specific research questions which it was aimed to investigate in a quantitative, questionnaire-based study of young people's beliefs about asthma and exertion.

Inevitably, these research questions ventured into territories associated with considerable debate in asthma research – in particular, that surrounding the phenomenon of exercise-induced broncho-constriction. As will be outlined, prevalence estimates of this phenomenon vary widely (van Veldhoven, Vermeer, Bogaard, Hessels, Wijnroks et al., 2001), and it is not clear to what degree subjective reporting of exercise-induced asthma symptoms tallies with objective measures such as lung function tests (Panditi & Silverman, 2003). Exercise-induced broncho-constriction has been found to be unrelated to degree of asthma severity, suggesting it has a more complex relationship to asthma than being merely symptomatic of it (C. Clark & Cochrane, 2001).

Equally, there has been debate about how to define such severity. In the UK, the British Guidelines on Asthma Management (cited by NAC, 2000a) apply a "stepwise" approach to treatment (NAC, 2000a), and asthma severity may therefore be categorised according to the nature of treatment. For example, at the mild end of the spectrum, treatment may be limited to occasional use of reliever inhalers at Step One. Regular prophylactic treatment delivered via a preventor inhalers is added to this at Step Two. At Step Three, higher doses of prophylactic medications may be administered through inhalers, possibly using spacers; alternatively, longer-lasting reliever medications may be used. Further prophylactic and reliever medications may be administered at Step Four, and spacers used with reliever and preventor inhalers. At the most severe end of the spectrum, daily steroid medications in tablet-form are prescribed alongside the other treatments. Thus, physicians' professional assessments of the severity of asthma symptoms and decisions surrounding the level of medication warranted are central to – as well as influenced by – this classification and treatment management system. Frequently, such judgements may be based on objective measures of asthma correlates: exhalation rate may be assessed as a measure of airway obstruction and inferred broncho-constriction (Lehrer et al.,
The reliability and validity of such measures are themselves debated (Lehrer et al., 2002). Thus there is no “gold standard” measure or classification of asthma.

**Adherence and self-management among adolescents with asthma**

Several models with bases in health psychology have emphasised the role of illness-related cognitions in shaping the strategies employed by individuals to manage physical health conditions (Taylor, 2003). An example is the self-regulation theory described by H. Leventhal et al. (1998), which argues that the way an illness is coped with (the coping procedures employed) will reflect the way that illness is thought about or represented schematically (illness representations). Such illness representations are argued to include beliefs relating to five domains: the identity of an illness (including its symptoms and label), its duration or timeline (for example, whether it is believed to be acute, chronic or cyclical), its assumed causes, its consequences (including its impacts on lifestyle) and understandings of cure and control – of how its symptoms can be minimised or underlying pathology can be treated.

The model is regarded as self-regulatory in that it is goal-orientated and linked with self-concepts – including concepts of “possible selves” incorporating both health and illness (H. Leventhal et al., 1998). The way a symptom or “health threat” is appraised (e.g. as a minor complaint versus something potentially life-threatening; as a condition causing minor discomfort versus an illness causing much pain or debilitation) will interact with emotional responses (such as fear) to shape coping procedures. Coping behaviour will be directed both towards coping with the illness as it is appraised and the emotional response to that appraisal (H. Leventhal et al., 1998). The self-regulation model has been applied to understanding how “common sense” representations of illnesses could lead to particular patterns of illness-management – explaining patterns of behaviour including treatment adherence, risk-management behaviour and attendance of healthcare appointments (Weinman & Petrie, 1997).

A growing body of research linking such cognitions with treatment adherence (Weinman & Petrie, 1997) has sparked interest in whether such constructs could influence adolescent illness-management behaviour. Medication non-adherence relating mainly to prophylactic but also to reliever medication, has become an area of
particular concern amongst this age group and linked with increased morbidity and mortality from asthma in this age-group (Logan et al., 2003). Kyngäs (1999) found that levels of adherence varied widely between individual adolescents: 42% of 13-17 year-olds who had asthma reported full compliance with health self-management plans, 42% regarded their level of adherence as “satisfactory”, and 18% conceded poor adherence in a questionnaire study. Similarly, McQuaid, Kopel, Klein and Fritz (2003), who used electronic devices to monitor prophylactic (preventor) inhaler-use amongst children and adolescents aged 8 to 16 years, found that the level of adherence ranged from no use at all to 99% regimen adherence. The mean adherence rate of 48% indicated that, overall, children were taking less than half of their prescribed doses (McQuaid et al., 2003). But the variation between individuals led Kyngäs (1999) to argue that adolescence should not in itself be regarded as a barrier to adherence, highlighting the need to understand the specific drivers and barriers to appropriate illness-management behaviour in this age-group.

The developments in cognitive abilities in adolescence might be expected to facilitate increases in levels of knowledge and conceptual understanding of asthma and its treatments. Indeed, McQuaid et al. (2003) found that age was significantly positively correlated with asthma knowledge and reasoning, as well as the level of responsibility taken for asthma management. However, while these developments might also be expected to enable improvements in self-management behaviours, McQuaid et al. (2003) not only found that they were not correlated with adherence to prophylactic medication, but that age correlated negatively with adherence. So, looking at this evidence, it seems the barriers to adherence peculiar to adolescence are not accounted for by limitations to knowledge or conceptual understanding of asthma (McQuaid et al., 2003).

Kyngäs (1999) found that some young people used "lying" to give the impression of greater adherence as a coping strategy to avoid conflict with health-professionals. 90% of those who were classified as demonstrating poor compliance complained that the regimens to which they were expected to adhere did not fit their lifestyle. Developing a self-report measure, the Illness Management Survey, Logan et al. (2003) found that older adolescents reported more barriers to adherence than younger
adolescents, including strain associated with the regimen, lack of social support and peer and family issues. If these findings were to be translated into the terms of the self-regulation model (H. Leventhal et al., 1998), they might be viewed as indications that treatment regimens are viewed as incompatible with the goals of young people — particularly older adolescents — and that these perceived consequences of treatment hinder medication adherence more greatly than do faulty illness representations.

Riekert & Drotar (2002) applied a social-cognitive approach to develop a measure examining how adolescents' perceptions of the threat posed by their chronic condition, expectations of positive and negative outcomes of taking medication, and intentions to take their medications as prescribed related to their self-reported adherence. They found that the four factors together accounted for 22% of the variance in self-reported adherence. Positive outcome expectations and intention to adhere correlated significantly positively with adherence. Negative outcome expectations were significantly negatively associated with adherence. The perceived threat posed by the condition (such as asthma) was not statistically significantly related. The findings of Riekert & Drotar (2002) could be viewed as evidence that such health-related belief processes influence adolescent self-management behaviour including the taking of inhaled medications.

However, qualitative research that formed part of a pilot study into adolescents' beliefs about asthma and medications by Clatworthy (2001) suggested that adult-oriented theories such as self-regulation theory might not be relevant to young people. Of the nine adolescents (aged 11 to 15) interviewed, few evidenced concerns that would be anticipated in an adult population according to such models (Clatworthy, 2001). Most had no idea of the cause of their asthma or any concerns about side-effects. The main perceived drawback of medication was that it could be "annoying" having to include it in daily routine. While several participants acknowledged occasionally forgetting medication, there was little sign that any of the adolescents decided not to take their medication — this appeared to be an area of responsibility delegated to parents and health-professionals (Clatworthy, 2001).
This is reminiscent of the debate surrounding the application of adult cognitive-behavioural models of conditions such as depression to children and adolescents, where, alongside interest and promising efficacy findings, there have also been criticisms that adult theories have been “downloaded” onto children and adolescents (Stallard, 2002a; Barrett, 2000). Particular concerns have been raised about neglecting the role of developmental factors including stage of cognitive development and the influence of family, peer and school systems (Stallard, 2002a, Barrett, 2000). Clatworthy (2001) suggested a need to link future research into adolescent health beliefs with developmental psychological theory.

**Developmental approaches to understanding health-management behaviour**

Two questions emerge regarding the appropriateness of models such as self-regulation theory to understanding the self-management of asthma by adolescents. Firstly, are such theories consistent with what is known about cognitive development including the development of understanding of illness? Secondly, is a focus on self-management behaviours, including treatment adherence, relevant to this population? These two questions will be considered in turn.

In many ways, the question of how conceptual understanding of health and illness develops reflects the controversies associated with cognitive development in general. Models from the Piagetian school have suggested that children’s general cognitive abilities are structurally constrained to a series of stages, each marking qualitative shifts in logical thinking processes (Thornton, 1995). Likewise, some theories of children’s developing understandings of illness have emphasised uniform stages of cognitive maturation by which children’s conceptualisations are bound: Bibace & Walsh (1980, cited by Bennett, 2000) mapped understandings of the causes of illness onto Piagetian pre-operational, concrete-operational and formal-operational stages. They argued that, prior to age three, children defined illnesses in terms of a single symptom and attributed their onset to arbitrary events (e.g. something on the television causing a tummy ache) (Bibace & Walsh, 1979, cited by A. Carr, 1999). The idea that illnesses could be “caught” from others was said to develop between three and five years (A. Carr, 1999) but was often over-generalised to all illnesses (Bennett, 2000). With the emergence of concrete-operational thinking between five and seven
years, children were argued to develop more complex understandings of the causes of illness, emphasising the mechanical processes involved – such as inhaling a “germ” which causes a cold (Bennett, 2000). Understandings of the need to carry out particular behaviours (such as cleaning teeth or washing hands) to prevent health problems was also argued to develop at this stage (A. Carr, 1999).

Adolescence, with the transition into formal-operational thinking, was reported to see the development of far more sophisticated concepts of illness including the ability to understand that illness may have multiple causes – physical, environmental and psychological – as well as multiple symptoms (A. Carr, 1999). Nevertheless, “magical thinking” was suggested to be a persistent influence on understandings of the causes and courses of illnesses from mid-childhood through adolescence (A. Carr, 1999). Observations made by Clatworthy (2001) may be consistent with this: for example, one young person, asked whether they thought they would grow out of their asthma, said they thought it “might finish in December… Because it’s Christmas” (p.2).

However, post-Piagetian approaches to cognitive development have rejected the idea of qualitative logical shifts in children’s thinking, and instead emphasised the role of acquired experience and knowledge in producing quantitative changes in conceptual understanding across the lifespan (Thornton, 1995). Likewise, some authors (e.g. Eiser, 1989, Carey, 1985, both cited by Bennett, 2000) have emphasised that children’s understandings of the causes of illness, while following the patterns described by Bibace & Walsh (1980, cited by Bennett, 2000), reflect environmental processes and the growth of knowledge gained from illness experiences. Children’s beliefs are therefore logically consistent with what they know of the world. Indeed, Bennett (2000) cited preliminary findings that children’s understandings of health and illness in general, rather than just the causes of illness in particular, reflect the five domains of the self-regulation model: identity, cause, timeline, consequences and control. However, it has been acknowledged that little is known about the health concepts individuals are likely to have acquired by adolescence, and the role of such cognitions in shaping appropriate self-management behaviours (e.g. Logan et al., 2003).
There has also been criticism that much research into the health behaviour and beliefs of adolescents with chronic health problems has relied on parental report as a "proxy", perhaps bearing little relation to the perceptions and conceptualisations of young people themselves (Noeker & Petermann, 1998). It therefore seems important to re-focus on what adolescents themselves report about their experience of living with and managing asthma. After all, given Clatworthy's (2001) findings that young people appeared to have few opinions regarding their asthma medications, it is possible adult-oriented health models could "miss the point" by focusing on issues of little relevance to adolescents, even if the cognitive processes proposed are consistent with level of cognitive development. For example, the involvement of wider systems (including family, peers and schools) in adolescents' lives and health-management may be such that some aspects of self-management are simply of less relevance, with responsibility for decision-making delegated.

Ideally, qualitative psychological research into adolescents' experiences of living with asthma might provide a useful starting-point for identifying issues of relevance to asthma self-management in this age-group. However, there appears to be a dearth of research in this respect. Indeed, conventional literature search utilising electronic data-bases provided such limited information that it was necessary instead to draw upon informal literature search – sourcing additional references from researchers in the field. Nevertheless, because asthma became the focus of this literature search, it is possible that relevant findings in other fields were overlooked.

Clatworthy's (2001) attempts to examine adolescents' beliefs about medicines qualitatively highlighted the apparent challenges in enabling young people to express their opinions and experiences within research. Clatworthy (2001, and personal communication, 2003) found that the quality of responses to "open" questions in qualitative research paradigms could be quite impoverished. A pattern of responding to questions with "vague, non-committal answers" (p.23, Stallard, 2002b) has been noted in clinical work with children and young people. In order to "coax out" information from young people, clinicians (or researchers) may be drawn into strategies of guessing adolescents' thoughts and asking more closed questions in an attempt to establish their views (Stallard, 2002b). Clatworthy (interview transcripts,
2001) noted this pattern in interviews with adolescents (see Figure 1 for a salient excerpt). While enabling some impression of young people’s views to be gained, this pattern obviously detracts from the central aim of finding out what young people themselves think.

**Figure 1:** Excerpt from qualitative research interview by Clatworthy (2001)

"Interviewer (I): What are the good things about your medicines?  
Participant (P): (no answer)  
I: No good things. Do they work?  
P: Yeah.  
I: Are there any bad things about your medicines?  
P: It’s annoying taking them in the mornings and evenings.  
...  
I: Have you ever had a time when you haven’t been taking them?  
P: Yeah.  
I: Did you notice a difference?  
P: Yeah.  
I: What happened there?  
P: Was worse”

(Clatworthy, p. 2-3, interview transcript (Participant 2), 2001)

Consultancy firm Sugar (2002) used other novel methods to access adolescents’ thoughts and concerns about their asthma. Sugar (2002) conducted a small-group study for the NAC with 32 adolescents aged 11 to 15, categorised by whether asthma had a “high impact” or “low impact” on their lives. Qualitative and quasi-quantitative questionnaires together with “Visualinguistix™” methods (visual, focus-group exercises such as story-boarding) were used to identify salient concerns. As this study (Sugar, 2002) was written up as a consultancy report for the NAC rather than as a piece of scientific psychological research, it is difficult to critique the methodology used. The report was instead focused on conveying what the researchers viewed as the key points made by young people in response to the combination of these questionnaire and Visualinguistix™ methods. For instance, it is unclear what points emerged from questionnaires completed by individuals, and which emerged from group-based Visualinguistix™ workshops, where peer-affiliation and identity processes may have affected responses. Nevertheless, this study was the only identified open-ended, qualitative research into general attitudes towards and
perceptions of asthma amongst young people with asthma in the UK. A study utilising open-ended semi-structured interviews with children aged 6 to 18 years already enrolled in a study of symptom-perception was also identified (Yoos & McMullen, 1996). However, as well as referring to a wider age-group, this study related to a population of children in the United States, where healthcare is delivered in a very different system and cultural “narratives” (Yoos & McMullen, 1996) about health and illness might be expected to diverge from those of adolescents in the UK receiving NHS care. Consequently, the Sugar (2002) report acted as the key study in identifying possible factors influencing adolescent self-management behaviour that might warrant further investigation, and its findings were then compared with those of Yoos & McMullen (1996).

A notable finding from the Sugar (2002) report was that adherence to medication did not emerge as an issue of particular importance to adolescents. 62% of the participants reported taking their medication exactly as instructed, while the remaining 38% said they used their medication in a way they felt was “in tune” with their bodies (Sugar, 2002). Instead, the Sugar report (2002) advocated a need to view asthma within a framework of “lifestyle development” – with greater clinical and research attention to how adolescents managed their asthma in “real life” situations, particularly in terms of avoiding risks. This recalls the finding of Kyngås (1999) that avoiding asthma triggers appeared to be an aspect of self-management that was harder than taking medication, and attracted lower adherence.

Questionnaire and workshop responses (Sugar, 2002) highlighted two main situations during which asthma became important to the young people: during asthma attacks, when symptoms created malaise and panic; and when asthma caused restrictions, leading to feelings of difference, disappointment and frustration. Sports were mentioned as a context for both these factors: exacerbations during exercise were important, as were the experiences of being restricted in sport. And while adherence to medication was reported to be generally high, adolescents did acknowledge engaging in “risk behaviours” – firstly by smoking, but secondly by “pushing too hard” in sports. When participants were asked about areas where they felt they had to behave differently because of their asthma, sport emerged as the predominant theme.
It also appeared to be linked with covert feelings of shame and low self-esteem:

- "(Sport) makes me feel unhappy as I feel I have to put on a show to make it look like being out of breath doesn't bother me" (male, 14-15 “low impact” group, p.21)
- "I tend not to exercise as hard as I can so as not to get breathless" (female, 11-13 “low impact” group, p.24)
- "...I feel that (asthma) affects my performance and that makes me depressed and unhappy" (male, 14-15, “low impact” group, p.26).

The Sugar (2002) study also highlighted discrepancies between overt attitudes portraying asthma as common and therefore quite “normal”, and covert coping strategies highlighted by group-based storyboard exercises depicting a day in the life of someone the participants’ age who had asthma. The material within these (Sugar, 2002) could be interpreted as representing different interactions between “social pressures” (for instance to fit in with friends, perform at school and in sports) and “asthma pressures” (to use inhalers, keep out of smoky places and avoid over-exertion). The storyboard by 11 to 13 year-old females described situations such as having to run for the bus or becoming separated from a group of friends who had their inhaler during a shopping trip – these seemed to describe social barriers to or pressures against asthma management. Meanwhile, the male 11 to 13 year-old group created a storyboard where asthma pressures seemed hinder social functioning – for instance an asthma attack making the central character late for school, being humiliated by falling from a gym rope because of breathlessness. Situations involving autonomic arousal – mainly exercise but also strong emotions such as fear and embarrassment – seemed to emerge as contexts in which the conflict between “social pressure” and “asthma pressure” became heightened.

Some of the findings of Yoos & McMullen (1996) echo those of the Sugar (2002) report. In their study of “narratives” about asthma amongst 28 children and adolescents, a predominant theme of “I can’t” emerged: for example “I can’t do activities like playing ball and running around, jumping rope” and “I love to play sports and I
can't" (p.287, Yoos & McMullen, 1996). Second was a related theme of "restrictions", emphasising prohibited pursuits such as playing outside or having pets. Thirdly, symptoms and treatments such as wheeze and "puffers" were mentioned. Yoos & McMullen (1996) were alarmed to find that some children possessed fears about dying from asthma (the fourth theme). These were raised by children from African-American backgrounds but not those from White Caucasian backgrounds, raising the question of whether such fears were more prevalent in one culture or simply more likely to be reported overtly. Finally, a theme of adaptation was identified – mainly in the older adolescents – emphasising potential for personal growth including developing more responsible attitudes and appreciating life's pleasures (Yoos & McMullen, 1996).

The findings of Yoos & McMullen appear quite consistent with the patterns of conflict between asthma pressure and social pressures (especially surrounding sports) identified in the data quoted in the Sugar report (2002), as well as the emphasis upon lifestyle-appropriate management of asthma. Williams et al. (2002), in a review of the field of adolescent health psychology, suggested that many health-promoting behaviours directly conflict with developmentally normative goals – in particular to forming peer relationships.

Where do these findings lead thinking in terms of influences on adolescent self-management of asthma? On the one hand, the relevance of social pressures and concerns is hardly surprising given the developmentally normative emphasis on developing social understanding and peer relationships in adolescence (A. Carr, 1999). On the other hand, that the exertion associated with exercise and other energetic activities should seem to emerge as such a context for conflict between asthma pressure and social pressure is of note. So long as asthma is well controlled (as would be expected in most adolescents, including those in Sugar's "low impact" groups) – sports should not really pose a big problem. Only those with very severe, intractable asthma would be expected to have to restrict their level of exercise (Gennusso, Epstein, Paluch and Cerny, 1998), and exercise is regarded as important for people with lung conditions to promote overall good health (BLF, 2002b, NAC, 2000b). In general, people with asthma are advised to use a reliever inhaler before
commencing exercise and warm-up gradually for five or ten minutes (NAC, 2000b). If exercise is not possible due to asthma symptoms, this would be regarded as an indication that asthma was not being effectively treated, and individuals would be advised to report this to a health-professional (NAC, 2000b).

Yet the Sugar (2002) storyboards and questionnaire responses suggest a sense of cognitive dissonance surrounding exercise – of being pulled in two directions at once and wanting to do one thing (exercise) whilst thinking one should do another (avoid exertion). Why should this be? The aims of this research were narrowed to focus on whether and why some adolescents might avoid exertion as part of their self-management of asthma. A tentative model was outlined to steer further literature search and the direction of this research.

**A speculative model of how exertion may be portrayed as a context for conflict between asthma pressure and social pressure**

Models from both clinical and health psychology could inform a “formulation”, or speculative account of the concerns surrounding exertion evidenced in the Sugar study (2002). Perhaps some adolescents possess a belief or schema portraying exertion (including exercise) as incompatible with, or harmful to asthma. For example, they might believe that exercise can trigger asthma attacks – regarding exercise as a cause (H. Leventhal et al., 1998) of acute exacerbations of asthma. How would such beliefs be maintained, given that it would not normally be expected that exercise would trigger such attacks, and that such beliefs would be quickly disconfirmed?

The cognitive model of panic disorder proposed by D. Clark (1989, 1997), which has its roots in clinical psychology, may be informative here. This empirically-supported model (D. Clark, 1989, 1997) suggests that individuals with panic disorder are prone to making catastrophic misinterpretations of ordinary somatic symptoms: for example, on climbing the stairs, they might interpret the exertion symptoms of increased heart and breathing rate as signs of an impending heart attack. Such an interpretation would be likely to cause anxiety, which would itself increase autonomic arousal, exaggerating the symptoms of breathlessness and raised heart
rate, and serving to confirm the individual's belief that something is catastrophically wrong — creating a vicious circle of anxiety about anxiety symptoms. One possibility here, is that some adolescents interpret normal exertion symptoms (such as a need to breathe faster and deeper) as signs of worsening asthma. Any resulting anxiety would be expected to increase symptoms of autonomic arousal, which might themselves be interpreted as asthma. In self-regulatory terms, faulty identity perceptions (H. Leventhal et al., 1998), whereby exertion symptoms are interpreted as asthma could give rise to emotional responses of fear, the symptoms of which may themselves be interpreted as asthma attack, leading to a vicious, "panic" cycle.

According to the D. Clark model (1989, 1997), when individuals are concerned that particular bodily sensations may signal danger, they become "hypervigilant" to them — devoting increased cognitive resources to scanning for further "warning signs". Consequently, they notice ordinary symptoms which would not normally be noticed, and again attribute these to some harmful physiological process. It would make sense if such hypervigilance was more likely to occur in situations where individuals are experiencing some cognitive dissonance — such as exercising in spite of beliefs that this may be harmful — compensating for the perceived risk by becoming extra-alert.

The D. Clark model (1989, 1997) suggests such vicious circles are maintained, in part, by the application of "safety behaviours", which are employed to reduce anxiety symptoms in the short-term, but in the long-term prevent learning that the symptoms are, in fact, harmless. For example, someone having a panic attack after climbing the stairs might breathe into a paper bag, sit down or lean against a wall for support while they "recovered". But by attributing their recovery to these measures, they would not learn that the symptoms were, in fact, harmless: thus, the symptoms would remain anxiety-provoking, giving potential for further panic attacks in future.

In the case of adolescents with asthma, safety behaviours could take the form of curtailing exertion in response to the sensation of needing to breathe faster and deeper. The subsequent "recovery" from the exertion symptoms might then be correctly attributed to stopping exercising, but incorrectly interpreted as a recovery from asthma rather than exertion, with the episode considered a "near miss" and the
beliefs that the exertion was harmful strengthened — maintaining the vicious circle (see Figure 2). In self-regulation terms, such avoidance or curtailment of exertion, and the attribution of subsequent recovery to such strategies, could represent control beliefs (H. Leventhal et al., 1998), which in this case also serve to strengthen the belief that asthma attacks are caused by exertion. In addition, it is possible that individuals might use reliever inhalers (delivering bronchodilator medication) in response to exertion symptoms, and attribute the recovery from exertion to the effects of the medication — leading to over-use of such drugs.

In the long-term, avoidance or premature curtailment of exertion would be expected to lead to “deconditioning” (reduced physical fitness) — a pattern which has been noted in adults in a variety of health problems including chronic fatigue (Sharpe, 1997) and chronic pain (Melzack & Wall, 1965, cited by Bennett, 2000). Such “deconditioning” reduces tolerance of physical exercise and can thereby exaggerate the symptoms of subsequent exertion — often enhancing the level of concern such symptoms provoke (Sharpe, 1997). In clinical psychological models, this is often regarded as a catastrophic misinterpretation which serves to maintain the belief that exertion is harmful (Sharpe, 1997). In self-regulatory models, such interpretations would be viewed as the products of illness representations. Identity assumptions portray the exertion symptoms as an underlying disorder such as chronic fatigue, exertion is viewed as a cause of the disorder, and avoidance of exertion as a means of controlling the disorder (Moss-Morris, 1997).

The (clinical) cognitive-behavioural model of chronic fatigue (Sharpe, 1997) posits that many individuals are prone to becoming frustrated by their lack of fitness and so, on what seems like a “good day”, or when motivation to be active becomes overwhelming, over-ride their concerns and sharply increase their level of exertion. By “over-doing it”, the symptoms of fatigue which result from exertion beyond fitness level are provoked, and act to confirm beliefs that exertion is harmful. In this way, cycles of sharp oscillation in exertion level are perpetuated (Sharpe, 1997). The model also posits that factors internal to the person (in particular, perfectionism (Sharpe, 1997)) make some individuals more vulnerable to such all-or-nothing patterns of exertion and rest. Moss-Morris (1997) links such high achievement-
orientation with the goal-oriented approach of self-regulation theory – the control beliefs depicting avoidance of exertion as a treatment for chronic fatigue (and a means of attaining the desired consequences of alleviating fatigue) come into conflict with other goals and desired consequences such as performance ideals.

In adolescents with asthma, the Sugar (2002) study suggests that social (rather than wholly internal) pressures to participate in joint activities or perform in sports may lead some young people to over-ride their beliefs that exertion is harmful and to “push themselves” beyond a helpful level. It is possible that such social influences are mediated by (or interact with) internal factors including self-concept – for instance, perceptions of being inadequate, slow or unattractive because of reduced fitness may underline efforts to “prove” capabilities. In consequence though, more severe symptoms of exertion may be experienced and misinterpreted, increasing both belief that asthma and exertion are incompatible (see Figure 2, p.216), and frustration at the restrictions this imposes. It may even undermine perceptions that prophylactic medication (such as preventor inhalers) can control asthma symptoms. This speculation might help explain findings suggesting that prophylactic medication is generally under-used, and that reliever medication is generally over-used (Hand & Bradley, 1996, cited by Lehrer et al., 2002).

By combining concepts from clinical models of panic (D. Clark, 1989, 1997) and chronic-fatigue (Sharpe, 1997), alongside concepts from self-regulation models of coping with illness (H. Leventhal et al., 1998; Moss-Morris, 1997), a tentative model accounting for avoidance of exertion amongst some adolescents with asthma can therefore be formulated. However, such a model is highly speculative because it not only rests on hypotheses about the cognitive processes involved in maintaining such beliefs and coping behaviours, but also on the assumption that some young people do indeed believe that asthma and exertion are incompatible. Yet were such a model to be supported, cognitive-behavioural strategies found helpful in reducing catastrophic misinterpretation of bodily sensations in panic (D. Clark, 1997) and oscillations in activity level in deconditioning and fatigue (Sharpe, 1997) might be indicated as potentially helpful in alleviating the disability caused by asthma in adolescents.
Figure 2: Diagram illustrating speculative model

- **Belief that asthma and exertion are incompatible**
- **Normal symptoms of exertion catastrophically misinterpreted as onset of asthma attack**
- **Interpretations:** e.g. recovery attributed to safety behaviours
  - "Safety behaviours"*
    - Curtailing/avoidance of exertion
    - Use of inhaler
- **Marked decrease in exertion levels**
- **Reduced fitness**
- **Cycles of oscillation in exertion level**
- **Social pressures to participate and perform**
- **Coping behaviours involving rapid increase in exertion levels**
- **Negative performance - oriented self-beliefs**
  => shame & frustration
- **Panic cycle**
- **Panic attack/anxiety symptoms (hyperventilation) - symptoms misinterpreted as signs of ongoing asthma attack**
- **Symptoms of exertion beyond fitness level**

* "Safety behaviours" refers to behaviors that are intended to protect or maintain health, such as curtailing or avoiding exertion and using inhalers. This can lead to a marked decrease in exertion levels, which can in turn affect reduced fitness. Negative performance-oriented self-beliefs can lead to shame and frustration. Coping behaviours may involve rapid increases in exertion levels, which can have by-products such as impacts on self-concept, concept of self-with-asthma and regimen adherence.
Further literature search was therefore focused on drawing from evidence in the fields of symptom-perception, panic and asthma, exertion and asthma and social influences on coping with asthma amongst adolescents. This literature search was hoped to establish any preliminary evidence (or refutation) of elements of the speculative model, in order to ascertain whether such hypotheses could justify research investigation.

**Symptom perception**

An extensive literature, much of it based on experimental evidence, already exists in relation to symptom-perception processes in paediatric asthma. Much of this study has focused on the factors influencing perceptual accuracy amongst children and adolescents who have asthma. As will be outlined, factors such as attentional processes, influencing the detection of symptoms have proved difficult to tease out from those influencing symptom interpretation (Rietveld & Brosschot, 1999). Schematic models that view the devotion of attentional resources to symptoms and the meaning assigned to them as interconnected have emanated from these findings (e.g. Rietveld & Prins, 1998), and lend some preliminary support to the tentative model's proposals regarding the roles of hypervigilance and symptom interpretations.

It is acknowledged by several authors that the task of distinguishing asthma, panic and exertion symptoms is by no means straightforward: “cardinal” to all three states is the symptom of dyspnoea (breathlessness) (Rietveld & Brosschot, 1999). Many authors (for instance, Rietveld & Prins, 1998) have therefore made a distinction between subjective symptoms and objective signs of asthma in order to examine levels of perceptual accuracy. Several studies have indicated lack of correlation between such symptoms and signs. For example, Fritz, McQuaid, Spirito & Klein (1996) analysed correlations between the subjective estimates of asthma severity made by 86 8-15 year-old children and their objective lung function test results. They found wide variation in children’s perceptual accuracy (from $r=-.39$ to $r=.88$).

Rietveld & Brosschot (1999) have highlighted the potential costs of both over- and under-perception of airway obstruction. Under-perception of asthma symptoms has been associated with mortality and late treatment initiation during asthma attacks,
while over-perception has been linked to higher functional morbidity and unnecessary medication use (Rietveld & Brosschot, 1999).

Some theories have suggested that the detection of symptoms is attenuated by the level of competition with other cues (Rietveld & Brosschot, 1999). Distracting stimuli would be predicted to reduce individuals' attentional capacities and therefore their abilities to detect symptoms, while unstimulating environments might be anticipated to increase individuals' attention to internal stimuli, prompting them to notice more symptoms. However, Rietveld, Kolk, Prins & van Beest (1997, cited by Rietveld & Brosschot, 1999) found that distracting participants with short films actually enhanced their accuracy at detecting interruptions to airflow — reducing the number of “false positive” perceptions. This raises questions about the level of conscious attention required to detect internal cues in the face of external stimulation, and suggests that individuals may be less passive in “receiving” such sensory information than a simple competition between cues would suggest. Rietveld & Brosschot (1999) suggested that those with experience of asthma might come to ascribe meaning to particular symptoms or sensations — enhancing the ability of survival-relevant afferent information to vie for an individual's attention.

This idea that, when conscious awareness is directed elsewhere, processes which are unconscious can somehow continue to monitor for cues which have acquired survival-relevant meaning is highly relevant to the concept of hypervigilance. It is in response to traumatic episodes (particularly events where one feared for one's life or safety) that an increase in vigilance and sensitivity to “warning signs” would be expected. Once the individual has been alerted to the symptoms and monitors them consciously, more conscious interpretations might then come into play in focusing or redirecting attention. For instance, someone with asthma, having detected (or become consciously aware of) dyspnoea, may interpret this as something innocuous (such as exertion) and decide to ignore it. Or they may assume it is something threatening — such as an impending asthma attack — and redirect their conscious attention and level of vigilance to the symptom accordingly.
But the findings of Rietveld, Kolk, Prins & van Beest (1997, ibid) appear, at least initially, to contrast with another experiment conducted by Rietveld, Everaerd and van Beest (2000), which examined the influence of emotional imagery on perceptions of breathlessness utilising a breath-holding paradigm. Rietveld, Everaerd and van Beest (2000) noted that positive imagery (imagining an experience of free, easy breathing) appeared to diminish the perception of breathlessness amongst adolescents (aged 15 to 19) when compared to no imagery, but that negative imagery did not increase the subjective experience of breathlessness. Rietveld, Everaerd and van Beest (2000) attributed the diminishing effects of positive imagery upon perceptual accuracy to its distracting qualities – contrasting with the findings of Rietveld, Kolk, Prins and van Beest (1997, ibid) that distraction increased perceptual accuracy. There are, though, important differences between the breath-holding and distraction paradigms employed in these two studies. For instance, in the distraction paradigm, participants’ conscious attention was directed to a short film but subconscious monitoring of afferent information would not have been prevented (Rietveld, Kolk, Prins & van Beest (1997, ibid). However, the breath-holding paradigm used to examine the effects of emotional imagery (Rietveld, Everaerd and van Beest, 2000) demanded not only the inhibition of exhalation, but also the maintenance of positive imagery in a context where this would have been incongruent with sensory information signalling the need to exhale. It may therefore have required the suppression of normally unconscious processes as well as the direction of conscious attention.

These findings suggest that attentional processes involved in detecting symptoms cannot be separated out from higher-level cognitions ascribing meaning to symptoms, including the (perhaps unconscious) coding of some patterns of sensory information as symptoms with survival-relevant meaning. Findings cited by Rietveld & Brosschot (1999) – that perceptual accuracy actually declines with greater experience of symptoms – lend some preliminary evidence to the idea that the meanings and associations gathered over time shape processing of current symptoms, including the “prioritising” of some symptoms over others. This could be suggestive of the involvement of schemata in directing cognitive resources to certain patterns of sensory information.
Rietveld & Prins (1998) argued that schematic models could account for mixed findings from a range of studies examining relationships between negative emotions and asthma. They suggested that negative affect states might have greater influence upon the subjective symptoms (breathlessness) than on the objective signs (airways obstruction) of asthma, proposing several possible mechanisms of influence of negative emotions on perceptual accuracy. These included the "prioritising" of asthma-related symptoms, the interpretation of ambiguous symptoms in negative (asthma-relevant) directions, and the misinterpretation of negative emotion-related symptoms as symptoms of asthma (Rietveld & Prins, 1998). These processes would all be consistent with the Interacting Cognitive Subsystems model of emotional processing (Teasdale & Barnard, 1993). This model, which has received considerable empirical support, suggests that some schemata, once "activated", can become self-perpetuating: biasing cognitive processing in ways which confirm the reasons for their activation (Teasdale & Barnard, 1993; Teasdale, 1997). In this case, such schemata could work through biasing information processing in ways that maintain the belief in the presence of asthma symptoms, and so promote the continuing activation of asthma-related schemata.

Rietveld & Prins (1998) reasoned that people who have asthma would be particularly vulnerable to such processes in situations where they are uncertain about condition of their airways, and when the consequences of interpreting symptoms as asthma act to confirm beliefs (for example by increasing breathlessness). This could be viewed as consistent with the idea from self-regulation theory (H. Leventhal et al., 1998) that illness representations, once activated, shape interpretations of and coping with symptoms via assumptions about identity, causes, timelines, consequences and controls.

The findings of Rietveld & Prins (1998) that children's perceptions of breathlessness during exercise were increased when they had watched an upsetting video, were interpreted as evidence of the involvement of such schemata. Further evidence of interpretative, possibly schematic processes in symptom-perception was found in an experimental study involving providing false feedback after exercise to children aged
7 to 17 years, both with and without asthma (Rietveld, Kolk, Prins & Colland (1997). Children who had asthma demonstrated significantly higher levels of breathlessness (but not airway obstruction) after being played false feedback of wheezing, compared to no sound. Rietveld, Kolk, Prins & Colland (1997) suggested that, in situations creating uncertainty about respiratory condition (including exercise) "secondary" symptoms of asthma such as the sounds of wheeze or the sensations of breathlessness were used as the basis for estimates of the "primary" symptom of airway obstruction.

Both these studies (Rietveld & Prins, 1998; Rietveld, Kolk, Prins & Colland, 1997) suggest an active, interpretative process at work in symptom-perception. This is consistent with self-regulation theory and with the model proposing that beliefs that exercise may be harmful (and associated anxiety about exercising) could bias interpretations of ambiguous symptoms including breathlessness during exercise.

Rietveld & Everaerd (2000) highlighted potential methodological limitations to experimental symptom-perception paradigms where the requirement to report perceived symptoms could prompt abnormal levels of introspection. They made a preliminary attempt to overcome this problem by monitoring adolescents with asthma at home during weekends when increases in symptoms had been noticed. In this study, contrary to others, a correlation was found between subjective breathlessness and the marker of objective airway obstruction (tracheal recordings of wheeze) (Rietveld & Evereard, 2000). This could be viewed as evidence that perceptual accuracy is, as Rietveld & Evereard (2000) put it, best regarded as a dimensional construct: rather than being regarded as "accurate" or "inaccurate" symptom-perceivers, individuals' accuracy may vary between times and contexts (perhaps also developmental stages). This notion could accommodate the tentative model's proposal that exertion may act as a context where beliefs that exercise and asthma are incompatible influence symptom-perception processes.

However, it must be noted that the correlation reported between subjective and objective symptoms of asthma (Rietveld & Evereard, 2000) and therefore the conclusions of the authors, rest upon the reliability and validity of ratings of wheeze
by researchers as a marker of airway obstruction. Beck, Dickson, Montgomery et al. (1992, cited by Rietveld & Everead, 2000), have apparently found support for such an assumption. But findings made by Rietveld, Kolk, Prins & Colland (1997) suggested that wheeze may be more strongly associated with breathlessness than objective lung function measures, and so would be expected to produce stronger correlations.

Nevertheless, supportive of a dimensional and context-sensitive view of perceptual accuracy were findings made by Yoos & McMullen (1999) utilising a five-week study protocol, whereby 28 child-parent dyads provided subjective estimates of asthma symptom severity alongside taking peak expiratory flow rate measurements. Correlational analysis of these subjective and objective measures suggested different levels of perceptual accuracy at different times: children’s and parents’ perceptual accuracy of asthma severity was moderate during symptomatic times (r=.39) but low at asymptomatic times (r=.29). Symptoms described by child participants in daily diaries also included many “non-standard” asthma symptoms, and the researchers classified 7% of participants as “hyper-vigilant” because they regarded themselves as symptomatic when objective measures suggested they were asymptomatic.

Experimental studies (e.g. Rietveld & Prins, 1998) have therefore found evidence that factors such as negative emotion or uncertainty about respiratory health can reduce the accuracy of symptom-perception, imputing the involvement of schematic representations in such interpretative processes. But the findings of Yoos & McMullen (1999) provide more direct evidence of the existence of beliefs about the meanings of particular symptoms, and some early indications that these can lead to inaccurate interpretations – particularly patterns of over-perception. What is not clear is whether and how such attributed meanings might influence interpretations of panic or exertion symptoms – in particular whether anxiety and exertion symptoms could be mistaken for asthma.

*Relationships between panic and asthma*

Baron & Marcotte (1994), drawing upon case study evidence and noting the similarities between asthma and panic symptoms, suggested that panic symptoms – particularly hyperventilation – might trigger asthma attacks, and that the frightening
symptoms of asthma attacks might also trigger panic attacks. They highlighted hypothetical bio-medical mechanisms that could make some children with asthma vulnerable to panic disorder. Lehrer et al. (2002) highlighted several further possible mechanisms that could mediate relationships between panic and asthma. It is important to note that these included mechanisms whereby the effects of panic exacerbated asthma. For example, autonomic arousal (associated with bronchodilation) and parasympathetic arousal (associated with broncho-constriction) could mediate effects on the respiratory system. In addition, the experience of asthma could create vulnerability to panic (Lehrer et al., 2002).

But Park, Sawyer & de Glaun (1996) proposed a cognitive-behavioural formulation of interactions between asthma and panic which, like that suggested herein, drew on the D. Clark model (1989, 1997). They carried out a retrospective study of 23 referrals of children aged 7 to 15 years who had asthma and whose presentation was “reminiscent of a developing panic disorder” (p. 186). These children demonstrated higher levels of subjective asthma symptoms than lung function tests would have predicted. Cognitive-behavioural interventions for panic were offered, and Park et al. (1996) reported significant reductions in attendance of hospital emergency departments following these. However, the study had no control group, and so spontaneous remission effects could not be contested. Neither was it possible to draw conclusions about the possible causal influences of cognitions purely from such efficacy data on cognitive-behavioural therapy.

Nevertheless, it is interesting to note that the referrals to the intervention (i.e. presentations suggestive of panic disorder) peaked between the ages of 11 and 12. Park et al. (1996) attributed this to a growing awareness of health and mortality in adolescence, increasing anxiety about the potentially fatal consequences of asthma in this age-group. It may also reflect a developmental vulnerability to panic amongst adolescents with or without asthma: A. Carr (1999) viewed panic as a product of increasing cognitive maturity, which gives adolescents the “sophistication” to come to catastrophic conclusions about their symptoms. This raises the possibility that the combination of developmental stage and the confusing overlap between symptoms of
asthma, panic and exertion could make adolescents with asthma particularly vulnerable to misattribution of symptoms, giving rise to panic.

Craske, Poulton, Tsao & Plotkin (2001) found that having a respiratory illness was a risk factor for panic disorder with agoraphobia in an analysis of longitudinal data following a cohort from age 3 to 21 years. R. Carr, Lehrer & Hochron (1995) found that, in adults, both asthma severity variables and measures of cognitive constructs (such as catastrophic interpretations of bodily symptoms) were independently correlated with illness-specific panic fear. Only cognitive variables related to more generalised panic-fear – suggesting that asthma symptoms and beliefs about those symptoms could contribute to panic specifically about asthma.

**Relationships between asthma, exertion and deconditioning**

Tenets of the current, tentative model propose that some adolescents may respond to anxieties about aggravating their asthma through exercise with “safety behaviours” (D. Clark, 1997) such as avoiding or curtailing exertion which, in the long-term, could lead to physical deconditioning. Examining the literature surrounding exercise and asthma highlights an important complicating factor to this proposal: the phenomenon of exercise-induced broncho-constriction (EIB) that, for some individuals, means exercise could indeed lead to airway obstruction.

Prevalence estimates of EIB in paediatric asthma have been reported to vary widely, from 50 to 90% of asthma cases (van Veldhoven, Vermeer, Bogaard, Hessels, Wijnroks et al., 2001). It is acknowledged that the phenomenon remains poorly understood, but it has been attributed to airway hypersensitivity and the consequent irritation caused to the respiratory tract by the cooling and drying effects of increased respiration (for example, Lehrer et al., 1998; C. Clark & Cochrane, 2001). However, as EIB has not been found to correlate with asthma severity, it has been hypothesised that psychological factors may have a bearing on its presentation (C. Clark & Cochrane, 2001).

Khan & Olson (1977), exemplifying earlier attempts to understand and treat EIB from a behaviourist perspective, viewed EIB as an acquired hypersensitivity: a conditioned
response resulting from broncho-constriction brought on by other stimuli (such as infections) repeatedly coinciding with exercise. Exercise was therefore regarded as a conditioned stimulus (Khan & Olson, 1977). By administering gradually titrated doses of bronchodilators to children prior to their performing standardised exercise challenges on seven consecutive days, the children were able to increase their tolerance of exercise (compared with those in a no-medication control group who continued to experience EIB). This tolerance to exercise without medication was maintained at six-month follow-up. Given the behaviourist perspective, "conditioning" was viewed as a sufficient explanation of this improvement (Khan & Olson, 1977). However, the study does raise questions about the mechanism through which EIB could be "extinguished": for instance, whether patterns of psychoneuroimmunological responses were somehow interrupted, allowing inflammatory processes to be "calmed", or whether the process reduced fear – (perhaps also assumptions that the exercise would be harmful) that might otherwise have exaggerated respiratory rate and increased EIB.

Indeed, the findings of van Veldhoven et al. (2001) could be viewed as supportive to the notion that quelling any anxiety-provoking assumptions that exercise is harmful can promote greater tolerance of exercise. Using a randomised-controlled design, they devised a programme of group- and home-based physical exercise alongside psychoeducational intervention to increase understanding of asthma and how to cope with exercise-induced exacerbations. The programme appeared to lead to improvements in cardiovascular fitness and endurance. No significant effects upon lung function were found, suggesting increased cardiovascular fitness mitigated against the effects of increasing workload – perhaps by reducing respiratory rate and concomitant cooling and drying of the respiratory tract. Improvements were also found in coping with asthma. This could be viewed as preliminary evidence that cognitive knowledge and attitude variables are influential.

The involvement of psychological as well as physical factors in EIB was supported by Panditi & Silverman (2003). They found only weak correlation between objective EIB and subjective perceptions of EIB in 46 7-14 year-old children, and noted that individuals' perceptual accuracy of EIB was not consistent across an eight-week time-
interval (Panditi & Silverman, 2003). Panditi & Silverman (2003) argued that perceptual processes surrounding EIB were under-researched and called for further research into children's concepts of their asthma and their beliefs about the impact of exercise upon it.

Furthermore, in a review of evidence surrounding exercise and asthma, C. Clark & Cochrane (1999) suggested that, as the disability caused by EIB was not related to asthma severity, the adjustment to asthma was likely to be as important as asthma itself in mediating the level of restriction it impinges upon daily living. They cited findings that experimental manipulations to increase the anticipated harm of exercise led both to exaggerated perception of symptoms and objective airway obstruction (Meyer, Kroner-Herwig & Sporkel, 1990, cited by C. Clark & Cochrane, 1999).

C. Clark & Cochrane (1999) highlighted two possible explanations for asthma-related restriction to physical exercise. Firstly (and in line with the formulation herein), fears emerging from “misconceptions” that exercise is harmful, and the concomitant avoidance of exercise, could lead to deconditioning and exaggerated exertion symptoms upon taking up exercise. Alternatively, exercise tolerance could be limited by the symptoms of airway obstruction itself. The deconditioning theory was lent support by findings that people with asthma generally have below-norm fitness levels. Indeed, van Velden et al. (2001) noted that the fitness of the majority of their participants fell at or below the tenth percentile for same-age peers. Gennuso et al. (1998) found that obesity was significantly more common in children with than without asthma, but was not correlated with asthma severity. They suggested lowered physical activity levels might account for the difference (Gennuso et al., 1998). In addition, exercise challenge tests have suggested that participants generally have a cardiovascular “endpoint” to exercise rather than being limited by lung function (C. Clark & Cochrane, 1999). This gives greater weight to the deconditioning than the symptom-related restriction theory, and would explain the stability of lung function in studies where workload has been increased – though by no means rules out EIB as a cause of disability in some individuals.
So, there appears to be some evidence that deconditioning processes are of particular relevance to people who have asthma. This might be brought about by avoidance of exercise due to the aversiveness of symptoms attributed to EIB, but could also result from mistaking ordinary exertion symptoms for asthma.

**Social influences upon coping with asthma**

Another speculation made within the proposed model was that beliefs that exercise amounted to a “risk behaviour” and should therefore be avoided could conflict with other, social, pressures to participate in energetic activities including play and sports. In self-regulatory terms (H. Leventhal et al., 1998), the consequences of avoiding exercise as an asthma self-management strategy would impact upon personal and social goals as well as the goal of alleviating asthma.

Gibson, Henry, Vimpani & Halliday (1995) found that 23% of an Australian sample of 13-14 year-olds with asthma reported quality of life impairment – particularly in relation to strenuous exercise: 35% limited their activity levels to cope with asthma and sports gave rise to experiences of restriction in 60% of adolescents with asthma. The researchers found poor knowledge about asthma – especially regarding EIB. These findings lend support to the idea that beliefs about exercise (and consequent limitations to activity level) give rise to experiences of restriction. What is not clear is how this frustration influences coping behaviour – in particular whether it leads to sudden “over-riding” of exercise-avoidance.

Schmidt, Petersen & Bullinger (2003) argued that, far from taking place in a social vacuum, children’s and adolescents’ coping with illness is likely to be largely aimed at mediating the social world, and illness-related coping will therefore represent “the tip of thousands of interactions” (p.72-73). Schmidt et al. (2003) suggested that the ability of social systems (including peer and school systems) to accommodate the needs of a child or adolescent with chronic health problems, likely depended on the degree of demand created by the strategies for managing that condition. Some aspects of asthma self-management might create more conflict with social requirements than others. For example, the use of inhalers, being relatively commonplace in most classrooms, may be much easier to accommodate than restrictions on physical
activity – which would restrict the activities of the peer-group if a child with asthma is not to be excluded from participation. Perhaps tellingly, Schmidt et al. (2003) cited findings that sports activities and teasing from peers represented the demands found most challenging and distressing by children and adolescents with chronic illness – more so than medical encounters.

In a review of the impacts of peers upon adolescents’ coping with chronic illness, La Greca, Bearman & Moore (2002) distinguished the influence of close friendships from larger “peer-crowd” affiliations. Close friends have been found to be highly important sources of support for young people with chronic health problems, and such friendships are likely to emphasise emotional support and acceptance (La Greca et al., 2002). Peer-crowd affiliations, however, were argued to create pressure to “fit-in” – perhaps more so if chronic illness already creates a sense of being “different” – and to craft a desirable image and reputation in order to affirm identity with the peer-crowd (La Greca et al., 2002). While some crowds may express their distinction and identity through being fashionable, rebellious, or academic, others may emphasise activity and sporting prowess (La Greca et al., 2002) – which would be expected to stimulate particular conflict between asthma pressure and social pressure where exercise is regarded as harmful.

**Need for research**

Examining these seemingly disparate areas of literature (symptom-perception, panic, exertion and deconditioning, and social influences upon coping in adolescents) was aimed at gaining an initial impression of whether the tentative model put forward merited further study. Each area of research examined has provided some preliminary backing to the model: there is evidence that interpretative processes, perhaps influenced by ascribed meanings of symptoms (Yoos & McMullen, 1999), shape symptom-perception and in particular may lead to over-perception of symptoms. The idea that panic symptoms may be interpreted as asthma has been lent some support by findings that asthma acts as a risk factor for panic (Craske et al., 2001), and has been echoed by the application of cognitive-behavioural therapies based on the D. Clark (1989, 1997) panic model by Park et al. (1996). Strategies of restricting exercise amongst adolescents with asthma and signs of deconditioning
patterns have also been evidenced (C. Clark & Cochrane, 1999) while theory and research into adolescent illness-management coping has emphasised social influences and the social conflicts that restricting activities may create (La Greca et al., 2002). Far from being refuted by current literature, the speculated model's potential utility in co-ordinating further research understanding of these issues and guiding future interventions has been highlighted. This justified research aimed at providing an initial exploration of the model's hypotheses.
Research questions, hypotheses and methodological approach

Given the acknowledged difficulties conducting qualitative research with this population (Clatworthy, 2001), it seemed a quantitative, questionnaire-based approach might be helpful in exploring whether any young people with asthma demonstrated the hypothesised attitudes, beliefs and perceptions. The hypothesised cognitions had not been directly tested before and no existing measures to operationalise them could be found. It was therefore necessary to develop a measure assessing the hypothesised cognitions to enable initial exploration of the speculated model. One aspect of the research was therefore to evaluate this approach to studying such processes. The questionnaire would be aimed at exploring the series of descriptive research questions and explanatory hypotheses outlined below.

Research questions

1. To what extent is exertion perceived as harmful to or incompatible with asthma by adolescents who have asthma? Specifically, to what extent is exercise perceived as a trigger of asthma attacks?
2. Are normal exertion symptoms and symptoms of anxiety or panic sometimes interpreted as asthma?
3. Do adolescents avoid or curtail exertion in an attempt to manage asthma?
4. Do adolescents experience social pressures to exert themselves beyond a perceived ideal level?
5. Do some adolescents show patterns of oscillation in exertion level?

Hypotheses

1. Beliefs that asthma and exertion are incompatible will be positively associated with the number of symptoms interpreted as symptoms or warning signs of an asthma attack.
2. Beliefs that asthma and exertion are incompatible will be positively associated with asthma-management strategies involving the avoidance or curtailment of exertion (safety behaviours).
3. Perceptions that safety behaviours are helpful will be positively correlated with beliefs that asthma and exertion are incompatible.
4. The number of symptoms interpreted as symptoms or warning signs of an asthma attack will be positively related to asthma-management strategies involving the curtailment and avoidance of exertion.

5. Beliefs that asthma and exertion are incompatible will be negatively associated with the level of weekly exercise.

6. Perceptions of social pressures and negative performance-oriented self-concept will correlate positively with oscillations in exertion level.
**Design:** A cross-sectional questionnaire study, with a view to initial descriptive and correlational analysis of the hypotheses and research questions.

**Participants and power analysis:**

**Participants:** Adolescents aged 11 to 16 years who were patients of outpatient paediatric asthma clinics and had a confirmed diagnosis of asthma.

**Power calculation:** *A priori* power analysis was conducted using the g*power computer application (Erdfelder, Faul & Buchner, 1996). Based on an anticipated medium effect size ($r=0.3$, $\alpha=.05$, $\beta=.20$, power=80%), a required total sample of 64 participants was indicated. Although several correlation coefficients were expected to be calculated, which could raise concerns about increasing the risk of a Type I error, it was not anticipated that a statistical correction such as a Bonferroni adjustment would be applied. This was due to the exploratory nature of the study and the use of a newly developed measure that might not tap the hypothesised constructs as powerfully as an established and well-refined measure. To increase the risk of a Type I error and consequently recommend further study on the basis of a random finding was therefore regarded as preferable to dismissing an alternate hypothesis that was true, precluding further research. However, it was anticipated that two-tailed tests of significance would be applied because, although the hypotheses were one-tailed, significant correlations in any direction would be of interest at this exploratory stage.

**Recruitment procedure:** Patients of two consultant paediatrician-led asthma clinics in an acute NHS Trust were identified from clinic lists and checked for their suitability to participate in the study by the consultant paediatrician. The primary inclusion criterion was having a confirmed diagnosis of asthma. There were no formal exclusion criteria but, as all the patients were known to the consultant paediatrician, they could be excluded at his discretion – for example for ethical purposes, if it was thought the procedure might cause undue distress or confusion; or if confounding factors were likely to influence responses to the questionnaire. Among the reasons patients were excluded from eligibility for the study were severe developmental
delay and severely restrictive physical disability in addition to having asthma, which would have been expected to contribute to non-asthma related experiences of restriction in sports or energetic activities. Patients of these paediatric asthma clinics would have been expected to have asthma classified as moderate or severe.

All eligible adolescents who were due to attend clinic in the five-month data collection period were invited to take part in the study at least one week prior to their prearranged clinic appointment. 62 adolescents due to attend clinic were identified as eligible during this time. Of these, 18 did not attend their clinic appointments. Of the 44 who attended clinic and were approached by the author, 41 participated. Of the remaining three, parents of two said they would consider letting their child participate but left clinic without participating, and one parent was happy for their child to participate but the adolescent himself did not wish to. The response rate can therefore be considered as 66.13% of those invited to participate and 93.18% of those who attended clinic. However, it does not reach the sample of 64 indicated by the a priori power analysis. The issue of power is addressed in the discussion.

**Materials:**

"What's it like to have asthma?" questionnaire

*Initial development of questionnaire*

A questionnaire entitled “What’s it like to have asthma?” (Appendix 1) was developed with the aim of measuring the constructs outlined in the above hypotheses and research questions.

*Structure and style*

Owing to the reported difficulties of encouraging young people to express their opinions in response to very open-ended questions, a format incorporating multiple-choice questions (for instance in the form of Likert-type scales) was employed. This methodology assumed the presence of hypothesised cognitions could be confirmed or refuted according to whether participants endorsed Likert-type items. This approach needed to be balanced against the risk of demand characteristics such as
leading participants into emphasising concerns about exercise relative to other aspects of asthma, simply by asking them about exercise. To avoid this, a structure was devised whereby a part about “asthma in general” was included at the beginning of the questionnaire, while the second part asked about attitudes and behaviours surrounding asthma and exercise more directly.

Structure: Part One was divided into three sections:

a) “What makes asthma attacks happen?” to examine beliefs about triggers including exercise;

b) “What is it like to have an asthma attack?” incorporating a symptom-checklist to examine interpretations of symptoms indicative of asthma, but that also included symptoms indicative of exertion and panic;

c) “What helps with asthma?” about coping behaviours including both conducting and avoiding exercise.

Part Two consisted of three sections:

a) “Opinions about exercise and asthma”;

b) “Level of exercise” including variability in exercise level;

c) “Thoughts and feelings about exercise” including experiences of social pressure and negative performance-oriented self-concept.

Part Three contained demographic items:

- age
- sex
- morbidity-related indices including:
  - age at diagnosis
  - prescribed asthma medications
  - typical weekly frequency of reliever-inhaler use
  - number of asthma-related visits to general practitioners (GPs)
  - number of asthma-related hospital admissions in the previous month.

Style: The questionnaire was designed to look lively and friendly and emphasised the value of each young person’s opinions and experiences. Efforts were made to avoid biasing responses. Items were presented in speech or thought bubbles as if they were
being said by another young person, and participants were asked how much they agreed with the comments or thoughts. Some items were deliberately reversed (so that agreement could be in line or against the hypotheses) to alleviate acquiescence.

Item Content

Possible questionnaire items were generated on the basis of the hypothesised constructs and literature about asthma (NAC, 2000a; NAC, 2000b), creating a pool of items that could be assigned to each section. The item pool was examined by a group of researchers consisting of a paediatric respiratory consultant, a professor of health psychology with a background in pharmacy, a health psychologist and the author (a trainee clinical psychologist). This functioned as an initial check of content validity, clarity of wording and appropriateness of the style for the population. At a later stage, an adult who had asthma and professional experience of working with young people, but not a background in healthcare, carried out a “dummy” completion of the questionnaire. This provided feedback about its layout, clarity and comprehensibility.

Elements of each hypothesised construct were defined. Items were generated on the basis of these elements, to form scales for each overall construct. The hypothetical constructs, their elements and cross-references to the items generated are outlined in Table I, below.

Additional items were developed primarily to conceal the research interest in exertion, to avoid response bias. These related to non-exertion-related triggers of asthma and asthma-management strategies, and were based on triggers and strategies described by the NAC (2000b) and BLF (2002a). These items subsequently enabled more detailed analysis of beliefs around triggers and behavioural avoidance of triggers, including the calculation of correlation coefficients to examine whether beliefs about exertion-related and environmental triggers were differentially related to avoidance of exertion and environmental triggers. The items, their purpose in the questionnaire or relationship to a construct, and the content source is outlined in Appendix 2.
Table 1: Hypothetical constructs to be tested, their suggested elements and relationships to questionnaire items.

<table>
<thead>
<tr>
<th>Hypothetical construct to be tested</th>
<th>Elements (or aspects) of construct [and items generated to operationalise these]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beliefs portraying asthma and exertion as incompatible</td>
<td>Exertion perceived as a trigger of asthma attacks [items IA2, IA5] Exertion perceived as harmful to the management of asthma [items (-)IC3b, IIA1, (-)IIA2] Asthma as a barrier or limit to exercise [items IIA3, IIA4, (-)IIA5, (-)IIC4]</td>
</tr>
<tr>
<td>Symptom perception (see Appendix 3 for items)</td>
<td>Tendency to interpret symptoms in general to asthma Tendency to interpret panic as asthma Tendency to interpret exertion symptoms as asthma Tendency to interpret ambiguous symptoms as asthma</td>
</tr>
<tr>
<td>Safety behaviours</td>
<td>Curtailment of exertion [items IC6a, IIA6, IIC7] Avoidance of exertion [items (-)IC3a, IC5a, IC8a, IC9a, IIA7]</td>
</tr>
<tr>
<td>Interpretations of recovery</td>
<td>Perceptions of safety behaviours as helpful [items IC5b, IC6b, IC8b, IC9b]</td>
</tr>
<tr>
<td>Exercise behaviour</td>
<td>Weekly exercise level [item IIB1] Variability in exercise level (oscillation) [items IIB2, IIC10]</td>
</tr>
<tr>
<td>Social pressure</td>
<td>Concept of self with asthma Performance-oriented self-concept and intrinsic motivation to exercise [items IIC8, IIC9] Frustration with asthma [items IIC2, (-)IIC6]</td>
</tr>
</tbody>
</table>

(-) = items reverse-scored for the construction of a scale

The symptom checklist in Part One was aimed to differentiate asthma, panic and exertion symptoms and to operationalise participants' interpretations of such symptoms. Items intended to represent asthma symptoms were based on NAC (2000a) and BLF (2002a) literature. Exertion and panic symptoms were based on those described by D. Clark (1989, 1997), which incorporate criteria from the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV, cited by D. Clark, 1989, 1997). Participants would be asked to endorse each symptom as part of an asthma attack, a warning sign, or something else (not an asthma attack) using a “traffic light” system (see Appendix 1), but were also allowed to respond that they were unsure, or had never experienced the symptom. The symptom checklist items were initially reviewed by the paediatric respiratory consultant. They were later subject to expert sampling. Six clinicians with specialist experience of respiratory conditions completed a symptom checklist similar to that for adolescent
participants but rated each symptom as “likely”, “possible” or “unlikely” to be symptomatic of asthma, panic and exertion (see Appendix 3a).

Ethical and Research & Development Review
The questionnaire (together with supplementary materials and research protocol) were subjected to review by and received approval from:

- a Local Research Ethics Committee (LREC) (Appendix 4)
- the University of Surrey Ethics Committee (Appendix 5)
- the host NHS Trust’s Research & Development Management Team (Appendix 6).

In response to feedback from the LREC, some items were re-worded and the format was changed so that speech bubbles appeared to the side of the Likert-type scales rather than above them, where it was feared they might bias responses by “pointing” toward certain parts of the scale.

Socio-economic status and ethnicity questionnaire
A separate questionnaire was used to obtain additional demographic information relating to ethnicity and socio-economic status. Two versions of this questionnaire were drawn up – one for parents of participants aged 11 to 15, the other for participants aged 16 (Appendices 7 and 8). The section on ethnicity used categories recommended by the Commission for Racial Equality (2004). The section on socio-economic status used an adapted version of the self-coded method of the National Statistics Socio-Economic Classification (NS-SEC) (National Statistics, 2002). This is a measure that categorises households to one of five “classes” according to the occupation and employment status of the main income-earner. On the advice of the LREC, an attempt was made to simplify the layout and language used.

Other materials
Other materials used were:

- invitation letters for parents of potential participants aged 11 to 15 (Appendix 9) and participants aged 16 years (Appendix 10);
• information sheets for participants aged 11-15 years (Appendix 11), participants aged 16 years (Appendix 12) and parents of participants aged 11 to 15 (Appendix 13);
• consent forms for parents of participants aged 11 to 15 (Appendix 14) and participants aged 16 years (Appendix 15);
• a "request form" for parents of participants aged 11 to 15 years or participants aged 16 years to provide details enabling them to receive a report of the research upon its completion (Appendix 16).

In addition, coloured folders were used to file consent forms and request forms, in order to visibly separate these from the anonymous questionnaire.

**Procedure**

Letters of invitation accompanied by appropriate information sheets were sent to 16 year-old potential-participants or parents of 11 to 15 year-old potential-participants at least one week prior to clinic. Parents and adolescents were then approached in clinic individually (i.e. as parent-child dyads) by the author, given a further opportunity to read information sheets, and invited to take part in the study. Parents and adolescents who were happy to participate were asked to sign three copies of a consent form (one for the researcher, one for the participant, one for medical notes), filed separately from the questionnaires to maintain anonymity. Participants were issued with a spiral-bound booklet containing the questionnaire. It was explained that the questionnaire was new, and that the researcher would be interested in participants' opinions about the questionnaire, in addition to their responses.

Owing to the wide variations in anticipated independence in completing the questionnaire, adolescents themselves were allowed to determine the degree to which help from parents or the author was sought, and the author aimed to facilitate this decision. Parents (or participants aged 16) were issued with the non-compulsory demographic questionnaire, and were then invited to complete a request form for the research report.
After completing the questionnaire, participants were asked for feedback on the questionnaire, guided by pilot-prompts (Appendix 17). Once these procedures had been completed, participants and parents were thanked and given an opportunity to withdraw from the study.
Results

Data Analysis
Questionnaire data were entered into a database and analysed using the SPSS for Windows (SPSS, 2002) statistical package.

Non-parametric tests were selected for inferential analytic purposes at this stage of initial exploration of the speculative model. There is debate about whether Likert-type scales should be regarded as interval or ordinal data (Tabachnick & Fiddell, 2001): if considered ordinal, then non-parametric tests would be indicated. In addition, as will be detailed, several scales, subscales and individual indices were found to significantly violate conventions for normal distribution, which also indicated that non-parametric tests were appropriate.

Data screening
The data file was checked for errors by examining whether all data were within the expected ranges (Pallant, 2001). A missing values analysis was conducted which revealed three variables with greater than 5% missing cases: ethnicity (missing values for three cases, amounting to 7.3% of the sample), NS-SEC (six missing values, amounting to 14.6% of the sample) and a symptom-perception variable, "Feeling like something is in the way when I breathe". Overall, the pattern of missing values was consistent with participants who had declined to complete or could not be categorised on the NS-SEC, and with missed pages in the main questionnaire. Missing cases were deleted from relevant analyses as per the SPSS default (SPSS, 2002).

The number of outliers identified by SPSS (2002) on each scale will be reported below, but outliers were not excluded, because the sample size was small and so the normal distribution may not have been fully represented. This also reflected the exploratory nature of the study, where the overall pattern of responses was of preliminary interest and an expected distribution was not established. Possible causes for outliers (such as missing data values not being specified) were excluded (Tabachnick & Fiddell, 2001).
Scales
For each of the scales, the anticipated component items were entered into a Cronbach’s alpha reliability analysis (SPSS). Items were removed if they were not sufficiently correlated (sufficient r≥0.3) (Pallant, 2001) with other items or if their removal led to a substantial increase in alpha coefficient. Given the small size of the sample, a minimum acceptable alpha coefficient for a scale was set at 0.6. If this minimum alpha coefficient or the item total correlation ≥0.3 could not be achieved, individual items rather than scales were analysed. The constructs, scale items included, scale items excluded, normality statistics, item total correlations and alpha coefficients for each scale are outlined in Tables 2 to 10, below.

The Belief Scale
The construction of the Belief Scale is outlined in Table 2 below. In addition to the procedures outlined above, two items were removed because, in retrospect, their wording was regarded as potentially confusing. These were “Light exercise is OK for people my age who have asthma” and “Exercise is fine for people with asthma, as long as they don’t overdo it”, which were instead analysed as individual items. Some adolescents had highlighted that such items could be interpreted as exercise is ok so long as it is light or moderate, or including when it is light or moderate. The five-item construction of the Belief Scale yielded good internal consistency. The Kolmogorov-Smirnov (KS) statistic found no significant violation of normality.
Table 2: Construction of the Belief Scale

<table>
<thead>
<tr>
<th>Construct scale is intended to tap: Beliefs portraying asthma and exertion as incompatible</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>“Elements” of construct:</strong></td>
</tr>
<tr>
<td>a) Exertion perceived as a trigger of asthma attacks</td>
</tr>
<tr>
<td>b) Exertion perceived as harmful to the management of asthma</td>
</tr>
<tr>
<td>c) Asthma as a barrier or limit to exercise</td>
</tr>
<tr>
<td><strong>Item</strong></td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>“Running fast can make me have an asthma attack”</td>
</tr>
<tr>
<td>“Doing energetic activity can set off an asthma attack”</td>
</tr>
<tr>
<td>Exercise regularly... how helpful is this for asthma? [reverse-scored]</td>
</tr>
<tr>
<td>“Exercise and asthma don’t go together”</td>
</tr>
<tr>
<td>“Regular exercise can help make my asthma less of a problem” [reverse-scored]</td>
</tr>
<tr>
<td>“Light exercise is O K for people my age who have asthma”</td>
</tr>
<tr>
<td>“Exercise is fine for people with asthma, as long as they don’t overdo it”</td>
</tr>
<tr>
<td>“Asthma shouldn’t stop people from exercising” [reverse-scored]</td>
</tr>
<tr>
<td>“If asthma stopped me exercising, I would expect my doctor to find some better medicine for me” [reverse-scored]</td>
</tr>
</tbody>
</table>

**Overall properties of scale:**
- Alpha coefficient: .85
- Skewness Statistic: -.33 (SE = .38)
- Kurtosis Statistic: -.42 (SE = .74)
- Kolmogorov-Smirnov test of normality: KS=.10 p=.20
- No. outliers identified by SPSS: 0
- N=39 Number of items in scale = 5

The Exertion-Related and Environmental Trigger Belief Subscales

The constructions of the both the Exertion-Related and Environmental Trigger Belief Subscales, which were calculated to enable more fine-grained analysis of belief-
related constructs, are outlined in Table 3 and 4 respectively. The Exertion-related Trigger Belief subscale, while consisting of only two items, demonstrated high inter-item correlation and alpha. The Environmental Trigger Belief subscale, consisting of two items, showed minimal alpha, but item-total correlations were adequate. The KS statistic indicated violations of normality on both subscales.

**Table 3: Construction of the Exertion-Related Trigger Belief Subscale**

| Construct scale is intended to tap: Exertion perceived as a trigger of asthma attacks |
|-----------------------------------|------------------|------------------|------------------|------------------|
| Item                              | Item total correlation coefficient (r) | Included/excluded | Alpha coefficient of scale if had been included | Alpha coefficient if excluded |
| “Running fast can make me have an asthma attack” | .84 | Included | - | - |
| “Doing energetic activity can set off an asthma attack” | .84 | Included | - | - |

**Overall properties of scale:**
- Alpha coefficient: .89
- Skewness Statistic: -1.17 (SE = .38)
- Kurtosis Statistic: .569 (SE = .741)
- Kolmogorov-Smirnov test of normality: KS = .28; p<.00
- No. outliers identified by SPSS: 4
- N = 39; Number of items in scale: 2

**Table 4: Construction of the Environmental Trigger Belief Subscale**

| Construct scale is intended to tap: Beliefs that environmental factors can trigger asthma attacks |
|-----------------------------------|------------------|------------------|------------------|------------------|
| Item                              | Item total correlation coefficient (r) | Included/excluded | Alpha coefficient of scale if had been included | Alpha coefficient if excluded |
| “If I am in a dusty place, it can give me an asthma attack” | .41 | Included | - | - |
| “Being in a damp or mouldy place can give me an asthma attack” | .41 | Included | - | - |
| “Being around traffic fumes could give me an asthma attack” | .13 | Excluded | .45 | .58 |

**Overall properties of scale:**
- Alpha coefficient: .58
- Skewness Statistic: -.53
- Kurtosis Statistic: .21
- Kolmogorov-Smirnov test of normality: KS = .142; p<.05
- No. outliers identified by SPSS: 0
- N=39; Number of items in scale: 3
The Safety Behaviour Scale

The construction of the Safety Behaviour Scale is outlined in Table 5 below. Cronbach's alpha coefficient indicated adequate internal consistency, while the KS statistic found no significant violation of normality.

**Table 5: Construction of the Safety Behaviour Scale**

<table>
<thead>
<tr>
<th>Construct scale is intended to tap: Performance of safety behaviours (Clark, 1997) (i.e. coping behaviours involving the avoidance of stimulus regarded as harmful – in this case exertion).</th>
<th>Item total correlation coefficient (r)</th>
<th>Included/ excluded</th>
<th>Alpha coefficient of scale if had been included</th>
<th>Alpha coefficient if excluded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Performance of safety behaviours (Clark, 1997) (i.e. coping behaviours involving the avoidance of stimulus regarded as harmful – in this case exertion).</td>
<td>“Stop or slow down if I think an asthma attack is coming on (frequency)”</td>
<td>.43</td>
<td>Included</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>“If a person has asthma and they start to get out of breath when they exercise, they should stop immediately”</td>
<td>.40</td>
<td>Included</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>“I would like to exercise more, but when I do I get breathless and think I should stop in case I get an asthma attack”</td>
<td>.57</td>
<td>Included</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>“Exercise regularly (frequency)” [reverse-scored]</td>
<td>.50</td>
<td>Included</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>“Try not to rush around and get out of breath (frequency)”</td>
<td>.45</td>
<td>Included</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>“Try not to exercise too hard or fast (frequency)””</td>
<td>.49</td>
<td>Included</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>“Avoid exercise if I think I might get an asthma attack (frequency)”</td>
<td>.43</td>
<td>Included</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>“If someone has asthma and they get out of breath when they exercise, they shouldn’t exercise that hard again.”</td>
<td>.36</td>
<td>Included</td>
<td>-</td>
</tr>
</tbody>
</table>

**Overall properties of scale:**

Alpha coefficient: .75  
Skewness Statistic: -.27 (SE=.38)  
Kurtosis Statistic: .108 (SE=.74)  
Kolmogorov-Smirnov test of normality: KS=.116 p=.20  
No. outliers identified by SPSS: 1  
N=39 Number of items in scale=8
Exertion-avoidance, Exertion-curtailment and Environmental Trigger Avoidance Subscales

Subscales were created for exertion-avoidance and exertion-curtailment strategies, as well as for avoidance of environmental triggers, to enable more detailed explanatory analysis of relationships between beliefs and strategies. The calculation of these subscales is reported in Tables 6, 7 and 8, respectively. The Exertion-avoidance subscale demonstrated minimum acceptable internal consistency, adequate item total correlations and was not found to significantly violate normality. The Exertion-curtailment subscale did not demonstrate acceptable internal consistency but item total correlations were the minimum acceptable. The KS statistic found significant violations of normality on this subscale. Cronbach’s alpha coefficient for the Environmental Trigger Avoidance subscale demonstrated adequate internal consistency, but the KS statistic found significant violations of normality.

Table 6: Construction of the Exertion-avoidance Subscale

<table>
<thead>
<tr>
<th>Construct scale is intended to tap: Avoidance of exertion as an asthma-management strategy</th>
<th>Item</th>
<th>Item total correlation coefficient (r)</th>
<th>Included/ Excluded</th>
<th>Alpha coefficient of scale if had been included</th>
<th>Alpha coefficient if excluded</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Exercise regularly (frequency)” [reverse-scored]</td>
<td>.39</td>
<td>Included</td>
<td>-</td>
<td>.67</td>
<td></td>
</tr>
<tr>
<td>“Try not to rush around and get myself out of breath (frequency)”</td>
<td>.48</td>
<td>Included</td>
<td>-</td>
<td>.61</td>
<td></td>
</tr>
<tr>
<td>“Try not to exercise too hard or fast (frequency)”</td>
<td>.58</td>
<td>Included</td>
<td>-</td>
<td>.54</td>
<td></td>
</tr>
<tr>
<td>“Avoid exercise if I think I might get an asthma attack (frequency)”</td>
<td>.43</td>
<td>Included</td>
<td>-</td>
<td>.64</td>
<td></td>
</tr>
<tr>
<td>“If someone has asthma and they get out of breath when they exercise, they shouldn’t exercise that hard again”</td>
<td>.17</td>
<td>Excluded</td>
<td>.63</td>
<td>.69</td>
<td></td>
</tr>
</tbody>
</table>

Overall properties of scale:
- Alpha coefficient: .69
- Skewness Statistic: -.171 (SE = .378)
- Kurtosis Statistic: -.441 (SE = .741)
- Kolmogorov-Smirnov test of normality: KS = .141; p<.05
- No. outliers identified by SPSS: 0
- N=39; Number of items in scale=5
Table 7: Construction of Exertion-curtailment Subscale

<table>
<thead>
<tr>
<th>Construct scale is intended to tap: Curtailment of exertion as an asthma-management strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item</td>
</tr>
<tr>
<td>&quot;Stop or slow down if I think an asthma attack might be coming on (frequency)&quot;</td>
</tr>
<tr>
<td>&quot;If a person has asthma and they start to get out of breath when they exercise, they should stop immediately&quot;</td>
</tr>
<tr>
<td>&quot;I would like to exercise more, but when I do I get breathless and think I should stop in case I get an asthma attack&quot;</td>
</tr>
</tbody>
</table>

Overall properties of scale:

- Alpha coefficient: .50
- Skewness Statistic: -.35 (SE = .38)
- Kurtosis Statistic: -1.00 (SE = .74)
- Kolmogorov-Smirnov test of normality: KS=.190; p<.01
- No. outliers identified by SPSS: 0
- N=39; Number of items in scale = 3

Table 8: Construction of Environmental Trigger Avoidance Subscale

<table>
<thead>
<tr>
<th>Construct scale is intended to tap: Performance of avoidance of environmental triggers as an asthma-management strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item</td>
</tr>
<tr>
<td>&quot;Avoiding dusty places (frequency)&quot;</td>
</tr>
<tr>
<td>&quot;Leave smoky or dusty places if I think an asthma attack is coming on (frequency)&quot;</td>
</tr>
<tr>
<td>&quot;Try to keep out of polluted or heavy-traffic places (frequency)&quot;</td>
</tr>
</tbody>
</table>

Overall properties of scale:

- Alpha coefficient: .61
- Skewness Statistic: .07 (SE = .38)
- Kurtosis Statistic: -.78 (SE = .74)
- Kolmogorov-Smirnov test of normality: KS=.12; p=.16
- No. outliers identified by SPSS: 0
- N=39; Number of items in scale = 3
The Recovery Interpretation Scale

The construction of the Recovery Interpretation Scale is outlined in Table 9 below. Cronbach's alpha coefficients indicated minimum acceptable internal consistency for this scale. The KS test for violation of normality approached significance.

Table 9: Construction of the Recovery Interpretation Scale

<table>
<thead>
<tr>
<th>Construct scale is intended to tap: Attributions of recovery toward safety behaviours</th>
<th>“Elements” of construct: Perceived helpfulness of safety behaviours</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Item</strong></td>
<td><strong>Item total correlation coefficient (r)</strong></td>
</tr>
<tr>
<td>&quot;Try not to rush around and get myself out of breath (helpfulness)&quot;</td>
<td>.36</td>
</tr>
<tr>
<td>&quot;Stop or slow down if I think an asthma attack might be coming on (helpfulness)&quot;</td>
<td>.30</td>
</tr>
<tr>
<td>“Try not to exercise too hard or fast (helpfulness)”</td>
<td>.43</td>
</tr>
<tr>
<td>“Avoid exercise if I think I might get an asthma attack (helpfulness)”</td>
<td>.46</td>
</tr>
</tbody>
</table>

**Overall properties of scale:**
- Alpha coefficient: .60
- Skewness Statistic: -.49 (SE = .37)
- Kurtosis Statistic: -.23 (SE = .73)
- Kolmogorov-Smirnov test of normality: KS = .14; p=.06
- No. outliers identified by SPSS: 2
- N=40; Number of items in scale = 4

The Social Pressure Scale

The construction of the Social Pressure Scale is outlined in Table 10 below. Cronbach’s alpha reliability coefficient indicated adequate internal consistency. The KS statistic found no significant violation of normality.
### Table 10: Construction of the Social Pressure Scale

**Construct scale is intended to tap:** Social motivations, drivers or pressures to engage in exertion

**“Elements” of construct:**
- a) The experience of pressure to keep up with peers
- b) Concept of self with asthma incorporating both
  - i) Performance-oriented self-concept and motivation to exercise, and
  - ii) Experience of frustration with asthma

<table>
<thead>
<tr>
<th>Item</th>
<th>Item total correlation coefficient (r)</th>
<th>Included/ Excluded</th>
<th>Alpha coefficient of scale if had been included</th>
<th>Alpha coefficient if excluded</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;I think I cannot be as fit as people my age who don’t have asthma”</td>
<td>.66</td>
<td>Included</td>
<td>.68</td>
<td></td>
</tr>
<tr>
<td>&quot;I can be just as fit as my friends who don’t have asthma” [reverse-scored]</td>
<td>.64</td>
<td>Included</td>
<td>.70</td>
<td></td>
</tr>
<tr>
<td>&quot;I worry my friends will tease me or think badly of me if I can’t keep up with them in sport or PE”</td>
<td>.31</td>
<td>Included</td>
<td>.81</td>
<td></td>
</tr>
<tr>
<td>&quot;Having asthma stops me being as good as I want to be at sports activities”</td>
<td>.65</td>
<td>Included</td>
<td>.69</td>
<td></td>
</tr>
<tr>
<td>&quot;Having asthma doesn’t bother me” [reverse-scored]</td>
<td>.49</td>
<td>Included</td>
<td>.75</td>
<td></td>
</tr>
<tr>
<td>&quot;I enjoy exercise”</td>
<td>-.48</td>
<td>Excluded</td>
<td>.50</td>
<td>.71</td>
</tr>
<tr>
<td>&quot;I exercise because I want to prove I can even though I have asthma”</td>
<td>.15</td>
<td>Excluded</td>
<td>.50</td>
<td>.50</td>
</tr>
</tbody>
</table>

**Overall properties of scale:**
- Alpha coefficient: .77
- Skewness Statistic: .23 (SE = .37)
- Kurtosis Statistic: - .40 (SE = .73)
- Kolmogorov-Smirnov test of normality: KS=.103; p=.20
- No. outliers identified by SPSS: 0
- N=41; Number of items in scale = 5

Items excluded from scales but relevant to the research questions were analysed individually.

**Symptom perception**

Limitations in the expert sampling procedure, which will be explored more fully in the discussion, restricted the interpretation of the symptom-perception data. In summary, it had been anticipated the expert sampling procedure would provide inter-rater comparisons for the assignment of symptoms to “asthma”, “exertion” and “panic” symptoms. However, a much more confused picture emerged (Appendix 18),
and consequently symptoms were assigned to categories of “not asthma”, “asthma” or “ambiguous” on the basis of the patterns of the majority of responses to the expert sampling questionnaire. This process was conducted by hand according to the criteria detailed in Appendix 19. This incorporated some bias toward classifying symptoms as asthma to avoid regarding participants as “over-perceivers” when many health-professionals would agree with their interpretations. Counts were then made of the total number of symptoms perceived as part of or warning signs of an asthma attack, and the number of “not asthma”, “asthma” and “ambiguous” symptoms so-perceived. Statistical properties of these indices are outlined in Table 11 below.

**Table 11: Properties of the symptom-perception indices**

<table>
<thead>
<tr>
<th></th>
<th>Total no. symptoms interpreted as asthma</th>
<th>Total no. non-asthma symptoms interpreted as asthma</th>
<th>Total no. ambiguous symptoms interpreted as asthma</th>
<th>Total no. asthma symptoms interpreted as asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skewness</td>
<td>.20</td>
<td>.84</td>
<td>-.35</td>
<td>-1.43</td>
</tr>
<tr>
<td>SE</td>
<td>.37</td>
<td>.37</td>
<td>.37</td>
<td>.37</td>
</tr>
<tr>
<td>Kurtosis</td>
<td>-.44</td>
<td>-.10</td>
<td>.14</td>
<td>1.99</td>
</tr>
<tr>
<td>SE</td>
<td>.72</td>
<td>.72</td>
<td>.72</td>
<td>.72</td>
</tr>
<tr>
<td>Kolmogorov-Smirnov (KS)</td>
<td>.132</td>
<td>.20**</td>
<td>.19**</td>
<td>.26**</td>
</tr>
<tr>
<td>No. outliers</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3</td>
</tr>
</tbody>
</table>

**KS statistic found violation of normality significant to p<.01 level**

**Exercise behaviour**

Exercise behaviour was examined in terms of three individual items: level of exercise, reported variation in normal exercise level and the agreement with the item “I tend to exercise in short, energetic bursts rather than keeping it up more regularly” (the “short burst indicator”). Properties of these measures are outlined in Table 12 below.

**Table 12: Properties of exercise behaviour measures (single item indicators)**

<table>
<thead>
<tr>
<th></th>
<th>Level of exercise</th>
<th>Variation in exercise level</th>
<th>“Short burst” indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skewness</td>
<td>.06</td>
<td>.38</td>
<td>.33</td>
</tr>
<tr>
<td>SE</td>
<td>.37</td>
<td>.37</td>
<td>.37</td>
</tr>
<tr>
<td>Kurtosis</td>
<td>-.11</td>
<td>-.97</td>
<td>-.69</td>
</tr>
<tr>
<td>SE</td>
<td>.72</td>
<td>.72</td>
<td>.72</td>
</tr>
<tr>
<td>Kolmogorov-Smirnov (KS)</td>
<td>.19**</td>
<td>.22**</td>
<td>.17**</td>
</tr>
<tr>
<td>No. outliers</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

**KS statistic found violation of normality significant to p<.01 level**
Demographic and morbidity characteristics of participant sample

Descriptive data relating to the demographic and morbidity characteristics of the sample are reported below. Inferential analysis relating to these characteristics will be presented later.

**Gender:** There were 22 girls (53.66%) 19 boys (46.34%) in the participant sample of 41.

**Ethnicity:** The majority of the 38 participants for whom ethnicity data were gathered were of White British origin (84.21% n=32). Three participants (7.89%) were categorised as “White, any other background” (not British or Irish), one participant (2.63%) was of Mixed White and Asian background, another was of Asian British Indian background, and one was of Other background (mixed White British and Indigenous South American).

**Socio-economic status:** Table 13 reports the socio-economic distribution of the sample according to the classification of participants’ households on the five-class NS-SEC. Three people declined to complete the NS-SEC. Three participants’ households could not be classified according to the NS-SEC criteria.

**Table 13:** Socio-economic distribution of the sample according to the five-class NS-SEC

<table>
<thead>
<tr>
<th>NS-SEC classification</th>
<th>No. participants’ households out of 35 in total (n)</th>
<th>Percentage of all classifiable NS-SEC responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managerial and professional occupations</td>
<td>17</td>
<td>48.58</td>
</tr>
<tr>
<td>Intermediate occupations</td>
<td>2</td>
<td>5.71</td>
</tr>
<tr>
<td>Small employers and account workers</td>
<td>12</td>
<td>34.29</td>
</tr>
<tr>
<td>Lower supervisory and technical occupations</td>
<td>2</td>
<td>5.71</td>
</tr>
<tr>
<td>Semi-routine and routine occupations</td>
<td>2</td>
<td>5.71</td>
</tr>
</tbody>
</table>
Age: The mean age of the sample was 12.88 years (Standard deviation (SD) = 1.73). There were slightly more participants in the younger year-groups than older, and age distribution is outlined in Table 14, below.

Table 14: Age distribution of participant sample

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Number of cases (n)</th>
<th>Percentage of participant sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>13</td>
<td>31.70</td>
</tr>
<tr>
<td>12</td>
<td>7</td>
<td>17.07</td>
</tr>
<tr>
<td>13</td>
<td>6</td>
<td>14.63</td>
</tr>
<tr>
<td>14</td>
<td>6</td>
<td>14.63</td>
</tr>
<tr>
<td>15</td>
<td>5</td>
<td>12.20</td>
</tr>
<tr>
<td>16</td>
<td>4</td>
<td>9.76</td>
</tr>
</tbody>
</table>

Morbidity indicators: Means, standard deviations and ranges for the morbidity indicators are reported in Table 15, below. Relationships between these morbidity indicators and other indicators, scales and subscales will be reported later. Very varied responses were given to the item regarding current medications for asthma: some participants detailed dosages while others simply put “inhalers”. In consequence, such data were not analysed.

Table 15: Morbidity characteristics of the participant sample

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Standard deviation (SD)</th>
<th>Range of responses (minimum to maximum)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. asthma-related visits to GP in previous six months</td>
<td>2.71</td>
<td>4.68</td>
<td>20 (0-20)</td>
</tr>
<tr>
<td>No. hospital admissions due to asthma in previous six months</td>
<td>0.49</td>
<td>1.55</td>
<td>9 (0-9)</td>
</tr>
<tr>
<td>Typical no. reliever inhaler uses in one week</td>
<td>5.73</td>
<td>6.71</td>
<td>30 (0-30)</td>
</tr>
</tbody>
</table>

Analysis of research questions

Salient findings relating to some individual questions will be presented in this section, alongside predominantly descriptive data on the scales and sub-scales. More detailed data on the frequency of responses to individual questionnaire items can be found in Appendix 20. The research questions will be considered in turn. Scores on the scales were scored so that higher scores represent higher agreement with the construct. Higher scores on individual items represent higher agreement with that individual
item, which may later have been reverse-scored for the purpose of constructing a scale.

**To what extent is exertion perceived as harmful or incompatible with asthma?**

Distributions and central tendencies for the Belief Scale, and for the Exertion-related and Environmental Trigger Belief Subscales, are illustrated in Figures 3 to 5. The mean score on the Belief Scale of 16.21 (SD=5.20) suggested participants, as a whole, were fairly equivocal about this construct, but ranged from 5 to 25 indicating that both strong agreement and strong disagreement with the idea that asthma and exertion are incompatible occurred in the participant sample.

The mean score of 7.80 (SD=2.19) on the Exertion-related Trigger Belief Subscale indicated an overall trend towards agreement with the idea that exertion can trigger asthma attacks. Of those who responded, 75.00% (n=30 of 40) agreed or strongly agreed that energetic activity could trigger asthma attacks, and 75.61% (n=31 of 41) saw running fast as a trigger. The mean level of agreement with the Environmental Trigger Belief scale, at 7.27 (SD=1.90) indicated an overall pattern between equivocal response and slight agreement towards the idea that environmental factors can trigger asthma attacks. A Wilcoxon test found no significant differences between responses to the Exertion-related Trigger Belief and Environmental Trigger Belief Subscales, suggesting no difference in levels of agreement that exertion and environmental factors can trigger asthma attacks.

41.46% (n=17) of participants indicated agreement that “exercise and asthma don’t go together”, and 35.00% (n=14 of 40) regarded exercise as unhelpful in the management of asthma.
**Figure 3:** Distribution of scores on the Belief Scale

![Belief Scale Score distribution graph](image)

- Mean: 16.50
- SD: 5.20
- Minimum possible score: 5
- Maximum possible score: 25
- n=39

**Figure 4:** Distribution of scores on the Exertion-related Trigger Belief Subscale

![Exertion-related Trigger Belief Subscale scores distribution graph](image)

- Mean: 7.80
- SD: 2.19
- Minimum possible score: 2
- Maximum possible score: 10
- n=40
Figure 5: Distribution of scores on the Environmental Trigger Belief Subscale

Are normal exertion symptoms and symptoms of anxiety or panic sometimes interpreted as asthma?
Owing to the way symptoms had to be classified, this question was reframed as “To what extent are non-asthma or ambiguous symptoms interpreted as asthma?”. It was examined alongside descriptive analysis of the degree to which asthma symptoms were recognised as asthma.

*Interpretations of asthma symptoms as asthma:* Frequencies of interpretations of asthma symptoms are presented in Table 16, below. All asthma symptoms were perceived as symptoms or warning signs of asthma by the majority of participants.
### Table 16: Frequency of interpretations of asthma symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>n</th>
<th>Definitely an asthma attack (%)</th>
<th>Warning sign of an asthma attack (%)</th>
<th>Not an asthma attack (%)</th>
<th>Not sure if asthma attack or not (%)</th>
<th>Never happens to me (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling like I can’t get enough breath</td>
<td>41</td>
<td>60.98</td>
<td>31.71</td>
<td>4.88</td>
<td>2.44</td>
<td>0.00</td>
</tr>
<tr>
<td>Feeling like I can’t breathe deep enough</td>
<td>40</td>
<td>45.00</td>
<td>37.50</td>
<td>10.00</td>
<td>7.50</td>
<td>0.00</td>
</tr>
<tr>
<td>Feeling wheezy</td>
<td>41</td>
<td>31.71</td>
<td>56.10</td>
<td>0.00</td>
<td>12.20</td>
<td>0.00</td>
</tr>
<tr>
<td>Chest feeling tight</td>
<td>40</td>
<td>27.50</td>
<td>65.00</td>
<td>2.50</td>
<td>2.50</td>
<td>2.50</td>
</tr>
<tr>
<td>Feeling out of breath</td>
<td>39</td>
<td>25.64</td>
<td>56.41</td>
<td>7.69</td>
<td>10.26</td>
<td>0.00</td>
</tr>
<tr>
<td>Feeling like something is pressing on my chest</td>
<td>41</td>
<td>24.39</td>
<td>46.34</td>
<td>9.76</td>
<td>14.63</td>
<td>4.88</td>
</tr>
<tr>
<td>Getting short of breath</td>
<td>41</td>
<td>24.39</td>
<td>63.41</td>
<td>4.88</td>
<td>7.32</td>
<td>0.00</td>
</tr>
<tr>
<td>Coughing when I exercise</td>
<td>41</td>
<td>12.20</td>
<td>48.78</td>
<td>17.07</td>
<td>19.51</td>
<td>2.44</td>
</tr>
</tbody>
</table>

Total no. symptoms classified as asthma on basis of expert sample: 8
Mean no. symptoms interpreted as asthma or warning signs by participants: 6.49
Standard Deviation: 1.66
Median: ...7.00
Mode: 7.00
Skewness: -1.43 (SE = .37)
Kurtosis: 1.99 (SE = .72)
KS Statistic: .26; p < .01

**Interpretation of non-asthma symptoms as asthma:** Frequencies of interpretations of non-asthma symptoms by participants are reported in Table 17, below. Three non-asthma symptoms were interpreted as symptoms or warning signs of asthma attack by the majority of participants: “heart beating really hard” (51.28%, n=20), “feeling like I am choking” (53.66%, n=22), and “needing to breathe deeper than normal” (84.62%, n=33). “Feeling shaky, wobbly or trembling” was interpreted as a symptom or warning sign of asthma attack by 42.50% (n=17) of participants.
Table 17: Frequency of interpretations of non-asthma symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>n</th>
<th>Definitely an asthma attack (%)</th>
<th>Warning sign of an asthma attack (%)</th>
<th>Not an asthma attack (%)</th>
<th>Not sure if asthma attack or not (%)</th>
<th>Never happens to me (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needing to breathe deeper than normal</td>
<td>39</td>
<td>30.77</td>
<td>53.85</td>
<td>2.56</td>
<td>12.82</td>
<td>0.00</td>
</tr>
<tr>
<td>Breathing hurting my throat</td>
<td>40</td>
<td>20.00</td>
<td>12.50</td>
<td>17.50</td>
<td>25.00</td>
<td>25.00</td>
</tr>
<tr>
<td>Feeling like I am choking</td>
<td>41</td>
<td>19.51</td>
<td>34.15</td>
<td>17.07</td>
<td>19.51</td>
<td>9.76</td>
</tr>
<tr>
<td>Feeling shaky, wobbly or trembling</td>
<td>40</td>
<td>17.50</td>
<td>25.00</td>
<td>30.00</td>
<td>20.00</td>
<td>7.50</td>
</tr>
<tr>
<td>Muscles in my arms or legs feeling tired or aching</td>
<td>40</td>
<td>10.00</td>
<td>7.50</td>
<td>52.50</td>
<td>22.50</td>
<td>7.50</td>
</tr>
<tr>
<td>Heart beating really hard</td>
<td>39</td>
<td>7.69</td>
<td>43.59</td>
<td>28.21</td>
<td>19.95</td>
<td>2.56</td>
</tr>
<tr>
<td>Going dizzy or giddy</td>
<td>41</td>
<td>7.32</td>
<td>29.27</td>
<td>39.02</td>
<td>19.51</td>
<td>4.88</td>
</tr>
<tr>
<td>Sweating</td>
<td>39</td>
<td>5.13</td>
<td>10.26</td>
<td>51.28</td>
<td>20.51</td>
<td>12.82</td>
</tr>
<tr>
<td>Thinking that something terrible is about to happen</td>
<td>40</td>
<td>5.00</td>
<td>15.00</td>
<td>55.00</td>
<td>17.50</td>
<td>7.50</td>
</tr>
<tr>
<td>Feeling sick</td>
<td>41</td>
<td>4.88</td>
<td>12.20</td>
<td>48.78</td>
<td>19.51</td>
<td>14.63</td>
</tr>
<tr>
<td>Things don’t seem real</td>
<td>40</td>
<td>2.50</td>
<td>15.00</td>
<td>37.50</td>
<td>15.00</td>
<td>30.00</td>
</tr>
<tr>
<td>Getting pins and needles in my hands and feet</td>
<td>41</td>
<td>2.44</td>
<td>4.88</td>
<td>56.10</td>
<td>12.20</td>
<td>24.39</td>
</tr>
<tr>
<td>Getting a stitch</td>
<td>40</td>
<td>0.00</td>
<td>17.50</td>
<td>52.50</td>
<td>22.50</td>
<td>7.50</td>
</tr>
</tbody>
</table>

**Total no. symptoms classified as not asthma on basis of expert sample:** 13

**Mean no. symptoms interpreted as asthma or warning signs by participants:** 4.02

**Standard Deviation:** 2.79

**Median:** 3.00

**Mode:** 2.00

**Skewness:** .84 (SE=.37)

**Kurtosis:** -.10 (SE=.72)

**KS Statistic:** .20; p<.01

*Interpretation of ambiguous symptoms as asthma:* Frequencies of interpretations by participants of ambiguous symptoms are presented in Table 18, below. Three of the five symptoms were interpreted as symptoms or warning signs of asthma attack by the majority of participants: “feeling like I can’t breathe fast enough (90.00%, n=36), “needing to breathe faster” (90.00%, n=36) and “feeling like something is in the way when I breathe” (57.89%, n=22).
Table 18: Frequencies of interpretations of ambiguous symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>n</th>
<th>Definitely an asthma attack (%)</th>
<th>Warning sign of an asthma attack (%)</th>
<th>Not an asthma attack (%)</th>
<th>Not sure if asthma attack or not (%)</th>
<th>Never happens to me (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling like I can’t breathe fast enough</td>
<td>40</td>
<td>37.50</td>
<td>52.50</td>
<td>2.50</td>
<td>5.00</td>
<td>2.50</td>
</tr>
<tr>
<td>Feeling like something is in the way when I breathe</td>
<td>38</td>
<td>34.21</td>
<td>23.68</td>
<td>10.53</td>
<td>13.16</td>
<td>18.42</td>
</tr>
<tr>
<td>Needing to breathe faster</td>
<td>40</td>
<td>25.00</td>
<td>65.00</td>
<td>0.00</td>
<td>10.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Thinking that I might collapse</td>
<td>40</td>
<td>20.00</td>
<td>20.00</td>
<td>22.50</td>
<td>15.00</td>
<td>22.50</td>
</tr>
<tr>
<td>Feeling scared or worried</td>
<td>39</td>
<td>7.69</td>
<td>23.08</td>
<td>35.90</td>
<td>20.51</td>
<td>12.82</td>
</tr>
</tbody>
</table>

Total no. symptoms classified as ambiguous on basis of expert sample: 5
Mean no. symptoms interpreted as asthma or warning signs by participants: 2.98
Standard Deviation: 1.25
Median: 3.00
Mode: 3.00
Skewness: -0.35 (SE=.37)
Kurtosis: 0.14 (SE=.72)
KS Statistic: 0.19; p<.01

Overall interpretations of symptoms as asthma: Frequency data for the total number of symptoms interpreted as symptoms or warning signs of an asthma attack are presented in Table 19, below.

Table 19: Frequency data on number of symptoms interpreted as symptoms or warning signs of asthma attack.

<table>
<thead>
<tr>
<th>Total no. symptoms in symptom checklist</th>
<th>26</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. classified as asthma</td>
<td>8</td>
</tr>
<tr>
<td>No. classified as not asthma</td>
<td>13</td>
</tr>
<tr>
<td>No. classified as ambiguous</td>
<td>5</td>
</tr>
<tr>
<td>Mean no. symptoms interpreted as symptoms or warning signs of asthma attack</td>
<td>13.49</td>
</tr>
<tr>
<td>Standard deviation</td>
<td>4.90</td>
</tr>
<tr>
<td>Median</td>
<td>12.00</td>
</tr>
<tr>
<td>Mode</td>
<td>12.00</td>
</tr>
<tr>
<td>Skewness</td>
<td>0.20 (SE=.37)</td>
</tr>
<tr>
<td>Kurtosis</td>
<td>-0.44 (SE=.72)</td>
</tr>
<tr>
<td>KS Statistic</td>
<td>0.13; p=.07</td>
</tr>
</tbody>
</table>

Do adolescents avoid or curtail exertion in an attempt to manage asthma?
Distributions and central tendencies for the Social Pressure Scale and for the Exertion-avoidance, Exertion-curtailment and Environmental Trigger Avoidance Subscales are presented below in Figures 6 to 9. The mean Safety Behaviour Scale
score of 24.08 (SD=5.59) is around the “sometimes” point. The mean score of 12.46 (SD=3.59) on the Exertion-Avoidance Subscale, being a four-item subscale, reflects responses nearest the “sometimes” point, equivalent to 3.06 on a single item. The mean score of 11.66 on the Exertion-Curtailment, being a three-item subscale, is equivalent to a single-item score of 3.89 – nearest the “often” mark. The mean score of 10.63 on the Environmental Trigger Avoidance subscale, being a three-item subscale, yields a single-item equivalent score of 3.54, a score approaching the “often” mark. Friedman and post-hoc Wilcoxon tests revealed that the differences between these three pro-rated subscales (corrected for number of items) were significant to at least p<.05 level.

Responses to single items comprising the Safety Behaviour Scale (Appendix 20b) indicated that the majority of participants (80.49%, n=33) always or usually stopped or slowed down if they thought that an asthma attack was starting, and would also avoid exercise if they felt an asthma attack might start (67.50%, n=27 of 40). For 43.90% (n=18), wanting to exercise but getting breathless and thinking one should stop was a “very often” or “often” a problem.

Figure 6: Distribution of scores on the Safety Behaviour Scale
Figure 7: Distribution of scores on the Exertion-avoidance Subscale

Figure 8: Distribution of scores on Exertion-curtailment Subscale
Do adolescents experience social pressures to exert themselves beyond a perceived ideal level?

The distribution of responses to the Social Pressure Scale, incorporating social motivators, drivers and pressures to exercise, is illustrated below in Figure 10. The mean score of 13.59 (SD=5.26) on this five-item scale was nearest the “sometimes” response, with a single-item equivalent score of 2.72.
The majority of participants (63.41%, n=26) reported enjoying exercise. 70.73% (n=29) seldom or never worried about teasing or negative evaluation from friends surrounding their performance in sport or PE. Feeling held back in sport due to asthma was experienced “sometimes”, “quite often” or “often” by 63.41% (n=26) of participants.

Do some adolescents show patterns of oscillation in exertion level?
Responses to the two single-item measures of oscillation or variability in exertion level (which were not significantly correlated) are outlined in Figures 11 and 12.
**Figure 11:** Proportions of participants reporting levels of variability in weekly exercise level

![Pie chart showing proportions of participants reporting levels of variability in weekly exercise level.](image)

- 21.95% report doing the same amount of exercise each week.
- 34.15% report doing more or less the same amount of exercise each week.
- 14.63% report occasionally having weeks when they do more or less exercise.
- 29.27% report doing a bit more or less exercise from week to week.
- 0.00% report doing much more or less exercise some weeks than other.

n=41

**Figure 12:** Responses to single-item indicator: “I tend to do exercise in short, energetic bursts, rather than keeping it up more regularly.”

![Bar chart showing frequency of responses to the single-item indicator.](image)

- Mean: 2.59
- SD: 1.20
- Minimum possible score: 1
- Maximum possible score: 5
- n=41
The majority of participants (63.41%, n=26) reported doing the same or more or less the same amount of exercise each week, with none reporting doing “much more or less”. 51.22% (n=21) of participants reported doing short, sharp bursts of exercise sometimes, often or very often. Only 7.32% (n=3) reported such sudden oscillations “very often”.

**Inferential analysis of hypotheses**

**Hypothesis 1:** Beliefs that asthma and exertion are incompatible will be positively associated with the number of symptoms interpreted as symptoms or warning signs of an asthma attack.

Correlation coefficients between the Belief Scale and each of the four Symptom-Perception “indices” were calculated using the Spearman’s rho test, and are reported in Table 20, below. Correlations with the Exertion-related and Environmental Trigger Belief subscales were calculated as a more detailed and rigorous examination of the relationships between hypothesised constructs, and are also reported, as are relationships between single items excluded from the Belief Scale.
Table 20: Correlation coefficients between Belief Scale and symptom-perception indices

<table>
<thead>
<tr>
<th></th>
<th>Total number of symptoms interpreted as asthma</th>
<th>Number of non-asthma symptoms interpreted as asthma</th>
<th>Number of ambiguous symptoms interpreted as asthma</th>
<th>Number of asthma symptoms interpreted as asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Belief scale</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.32*</td>
<td>.12</td>
<td>.28</td>
<td>.41**</td>
</tr>
<tr>
<td>Significance (2-tailed) n</td>
<td>.049</td>
<td>.45</td>
<td>.08</td>
<td>.01</td>
</tr>
<tr>
<td><strong>Exertion-related Trigger Belief Subscale</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.20</td>
<td>.04</td>
<td>.15</td>
<td>.33*</td>
</tr>
<tr>
<td>Significance (2-tailed) n</td>
<td>.21</td>
<td>.80</td>
<td>.34</td>
<td>.04</td>
</tr>
<tr>
<td><strong>Environmental Trigger Belief Subscale</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.23</td>
<td>.11</td>
<td>.22</td>
<td>.35*</td>
</tr>
<tr>
<td>Significance (2-tailed) n</td>
<td>.14</td>
<td>.48</td>
<td>.16</td>
<td>.03</td>
</tr>
<tr>
<td>“Light exercise is OK for people my age who have asthma”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.20</td>
<td>.15</td>
<td>.26</td>
<td>.13</td>
</tr>
<tr>
<td>Significance (2-tailed) n</td>
<td>.21</td>
<td>.37</td>
<td>.10</td>
<td>.43</td>
</tr>
<tr>
<td>“Exercise is fine for people with asthma – as long as they don’t overdo it”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.32*</td>
<td>.20</td>
<td>.26</td>
<td>.36*</td>
</tr>
<tr>
<td>Significance (2-tailed) n</td>
<td>.04</td>
<td>.22</td>
<td>.11</td>
<td>.02</td>
</tr>
<tr>
<td>“Asthma shouldn’t stop people from exercising”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.08</td>
<td>.10</td>
<td>.15</td>
<td>.01</td>
</tr>
<tr>
<td>Significance (2-tailed) n</td>
<td>.63</td>
<td>.56</td>
<td>.35</td>
<td>.94</td>
</tr>
<tr>
<td>“If asthma stopped me exercising, I would expect my doctor to try to find some better medicine for me”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.25</td>
<td>.31</td>
<td>.20</td>
<td>.15</td>
</tr>
<tr>
<td>Significance (2-tailed) n</td>
<td>.12</td>
<td>.052</td>
<td>.21</td>
<td>.36</td>
</tr>
</tbody>
</table>

*Correlation coefficient is significant at p≤.05 level (two-tailed)
**Correlation coefficient is significant at p≤.01 level (two-tailed)
Significant positive correlations were found between the Belief Scale and both the total number of symptoms and the number of asthma symptoms interpreted as symptoms or warning signs of asthma attack. In other words, the greater the endorsement of the idea that asthma and exertion are incompatible, the greater was the total number of symptoms and number of asthma symptoms interpreted as symptoms or warning signs of asthma attack. The numbers of non-asthma and ambiguous symptoms interpreted as asthma were not significantly correlated with the Belief Scale, yielding limited support for Hypothesis 1. Significant positive correlations were found between both the Exertion-related and Environmental Trigger Belief Subscales and the number of asthma symptoms interpreted as asthma, suggesting that greater belief that exertion and environmental factors trigger asthma attacks is associated with greater recognition of asthma symptoms. They were not related to total number of symptoms, non-asthma or ambiguous symptoms interpreted as asthma. The single item “Exercise is fine for people with asthma – as long as they don’t overdo it” was significantly positively associated with both the total number of symptoms and the number of asthma symptoms interpreted as asthma.

Hypothesis 2: Beliefs that asthma and exertion are incompatible will be positively associated with asthma-management strategies involving the avoidance or curtailment of exertion (safety behaviours)

The Spearman’s rho analysis of the relationship between the Belief and Safety Behaviour Scales is outlined in Table 21 below. Relationships between the Exertion-Related and Environmental Trigger Belief Subscales and the Exertion-avoidance, Exertion-curtailment and Environmental Trigger Avoidance Subscales are also presented, as are relationships with single items excluded from the Belief Scale.
Table 21: Correlation coefficients between the Belief Scale, subscales and single, excluded items, and Safety Behaviour Scale and subscales.

<table>
<thead>
<tr>
<th></th>
<th>Safety Behaviour Scale</th>
<th>Exertion-avoidance Subscale</th>
<th>Exertion-curtailment Subscale</th>
<th>Environmental Trigger Avoidance Subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belief scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>r .73**</td>
<td>.64**</td>
<td>.53**</td>
<td>.26</td>
</tr>
<tr>
<td>Significance (2-tailed)</td>
<td>.00</td>
<td>.00</td>
<td>.00</td>
<td>.11</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>39</td>
<td>39</td>
<td>39</td>
</tr>
<tr>
<td>Exertion-related Trigger Belief Subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>r .58**</td>
<td>.49**</td>
<td>.51**</td>
<td>.22</td>
</tr>
<tr>
<td>Significance (2-tailed)</td>
<td>.00</td>
<td>.00</td>
<td>.00</td>
<td>.17</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>39</td>
<td>40</td>
<td>40</td>
</tr>
<tr>
<td>Environmental Trigger Belief Subscale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>r .26</td>
<td>.34*</td>
<td>.18</td>
<td>.24</td>
</tr>
<tr>
<td>Significance (2-tailed)</td>
<td>.12</td>
<td>.04</td>
<td>.25</td>
<td>.14</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>39</td>
<td>41</td>
<td>41</td>
</tr>
<tr>
<td>“Light exercise is OK for people my age who have asthma”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>r .24</td>
<td>.23</td>
<td>.19</td>
<td>.01</td>
</tr>
<tr>
<td>Significance (2-tailed)</td>
<td>.14</td>
<td>.15</td>
<td>.25</td>
<td>.94</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>39</td>
<td>41</td>
<td>41</td>
</tr>
<tr>
<td>“Exercise is fine for people with asthma – as long as they don’t overdo it”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>r .31</td>
<td>.21</td>
<td>.27</td>
<td>.41**</td>
</tr>
<tr>
<td>Significance (2-tailed)</td>
<td>.053</td>
<td>.20</td>
<td>.09</td>
<td>.01</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>39</td>
<td>41</td>
<td>41</td>
</tr>
<tr>
<td>“Asthma shouldn’t stop people from exercising”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>r -.03</td>
<td>-.17</td>
<td>.00</td>
<td>.00</td>
</tr>
<tr>
<td>Significance (2-tailed)</td>
<td>.84</td>
<td>.30</td>
<td>1.00</td>
<td>1.00</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>39</td>
<td>41</td>
<td>41</td>
</tr>
<tr>
<td>“If asthma stopped me exercising, I would expect my doctor to try to find some better medicine for me”</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>r .18</td>
<td>.06</td>
<td>.13</td>
<td>.10</td>
</tr>
<tr>
<td>Significance (2-tailed)</td>
<td>.29</td>
<td>.73</td>
<td>.41</td>
<td>.53</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>39</td>
<td>41</td>
<td>41</td>
</tr>
</tbody>
</table>

**Correlation coefficient is significant to the p≤.01 level
*Correlation coefficient is significant to the p≤.05 level

A strong and highly significant positive relationship, illustrated in Figure 13, was found between the Belief Scale and the Safety Behaviour Scale. This indicates that stronger belief in the idea that asthma and exertion are incompatible was associated with more frequent performance of behaviours involving avoidance and curtailment of exertion as an asthma management strategy, and is in line with Hypothesis 2. The Belief Scale was significantly positively correlated with both the Exertion-avoidance
and Exertion-curtailment subscales. The Exertion-Related Trigger Subscale was significantly positively correlated with the Safety Behaviour Scale and the Exertion-avoidance and Exertion-curtailment subscales, but not with the Environmental Trigger Avoidance Subscale. This finding that the belief that exertion triggers asthma attacks is linked with avoidance and curtailment of exertion but not avoidance of triggers such as dust was in line with expectations. However, it would have been expected that the Environmental Trigger Belief Subscale would have been positively correlated with Environmental Trigger Avoidance Subscale – it was not significantly correlated – and not that it was positively associated, as it was, with Exertion-avoidance.

**Figure 13:** Scatterplot illustrating relationship between the Belief Scale and the Safety Behaviour Scale

Hypothesis 3: Perceptions that safety behaviours are helpful will be positively correlated with beliefs that asthma and exertion are incompatible

This hypothesis was theoretically linked to the speculative model's suggestion that attributions of recovery from exertion to safety behaviours would serve to confirm beliefs that asthma and exertion was incompatible. The Recovery Interpretation Scale therefore examined the perception that safety behaviours (avoidance and curtailment
of exertion) were helpful in the management of asthma. The Spearman’s rho analysis of the relationships between the Recovery Interpretation Scale and the Belief Scale, Exertion-related Trigger and Environmental Trigger Belief Subscales are outlined in Table 22 below.

**Table 22: Correlation coefficient between the Belief Scale, Exertion-related and Environmental Trigger Beliefs Subscales and the Recovery Interpretation Scale**

<table>
<thead>
<tr>
<th>Recovery Interpretation Scale</th>
<th>Belief Scale</th>
<th>Exertion-related Trigger Belief Subscale</th>
<th>Environmental Trigger Belief Subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r .35*</td>
<td>.37*</td>
<td>.29</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.03</td>
<td>.02</td>
<td>.07</td>
</tr>
<tr>
<td>n 39</td>
<td></td>
<td>40</td>
<td>40</td>
</tr>
</tbody>
</table>

Correlation coefficient significant to p≤.05 level.

The analysis indicated a significant positive correlation between the Recovery Scale and the Belief Scale indicating that stronger perceptions that safety behaviours are helpful in the management of asthma were associated with stronger belief in the idea that asthma and exertion are incompatible, in line with Hypothesis 3. The Recovery Scale was also significantly positively correlated with the Exertion-related Trigger Belief Subscale, but not with the Environmental Trigger Belief Subscale, as would have been expected from the speculated model’s viewpoint.

**Hypothesis 4:** The number of symptoms interpreted as symptoms or warning signs of an asthma attack will be positively related to asthma management strategies involving the curtailment and avoidance of exertion

The Spearman’s rho analysis of the relationship between the Safety Behaviour Scale and the four Symptom-Perception “indices” is outlined in Table 23 below. Relationships between the Symptom-Perception indices and the Exertion-avoidance, Exertion-curtailment and Environmental Trigger Avoidance Subscales are also presented.
**Table 23:** Correlation coefficients between the Safety Behaviour Scale and subscales, and four symptom-perception indices

<table>
<thead>
<tr>
<th>Safety Behaviour Scale</th>
<th>Total number of symptoms interpreted as asthma</th>
<th>Number of non-asthma symptoms interpreted as asthma</th>
<th>Number of ambiguous symptoms interpreted as asthma</th>
<th>Number of asthma symptoms interpreted as asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r</td>
<td>.58**</td>
<td>.35*</td>
<td>.57**</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>.00</td>
<td>.03</td>
<td>.00</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>39</td>
<td>39</td>
<td>39</td>
</tr>
<tr>
<td>Exertion-avoidance</td>
<td>r</td>
<td>.28</td>
<td>.13</td>
<td>.34**</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>.09</td>
<td>.42</td>
<td>.04</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>39</td>
<td>39</td>
<td>39</td>
</tr>
<tr>
<td>Exertion-curtailment</td>
<td>r</td>
<td>.50**</td>
<td>.35*</td>
<td>.51**</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>.00</td>
<td>.03</td>
<td>.00</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>41</td>
<td>41</td>
<td>41</td>
</tr>
<tr>
<td>Environmental Trigger Avoidance</td>
<td>r</td>
<td>.41**</td>
<td>.32*</td>
<td>.44**</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
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<td>.04</td>
<td>.00</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>41</td>
<td>41</td>
<td>41</td>
</tr>
</tbody>
</table>

** Correlation coefficient is significant to p≤.01 level.  
* Correlation coefficient is significant to p≤.05 level.

Significant positive correlation was found between the Safety Behaviour Scale and all four symptom-perception "indices", meaning that the greater the number of asthma, non-asthma and ambiguous symptoms interpreted as asthma, the more likely participants were to engage in safety behaviours. This supported Hypothesis 4. Correlational analyses conducted to tease out differential aspects of such a relationship revealed all four Symptom-Perception indices were significantly positively correlated with the performance of behaviours involving the curtailment of exertion (stopping exercise in response to the perception that an asthma attack might commence). However, only the interpretation of asthma and ambiguous symptoms as asthma were significantly positively correlated to avoiding exertion as an asthma management strategy – the interpretation of non-asthma symptoms and all symptoms as asthma were not. An additional finding that had not been predicted was that all four symptom-perception indices were significantly positively associated with the avoidance of environmental triggers as an asthma management strategy.
Hypothesis 5: Beliefs that asthma and exertion are incompatible will be negatively associated with the level of weekly exercise.

The Spearman's rho analysis of the relationship between the Belief Scale and the single-item measure of weekly exercise level is outlined in Table 24 below. Relationships between weekly exercise level and the belief-related subscales and excluded items are also reported.

**Table 24:** Correlations between weekly exercise level and Belief Scale, Exertion-related and Environmental Trigger Belief subscales, and single belief-related items

<table>
<thead>
<tr>
<th>Belief scale</th>
<th>Weekly exercise level</th>
</tr>
</thead>
<tbody>
<tr>
<td>r</td>
<td>-.39**</td>
</tr>
<tr>
<td>Significance (2-tailed)</td>
<td>.006</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
</tr>
</tbody>
</table>

| Exertion-related Trigger Belief Subscale   |                       |
| r                                         | -.33*                 |
| Significance (2-tailed)                    | .04                   |
| n                                         | 40                    |

| Environmental Trigger Belief Subscale      |                       |
| r                                         | -.09                  |
| Significance (2-tailed)                    | .59                   |
| n                                         | 41                    |

| “Light exercise is OK for people my age who have asthma” |                       |
| r                                         | -.35*                 |
| Significance (2-tailed)                    | .024                  |
| n                                         | 41                    |

| “Exercise is fine for people with asthma – as long as they don’t overdo it” |                       |
| r                                         | -.36*                 |
| Significance (2-tailed)                    | .02                   |
| n                                         | 41                    |

| “Asthma shouldn’t stop people from exercising” |                       |
| r                                         | .13                   |
| Significance (2-tailed)                    | .41                   |
| n                                         | 41                    |

| “If asthma stopped me exercising, I would expect my doctor to try to find some better medicine for me” |                       |
| r                                         | -.06                  |
| Significance (2-tailed)                    | .73                   |
| n                                         | 41                    |

**Correlation coefficient is significant to p≤.01 level.**

* Correlation coefficient is significant to p≤.05 level
This analysis indicated a significant negative association of medium effect size ($r = -0.39$, $p < 0.01$) between the Belief Scale and reported weekly exercise level — greater belief that asthma and exertion are incompatible was associated with a lower weekly-exercise level. The perception of exercise as a trigger of asthma attacks was also negatively associated with weekly exercise level. These correlations support Hypothesis 5. The perception of environmental stimuli as triggers for asthma attacks was not significantly correlated with weekly exercise. The two single items relating to the idea that exercise was ok only if it was light or moderate were both significantly negatively associated with weekly exercise level — agreement with these two items was associated with lower weekly exercise level.

**Hypothesis 6:** Perceptions of social pressures and negative performance-oriented self-concept will correlate positively with oscillations in exertion level and weekly exercise level

The Spearman's rho analyses of the relationships between the Social Pressure Scale and reported variability of weekly exercise level, frequency of the experience “I tend to exercise in short, energetic bursts, rather than keeping it up more regularly”, and weekly exercise level are outlined in Table 25, below. Correlations between exercise behaviour measures and individual questionnaire items excluded from the Social Pressure Scale are also presented.
Table 25: Correlation coefficients between the Social Pressure Scale and exercise behaviour indicators

<table>
<thead>
<tr>
<th>Social Pressure Scale</th>
<th>&quot;I enjoy exercise&quot;</th>
<th>&quot;I exercise because I want to prove I can even though I have asthma&quot;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-reported variability in weekly exercise level</td>
<td>r = -0.02</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>0.926</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>41</td>
</tr>
<tr>
<td>&quot;I tend to exercise in short energetic bursts...&quot;</td>
<td>r = 0.43**</td>
<td>-24</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>0.01</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>41</td>
</tr>
<tr>
<td>Self-reported weekly exercise level</td>
<td>r = -0.50**</td>
<td>0.62*</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>0.00</td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>41</td>
</tr>
</tbody>
</table>

* Correlation coefficient was significant to p≤0.05 level.
**Correlation coefficient was significant to p≤0.01 level.

In line with Hypothesis 6, a significant positive correlation of medium effect size (r=0.43, p<0.01) was found between the Social Pressure scale and oscillations in exertion operationalised by the “short, energetic burst” item. However, no significant correlation was found between the Social Pressure Scale and reported week-to-week variation in exercise level, and a significant negative correlation approaching large effect size (r=0.50, p<0.01) was found between the Social Pressure scale and the weekly exercise level. Thus, greater experiences of social pressures and concerns such as worries about teasing or performance in sports were associated with doing less exercise – contradicting the hypothesis. The single item “I enjoy exercise” was significantly positively associated with greater number of hours of weekly exercise. The single item “I exercise because I want to prove I can even though I have asthma” was significantly associated with week-to-week variation in exercise level but not to the “short burst” indicator.

Are beliefs and perceptions associated with other health outcomes?
Table 26 presents relationships that were explored between the scales and subscales and health-related behaviours and perceptions.
Table 26: Relationships between hypothetical constructs and health outcomes

a) Beliefs:

<table>
<thead>
<tr>
<th>Belief Scale</th>
<th>Exertion-related Trigger Belief Subscale</th>
<th>Environmental Trigger Belief Subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reported regularity (always-never) of using preventor inhaler every day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.32*</td>
<td>.52**</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.05</td>
<td>.00</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>39</td>
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<tr>
<td>Perceived helpfulness of using preventor inhaler every day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.14</td>
<td>.19</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.39</td>
<td>.25</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>39</td>
</tr>
<tr>
<td>Reported regularity (always-never) of using reliever inhaler when start of asthma attack is perceived</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.39*</td>
<td>.44**</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.01</td>
<td>.00</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>40</td>
</tr>
<tr>
<td>Perceived helpfulness of using reliever inhaler when start of asthma attack is perceived</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>-.07</td>
<td>.05</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.69</td>
<td>.74</td>
</tr>
<tr>
<td>n</td>
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<td>40</td>
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<tr>
<td>No. asthma-related visits to GP in previous six months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.42**</td>
<td>.18</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.01</td>
<td>.26</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
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<tr>
<td>Typical no. reliever inhaler uses per week</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.40*</td>
<td>.34*</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.01</td>
<td>.03</td>
</tr>
<tr>
<td>n</td>
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</table>

(continues)
### b) Symptom perception:

<table>
<thead>
<tr>
<th></th>
<th>Total number of symptoms interpreted as asthma</th>
<th>Number of non-asthma symptoms interpreted as asthma</th>
<th>Number of ambiguous symptoms interpreted as asthma</th>
<th>Number of asthma symptoms interpreted as asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reported regularity (always-never) of using preventor inhaler every day</td>
<td>r .07</td>
<td>.01</td>
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<td></td>
<td>Significance (two-tailed)</td>
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<td>.97</td>
<td>.61</td>
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<td>40</td>
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<tr>
<td>Perceived helpfulness of using preventor inhaler every day</td>
<td>r .23</td>
<td>.18</td>
<td>.21</td>
<td>.27</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>.15</td>
<td>.26</td>
<td>.20</td>
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<tr>
<td></td>
<td>n 40</td>
<td>40</td>
<td>40</td>
<td>40</td>
</tr>
<tr>
<td>Reported regularity (always-never) of using reliever inhaler when start of asthma attack is perceived</td>
<td>r .13</td>
<td>.05</td>
<td>.06</td>
<td>.23</td>
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<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>.42</td>
<td>.76</td>
<td>.72</td>
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<tr>
<td></td>
<td>n 41</td>
<td>41</td>
<td>41</td>
<td>41</td>
</tr>
<tr>
<td>Perceived helpfulness of using reliever inhaler when start of asthma attack is perceived</td>
<td>r .10</td>
<td>.08</td>
<td>.09</td>
<td>.17</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>.53</td>
<td>.61</td>
<td>.59</td>
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<td></td>
<td>n 41</td>
<td>41</td>
<td>41</td>
<td>41</td>
</tr>
<tr>
<td>No. asthma-related visits to GP in previous six months</td>
<td>r .15</td>
<td>.17</td>
<td>.05</td>
<td>.05</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
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<td>.30</td>
<td>.76</td>
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<tr>
<td></td>
<td>n 41</td>
<td>41</td>
<td>41</td>
<td>41</td>
</tr>
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<td>Typical no. reliever inhaler uses per week</td>
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<tr>
<td></td>
<td>Significance (two-tailed)</td>
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<tr>
<td></td>
<td>n 41</td>
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</table>
### c) Safety behaviours

<table>
<thead>
<tr>
<th>Reported regularity (always-never) of using preventor inhaler every day</th>
<th>Safety Behaviour Scale</th>
<th>Exertion-avoidance Subscale</th>
<th>Exertion-curtailment Subscale</th>
<th>Environmental Trigger Avoidance Subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>r</td>
<td>.25</td>
<td>.20</td>
<td>.28</td>
</tr>
<tr>
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<td>Significance (two-tailed)</td>
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<td>.22</td>
<td>.09</td>
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<table>
<thead>
<tr>
<th>Perceived helpfulness of using preventor inhaler every day</th>
<th>Safety Behaviour Scale</th>
<th>Exertion-avoidance Subscale</th>
<th>Exertion-curtailment Subscale</th>
<th>Environmental Trigger Avoidance Subscale</th>
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</thead>
<tbody>
<tr>
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<td>r</td>
<td>.27</td>
<td>.15</td>
<td>.27</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
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<td>.37</td>
<td>.10</td>
</tr>
<tr>
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</tr>
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</table>

<table>
<thead>
<tr>
<th>Reported regularity (always-never) of using reliever inhaler when start of asthma attack is perceived</th>
<th>Safety Behaviour Scale</th>
<th>Exertion-avoidance Subscale</th>
<th>Exertion-curtailment Subscale</th>
<th>Environmental Trigger Avoidance Subscale</th>
</tr>
</thead>
<tbody>
<tr>
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<td>.22</td>
<td>.12</td>
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<table>
<thead>
<tr>
<th>Perceived helpfulness of using reliever inhaler when start of asthma attack is perceived</th>
<th>Safety Behaviour Scale</th>
<th>Exertion-avoidance Subscale</th>
<th>Exertion-curtailment Subscale</th>
<th>Environmental Trigger Avoidance Subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>-.06</td>
<td>-.16</td>
<td>-.08</td>
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<td>.62</td>
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<table>
<thead>
<tr>
<th>No. asthma-related visits to GP in previous six months</th>
<th>Safety Behaviour Scale</th>
<th>Exertion-avoidance Subscale</th>
<th>Exertion-curtailment Subscale</th>
<th>Environmental Trigger Avoidance Subscale</th>
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<tbody>
<tr>
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</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>.03</td>
<td>.20</td>
<td>.06</td>
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</table>

<table>
<thead>
<tr>
<th>Typical no. reliever inhaler uses per week</th>
<th>Safety Behaviour Scale</th>
<th>Exertion-avoidance Subscale</th>
<th>Exertion-curtailment Subscale</th>
<th>Environmental Trigger Avoidance Subscale</th>
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<tbody>
<tr>
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<td>r</td>
<td>.29</td>
<td>.35*</td>
<td>.14</td>
</tr>
<tr>
<td></td>
<td>Significance (two-tailed)</td>
<td>.07</td>
<td>.03</td>
<td>.39</td>
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</table>
### Recovery Interpretation and Safety Behaviour Scale

<table>
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<tr>
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<th>Recovery Interpretation Scale</th>
<th>Social Pressure Scale</th>
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<tbody>
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<td>Reported regularity (always-never) of using preventor inhaler every day</td>
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<td>.34*</td>
</tr>
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<td>Significance (two-tailed)</td>
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<td>.03</td>
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<tr>
<td>Perceived helpfulness of using preventor inhaler every day</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.19</td>
<td>.06</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.25</td>
<td>.74</td>
</tr>
<tr>
<td>n</td>
<td>39</td>
<td>40</td>
</tr>
<tr>
<td>Reported regularity (always-never) of using reliever inhaler when start of asthma attack is perceived</td>
<td></td>
<td></td>
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<tr>
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<tr>
<td>Significance (two-tailed)</td>
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<td>.50</td>
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<td>41</td>
</tr>
<tr>
<td>Perceived helpfulness of using reliever inhaler when start of asthma attack is perceived</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>-.28</td>
<td>-.17</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.09</td>
<td>.29</td>
</tr>
<tr>
<td>n</td>
<td>40</td>
<td>41</td>
</tr>
<tr>
<td>No. asthma-related visits to GP in previous six months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>-.10</td>
<td>.16</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.56</td>
<td>.33</td>
</tr>
<tr>
<td>n</td>
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</tr>
<tr>
<td>Typical no. reliever inhaler uses per week</td>
<td></td>
<td></td>
</tr>
<tr>
<td>r</td>
<td>.23</td>
<td>.35*</td>
</tr>
<tr>
<td>Significance (two-tailed)</td>
<td>.16</td>
<td>.03</td>
</tr>
<tr>
<td>n</td>
<td>40</td>
<td>41</td>
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</tbody>
</table>
### e) Exercise behaviour

<table>
<thead>
<tr>
<th>Reported regularity (always-never) of using preventor inhaler every day</th>
<th>Reported weekly exercise level</th>
<th>Reported variability in exercise level</th>
<th>&quot;Short burst&quot; indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>r</td>
<td>-.05</td>
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<table>
<thead>
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<th>Perceived helpfulness of using preventor inhaler every day</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>r</td>
<td>.10</td>
<td>.00</td>
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<th>Reported regularity (always-never) of using reliever inhaler when start of asthma attack is perceived</th>
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<tr>
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<th>Perceived helpfulness of using reliever inhaler when start of asthma attack is perceived</th>
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<th>No. asthma-related visits to GP in previous six months</th>
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<th>Typical no. reliever inhaler uses per week</th>
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* Correlation coefficient is significant to p≤.05 level.
** Correlation coefficient is significant to p≤.01 level.

Typical weekly reliever-inhaler usage was significantly positively associated with the Belief Scale, the Exertion-related and Environmental Trigger Belief Subscales, Exertion-Avoidance and Environmental Trigger Avoidance and the Social Pressure Scale. Regularity of reliever inhaler usage at the commencement of asthma attacks was significantly positively associated with the Belief Scale and Exertion-related and Environmental Trigger Belief Subscales. Meanwhile, regular preventor inhaler usage was significantly positively associated with the Belief Scale, Exertion-related Trigger Beliefs, the Recovery Interpretation and Social Pressure Scales. The perception of
either preventor or reliever inhalers as helpful was unrelated to the scales. A separate correlational analysis using Spearman's rho found no correlation between the perceived helpfulness and regularity of taking preventor and reliever medications.

The number of GP visits was significantly positively correlated with the Belief Scale \( (r=0.42, p<0.01) \) and the Safety Behaviour Scale \( (r=0.35, p=0.05) \), and was significantly negatively correlated with weekly exercise level \( (r=-0.36, p<0.05) \) – the more exercise participants did, the fewer asthma-related GP visits they made.

**Demographic effects**

Spearman's rho tests suggested that age was significantly negatively correlated with the Safety Behaviour Scale \( (r=-0.37; p<0.05) \), Environmental Trigger Avoidance \( (-0.33, p<0.05) \), the number of non-asthma symptoms interpreted as asthma \( (r=-0.32, p<0.05) \), and level of exercise \( (r=-0.36; p<0.05) \). This indicated that older adolescents did less exercise, were less likely to engage in safety behaviours or avoidance of environmental triggers, and interpreted fewer non-asthma symptoms as symptoms or warning signs of asthma attack. Age was significantly positively associated with week-to-week variation in exercise level \( (r=0.32; p<0.05) \). Age at diagnosis was negatively associated with the number of asthma symptoms interpreted as asthma \( (r=-0.37; p<0.05) \), suggesting participants diagnosed when they were older recognised fewer asthma symptoms. The number of years since diagnosis was not found to correlate with any of the measures.

Mann-Whitney U tests indicated a significant difference \( (U=117.5; n_1=19, n_2=22; p<0.05) \) between males' and females' scores on the Environmental Trigger Belief Subscale. Females' mean score was 7.95 (SD=1.40) while the males' was 6.47 (SD=2.12), suggesting that females were more likely to believe that environmental stimuli could trigger asthma attacks. No other significant differences were found between sexes by Mann Whitney U tests.

For statistical purposes, there were few cases in any condition other than “White British”, rendering a Kruskal Wallis test for differences between ethnic classifications on any of the scales or indicators unreliable. Kruskal Wallis tests revealed no
significant differences between the NS-SEC classifications on any of the scales or indicators, though it is again unlikely that this would have detected differences in groups represented by small sample sizes.

**Pilot data**

Responses to the pilot prompts were classified as "positive" or "negative". Forty of the 41 participants were asked the pilot prompts. Of these 40, 90% (36 participants) were broadly positive about the questionnaire. Some of the comments made by those who were positive included: "It asked about thoughts and feelings that you don't normally get asked about," and "It was quite interesting – and I thought the questions about exercise were quite important". The remaining 10% of responses (4 participants) were negative. One participant said he thought it was "Rubbish – it didn't ask the right questions". Another found the questionnaire "Confusing". Of the broadly-positive responses, 22% of participants (n=8) made suggestions for improving the questionnaire as did 50% (n=2) of those who made negative comments. Suggestions included to ask more about the emotional impact of asthma and how it feels to have an attack, to ask how many asthma attacks participants have, to ask less about teasing from friends, to make the questionnaire shorter, and to give space for putting a few opinions if wanted.
Discussion
The main objective of this study was to conduct an initial examination of the model speculating that beliefs portraying asthma and exertion as incompatible could underline:

- misinterpretation of symptoms of exertion and anxiety as asthma;
- the avoidance and premature curtailment of exercise as asthma-management strategies (safety behaviours);
- a pattern whereby the recovery from exertion caused by curtailment of exercise is interpreted as a recovery from asthma attributed to the efficacy of such safety behaviours.

Alongside this, the model speculated that social pressures to exercise might create conflict with intentions to avoid exercise – provoking oscillations in exertion level. It was necessary to develop a measure to test for beliefs and perceptions specific to this tentative model, and a secondary aim of the study was therefore to evaluate this approach.

The discussion will initially examine the study's findings: firstly in relation to the hypotheses and speculated cognitive processes; secondly with regard to the research questions, which relate to the prevalence of such processes; and thirdly, in respect of relationships between the constructs and health-related outcomes. The potential clinical and research implications of the findings will then be discussed. Finally, the methodology employed will be evaluated, with a view to how further research could build on this study's strengths and alleviate its limitations.

Research findings and relevance to current theory
Hypothesis I – that beliefs that asthma and exertion are incompatible would be positively associated with the number of symptoms interpreted as symptoms or warning signs of an asthma attack – was, at surface-level, supported. A significant positive correlation was found between the Belief Scale and the total number of symptoms interpreted as symptoms or warning signs of an asthma attack. However, more detailed exploration of the data was not consistent with the underlying model. Dividing the symptom checklist into asthma, non-asthma and ambiguous symptoms, it
was found that the Belief Scale was only positively correlated with the number of asthma symptoms interpreted as asthma. This contradicted the speculated model's assumption that misinterpretation of symptoms results from and serves to confirm the belief that asthma and exertion are incompatible. Instead, the ability to recognise asthma symptoms may be related to this belief. Furthermore, the recognition of asthma symptoms was positively correlated with both the belief that exertion triggers asthma attacks and the belief that environmental stimuli – such as dust, damp and mould – can act as triggers. This raises the possibility that such beliefs are formed in response to accurate perception. Agreement with the single item “Exercise is fine for people with asthma – as long as they don’t overdo it” was also significantly positively related with the recognition of asthma symptoms. This could suggest that adolescents who perceive a threshold for safe exertion do so on the basis of their ability to monitor for asthmatic reactions to exertion and environmental triggers. Such a pattern would complicate (but not necessarily contradict) the picture created by the findings of Panditi & Silverman (2003) that individuals were inconsistent in their accuracy of perceiving EIB (exercise-induced broncho-constriction), and the conclusions of C. Clark and Cochrane (1999) that deconditioning rather than EIB limits exertion in most cases.

Nevertheless, the fact that participants could complete the symptom-checklist is evidence of top-down, interpretative processes in symptom-perception, and could add to the inferred, experimental evidence of such processes by researchers including Rietveld & Prins (1998). Just as it has been argued that individuals may possess lexicons or mental dictionaries enabling them to identify words from sequences of acoustic information (e.g. Teasdale & Barnard, 1993), so they may carry mental “dictionaries of symptoms” which make sense of streams of somatic data. Such processes are central to the speculated model’s proposals regarding the role of pre-assumed meanings of symptoms in shaping symptom-perception.

Hypothesis 2 – that beliefs that asthma and exertion are incompatible would be positively associated with asthma-management strategies involving the avoidance or curtailment of exertion – was supported by a strong positive correlation found between the Belief Scale and the Safety Behaviour Scale. More detailed analysis
indicated that the both the Belief Scale and the subscale relating to the specific belief that exertion triggers asthma attacks were positively correlated with the Safety Behaviour Scale generally, and the Exertion-avoidance and Exertion-curtailment Subscales more specifically. In line with expectations, the Belief Scale and Exertion-related Trigger Belief Subscale were not correlated with the avoidance of environmental triggers. However, contrary to expectations, the belief that environmental stimuli could trigger asthma attacks was positively associated with avoidance of exertion but not environmental triggers. This is a puzzling finding. One possible explanation is that adolescents may find it easier to avoid exertion than triggers such as dust and traffic fumes, and so apply exertion-avoidance as a compensatory strategy. Nevertheless, these findings were broadly consistent with the speculated model, as well as with the suggestion of C. Clark & Cochrane (1999) that avoidance of exertion could result from “misconceptions” that exercise will be harmful.

The third hypothesis – that perceptions that safety behaviours were helpful would be positively correlated with beliefs that asthma and exertion are incompatible – was supported by the significant positive relationships found between the Recovery Interpretation Scale and both the Belief Scale and specific belief that exertion triggers asthma attacks. The conclusions that can be drawn from this will be discussed further in the critique.

Hypothesis 4 – that the number of symptoms interpreted as symptoms or warning signs of an asthma attack would be positively related to asthma-management strategies involving the curtailment and avoidance of exertion – was supported by highly significant positive relationships found between the Safety Behaviour Scale and all four Symptom-Perception indices. This finding would be more in line with the proposed panic-like processes (D. Clark, 1989, 1997) and the idea that misinterpretation of symptoms could promote the avoidance and curtailment of exercise. Exertion-curtailment was also positively correlated with the total number of asthma symptoms, and the number of non-asthma, ambiguous and asthma symptoms interpreted as symptoms or warning signs of asthma attack, while the avoidance of exertion was positively associated with the number of ambiguous and
asthma symptoms interpreted as asthma. The avoidance of environmental triggers was positively correlated with all four Symptom-Perception indices. This raises the question of whether interpreting a wide range of symptoms as asthma and consequently over-perceiving asthma (Yoos & McMullen, 1999) could be linked with a general tendency to perceive multiple asthma triggers, increasing lifestyle restriction.

The fifth hypothesis – that beliefs that asthma and exertion are incompatible would be negatively associated with the level of weekly exercise – was supported by the finding of a significant negative relationship between weekly exercise level and both the Belief Scale and the perception of exertion as an asthma trigger. The specificity of this relationship was supported by the absence of a significant correlation between weekly exercise level and the perception of environmental triggers. This is in line with both the tentative model and the arguments of C. Clark and Cochrane (1999) that beliefs that exercise is harmful could prevent some individuals with asthma from participating in exercise, regardless of the severity of their asthma. The agreement with both the individual items portraying a threshold of acceptable exertion (“Light exercise is OK for people my age who have asthma” and “Exercise is fine for people with asthma – as long as they don’t overdo it”) was associated with lower level of weekly exercise. This could suggest the idea of a safe threshold diminishes rather than enables engagement with exercise.

Hypothesis 6 predicted that perceptions of social pressure and negative performance-oriented self-concept would correlate positively with oscillations in weekly exercise level and with overall weekly exercise level. Social Pressure and agreement with the item “I tend to exercise in short, energetic bursts rather than keeping it up more regularly” were positively correlated – giving partial support to the hypothesis. However, Social Pressure was negatively associated with weekly exercise level – greater social pressure and negative performance-oriented self-concept was associated with lower weekly exercise level – contradicting the hypothesis. One explanation of this finding could be that not participating in exercise itself exacerbates the experience of pressure to do so – a case of asthma pressure
versus social pressure, perhaps. Enjoying exercise was positively correlated with weekly exercise, but not oscillation in exercise level.

These findings appear to offer initial support to several aspects of the model: that beliefs portraying asthma and exertion are incompatible are related to the avoidance and premature curtailment of exercise, which function as "safety behaviours", possibly confirming the beliefs via attributions of recovery. However, they suggest it could be over-simplistic to assume that such beliefs are necessarily promoted by misinterpretation of symptoms and consequent faulty perceptions of exercise-induced asthma: they may be based on genuine experiences of EIB.

The descriptive analysis of the research questions also suggested such processes influenced a substantial proportion of the participant sample. For example, 75% of participants viewed exercise as an asthma trigger, 41% agreed asthma and exercise "don't go together" and 35% saw exercise as unhelpful in the management of asthma – a substantial minority. Wanting to exercise but getting breathless and thinking one should stop was a problem conceded by 44% of participants. Feeling held back in sports due to asthma was reported by 63%. If these findings can be generalised to the wider population of adolescents who have asthma, they could represent a high degree of restriction and disability which, according to current health advice (e.g. NAC, 2000b) is unnecessary and could be overcome. These findings add to those of van Velden et al. (2001), that fitness levels of the majority their participants fell at or below the tenth percentile for same-age peers. They also echo the experiences described by adolescent participants in the Sugar (2002) study. It appears such perceived restrictions could represent a key area of lifestyle and quality of life impairment, as well as undermining overall physical health and fitness.

It also appears the constructs could be of relevance to other health-related behaviours. In particular, the belief that asthma and exertion are incompatible was significantly positively related to several health-related outcomes including adherence to prophylactic and reliever medication, and GP visits. It is possible that asthma severity mediates such relationships. This could be due to perceptions of health threat – consistent with self-regulation theory (H. Leventhal et al., 1998) – or could
reflect parental control and coping behaviours, from which adolescents may pick up the idea that they are vulnerable. Avoidance of exercise or perception of exercise as harmful could therefore represent sick-role behaviour (Taylor, 2003). The involvement of parents could explain the absence of a relationship between the perceived helpfulness of preventor and reliever medications and the regularity of taking them. As Clatworthy (2001) suggested, such responsibility for judging helpfulness and deciding whether to adhere may be delegated to parents.

Understandings of these findings will need to be tempered by an appreciation of the strengths and limitations of the research, which will be discussed later. The findings' potential clinical and research implications will first be considered.

**Clinical and research implications of the findings**

The clinical implications of these findings emerge partly from the support they have given to integrating literature from the areas of symptom perception, panic and deconditioning. They suggest the involvement of symptom-perception and belief processes may promote strategies of avoiding or curtailing exercise which would be anticipated to lead to negative consequences including reduced fitness (a key public health concern (Bennett, 2000)), increased asthma-related disability and reduced quality of life. Feelings of restriction or being unable participate may even create increased pressure to “join in” with peers, adding to the concerns raised by Schmidt et al. (2003) that this may increase the experience of peer-pressure to engage in other risk behaviours including substance misuse.

Psychological interventions for asthma have, until recently, been largely restricted to attempting to reduce stress which is seen as a contributor to asthma, or reducing the distress which is argued to result from it. Relaxation and cognitive-behavioural stress-management programmes have been applied, based on the assumption that these could mitigate against the effects of stress on the immune system and thereby alleviate airway hypersensitivity (Lehrer et al., 2002). Others have focused on asthma’s role as a possible stressor, attributing the high prevalence of anxiety and depression amongst adolescents with asthma to asthma’s distressing effects (Gillaspy, Hoff, Mullins, van Pelt & Chaney, 2002), and have consequently focused on
ameliorating such psychological distress. Another approach supported by this research would be to aim psychological interventions at reducing the disability and restriction associated with asthma. This would parallel developments in psychological interventions for chronic pain where individuals have been helped to cope more effectively with their day-to-day management of pain which cannot be fully remedied by medical means (e.g. Bennett, 2000).

This research was informed, in part, by the cognitive-behavioural panic model of D. Clark (1989, 1997) – a model which has promoted cognitive-behavioural interventions involving behavioural experiments aimed at alleviating anxiety by teaching individuals that panic symptoms are not harmful. Park et al. (1996) applied the cognitive-behavioural panic model to childhood asthma, focusing on cognitive restructuring – normalising hyperventilation and explaining to children how it could be misinterpreted as asthma – and teaching children to slow their breathing rate and use distraction techniques when anxious.

The application of such methods to reducing exercise-related avoidance would rest on the assumption that exercise symptoms are mistaken for asthma – an assumption that this research has suggested may not be valid. An emphasis on teasing out what is and what is not symptomatic of asthma might therefore be required if cognitive-behavioural therapies are to be applied in reducing such restriction. It may be helpful to explore biofeedback paradigms – for example, performing exercise challenges, estimating anxiety and airway obstruction level, then carrying out lung function tests to confirm or refute the estimates. These would be aimed at helping adolescents with asthma to learn more about their own symptoms of exertion, anxiety and asthma. The collaborative and Socratic emphasis of cognitive-behavioural therapies (Beck, 1995), might be especially valuable in such a process – with adolescent and clinician working together as “scientists”. Indeed, such a procedure may yield information helpful to further developing theoretical understanding of symptomatology. In self-regulatory terms (H. Leventhal et al., 1998), such a process could help facilitate more accurate appraisals of the identity and cause of symptoms. The outcome of this process could be to help diminish beliefs that asthma and exertion are incompatible, or to identify when appropriate coping strategies for
exercise-induced broncho-constriction, as outlined by van Velden et al. (2001), are needed.

The finding that the perceived helpfulness of safety behaviours involving the avoidance and curtailment of exertion was positively related to beliefs portraying asthma and exertion as incompatible suggests that effective alternative behavioural strategies may help to alleviate such restrictive control perceptions. Cognitive-behavioural therapies for conditions including chronic pain (e.g. Bennett, 2000) and chronic fatigue (Sharpe, 1997) have involved helping individuals to “pace” their level of exertion and gradually increase their level of activity and fitness – rather than suffer the effects of over-exertion associated with sudden increases in activity level following deconditioning. Such procedures are also aimed at alleviating concerns that exertion can have catastrophic consequences (Sharpe, 1997). Van Velden et al. (2001) found such graded increases in activity level appeared to negate the effects of exercise-induced broncho-constriction.

This research therefore highlights that psychological therapies may need to address perceptions of identity and cause on the one hand, and control perceptions and coping behaviours on the other – they would need to be both cognitive and behavioural. The development of the speculative model and the preliminary support for many of its hypotheses may also highlight the potential value of a dialogue between, and integration of theories from both clinical and health psychology. As an applied research discipline, health psychology has yielded insights into areas including health-promoting and risk behaviours, cognitive processes involved in coping with health problems, links between stress and health, and the organisation of health services including communication between clinicians and patients (Bennett, 2000). In the mean time, more clinical psychologists have begun to work in physical health settings, drawing upon their skills in understanding and facilitating processes of change, adjustment and coping (Bennett, 2000). It is possible many clinical psychologists may feel better-equipped to devise clinical interventions, including cognitive-behavioural interventions for physical health problems, from clinical psychological rather than health psychology models, because such models are designed to guide therapy. Increased dialogue between clinical and health psychology,
as well as developmental psychology, may therefore be a helpful direction in research aimed at delivering evidence-based psychological interventions for physical health problems such as asthma.

**Strengths and limitations of the research**

This research project was ambitious in speculating a model based on diverse areas of research and theory, and attempting an initial exploration of its hypotheses, which necessitated developing a measure suitable for the 11-16 year-old age-group. The measure developed yielded several scales and subscales with adequate internal reliability — including the Belief Scale, Safety Behaviour Scale and the Recovery Interpretation Scale. The relationships of some of these, most notably the Belief Scale, with health-related outcomes including GP visits and reliever inhaler usage may be indicative of relevance to health-related cognition and behaviour. On the other hand, it is important to recognise that the scales were formed on the basis of pre-determined constructs and through post-hoc reliability analysis, rather than through statistical means such as factor analysis. The findings’ support for the hypotheses therefore rests upon the scales’ assumed content validity in representing the hypothesised constructs.

Possible limitations to content validity were particularly apparent in respect to the Recovery Interpretation Scale, which was formed of items relating to the perceived helpfulness of asthma-management strategies involving avoidance and curtailment of exertion. This was intended to operationalise interpretations portraying the recovery from exertion as recovery from asthma attributable to such safety behaviours. However, the scale may only have tapped beliefs that such strategies were helpful in managing asthma generally: more direct items such as “I have avoided asthma attacks by stopping exercising when I got breathless” might provide a more content-valid examination of attributions that the strategies prevented asthma attacks specifically.

The Social Pressure Scale was intended to measure the degree to which individuals would be motivated to exercise by pressures to participate in energetic activities and by performance-related self-concepts giving rise to desires to “prove” oneself. But while “social pressure” might function as a neat shorthand, combining social and self-
concept influences may have underplayed the complexity of possible interactions between self-concept, social behaviour and more intrinsic motivators such as simply liking an activity. Some responses to the pilot prompts suggested that issues such as teasing were irrelevant. Then again, for the 15% of participants who experienced worries about this often, teasing could represent a very important issue. In future, factor analysis could be an important means of addressing reliability and validity issues by developing an empirically-supported factor structure to such questionnaire measures. However, this would require a far larger participant sample.

A key strength of the measure was that it was developed with the age-group in mind. Several participants commented that they liked the presentation of the questionnaire, and the majority of responses to pilot prompts gave positive feedback. The high response rate from participants approached in clinic was another strength. This increases the likelihood that the participant sample was representative of clinic-attending adolescents. However, the possibility of selection effects resulting from the unavoidable absence of responses of those who did not attend appointments may attenuate the representativeness of the sample to the wider population of adolescents who have asthma.

One of the most serious limitations to the study related to the measurement of symptom-perception. It was intended to produce a symptom checklist that could be divided into asthma, panic and exertion symptoms. Flaws in the expert-sampling procedure prevented this, because clinicians' interpretations were far less consistent with one another than expected. While this may be an interesting reflection on how difficult the distinction of asthma, exertion and panic symptoms must be, it meant that symptoms could not be assigned to categories, then checked for inter-rater reliability as planned. Instead, symptoms had to be coded according to expert responses by hand — making the reliability as well as the validity of the indices questionable. This also meant there was no measure relating to panic — a construct central to the speculated model. The symptom-checklist did not appear to cause participants any difficulties — suggesting it could be a useful approach to examining top-down processes in symptom-perception. But to enable analysis of accuracy of participants' interpretations, comparisons with expert opinions would need to be
more reliable. One way of furthering this could be to ask separate groups of clinicians with expert understanding of asthma, panic and exertion symptoms to identify the most likely combinations of symptoms for each condition, and regard any overlaps as ambiguous symptoms. In the light of the findings of Panditi & Silverman (2003) that perceptual accuracy of EIB was inconsistent over time, examining the test-retest reliability of the symptom checklist would also be important in improving this aspect of the measurement in future.

The questionnaire approach is founded on the utility of self-report in analysing the hypothesised constructs. This has strengths and weaknesses. A key principle guiding the study’s methodology was to take an adolescent-centred approach, exploring issues of relevance to young people who have asthma. Feedback from pilot responses suggested many participants felt the questionnaire was relevant to them and appreciated the opportunity to give their opinions on such issues. Self-report therefore enabled a view of the relevance of particular, hypothesised cognitions to participants. However, self-report has been regarded as error-prone as a measure of adherence and health-related behaviours (Lehrer et al., 2002). The lack of correlation found between the week-to-week variation in exercise level and reported short energetic bursts in activity could be indicative that oscillations in exertion level were poorly operationalised by these self-report measures, and behavioural records such as diaries may be a useful strategy in future research. Current validated approaches to measuring exercise behaviour include examining the frequency of planned exercise, and the number of times particular forms of exercise are engaged in during a week (Bennett, 2000). These would require a longer questionnaire format.

The recruited sample of 41 participants fell short of the participant sample of 64 indicated by the a priori power analysis. This would be expected to have increased the risk of a Type 2 error. Many significant correlations were nevertheless found because effect sizes were higher than anticipated, but it should be noted that this study had insufficient power to reliably detect smaller effects. Alongside this, the risk of Type I error has been increased by examining a large number of correlations, some on an unplanned, exploratory basis, without using a correction such as the Bonferroni adjustment. This compromise was deemed acceptable at this initial stage.
of examining such a tentative model. However, these limitations would be important to address in future research.

The research has succeeded in indicating the potential value of the speculative model and the hypotheses. However, it has also relied on a correlational approach to conducting initial examination of this model. While some large effect sizes were found, no conclusions can be drawn about the direction of relationships nor causality. Recruiting a large enough sample to conduct regression analyses may be a fruitful line of enquiry elucidating the predictive value of such relationships in future research, as would longitudinal study.

Conclusions
This research project has involved drawing together diverse areas of research and theory to provide a speculative account of apparent patterns of exertion-avoidance identified in other research studies of adolescents who have asthma (e.g. Sugar, 2002). The questionnaire approach has yielded some promising successes in enabling an initial examination of the tentative model and facilitating insights into adolescents' cognitions and coping strategies surrounding asthma and exercise. The results have not only suggested that beliefs portraying exertion and asthma as incompatible may be related to strategies involving the avoidance and curtailment of exertion, but that such beliefs may be held by a substantial proportion of adolescents. These findings could have potential clinical and public health implications, and inform the development of psychological therapies for adolescents who have asthma. However, the findings are currently limited by difficulties with some aspects of measurement – most notably with symptom-perception. Further research to refine the questionnaire and administer it to a larger sample allowing for factor analysis and regression analyses, could address these difficulties. Such research is merited by the potential relevance of the constructs to reducing asthma-related disability and improving quality of life for the one in seven adolescents (NAC, 2000a) who may have this condition.
References


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WHAT'S IT LIKE TO HAVE ASTHMA?

In this questionnaire, we want to find out:

➢ what it's like for you and people your age to have asthma
➢ your opinion about what is helpful and unhelpful for asthma
➢ what you do to try to manage and cope with your asthma
WHAT MAKES ASTHMA ATTACKS HAPPEN?

(A) People have different ideas about what sets off or triggers asthma attacks. We want to know what you think, and how much you agree or disagree with the statements below.

Please circle numbers in each table to show how much you agree or disagree with the comments...

(1) "If I am in a dusty place, it can give me an asthma attack"

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
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<td>5</td>
<td>4</td>
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"Running fast can make me have an asthma attack."

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<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
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<tbody>
<tr>
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</table>

"Being in a damp or mouldy place can give me an asthma attack."

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<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
(4) "If I get a cold, I am more likely to have an asthma attack."

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

(5) "Doing energetic activity can set off an asthma attack."

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
"Being around traffic fumes could give me an asthma attack."

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Please turn over to the next page
WHAT IS IT LIKE TO HAVE AN ASTHMA ATTACK?

Asthma attacks are different for different people. On the following pages, there is a list of symptoms, feelings and experiences that people sometimes have. We want to know which of them you have when you have an asthma attack, and which might make you think you were about to have an asthma attack. There are no right or wrong answers.

For each symptom in the list, please tell us whether you think it is part of an asthma attack or not, by putting a tick in the circle that goes best with your opinion.
| 1 | Heart beating really hard | • | • | • | • | • |
| 2 | Needing to breathe faster | • | • | • | • | • |
| 3 | Chest feeling tight | • | • | • | • | • |
| 4 | Muscles in my arms or legs feeling tired or aching | • | • | • | • | • |
| 5 | Feeling scared or worried | • | • | • | • | • |
| 6 | Feeling out of breath | • | • | • | • | • |
| 7 | Getting a stitch | • | • | • | • | • |
| 8 | Feeling like I can't get enough breath | • | • | • | • | • |

<table>
<thead>
<tr>
<th>Definitely an asthma attack</th>
<th>Warning sign of an asthma attack</th>
<th>Not an asthma attack</th>
<th>Not sure if asthma attack or not</th>
<th>Never happens to me</th>
</tr>
</thead>
<tbody>
<tr>
<td>Circle</td>
<td>Circle</td>
<td>Circle</td>
<td>Circle</td>
<td>Circle</td>
</tr>
<tr>
<td>Circle</td>
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<td>Circle</td>
<td>Circle</td>
<td>Circle</td>
<td>Circle</td>
<td>Circle</td>
</tr>
<tr>
<td></td>
<td>Definitely an asthma attack</td>
<td>Warning sign of an asthma attack</td>
<td>Not an asthma attack</td>
<td>Not sure if asthma attack or not</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------</td>
<td>----------------------------------</td>
<td>---------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>9</td>
<td>Feeling like something is pressing on my chest</td>
<td>●</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td>10</td>
<td>Needing to breathe deeper than normal</td>
<td>●</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td>11</td>
<td>Breathing hurting my throat</td>
<td>●</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td>12</td>
<td>Feeling like something is in the way when I breathe</td>
<td>●</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td>13</td>
<td>Sweating</td>
<td>●</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td>14</td>
<td>Getting short of breath</td>
<td>●</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td>15</td>
<td>Feeling like I can't breathe fast enough</td>
<td>●</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td>16</td>
<td>Feeling like I can't breathe deep enough</td>
<td>●</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td>17</td>
<td>Feeling sick</td>
<td>●</td>
<td>○</td>
<td>●</td>
</tr>
<tr>
<td></td>
<td>Definitely an asthma attack</td>
<td>Warning sign of an asthma attack</td>
<td>Not an asthma attack</td>
<td>Not sure if asthma attack or not</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------</td>
<td>---------------------------------</td>
<td>----------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>18</td>
<td>Feeling wheezy</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>19</td>
<td>Going dizzy or giddy</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>20</td>
<td>Thinking that something terrible is about to happen</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>21</td>
<td>Feeling shaky, wobbly or trembling</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>22</td>
<td>Coughing when I exercise</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>23</td>
<td>Thinking that I might collapse</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>24</td>
<td>Getting pins and needles in my hands and feet</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>25</td>
<td>Feeling like I am choking</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>26</td>
<td>Things don’t seem real</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
**WHAT HELPS WITH ASTHMA?**

Different people find different things help to make their asthma less of a problem for them. We want to know what you do to help manage your asthma and how helpful you find different strategies (ways of coping).

<table>
<thead>
<tr>
<th>Avoiding dusty places</th>
<th>Please circle a number below to show how often you do this to help with your asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Always</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>

Please circle a number below to show how helpful this is for managing asthma:

- **Very helpful** 5
- **A bit helpful** 4
- **Makes no difference** 3
- **A bit unhelpful** 2
- **Very unhelpful** 1
<table>
<thead>
<tr>
<th>Use preventor inhaler (brown, orange or purple) every day</th>
<th>How often do you do this to help with your asthma?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Always</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
<tr>
<td>How helpful is this for managing asthma?</td>
<td></td>
</tr>
<tr>
<td>Very helpful</td>
<td>5</td>
</tr>
<tr>
<td>A bit</td>
<td></td>
</tr>
<tr>
<td>Makes no difference</td>
<td></td>
</tr>
<tr>
<td>Unhelpful</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Exercise regularly</th>
<th>How often do you do this to help with your asthma?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Always</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
<tr>
<td>How helpful is this for managing asthma?</td>
<td></td>
</tr>
<tr>
<td>Very helpful</td>
<td>5</td>
</tr>
<tr>
<td>A bit</td>
<td></td>
</tr>
<tr>
<td>Makes no difference</td>
<td></td>
</tr>
<tr>
<td>Unhelpful</td>
<td></td>
</tr>
<tr>
<td>Use blue inhaler if I think an asthma attack is starting</td>
<td>How often do you do this to help with your asthma?</td>
</tr>
<tr>
<td>---------------------------------------------------------</td>
<td>-----------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>Always</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
<tr>
<td>How helpful is this for managing asthma?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very</td>
</tr>
<tr>
<td></td>
<td>helpful</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Try not to rush around and get myself out of breath</th>
<th>How often do you do this to help with your asthma?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Always</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
<tr>
<td>How helpful is this for managing asthma?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Very</td>
</tr>
<tr>
<td></td>
<td>helpful</td>
</tr>
<tr>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>
### Stop or slow down if I think an asthma attack might be coming on

<table>
<thead>
<tr>
<th>How often do you do this to help with your asthma?</th>
<th>Always</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How helpful is this for managing asthma?</th>
<th>Very helpful</th>
<th>A bit helpful</th>
<th>Makes no difference</th>
<th>A bit unhelpful</th>
<th>Very unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

### Leave smoky or dusty places if I think an asthma attack is coming on

<table>
<thead>
<tr>
<th>How often do you do this to help with your asthma?</th>
<th>Always</th>
<th>Usually</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How helpful is this for managing asthma?</th>
<th>Very helpful</th>
<th>A bit helpful</th>
<th>Makes no difference</th>
<th>A bit unhelpful</th>
<th>Very unhelpful</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Try not to exercise too hard or fast</td>
<td>How often do you do this to help with your asthma?</td>
<td>How helpful is this for managing asthma?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------------</td>
<td>-------------------------------------------------</td>
<td>----------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always 5</td>
<td>Very helpful 5</td>
<td>Makes no difference 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Usually 4</td>
<td>A bit helpful 4</td>
<td>Sometimes 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sometimes 3</td>
<td>Rarely 2</td>
<td>Makes no difference 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never 1</td>
<td>Very unhelpful 1</td>
<td>Makes no difference 3</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Avoid exercise if I think I might get an asthma attack</th>
<th>How often do you do this to help with your asthma?</th>
<th>How helpful is this for managing asthma?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always 5</td>
<td>Very helpful 5</td>
<td>Makes no difference 3</td>
</tr>
<tr>
<td>Usually 4</td>
<td>A bit helpful 4</td>
<td>Sometimes 3</td>
</tr>
<tr>
<td>Sometimes 3</td>
<td>Rarely 2</td>
<td>Makes no difference 3</td>
</tr>
<tr>
<td>Never 1</td>
<td>Very unhelpful 1</td>
<td>Makes no difference 3</td>
</tr>
<tr>
<td>Try to keep out of polluted or heavy-traffic places</td>
<td>How often do you do this to help with your asthma?</td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------</td>
<td>--------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Always</td>
<td>Usually</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How helpful is this for managing asthma?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very helpful</td>
</tr>
<tr>
<td>5</td>
</tr>
</tbody>
</table>

*Please turn over to the next page*
EXERCISE AND ASTHMA

In this part of the questionnaire we want to find out:

- How people your age who have asthma feel about exercise
- What you think about exercise when you have asthma
OPINIONS ABOUT EXERCISE AND ASTHMA

(A)
Below are some "quotes" or statements about exercise and asthma. Please tell us what you think by circling a number to show how much you agree or disagree with each statement.

(1) "Exercise and asthma don't go together."

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

(2) "Regular exercise can help make my asthma less of a problem."

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
(3) "Light exercise is OK for people my age who have asthma."

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

(4) "Exercise is fine for people with asthma – as long as they don't overdo it."

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
(5) "Asthma shouldn't stop people from exercising."

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

(6) "If a person has asthma and they start to get out of breath when they exercise, they should stop immediately."

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
"If someone has asthma and they get out of breath when they exercise, they shouldn't exercise that hard again."

<table>
<thead>
<tr>
<th>Agree a lot</th>
<th>Agree a bit</th>
<th>Neither agree nor disagree</th>
<th>Disagree a bit</th>
<th>Disagree a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Please turn over to the next page
LEVEL OF EXERCISE:

It would be really useful to know how much exercise you tend to do in an average week. One way of measuring how much exercise you do is to think about how many hours a week you would exercise to the point where you would be working up a sweat.

(1) How many hours of exercise a week do you do? Please circle:

Less than 2-3 hours 4-5 hours 6-8 hours More than 2 hours a week a week a week 8 hours a week
How much does the amount of exercise you do vary from week to week? Please circle:

I do the same amount of exercise each week  I do more or less the same amount of exercise each week  Occasionally, I have weeks when I do more or less exercise  I do a bit more or less exercise from week to week  I do much more or less exercise than others
THOUGHTS AND FEELINGS ABOUT EXERCISE

We would like to know about the thoughts, feelings and experiences you have surrounding exercise.

Please tell us about them by putting a circle around a number to show how often you have the thoughts, feelings and experiences described below.

<table>
<thead>
<tr>
<th>Very often</th>
<th>Quite often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

"I think I can not be as fit as people my age who don't have asthma."
"Having asthma stops me being as good as I want to be at sports activities."

<table>
<thead>
<tr>
<th>Very often</th>
<th>Quite often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

"I can be just as fit as my friends who don't have asthma"
<table>
<thead>
<tr>
<th>Very often</th>
<th>Quite often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

"I worry my friends will tease me or think badly of me if I can't keep up with them in sports or PE."

"If asthma stopped me exercising, I would expect my doctor to try to find some better medicine for me."
"Having asthma doesn't bother me."

"I would like to exercise more, but when I do I get breathless and think I should stop in case I get an asthma attack."

<table>
<thead>
<tr>
<th>Very often</th>
<th>Quite often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Very often</th>
<th>Quite often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
"I enjoy exercise."

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Very often</th>
<th>Quite often</th>
<th>Sometimes</th>
<th>Rarely</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>4</td>
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<td>2</td>
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</tr>
</tbody>
</table>

"I exercise because I want to prove I can even though I have asthma."
<table>
<thead>
<tr>
<th>Very often</th>
<th>Quite often</th>
<th>Sometimes</th>
<th>Rarely</th>
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<tr>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

"I tend to exercise in short, energetic bursts, rather than keeping it up more regularly."

Please turn over to the next page.
THANK YOU FOR ANSWERING ALL THOSE QUESTIONS!

Now it would be nice to know a little bit about you...

(1) Are you: Male    Female? (please circle)

(2) How old are you? ................... years-old

(3) How old were you when you (or the adult who looks after you) found out you had asthma? ................ years-old
(4) What medicines do you take for your asthma at the moment?

(5) In the last six months, about how many times did you have to go to your GP (family doctor) because of your asthma? ....................... times

(6) In the last six months, how many times have you had to go into hospital for extra care (been admitted) because of your asthma? ........... times

(7) About how many times a week do you have to use your reliever inhaler? ........ times

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE
## Appendix 2: Questionnaire items, their purposes or related constructs, and sources for content

<table>
<thead>
<tr>
<th>Item no. and content</th>
<th>Operationalised construct or purpose of item</th>
<th>Source of content</th>
</tr>
</thead>
<tbody>
<tr>
<td>IA1: &quot;If I am in a dusty place it can give me asthma.&quot;</td>
<td>Additional item (triggers)</td>
<td>NAC, 2000b; BLF, 2002a.</td>
</tr>
<tr>
<td>IA2: &quot;Running fast can make me have an asthma attack.&quot;</td>
<td>Beliefs portraying asthma and exertion as incompatible (trigger)</td>
<td>NAC, 2000b; BLF, 2002a.</td>
</tr>
<tr>
<td>IA3: &quot;Being in a damp or mouldy place can give me an asthma attack.&quot;</td>
<td>Additional item (triggers) — used for detailed analysis of relationships between constructs</td>
<td>NAC, 2000b; BLF, 2002a.</td>
</tr>
<tr>
<td>IA4: &quot;If I get a cold I am more likely to have an asthma attack.&quot;</td>
<td>Additional item (triggers)</td>
<td>NAC, 2000b; BLF, 2002a.</td>
</tr>
<tr>
<td>IA5: &quot;Doing energetic activity can set off an asthma attack.&quot;</td>
<td>Belief portraying asthma and exertion as incompatible (trigger)</td>
<td>NAC, 2000b; BLF, 2002a.</td>
</tr>
<tr>
<td>IA6: &quot;Being around traffic fumes could give me an asthma attack.&quot;</td>
<td>Additional item (triggers) — used for detailed analysis of relationships between constructs</td>
<td>NAC, 2000b; BLF, 2002a.</td>
</tr>
<tr>
<td>IB: Symptom perception</td>
<td>See Appendix 3</td>
<td>Asthma symptoms described by NAC, 2000a; BLF, 2002a. Panic and exertion symptoms described by D. Clark (1989, 1997) Expert sampling to provide initial content validation</td>
</tr>
<tr>
<td>IC1a: Avoiding dusty places (how often do you do this to help with your asthma?)</td>
<td>Additional item (strategy) — used for detailed analysis of relationships between constructs</td>
<td>NAC, 2000a; BLF, 2002a.</td>
</tr>
<tr>
<td>IC1b: Avoiding dusty places (how helpful is this for managing asthma?)</td>
<td>Additional item (strategy)</td>
<td>NAC, 2000a; BLF, 2002a.</td>
</tr>
<tr>
<td>IC2a: Use preventor inhaler (how often do you...?)</td>
<td>Additional item (strategy) and health outcome</td>
<td>NAC, 2000a; BLF, 2002a.</td>
</tr>
<tr>
<td>IC2b: Use preventor inhaler (how helpful...?)</td>
<td>Additional item (strategy) and health outcome</td>
<td>NAC, 2000a; BLF, 2002a.</td>
</tr>
<tr>
<td>IC3a: Exercise regularly (how often do you...?)</td>
<td>(Reverse scored) Safety behaviours (avoidance of exertion)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IC3b: Exercise regularly (how helpful...?)</td>
<td>(Reverse scored) Beliefs portraying asthma and exertion as incompatible (exertion as harmful to the management of asthma)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>Item no. and content</td>
<td>Operationalised construct or purpose of item</td>
<td>Source of content</td>
</tr>
<tr>
<td>----------------------</td>
<td>---------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>IC4a: Use blue inhaler (how often do you...)</td>
<td>Additional item (strategy) and health outcome</td>
<td>NAC, 2000a; BLF, 2002a.</td>
</tr>
<tr>
<td>IC4b: Use blue inhaler (how helpful...?)</td>
<td>Additional item (strategy) and health outcome</td>
<td>NAC, 2000a; BLF, 2002a.</td>
</tr>
<tr>
<td>IC5a: Try not to rush around and get myself out of breath (how often do you...?)</td>
<td>Safety behaviours: Avoidance of exertion</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IC5b: Try not to rush around and get myself out of breath (how helpful...?)</td>
<td>Interpretations of recovery – perceiving safety behaviour as helpful</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IC6a: Stop or slow down if I think an asthma attack might be coming on (how often do you...)</td>
<td>Safety behaviours: Curtailment of exertion</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IC6b: Stop or slow down if I think an asthma attack might be coming on (how helpful...?)</td>
<td>Interpretations of recovery – perceiving safety behaviours as helpful</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IC7a: Leave smoky or dusty places if I think an asthma attack is coming on (how often do you...)</td>
<td>Additional item (strategy) – used for detailed analysis of relationships between constructs</td>
<td>NAC, 2000a; BLF, 2002a.</td>
</tr>
<tr>
<td>IC7b: Leave smoky or dusty places if I think an asthma attack is coming on (how helpful...?)</td>
<td>Additional item (strategy) – used for detailed analysis of relationships between constructs</td>
<td>NAC, 2000a; BLF, 2002a.</td>
</tr>
<tr>
<td>IC8a: Try not to exercise to hard or fast (how often do you...)</td>
<td>Safety behaviours: Avoidance of exertion</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IC8b: Try not to exercise to hard or fast (how helpful...?)</td>
<td>Interpretations of recovery – perceiving safety behaviours as helpful</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IC9a: Try to keep out of heavy traffic places (how often do you...)</td>
<td>Additional item (strategy) – used for detailed analysis of relationships between constructs</td>
<td>NAC, 2000a; BLF, 2002a.</td>
</tr>
<tr>
<td>IC9b: Try to keep out of heavy traffic places (how helpful...?)</td>
<td>Additional item (strategy) – used for detailed analysis of relationships between constructs</td>
<td>NAC, 2000a; BLF, 2002a.</td>
</tr>
<tr>
<td>IIA1: “Exercise and asthma don’t go together.”</td>
<td>Beliefs portraying asthma and exertion as incompatible (exertion as harmful to the management of asthma)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIA2: “Regular exercise can help make my asthma less of a problem.”</td>
<td>(Reverse scored) Beliefs portraying asthma and exertion as incompatible (exertion as harmful to the management of asthma)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIA3: “Light exercise is OK for people my age who have asthma.”</td>
<td>Beliefs portraying asthma and exertion as incompatible (asthma as a barrier/limit to exercise)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>Item no. and content</td>
<td>Operationalised construct or purpose of item</td>
<td>Source of content</td>
</tr>
<tr>
<td>----------------------</td>
<td>---------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>IIA4: “Exercise is fine for people with asthma – so long as they don’t overdo it.”</td>
<td>Beliefs portraying asthma and exertion as incompatible (asthma as a barrier/limit to exercise)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIA5: “Asthma shouldn’t stop people from exercising.”</td>
<td>(Reverse scored) Beliefs portraying asthma and exertion as incompatible (asthma as a barrier/limit to exercise)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIA6: “If a person has asthma and they start to get out of breath when they exercise, they should stop immediately.”</td>
<td>Safety behaviour (curtailment of exertion)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIA7: “If someone has asthma and they get out of breath when they exercise, they shouldn’t exercise that hard again.”</td>
<td>Safety behaviour (avoidance of exertion)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIB1: How many hours of exercise a week do you do?</td>
<td>Level of exercise</td>
<td></td>
</tr>
<tr>
<td>IIB2: How much does the amount of exercise you do vary from week to week?</td>
<td>Variability in exertion – oscillation</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIC1: “I think I can not be as fit as people my age who don’t have asthma.”</td>
<td>Social pressure (to keep up with peers)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIC2: “Having asthma stops me being as good as I want to be at sports activities.”</td>
<td>Social pressure (self concept/frustration)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIC3: “I can be just as fit as my friends who don’t have asthma”</td>
<td>(Reverse scored) Social pressure (to keep up with peers)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIC4: “If asthma stopped me exercising, I would expect my doctor to try to find some better medicine for me.”</td>
<td>(Reverse scored) Beliefs portraying asthma and exertion as incompatible (asthma as barrier/limitation to exercise)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIC5: “I worry my friends will tease me or think badly of me if I can’t keep up with them in sports or PE”.</td>
<td>Social pressure (to keep up with peers)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIC6: “Having asthma doesn’t bother me.”</td>
<td>(Reverse scored) Social pressure (Concept of self with asthma – frustration with asthma)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIC7: “I would like to exercise more but when I do I get breathless and think I should stop in case I get an asthma attack.”</td>
<td>Safety behaviours (curtailment of exertion)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>Item no. and content</td>
<td>Operationalised construct or purpose of item</td>
<td>Source of content</td>
</tr>
<tr>
<td>----------------------</td>
<td>---------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>IIC8: “I enjoy exercise.”</td>
<td>Social pressure (Concept of self with asthma – performance-related self-concept and intrinsic motivation)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIC9: “I exercise because I want to prove I can even though I have asthma.”</td>
<td>Social pressure (Concept of self with asthma – performance related self-concept and intrinsic motivation)</td>
<td>Construct-driven content</td>
</tr>
<tr>
<td>IIC10: “I tend to exercise in short, energetic bursts, rather than keeping it up more regularly.”</td>
<td>Variability in exertion – oscillation.</td>
<td>Construct-driven content</td>
</tr>
</tbody>
</table>
Appendix 3: Expert sampling questionnaire

Dear Expert,

You are being invited to help examine the validity of a new measure designed to assess the interpretations of particular symptoms made by adolescents who have asthma. The measure forms part of a questionnaire, which is currently being piloted, that aims to examine whether adolescents perceive symptoms of exertion or panic as symptoms of asthma – perhaps exacerbating any level of disability. The research is being conducted by a multi-disciplinary group based at the Centre for Health Care Research at the University of Brighton.

It is hoped that the responses of participants aged 11-16 can be compared with the opinions of experts in the field, including paediatricians, respiratory nurses, and health and clinical psychologists with interests in asthma or paediatric care. Please would you consider participating in the expert-sampling procedures for this research, by completing the symptom checklist below? For each symptom on the checklist, you will be asked if you would regard this as likely, possible or unlikely to be symptomatic of asthma, exertion or panic respectively. You may regard some symptoms as indicative of all or none of the conditions, and your responses may reflect this.

The checklist should take around five minutes to complete. It can then be submitted by real-mail by printing it out and sending it to the postal address below. Alternatively, it can be submitted electronically by typing a letter in each box and e-mailing the table as an attachment (you will need to re-save this document and attach it to your e-mail reply in order to do so).

This is not a compulsory survey, but your help would be very much appreciated in supporting this research. Many thanks for considering whether or not you would like to take part. It would be very much appreciated if you could return your questionnaire by Monday 14 June 2004.

Yours faithfully, (name, address)
Please complete the checklist by writing or typing a letter L, P or U in each box to indicate whether you think the experience described is likely, possible or unlikely to be symptomatic of asthma, exertion or panic respectively. If you are completing this form electronically, please remember to re-save the document onto the computer you are using before you start, to avoid losing any data.

<table>
<thead>
<tr>
<th></th>
<th>Is this a symptom of asthma?</th>
<th>Is this a symptom of exertion?</th>
<th>Is this a symptom of panic?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>L=likely</td>
<td>L=likely</td>
<td>L=likely</td>
</tr>
<tr>
<td></td>
<td>P=possible</td>
<td>P=possible</td>
<td>P=possible</td>
</tr>
<tr>
<td></td>
<td>U=unlikely</td>
<td>U=unlikely</td>
<td>U=unlikely</td>
</tr>
</tbody>
</table>

1 "Heart beating really hard"

2 "Needing to breathe faster"

3 "Chest feeling tight"

4 "Muscles in my arms or legs feeling tired or aching"

5 "Feeling scared or worried"

6 "Feeling out of breath"

7 "Getting a stitch"

8 "Feeling like I can’t get enough breath"

9 "Feeling like something is pressing on my chest"

10 "Needing to breathe deeper than normal"

11 "Breathing hurting my throat"

12 "Feeling like something is in the way when I breathe"

13 "Sweating"

14 "Getting short of breath"

15 "Feeling like I can’t breathe fast enough"

16 "Feeling like I can’t breathe deep enough"

17 "Feeling sick"

18 "Feeling wheezy"
<table>
<thead>
<tr>
<th></th>
<th>Is this a symptom of asthma?</th>
<th>Is this a symptom of exertion?</th>
<th>Is this a symptom of panic?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>L=likely</td>
<td>L=likely</td>
<td>L=likely</td>
</tr>
<tr>
<td></td>
<td>P=possible</td>
<td>P=possible</td>
<td>P=possible</td>
</tr>
<tr>
<td></td>
<td>U=unlikely</td>
<td>U=unlikely</td>
<td>U=unlikely</td>
</tr>
<tr>
<td>19</td>
<td>&quot;Going dizzy or giddy&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>&quot;Thinking that something terrible is about to happen&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>&quot;Feeling shaky, wobbly or trembling&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>&quot;Coughing when I exercise&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>&quot;Thinking that I might collapse&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>&quot;Getting pins and needles in my hands and feet&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>&quot;Feeling like I am choking&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>&quot;Things don’t seem real&quot;</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please describe your profession (e.g. paediatric registrar, child clinical psychologist):

Do you have special expertise or professional interest in asthma or paediatrics? If so, please describe below (e.g. nurse with research interest in child health):

MANY THANKS FOR HELPING WITH THIS RESEARCH
APPLICATION FORM FOR ETHICAL APPROVAL OF PROPOSED

STUDENT RESEARCH

or

Local Research Ethics Committees

Full Title of Study

Social Pressure versus Asthma Pressure — The example of exertion as a context for conflict amongst adolescents with asthma

(On survey materials, the study is entitled “Questionnaire Survey of Young People who have Asthma” in order to avoid bias to responses.)

SECTION I - The Investigator

1 Please provide the following details of the Investigator

Name, Title and Professional Qualification(s)

Ms Hazel Fell-Rayner, Trainee Clinical Psychologist, BA (Hons) Psychology

University and Course being undertaken

University of Surrey, PsychD Clinical Psychology

Address for correspondence

Clinical Psychology Office, Department of Psychology, University of Surrey, Guildford, GU2 7XH

Tel No: E-mail:

Place of employment and position

University of Surrey/Surrey Oaklands NHS Trust, Trainee Clinical Psychologist

SECTION II - Supervisor

2 Please provide in the space below the name and address of the person supervising this piece of research

Dr Victoria Senior, Lecturer, Department of Psychology, University of Surrey, Guildford, Surrey, GU2 7XH

Tel No: 01483 300800

(Research studies must be accompanied by a letter from your supervisor confirming that you are undertaking this study as part of your course and with your supervisor's approval. This letter should also include a comment from your supervisor to confirm that they have read your application and that you have actioned any suggestions or amendments that they have made.)
SECTION III - The Research

3 Please state the hypothesis to be tested by the proposed research.

A series of hypotheses outlined in the study protocol propose that some adolescents with asthma misinterpret normal symptoms of exertion or panic symptoms as signs of asthma attack and consequently avoid exertion including exercise. It is proposed that conflict arises between social pressure to perform (for instance in sports or PE) and a belief that asthma and exertion are incompatible, producing oscillations in activity and exertion level similar to those thought to maintain symptoms of chronic fatigue.

4 Please state the design of the research and the methodology to be adopted. In the case of studies involving questionnaires, psychological tests or interviews, please indicate how the data from these will be analysed and evaluated.

The design is cross-sectional – participants will complete a questionnaire at one time-point – and utilises a researcher-administered questionnaire. Inferential statistical tests (e.g. Spearman's rho, Pearson's product moment correlation) will be used to examine correlations between construct-relevant items. For instance, endorsement of typical exertion-symptoms as signs of an asthma attack will be examined for correlation with endorsement of avoidance of exercise as an asthma-management strategy.

5 Please state the local site(s) at which the research will be conducted and the facilities that will be used.

Consultant Paediatrician Dr. is part of the research group (based at ) and research will be conducted at his clinics in the NHS Trust (at the Hospital). The survey may, at a later date, be extended to other sites within the Trust and sites outside this Trust.

6 Please state the start date and the expected duration of the proposed research project and the number, age and sex of participants it is hoped to recruit.

Start and Completion Dates: November 2003 - June 2004

Number/Age/Sex To Be Recruited: A total sample of 64 participants is required based on a power calculation with anticipated medium effect size (r=0.3; α<0.05; power=80%). Males and females aged 12-18 years will be recruited.

7 Please indicate the value of and need for the research. If this project, or a similar one, has been carried out previously, state justification for its repetition.

The research explores hypotheses relating to a cognitive-behavioural model of exertion avoidance in asthma. Study findings would enable evaluation and development of the model, which has important therapeutic implications. Were the model to be supported, existing cognitive-behavioural treatments for panic and chronic fatigue would be indicated as being of potential value in helping adolescents who have asthma and who may avoid exertion and exercise. The study is therefore of value and importance to developing interventions which limit the distress and disability associated with asthma.

8 Please confirm that participants will be informed of any possible pain, discomfort, distress or inconvenience or any particular requirements or abstentions (eg multiple visits, dietary restrictions) prior to their consent being obtained.

Information sheets will highlight to participants and their parents that the questionnaire asks about experiences of asthma attacks, which may therefore relate to distressing experiences. Information sheets will be presented to potential-participants and their parents at least one week prior to consent being sought or obtained.
9 Please specify the risk(s) if any to the physical or mental health of the participant, indicating their probability and seriousness and, if appropriate, what measures have been taken to minimise them.

Questionnaire items relate to different thoughts and ideas about asthma symptoms, causes and management. Therefore, there is some slight risk that such items may be misinterpreted as fact and cause confusion, and thereby influence adolescents' management of their asthma. To minimise this risk, the questionnaire highlights that the items relate to the different sorts of opinions that people may have. The questionnaire will be researcher-administered providing scope for the researcher to explain any apparent cause of confusion or to recommend participants consult an appropriate health-care professional should this be necessary to clarify concerns.

10 What particular ethical problems or considerations do you consider to be important or difficult with the proposed study?

Due to the need to avoid biasing participant responses to questionnaire items, it is not possible to be explicit about the hypotheses being investigated and the focus upon beliefs surrounding exertion and asthma. However, this focus becomes more transparent in the latter part of the questionnaire where it is stated that the researchers are seeking participant's views about exercise.

11 In the case of research on patients, describe the alternative/standard treatments (if any) that are normally available. Where a participant has been receiving (or would receive) treatment prior to enrolment in the research, state whether the treatment will be suspended or withheld during the period of the research. If some patients who normally receive active treatment will be on a placebo during the study trial, please give an explanation to justify this.

This study does not involve any trial of any intervention. Therefore, standard medical treatment of asthma will not be suspended or withheld as a result of the study.

12 What precautions have been taken to safeguard the confidentiality of the information collected. (For example, will data stored in computers be registered under the Data Protection Act?)

Any information stored on computer will be anonymous and password-protected to safeguard the confidentiality of the information.

SECTION IV - The Participants

13 Please indicate, by ticking the appropriate box, whether the participants of the research are

Healthy volunteers (including all NHS staff) □  Patients □

14 Please describe the kind of participants to be recruited (inclusion criteria) and how they will be recruited. (If by letter of invitation or advertisement, please confirm that a copy of one of these is enclosed.)

Participants will be 12-18 year-old patients of a paediatric asthma clinic. Letters of invitation to participate in the study will be sent to parents of potential-participants under 16, and to potential-participants over 16, alongside information sheets, at least one week prior to consent being sought or obtained. These letters of invitation and information sheets are enclosed with the application. Potential-participants and (if participants are under 16) their parents will be approached at the Clinic, and invited to participate. Participants must have a medical diagnosis of asthma to be recruited.
15 Please state any exclusion criteria.

There are no formal exclusion criteria. However, as the participants will be known to Dr., they may be excluded from the study at his discretion (for instance, if there is concern that participation may cause undue distress).

16 Please indicate the manner by which the participant's consent to participation will be obtained. If the research involves: children, the elderly, the mentally impaired, the unconscious, please indicate what, if any, special arrangements will be made regarding consent or regarding the taking of action without consent.

The research involves adolescents, many of whom will be legal minors. Where participants are under 16, both the participant and his/her parent/guardian will be provided with an information sheet. Written consent will be sought from the parent/guardian through use of a consent form which will also be signed by the child. Participants over 16 will be issued with information sheets and will be asked to sign a consent form if they wish to participate. Different Information Sheets will be given for parents, under-16 participants and over-16 participants, reflecting attempts to ensure the information given is developmentally-appropriate. Copies of these are enclosed with the application.

17 Please confirm, by ticking the box, that a Participant Information Sheet (including if appropriate a Parent/Guardian Information Sheet, Child Information Sheet or Carer Information Sheet) is enclosed with this application.


18 Please confirm, by ticking the box, that a Participant Consent Form (including, if appropriate, a Child Consent Form) is enclosed with this application.


19 As you are not the participant's GP or hospital consultant, will arrangements be made to inform the GP or hospital consultant and, if appropriate, obtain his/her consent?

As the research will be taking place in asthma clinics led by Consultant Paediatrician Dr. Paul Seddon, who will be providing a list of potential participants to approach, his consent as a hospital consultant will be obtained.

......

DECLARATION (to be signed by the Investigator)

The information I have given in this form is to the best of my knowledge accurate and complete.
I understand that I may be invited to explain my study to the Committee.
I understand that I will have to inform the Committee of any proposed amendments or modifications to my research.
I understand that I must inform the Committee of any adverse events to participants involved in the research.
I understand that I should submit a brief report to the Committee on the outcome of the research.
I understand that the Committee gives ethical approval only and that I must also obtain approval from my department head/employing authority/supervisor.

Signed: [Signature]

Date: 2 September 2003

338
Social Pressure versus Asthma Pressure —
The example of exertion as a context for conflict amongst adolescents with asthma

Background:
How people manage chronic conditions such as asthma is regarded as of crucial importance to health outcomes. Amongst adults, research and theory (e.g. Leventhal's self-regulatory theory) has tended to focus on the processes that determine treatment adherence behaviour. Many clinicians have particular concerns about medical adherence amongst adolescents, suspecting low adherence to medical regimens underlies relatively high mortality rates amongst people in this age group who have asthma.

However, research attempting to examine adolescent adherence to asthma treatment regimens has not been particularly fruitful in developing understanding of such processes in this age group. Clatworthy (2002) noted problems in encouraging young people to discuss adherence or concerns about medication in research interviews. Consultancy firm Sugar, in discussion and storyboarding workshops commissioned by the National Asthma Council, also found that medical adherence was of relatively low salience to teenagers with asthma. Instead, the adolescents expressed more concern surrounding how to manage their asthma in the context of social situations and relationships. When the participants were asked to story-board “A Day in the Life of someone their age who had asthma, a picture emerged of a conflict between the demands of managing asthma against social demands (such as keeping up with peers in PE lessons or remembering to take inhalers when rushing around).

Attempting to understand more about the conflict adolescents may experience between “asthma pressure” and “social pressure” may therefore provide a way forward in developing more developmentally-appropriate, adolescent-centred theories and interventions surrounding asthma management. Indeed, such emphasis would fit with developmental theory suggesting that increases in social awareness dominate the psychological development taking place during adolescence.

The conflict adolescents have described between wanting to participate in sports and exercise versus the belief that this is unhelpful for their asthma seems an interesting example of the tension between asthma-pressure and social-pressure. Many clinicians would regard problems with exercising due to asthma symptoms as a sign that the asthma is being insufficiently treated, and instead view moderate exercise as an important part of a healthy lifestyle.

This study proposes that, among some adolescents, there may be a belief that asthma and exertion (including exercise) are incompatible (for instance, that exertion causes asthma attacks). Such belief may be involved in the catastrophic misinterpretation of normal symptoms of exertion (such as increased heart rate and breathing) as signs of an asthma attack, causing panic (e.g. Clark, 1997), which itself may mimic and be misinterpreted as an asthma attack. Indeed, some research findings note a higher rate of panic disorder amongst people with asthma than in the
"normal" population. It is proposed that adolescents experiencing such panic will respond by curtailing their exertion – their recovery from exertion symptoms (heart-rate and breathing slowing back down) being interpreted as a recovery from the asthma attack and thus confirming the idea that the exertion caused the "asthma attack". In the long-term, avoidance of exertion would be expected to reduce fitness, and any sudden increase in exertion level (for instance brought about by frustration, social pressure to perform, or self-inadequacy perceptions) would be expected to lead to greater symptoms of exertion associated with exertion beyond fitness level. Such de-conditioning and catastrophic misinterpretation of exertion symptoms is regarded as central to many cases of chronic-fatigue (Sharpe, 1997) – a condition which also shows some co-morbidity with asthma – and also to chronic pain. In the long-term, such processes would be expected to heighten the disability associated with asthma and may also blur perceptions of the treatment-efficacy. Were such processes found to be relevant to some cases of asthma in adolescence, then it is possible that existing cognitive-behavioural interventions for panic and chronic-fatigue could be readily adapted to help alleviate such disability.

Aims and hypotheses:
The aim of this study is to seek preliminary evidence relating to the hypothetical model outlined above. The alternate hypotheses are:

- Beliefs that exertion and asthma are incompatible will correlate positively with the number of symptoms interpreted as symptoms or warning signs of asthma attack, and asthma-management strategies involving the avoidance or curtailment of exertion.
- Beliefs that asthma and exertion are incompatible will correlate negatively with weekly exercise level.
- Negative performance-oriented self-beliefs or anticipated social evaluations (e.g. "I worry that my friends will tease me or think badly of me if I can't keep up with them in sports or PE") will correlate positively with reported oscillations in exertion levels.

Method:

Participants: A total sample of 64 participants is required based on a power calculation with anticipated medium effect size (r=0.3, α<.05, power=80%). 64 young people aged between 12-18 will be recruited from a child asthma clinic led by Consultant Paediatrician Dr , based at the Hospital in . Participants must have a medical diagnosis of asthma to be included in the study. There will be no formal exclusion criteria. However, as the participants will be known to Dr , they may be excluded from the study at his discretion (for instance, if there is concern that participating in the study may cause undue distress).

Design: The design is cross-sectional – participants complete a questionnaire at one time-point.

Measures: A questionnaire will be used. Since this study addresses constructs and hypotheses that have not been previously investigated, it has been necessary to develop new measures. An attempt has been made to make these measures developmentally-appropriate. Five-point Likert-type scales measure level of endorsement of beliefs surrounding triggers to asthma attacks (six items, two related
to hypotheses), asthma management-strategies (ten items, five relate to hypotheses), general beliefs regarding exercise and asthma (seven items), and performance-oriented beliefs, motivations and expectations of self (ten items). Five-point Likert-type scales are also used to measure weekly exercise level and amount of variation (oscillation) in exercise level. A 26-item symptom checklist measures interpretation of potential asthma-, exertion- or panic-related symptoms. The use of Likert-type scales to assess beliefs is an established technique adopted in many clinical standardised assessment instruments such as the Beck Youth Inventory.

The questionnaire also contains items requesting demographic information (age, sex, age at diagnosis). An appropriate measure of socio-economic status is being sought, and a parental questionnaire is likely to be used to request such data. The ethnicity of participants will be recorded in accordance with the codes used in the 2001 Census and guidelines issued by the Commission for Racial Equality. It is likely this measure will also be included in a parental questionnaire (i.e. parents will be asked to record their child’s ethnicity) due to the complexity of these codes for younger adolescents.

Procedure: Letters and information sheets will be sent out to parents of young people attending the Clinic at least one week prior to the survey commencing. Parents and young people will be approached individually (i.e. as parent-child dyads) by a researcher and invited to participate in the study. Information sheets will be issued to both parents and young people, and the researcher will invite parents and young people to ask any questions they may have. Parents and young people who are happy to participate will be asked to sign a consent form, which will be kept separately from questionnaires to maintain anonymity. Participants will then be issued with a questionnaire booklet, and asked to work through the questions in order. The researcher will provide explanation as required. When participants reach the section of the questionnaire relating to demographic information, parents will be asked to complete a questionnaire providing socio-economic and ethnicity data. Once the questionnaires are completed, parents and participants will be thanked and given the opportunity to withdraw their data from the study.

Questionnaire data will be entered into a computer file in anonymous format and these data will be kept password-protected. Data will be analysed using inferential correlational tests such as Spearman’s rho or Pearson’s product moment.

Hazel Fell Rayner
Trainee Clinical Psychologist
University of Surrey

2 September 2003
05 September 2003

Ms Hazel Fell-Rayner
Trainee Clinical Psychologist
Clinical Psychology Office
Department of Psychology
University of Surrey
Guildford
GU2 7XH

Dear Hazel

Study title: Social Pressure versus Asthma Pressure – The example of exertion as a context for conflict amongst adolescents with asthma

Thank you for your submission of the above mentioned study to the Local Research Ethics Committee.

The Committee will be meeting on 25 September 2003 and I shall write to you after that date with their decision.

You are invited to be available during this meeting while your application is reviewed to enable the Committee to clarify any specific issues raised by members about your research. You should note that if you do make yourself available to be present at the meeting the Committee might not call you in. If you would like to take up this offer please telephone me as soon as possible and I will then be able to give you more details.

Please quote reference (B) 03/38 on any correspondence connected with this submission.

NHS Trust now operates a research & development approvals process. If you are an employee of the Trust, or wish to undertake research using either Trust patients or facilities you will need to apply for trust approval before the project can commence. In order to do this you will need to complete and sign a Trust approval project record. To obtain a copy, please contact R&D Manager on or email .

If you have any queries please do not hesitate to contact me.

Yours sincerely

Research Ethics Committee Administrator

Switchboard: General Fax: Chair: Chief Executive.
Dear Hazel

Re: Social Pressure versus Asthma Pressure – The Example of Exertion as a Context for Conflict Amongst Adolescents with Asthma

The above study was reviewed by the Local Research Ethics Committee, under their Chairman Dr , at the meeting on Thursday 25 September 2003.

Dr declared a small interest in this study.

The members felt that this was a well-presented application.

The following comments were made about the questionnaires for the study:

1. It was felt that the layout should be looked at again; it seems rather cluttered at present. It is not necessary to give the instruction “please circle a number below to show how much you agree or disagree” after every question, just once in each section would be sufficient.

2. Thought should be given to a most appropriate way to identifying the question – it was felt that at present with the speech/thought bubble’s it was pointing the participant to circle the first option because the bubble comes from that one.

3. It was felt that question 2 of section 2 in the What’s it like to have asthma questionnaire should be reworded “Use preventor inhaler (brown, orange or purple) every day”.

4. With regard to the information sheet for the 16 and under group the following changes were requested:

   4.1 It should be stated which group this is for (ie information for participants 16 years old and under.

   4.2 In the 2nd paragraph of the “Will you know it was me who filled in the questionnaire?” section it was felt that it should be stated more clearly that the report would be a summary of things that all the participants said not a report of their own comments.

The word information at the start of the 3rd sentence should be changed to report and at the end of this sentence when referring to the journal it was felt that it should be stated – for instance by publishing it in a scientific journal (participants might misunderstand “Journal” by itself).

Continued/...
It was envisaged that once the amended patient information sheet and questionnaires had been received approval by Chairman's Action could be given.

Yours sincerely

Senior Research Ethics Committee Administrator

Email: nhs.uk

cc Dr V Senior
Dear Mrs Longhurst,

Re: Social Pressure versus Asthma Pressure – The Example of Exertion as a Context for Conflict Amongst Adolescents with Asthma

Thank you for your letter of 9 October 2003 detailing the comments of the Local Research Ethics Committee regarding the above study.

I will outline how I have addressed the points raised below:

1&2: Comments:

1. It was felt that the layout should be looked at again; it seems rather cluttered at present. It is not necessary to give the instruction “please circle a number below to show how much you agree or disagree” after every question, just once in each section would be sufficient.

2. Thought should be given to a most appropriate way to identifying the question – it was felt that at present with the speech/thought bubble’s it was pointing the participant to circle the first option because the bubble comes from that one.

Actions taken:
The layout of the questionnaire has been altered so that fewer questionnaire items appear on each page and each speech or thought bubble is presented alongside, rather than above the rating scale so that it no longer appears to point towards any particular response. It is now intended to present the questionnaire in a landscape, spiral-bound (or similar) format making the
questionnaire easier to work through. The repetition of instructions to circle numbers has been removed – with the instruction appearing once at the beginning of each section.

3: Comment:
3 It was felt that question 2 of section 2 in the What’s it like to have asthma questionnaire should be reworded “Use preventor inhaler (brown, orange or purple) every day”.

Action taken:
The wording has been amended as advised.

4: Comments:
4 With regard to the information sheet for the 16 and under group the following changes were requested:

4.1 It should be stated which group this is for (ie information for participants 16 years old and under).

4.2 In the 2nd paragraph of the “Will you know it was me who filled in the questionnaire?” section it was felt that it should be stated more clearly that the report would be a summary of things that all the participants said not a report of their own comments.

The word information at the start of the 3rd sentence should be changed to report and at the end of this sentence when referring to the journal it was felt that it should be stated - for instance by publishing it in a scientific journal (participants might misunderstand “Journal” by itself).

Actions taken: These amendments to the information sheet for participants aged under 16 (i.e. 15 and under) have been made as advised. Where appropriate, wording in the information sheets for participants aged 16 and over, and parents of participants aged under 16 has been altered in line with these concerns.

Additional changes:
• The age range of participants it is intended to recruit has been changed from 12-18 to 11-16 to reflect better the age of patients attending Dr Seddon’s Clinic.
• Items to measure asthma severity level have been included in the final section of the questionnaire (see enclosure).
• An adapted version of the National Statistics Socio-Economic Classification has been included in the questionnaire for parents and for participants aged 16 and over (see enclosures).

Enclosed are:
a) Questionnaire: “What’s it like to have asthma?”
b) Information for participants aged 11-15
c) Information for participants aged 16+
d) Information for parents/guardians of participants aged 11-15
e) Questionnaire for participants aged 16+ (ethnicity and socio-economic status measures)
f) Questionnaire for parents/guardians of participants aged 11-15 (ethnicity and socio-economic status measures)

I hope this will provide the information you need, but please do not hesitate to contact me if further information of clarification is required.

Once again, many thanks for your help and the feedback from the Committee.

Yours sincerely,

Hazel Fell-Rayner
Trainee Clinical Psychologist
University of Surrey
Our Ref:  (B) 03/38
Your Ref:  

Ms Hazel Fell-Rayner  
Trainee Clinical Psychologist  
Clinical Psychology Office  
Department of Psychology  
University of Surrey  
Guildford  
GU2 7XH  

28 November 2003  

Dear Hazel  

Re:  Social Pressure versus Asthma Pressure – The Example of Exertion as a Context for Conflict Amongst Adolescents with Asthma  

- Information sheet for parent/guardians of participants aged 11-15 (version 2 – dated 3/11/03)  
- Information sheet for participants aged 16+ (version 2 – dated 3/11/03)  
- Information for participants aged 11-15 (version 2 – dated 3/11/03)  
- Questionnaire  

Thank you for your letter and enclosures of 12 November 2003, which I discussed with Dr Chairman of the Local Research Ethics Committee, when I met with him yesterday.  

Dr  is happy with the responses and amended documentation that have been provided to the point raised when the Committee reviewed the study. However he feels that the wording of the adapted National Statistics Socio-Economic Classification questionnaires is too complicated and should be simplified.  

I look forward to receiving the amended National Statistics Socio-Economic Classification questionnaires in the near future.  

Yours sincerely  

Senior Research Ethics Committee Administrator  

Email: nhs.uk
Dear Hazel,

Re: Social Pressure versus Asthma Pressure – The Example of Exertion as a Context for Conflict Amongst Adolescents with Asthma

- Information sheet for parent/guardians of participants aged 11-15 (version 2 – dated 3/11/03)
- Information sheet for participants aged 16+ (version 2 – dated 3/11/03)
- Information for participants aged 11-15 (version 2 – dated 3/11/03)
- Questionnaire
- Adapted National Statistics Socio-Economic Classification (NS-SEC) – aged 16+ (undated)
- Adapted National Statistics Socio-Economic Classification (NS-SEC) – aged 11-15 (undated)

Thank you for your letter and enclosures of 1 December, which have I discussed with Dr [Chairman’s name], Chairman of the (B) Local Research Ethics Committee.

Dr [Chairman’s name] is happy with the amended adapted National Statistics Socio-Economic Classification questionnaires and I am therefore writing to inform you that Chairman’s Action has been given to approve this study.

Approval is granted on the understanding that:

i) Any ethical problem arising in the course of the project will be reported to the Committee.
ii) Any change in the protocol or subsequent protocol amendments will be forwarded to the LREC. The principal investigator should see and approve any such changes and this needs to be indicated in the forwarding letter to the Committee.
iii) All serious adverse events must be reported within one week to the Ethics Committee, at the same time indicating that the principal investigator has seen the report and whether or not they feel it poses any new ethical or safety issues.
iv) A brief report will be submitted one year after commencement, thereafter annually, and after completion of the study.
v) Approval is given for research to start within 12 months of the date of application. If the start is delayed beyond this time, applicants are required to consult the Chairman of the Committee.

NHS Trust now operates a research & development approvals process. If you are an employee of the Trust, or wish to undertake research using either Trust patients or facilities you will need to apply for trust approval before the project can commence. In order to do this you will need to complete and sign a Trust approval project record. To obtain a copy, please contact [Manager’s name] on ext or email .

Yours sincerely,

Senior Research Ethics Committee Administrator
Email: nhs.uk
Appendix 5: Application and approval from the University of Surrey Ethics Committee

Submission To The University’s Ethics Committee For The Approval Of Study Protocol
Cover Sheet

1. Title of project:

2. Social Pressure versus Asthma Pressure — The example of exertion as a context for conflict amongst adolescents with asthma

(On survey materials, the study is entitled “Questionnaire Survey of Young People who have Asthma” in order to avoid bias to responses.)

<table>
<thead>
<tr>
<th>Names of Principal Investigators</th>
<th>Qualifications</th>
<th>Department/Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hazel Fell-Rayner</td>
<td>BA (Hons) Psychology</td>
<td>Department of Psychology, University of Surrey, (Trainee on PsychD Clinical Psychology)</td>
</tr>
<tr>
<td>Supervised by:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dr Victoria Senior</td>
<td>Lecturer</td>
<td>Department of Psychology, University of Surrey</td>
</tr>
<tr>
<td>Names of Co-Investigators</td>
<td>None</td>
<td></td>
</tr>
</tbody>
</table>

3. Signature of Supervisor (where appropriate) to indicate that (s)he has read and approved the protocol submission:

Date:

4. Details of Other Collaborators:

The research is being conducted in collaboration with a research group based at the Centre for Health Care Research at the Brighton & Sussex Medical School, University of Brighton – where it is hoped it may form part of an on-going research programme. This research group includes: Professor Rob Horne of the Centre for Health Care Research, Dr Victoria Senior of the Department of Psychology, University of Surrey, and Consultant Paediatrician Dr NHS Trust. The research will not bring any of the collaborators into direct contact with the participants (i.e. no further contact above the clinical contact Dr would have with the participants as his patients).
5. Details of Sponsors:
None

6. Details of payments to Investigators, Departments, Schools or Institutions. Investigators who receive payment as part of an annual consultancy fee should advise the Committee of the situation:
None

7. Where will the project be carried out? (e.g. University, hospital, etc.):
The research will be conducted at Consultant Paediatrician Dr clinics in NHS Trust (at the Royal Alexandra Hospital, Brighton). The survey may, at a later date, be extended to other sites within the Trust and to sites in other NHS Trusts. The study has received ethical approval from Local Research Ethics Committee, and the attached documentation reflects this.

8. Source of the subjects to be studied:
Participants will be 11-16 year-old patients of a paediatric asthma clinic and clinic lists will be used to identify potential-participants. Letters of invitation to participate in the study will be sent to parents of potential-participants aged 11-15, and to potential-participants aged 16+, alongside information sheets, at least one week prior to consent being sought or obtained. Potential-participants and (if participants are under 16) their parents will be approached at the Clinic, and invited to participate. Participants must have a medical diagnosis of asthma to be recruited. There are no formal exclusion criteria. However, as the participants will be known to Dr., they may be excluded from the study at his discretion (for instance, if there is concern that participation may cause undue distress).

9. Details of payments to subjects:
None
10. For Drugs Trials

i. Please state Phase:
   N/A

ii. If a new drug, does it have a Clinical Trials Exemption Certificate or Product Licence Number?
   N/A

iii. If a new drug, give details of toxic/side effects so far reported:
   N/A

iv. In addition to the recorded toxic/side effects, state any potential risks to the subjects and the precautions taken to deal with the situation:
   N/A

11. Checklist of Accompanying Documents (Please tick the appropriate boxes)

The attached documentation is that submitted to, and correspondence received from, Local Research Ethics Committee, as listed:

1. Copy of Application Form for Ethical Approval of Proposed Student Research*;
2. Copy of Letter from supervisor (Dr Victoria Senior);
3. Research Protocol*;
4. Information Sheet for participants aged 16+ (amended version following advice from LREC);
5. Information Sheet for parents/guardians of participants aged 11-15 (amended version following advice from LREC);
6. Information Sheet for participants aged 11-15 (amended version following advice from LREC);
7. Consent form for participants who are 16 years-old and above;
8. Parent/Guardian consent form;
9. Questionnaire: "What's it like to have asthma?" (amended version following advice from LREC);
10. Questionnaire for participants aged 16+ (amended version following advice from LREC);
11. Questionnaire for parents/guardians of participants aged 11-15 (amended version following advice from LREC);
12. Invitation letter to participants aged 16+;
13. Invitation letter to parents/guardians of participants aged 11-15;
14. Request sheet for copy of research study report;
15. Copy of certificate of professional indemnity insurance;
16. Copy of letter from LREC dated 9 October 2003;
17. Letter to LREC accompanying resubmission dated 12 November 2003;
18. Copy of letter from LREC dated 28 November 2003;
19. Letter to LREC accompanying resubmission dated 1 December 2003;

*Some details have changed since initial submission to the LREC. These changes are outlined in the Letter to LREC accompanying resubmission dated 12 November 2003 (Enclosure 17).

Please ensure that, where appropriate, the following documents are submitted along with your application:

See documentation listed above.

i Summary of project including principal aims and objectives

ii The detailed protocol for the project

iii Evidence of agreement of other collaborators
iv Copy of the Information Sheet for volunteers
v Copy of the Consent Form
vi Copy of questionnaire
vii Copies of standard letters related to the project
viii Protocol Submission Proforma: Insurance
ix Evidence of insurance cover/indemnity, particularly for drugs trials (Please refer to the Insurance Guidelines)
x Copy of the Clinical Trials Exemption Certificate or Product Licence Number
xi Information concerning any other Ethical Committee to which an application for approval is being made

12. Names and signatures of all Investigators:

Hazel Fell-Rayner

13. Date of Application:
19 December 2003
14 January 2004

Ms Hazel Fell-Rayner
Trainee Clinical Psychologist
Department of Psychology
School of Human Sciences

Dear Ms Fell-Rayner

Social pressure versus asthma pressure - The example of exertion as a context for conflict amongst adolescents with asthma (EC/2004/03/Psych) - FAST TRACK

I am writing to inform you that the University Ethics Committee has considered the above protocol under its 'Fast Track' procedure, and has approved it on the understanding that the Ethical Guidelines for Teaching and Research are observed. For your information, and future reference, these Guidelines can be downloaded from the Committee’s website at http://www.surrey.ac.uk/Surrey/ACE/.

This letter of approval relates only to the study specified in your research protocol (EC/2004/03/Psych) - Fast Track. The Committee should be notified of any changes to the proposal, any adverse reactions and if the study is terminated earlier than expected, with reasons.

Date of approval by the Ethics Committee: 14 January 2004
Date of expiry of approval by the Ethics Committee: 13 January 2009

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
    Dr V Senior, Supervisor, Dept of Psychology
**Appendix 6: NHS Trust Research & Development application, approval and honorary contract**

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### RESEARCH AND DEVELOPMENT PROJECT APPROVAL RECORD

<table>
<thead>
<tr>
<th>Full title:</th>
<th>Social Pressure verses Asthma Pressure – The Example of Exertion as a Context for Conflict Amongst Adolescents with Asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short title:</td>
<td>(On survey materials, the study is entitled “Questionnaire Survey of Young People who have Asthma” in order to avoid bias to responses.)</td>
</tr>
<tr>
<td>LREC reference No.:</td>
<td>(B) 03/38</td>
</tr>
<tr>
<td>Date of LREC approval:</td>
<td>17 December 2003</td>
</tr>
<tr>
<td>MREC Reference No.:</td>
<td>N/A</td>
</tr>
<tr>
<td>Protocol No.:</td>
<td>N/A</td>
</tr>
<tr>
<td>Planned start date:</td>
<td>November 2003</td>
</tr>
<tr>
<td>Anticipated end date:</td>
<td>June 2004</td>
</tr>
</tbody>
</table>

**Name and contact details of the Principal Investigator**

| Name: | Hazel Fell-Rayner |
| Position: | Trainee Clinical Psychologist |
| Department: | Department of Psychology, University of Surrey |
| Email: |  |
| Phone: |  |

**Address (if not an employee of NHS Trust)**

Clinical Psychology Office, Department of Psychology, University of Surrey, Guildford, GU2 7XH
SECTION A: PROJECT DETAILS

1. Please list all local investigators employed by the Trust who will be contributing to this project (continue on a separate sheet if necessary).

<table>
<thead>
<tr>
<th>Name</th>
<th>Profession</th>
<th>Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr</td>
<td>Consultant Paediatrician</td>
<td>PEDIATRICS</td>
</tr>
<tr>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hazel Fell-Rayner</td>
<td>Trainee Clinical Psychologist</td>
<td>(Employed by Surrey Oaklands NHS Trust)</td>
</tr>
</tbody>
</table>

2. If anyone who is not an employee will have contact with patients, their data or materials on a Trust site, please list them here (continue on a separate sheet if necessary).

<table>
<thead>
<tr>
<th>Name</th>
<th>Profession</th>
<th>Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hazel Fell-Rayner</td>
<td>Trainee Clinical Psychologist</td>
<td>(Employed by Surrey Oaklands NHS Trust)</td>
</tr>
</tbody>
</table>

3. Are any other organisations participating in this project? ☐ Yes  ☐ No - Go to Q6

4. Is the lead organisation for the project in the UK?  ☑ Yes - Go to Q6  ☐ No

5. Please name the lead organisation and principal investigator for the project in the UK.

Name of lead organisation: A research group based at the Centre for Health Care Research (CHCR) at Brighton & Sussex Medical School, University of Brighton is leading this project. This research group includes a Consultant Paediatrician from ..., a professor from CHCR, a lecturer and health psychologist from the University of Surrey, and a Trainee Clinical Psychologist based at the University of Surrey employed by Surrey Oaklands NHS Trust.

Name of principal investigator: Hazel Fell-Rayner

6. Which of the following will be subjects of the project? (please tick all that apply and estimate numbers)

☐ NHS patients, their data or material if so, how many?
☐ Healthy volunteers if so, how many?
☐ NHS staff if so, how many?
SECTION A: PROJECT DETAILS

☐ Medical device(s)
☐ Other (please give details) ___________________________________________________________________

7. Which kind of peer review has the protocol had?

☐ Protocol is sponsored/funded by a Dept of Health approved organisation
☐ Protocol is funded by a commercial organisation providing indemnity
☐ Formal external review with 'A' grade approval from approved sponsor but no funding
☐ Informal external review

☐ Informal internal review ☐ Yes ☐ No

☐ Student project reviewed and approved by University supervisor
☐ None of the above

8. Will the project involve any of the following?

Material removed after death ☐ Yes ☐ No

Live animals ☐ Yes ☐ No

Genetically modified material ☐ Yes ☐ No

Human embryos ☐ Yes ☐ No

Other controversial subject/material ☐ Yes ☐ No

9. Which of the following BSUH services will be called upon by the project? (Please tick all that apply)

☐ Dietetics ☐ Nuclear medicine ☐ Imaging

☐ Endoscopy ☐ Physiotherapy ☐ Pharmacy

☐ Medical physics ☐ Pathology ☐ Medical records

☐ Information management & technology ☐ ECG

☐ Other (please give details) ___________________________________________________________________

The research will be conducted at the clinics of Consultant Paediatrician Dr [Name] in the [Name of Hospital], NHS Trust (at the Hospital, The survey may, at a later date, be extended to other sites within the Trust and sites outside this Trust.

10. How do you plan to disseminate the finding of this research project?

☐ Publication in journal ☐ Poster / Information sheet ☐ Presentation at a conference

☐ Other (please give details) ___________________________________________________________________
SECTION A: PROJECT DETAILS

11. How will you inform patients and/or carers participating in this research project about the outcome?

Participants aged 16+ or parents of participants aged 11-15 will be given a request-form enabling them to request a copy of the report of the research. This form can then be handed to the researcher (principal investigator) who will be present.
### SECTION B: NATIONAL RESEARCH REGISTER

If this is a *non-commercially* sponsored project, please provide a brief outline of your project for inclusion in the National Research Register. One sentence on each topic is enough.

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Do some adolescents with asthma misinterpret normal symptoms of exertion or panic symptoms as signs of asthma, and consequently avoid exertion including exercise?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methodology</td>
<td>The design is cross-sectional – participants will complete a questionnaire at one time-point – and utilises a researcher-administered questionnaire to examine correlations between construct-relevant items.</td>
</tr>
<tr>
<td>Sample Group</td>
<td>Participants will be 11-16 year-old patients of a paediatric asthma clinic, recruited through an invitation-letter (accompanied by information sheet) sent to potential-participants aged 16+, or parents of potential-participants aged 11-15 at least one week prior to being approached in the Clinic, where informed consent will be sought.</td>
</tr>
<tr>
<td>Outcome Measures</td>
<td>A questionnaire will be used to obtain data at one time-point.</td>
</tr>
</tbody>
</table>
SECTION C: PROJECT COSTS AND INCOME

1. Does this project have an external sponsor(s)? ☒ Yes ☐ No - Go to Q 4

2. Please give the name of the sponsoring organisation(s) and a contact name:

   Name of sponsoring organisation 1: \\
   Name of contact: \\
   Name of sponsoring organisation 2: \\
   Name of contact: \\
   Name of sponsoring organisation 3: \\
   Name of contact: \\

3. Is the external sponsor providing funding? ☒ Yes ☐ No

4. Is any other external organisation providing funding? ☒ Yes ☐ No

5. Please give the name of the additional funding organisation(s) and a contact name:

   Name of funding organisation 1: This research forms part of a training course (PsychD Clinical Psychology) which is funded by an NHS Consortium and includes a research expense budget of £200.
   Name of contact: \\
   Name of funding organisation 2: \\
   Name of contact: \\

6. Organisation in receipt of grant: \\

7. Sum awarded: \\

8. Grant award date: start date: end date: \\

9. Costs and Income

<table>
<thead>
<tr>
<th>Income &amp; savings</th>
<th>Year 1 - £</th>
<th>Year 2 - £</th>
<th>Year 3 - £</th>
<th>Year 4 - £</th>
<th>Year 5 - £</th>
<th>Total - £</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient related staff costs</td>
<td>£200</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-patient related staff costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Consumables</td>
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<td></td>
<td></td>
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<tr>
<td>Non-patient related costs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Overheads</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10. Is indemnity/insurance provided by an external sponsor/funder? ☒ Yes ☐ No

11. Will the project findings have any potential for commercial exploitation or generate any Intellectual Property? ☒ Yes ☐ No ☐ Don't Know
SECTION D: MEDICINES

1. Does the project involve any medicine(s)?  
- [ ] Yes  
- [ ] No - Go to section E

2. Please list the name and indication of the Drug to be used and indicate whether regulatory approval has been obtained. If more than one drug (including a concomitant drug) is being used please duplicate this sheet.

<table>
<thead>
<tr>
<th>Drug Name</th>
<th>Indication</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- [ ] Yes - Please specify (e.g. CTX, DDX)

- [ ] No  
- [ ] No regulatory approval required (for licensed drug used within licensed indication)

- [ ] Other (please state)  

3. Who will supply the study drug?

- [ ] Hospital Pharmacy ( )
- [ ] Research Sponsor (pharmaceutical company, MRC, etc.)
- [ ] Hospital Pharmacy (Another Trust)  
- [ ] Pharmaceutical company (not sponsoring research)

- [ ] Other (please state)  

4. Will the Trust be required to pay for the study drug?

- [ ] No - supply is free of charge (Go to Q7)  
- [ ] Yes - full price

- [ ] Yes - discounted price (please specify terms and price including VAT)  

5. Would this drug have been used as part of routine clinical practice and prescribed to patients in the trial anyway?

- [ ] Yes  
- [ ] No  
- [ ] Yes, but change in practice (please specify changes i.e. length of treatment / dose)  

6. If the Trust has to pay full or part price for the study drug has this been agreed with the drug budget holders?

- [ ] Yes  
- [ ] No (please contact pharmacy for input)

7. If the study drug requires special storage (e.g. Fridge/Freezer), handling (e.g. cytotoxic drugs) or preparation (e.g. aseptic) please state below.

<table>
<thead>
<tr>
<th>Storage</th>
<th>Handling</th>
<th>Preparation</th>
</tr>
</thead>
</table>

Declaration by Clinical Trials / Principal / Directorate Pharmacist or Head of Pharmacy

I declare that I have received a copy of the final protocol (including any amendments)

Signed: ___________________________ Date: ___________________________
Name: ___________________________ Position: ___________________________
SECTION E: COMPLIANCE WITH THE DATA PROTECTION ACT AND CALDICOTT PRINCIPLES

1. As part of this project will any personal information about patients or participants be passed to any person or organisation beyond this Trust without having first been anonymised?
   - Yes
   - No - Go to Section F

2. Has the collection and retention of person identifiable information been explicitly identified as a reason for obtaining patient/participant consent?
   - Yes
   - No

3. How will this person identifiable information be collected? (please tick all that apply)
   - Retrieved from manual records, eg. case notes
   - Retrieved from computerised records, eg. PAS
   - Created from questionnaires, interviews, etc. in the course of the study
   - Other (please give details)

4. Who will collect person identifiable information? (please tick all that apply)
   - Members of the research team employed by the Trust (as listed at Section A Q2)
   - Members of the research team who are not employed by the Trust (as listed at Section A Q3)
   - Other Trust staff
   - Other (please give details)

5. How will the person identifiable information collected be held? (please tick all that apply)
   - Manual records
   - Computerised records

6. Where will these records be stored during the course of the project? (please tick all that apply)
   - NHS premises - in a secure environment
   - NHS premises - in an environment which is not secure
   - Premises belonging to one of the academic/commercial partners in the research study
   - Elsewhere (please give details)

7. How long will these records be retained after the completion of the end of project report to the Ethics Committee?
   - Less than 6 months
   - 6 months to 1 year
   - 1 to 3 years
   - More than 3 years

8. How will the person identifiable information be destroyed when no longer required?
   - Shredded by members of the research team on Trust premises
   - Bagged and disposed of as confidential waste within the Trust
   - Other (please give brief details)
SECTION F: DECLARATION

DECLARATION BY RESPONSIBLE RESEARCHER

I declare that I have read the Trust’s R&D Policy, I understand the role of the Responsible Researcher, and I am willing to assume that responsibility. I confirm that the details of this project which have been provided are complete and accurate to the best of my knowledge.

Signed: Hazel Fell-Rayner  Date: 10 January 2004
Name: Hazel Fell-Rayner  Position: Consultant Clinical Psychologist

CHECKLIST FOR CLINICAL DIRECTORS/GENERAL MANAGERS REVIEWING R&D PROJECTS

The people involved have the right skills and the time to undertake the tasks allotted
☐ Satisfied  ☐ Not Satisfied

Adequate space, equipment and other physical resources are available
☐ Satisfied  ☐ Not Satisfied

The project does not conflict with departmental or directorate strategy
☐ Satisfied  ☐ Not Satisfied

I have reviewed the information given in the Project Record together with any attachments and supplementary information and I confirm that this Directorate is willing to host this project.

Signed:  Date: 12/11/04
Name:  Position: Consultant Psychiatrist

TRUST AGREEMENT TO HOST R&D PROJECT

Signed:  Date: 
Name:  Position: 
HONOURARY CONTRACT

Dear Ms Fell-Rayner

I am instructed by the NHS Trust to confirm the offer to you of an honorary attachment as a Researcher for a period of 18 months.

1. The Trust has an obligation under the Health and Safety at Work Act 1974 to provide safe and healthy working conditions and methods. You are required to co-operate with Management in discharging its responsibilities under the Act and to take reasonable care for the health and safety of yourself and others. The policy of the Trust is attached.

2. Whilst on an honorary attachment to the Trust you will be required to comply with policies and procedures.

3. You must comply with the Trust’s Research & Development Policy and abide by the Research Governance Framework for Health and Social Care as amended from time to time.

4. Your honorary contract is effective from 23rd December 2003.

5. You will be accountable to the Associate Medical Director responsible for Research and Development.

6. Your honorary attachment to the Trust does not constitute employment per se, and you will not be entitled to any form of payment on its cessation. Employment with the Trust is not guaranteed in any way or conferred by this letter.

7. During the course of the attachment you may have access to see or hear information of a confidential nature and you are required to undertake not to disclose such information to any unauthorised persons. Breach in confidentiality may result in the termination of this attachment.

8. Any event of misconduct or poor performance may result in the termination of your honorary attachment. In cases of alleged serious misconduct you may be required to leave the Trust’s premises pending investigation.

9. The Trust does not normally accept responsibility for articles lost or damaged on Health Service property as a result of burglary, fire, theft or otherwise. You are advised accordingly not to bring items of value to your place of work and to provide your own insurance cover.

10. If for any reason e.g. sickness you are unable to attend for the purpose of your attachment you should inform your line manager as soon as possible.
This attachment can be terminated by either side on the notice of one week.

I shall be glad if you will kindly let me have formal acceptance of this appointment by signing the form at the foot of this letter and returning a copy to me.

Yours sincerely

Signature: ................................................................. Date: ............

Designation: PERSONNEL ADVISER

Please sign both copies and return one to the R&D Management Office. Please retain the second copy for your own records.

I have read and accept the terms of the Honorary Contract

Signed: ................................................................. Date: .........
Dear Hazel,

(B) 03/38 Social pressure Versus asthma Pressure – The example of Exertion as a Context for Conflict Amongst adolescents with Asthma

Thank you for receipt of your completed Trust Research Approval Form for the above named study.

I can confirm that the Trust’s Research & Development Management Office have approved the study.

To ensure that the conduct of this study is compliant with the Research Governance Framework and Good Clinical Practice Guidelines, a periodic review will be undertaken by the R&D Co-ordinator, who will contact you within three months of the study start date. To help you prepare for a quality assurance visit a set of guidance notes have been enclosed with this letter. Should you require any further assistance please contact Nicky Perry on the number listed above.

It would be appreciated if you could inform me when the study is complete and provide a brief report on the outcome of the project or details of any publications.

Yours sincerely,

Research & Development Manager
Appendix 7: Demographic questionnaire for parents of participants aged 11 to 15 years

**QUESTIONNAIRE FOR PARENTS/GUARDIANS OF PARTICIPANTS AGED 11-15**

It is helpful to have some information on the socio-economic background and ethnicity of participants. This is so that we can check the people we have invited to participate in the study are representative of the general population and so that, if particular concerns or needs are associated with particular backgrounds, health service professionals can be made more aware of these.

Below are some questions regarding your child's socio-economic background and ethnicity. We would be grateful if you would consider providing this information. However, you do not have to disclose this if you do not wish to.

Thank you for considering whether or not you wish to provide this information.

Ethnicity: What is your child’s ethnicity? The categories below are based on those used for the 2001 Census. However, if you wish to describe your child differently, please do so in the space provided in Section E of the question. Please tick the appropriate category below, or write how you would describe your child's ethnicity below:

A) White
   - British
   - Irish
   - Any other White background, please write in ..........................................

B) Mixed
   - White and Black Caribbean
   - White and Black African
   - White and Asian

C) Asian or Asian British
   - Indian
   - Pakistani
   - Bangladeshi
   - Any other Asian background, please write in ..........................................

D) Black or Black British
   - Caribbean
   - African
   - Any other Black background, please write in ..........................................

E) Chinese or other ethnic group
   - Chinese
   - Any other, please write in .........................................................

Please continue over
Socio-Economic Background: Below is a version of a questionnaire used by National Statistics to gain an impression of individuals' socio-economic backgrounds. You may find some of the questions a little complicated – please feel free to seek clarification from the researcher if you wish.

I. Who is the main wage-earner in your family/home/household? In other words, whose wage or salary contributes the most to your family's/home's/household’s income? ________________

The following questions are about the main wage-earner in your household, so please complete as if for the person you named above. The questions refer to their current or most recent job.

Please tick one box only per question.

2. Is/was the main wage-earner working as an employee or self-employed in their current or most recent job?

- Employee
- Self-employed
- Self-employed / freelance without employees (go to question 5)

3. For employees: How many people are/were working for the main wage-earner's employer at their current or most recent place of work?
   For self-employed: How many people are/were employed by the main wage-earner? Go to question 8 when you have completed this question.

- 1 to 24
- 25 or more

4. Is/was the main wage-earner supervising any other employees?
   (A supervisor or foreman is responsible for overseeing the work of other employees on a day-to-day basis)

- Yes
- No

Please continue over
5. Please tick one box to show which best describes the sort of work the main wage-earner does/did.

PLEASE TICK ONE BOX ONLY

Modern professional occupations
such as: teacher - nurse - physiotherapist - social worker - welfare officer - artist - musician - police officer (sergeant or above) - software designer

Clerical and intermediate occupations
such as: secretary - personal assistant - clerical worker - office clerk - call centre agent - nursing auxiliary - nursery nurse

Senior managers or administrators
(usually responsible for planning, organising and co-ordinating work and for finance)
such as: finance manager - chief executive

Technical and craft occupations
such as: motor mechanic - fitter - inspector - plumber - printer - tool maker - electrician - gardener - train driver

Semi-routine manual and service occupations
such as: postal worker - machine operative - security guard - caretaker - farm worker - catering assistant - receptionist - sales assistant

Routine manual and service occupations
such as: HGV driver - van driver - cleaner - porter - packer - sewing machinist - messenger - labourer - waiter / waitress - bar staff

Middle or junior managers
such as: office manager - retail manager - bank manager - restaurant manager - warehouse manager - publican

Traditional professional occupations
such as: accountant - solicitor - medical practitioner - scientist - civil / mechanical engineer

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE
Appendix 8: Demographic questionnaire for participants aged 16 years

QUESTIONNAIRE FOR PARTICIPANTS AGED 16+

It is helpful to have some information on the socio-economic background and ethnicity of participants. This is so that we can check the people we have invited to participate in the study are representative of the general population and so that, if particular concerns or needs are associated with particular backgrounds, health service professionals can be made more aware of these.

Below are some questions regarding your socio-economic background and ethnicity. We would be grateful if you would consider providing this information. However, you do not have to disclose this if you do not wish to.

Thank you for considering whether or not you wish to provide this information.

Ethnicity: What is your ethnicity? The categories below are based on those used for the 2001 Census. However, if you wish to describe yourself differently, please do so in the space provided in Section E of the question. Please tick the appropriate category below, or write how you would describe your ethnicity below:

B) White
- British
- Irish
- Any other White background, please write in ............................................

B) Mixed
- White and Black Caribbean
- White and Black African
- White and Asian

D) Asian or Asian British
- Indian
- Pakistani
- Bangladeshi
- Any other Asian background, please write in.............................................

D) Black or Black British
- Caribbean
- African
- Any other Black background, please write in.............................................

F) Chinese or other ethnic group
- Chinese
- Any other, please write in............................................................................

Please continue over
Socio-Economic Background: Below is a version of a questionnaire used by National Statistics to gain an impression of persons' socio-economic backgrounds. Please feel free to seek clarification from the researcher if you find any of the questions confusing.

6. Who is the main wage-earner in your household/home/family? In other words, whose wage or salary contributes the most to your household's income?

The following questions are about the main wage-earner in your household, so please complete as if for the person you named above. The questions refer to their current or most recent job.

Please tick one box only per question.

7. Is/was the main wage-earner working as an employee or self-employed in their current or most recent job?

   Employee
   □

   Self-employed
   □

   Self-employed / freelance without employees
   (go to question 5)
   □

8. For employees: How many people are/were working for the main wage-earner's employer at their current or most recent place of work? For self-employed: How many people are/were employed by the main wage-earner? Go to question 8 when you have completed this question.

   1 to 24
   □

   25 or more
   □

9. Is/was the main wage-earner supervising any other employees? (A supervisor or foreman is responsible for overseeing the work of other employees on a day-to-day basis)

   Yes
   □

   No
   □

   Please continue over
10. Please tick one box to show which best describes the sort of work the main wage-earner does/did.

PLEASE TICK ONE BOX ONLY

Modern professional occupations
such as: teacher - nurse - physiotherapist - social worker - welfare officer
- artist - musician - police officer (sergeant or above) - software designer

Clerical and intermediate occupations
such as: secretary - personal assistant - clerical worker - office clerk - call centre agent - nursing auxiliary - nursery nurse

Senior managers or administrators
(usually responsible for planning, organising and co-ordinating work and for finance)
such as: finance manager - chief executive

Technical and craft occupations
such as: motor mechanic - fitter - inspector - plumber - printer - tool maker - electrician - gardener - train driver

Semi-routine manual and service occupations
such as: postal worker - machine operative - security guard - caretaker - farm worker - catering assistant - receptionist - sales assistant

Routine manual and service occupations
such as: HGV driver - van driver - cleaner - porter - packer - sewing machinist - messenger - labourer - waiter / waitress - bar staff

Middle or junior managers
such as: office manager - retail manager - bank manager - restaurant manager - warehouse manager - publican

Traditional professional occupations
such as: accountant - solicitor - medical practitioner - scientist - civil / mechanical engineer

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE
Appendix 9: Invitation letter to parents of participants aged 11 to 15 years

DR ’S ASTHMA CLINIC (on headed paper)
20 April 2004
Parent(s)/Guardian(s) of

Dear Parent(s)/Guardian(s),

Over the next few weeks, researchers from the Centre for Health Care Research at the University of Brighton will be working in the Clinic conducting a Questionnaire Survey of Young People who have Asthma.

You and your child may be approached by a researcher when you attend the Clinic, and invited to participate in the Survey if you wish.

Please find attached an Information Sheet for Parents/Guardians, and an Information Sheet for Participants which explains the purpose of the Survey and what it involves. You may wish to read this for information prior to your next Clinic appointment, although the Information Sheet will also be available if a researcher approaches you. Both you and your child will be more than welcome to ask the researcher any questions you may have regarding the Survey.

Yours faithfully,

Hazel Fell-Rayner
Clinical Psychologist in Training
University of Surrey

Supervised by:

- Dr Victoria Senior, Department of Psychology, University of Surrey
- Professor Rob Horne, Centre for Health Care Research, University of Brighton
Appendix 10: Invitation letter to participants aged 16 years

To be on headed paper (Clinic address)

DATE:

Dear (Name of young person over 16),

Over the next few weeks, researchers from the Centre for Health Care Research at the University of Brighton will be working in the Clinic conducting a Questionnaire Survey of Young People who have Asthma.

You may be approached by a researcher when you attend the Clinic, and invited to participate in the Survey if you wish.

Please find attached an Information Sheet for Participants Who Are Over 16 Years-Old, which explains the purpose of the Survey and what it involves. You may wish to read this for information prior to your next Clinic appointment, although the Information Sheet will also be available if a researcher approaches you. You will be more than welcome to ask the researcher any questions you may have regarding the Survey.

Yours sincerely,

Hazel Fell-Rayner
Clinical Psychologist in Training
University of Surrey

Supervised by:
- Dr Victoria Senior, Department of Psychology, University of Surrey
- Professor Rob Horne, Centre for Health Care Research, University of Brighton
Appendix 11: Information sheet for participants aged 11-15

QUESTIONNAIRE SURVEY OF YOUNG PEOPLE WHO HAVE ASTHMA

INFORMATION FOR PARTICIPANTS AGED 11-15

When you come to the Clinic, a researcher may invite you to take part in a research study. It is up to you and your parent/guardian to decide whether you would like to take part. Before you decide, it is important for you to understand what the research study is about, and what is involved.

Please take time to read this information and feel free to talk about it to anyone else if you wish. If you have any questions or anything is confusing or unclear, please ask us about it. Take time to decide whether you want to take part or not.

Thank you for reading this.

WHO IS CARRYING OUT THIS SURVEY?
This study is being carried out by a group of people working to try to find out more about how young people who have asthma can be helped.

The people in the group include a paediatrician (children’s doctor) and health and clinical psychologists (people who try to understand how people think, behave and feel when they are either trying to get better or trying to stay well).

WHAT IS THIS SURVEY ABOUT?
We are doing this survey because we want to know more about what it is like for young people who have asthma.

We hope to survey more than 60 young people aged 11-16 who have asthma, to help us find out their opinions about:
- The things they think make asthma attacks happen
- What it’s like to have an asthma attack
- What they find helpful to make their asthma less of a problem, and what makes it worse.

We hope that, by finding out more about what it’s like for young people who have asthma, we will be able to learn ways of improving the services offered to them.

WHAT DOES THE SURVEY INVOLVE
Being a “participant” (someone who takes part in the survey) involves filling in a questionnaire. The questionnaire takes about 20 minutes to complete. It asks questions about your opinions and thoughts about having asthma. There are no right or wrong answers to any of the questions – we want to know what YOU think! Most of the questions involve ticking boxes or putting circles around numbers to tell us what you think.
WILL YOU KNOW IT WAS ME WHO FILLED IN THE QUESTIONNAIRE?

No! At the end of the questionnaire, there are a few questions about you, such as whether you are male or female, how old you are, and how long you have had asthma. BUT, you do not need to put your name anywhere on the questionnaire. This is because the questionnaire is kept anonymous and private — we will not know who filled in which questionnaire.

After you have finished filling in the questionnaire, the researcher who gave it to you will ask if you are happy to let him or her keep it. If you are, then we will use your answers — and everyone else’s answers — to write a report about what it is like for young people to have asthma. This report will be a summary of the things that everybody said — it wouldn’t detail your own comments. If the report tells us something we didn’t know and we think is important, then we might try to share this information with other people who work in the health service — for instance by publishing it in a scientific journal. But we would never share information that would let someone work out who you were or what you told us — because it is anonymous.

However, there are some limits to what we keep anonymous and private. If, for any reason, the researcher became concerned that you or someone else was at risk of serious harm, then he or she would talk to your medical doctor, nurse, or someone else involved in your care about it. This is to make sure that things are made safer. The researcher would normally tell you if he or she was going to do that, but might not do if they think it is a real emergency.

DO I HAVE TO TAKE PART IN THE SURVEY?

No! We would like to invite you to take part — because we would like to know about your opinions and experiences. But you do not have to take part if you do not want to. It is your choice whether you want to take part or not, and whatever you choose it will not affect the care you are offered or your rights in law in any way.

If you start the questionnaire, you can change your mind at any time and decide not to take part. This means that you can decide not to begin the questionnaire, or to stop filling in the questionnaire when you are part-way through, or not to hand in the questionnaire to the researcher when you have finished it.

YOU CAN ASK THE RESEARCHER ANY QUESTIONS YOU MAY HAVE.

Hazel Fell-Rayner
Clinical Psychologist in Training
University of Surrey

Version no: 2
Date compiled: 3 November 2003
Appendix 12: Information for participants aged 16 years

QUESTIONNAIRE SURVEY OF YOUNG PEOPLE WHO HAVE ASTHMA

INFORMATION FOR PARTICIPANTS AGED 16+

You may be approached and invited to take part in a research study. Before you decide whether you would like to take part, it is important for you to understand why the study is being carried out and what is involved.

Please take the time to read the information below and feel free to discuss it with others if you wish. If you have any questions or anything is unclear, please ask us. Take time to decide whether you would like to take part or not.

Thank you for reading this.

WHO IS CARRYING OUT THIS SURVEY?
This study is being carried out by a research group based at the Centre for Health Care Research at the University of Brighton. The group includes both research-professionals and clinicians who work in the National Health Service – including a paediatrician and health and clinical psychologists. The group is researching adolescent asthma with a particular focus upon psychological/behavioural factors that may influence how young people cope with and manage asthma.

WHAT IS THIS SURVEY ABOUT?
This survey is being conducted to try to gain a clearer picture of what the experience of having asthma is like for young people. We are hoping to survey over 60 young people who have asthma to help us gain greater understanding of the opinions they have about:

- Perceived triggers to asthma attacks
- The experience of having an asthma attack
- What they find helpful or unhelpful in managing their asthma.

We hope that, by finding out more about what it's like for young people who have asthma, we will be able to learn ways of improving the services offered to them in future.

WHAT DOES THE SURVEY INVOLVE?
Young people who participate in the survey will be asked to complete a questionnaire about their opinions and thoughts regarding asthma. The questionnaire takes about 20 minutes to complete. Most of the questions ask about thoughts and feelings about asthma and asthma attacks and so there are no right or wrong answers to any of the questions. Most of the questions involve ticking boxes or putting circles around numbers.

ANONYMITY AND CONFIDENTIALITY
The questionnaire is anonymous, and those who participate are asked not to put their names anywhere on the questionnaire. At the end of the questionnaire, there are a few questions requesting statistical information about yourself such as whether you are male or female, your age, and how long you have had asthma. You will also be invited complete a brief questionnaire asking for information about your socio-economic background and ethnicity. This information is requested because it helps us to check whether the people we have asked to take part in the survey are representative of the
general population. It also helps us learn about whether people from particular backgrounds have any particular needs that health service professionals should be aware of. However, you do not have to provide this information if you do not wish to.

Completed questionnaires will be used to write a report about what it is like for young people in general to have asthma, rather than for you as an individual. We may at a later date seek to publish findings of the study in scientific journals. Any such report or publication would never involve the disclosure of information that would identify you or how you responded to the questionnaire. You can request a copy of the report if you wish.

There are some important limits to confidentiality. If, for any reason, the researcher became concerned that your or someone else was at risk of serious harm, then he or she would need to disclose their concern to an appropriate person – such as your medical doctor, nurse, or someone else involved in your care. The researcher would normally explain if they were going to do this but reserves the right not to in a serious situation that he or she regards as requiring urgent attention.

DO I HAVE TO TAKE PART IN THE SURVEY?

No! Participation in the study is entirely voluntary. Whether you take part is your choice. Accepting or declining to take part will not affect your care or legal rights in any way. You are free to withdraw from participating in the study at any time, without giving any reason.

You are also free to ask the researcher any questions you may have.

If you would like further information, please contact:
Hazel Fell-Rayner
Clinical Psychologist in Training
Department of Psychology
University of Surrey
Guildford
GU2 7XH
Tel: 01483 689441
Please leave a message and contact number and your call will be returned.

Participants will be given a copy of the information sheet to keep, as well as a consent form they will be asked to sign if they are happy to participate.

This study has received approval from XXXX Local Research Ethics Committee, XXXX Research & Development Management Team, University of Surrey Ethics Committee.

Version no: 2
Date compiled: 3 November 2003
Appendix 13: Information sheet for parents of participants aged 11 to 15 years

QUESTIONNAIRE SURVEY OF YOUNG PEOPLE WHO HAVE ASTHMA

INFORMATION FOR PARENTS/GUARDIANS OF PARTICIPANTS AGED 11-15

You and your child may be approached and invited to take part in a research study. Before you and your child decide whether you would like to take part, it is important for you to understand why the study is being carried out and what is involved.

Please take the time to read the information below and feel free to discuss it with others if you wish. If you have any questions or anything is unclear, please ask us. Let your child take time to decide whether he or she would like to take part, and to decide whether you wish your child to take part.

Thank you for reading this.

WHO IS CARRYING OUT THIS SURVEY?

This study is being carried out by a research group based at the Centre for Health Care Research at the University of Brighton. The group includes both research-professionals and clinicians who work in the National Health Service – including a paediatrician and health and clinical psychologists. The group is researching adolescent asthma with a particular focus upon psychological/behavioural factors that may influence how young people cope with and manage asthma.

WHAT IS THIS SURVEY ABOUT?

This survey is being conducted to try to gain a clearer picture of what the experience of having asthma is like for young people. We are hoping to survey over 60 young people who have asthma to help us gain greater understanding of the opinions they have about:

- Perceived triggers to asthma attacks
- The experience of having an asthma attack
- What they find helpful or unhelpful in managing their asthma.

We hope that, by finding out more about what it's like for young people who have asthma, we will be able to learn ways of improving the services offered to them in future.

WHAT DOES THE SURVEY INVOLVE

Young people who participate in the survey will be asked to complete a questionnaire about their opinions and thoughts regarding asthma. The questionnaire takes about 20 minutes to complete. Most of the questions ask about thoughts and feelings about asthma and asthma attacks and so there are no right or wrong answers to any of the questions. Most of the questions involve ticking boxes or putting circles around numbers.

Parents/guardians of young people who wish to participate in the survey will be asked to sign a consent form to say they are happy for their child to take part. You will also be invited complete a brief questionnaire asking for information about your child's socio-economic background and ethnicity. This information is requested because it helps us to check whether the people we have asked to take part in the survey are representative of
ANONYMITY AND CONFIDENTIALITY
The questionnaire is anonymous, and young people who participate are asked not to put their names anywhere on the questionnaire. At the end of the questionnaire, there are a few questions requesting statistical information about your child such as whether your child is male or female, his or her age, and how long your child has had asthma. However, it is not compulsory to complete this information if you or your child prefer not to.

Completed questionnaires will be used to write a report about what it is like for young people in general to have asthma, rather than for your child as an individual. We may at a later date seek to publish findings of the study in scientific journals. Any such report or publication would never involve the disclosure of information that would identify your child or how they responded to the questionnaire. You can request a copy of the report if you wish.

There are some important limits to confidentiality. If, for any reason, the researcher became concerned that your child or someone else was at risk of serious harm, then he or she would need to disclose this concern to an appropriate person – such as your child’s medical doctor, nurse, or someone else involved in their care. The researcher would normally explain if they were going to do this but reserves the right not to in a serious situation that he or she regards as requiring urgent attention.

DOES MY CHILD HAVE TO TAKE PART IN THE SURVEY?
No! Participation in the study is entirely voluntary. Whether your child takes part is down to both their choice and yours as a parent/guardian. Accepting or declining to take part will not affect your or your child’s care or legal rights in any way. You are free to withdraw your child from participating in the study at any time, without giving any reason.

You are also free to ask the researcher any questions you may have.

If you would like further information, please contact:
Hazel Fell-Rayner
Clinical Psychologist in Training
Department of Psychology
University of Surrey
Guildford
GU2 7XH
Tel: 01483 689441
Please leave a message and contact number and your call will be returned.

Participants and their parents/guardians will be given a copy of the information sheet and signed consent form to keep.

This study has received approval from XXXX Local Research Ethics Committee, XXXX Research & Development Management Team, University of Surrey Ethics Committee.

Version no: 2 Date compiled: 3 November 2003
Appendix 14: Consent form for parents of participants aged 11 to 15 years

UniS
University of Surrey
School of Human Sciences
Department of Psychology
Guildford
Surrey GU2 7XH
Tel: +44 (0)1483 300800
Facsimile: +44 (0)1483 689553

Centre Number: 
Study Number: (B) 03/38 
Patient Identification Number for this trial:

PARENT/GUARDIAN CONSENT FORM

Title of Project: Questionnaire Survey of Young People who have Asthma

Name of Researcher: Hazel Fell Rayner, Clinical Psychologist in Training, University of Surrey
Supervised by:
Dr Victoria Senior, University of Surrey
Professor Rob Horne, Centre for Health Care Research
Dr Paul Seddon, Brighton & Sussex University Hospitals NHS Trust

Please initial box

1. I confirm that I have read and understand the information sheet dated 3 November 2003 (version: “Information for Parents/Guardians”) for the above study and have had the opportunity to ask questions.

2. I understand that my allowing my child to participate is voluntary and that I am free to withdraw my child from the study without giving any reason, without my or my child’s medical care or legal rights being affected.

3. I agree to take part in the above study.

Name of Parent Date Signature

Name of Child under 16 Date Signature

Name of Person taking consent Date Signature
(if different from researcher)

Researcher Date
Signature

I for patient; I for researcher; I to be kept with hospital notes
Appendix 15: Consent form for participants aged 16 years

CONSENT FORM FOR PARTICIPANTS WHO ARE 16 YEARS-OLD AND ABOVE

Title of Project: Questionnaire Survey of Young People who have Asthma

Name of Researcher: Hazel Fell Rayner, Clinical Psychologist in Training, University of Surrey
Supervised by:
Dr Victoria Senior, University of Surrey
Professor Rob Horne, Centre for Health Care Research
Dr Paul Seddon, Brighton & Sussex University Hospitals NHS Trust

Please initial box

1. I confirm that I have read and understand the information sheet dated 3 November 2003 (version "Information for Participants Who Are Over 16 Years-Old) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I agree to take part in the above study.

Name of Patient ____________________________ Date ____________________________ Signature ____________________________

Name of Person taking consent (if different from researcher) ____________________________ Date ____________________________ Signature ____________________________

Researcher ____________________________ Date ____________________________ Signature ____________________________

I for patient; I for researcher; I to be kept with hospital notes
Appendix 16: Form to request copy of report of research

QUESTIONNAIRE SURVEY OF
YOUNG PEOPLE WHO HAVE ASTHMA

Request for copy of research study report

If you would like to obtain a copy of the report of this research study, please give details of where we can send it below. This information will be kept separate from the questionnaire, to maintain anonymity.

Name:..............................................................

Address:................................................................

.................................................................

.................................................................

.................................................................
Appendix 17: Pilot prompts used to gain feedback on questionnaire

"WHAT'S IT LIKE TO HAVE ASTHMA?" SURVEY

PILOT PROMPTS

1. What did you think of the questionnaire?
2. Did you think the questionnaire seemed to be about things that are relevant/important to what it's like for you to have asthma? Or did it ask things that weren't really important to your asthma?
3. Can you think of any ways we could improve the questionnaire e.g. any other questions we should ask?

Write responses below:
### Appendix 18: Summary of responses to expert sampling questionnaire

<table>
<thead>
<tr>
<th>Symptom and assigned classification</th>
<th>Is this a symptom of asthma? (frequencies)</th>
<th>Is this a symptom of exertion? (frequencies)</th>
<th>Is this a symptom of panic? (frequencies)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>L=likely</td>
<td>P=possible</td>
<td>U=unlikely</td>
</tr>
<tr>
<td>1 “Heart beating really hard”</td>
<td>L: 0</td>
<td>P: 1</td>
<td>U: 5</td>
</tr>
<tr>
<td>(Not asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 “Needing to breathe faster”</td>
<td>L: 3</td>
<td>P: 2</td>
<td>U: 1</td>
</tr>
<tr>
<td>(Ambiguous)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 “Chest feeling tight”</td>
<td>L: 6</td>
<td>P: 0</td>
<td>U: 0</td>
</tr>
<tr>
<td>(Asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 “Muscles in my arms or legs</td>
<td>L: 0</td>
<td>P: 0</td>
<td>U: 6</td>
</tr>
<tr>
<td>feeling tired or aching”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Not asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 “Feeling scared or worried”</td>
<td>L: 1</td>
<td>P: 4</td>
<td>U: 1</td>
</tr>
<tr>
<td>(Asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 “Feeling out of breath”</td>
<td>L: 5</td>
<td>P: 1</td>
<td>U: 0</td>
</tr>
<tr>
<td>(Asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 “Getting a stitch”</td>
<td>L: 0</td>
<td>P: 3</td>
<td>U: 3</td>
</tr>
<tr>
<td>(Not asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 “Feeling like I can’t get enough</td>
<td>L: 5</td>
<td>P: 1</td>
<td>U: 0</td>
</tr>
<tr>
<td>breath” (Asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 “Feeling like something is pressing</td>
<td>L: 1</td>
<td>P: 3</td>
<td>U: 1</td>
</tr>
<tr>
<td>on my chest”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 “Needing to breathe deeper than</td>
<td>L: 1</td>
<td>P: 1</td>
<td>U: 3</td>
</tr>
<tr>
<td>normal” (Not asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 “Breathing hurting my throat”</td>
<td>L: 0</td>
<td>P: 1</td>
<td>U: 5</td>
</tr>
<tr>
<td>(Not asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 “Feeling like something is in the</td>
<td>L: 1</td>
<td>P: 4</td>
<td>U: 1</td>
</tr>
<tr>
<td>way when I breathe”</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Ambiguous)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 “Sweating”</td>
<td>L: 0</td>
<td>P: 1</td>
<td>U: 5</td>
</tr>
<tr>
<td>(Not asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom and assigned classification</td>
<td>Is this a symptom of asthma? (frequencies)</td>
<td>Is this a symptom of exertion? (frequencies)</td>
<td>Is this a symptom of panic? (frequencies)</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>------------------------------------------</td>
<td>-------------------------------------------</td>
<td>------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>L=likely</td>
<td>P=possible</td>
<td>U=unlikely</td>
</tr>
<tr>
<td>14 “Getting short of breath”</td>
<td>L:5</td>
<td>L:4</td>
<td>L:1</td>
</tr>
<tr>
<td>(Asthma)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 “Feeling like I can’t breathe fast enough” (Ambiguous)</td>
<td>L:0</td>
<td>L:2</td>
<td>L:1</td>
</tr>
<tr>
<td>16 “Feeling like I can’t breathe deep enough” (Asthma)</td>
<td>L:3</td>
<td>L:1</td>
<td>L:0</td>
</tr>
<tr>
<td>17 “Feeling sick” (Not asthma)</td>
<td>L:0</td>
<td>L:0</td>
<td>L:0</td>
</tr>
<tr>
<td>18 “Feeling wheezy” (Asthma)</td>
<td>L:6</td>
<td>L:0</td>
<td>L:0</td>
</tr>
<tr>
<td>19 “Going dizzy or giddy” (Not asthma)</td>
<td>L:0</td>
<td>L:0</td>
<td>L:2</td>
</tr>
<tr>
<td>20 “Thinking that something terrible is about to happen” (Not asthma)</td>
<td>L:1</td>
<td>L:0</td>
<td>L:6</td>
</tr>
<tr>
<td>21 “Feeling shaky, wobbly or trembling” (Not asthma)</td>
<td>L:0</td>
<td>L:0</td>
<td>L:6</td>
</tr>
<tr>
<td>22 “Coughing when I exercise” (Asthma)</td>
<td>L:5</td>
<td>L:1</td>
<td>L:0</td>
</tr>
<tr>
<td>23 “Thinking that I might collapse” (Ambiguous)</td>
<td>L:0</td>
<td>L:0</td>
<td>L:2</td>
</tr>
<tr>
<td>24 “Getting pins and needles in my hands and feet” (Not asthma)</td>
<td>L:0</td>
<td>L:0</td>
<td>L:3</td>
</tr>
<tr>
<td>25 “Feeling like I am choking” (Not asthma)</td>
<td>L:1</td>
<td>L:0</td>
<td>L:0</td>
</tr>
<tr>
<td>26 “Things don’t seem real” (Not asthma)</td>
<td>L:0</td>
<td>L:0</td>
<td>L:2</td>
</tr>
</tbody>
</table>
# Appendix 19: Criteria for by-hand classification of symptoms from checklist

<table>
<thead>
<tr>
<th>Classification of symptom</th>
<th>Criteria for classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not asthma</td>
<td>Majority of six experts classify as “unlikely” to be asthma (or, if evenly split between “unlikely” and “possible”, author’s classification would also have been “not asthma” and majority of experts would classify as “likely” to be symptomatic of exertion or panic.</td>
</tr>
<tr>
<td>Asthma</td>
<td>Majority of six experts classify as “likely” or “possible” to be asthma (author’s classification used if evenly split) and majority of experts classify as “unlikely” or “possible” to be exertion or panic.</td>
</tr>
<tr>
<td>Ambiguous</td>
<td>Majority of six experts classify as “possible” that symptomatic of asthma, or cannot be assigned to “not asthma” or “asthma” on above criteria.</td>
</tr>
</tbody>
</table>
Appendix 20: Frequencies for individual questionnaire items

Likert-type Scales: The five-point Likert-type scales were worded differently in each section, but all were designed so that a score of 5 represented high agreement and 1 represented disagreement. The variations are described in the table below.

<table>
<thead>
<tr>
<th>Context in which Likert-type scale used</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agreement with statements (speech bubbles)</td>
<td>Disagree a lot</td>
<td>Disagree a bit</td>
<td>Neither agree nor disagree</td>
<td>Agree a bit</td>
<td>Agree a lot</td>
</tr>
<tr>
<td>Reported frequency of performing asthma-management strategies</td>
<td>Never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Usually</td>
<td>Always</td>
</tr>
<tr>
<td>Perceived helpfulness of asthma-management strategies</td>
<td>Very unhelpful</td>
<td>A bit unhelpful</td>
<td>Makes no difference</td>
<td>A bit helpful</td>
<td>Very helpful</td>
</tr>
<tr>
<td>Reported frequency of having similar thought or experience (thought clouds)</td>
<td>Never</td>
<td>Rarely</td>
<td>Sometimes</td>
<td>Quite often</td>
<td>Very often</td>
</tr>
</tbody>
</table>

Appendix 20a: Frequency of responses to individual questionnaire items related to attitudes to exertion and asthma

<table>
<thead>
<tr>
<th>Item</th>
<th>1 (%)</th>
<th>2 (%)</th>
<th>3 (%)</th>
<th>4 (%)</th>
<th>5 (%)</th>
<th>Mean</th>
<th>Median</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Running fast can make me have an asthma attack.&quot;</td>
<td>4.9</td>
<td>7.3</td>
<td>12.2</td>
<td>46.3</td>
<td>29.3</td>
<td>3.88</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>&quot;Doing energetic activity can set off an asthma attack.&quot;</td>
<td>9.8</td>
<td>7.3</td>
<td>7.3</td>
<td>36.6</td>
<td>36.6</td>
<td>3.85</td>
<td>4</td>
<td>4/5</td>
</tr>
<tr>
<td>&quot;Exercise and asthma don’t go together.&quot;</td>
<td>24.4</td>
<td>14.6</td>
<td>19.5</td>
<td>24.4</td>
<td>17.1</td>
<td>2.95</td>
<td>3</td>
<td>1/4</td>
</tr>
<tr>
<td>&quot;Exercise is fine for people with asthma – as long as they don’t overdo it.&quot;</td>
<td>0</td>
<td>0</td>
<td>7.3</td>
<td>26.8</td>
<td>65.9</td>
<td>4.58</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>&quot;Light exercise is OK for people my age who have asthma.&quot;</td>
<td>4.9</td>
<td>4.9</td>
<td>22.0</td>
<td>31.7</td>
<td>36.6</td>
<td>3.90</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>&quot;Regular exercise can help make my asthma less of a problem.&quot;</td>
<td>14.6</td>
<td>17.1</td>
<td>22.0</td>
<td>29.3</td>
<td>17.1</td>
<td>3.17</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>&quot;Asthma shouldn’t stop people from exercising.&quot;</td>
<td>2.4</td>
<td>4.9</td>
<td>0.0</td>
<td>19.5</td>
<td>73.2</td>
<td>4.56</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>&quot;Exercise regularly.&quot;</td>
<td>20.0</td>
<td>15.0</td>
<td>17.5</td>
<td>25.0</td>
<td>22.5</td>
<td>3.15</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>&quot;Try not to rush around and get myself out of breath.&quot;</td>
<td>9.8</td>
<td>2.4</td>
<td>24.4</td>
<td>34.1</td>
<td>29.3</td>
<td>3.71</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>&quot;Stop or slow down if I think an asthma attack might be coming on.&quot;</td>
<td>0.0</td>
<td>4.9</td>
<td>4.9</td>
<td>31.7</td>
<td>58.5</td>
<td>4.44</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>&quot;Avoid exercise if I think I might get an asthma attack.&quot;</td>
<td>2.5</td>
<td>2.5</td>
<td>12.5</td>
<td>45.0</td>
<td>37.5</td>
<td>4.13</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>
### Appendix 20b: Reported frequency of “safety behaviours” or agreement with safety behaviour strategies

<table>
<thead>
<tr>
<th>Item</th>
<th>1 (%)</th>
<th>2 (%)</th>
<th>3 (%)</th>
<th>4 (%)</th>
<th>5 (%)</th>
<th>Mean</th>
<th>Median</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise regularly</td>
<td>10.0</td>
<td>12.5</td>
<td>17.5</td>
<td>37.5</td>
<td>22.5</td>
<td>3.50</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Try not to rush around and get myself out of breath</td>
<td>9.8</td>
<td>19.5</td>
<td>24.4</td>
<td>29.3</td>
<td>17.1</td>
<td>3.24</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Stop or slow down if I think an asthma attack might be coming on</td>
<td>7.3</td>
<td>4.9</td>
<td>7.3</td>
<td>34.1</td>
<td>46.3</td>
<td>4.07</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Try not to exercise to hard or fast</td>
<td>12.5</td>
<td>27.5</td>
<td>22.5</td>
<td>25.0</td>
<td>12.5</td>
<td>2.97</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Avoid exercise if I think I might get an asthma attack</td>
<td>7.5</td>
<td>15.0</td>
<td>10.0</td>
<td>40.0</td>
<td>27.5</td>
<td>3.65</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>“I would like to exercise more but when I do I get breathless and think I should stop in case I get an asthma attack.”</td>
<td>9.8</td>
<td>12.2</td>
<td>34.1</td>
<td>12.2</td>
<td>31.7</td>
<td>3.43</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>“If a person has asthma and they start to get out of breath when they exercise, they should stop immediately.”</td>
<td>4.9</td>
<td>9.8</td>
<td>9.8</td>
<td>17.1</td>
<td>58.5</td>
<td>4.14</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>“If someone has asthma and they get out of breath when they exercise, they shouldn’t exercise that hard again.”</td>
<td>14.6</td>
<td>24.4</td>
<td>12.2</td>
<td>22.0</td>
<td>26.8</td>
<td>3.22</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

### Appendix 20c: Frequency of responses to individual social pressure items

<table>
<thead>
<tr>
<th>Item</th>
<th>1 (%)</th>
<th>2 (%)</th>
<th>3 (%)</th>
<th>4 (%)</th>
<th>5 (%)</th>
<th>Mean</th>
<th>Median</th>
<th>Mode</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I think I cannot be as fit as people my age who don’t have asthma.”</td>
<td>29.3</td>
<td>9.8</td>
<td>24.4</td>
<td>17.1</td>
<td>19.5</td>
<td>2.87</td>
<td>3</td>
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<td>“Having asthma stops me being as good as I want to be at sports activities”</td>
<td>26.8</td>
<td>9.8</td>
<td>17.1</td>
<td>26.8</td>
<td>19.5</td>
<td>3.02</td>
<td>3</td>
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</tr>
<tr>
<td>“I can be just as fit as my friends who don’t have asthma”</td>
<td>9.8</td>
<td>22.0</td>
<td>31.7</td>
<td>17.1</td>
<td>19.5</td>
<td>3.15</td>
<td>3</td>
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<tr>
<td>“I worry my friends will tease me or think badly of me if I can’t keep up with them in sports or PE.”</td>
<td>63.4</td>
<td>7.3</td>
<td>4.9</td>
<td>9.8</td>
<td>14.6</td>
<td>2.05</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>“Having asthma doesn’t bother me.”</td>
<td>19.5</td>
<td>7.3</td>
<td>31.7</td>
<td>14.6</td>
<td>26.8</td>
<td>3.22</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>“I enjoy exercise.”</td>
<td>14.6</td>
<td>2.4</td>
<td>19.5</td>
<td>24.4</td>
<td>39.0</td>
<td>3.71</td>
<td>4</td>
<td>5</td>
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<tr>
<td>“I exercise because I want to prove I can even though I have asthma.”</td>
<td>36.6</td>
<td>19.5</td>
<td>14.6</td>
<td>9.8</td>
<td>19.5</td>
<td>2.56</td>
<td>2</td>
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</table>
Appendix to Volume I
APPENDIX TO VOLUME I

This Appendix to Volume I of the portfolio contains evidence of teaching conducted on placement and feedback to the service resulting from the Service-Related Research Project.

In addition, it contains the Placement Summary relating to the final Specialist Clinical Health Psychology Placement, submitted in September 2004.
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<td>Letter acknowledging presentation given by trainee during Adult Mental Health Placement</td>
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<td>Appendix C:</td>
<td>Letter acknowledging presentation given by trainee during Specialist Adolescence Placement</td>
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</table>
Dear Hazel

Re: A Baseline Audit Using the Staff Clinical Governance Survey

Thank you for sending the completed audit to me.

The outcomes of the audit appear to support research findings and do not present a major surprise to me. I am relatively new in post and have been ascertaining staff views and perceptions towards clinical governance informally through induction interviews.

The audit does, however, lend support to the following plans which our Clinical and Social Care Governance Committee is discussing this month:

- Clinical and Social Care Governance Week – 8-12 March 2004
  - Chairman and Chief Executive Roadshows – strategic vision
  - Launch of pocket guide to Clinical and Social Care Governance
  - Menu of learning opportunities on key components of Clinical and Social Care Governance across all care groups
  - Excellence in Practice Conference
- Two Sides of the Same Coin – aimed at frontline staff (copy attached)
- CAST – Clinical Audit Support Time

I would like to disseminate the summary of key findings to Heads of Service in... and register your audit within our Annual Audit Report for 2002-2003. I will also plan a re-audit to determine progress following implementation of the above proposals in our forward audit plan for 2004/2005.
2
14 October 2003
Ms H Fell-Rayner

Whilst I was not involved in commissioning this audit I would like to thank you for undertaking and completing the work, particularly given your personal circumstances. I have forwarded a copy, for information, to PCT and who still works for the Trust.

Please contact me if you wish to discuss any of the above further.

I have also enclosed a copy of our Clinical and Social Care Governance Annual Report for the period 2002-2003. This describes progress made in implementing clinical governance since the Trust was formed in April 2002

Yours sincerely

Head of Clinical Governance

cc Dr., Executive Lead for Clinical Governance
West Sussex Health and Social Care
NHS Trust

Linwood Community Mental Health Centre
Butlers Green Road
Haywards Heath
West Sussex RH16 4BE

Hazel Rayner

8th April 2002

Re: Presentation held on the 28th March 2002 - 'Working with Metaphors'

Dear Hazel,

I wish to express my appreciation, on behalf of the Linwood Team on the above presentation.

Whilst it was very interesting and thought provoking during the session, it has attracted a number of comments on when we can run it again and how we can use the topic to help develop a clearer awareness of our use of metaphor in our everyday work.

Thank you for this and may I take this opportunity of thanking you for you positive and creative input whilst on your placement with us at Linwood.

Best wishes for the remainder of your course.

Yours sincerely,

Charles F Nicholls,
Manager Linwood CMHIC.
Dear Hazel

Re: Presentation to Child Psychologists on 21st August 2003

Thank you for such an excellent presentation around the evidence base for interventions in conduct disorder. It was so useful both for me in the work on the project we are working on, but also to the other Child Psychologists in the Children Looked After Team.

Yours sincerely

Nick Kirby-Turner
Consultant Clinical Child Psychologist
MINUTES OF CHILD PSYCHOLOGY MEETING
21st AUGUST 2003

PRESENT;

APOLOGIES;

Hazel gave a presentation to the meeting about Conduct Disorder and the evidence base for intervention. This was a very thoughtful presentation, which led to considerable discussion. This meant that there was no time for any other business items; all items to be carried over to the next meeting on 11th September.

The handouts provided by Hazel are attached to these minutes for those who were unable to attend.
Dear Hazel & Ali,

Thank you both for doing the joint workshop on externalising for the child developmental staff from the two child units on campus. I was very sorry that I was away so not able to be there.

Yours

Nick (Chairman)
SPECIALIST CLINICAL HEALTH PSYCHOLOGY PLACEMENT

SUMMARY

PLACEMENT DETAILS:

Dates: 7 April 2004 – 24 September 2004
Supervisor: Jackie Allt, Clinical Psychologist
NHS Trust: South Downs Health NHS Trust
Base: Department of Clinical & Counselling Psychology, Hove Polyclinic, Nevill Avenue, Hove, City of Brighton & Hove

Summary of experience: Experience was gained of delivering clinical psychology services within a health psychology specialty and local physical healthcare settings. This included therapeutic work incorporating cognitive-behavioural, solution-focused, narrative, structural systemic and psychodynamic approaches. Assessment measures administered included the BDI-II, HADS, CORE, Multi-dimensional Health Locus of Control Scale, General Self-Efficacy Scale, Brief Pain Inventory, Pain Catastrophising Scale, Roland-Morris Back Pain Questionnaire, Pain Self-Efficacy Questionnaire and Fatigue Scale. Vicarious experience of service-development work was also gained.

Clinical skills and experience: Clinical work with men and women aged 30 to 54 was conducted. These individuals presented with a wide range of concerns including multiple sclerosis, auto-immune disorders including lupus and anti-phospholipid syndrome, sight loss and mobility restrictions, endometriosis, chronic fatigue, chronic pain, heart disease and hypertension, diabetes and Crohn’s disease. An extended assessment with a woman with complex presenting needs including chronic pain, suicide risk and possible personality disorder involved multi-disciplinary liaison work.

Other experience:

• Shadowing supervisor at meetings and consultations with Palliative Care Team, Cardiac Rehabilitation Team and Sussex-wide CFS/ME Service Steering Group
• Meeting and shadowing Critical Care Outreach Nurse on ICU and ward visits
• Observing multi-disciplinary cystic fibrosis clinic