Abstract

Background: Cardiac disease is associated with adverse outcomes in pregnancy and is the leading cause of indirect maternal death in the United Kingdom (UK) and internationally. National and international guidelines recommend women should receive care from multidisciplinary teams; however evidence is lacking to inform how they should be operationalised.
**Objectives:** To describe the composition and processes of multidisciplinary care between maternity and cardiac services before, during and after pregnancy for women with cardiac disease, and explore clinicians’ (cardiologists, obstetricians, nurses, midwives) and women’s experiences of delivering/receiving care within these models.

**Design:** Mixed-methods comprising case-note audit, interviews and observation.

**Setting:** Two inner-city National Health Service (NHS) maternity units in the south of England serving similar obstetric populations, selected to represent different models of multidisciplinary team care.

**Participants:** Women with significant cardiac disease (either arrhythmic or structural, e.g. tetralogy of fallot) who gave birth between June 1st 2014 and 31st May 2015 (audit/interviews), or attended an multidisciplinary team clinic (obstetric/cardiac) during April 2016 (observation).

**Methods:** A two-phase sequential explanatory design was undertaken. A retrospective case-note audit of maternity and medical records (n=42 women) followed by interviews with a sub-sample (n=7 women). Interviews were conducted with clinicians (n=7) and observation of a multidisciplinary team clinic in one site (n=8 women, n=4 clinicians).

**Results:** The interests and expertise of individual clinicians employed by the hospital trusts influenced the degree of integration between cardiac and maternity care. Integration between cardiac and maternity services varied from an ad-hoc ‘collaborative’ model at Site B to an ‘interdisciplinary’ approach at Site A. In both sites there was limited documented evidence of individualised postnatal care plans in line with national guidance. Unlike pathways for risk assessment, referral and joined care in pregnancy for women with congenital cardiac disease, pathways for women with acquired conditions lacked clarity. Midwives at both sites were often responsible for performing the initial maternal cardiac risk assessment despite minimal training in this.
Clinicians and women’s perceptions of ‘normality’ in pregnancy/birth, and its relationship to ‘safe’ maternity care were at odds.

Conclusion: The limited evidence and guidance to support multidisciplinary team working for pregnancy in women with cardiac disease – particularly those with acquired conditions – has resulted in variable models and pathways of care. Evidence-based guidance regarding the operationalisation of integrated care between maternity and cardiac services – including pathways between local and specialist centres – for all women with cardiac disease in pregnancy is urgently required.

Keywords: cardiac disease, multidisciplinary team, preconception care, pregnancy, postnatal care.
Highlights

What is known already:

- Cardiac disease – particularly acquired conditions – is the leading cause of indirect maternal death in the United Kingdom (UK) during or up to six weeks after pregnancy with no significant change in maternal mortality rates from cardiac disease between 2006 and 2015.
- Reports have called for access to a coordinated multidisciplinary team to improve outcomes for mother and infant, yet there is limited evidence in health care literature, including systematic reviews, to support definition of optimal models of care.
- A survey of UK maternity providers has highlighted the lack of guidance for operationalising multidisciplinary teams, resulting in disparate models of care.

What this paper adds:

- This is the first study of integrated care for women in pregnancy with pre-existing cardiac disease.
- Key findings include the lack of clear guidance/pathways for women with acquired conditions; the influence of individual clinicians’ expertise and interest in pregnancy and cardiac conditions on the model of care provided; inadequate provision of training to ensure appropriate knowledge and skills for risk assessment and management; and lack of individualised care pathways for women.
- Research to identify the key elements of effective multidisciplinary team care across maternity settings and before, during and after pregnancy is needed.

Introduction and background

Pre-existing cardiac disease (disease that exists prior to pregnancy, rather than pregnancy induced) affects between 0.2-4% of pregnant women in the United Kingdom (UK)(1) and remains the leading indirect cause of maternal death globally(6-
11), including in the UK and Ireland(2-4). This includes for example arrhythmias (acquired) and structural defects such as tetralogy of fallot (congenital). Approximately two thirds of cases seen in specialist clinics are congenital in nature (5) but this is likely to underestimate the prevalence of acquired conditions that often go undetected/un-referred to such clinics. Recent UK data published on severe morbidity and deaths from cardiac causes during 2009 to 2014 found lack of co-location of obstetric and cardiac services jeopardised interdisciplinary working, communication and referral between clinical specialties(2).

Guidelines published in a number of countries worldwide (including UK, Australia, Canada, Japan and South Africa) for the management of pregnant and postnatal women with cardiac disease have recommended that women should have access to a coordinated multidisciplinary team with input from specialist obstetric and medical professionals(2, 3, 12-16). The multidisciplinary team members generally referred to in such guidelines include an obstetrician, cardiologist (or obstetric physician) and anaesthetist. Only one guideline (from Japan)(16) includes a nurse or midwife being present. This omission is despite some maternity care settings, such as in the UK, where all pregnant women have access to midwifery care as part of a universal health system, regardless of whether their pregnancies are deemed high or low risk (17). In 2016 National Health Service England published ‘Congenital Heart Disease Standards & Specifications’(18) which included that women should have access to a multidisciplinary cardiac-obstetric team, and specifying referral pathways based on cardiac risk (based on the modified World Health Organization (WHO) criteria I-IV depending on risk of maternal mortality or morbidity; repaired tetralogy of fallot and unrepaired cyanotic heart disease are examples of WHO II and III respectively)(19).
Team composition for specialist adult congenital heart disease centres should include “consultant obstetrician, midwives, adult congenital heart disease cardiologist, a nurse specialist and access to consultant obstetric and cardiac anaesthetists and haematologists with expertise in the care of pregnant women with congenital heart disease. There is no equivalent guidance for women with acquired cardiac conditions. A UK-wide survey of current models of multidisciplinary team care for women with cardiac disease reported wide variability across the UK(20) and a systematic review undertaken by the same team, identified limited primary evidence to inform the structure or working practices of such teams, their impact on clinical outcomes or patient experience(21).

Multidisciplinary team working, including the features of team composition, function and processes are well defined in national guidance in other clinical areas, including cancer care(22) with evidence of benefits including improved patient outcomes(23) and better coordinated patient care(24). Team composition for breast cancer, for example, should include personnel who “have experience with breast cancer patients, substantial fixed time commitment to breast cancer patients, and where appropriate specialist qualifications in breast cancer work” Membership includes: breast surgeon(s), breast care nurse(s), pathologist, radiologist, oncologist, coordinator and team secretary.

Given that women with cardiac disease who become pregnant have (at least) two ‘conditions’, the guidance regarding management of co- or multi- morbidity is relevant to consider. In 2014, the Department of Health in England(25) recommended changes in the structure of health services to implement multidisciplinary team models for
people with co-morbidity in the general population, however the guidance lacks specific detail, simply recommending use of ‘multidisciplinary approaches’ but not what these should comprise. More recently, the UK National Institute for Health and Care Excellence (26) has published guidance on the clinical assessment and management of adults with multi-morbidity (multiple long-term conditions). Whilst this lacks specific reference to multidisciplinary team working, they recommended further high-quality research on alternative approaches to organising care for these individuals, particularly in primary care.

1. Research Aims
In the absence of formal guidelines regarding how multidisciplinary teams should be operationalised in maternity care(21), this mixed methods study aimed to (i) describe, and examine factors influencing, the multidisciplinary team models offered in two National Health Service (NHS) hospitals between maternity and cardiac services before, during and after pregnancy for women with pre-existing cardiac disease (acquired or congenital); (ii) audit the multidisciplinary team care provided for a cohort of women with cardiac disease against best practice recommendations(12, 19, 27, 28); and (iii) explore clinicians’ and women’s experiences of delivering/receiving care within these models.

3. Methods
3.1 Setting & Sampling
Data were collected from two inner-city NHS maternity units in the south of England situated within the same local health authority area (Site A and Site B). Sites were purposively selected that served similar obstetric populations. Both had around
6,000 births each year, served populations with high levels of social-deprivation, with high proportions of women from black and other ethnic minority groups. The sites were known to have different multidisciplinary team models of care and cardiac populations based on previous survey work by the authors (20). Study site selection meant that findings could be more generalizable by including examination of multidisciplinary team care in the context of more ‘routine’ lower risk populations and populations with broader categories of cardiac disease. The risk profile of populations was defined though application of the modified WHO classification of maternal cardiovascular risk to the cardiac diagnoses of women (19). In this classification, women with conditions such as uncomplicated, small or mild pulmonary stenosis; and most arrhythmias have small to moderate maternal cardiovascular risk and are classified as WHO I or II, whereas conditions such as Marfan syndrome and other complex congenital conditions, or Pulmonary arterial hypertension have higher risk (or pregnancy is contraindicated) and would be classified as WHO III or IV. Site A was a specialist centre for congenital cardiac disease in pregnancy, which accepted local, regional and national referrals of women with acquired and congenital conditions in all cardiac risk categories (WHO I-IV). In comparison, the women with cardiac disease in pregnancy cared for by Site B were predominantly ‘low-risk’ (WHO I-II) local women with acquired cardiac conditions. All women, classified as having significant cardiac disease (WHO II-IV), either structural or arrhythmic, were included, based on the maternal cardiac risk classification developed by WHO (19,29).
3.2 Theoretical Model

An evidence-based model describing factors influencing effectiveness in healthcare teams underpinned this study. The model extends the integrated team effectiveness model, developed by Lemieux-Charles and McGuire (30) by incorporating a typology of degree of integration in healthcare teams developed by Boon et al. (31), hypothesised to moderate team effectiveness (Figure 1). Boon et al. (31) provide a typology of degree of integration, from working 'in parallel' (working in a common setting but each practitioner performs their job within their own scope of practice) to multidisciplinary (a team that plans patient care but where individual team members continue to make their own decision/recommendations that may be integrated by the team leader) through to integrative care (interdisciplinary, non-hierarchical blending of both conventional medicine and complementary and alternative health care that provides a seamless continuum of decision-making and patient-centred care and support).

Figure 1: Extended integrated team effectiveness model (Lemieux-Charles & McGuire 30 incorporating Boon et al. 31)
3.3 Design

3.3.1 Phase one: case-note audit

Women who gave birth between June 1st 2014 and 31st May 2015 at either site were screened for audit inclusion. All women classified as having significant cardiac disease – either structural (e.g. tetralogy of fallot) or arrhythmic – were included, based on the modified maternal cardiac risk classification developed by the WHO from the European Cardiac Society guidelines(29). Those diagnosed, for example, with Postural Orthostatic Tachycardia Syndrome and palpitations thought to be physiological awareness of normal tachycardia were excluded.

Recommended processes of care, based on the available guidance (12, 27-28) for the antenatal and postnatal periods were collated and formed the basis of the audit standards. Four processes of care at the two stages of the pathway which involved co-ordinated multidisciplinary care were identified and included in the data collection form used for each woman (Table 2). Each was rated as either present or absent on the basis of review of electronic and paper maternity and medical records. Demographics and pregnancy and cardiac condition details were also collected (Table 1). The audit was completed by (FM) at both sites, with support from a clinical research fellow at each site (who had experience of searching maternity notes at each site).

Data were collected over a five month period between February 2016 and June 2016 inclusively. Local research approvals were obtained with confirmation by Caldicott
Guardians at each site that ethical approval was not required due to being an audit of practice to collate data which would be anonymised.

3.3.2 Phase two: interviews

At both sites, clinicians from maternity and medical teams were purposively selected for interview to ensure breadth and inclusion of all main clinical specialities. This included consultant obstetricians and physicians (medical doctors), specialist cardiac nurses (registered nurses who may have completed additional training in coronary care), and specialist midwives (registered midwives who may have completed additional training in coronary care). Women were purposively sampled from the case-note audit sample to enable exploration of multidisciplinary team care received before, during and after pregnancy, aiming for maximum diversity in relation to factors including type of cardiac condition (congenital and acquired), maternal cardiac risk (diagnoses that are WHO I, II and III rated) and adherence to guideline recommendations. As audit data were anonymised and women’s permissions were not required to review their maternity records, a member of the clinical team identified women eligible to participate, and made the initial approach with respect to asking if they would be prepared to be interviewed by the research team. Women were aware that they were being asked to participate because of their cardiac history and as they had given birth between June 1st 2015 and May 31st 2015.

Semi-structured interviews with clinicians and women took place either face-to-face or over the telephone between April and May 2016. Interviews lasted 20-40 minutes and were digitally recorded and transcribed verbatim. Interviews were conducted by (FM)
who had received formal training in qualitative research methods, supported by supervisors with expertise in qualitative methods (CT, DB).

The purpose of the interview with clinicians was to explore their perceptions and experiences of multidisciplinary team working practices, guided by the model (Figure 1)(30,31). The topic guide for women encouraged discussion of their experiences of obstetric and cardiac care (in particular the extent of integration) from planning their pregnancy through to the late postnatal period (e.g. up to 42 days post-birth). Emergent findings from the observation phase (e.g. lack of midwifery involvement) and case-note audit (e.g. lack of evidence of pre-pregnancy counselling) informed subsequent interviews with staff and women. Where possible, results from the audit were checked with women during interviews to validate the audit and support interpretation of the data (e.g. whether absence was likely to infer missed care or missed documentation of care).

3.3.3 Phase three: observation of multidisciplinary team care

Non-participant observation of joint obstetric-cardiac care was planned at both sites. However, it was only possible to observe the multidisciplinary team care at Site A. At Site B women were seen in a uni-disciplinary (obstetric only) clinic that included women with a range of medical conditions (not solely cardiac). There were no joint cardiac/obstetric meetings held in the period of data collection. We were unable to observe consultations with women in the obstetric clinic as the obstetricians did not know women’s diagnoses prior to them attending, and therefore we could not assess for eligibility and send information about the study prior to attendance to allow for informed consent for observation.
Clinicians and women who attended the cardiac-obstetric clinic at Site A for a pre-pregnancy or antenatal appointment during three week period were invited to participate in the observation study. An observational proforma was developed that incorporated two parts (part A for general information on the clinic e.g. room layout and positioning of team members/women in the room; and part B completed for each individual woman/appointment with prompts regarding aspects of the model (figure 1)(30,31), to capture communication, decision-making, leadership, and the degree of integration between health professionals to plan and implement joint working. The capture of data in relation to the content of the discussion between women/partners and clinicians was additionally informed by the ‘patient centred consultation model’ (32) in relation to the extent to which discussions and decisions incorporated both the perceptions and experiences of the women (e.g. concerns, expectations, effects) and the disease/pregnancy focus of the clinicians (e.g. symptom monitoring, signs, investigations, underlying pathology).

**Details of ethical approval**

The research was carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) (34). Nottingham 1 Research Ethics Committee approved this study on the 11th March 2016 (Ref: 16/EM/0071). Written informed consent for interviews and observation was obtained from all participants.

**3.4 Data Analysis**

Audit data are presented descriptively (percentage adherence with recommendations).
Interview/observation data were analysed thematically using Framework method(34) and applied a combined deductive and inductive approach with the evidence-based model (Figure 1)(30,31) providing the framework for identifying initial themes. As new themes emerged from the data, the theoretical model was used to help interpret the findings and to integrate observation and audit data.

Interview transcripts were analysed using an iterative process, starting with one transcript and gradually encompassing more of the data, and discussion of emergent themes/sub-themes with the research team (FM, DB, CT). This resultant thematic framework was applied to each transcript. Data pertaining to each theme/sub-theme were extracted from each transcript and organised in matrices. This facilitated comparison across and within individual and grouped cases (e.g. staff vs. women; by study site), resulting in descriptive conclusions clustered around the themes(35). Patterns and relationships between themes were then analysed to ensure conclusions moved beyond these descriptive inferences.

4. Results
4.1 Quantitative
Forty-two women were included in the audit of maternity and medical records (20 women from Site A and 22 from Site B). Most were white European, aged 30-39 and primiparous (first pregnancy) (Table 1). The women cared for at Site A and B had similar clinical and demographic characteristics (Table 1); the key difference being that Site B predominantly cared for women with acquired cardiac conditions, and all had ‘lower risk’ conditions.
Table 1: Demographic details of audit

<table>
<thead>
<tr>
<th>Demographic Information</th>
<th>Site A N (% of women) N=20</th>
<th>Site B N (% of women) N=22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤19</td>
<td>1 (5)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>20-24</td>
<td>0 (0)</td>
<td>3 (14)</td>
</tr>
<tr>
<td>25-29</td>
<td>3 (15)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>30-34</td>
<td>8 (40)</td>
<td>11 (50)</td>
</tr>
<tr>
<td>35-39</td>
<td>6 (30)</td>
<td>5 (23)</td>
</tr>
<tr>
<td>≥40</td>
<td>2 (10)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Nationality</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White European</td>
<td>17 (80)</td>
<td>16 (74)</td>
</tr>
<tr>
<td>Asian</td>
<td>0 (0)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>1 (5)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Black African</td>
<td>1 (5)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Missing</td>
<td>1 (5)</td>
<td>2 (9)</td>
</tr>
<tr>
<td>Parity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>11 (55)</td>
<td>16 (74)</td>
</tr>
<tr>
<td>1</td>
<td>6 (30)</td>
<td>4 (18)</td>
</tr>
<tr>
<td>2</td>
<td>2 (10)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>≥3</td>
<td>1 (5)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>BMI at first antenatal appointment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤18</td>
<td>3 (15)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>19-24</td>
<td>12 (60)</td>
<td>15 (69)</td>
</tr>
<tr>
<td>25-29</td>
<td>4 (20)</td>
<td>6 (27)</td>
</tr>
<tr>
<td>≥30</td>
<td>1 (5)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Missing</td>
<td>0 (0)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Gestation at first antenatal appointment (weeks)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤10</td>
<td>4 (20)</td>
<td>9 (42)</td>
</tr>
<tr>
<td>11 to 20 weeks</td>
<td>8 (40)</td>
<td>11 (50)</td>
</tr>
<tr>
<td>21 to 29</td>
<td>5 (25)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>≥30</td>
<td>3 (15)</td>
<td>1 (4)</td>
</tr>
<tr>
<td>Mode of birth</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spontaneous</td>
<td>11 (55)</td>
<td>10 (45)</td>
</tr>
<tr>
<td>Instrumental</td>
<td>3 (15)</td>
<td>25 (23)</td>
</tr>
<tr>
<td>Caesarean</td>
<td>6 (30)</td>
<td>7 (32)</td>
</tr>
<tr>
<td>Type of Cardiac Disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Acquired</td>
<td>9 (45)</td>
<td>18 (82)</td>
</tr>
<tr>
<td>Congenital</td>
<td>11 (55)</td>
<td>4 (18)</td>
</tr>
</tbody>
</table>
Receipt of multidisciplinary team care as documented in their maternity records varied according to site (Table 2). This was not unexpected (due to differences in populations of women with acquired and congenital disease, and the purposive sampling of different multidisciplinary team models), but was more noticeable than anticipated. While all women at Site A attended at least one multidisciplinary team clinic during their pregnancy, no women attended a joint cardiac obstetric clinic at Site B. In the notes for five women at Site B, the need for cardiac specialist input during their pregnancy was mentioned. These five women saw a cardiologist during their pregnancy but at separate appointments to their obstetric care.

Guidance recommends that individual care plans are developed which include management of a woman’s labour and her immediate postnatal care(36). These were poorly documented at both sites, with only a fifth (8) of women’s notes including a pre-specified care plan. Similarly, less than half of women (n=17, 40%) had an individualised postnatal follow-up care plan in their notes that included documentation of timing of General Practitioner and cardiology appointments.

Table 2: Key processes from case-note audit

<table>
<thead>
<tr>
<th>Stage</th>
<th>Outcome</th>
<th>Site A N (% of women) N=20</th>
<th>Site B N (% of women) N=22</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antenatal</td>
<td>Women with medical disorders in pregnancy should have access to a coordinated</td>
<td>10-19 weeks</td>
<td>8 (40)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>20-29 weeks</td>
<td>4 (20)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>≥30 weeks</td>
<td>7 (35)</td>
<td>0 (0)</td>
</tr>
<tr>
<td><strong>multidisciplinary team obstetric and medical clinic.</strong></td>
<td><strong>Not seen</strong></td>
<td><strong>1 (5)</strong></td>
<td><strong>22 (100)</strong></td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
<td>-------------</td>
<td>-----------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>Did women with cardiac conditions receive obstetric AND cardiac input together OR a cardiologist with expertise in the care of pregnant women?</td>
<td><strong>Yes</strong></td>
<td>20 (100)</td>
<td>0 (0)</td>
<td>Knight et al. (2014)</td>
</tr>
<tr>
<td></td>
<td><strong>No</strong></td>
<td>0 (0)</td>
<td>22 (100)</td>
<td></td>
</tr>
<tr>
<td>Did women receive an individual care-plan with input from relevant specialties?</td>
<td><strong>Yes</strong></td>
<td>7 (35)</td>
<td>1 (5)</td>
<td>Knight et al. (2014)</td>
</tr>
<tr>
<td></td>
<td><strong>Not documented</strong></td>
<td>13 (65)</td>
<td>21 (95)</td>
<td></td>
</tr>
</tbody>
</table>

| **Postnatal** | Was a postnatal care-plan completed including timing of follow-up appointments with appropriate services? | **Yes** | 9 (45) | 8 36) | Knight et al. (2014) |
|--------------|--------------------------------------------------|----------|----------|-------------------|
|              | **Not documented**                               | 11 (55) | 14 (64) |                  |

### 4.2 Qualitative

Eight clinic appointments were observed at Site A by (FM), and interviews were conducted with seven clinicians (Site A=5, Site B=2) and seven women (Site A=4, Site B=3). All women had congenital cardiac disease. The sample for interview at Site A consisted of three women with congenital cardiac disease and one woman with acquired cardiac disease. At Site B all three women had acquired cardiac disease. No participants declined to take part.

#### 4.2.1 Model of integrated care

The degree of integration between healthcare professionals – using a typology of team oriented healthcare practice which describes seven models ranging from parallel to integrated (31) – varied between the two sites. Site A provided a weekly cardiac-obstetric multidisciplinary team clinic for women with either acquired or congenital conditions. The clinic was run by a cardiologist, cardiac specialist nurse, obstetrician and obstetric physician and would be defined as an ‘interdisciplinary’ model of team
working: where “team members begin to make group decisions) about patient care facilitated by regular face-to-face meetings” (31). Team processes, such as decision-making and leadership, underpinned by the integrated team effectiveness model (30) model were documented in observational field-notes:

“Problem solving occurs between team members to obtain a full background history of the woman. It happens swiftly and efficiently – for example, whilst the obstetrician is conducting her examination of the woman behind the curtain, the obstetric physician and cardiac nurse specialist discuss the bundle of notes in the corner discreetly and the cardiologist works at the computer. In areas unfamiliar their clinical field, they will fact check with each other. For example the obstetrician checks with the obstetric physician about the cleft palate team and choice of lamotrigine for medication. There follows a discussion without conflict or interruptions to gain clarification and knowledge” – Researcher field-notes

The obstetrician described the clinic as a “one stop shop” for women who required high levels of clinical input and that decision-making was “ironed out within thirty seconds of conversation” which facilitated joint working, team cohesion and communication between clinical disciplines.

In comparison, Site B’s model of team working would be defined as ‘collaborative’: “practitioners who normally practice independently share information concerning a patient who is being treated by each of them. The collaborations are ad-hoc in nature and occur informally on a case-by-case basis”(31). Team membership of the obstetric clinic attended by women with cardiac conditions was uni-disciplinary and varied
weekly due to the rotation of junior doctors. Furthermore, clinicians had no prior information on which women were attending or their medical conditions. Site B cared for lower risk women with a diagnosis of acquired cardiac disease. Women with congenital conditions were usually referred to Site A or other specialist congenital centres within the region. The lead obstetrician at Site B reported that they were responsible for assessing maternal cardiac risk and deciding if specialist cardiac input was required, in which case an ad-hoc multidisciplinary team meeting would be arranged, usually with the hospital’s heart failure team. Membership of the multidisciplinary team in these cases comprised a cardiologist, obstetrician, and anaesthetist. It was unclear if midwives were included: the obstetrician at Site B stated they were, but a midwife interviewed from this site stated they were not. The women themselves (or their family members) were not present at these multidisciplinary team meetings and clinicians at Site B said they acted as the woman’s advocate.

Four main themes emerged from analysis of interview and observational data: 1) the influence of clinicians’ specialist interest in pregnancy and cardiac conditions on model of care; 2) clarity of acquired vs. congenital pathways; 3) midwifery involvement; and 4) the interpretation of normality. These four themes map directly to core components in the integrated team effectiveness model (30), illustrated in Figure 2.
4.2.2 The influence of clinicians’ specialist interest in pregnancy and cardiac conditions on model of care

Employing individuals with expertise and interest in pregnancy and cardiac disease clearly impacted on the model of multidisciplinary team working. At Site A, the appointment of a cardiologist with specialist interest in adult congenital cardiac disease and pregnancy had informed the evolution of their multidisciplinary team clinic and its composition, including the involvement of a cardiac nurse specialist rather than a midwife:

“The cardiac nurse specialist is a very strong part of the congenital heart disease team. So it was almost a given once you had the consultant, you would have the cardiac nurse specialist as well.” – Clinician, Site A
Clinicians at Site B described that lack of expertise/interest in pregnancy complications amongst the cardiologists in the hospital as a key barrier to joint working, and rationale for the ad-hoc ‘collaborative’ team working that subsequently emerged. The cardiologists women were referred to in pregnancy were therefore selected according to cardiac sub-type rather than because of their joint pregnancy/obstetric and cardiac knowledge.

“Our cardiology department didn’t want to identify a consultant with an interest in heart disease in pregnancy… their preference was that we would ask a cardiologist who had the correct sub-specialty interest to see the patient” – Clinician, Site B

4.2.3 Clarity of acquired vs. congenital pathways

Clarity in relation to care pathways including access to specialists differed for women with acquired cardiac disease and those with congenital cardiac disease.

*Congenital Conditions*

The three women interviewed with congenital conditions at Site A described a good understanding of their condition and therefore knew who to approach when they became pregnant:

“I have a good understanding of care because they’ve been good from when I was diagnosed with it – I’ve always been under the care of somebody.” – Woman, Site A
Although pre-pregnancy counselling was offered as standard in the cardiac-obstetric and adult congenital cardiac disease clinic at Site A, all three women interviewed from this site had been cared for previously at another hospital, and only referred once pregnant. All stated they had not received pre-pregnancy counselling from their local hospital.

Clinicians at Site A described offering a clear antenatal pathway of care for women with congenital conditions who delivered at Site A. If women with congenital cardiac disease booked for their pregnancy care and planned to give birth at Site A, they were referred to the cardiac-obstetric multidisciplinary team and specialist high-risk midwifery team for antenatal care. Postnatal transfer of these women to the primary care team was described as “straightforward” by the clinicians, with support from the cardiac nurse specialist who provided continuity of contact for women from pre-pregnancy to post-natal inpatient discharge. This ensured women received on-going care and referral back to local services. One woman described the presence of the cardiac nurse specialist in the multidisciplinary team as reassuring:

“I was glad that I knew that the cardiac nurse specialist was there because I used to see her at my district general with my other doctors. That was nice that she was there.”

– Woman, Site A

Two of the three women also described a fairly quick referral process:
“It seemed very smooth. I remember I got a letter about it, because I remember giving it to work so they could see why I had to take the time off. And it was like a matter of weeks really I had to wait” – Woman, Site A

The challenge arose when women chose to deliver locally, as clinicians had “no control” over the planned antenatal or on-going postnatal care a woman received at her local unit. Women and clinicians at Site A described that postnatal cardiac care was often fragmented when women were referred back to their local hospital, as one woman with congenital cardiac disease explained:

“I went to my local hospital here to see someone and to be honest, they didn’t have my notes, and they were just like “so what’s your heart condition and this and that”. And I’ve been suffering with chest pains quite a lot now, so I’ve been suffering with that, and I went to her and she said “I can’t give you any medicine because to be honest I’m not a specialist”. And I was like “well why am I here then? Why did you not just give me to the specialist in the first place?!?” – Woman, Site A

Site B described using ‘informal referral pathways’ - rather than clearly defined guidance and pathways - to determine the best placement of care for women who presented with adult congenital cardiac disease. Decisions about whether to refer were based upon the lead obstetrician’s “knowledge and experience of cardiac disease in pregnancy” – Clinician, Site B.
Acquired Conditions

In contrast to the congenital pathway, clinicians and women at both study sites highlighted that pathways for women with acquired cardiac conditions in pregnancy were unclear and fragmented. Prior to becoming pregnant, only one of the four women with acquired conditions interviewed were offered pre-pregnancy counselling and this was at a hospital outside the UK. Clinicians corroborated the lack of appropriate pre-pregnancy care for women with acquired cardiac conditions, as one clinician explained:

“It’s a massive hole, just like postnatal follow-up is a massive hole. There’s all this money put in antenatal care, but actually the bit before is really important” – Clinician, Site A

Once pregnant, women described confusion about their on-going pregnancy and cardiac care, often because they were not previously under the care of a cardiologist:

“…it was very confusing, I had a lot of mixed messages from various different people telling me completely different things.” – Woman, Site A

Postnatal care was similarly described as not joined up, resulting in women being uncertain over who to approach and when for postnatal cardiac follow-up. This was particularly the case for women having their first babies:
“I saw the cardiologist six months after I delivered, nothing before the six months, I haven’t seen any one or spoken to anyone about how I feel or what happened… the midwife visits I had but no one asked about my heart” – Woman, Site B.

4.2.4 Midwifery involvement

Midwifery involvement in the multidisciplinary team was lacking at both sites. The midwives interviewed viewed their role as distinct from medical personnel and did not consider that they needed to be included in the multidisciplinary team:

“My job isn’t to determine medical care that a woman gets. My job is to make sure she understands what is going on around her... I don’t need to be involved in an multidisciplinary team to do that.” – Midwife, Site B

In contrast, other clinicians at both sites referred to the important role of midwives in undertaking maternal cardiac risk assessment at antenatal booking and their role in ensuring women identified with problems were placed on an appropriate pathway of care. However, midwives reported receiving minimal training on maternal and/or infant morbidity associated with high risk pregnancies, including cardiac disease, or how to assess a woman’s level of health risk. One midwife described:

“We do a few extra [post qualification] study days on any complications in pregnancy… but not a whole course.” – Midwife, Site A
Despite this, women interviewed identified their midwife as a key clinician in their antenatal care, who could help to dispel fear or anxiety surrounding their diagnosis and reassure them about their safety and that of their infant:

“Once I met the midwives I felt much happier. It was the midwives that made me feel comfortable, made me feel actually, I was being looked after well. Because until that point I’d felt people weren’t really taking it very seriously.” – Woman, Site A

However, two women interviewed reported that cardiac health and wellbeing was lacking in the postnatal care they received from community midwives once they were home:

“The midwife visits I had, but no one asked about my heart… It’s really sad to be honest because I know how busy all midwives are, but really they’re just doing a box ticking exercise most of the time when they come after birth.” – Woman, Site B

4.2.5 Normality

Clinicians at both sites articulated that they wanted to avoid ‘over-medicalising’ women’s care, and ensure they experienced as ‘normal’ a labour/birth as possible:

“Our absolute mission statement is to achieve as normal a pregnancy, delivery and postpartum care for a woman with cardiac disease as we can safely achieve.” – Clinician, Site A
Site A clinicians explained part of their role was to offer reassurance to women with low maternal cardiac risk who were, in their opinion, inappropriately categorised as ‘high-risk’ at their local hospital. An obstetrician at Site A explained they often received inappropriate referrals of women with congenital cardiac disease because there was no specialist clinician available to perform the risk assessment in the woman’s local unit:

“We see a significant number of women who’ve been freaked out often by one member of staff at the home hospital who’s gone “Oh my god what are you doing here?! You need to be at Site A!” And often completely unjustifiably.” – Clinician, Site A

In contrast to clinicians’ interpretation of achieving ‘normality’ as a positive outcome, being told that they could be treated ‘normally’ instilled anxiety in some women. These women considered that their diagnosis of cardiac disease differentiated them from ‘normal’ women resulting in them feeling unsafe if placed on a low-risk care pathway:

“It was upsetting for me because with my medical past, I believe that I should have been treated a little bit different from a normal person. Because it’s my heart and it is my baby. And they said “no” they wouldn’t.” – Woman, Site A

One woman with acquired cardiac disease from Site B described the poor ‘fit’ between the label of ‘high risk’ with the care she received and the impact this had on her experience of labour:
“All the doctors were reassuring me that my situation was not really risky, there was not a serious problem, in the same moment I was assigned like ‘high risk pregnancy’ and this didn’t give me the opportunity to give birth naturally. And they told me that because of your heart problem the doctor has to have more easy access to you in case something would happen. So they didn’t let me do what I wanted. And I think also this is something that stressed me more… I mean if it was a ‘high risk’ pregnancy, I’m asking myself why there was not a doctor all the time with me, or why I gave birth with just one midwife if it was a ‘high risk pregnancy’. – Woman, Site B

5. Discussion

The importance of examining the organisation of care for women with cardiac disease in pregnancy is evident, given that this is the main indirect cause of maternal death in the UK and many other countries (1-3, 6-11). This exploratory study is novel in its exploration of views and perspectives of women and clinicians about antenatal and postnatal management of cardiac conditions in pregnancy, and audit of care processes provided at two sites. Underpinned by an evidence-based team effectiveness model(30) and consideration of degree of integration(31), the study extends understanding of the variability in multidisciplinary team care found in our earlier national survey(20), highlighting factors that influenced this variability.

A key finding of the current study was the lack of guidance/clarity regarding how joint maternity/cardiac care should be operationalised, with particular concern for women with acquired cardiac disease. Few women had an individualised care pathway, and joint working between local and specialist centres was lacking. Other key findings included limited documented evidence of women being in receipt of individualised
postnatal care plans, the influence of individual clinicians’ expertise and interest in pregnancy and cardiac conditions on the model of care provided, and an inadequate education/training strategy to ensure appropriate knowledge and skills in the maternity workforce to undertake risk assessment, referral and management of women with cardiac conditions in pregnancy. Clinicians and women’s perception of a ‘normal’ pregnancy and birth were at odds and care was described by women with acquired cardiac disease in particular as fragmented and uncoordinated.

There is a clear need to develop tailored maternity services for pregnant women who have acquired cardiac disease, with a more defined role for midwives, who could coordinate maternity care needs of women alongside multidisciplinary team input. In many high income settings (UK, Australia, New Zealand, Northern Europe), women have routine access to midwifery models of care, and further evidence of the midwifery role in support of women with medically complex pregnancies is needed. In the many settings which do not have midwifery models of care (for example, North America), the role of nurse-midwives in the multidisciplinary team who can also coordinate obstetric care needs to be considered further, as pregnant women who have cardiac disease will require alongside high quality pregnancy care.

Given maternal mortality rates attributed to women with structurally normal hearts, this is an important area for future research on system and service organisation(2). There have been calls for the development of services for these women, including screening and educational service(37) but UK National Institute for Health and Care Excellence or other organisations informing NHS care have not published guidance on the organisational care of women with acquired disease. The lack of guidance may explain
the fragmented care and poor communication (between clinicians and women, and between ‘hub and spoke’ sites) we identified. Study findings suggest the need for effective clinical staff training and education to ensure those providing care in local units have the knowledge and confidence to offer pre-pregnancy counselling to women who require this, and manage low risk women during and after pregnancy.

The audit of women’s case-note data suggests poor provision of care plans for postnatal cardiac follow-up. Similar findings have been reported in national reports for the care of complex conditions in pregnancy including epilepsy (38) and diabetes (39) and internationally, for example management of obesity risk knowledge for women giving birth in the United States (US) (40). Women with acquired conditions in particular in the current study described on-going cardiac care as not joined up with maternity care. UK National Institute for Health and Care Excellence guidance on routine postnatal care is currently under review to incorporate an increased focus on individualised models of care (41), however our findings suggest the need for additional specialist guidance for postnatal care of women with cardiac disease, in line with UK National Institute for Health and Care Excellence guidance on diabetes in pregnancy (42) antenatal and postnatal mental health problems (43) and hypertension in pregnancy (44).

The presence or absence of medical doctors, registered nurses and registered midwives with specialist interests in pregnancy and cardiac disease in the two sites appeared to directly influence the model of care provided. National Health Service England has published guidance on the configuration of congenital cardiac disease services, specifying procedures for referral, risk assessment and multidisciplinary
team composition (18) However, the guidance does not specify how multidisciplinary team members should work together in maternity settings. Guidance in other health care areas such as cancer where multidisciplinary team models are associated with improved care (23,45), specifies which clinicians should be part of the multidisciplinary team, which patients they should discuss and how frequently they should meet, as well as referral procedures between local, regional and supra-regional centres. Furthermore, guidance from the Royal College of Obstetricians and Gynaecologists on management of cardiac disease in pregnancy (12) which is based on expert opinion, also recommends the presence of an anaesthetist within the multidisciplinary team, however this was not routine practice at either site.

It was surprising that midwives were not included in multidisciplinary team meetings/clinics, and that those interviewed did not view their input to the multidisciplinary team as necessary. This is despite acknowledgement from the doctors interviewed of the benefits of midwifery involvement, including ensuring continuity of care and opportunities for shared learning between clinical disciplines consistent with recommendations from the recent National Maternity Review in England (46). If multidisciplinary team collaboration is to be achieved to optimise pregnancy outcomes for women with medically complex pregnancies, it will require provision of pre and post-registration education with inter-professional modules and training days, supported and endorsed by healthcare organisations responsible for setting standards in healthcare safety and quality. Services for planned joint clinical contacts and for women who require emergency admission will also need appropriate funding, with resources planned to meet need.
The Royal College of Obstetricians and Gynaecologists(12) recommend in guidance on the management of cardiac disease in pregnancy that clinicians performing maternal cardiac risk assessment in early pregnancy should have “appropriate experience” to ensure women are referred onto the correct pathway of care, but no further guidance on what this would look like was provided, probably based on an assumption that relevant pathways are available. The obstetrician at Site B and midwives at both sites undertook maternal cardiac risk assessments but without specialist training or frameworks to support this.

Findings from the current study suggest that clinicians would benefit from education and training to appropriately plan, manage and support the increasing number of women with more complex pregnancies. Midwifery 2020(17) which set out the vision for how UK midwives could lead and deliver care in a changing healthcare environment recommended that pre-registration midwifery curricula incorporated management of high-risk pregnancies, although does not describe how this could be supported in midwifery education programmes or clinical settings. The National Maternity Review in England (46) also called for improved multi-professional training to be provided as standard to ensure safe and effective maternity care, recognising that multidisciplinary team involvement is fundamental to achieving better outcomes. In England, the need to urgently review maternity workforce training follows recent investigations into poor outcomes at some maternity units for example, the Morecambe Bay Investigation Report (47). The need for qualitative research is recommended to explore what support and training is available for clinicians at local centres to undertake a maternal cardiac risk assessment.
Ensuring women were not over-managed and achieved a ‘normal and safe’ experience of pregnancy and labour was a focus of the clinicians’ practice, however, women’s perspectives highlighted that the use of such language (“normal”; “low risk”) did not make them feel safe, and some felt that their level of care did not reflect the label they were given. There was a possible poor understanding by women about ‘risk’ and women’s expectations of care differed from what happened in reality. The use of “high risk” labels by clinicians in local sites who referred women and often provided the majority of their care generated fear and stigma among women, which was difficult for clinicians in the specialist sites to undo. This emphasises the subjective nature of risk perception among those providing and those in receipt of care (48) and how use of medical terminology can impact on women’s experience of perinatal care (49). This is consistent with findings nationally (50) and internationally (51) on the impact ‘risk’ language has for pregnant women who are classed as obese at pregnancy commencement. There is a need to ensure that cardiac ‘risk’ is clearly understood by the women, this was particularly lacking in those with acquired conditions. The women interviewed explained they were unaware of the implications their cardiac condition on their or their baby’s safety.

6. Strengths and limitations

This study provides new insights to an aspect of maternity care that is currently lacking in guidance: the optimal management of women with pre-existing cardiac disease (20). The use of mixed methods allowing for depth of data collection and analyses, and the purposive selection of two organisations with different service models supports further depth of understanding regarding the current provision of care in this context.
The audit was based on review of maternity notes and electronic patient records to identify relevant patient information. It had been intended to audit the receipt of pre-pregnancy counselling due to the importance in this population; however it was not possible to do this reliably as some women, particularly at Site A, were referred during pregnancy. Therefore, any pre-pregnancy counselling they received would not have been documented in the notes that we had permission to review. The interview and audit samples were small and findings cannot necessarily be generalised, they do build upon a previous national survey of diversity in models of multidisciplinary team obstetric-cardiac care(20) and provide evidence to consider reasons and consequences for this. Future research should examine the relationship between multidisciplinary team care and clinical outcomes.

It was only possible to observe the multidisciplinary team care at Site A which means the findings cannot be compared between sites. Observational methods provide direct access to the phenomena being researched – in this case multidisciplinary teamwork – providing rich insights that cannot be gained through others’ perspectives alone. This enabled us to see how the team worked – how decisions and plans were made and the role of the woman and her partner in this - rather than simply asking others to describe this to us. The sample of women interviewed was similar across the two sites with respect to demographic factors.

7. Conclusion
There is limited evidence to support multidisciplinary team working in the care of pregnant women with cardiac disease, particularly those with acquired conditions. The
expertise/interests of individual clinicians within multidisciplinary teams have resulted in variable models and pathways. Evidence based guidance regarding the operationalisation of joined care between maternity and cardiac services – including pathways between local and specialist centres – for all women with cardiac disease in pregnancy is urgently required.

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