

The Internet, Online Support and You

Introduction

****YOU NEED ONLY COMPLETE THIS SURVEY ONCE. PLEASE DO NOT COMPLETE IT AGAIN IF YOU OR ANYONE ELSE LIVING IN YOUR HOUSEHOLD HAS ALREADY COMPLETED ONE.****

****THIS SURVEY IS FOR UK-RESIDENT PARENTS OF PEOPLE WITH RETT SYNDROME ONLY.****

WHAT IS THIS ABOUT?

I am investigating whether the Internet and online support is used more by any particular groups of parents of people with Rett syndrome.

WHAT IS THIS FOR?

It is being carried out for the first part of my PhD at the University of Surrey. Rett UK and other support organisations have helped me to reach parents who might be interested and Rett UK members have helped me to edit this survey. However, nobody but me will see the results of each survey.

HOW LONG WILL IT TAKE?

In tests it took between 10-15 minutes to complete. You can leave this survey and return to it later **ONLY** if you use the same computer **AND** you have Cookies enabled (see your help menu for how to do this for your web browser). If you do this, please be aware that anyone else using your computer will be able to see your responses until you complete or exit the survey. There is an option to participate in the next stage of the research for current and recent users of online support.

HOW WILL MY INFORMATION BE PROTECTED?

All data from these questionnaires and future stages of research will be anonymised and kept securely in accordance with the Data Protection Act (1998). **YOUR IDENTITY WILL NOT BE REVEALED TO ANYONE ELSE AT ANY POINT.** Only anonymised summaries of data will be published as part of my PhD report and in related publications, presentations and teaching materials. By taking part you are consenting to the use of your data in this way.

WHAT IF I DON'T WANT TO ANSWER SOMETHING OR I CHANGE MY MIND ABOUT TAKING PART?

There is no obligation to complete this survey if you change your mind nor to answer any questions you do not wish to answer. If you change your mind and do not complete the survey, your data will not be included in the study. However, please be aware that if you do complete the survey your data cannot be withdrawn at that point.

IF YOU HAVE ANY QUESTIONS BEFORE COMPLETING THIS SURVEY, please contact Jo Belcher at j.belcher@surrey.ac.uk or on 07583 641437. You can also contact my lead university supervisor, Dr Christine Hine, if you have any concerns about the study (c.hine@surrey.ac.uk or 01483 68 6986).

THANK YOU for your interest in my research.

Jo Belcher
(PhD student, University of Surrey)

Sources of support

1. Did you hear about this survey from... (Please choose and tick one answer per row)

	Yes	No
a. ...a letter addressed to someone in your household?	<input type="radio"/>	<input type="radio"/>
b. ...Rett UK's newsletter?	<input type="radio"/>	<input type="radio"/>
c. ...Rett UK's Facebook page?	<input type="radio"/>	<input type="radio"/>
d. ...@RettUK on Twitter?	<input type="radio"/>	<input type="radio"/>
e. ...Carers UK's Online Forum?	<input type="radio"/>	<input type="radio"/>
f. ...a PMLD Network Forum email?	<input type="radio"/>	<input type="radio"/>
g. ...a friend?	<input type="radio"/>	<input type="radio"/>
h. ...another place or places? (Please describe below)		

2. How important do you yourself find the following sources of support related to parenting someone with Rett syndrome?

(This includes INFORMATION, ADVICE or SUPPORT related to Rett syndrome, learning and/or physical disability and caring for someone with Rett syndrome).

Please choose and tick one answer per row.

	Essential	Very important	Important	Not so important	Not important at all	Never used
a. Telephone helplines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Online support and advice (seen on websites, blogs, discussion boards, Facebook groups, chat rooms or emails from email groups)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Local support groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Local health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***3. Do you currently use the Internet on any device (at home, work, school, college or elsewhere)?**

Please choose and tick one answer

Yes

No

4. Have you EVER used the Internet on any device (at home, work, school, college or elsewhere)?

Yes

No

Use of the Internet

5. Do you currently access the Internet in the following places?

(Please choose and tick one answer per row)

	No	Yes
a. At home	<input type="radio"/>	<input type="radio"/>
b. On the move/while travelling (e.g. through a mobile phone, tablet or wireless dongle)	<input type="radio"/>	<input type="radio"/>
c. Another person's home	<input type="radio"/>	<input type="radio"/>
d. At work	<input type="radio"/>	<input type="radio"/>
e. At school/At college/At university	<input type="radio"/>	<input type="radio"/>
f. Internet Café	<input type="radio"/>	<input type="radio"/>
g. Public library	<input type="radio"/>	<input type="radio"/>

*6. Have you been using the Internet for over a year?

- Yes
- No

7. For about how many months have you been using the Internet?

(Please type the number of months into the box below)

8. For about how many years have you been using the Internet?

(Please type the number of years into the box below)

9. How would you rate your ability to use the Internet?

(Please choose and tick one answer)

- Excellent
- Good
- Fair
- Poor
- Bad
- Don't know/can't say

10. The next questions ask about ‘shared online support messages’ posted by other carers. These are messages asking for or giving support and advice related to caring for someone else. These messages are posted on a website or in an email group so they can be seen by others using it. The following statements give examples of places you can read shared online support messages posted by carers.

Have you EVER read a shared online support message posted by a carer...

(Please choose and tick one answer per row)

	Yes	No	Don't know
a. ...in an EMAIL GROUP/DISTRIBUTION LIST (e.g. PMLD Network Forum)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...in a CHAT ROOM (an online space where people can talk to other people who are online at the same time)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...on a WEB-LOG OR BLOG where other people can leave comments (e.g. a parent's record of their experiences)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...in THE COMMENTS SECTION OF A WEBSITE?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...in a DISCUSSION OR MESSAGE BOARD (e.g. Mencap's Families' Forum or Mumsnet, where messages are left)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...in comments left on FACEBOOK PAGES OR GROUPS (e.g. Rett UK Facebook page)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...on TWITTER (e.g. tweets under a hashtag #rettsyndrome, #carers)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

***11. When did you last read a shared online support message posted by a carer?**

(Please choose and tick one answer)

- Never
- Between 0-30 days ago
- Between 31 days ago to under three months ago
- Between three months ago to under six months ago
- Between six months ago to under a year ago
- Between a year and under two years ago
- Between two years and under three years ago
- Three years ago or longer

12. About how many years ago did you last read a shared online support message posted by a carer?

(Please type the number of years into the box)

13. People often read shared online support messages posted by carers **WITHOUT POSTING RESPONSES** themselves.

Please indicate how much you agree or disagree with these statements about reading shared online support messages posted by carers.

(Please choose and tick one answer per row).

	Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree strongly
a. Reading about other parents' experiences has made me feel less alone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Reading information and advice in shared online support messages has helped me to solve problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 14. Do you think you will read shared online support messages posted by carers again?

(Please choose and tick one answer).

- Definitely won't
- Probably won't
- Probably will
- Definitely will
- Don't know

15. There are a number of reasons why people might decide to stop reading shared online support messages posted by carers. Please say which of these reasons apply to you (if any).

(Please choose and tick one answer per row).

	Yes	No
a. I don't need any information, advice or support at the moment	<input type="radio"/>	<input type="radio"/>
b. I don't find them very useful	<input type="radio"/>	<input type="radio"/>
c. I disagree with most of what people say in them	<input type="radio"/>	<input type="radio"/>
d. I find it difficult to understand the jargon or language used in them	<input type="radio"/>	<input type="radio"/>
e. It is too time consuming	<input type="radio"/>	<input type="radio"/>
f. It's not for people of my age	<input type="radio"/>	<input type="radio"/>
g. I had a bad experience using one	<input type="radio"/>	<input type="radio"/>
h. Other (please describe below)	<input type="text"/>	

16. Have you EVER looked at...

	Yes	No	Don't know
a. ...PMLD Network Forum emails?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...The RettNet email list emails?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...Rett UK's Facebook page?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...IRSF (International Rett Syndrome Foundation)'s Facebook page?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...the Rett Syndrome Group for UK families (Facebook)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...the Rett Syndrome group (Facebook)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...Carers UK's Online Forum?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. ...Mencap's Families' Forum?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. ...the Special Kids in the UK Forum?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. ...the Mumsnet special needs discussion threads?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. ...the Rett Syndrome Parents Yahoo Group?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

17. How recently did you read ANY of the above sites and/or email group messages?

(Please choose and tick one answer).

- Never
- Between 0-30 days ago
- Between 31 days ago to under three months ago
- Between three months ago to under six months ago
- Between six months ago to under a year ago
- Between a year and under two years ago
- Between two years and under three years ago
- Three years ago or longer

18. About how many years ago did you read ANY of the above sites and/or email group messages? (Please click on the 'prev' button if you need to see the list again)

(Please type the number of years into the box)

19. Please list any other sites or email groups where you like to read shared online support messages posted by carers.

(Please type into the box below).

20. The following statements describe ways you can post a shared online support message to a website or email group used by other carers.

Have you EVER posted a shared online support message...

(Please choose and tick one answer per row).

	Yes	No	Don't know
a. ...in an EMAIL GROUP/DISTRIBUTION LIST (e.g. PMLD Network Forum)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...in A CHAT ROOM (an online space where people can talk to other people who are online at the same time) ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...on YOUR OWN BLOG?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...in THE COMMENTS SECTION ON A WEBSITE OR BLOG?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...on A DISCUSSION OR MESSAGE BOARD (e.g. Mencap's Families' Forum or Mumsnet, where messages are left)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...on A RELEVANT FACEBOOK PAGE OR GROUP (e.g. Rett UK Facebook page)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...on TWITTER (e.g. tweets under a hashtag #rettsyndrome, #carers)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

21. When did you last post a shared online support message?

(Please choose and tick one answer).

- Never
- Between 0-30 days ago
- Between 31 days ago to under three months ago
- Between three months ago to under six months ago
- Between six months ago to under a year ago
- Between a year and under two years ago
- Between two years and under three years ago
- Three years ago or longer

22. About how many years ago did you last post a shared online support message?

(Please type the number of years into the box)

23. Do you think you will post a shared online support message again?

(Please choose and tick one answer).

- Definitely won't
- Probably won't
- Probably will
- Definitely will
- Don't know

24. There are a number of reasons why some people might decide to stop posting shared online support messages. Please say which of these reasons apply to you (if any).

(Please choose and tick one answer per row).

	Yes	No
a. My posts/emails/tweets tend to get ignored	<input type="radio"/>	<input type="radio"/>
b. I don't need any information, advice or support at the moment	<input type="radio"/>	<input type="radio"/>
c. I haven't found responses very useful	<input type="radio"/>	<input type="radio"/>
d. I find it difficult to understand the jargon or language used in responses	<input type="radio"/>	<input type="radio"/>
e. It is too time consuming	<input type="radio"/>	<input type="radio"/>
f. It's not for people of my age	<input type="radio"/>	<input type="radio"/>
g. It's not for people like me	<input type="radio"/>	<input type="radio"/>
h. I had a bad experience	<input type="radio"/>	<input type="radio"/>

i. Other (please describe below)

25. Are there any other carers you have ONLY communicated with through shared online support messages?

(Please choose and tick one answer).

- No
- Yes
- Don't know

26. The following statements are about other carers you have ONLY communicated with through shared online support messages.

Please indicate how much you agree or disagree with each of the following statements.

(Please choose and tick one answer per row).

	Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree strongly
a. They would help me fight an injustice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. They have given me information and advice that has helped me to solve problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. There was at least one person I could turn to for advice about making very important decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. When I felt lonely, there was at least one person I could talk to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following questions are for people who have used the Internet in the past but are not currently using it.

***27. Did you use the Internet for more than a year?**

- Yes
- No

28. For about how many years did you use the Internet?

(Please write the number of years in the box below)

29. For about how many months did you use the Internet?

(Please write the number of months in the box below)

30. People have given a number of reasons for stopping use of the Internet. Please say which of these reasons apply to you (if any).

(Please choose and tick one answer per row).

	Yes	No
a. I am just not interested	<input type="radio"/>	<input type="radio"/>
b. I moved house and have not had a new connection installed or moved job/left college where it was available	<input type="radio"/>	<input type="radio"/>
c. I no longer have a computer available	<input type="radio"/>	<input type="radio"/>
d. It was too difficult to use	<input type="radio"/>	<input type="radio"/>
e. It's not useful	<input type="radio"/>	<input type="radio"/>
f. It's too expensive	<input type="radio"/>	<input type="radio"/>
g. I was worried about my privacy	<input type="radio"/>	<input type="radio"/>
h. I had bad experiences with SPAM or viruses	<input type="radio"/>	<input type="radio"/>
i. I do not have enough time	<input type="radio"/>	<input type="radio"/>
j. There's nothing of interest on the Internet	<input type="radio"/>	<input type="radio"/>
k. I never really figured out how to use it	<input type="radio"/>	<input type="radio"/>
l. Because I was spending too much time on it	<input type="radio"/>	<input type="radio"/>
m. It's not for people of my age	<input type="radio"/>	<input type="radio"/>
n. It's not for people like me	<input type="radio"/>	<input type="radio"/>
o. Other (please describe below)		

31. Are you planning to get access to the Internet in the next year or so?

(Please choose and tick one answer).

- Definitely won't
- Probably won't
- Probably will
- Definitely will
- Don't know

*32. How would you rate your ability to use the Internet?

(Please choose and tick one answer).

- Excellent
- Good
- Fair
- Poor
- Bad
- Don't know/can't say

33. When did you stop using the Internet?

- Between 0-30 days ago
- Between 31 days ago to under three months ago
- Between three months ago to under six months ago
- Between six months ago to under a year ago
- Between a year and under two years ago
- Between two years and under three years ago
- Three years ago or longer

Ex-user of the Internet - years ago stopped using the Internet

34. About how many years ago did you stop using the Internet?

(Please write the number of years in the box below).

35. The next questions ask about ‘shared online support messages’ posted by other carers. These are messages asking for or giving support or advice related to caring for someone else. These messages are posted on a website or in an email group so they can be seen by others using it. The following statements give examples of places you may have read shared online support messages posted by carers.

WHEN YOU USED THE INTERNET did you EVER read a shared online support message posted by a carer...

(Please choose and tick one answer per row).

	Yes	No	Don't know
a. ...in an EMAIL GROUP/DISTRIBUTION LIST (e.g. PMLD Network Forum)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...in a CHAT ROOM (an online space where people can talk to other people who are online at the same time)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ... in a WEBLOG OR BLOG (e.g. a parent's record of their experiences)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...in the COMMENTS SECTION OF A WEBSITE?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ... on a DISCUSSION OR MESSAGE BOARD (e.g. Mencap's Families' Forum or Mumsnet, where messages are left)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...in comments left on FACEBOOK PAGES OR GROUPS (e.g. Rett UK Facebook page)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ... on TWITTER (e.g. tweets under a hashtag #rettsyndrome, #carers)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*** 36. Did you answer 'Yes' to any of the above?**

- No
- Yes

37. People often read shared online support messages posted by carers **WITHOUT POSTING RESPONSES** themselves.

Please indicate how much you agree or disagree with these statements about reading shared online support messages posted by carers

(Please choose and tick one answer per row)

	Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree strongly
a. Reading about other parents' experiences made me feel less alone.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Reading information and advice in shared online support messages helped me to solve problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

38. When did you last read a shared online support message posted by a carer?

(Please choose and tick one answer).

- Between 0-30 days ago
- Between 31 days ago to under three months ago
- Between three months ago to under six months ago
- Between six months ago to under a year ago
- Between a year and under two years ago
- Between two years and under three years ago
- Three years ago or longer

39. About how many years ago did you last read a shared online support message?

(Please write the number of years)

40. WHEN YOU USED THE INTERNET...

Did you EVER look at...

(Please choose and tick one answer per row)

	Yes	No	Don't know
a. ...PMLD Network Forum emails?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...The RettNet email list emails?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...Rett UK's Facebook page?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...IRSF (International Rett Syndrome Foundation) Facebook page?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...the Rett Syndrome Group for UK families (Facebook)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...the Rett Syndrome group (Facebook)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...Carers UK's Online Forum?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. ...Mencap's Families' Forum?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. ...the Special Kids in the UK Forum?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. ...the Mumsnet special needs discussion threads?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. ...the Rett Syndrome Parents Yahoo Group?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

41. Please list any (other) sites or email groups where you liked to read shared online support messages posted by carers WHEN YOU USED THE INTERNET.

(Please write in the box below).

42. The following statements describe ways people can post a shared online support message to a website or email group used by other carers.

Did you EVER post a shared online support message...

(Please choose and tick one answer per row).

	Yes	No	Don't know
a. ...in an EMAIL GROUP/DISTRIBUTION LIST (e.g. PMLD Network Forum)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. ...in a CHAT ROOM (an online space where people can talk to other people who are online at the same time) ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. ...on YOUR OWN BLOG?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. ...in THE COMMENTS SECTION ON A WEBSITE OR BLOG?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. ...on a DISCUSSION OR MESSAGE BOARD (e.g. Mencap's Families' Forum or Mumsnet, where messages are left)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. ...on a RELEVANT FACEBOOK PAGE OR GROUP (e.g. Rett UK Facebook page)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. ...on TWITTER (e.g. tweets under a hashtag #rettsyndrome, #carers)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

43. Did you answer 'Yes' to any of the above?

(Please choose and tick one answer).

- No
- Yes

Ex-users of the Internet: People known only online

44. When did you last read a shared online support message posted by a carer?

(Please choose and tick one answer).

- Between 0-30 days ago
- Between 31 days ago to under three months ago
- Between three months ago to under six months ago
- Between six months ago to under a year ago
- Between a year and under two years ago
- Between two years and under three years ago
- Three years ago or longer

45. About how many years ago did you last read a shared online support message?

(Please write the number of years in the box below)

*46. WHEN YOU USED THE INTERNET...

Were there any other carers you ONLY communicated with through shared online support messages?

(Please choose and tick one answer).

- No
- Yes
- Don't know

The Internet, Online Support and You

Ex-user of the Internet - people known only online

47. The following statements are about other carers you ONLY communicated with through shared online support messages.

Please indicate how much you agree or disagree with each of the following statements.

(Please choose and tick one answer per row).

	Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree strongly	Don't know
a. They would have helped me fight an injustice.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. They gave me information and advice that helped me to solve problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. There was at least one person I could turn to for advice about making very important decisions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. When I felt lonely, there was at least one person I could talk to.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

48. People give a number of reasons for not using the Internet. Please say which of these reasons apply to you (if any).

(Please choose and tick one answer per row).

	Yes	No
a. I am just not interested	<input type="radio"/>	<input type="radio"/>
b. I have no connection available where I live or where I work	<input type="radio"/>	<input type="radio"/>
c. I have no computer available	<input type="radio"/>	<input type="radio"/>
d. It's too difficult to use	<input type="radio"/>	<input type="radio"/>
e. It's not useful	<input type="radio"/>	<input type="radio"/>
f. It's too expensive	<input type="radio"/>	<input type="radio"/>
g. I am worried about my privacy	<input type="radio"/>	<input type="radio"/>
h. I worry about bad experiences with SPAM or viruses	<input type="radio"/>	<input type="radio"/>
i. I do not have enough time	<input type="radio"/>	<input type="radio"/>
j. There's nothing of interest on the Internet	<input type="radio"/>	<input type="radio"/>
k. Do not yet know how to use the Internet	<input type="radio"/>	<input type="radio"/>
l. It is too time consuming	<input type="radio"/>	<input type="radio"/>
m. It's not for people of my age	<input type="radio"/>	<input type="radio"/>
n. It's not for people like me	<input type="radio"/>	<input type="radio"/>

o. Other (please describe below)

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49. Please indicate how much you agree or disagree with the following statements.

(Please choose and tick one answer per row).

	Disagree strongly	Disagree	Neither agree nor disagree	Agree	Agree strongly
a. I miss out by not using the Internet and E-mail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. I sometimes feel left out when my friends talk about the Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. I am better off not using the Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. I would like to use the Internet in the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. I could perform better in my daily tasks if I used the Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. It would be easier to get advice and support about parenting someone with Rett syndrome if I used the Internet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Never used - planned future access

50. Are you planning to get access to the Internet in the next year or so?

- Definitely won't
- Probably won't
- Probably will
- Definitely will
- Don't know

FOR EVERYONE - about you

This final section asks about you, your household and your children. This is to understand if there are certain groups of parents of people with Rett syndrome who use the Internet in different ways. This will help in developing recommendations about support for carers of people with Rett syndrome.

51. Are you male or female?

- Male
- Female

52. What is your age?

53. How many years in total have you lived in the UK?

(Please type the number of years into the box below)

54. To which of these groups do you consider you belong?

(Please choose and tick one answer)

- Asian: of Indian origin
- Asian: of Pakistani origin
- Asian: of Bangladeshi origin
- Asian: of Chinese origin
- Asian: of other origin (please write in additional details box below)
- Black: of African origin
- Black: of Caribbean origin
- Black: of other origin (please write in additional details box below)
- White: of British origin
- White: of other origin (please write in additional details box below)
- Don't know

Please type any additional details into the box below

55. Do you have a health problem or disability that limits your use of a computer or the Internet?

(Please choose and tick one answer)

- Yes
- No

56. How would you describe the place where you live?

(Please choose and tick one answer)

- A big city
- The suburbs or outskirts of a big city
- A small city or town
- A country village
- A farm or home in the country
- Other
- Don't know

57. Which region of the UK do you live in?

(Please choose and tick one answer)

- Scotland
- North West
- South West
- Wales
- South East
- London
- East of England
- East Midlands
- West Midlands
- Yorkshire & the Humber
- North East

58. Are you..?

(Please choose and tick one answer)

- Single
- Married
- In a Civil Partnership
- Living together with a partner
- Divorced or separated
- Widowed

These questions are about your education. I am interested in whether use of the Internet by parents of people with Rett syndrome is influenced by education.

59. What is the highest educational or vocational qualification that you have or that you will receive if you complete your next set of exams?

(Please choose and tick one answer)

- No qualifications
- 5 or more GCSE grades A-C
- 4 or less GCSE grade A- C
- GCSE grade D-G
- 5 or more Scottish Standard Grades, grades 1-3
- 4 or less Scottish Standard Grades, grades 1-3
- Scottish Standard Grades, grades 4-7
- Scottish Highers
- CSEs
- 5 or more O levels
- 4 or less O levels
- GCE A levels or equivalent
- NVQ 1 or 2
- NVQ 3 or 4
- GNVQ Foundation
- GNVQ Intermediate
- GNVQ Advanced
- Certificate or Diploma of Higher Education
- Bachelors degree
- Graduate Certificates and Diploma
- Masters Degree
- Doctoral Degree
- Don't know

The following questions ask about your occupation and the occupation of the chief wage earner in your household. I am interested in whether use of the Internet by parents of people with Rett Syndrome is influenced by occupation.

*** 60. Which of these descriptions best describes your current situation?**

If you are doing more than one thing, please choose what you consider to be your principal activity.

(Please choose and tick one answer)

- Working Full time (30 hours a week or more)
- Working Part time (8-29 hours a week)
- Retired
- Unemployed
- Permanently sick or disabled
- In community or military service
- Undergraduate Student
- Post graduate student
- In full time education (not higher degree)
- In part time education (not higher degree)
- Doing housework, looking after children or other persons

61. What is your occupation? (If you are retired, what was your last occupation?)

62. How many people report to you? (If you are retired, how many people reported to you in your last post?)

63. Who brings in the majority of your household income?

- Me
- Someone else

64. What is the occupation of the person who brings in the majority of your household income? (If they have retired, what was their last occupation?)

65. How many people report at work to the person who brings in the majority of your household income? (If they are retired, how many people reported to them in their last post?)

The following questions ask about your household, family and trust. I am interested in whether use of the Internet is influenced by parents' living situation, caring responsibilities, trust and the age(s) of their daughter(s) and/or son(s) with Rett syndrome.

66. The incomes of households differ a lot in Britain today.

Please indicate which option best represents the total income of your household before tax.

(Please choose and tick one answer)

- Under £12,500 per year
- Between £12,500 and under £20,000 per year
- Between £20,000 and under £30,000 per year
- Between £30,000 and under £40,000 per year
- Between £40,000 and under £50,000 per year
- Between £50,000 and under £60,000 per year
- Between £60,000 and under £70,000 per year
- Between £70,000 and under £80,000 per year
- £80,000 or over per year

*67. Please indicate whether you have a daughter and/or a son with Rett syndrome

- Daughter
- Son

If you have more than one daughter or son with Rett syndrome, please type how many daughters and/or sons with Rett syndrome you have into the box below

68. What age(s) is/are your daughter(s) and/or son(s) with Rett syndrome?

69. What age(s) was/were your daughter(s) and/or son(s) when they received a formal diagnosis of Rett syndrome?

70. Does/do your daughter(s) and/or son(s) with Rett syndrome live with you?

- Yes, part of the time
- Yes, all of the time
- No

Other arrangement (please describe below)

71. Do you have any other daughters and/or sons living at home with you?

- Yes, part of the time
- Yes, all of the time
- No

Other arrangement (please describe below)

72. Please list the ages of any other daughters and/or sons living at home with you.

73. I'd now like to ask you about trust, to find out if this is connected to how parents of people with Rett syndrome use the Internet.

Generally speaking, would you say that most people can be trusted, or that you can't be too careful in dealing with people?

Please use a 5 point scale where 1 means that you can't be too careful and 5 means that most people can be trusted.

(Please choose and tick one answer)

5 (Most people can be trusted)

4

3

2

1 (You can't be too careful)

The Internet, Online Support and You

74. In the next stage of my research I am interested in finding out more about people's experiences of reading shared online support messages posted by other carers. These can be seen on websites, online groups or in email groups.

Have you read ANY shared online support messages posted by carers IN THE LAST THREE YEARS?

(Please choose and tick one answer).

- No
- Yes

The Internet, Online Support and You

For people who have read shared online support messages in the last three y...

I am looking for people who might be interested in taking part in the next stage of my research. In this stage I want to learn more about how online sources of support and advice are used and experienced by parents of people with Rett syndrome.

If selected, this will involve an interview and filling out a very short record if you use relevant sites or email groups over an agreed period.

YOU ARE FREE TO CHANGE YOUR MIND WHEN CONTACTED IF YOU NO LONGER WISH TO TAKE PART IN THIS RESEARCH.

I will use some of your survey answers to make the interview more relevant, so am asking interested people to include their contact details below. These will be used to contact you if selected and to retrieve your survey results. All contact details will be removed from data once the survey has closed and treated with confidentiality. All information will be stored securely in accordance with the Data Protection Act (1998) at all times. Reports and shared information will not identify anyone by name and your identity will not be revealed to anybody else.

HOWEVER, IF YOU WISH, YOU DON'T HAVE TO INCLUDE YOUR NAME, OR CAN JUST INCLUDE PART OF YOUR NAME OR A PSEUDONYM (e.g. an online username or other fake name). If you'd prefer to contact me separately, please email me at j.belcher@surrey.ac.uk or call me on 07583 641437

75. If you might be interested in taking part in this further stage, please include your contact details here, or email or phone me on the details above.

Name/pseudonym (optional)	<input type="text"/>
Email	<input type="text"/>
Telephone number	<input type="text"/>

76. Please indicate your preferred method of contact

- Telephone
- Email
- Either

Thank you

Thank you very much for taking part in this survey.

If there is anything else you'd like to add or clarify, or any further comments you'd like to make, please use the space below to do so.

If you would like to discuss this survey further or would like a copy of the overall research results, please contact me at j.belcher@surrey.ac.uk or on 07583 641437.

77. Please include any further comments here

