Appendix i: NIHR Programme Grant RP-PG-0608-10147: Examining the role of information on patients' experiences as a resource for choice and decision-making in health care

This doctoral research is part of a wider NIHR funded programme entitled: *Examining the role of information on patients' experiences as a resource for choice and decision-making in health care*. This Oxford led programme is being carried out in collaboration with research groups in Warwick, Glasgow, Northumbria and Sheffield.

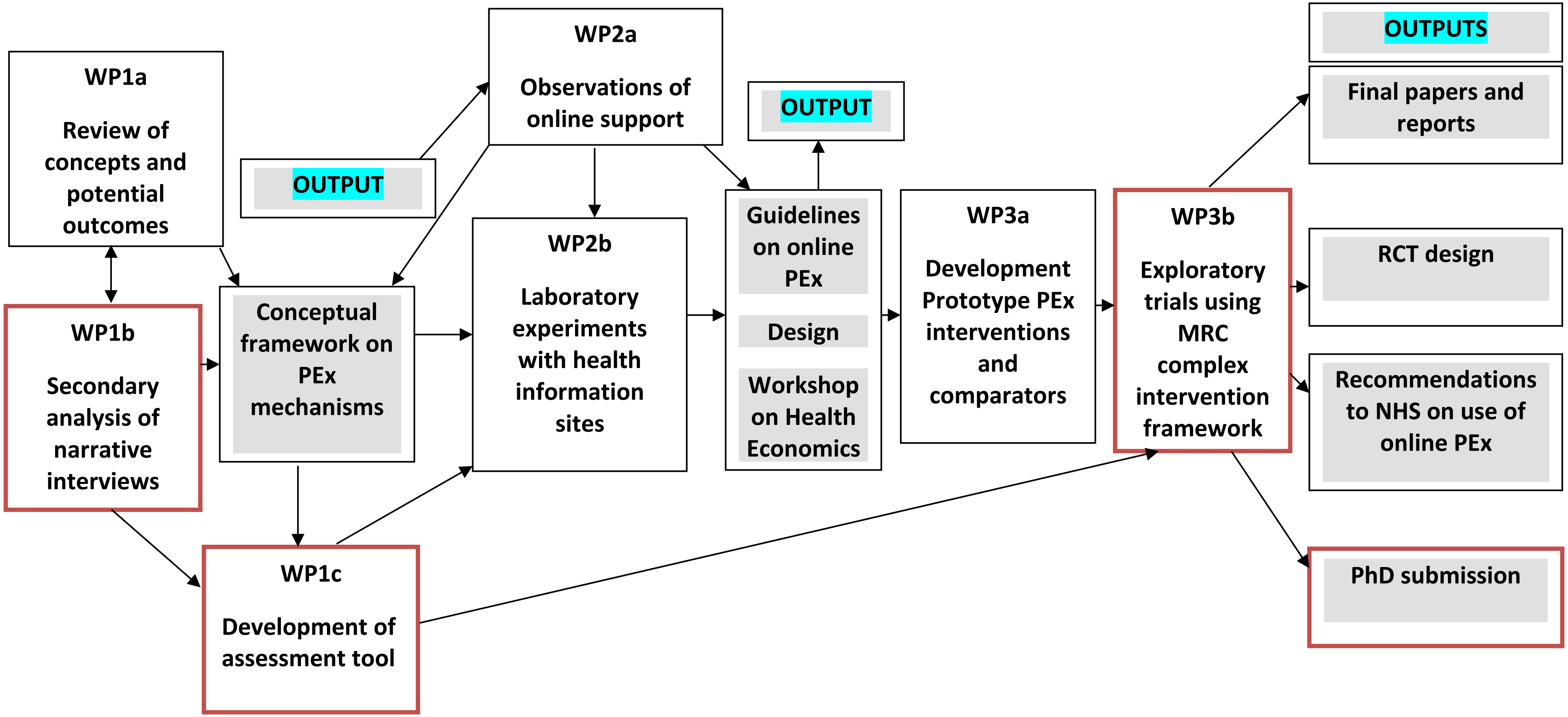
The aim of the Programme is to find out whether, when and how the NHS should incorporate people's experiences (PEx) into online health information. To do this the Programme aims to understand the mechanisms through which PEx may influence health, develop a tool to measure these effects and explore how PEx are used. The Programme culminates in an exploratory clinical trial comparing six health information websites: three intervention websites which will contain patient experiences on exemplar conditions and three comparator sites which do not contain experiential information.

One component of the Programme was carried out as for this doctoral research and primarily concerned the work packages outlined below:

- WP 1b: Secondary data analysis to determine item content
- WP 1c: Development of assessment tool
- WP3b: Exploratory trials with prototype websites

See overleaf for doctoral research integration with other work packages in Programme.

Integration of work packages in programme and key outputs



WP1a

Review of concepts and potential outcomes

OUTPUT

WP2a

Observations of online support

OUTPUT

OUTPUTS

Final papers and reports

WP1b

Secondary analysis of narrative interviews

Conceptual framework on PEx mechanisms

WP2b

Laboratory experiments with health information sites

Guidelines on online PEx

Design

Workshop on Health Economics

WP3a

Development Prototype PEx interventions and comparators

WP3b

Exploratory trials using MRC complex intervention framework

RCT design

Recommendations to NHS on use of online PEx

PhD submission

WP1c

Development of assessment tool

Appendix 4.1 Secondary data analysis ethical approval form issued by HERG

FORM C(B)

UNIVERSITY OF OXFORD

For use by persons not employed by the University, but engaged on the project (including students)

Ref No. GM/1/1, OG Ref: BZRRQW0

Project title: Examining the role of online patient experiences as a resource for choice and decision-making in health care

Sponsor: National Institute for Medical Research via Oxfordshire PCT

In consideration of the University agreeing to employ me or allowing me to participate in the project described in the agreement dated 10th February 2010 with the Sponsor named above. I hereby agree to abide by the terms of that agreement, a copy of which may be consulted on application to the principal investigator, and to do everything that is required to give effect to it. Specifically I agree that inventions, patents, copyright, know-how, confidential information and publication of results shall be dealt with as prescribed by that agreement.

I understand that my undertakings continue in force notwithstanding the termination of the project or my employment by or my work in the University.

Name (Block capitals please)...

Department ....

Signed ....#

(Date) ....

Employee, consultant, student or other person engaged on the project.

Appendix 4.2: Preliminary consideration of HERG interview collections

Table 1 Summary of relevant HERG interview collection topics for selected conditions (Table complied using online modules containing HERG interview content).

Collection	Characteristics	Potential effects of using internet	Evidence of relevant topics from information in HTO modules	Reasons supporting potential use in secondary analysis
Diabetes-(Young people) N=38	Young people, Long term condition	Support Knowledge Decision-making Self-management Behavioural change	Following celebrity stories Internet as a source of in-depth scientific information Internet as a source for gaining practical tips	Gives good insight into chronic disease. Young people tend to discuss internet use more than older people so potentially a rich data source. This collection is likely to be particularly valuable for self-management and internet use
Long term conditions (Young people) N=31	Young people, Long term conditions	Support Knowledge Decision-making Self-management Behavioural change	Actively avoiding depressing or negative information Awareness of importance of reputable scientific websites Internet facilitates sharing health experiences, but without the necessity of meeting people in person Can provide reassurance that others are the same as you Emotional aspects of internet support	Sufficient evidence of internet use. Young people tend to discuss internet use more than older people so potentially a rich data source.
Depression (Young people) N=35	Young people, Mental health	Support Emotional Knowledge Decision-making Self-management Coping	Access to the internet 24/7 Friends can be made on the internet when lacking skills to seek face-to-face support	Potentially valuable for highlighting emotional support and coping. Young people tend to discuss internet use more than older people so potentially a rich data source.
Epilepsy (Young people) N=44	Young people, Long term condition	Support Knowledge Decision-making Self-management	Humour on the internet to help people cope Others who have same condition understand what it is like to go through the same illness Internet as a source for gaining practical tips	References to online patient experiences. However, other collections also include young people. A number of people with epilepsy also feature in the 'Long term conditions'

				collection.
Parkinson's Disease (Carers) N=4	Carers, Degenerative conditions	Support Knowledge Decision-making	Internet used to obtain information not provided by health professional Following celebrity stories Filtering information for person you care for Reassurance other carers have similar experiences Practical tips and information Can increase anxiety about how things may be in the future, but anxiety may be higher when meeting face-to-face	Extracts suggest this collection will be particularly useful for support and decision-making.
Motor Neurones Disease (Carers) N=14	Carers, Degenerative conditions	Support Knowledge Decision-making	Helping other people through sharing information A sense of maintaining distance is important (i.e. some do not want to meet others face-to-face) Information on the internet can be depressing	Experiential rich information and discussion of internet evident
Dementia (Carers) N=40	Carers, Degenerative conditions	Support Knowledge Decision-making Self-management	Wanting to share information in order to help others Most useful information received from other carers Many refer to timing of face-to-face support group meetings- not able to attend if held in the day Carers information requirements change over time	Experiential rich information, but may be somewhat limited on internet rich data.
Colorectal Cancer N=39	Life threatening condition Treatment choices	Support Knowledge Decision-making Self-management	Many references to face-to-face shared experiences	Very little evidence of internet related content evident on health talk online

Heart attack N=37	Behavioural change	Support Knowledge Decision-making Self-management	Feeling like you are not alone Reference to the internet and importance of getting accurate information.	Very little evidence of internet related content evident across respondents.
Heart Failure N=42	Health-related decisions	Support Knowledge Decision-making Self-management	Information sought from support groups, the internet, books and medical journals. Information can be gloomy: 'the more you know the more you worry' Internet used to find further information and to check side effects of medication.	Some evidence on internet related content in this collection, however, it would be useful to speak to primary researcher on this collection/ request all transcripts to get a better idea of its value.
Mental health (Ethnic minorities) N=30	Mental health, ethnic minorities	Support Knowledge Decision-making Self-management	Internet as a source of further information Face-to-face support groups can encourage a range of feelings: 'not alone', feeling stronger, new ideas, tips, depressing moods	Very little evidence of internet related content evident.
Mental health: Ethnic minority (Carers) N=32	Carers, Ethnic minorities	Support Knowledge Decision-making Self-management	Finding information on the internet: carers groups Local support groups: more likely to offer more culturally acceptable support Support groups offered in native language Depressing- reminder of commitment of carer for rest of life	Useful to include collection, but arrange to meet with primary researcher.
HIV N=50	Long term condition, Large representation for ethnic minorities	Support Knowledge Decision-making Self-management	Seeing others make you realise you can be healthy Emotional support Encouraging to see others- longevity of life Advice on managing medication Depressing Anonymity on the internet	Very little evidence of internet related content evident.

Appendix 4.3: Secondary data analysis transcript coding sheet

1) Accessibility of information
    a) Internet
    b) Other forms of information (e.g. Face-to-face)

2) Anxiety in relation to information
    a) About the future
    b) Having the confidence to participate
    c) Exposure to negative outlooks/people
    d) Gaining perspective – others are worse than you
    e) Uncertainty about the right course of treatment
    f) Help foreseeing stressful situations

3) Information gathering/giving
    a) Learning from others at same time point of condition
    b) 'Giving back' – rewarding
    c) Trust in information source (contradictions/healthcare professionals v. Internet)
    d) Value – Experiential v. Facts
    e) Sensitive issues
    f) Learning about side effects or alternative treatments
    g) Expectations for the future

4) Use of information for support
    a) Coping through humour
    b) Practical tips and support

5) Control over information
    a) Controlling information/protection (carers)
    b) Avoiding experiential information
    c) Feeling under control and confident
    d) Over-relying on experiential information excludes person from offline relationships

6) Reassurance
    a) Not having to rely on healthcare professionals (24/7 support)
    b) Help making decisions
    c) Encouragement to carry on/ you are doing things right

7) Managing conditions
    a) Reinforcing the value of self-management
    b) Practical advice for managing care
    c) Maintaining the lifestyle you want

8) Understanding
    a) Feeling understood (instantly)
    b) Finding niche groups e.g. similar age/condition
    c) Finding out you are 'not alone' (or you are alone in some cases)
    d) Comradeship- mutual advice/support
    e) Feeling judged

9) Convenience
    a) No time pressure to absorb information
    b) Anonymity
    c) 'Engaging without engaging' e.g. lurking

Appendix 4.4: Example of a consistency table

Table 1 Example of a consistency table used to confirm presence of themes within each interview collection

Theme	Interview collection				
	Health condition 1	Health condition 2	Health condition 3	Health condition 4	Health condition 5
Theme 1	✓	✓	✓	✓	✓
Theme 2	✓	✓	✓	✓	✓
Theme 3	✓	✓	✓	✓	✓
Theme 4	✓	✓			
Theme 5	✓	✓	✓		
Theme 6	✓				

During analysis it was important to ascertain if a theme was applicable across conditions or whether it was specific to one health condition. When a specific theme was evident in an interview collection, it was ticked in a consistency table like that shown above. Table 1 states that:

- Theme 1, 2 and 3: Theme consistent across all health conditions
- Themes 4 and 5: These themes have some consistency across collections but may need further consideration to ascertain if it is applicable across conditions (i.e. whether it is generic).
- Theme 6: Theme 6 has only been found in one interview collection (Health condition 1). It may be likely that this theme is condition specific and would need further investigation before it can be included in the generic item pool.

Appendix 4.5: Question Appraisal System (QAS-99) used in Expert Review

Question Appraisal System (QAS-99)[1]

STEP 1 – INSTRUCTIONS

Look for problems with any introductions, instructions, or explanations from the *respondent's* point of view.

1a. Conflicting or inaccurate instructions
1b. Complicated instructions

STEP 2 – CLARITY

Identify problems related to communicating the intent or meaning of the question to the respondent.

2a. Wording- Question is lengthy, awkward, ungrammatical or complicated
2b. Technical terms are undefined, unclear or complex
2c. Vague- There are multiple ways to interpret the question

STEP 3 - ASSUMPTIONS

Determine if there are problems with assumptions made or the underlying logic.

3a. Inappropriate assumptions are made about the respondent or about his/her living situation
3b. Double-barrelled – contains more than one question

STEP 4 - SENSITIVITY/BIAS

Assess questions for sensitive nature or wording, and for bias.

4a. Sensitive content (general): The question asks about a topic that is embarrassing, very private, or that involves illegal behaviour
4b. Socially acceptable response is implied by the question

STEP 5 - RESPONSE CATEGORIES

Assess the adequacy of the range of responses to be recorded.

5a. Mismatch between question and response categories
5b. Vague: response categories are subject to multiple interpretations

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[1] Gordon B.Willis and Judith T. Lessler (1999) Question Appraisal System QAS-99, Research Triangle Institute, Rockville, MD

Appendix 4.6: Consistency tables for identified themes

Table 1: Consistency table for Long term conditions

Theme	Interview collection		
	Long term conditions	Depression	Diabetes
Information	✓		✓
Feeling supported	✓	✓	✓
Relationships with others	✓	✓	✓
Experiencing Health Services	✓		✓
Affecting behaviour		✓	✓

Table 2: Consistency table for Carers

Theme	Interview collection		
	Motor Neurone Disease	Parkinson’s disease	Dementia
Information	✓	✓	✓
Feeling supported	✓	✓	✓
Relationships with others	✓		
Experiencing Health Services	✓		✓
Affecting behaviour	✓		✓

Table 3: Consistency table for screening or treatment

Theme	Interview collection			
	Antenatal screening	Ending pregnancy for foetal abnormality	Menopause	Black and Minority Ethnic
Information		✓	✓	✓
Feeling supported	✓	✓	✓	
Relationships with others		✓	✓	
Experiencing Health Services	✓	✓	✓	✓
Affecting behaviour	✓	✓	✓	

Appendix 4.7 Stage One item pools

Item pool eHIQ-Part 1

1) There are people out there who understand what I am going through.
2) People have coped successfully with similar experiences to mine.
3) I feel hopeful about my health in the future.
4) I feel alone with my worries.
5) The issues that are important to me are completely different to those that are important to other people.
6) My response to what I am going through is quite normal.
7) I feel there are ways of coping with my health concerns.
8) I worry a lot about my health.
9) I think that others have had similar worries to me when making health related decisions.
10) I feel that people do not understand what it is like to be in my situation.
11) I feel equipped to make health related decisions that may face me.
12) I prefer to receive extensive information about my health.
13) I prefer to receive little information about my health.
14) I prefer not to know too much about my health.
15) It worries me that I am not getting correct information about my health.
16) I can explain my health concerns to others.
17) I feel anxious telling others about my health experiences.
18) I feel that other people may benefit from hearing my experiences.
19) I feel I can help people with similar experiences to mine.
20) I am not interested in how other people deal with health issues which are similar to mine.
21) I feel like I am in control of my health.
22) I don’t know who to turn to for support.
23) I feel different from other people with this problem.
24) I am able to challenge any negative views that people hold about what I am going through.
25) I know how to describe my health concerns to my doctor.
26) There are too many horror stories about people’s health experiences on the internet.
27) It is difficult to know what health information to trust on the internet.
28) Health websites can contain contradictory information.
29) I can work out what to trust on the internet.
30) It is difficult to find reliable health information on the internet.
31) There is much to be gained from seeing other people’s health experiences on the internet.
32) I like to see photos and images on the internet of people who are dealing with similar health issues.
33) When I look at people’s health experiences on a website I like to see what they look like.
34) I prefer to avoid websites that include photographs of people with health problems.
35) It can be reassuring to know there is help on the internet at any time of the night or day.

36) Websites can make you think more positively about your health.
37) It is easier to connect with a stranger on the internet than with those around you.
38) The internet is useful if you don’t want to tell people in your everyday life how you feel.
39) People can become too isolated from real life when they use the internet extensively.
40) The internet is a good way of finding other people who are experiencing similar problems.
41) The internet can be useful to confirm advice given to me by my doctor.
42) The internet is a good resource which I can use to clarify what a doctor tells me.
43) The internet causes people to worry unnecessarily about their health.
44) The internet provides tailored health advice to meet my needs.
45) The internet is a good resource which I can use to check the doctor is giving me appropriate advice.

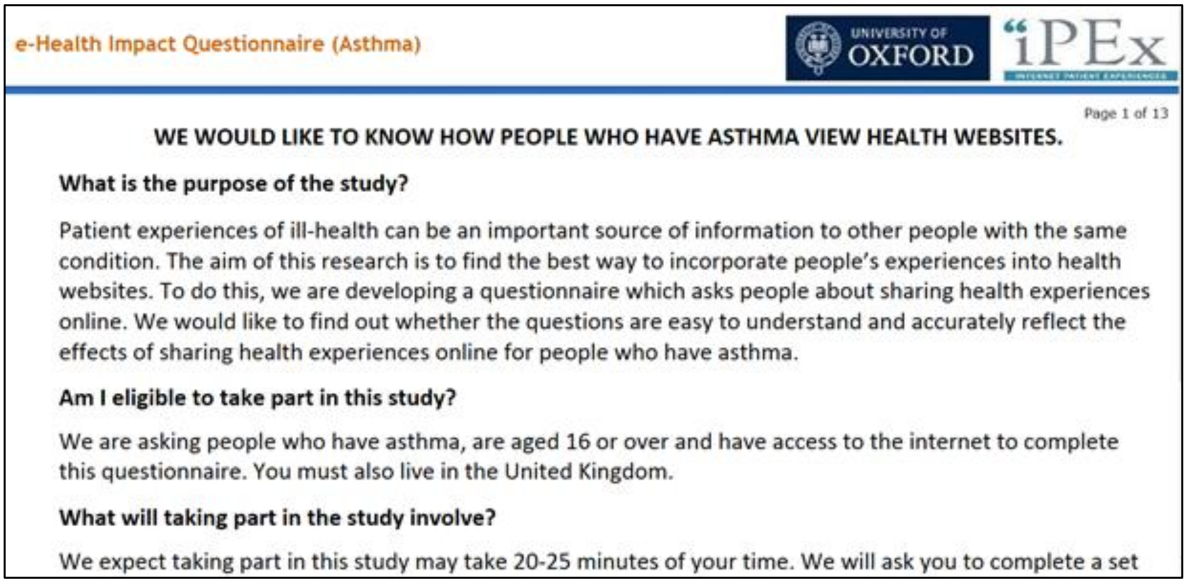
Item pool eHIQ-Part 2

1) I feel more inclined to look after myself after visiting this website.
2) The contributors to this website sounded patronising.
3) This website could encourage people to try to make positive changes to improve their health.
4) This website raises questions I might ask a doctor or nurse.
5) This website includes useful tips on how to make life better.
6) This website seems to be aimed at a different age group to my needs.
7) This website gives a good range of information.
8) The language on this website made it easy to understand.
9) I wish I could have seen this website at an earlier stage.
10) The information on this website left me feeling confused.
11) This website left me with a lot of unanswered questions.
12) I have learnt something new from this website.
13) I can easily understand the information on this website.
14) This website provides more useful information than my doctor can give me.
15) This website prepares me for what might happen to me.
16) I don’t feel the information on this website really applies to me.
17) I want to avoid the type of information found on this website.
18) I trust the information on this website.
19) This website could help me make health-related decisions which I may face.
20) I feel I have a sense of solidarity with other people using this website.
21) I feel I have a lot in common with other people using this website.
22) This website gave me a sense of being part of a community.
23) On the whole, I found this website depressing.
24) The contributors to this website seem to understand what is important to people like me.
25) This website makes me feel anxious.
26) I find this website reassuring.
27) I would not want someone I care for to see some of the information on this website.
28) It was shocking to see what may happen in the future.
29) After looking at this website, I worry more about what the future will hold.
30) Photographs were used appropriately on the website.
31) This website is attractive.
32) This website is easy to use.
33) I feel reassured that I do not need to seek further medical advice after looking at this website
34) This website gives me little confidence in my health care.
35) This website gives me the confidence to explain my health concerns to others.
36) I value the advice given on this website.
37) This website gives me confidence that I can manage my health.

Appendix 5.1: Stage Two online questionnaire layout

(Bristol Online Survey software)

Figure 1: Questionnaire front page using Bristol Online Survey software



e-Health Impact Questionnaire (Asthma)

Page 1 of 13

WE WOULD LIKE TO KNOW HOW PEOPLE WHO HAVE ASTHMA VIEW HEALTH WEBSITES.

What is the purpose of the study?

Patient experiences of ill-health can be an important source of information to other people with the same condition. The aim of this research is to find the best way to incorporate people's experiences into health websites. To do this, we are developing a questionnaire which asks people about sharing health experiences online. We would like to find out whether the questions are easy to understand and accurately reflect the effects of sharing health experiences online for people who have asthma.

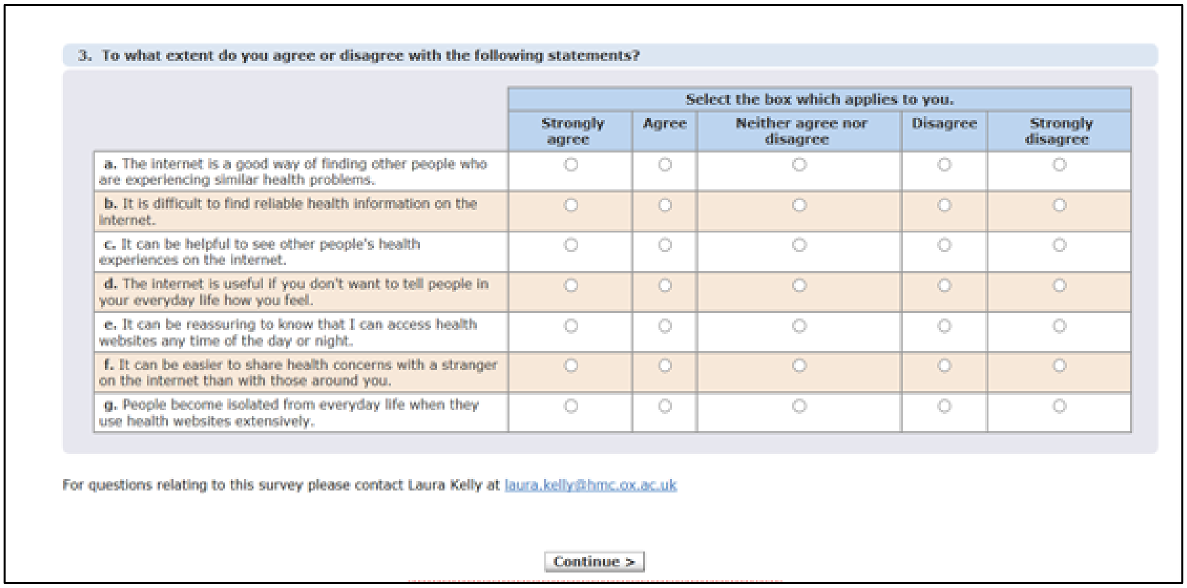
Am I eligible to take part in this study?

We are asking people who have asthma, are aged 16 or over and have access to the internet to complete this questionnaire. You must also live in the United Kingdom.

What will taking part in the study involve?

We expect taking part in this study may take 20-25 minutes of your time. We will ask you to complete a set

Figure 2: Grid format layout and contact details using Bristol Online Survey software



3. To what extent do you agree or disagree with the following statements?

	Select the box which applies to you.				
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
a. The internet is a good way of finding other people who are experiencing similar health problems.	○	○	○	○	○
b. It is difficult to find reliable health information on the internet.	○	○	○	○	○
c. It can be helpful to see other people's health experiences on the internet.	○	○	○	○	○
d. The internet is useful if you don't want to tell people in your everyday life how you feel.	○	○	○	○	○
e. It can be reassuring to know that I can access health websites any time of the day or night.	○	○	○	○	○
f. It can be easier to share health concerns with a stranger on the internet than with those around you.	○	○	○	○	○
g. People become isolated from everyday life when they use health websites extensively.	○	○	○	○	○

For questions relating to this survey please contact Laura Kelly at laura.kelly@hmc.ox.ac.uk

Figure 3: Inserted logo and page numbers using Bristol Online Survey software

Page 13 of 13

Appendix 5.2: Stage Two Participant Information Sheet

(Cognitive interviews)

UNIVERSITY OF OXFORD

iPEx INTERNET PATIENT EXPERIENCES

‘Examining the role of information on patients’ experiences as a resource for choice and decision-making in health care’

INFORMATION ABOUT THE RESEARCH

What is the purpose of the study?

Patient experiences of ill-health can be an important source of information to other people with the same condition. The aim of this research is to find out how we should incorporate people’s experiences in health websites. To do this, we need to develop a questionnaire which asks people about sharing health experiences online.

We have developed a series of questions following the in-depth analysis of interviews with people who have a wide variety of illnesses. We would like to find out whether the questions are both easy to understand and accurately reflect the effects of sharing health experiences online.

Why have I been asked to take part in the study?

You have been identified by the researcher, or by someone known to the researcher, as someone who may have a personal interest in a particular health condition (perhaps as a patient yourself or on behalf of someone you care for).

Am I eligible to take part in this study?

We are looking for people aged 18 or over. You must also be able to use the internet and answer a questionnaire independently.

What will taking part in the interview involve?

We will ask you to take some time to look at a health website relevant to you. We will then ask you to complete a set of questions. The researcher will discuss your answers with you to see how you arrived at your answer. By doing this we can identify questions which people may find difficult to answer or questions which may be unclearly worded. We can use your opinions to improve our questions.

The interview will take place at a location of your choice (for example, this may be in your own home or in the Department of Public Health, University of Oxford) at a time that suits you. If the interview takes place at your home, you must have access to the internet. The interview will be audio recorded so that the interviewer does not have to spend time writing notes during the interview.

What are the possible disadvantages or risks of taking part?

Taking part in this study will take about 60-90 minutes your time. The interview will be recorded to save the researcher time writing notes; however, all information you give will remain strictly confidential and will only be seen by members of the research team. You can decide not to take part at any point during the study and you can choose not to discuss your responses to the questions if you feel that it may make you uncomfortable.

What are the possible benefits of taking part?

There are no immediate benefits to you but the information you provide may help health information providers distribute information in a useful way.

We offer £20 to those taking part in this research and will reimburse any travel expenses you may incur.

What will happen to the results of the study?

The results of this study will be used to refine the questions we have developed. These questions will be used to test various health websites so we can best present useful health information online. Findings from the study will be written up as a journal article and presented at conferences.

This study will also contribute to doctoral research.

Who is organising and funding the research?

This research will be undertaken by the Departments of Public Health and Primary Health Care, University of Oxford, in collaboration with research groups in Warwick, Northumbria, Sheffield and Glasgow. This programme presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0608-10147).

Questions or help?

Please contact Laura Kelly (doctoral student) by telephone on 01865 289425 or by email laura.kelly@hmc.ox.ac.uk

Appendix 5.3: Stage Two Consent form

(Cognitive interviews)

CONSENT FORM

‘Examining the role of information on patients’ experiences as a resource for choice and decision-making in health care’

Investigators: Laura Kelly (DPhil student), Professor Crispin Jenkinson and Professor Sue Ziebland

Please indicate that you understand the following by placing a tick [✓] in each box:

I understand my participation is entirely voluntary	
I understand I can refuse to answer a question at any time	
I understand I am free to withdraw at any time, without giving any reason	
I understand the interview will be audio recorded	
The results of the study will only be presented in anonymous form	
If any direct quotes from the interview are used in reports, these will be anonymous	

Please sign this form to indicate that you are willing to take part in this study:

Interviewee: ____

Researcher: ____

Date: ____

Appendix 5.4: Stage Two interview topic guide

(Cognitive interviews)

Topic guide

1. Explain
    - Purpose of interview
    - How interview will be conducted
    - Assure confidentiality

2. Questionnaire completion
    - Allow interviewee to complete questionnaire unaided as far as possible.
    - *Reassure interviewee that there is plenty of time and there is no need to rush*
    - Record time and note if hesitant

Once questionnaire is completed:

3. Probe interviewee's initial impressions of questionnaire
    - easy or difficult?
    - liked or disliked?
    - any concerns?
    - repetitive?

4. Format
    - Liked/disliked
    - Difficulties with font/grid questions…

5. Response options
    - Response direction
    - Middle category

6. For each question, probe….

    - How interviewee arrived at answer
    - Overall understanding of question
    - Ease of answering question
    - Difficult terms
    - Disliked terms
    - Willingness to answer

Appendix 5.5: Stage Two deleted questionnaire items

Items deleted after Phase 1

1) People have coped successfully with similar experiences to mine. (Content validity)
2) I feel hopeful about my health in the future. (Content validity)
3) I feel alone with my worries. (Content validity)
4) The issues that are important to me are completely different to those that are important to other people. (Duplicate)
5) I feel there are ways of coping with my health concerns. (Content validity)
6) I worry a lot about my health. (Content validity)
7) I feel that people do not understand what it is like to be in my situation. (Duplicate)
8) I prefer to receive extensive information about my health. (Content validity)
9) I prefer to receive little information about my health. (Content validity)
10) I prefer not to know too much about my health. (Content validity)
11) It worries me that I am not getting correct information about my health.
12) I can explain my health concerns to others. (Content validity)
13) I feel that other people may benefit from hearing my experiences.
14) I feel I can help people with similar experiences to mine. (Content validity)
15) I am not interested in how other people deal with health issues which are similar to mine. (Content validity)
16) I feel like I am in control of my health. (Content validity)
17) I don’t know who to turn to for support. (Content validity)
18) I feel different from other people with this problem. (Content validity)
19) I am able to challenge any negative views that people hold about what I am going through. (Content validity)

Items deleted after Phase 2

1) There are people who use the internet who understand what I am going through. (Duplicate)

Items deleted after Phase 3

1) It is difficult to know what health information to trust on the internet. (Duplicate)
2) Health websites contain contradictory information. (Duplicate)
3) It is dangerous for people to make a self-diagnosis using the internet. (Duplicate)
4) I like to see photographs on the internet of people who are dealing with similar health issues. (Duplicate)
5) The internet can be useful to help me follow/confirm advice given to me by my doctor. (Duplicate)
6) This website makes me feel anxious. (Duplicate)
7) This website gave me a sense of being part of a community. (Duplicate)
8) After looking at this website, I worry more about things I cannot control in the future. (Duplicate)
9) It was shocking to see what may happen in the future. (Duplicate)

Appendix 5.6 Stage Two final eHIQ design and items

WE WOULD LIKE TO KNOW HOW PEOPLE WHO HAVE ASTHMA VIEW HEALTH WEBSITES.

What is the purpose of the study?

Patient experiences of ill-health can be an important source of information to other people with the same condition. The aim of this research is to find the best way to incorporate people’s experiences into health websites. To do this, we are developing a questionnaire which asks people about sharing health experiences online. We would like to find out whether the questions are easy to understand and accurately reflect the effects of sharing health experiences online for people who have asthma.

Am I eligible to take part in this study?

We are asking people who have asthma, are aged 18 or over and have access to the internet to complete this questionnaire. You must also live in the United Kingdom.

What will taking part in the study involve?

We expect taking part in this study may take 20-25 minutes of your time. We will ask you to complete a set of questions about your general views of health websites. We will then ask you to look at a health website and answer a set of questions relating to the health website.

For more detailed information about participating in this research please go to:

www.publichealth.ox.ac.uk/research/hsru/ehealthasthma

Data protection, navigation and consent

The information that you supply in response to this survey will be treated in accordance with the University's Data Protection policy.

Please note that if the survey is inactive for 30 **minutes** the system may **time out** and **data will be lost**.

Cookies, personal data stored by your Web browser, are not used in this survey.

Please note that once you have clicked the **Continue** button at the bottom of each page you **cannot return** to review or amend that page.

Please begin by completing the questions below.

1. Do you live in the United Kingdom?

Yes

No (Thank you for your interest in this study. Unfortunately you may not currently take part in this survey.)

2. Please indicate your consent to take part in this study.

I consent to take part in this study

I cannot take part in this study on this occasion (Please click continue before you exit this survey. This will help us to calculate a response rate.)

Section 1

This section asks about ***your** general attitudes towards health websites.*

In this section *'health websites'*can include websites that contain factual health information, accounts or stories of peoples experiences of health, blogs about health or health discussion forums.

To what extent do you agree or disagree with the following statements?	Strongly Agree	Agree	Neutral	Disagree	Strongly disagree
1) The internet is a good way of finding other people who are experiencing similar health problems.					
2) It is difficult to find reliable health information on the internet.					
3) It can be helpful to see other people's health experiences on the internet.					
4) The internet is useful if you don't want to tell people in your everyday life how you feel.					
5) It can be reassuring to know that I can access health websites at any time of the day or night.					
6) It can be easier to share health concerns with a stranger on the internet than with those around you.					
7) People become isolated from everyday life when they use health websites extensively.					

For questions relating to this survey please contact Laura Kelly at [Enter]

To what extent do you agree or disagree with the following statements?	Strongly Agree	Agree	Neutral	Disagree	Strongly disagree
8) The internet can be useful to help people decide if their symptoms are important enough to go and see a doctor.					
9) I prefer to avoid websites that include images of health problems. (For example, a rash on a person’s skin)					
10) I would use the internet if I needed help to make a decision about my health. (For example, whether I should seek medical advice, take medication or seek alternative therapies)					
11) I can work out what health information to trust on the internet.					
12) The internet is a good resource to help me understand what a doctor tells me.					
13) When I look at someone’s health experience on a website I like to see what the person looks like.					
14) I worry about all the horror stories on health websites.					
15) I can usually find relevant health information on the internet.					

For questions relating to this survey please contact Laura Kelly at [Enter]

To what extent do you agree or disagree with the following statements?	Strongly Agree	Agree	Neutral	Disagree	Strongly disagree
16) The internet is a good way of finding other people who are facing health related decisions I may also face.					
17) I feel my health experiences could be of value to other people on the internet.					
18) I think I can tell if a person’s story on a health website sounds accurate.					
19) I worry about people making negative personal comments on health websites.					
20) Looking at health websites reassures me that I am not alone with my health concerns.					
21) The internet causes people to worry unnecessarily about their health.					
22) Health websites can help the public to know what it is like to live with a health problem.					
23) The internet is a good resource which I can use to check the doctor is giving me appropriate advice.					

For questions relating to this survey please contact Laura Kelly at [Enter]

You have completed one of three sections in this questionnaire.

Please follow the instructions below:

1. Click on the link to the health website below. This will **open a new page** in your browser.

2. Please take 10-15 minutes to explore the areas of this website which are of **interest to you.**

3. When you have finished exploring the website, **return to this page and click 'continue'** to complete the remaining questions.

Health website: www.nhs.uk/conditions/asthma

(Please note that if you do not return to this questionnaire within 30 minutes, this session will have timed out.)

This section asks about ***your views** on the health website you have just looked at.*

Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
1) This website encourages me to take steps that could be beneficial to my health.					
2) This website has a positive outlook.					
3) The information on this website left me feeling confused.					
4) This website seems to be aimed at a different age group to my needs.					
5) This website raises questions I might ask a doctor or nurse.					
6) This website includes useful tips on how to make life better.					
7) This website seems patronising.					
8) This website gives a good range of information.					
9) The language on this website made it easy to understand.					
10) This website left me with a lot of unanswered questions.					

For questions relating to this survey please contact Laura Kelly at [Enter]

Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
11) I feel more inclined to look after myself after visiting this website.					
12) I have learnt something new from this website.					
13) I can easily understand the information on this website.					
14) This website provides more useful information than my doctor is likely to give me.					
15) This website prepares me for what might happen to my health.					
16) This website makes me worry about things that are out of my control.					
17) The information on this website does not apply to me.					
18) The contributors to this website understand what is important to me.					
19) I found the information on this website distressing.					
20) I wish I had seen this website at an earlier stage.					

For questions relating to this survey please contact Laura Kelly at [Enter]

Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
21) I trust the information on this website.					
22) I would consult this website if I had to make a decision about my health.					
23) I feel I have a sense of solidarity with other people using this website.					
24) On the whole, I found this website depressing.					
25) I can identify with other people using this website.					
26) On the whole, I find this website reassuring.					
27) I would not want someone I care for to see this website.					
28) I value the advice given on this website.					
29) This website gives me confidence that I am able to manage my health.					
30) I feel I have a lot in common with other people using this website.					

For questions relating to this survey please contact Laura Kelly at [Enter]

Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
31) This website makes me worry that I may not receive the health care I need.					
32) This website gives me the confidence to explain my health concerns to others.					
33) This website helped me to develop a better understanding of my personal health.					
34) This website makes me want to play a more active role in my healthcare.					
35) This websites makes gives me more confidence to discuss my health with the people in my life (For example, my family or people at work)					
36) Photographs and other images were used appropriately on the website.					
37) I found the images on this website distressing.					
38) This website is attractive.					
39) This website is easy to use.					

For questions relating to this survey please contact Laura Kelly at [Enter]

You have completed two of three sections of this questionnaire.

Section 4

This section asks about *you and your use of the internet.*

10. How old are you in years?

____

11. Are you male or female?

[ ] Male
[ ] Female

12. Select the highest level of education you have **completed**?

[ ] No formal education
[ ] Primary school
[ ] Secondary school
[ ] Third level (diploma, degree or higher)
[ ] Don’t know
[ ] Other ___________________

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

[ ] ASIAN: of Indian origin
[ ] ASIAN: of Pakistani origin
[ ] ASIAN: of Bangladeshi origin
[ ] ASIAN: of Chinese origin
[ ] ASIAN: of other origin
[ ] BLACK: of other origin
[ ] WHITE: of British origin
[ ] WHITE: of other origin
[ ] Don’t know
[ ] Other

[ ] BLACK: of African origin ___________________
[ ] BLACK: of Caribbean origin

14. Which of these descriptions most accurately describes you?

[ ] At work
[ ] Unemployed
[ ] Student
[ ] Not working due to ill health
[ ] On home duties (e.g. doing housework, looking after children or other persons)
[ ] Retired (at retirement age)
[ ] Retired (due to ill health)
[ ] Other _________________

15. To which group do you belong?

[ ] I think I might have asthma
[ ] I have been diagnosed with asthma
[ ] Other ______________________________

16. How severe is your asthma?

[ ] Mild
[ ] Moderate
[ ] Severe

17. If you have been diagnosed with asthma, how long ago in years and months were you diagnosed?

18. How often do you have someone help you read hospital materials? Always/Often/Sometimes/Occasionally/Never

19. How confident are you filling out medical forms yourself? Extremely/Quite a bit/Somewhat/A little bit/Not at all

20. How often do you have problems learning about your medical condition because of difficulty understanding written information? Always/Often/Sometimes/Occasionally/Never

Your use of the internet

On average how often do you do the following?	Several times a day	Daily	Weekly	Monthly	Less than monthly	Never	Don’t know
a. Check your personal or work email							
b. Do instant messaging on the internet (such as MSN or chat on Facebook)							
c. Participate in chat rooms							
d. Make or receive phone calls over the Internet							
e. Read a web-log or blog							
f. Write a web-log or blog							
g. Post messages on discussion or message boards							
h. Post pictures or photos on the Internet							
i. Use a social networking site such as MySpace or Facebook							
j. Visit a health website							

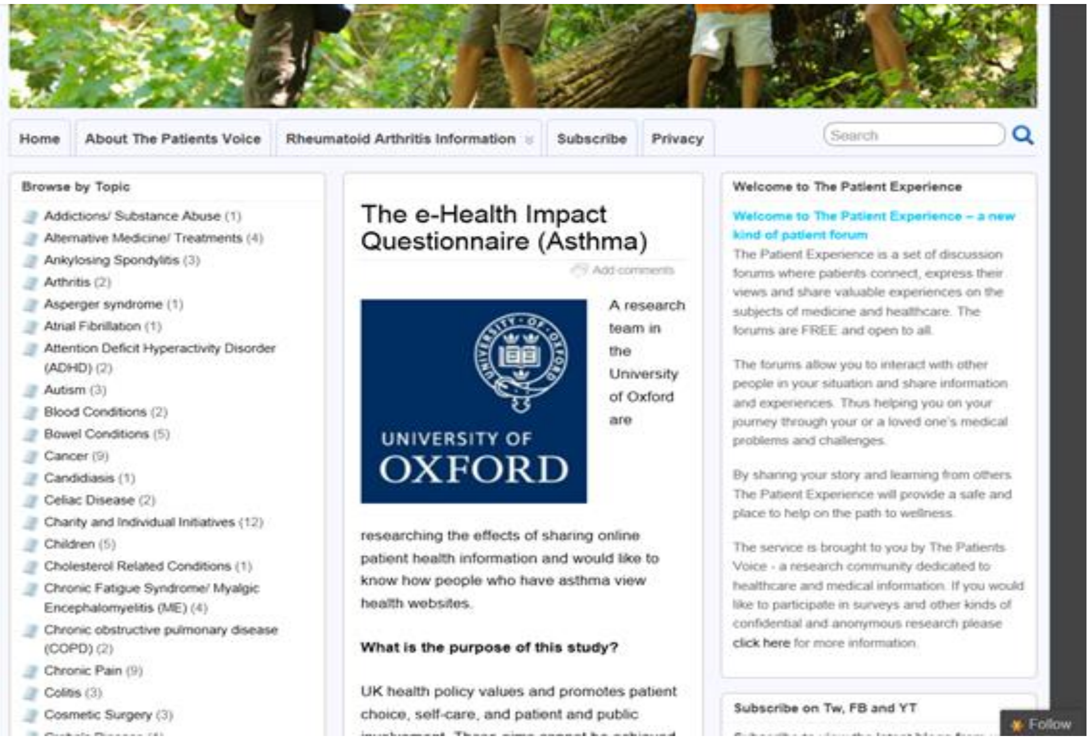
Please enter your email address to register with this study. *Any contact details given will be known only to the research team for the purposes of this study. Through providing your email address we will try to avoid contacting the same people again to complete this questionnaire.*

Appendix 6.1 Stage Three Recruitment sources and advertisements

Table 1: Stage Three Recruitment sources

Recruitment source	Example
Health blogs	The Patients Voice *(see Figure 1)* Berkshire MS Therapy Centre
Discussion forums	MND Association Build-UK (MND)
Social networking sites	Facebook *(see Figure 2)* Twitter
Health websites news pages	Multiple Sclerosis Resource Centre Health talk online
Health websites research volunteer pages	MS Society
Local news online advertisements	Oxford Daily Info
Research and policy volunteer email list	Asthma UK
Newspaper advertisements	London Metro

Figure 1: Research advertisement on health blog (The Patients Voice)



The e-Health Impact Questionnaire (Asthma)

A research team in the University of Oxford are researching the effects of sharing online patient health information and would like to know how people who have asthma view health websites.

What is the purpose of this study?

UK health policy values and promotes patient choice, self-care, and patient and public

Welcome to The Patient Experience

Welcome to The Patient Experience – a new kind of patient forum

The Patient Experience is a set of discussion forums where patients connect, express their views and share valuable experiences on the subjects of medicine and healthcare. The forums are FREE and open to all.

The forums allow you to interact with other people in your situation and share information and experiences. Thus helping you on your journey through your or a loved one's medical problems and challenges.

By sharing your story and learning from others The Patient Experience will provide a safe and place to help on the path to wellness.

The service is brought to you by The Patients Voice - a research community dedicated to healthcare and medical information. If you would like to participate in surveys and other kinds of confidential and anonymous research please click here for more information.

Figure 2: Research advertisement posts (Examples of NHS Choices post)

The NHS Twitter accounts had approximately 30,000 followers at the time of recruitment. The NHS Facebook pages had approximately 48,000 likers at the time of recruitment. Posts appear on 'followers' or 'likers' news feed.


Face book post by NHS Choices

NHS Choices shared a link.

he recession made you more stressed in your job? Is your
oyer doing all it could to look after your wellbeing?

Recession 'leads to rise in stress and sick days' - Health News - NHS Choices
www.nhs.uk
Work-related stress has "soared" by 40% and absentee rates by 25% during the recession, th
Daily Mail reported yesterday.

Jo Wood Because our sickness scores are used as redundanc
criteria our sickness has fallen!!!
February 24 at 1:01pm · Like

Karen Smith See Capita results announcement yesterday :-)
February 24 at 2:07pm · Like

NHS Choices shared a link.
February 21

u have a food allergy or intolerance, or think you migh
? If so, why not ask the specialist doctors in our online clinic
your problem. They're waiting to answer questions al this

Online clinic on food allergy - open now
www.nhs.uk

Steve Steele also for those who are really over-weight with an underactive thyroid, then technically this can be really difficult and in rare cases the subject hardly has to eat at all to gain weight.........Always seek an experts opinion
March 2 at 9:34pm · Like

NHS Choices shared a link.
February 22

If you're a smoker and want to stop, a research team at the University of Oxford would like your help for a study researching the effects of online health information. They're developing a questionnaire and want to ensure it's easy to under...See More

e - Health Impact Questionnaire
www.survey.bris.ac.uk

6 people like this.

Ирена Јордан Is there any work on prevention of smoking? I just don't get it why people would ever start smoking...
February 22 at 10:29am · Like

'Tash Campbell I'm quitting :)
February 22 at 10:51am · Like

NHS Choices shared a link.
February 17

Posted links can also be shared by other Facebook users. This posts the link onto their page and increases the number of people who can view the post.


Link shared by five other Facebook users

Discussion and 'likes'

Healthy Living shared a link via NHS Choices.
February 22

If you're a smoker and want to stop, a research team at the University of Oxford would like your help for a study researching the effects of online health information. They're developing a questionnaire and want to ensure it's easy to under...See More

e - Health Impact Questionnaire
www.survey.bris.ac.uk

19 people like this.

Doreen Sibley I quit smoking and joined a forum on line. After 42 years smoking. the forum helped me understand what was going on and I wasn't really going mad. We had rewards too which made even easier. I would recommend joining a forum online.
February 22 at 10:49am · Like

Kut Kut Barlaas i dont know whats attractive in smoking
February 22 at 12:54pm · Like

Mary Fisher Not starting is the key but you don't realise how dependent you'll become when you start :-(
February 23 at 9:15pm · Like

Healthy Living shared a link.
February 19

30 people like this.

ete Ellison Really good information, thanks, I'm 60
ebruary 27 at 10:00am · Like

obert Chapman Readinh that NHS page made me put the
ttle of coke i was drinking in the bin and im only 20! Ughh
esday at 3:21pm · Like

ealthy Living shared a link via NHS Choices.
ebruary 21

Do you have a food allergy or intolerance, or think you might have? I so, why not ask the specialist doctors in our online clinic about y ur problem. They're waiting to answer questi
week.

Online clinic on food allergy - open n
www.nhs.uk
Online clinic on food allergies and food intolerance, enabling patients to get answers to their questions on food allergy and intolerance from specialists.

6 people like this.

Derek Reale Yes,i am intolerant but doubt i can blame my food..only joking

Appendix 6.2 Stage Three Participant Information Sheet

‘Examining the role of information on patients’ experiences as a resource for choice and decision-making in health care’

INFORMATION ABOUT THE RESEARCH

What is the purpose of the study?

Patient experiences of ill-health can be an important source of information to other people with the same condition. The aim of this research is to find out how the NHS should incorporate people’s experiences into online health information. To do this, we need to develop a questionnaire which asks people about sharing health experiences online.

We have developed questions following the analysis of interviews with a wide variety of illnesses. We would like to find out whether the questions are both easy to understand and accurately reflect the effects of sharing health experiences online.

Why have I been asked to take part in the study?

You have been identified through [insert organisation]. We will ask up to up to 500 people to complete the questionnaire.

Am I eligible to take part in this study?

We are looking for people aged 18 or over who have access to the internet and are able to answer the questionnaire independently.

What will taking part in the study involve?

We are asking you to take some time to look at the following website: [insert website]. We then ask you to complete our online questionnaire [insert web link].

What are the possible disadvantages or risks of taking part?

Taking part in this study will take about half an hour of your time. All information you give will remain <u>strictly confidential</u> and will only be seen by members of the research team. You can decide not to complete the questionnaire at any point during the study.

What are the possible benefits of taking part?
There may be no immediate benefits to you but the information you provide may help health information providers distribute information in a useful way.

What will happen to the results of the study?
The results of this study will be used to refine the questionnaire we have developed. The questionnaire will be used to test various health websites so we can best present useful health information online. Findings will be written up as a journal article and presented at conferences.

This study will also contribute to doctoral research. The University of Oxford is committed to the dissemination of its research and has established an online archive of research materials. This research will be written up as a thesis and, upon successful submission, will be deposited both in print and online in the University archives. The thesis may be published with open access to facilitate its use in future research and be available to every internet user.

Who is organising and funding the research?
This research will be undertaken by the Departments of Public Health and Primary Health Care, University of Oxford, in collaboration with research groups in Warwick, Stirling, Northumbria and Sheffield. It is funded by the Department of Health.

Who has ethically approved this study?
This study was given ethical approval by the Central University Research Ethics Committee, University of Oxford.

Questions or help?
Please contact Laura Kelly (doctoral student) by telephone on [Enter] or by email [Enter].

Appendix 7.1 Stage Four, Phase 1

Ccover letter to General Practitioner

Health Services Research Unit
Department of Public Health

Rosemary Rue Building, Old Road Campus, Headington, Oxford OX3 7LF
Tel: +44 (0)1865 289XXX, email: laura.kelly@XXX

Validation study of the e-Health Impact Questionnaire

Short title: Validation study of the e-Health Impact questionnaire

Full title: Developing a valid and reliable measure to capture the effects of exposure to health websites. (Work package 1c of Programme Grant RP-PG-0608-10147: Examining the role of information on patients' experiences as a resource for choice and decision-making in health care)

CLRN number: 104246

REC reference number: 12/SW/0209

Dear Doctor,

My colleagues and I at the University of Oxford are undertaking research on the best way to present experiential information on health websites in order to inform users and help them with decision-making in healthcare. We aim to make recommendations about how online personal experience information can best be used by the NHS and others to improve patient and carer support and well-being.

As part of this research we are developing a valid and reliable generic measure to capture the effects of exposure to health websites which contain patient experiences. To do this we are asking patients with a range of conditions to complete our online questionnaire. We are writing to request that you help us with our study by identifying suitable participants and distributing our participant literature. If you would be willing to assist us, we would require your practice to:

1) Identify a random list of 250 patients who are 18 or over and have been [INSERT diagnosed with asthma OR have been referred to NHS smoking services within the last year]

2) Send invitation packs supplied by our research team to these patients

Patients who agree to take part will be asked to complete an online questionnaire on two occasions in their own home.

Our aim is to minimise inconvenience to your Practice, but we need your support for this study to be successful. If you choose to help, your Practice will receive appropriate reimbursement for its time.

Further information on the study is available at in the enclosed information sheet. If you would rather discuss the project in person, please contact Laura Kelly on [Enter].

Many thanks for your time.

Appendix 7.2 Stage Four, Phase 1

Further Information Sheet for General Practitioner

Further information:
Validation study of the e-Health Impact Questionnaire

INFORMATION ABOUT THE RESEARCH

What is the purpose of the study?

People's experiences of asthma can be an important source of information to other people who have been diagnosed with [asthma OR to other people who wish to stop smoking]. The aim of this research is to find out how the NHS should incorporate people's experiences into health websites in an effective manner.

One component of this research seeks to develop and pilot-test a questionnaire to measure the effects of exposure to online health websites. This measure will be used in a clinical trial to assess the impact of an asthma website on people who have been diagnosed the condition. It is therefore extremely important to establish if this questionnaire is suitable for use within an asthmatic population.

Who is eligible to take part in this study?

We are asking patients who are 18 or over and [have been diagnosed with asthma OR have expressed an interest in trying to stop smoking during the past year]. Patients must have access to the internet and be able to read English in order to complete this questionnaire; however, this is not a screening criterion.

What will taking part in the study involve for your patients?

Your patients will receive a research invitation letter and further information about the study. Those wishing to take part in the study will be asked to visit a website, provide their consent online by clicking on boxes provided and complete a series of questions about their general views of internet based information. They will then be asked to spend 10-15 minutes exploring an asthma website and then answer a series of questions relating to that website. We expect this task may take approximately 20-25 minutes in total. Patients will be asked to provide their email address and will be asked to complete the questionnaire again after a two week period so that we can assess the reliability of the measure. Our questionnaire is enclosed for your reference.

What will taking part in the study involve for your practice?

If you agree to help us with our study, we will ask you to search your database for potential participants according to the eligibility criteria [(patients who are aged 18 or over and have been diagnosed with asthma) OR (patients who are aged 18 or over and have expressed an interest in trying to stop smoking during the past year)]. Your staff will be responsible for attaching address labels to each research invitation pack and for sending them to potential participants. You will also be asked to send a reminder letter to potential participants after 10 days.

What are the possible benefits to individuals taking part?

Whilst we cannot guarantee immediate benefits to individuals taking part in this research, the information they provide may help health information providers distribute information in a useful way. Existing evidence suggests there are many health benefits a person may experience from accessing health websites. For instance, access may lead to an increased understanding of their health, increased confidence and motivation to take steps to improve their health and enable better use of health services.

What will happen to the results of the study?
The results of this study will be used to refine the questionnaire we have developed. The questionnaire will be used in clinical trials to test various health websites so we can best present useful health information online. Findings will be written up as a journal article and presented at conferences. This study will also contribute to doctoral research. All information gathered in the study will remain strictly confidential and results will be presented in an anonymous format. Upon completion of the study, participating GP practices will receive a briefing document outlining the results of the study and will be directed to where they can find further information.

Who is organising and funding the research?
This research will be undertaken by the Departments of Public Health and Primary Health Care, University of Oxford, in collaboration with research groups in the Universities of Warwick, Glasgow, Northumbria and Sheffield. It is funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme RP-PG-0608-10147.

Who has ethically approved this study?
This study was given ethical approval by [Insert]

Questions or help?
Please contact Laura Kelly by telephone on 01865 [Enter] or by email [Enter] or Professor Crispin Jenkinson (e-mail [Enter]).

Appendix 7.3 Stage Four, Phase 1

Participant Research invitation cover letter (Smoking cessation)

[GP practice headed paper]

Validation study of the e-Health Impact Questionnaire

Dear Patient,

I am writing to you to ask for your help in a research study being conducted within the University of Oxford. You are invited to participate in this study as you have been identified from your general practice database as having expressed an interest in trying to stop smoking in the past year.

We are researching the effects of patient information on the internet. To do this, we are developing an online questionnaire which is based on what people say is important to them.

Please take time to read the enclosed information before you decide if you would like to take part. This research study has been approved by an NHS Research Committee (Reference number: 12/SW/0209). If you decide you would like to take part in this research study, you can do so by going to the following web address: www.dph.ox.ac.uk/research/hsru/stopsmoking. Before completing the questionnaire you will be asked to confirm your consent to take part in the study by clicking on the boxes provided.

Your name and address have not been made known to the research team by your practice. Your decision concerning whether or not you participate will not affect the medical care you receive. You have the right to withdraw at any time without giving reason.

If you have any questions, please contact the research team (telephone on [Enter]or email [Enter].

With kind regards, [Insert signature]

Appendix 7.4 Stage Four, Phase 1

Participant research invitation cover letter (Asthma)

[GP practice headed paper]

Validation study of the e-Health Impact Questionnaire

Dear Patient,

I am writing to you to ask for your help in a research study being conducted within the University of Oxford. You are invited to participate in this study as you have been identified from your general practice database as having been diagnosed with asthma.

We are researching the effects of patient information on the internet. To do this, we are developing an online questionnaire which is based on what people say is important to them.

Please take time to read the enclosed information before you decide if you would like to take part. This research study has been approved by an NHS Research Committee (Reference number: 12/SW/0209). If you decide you would like to take part in this research study, you can do so by going to the following web address: www.dph.ox.ac.uk/research/hsru/asthma. Before completing the questionnaire you will be asked to confirm your consent to take part in the study by clicking on the boxes provided.

Your name and address have not been made known to the research team by your practice. Your decision concerning whether or not you participate will not affect the medical care you receive. You have the right to withdraw at any time without giving reason.

If you have any questions, please contact the research team (telephone on [Enter] or email [Enter].

With kind regards, [Insert signature

Appendix 7.5 Stage Four, Phase 1

Participant Information Sheet

(Smoking cessation)

Validation study of the e-Health Impact Questionnaire

INFORMATION ABOUT THE RESEARCH

What is the purpose of the study?

Patient experiences of health can be an important source of information to other people who are going through similar experiences. The aim of this research is to find out how we should incorporate people's experiences into online health information. To do this, we have developed a questionnaire which asks people about their views of health websites. We would like to find out whether the questions are suitable for use among people who are interested in trying to stop smoking.

Why have I been asked to take part in the study?

You have been identified through your GP Practice as someone who has expressed an interest in trying to stop smoking during the past year. We will ask up to 750 people to complete this questionnaire.

Am I eligible to take part in this study?

We are asking people who would like to stop smoking, are aged 18 or over and who have access to the internet to complete the questionnaire.

Do I have to take part?

You do not have to take part in this study. Participation in this research is voluntary and taking part will not affect your medical care in any way. You are free to withdraw from the study at any time without giving reasons. You can decide if you would like to take part in this study for up to four weeks after you receive this letter, after which the questionnaire will no longer be accessible online.

What will taking part in this study involve?

To take part in this study, you will need to complete an online questionnaire by going to the following web address: www.dph.ox.ac.uk/research/hsru/stopsmoking. We will ask you for your consent to take part in the study by clicking on boxes provided at the beginning of the online questionnaire. We will ask you to take some time to complete a set of questions asking about your general attitudes towards health websites. We will then ask you to look at a health website and answer a set of questions relating to the website. We will send you an email reminder asking you to repeat this task after a period of two weeks. In order to do this we will ask you to provide an email address where we can contact you. We expect this will take 20-25 minutes of your time on two separate occasions.

What are the possible disadvantages or risks of taking part?
Taking part in this study will take 20 -25 minutes of your time on two occasions. In order to make the best use of your time, we have tried to ensure the questionnaire is as simple as possible to complete through carrying out interviews and piloting the questionnaire.

We do not consider it likely that you will come to any harm or risk through taking part in this study, although it is possible that you may have concerns about your health following reading information on the specified website. If you read something which makes you concerned about your health you should contact your GP or call NHS Direct.

What are the possible benefits of taking part?
There may be no immediate benefits to you but the information you provide may help health information providers to design and distribute information in a way that is appropriate to the needs and preferences of people like you.

Will my taking part be kept confidential?
If you choose to take part, all information you give will be anonymised and remain strictly confidential. Information will be collected in secure survey software and stored in a secure, password protected file. Where you provide your email address, this will be kept in a separate password protected file and will only be kept for the duration of the study. Only the principal investigator will have access to your email address.

Responsible members of the University of Oxford or the Oxford University Hospitals NHS Trust may be given access to data for monitoring and/or audit of the study to ensure we are complying with regulations.

What will happen if I don't want to continue?
You are free to withdraw from the study at any time without giving reason. If you decide to withdraw during the study and prefer to withdraw data you have previously submitted, you can contact the research team to ask them to remove this.

What if there is a problem?
Given the nature of this study, it is highly unlikely that you will suffer harm by taking part.

However, the University has arrangements in place to provide for harm arising from participation in the study for which the University is the Research Sponsor.

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Laura Kelly (telephone [Enter]or email [Enter])or you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224 or the head of CTRG, email heather.house@admin.ox.ac.uk

What will happen to the results of the study?

The results of this study will be used to ensure that the questionnaire is suitable for use with people who wish to stop smoking. The questionnaire will be used to test various health websites so we can best present useful health information online. Only anonymised data will be written up, published or presented at conferences, and it will not be possible to identify a participant in any publications or presentations. In order to receive the results of this study by email, you can click on a box provided in the online questionnaire.

This study is part of a DPhil (Doctor of Philosophy) study and will therefore contribute to doctoral research. The University of Oxford is committed to the dissemination of its research and has established an online archive of research materials. This research will be written up as a thesis and, upon successful submission, will be deposited both in print and online in the University archives. The thesis may be published with open access to facilitate its use in future research and be available to every internet user.

Who is organising and funding the research?

This research will be undertaken by the Departments of Public Health and Primary Health Care, University of Oxford, in collaboration with research groups in the Universities of Warwick, Northumbria, Sheffield and Glasgow. This programme presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0608-10147).

Who has ethically approved this study?

This study was given ethical approval by the NHS Research Ethics Committee (Reference number: 12/SW/0209).

Questions or help?

Please contact Laura Kelly (doctoral student) by telephone on [Enter]or by email [Enter].

Appendix 7.6 Stage Four, Phase 1

Participant Information Sheet

(Asthma)

Validation study of the e-Health Impact Questionnaire

INFORMATION ABOUT THE RESEARCH

What is the purpose of the study?

Patient experiences of health can be an important source of information to other people with similar experiences. The aim of this research is to find out how we should incorporate people's experiences into online health information. To do this, we have developed a questionnaire which asks people about their views of health websites. We would like to find out whether the questions are suitable for use among people who have been diagnosed with asthma.

Why have I been asked to take part in the study?

You have been identified through your GP Practice as someone who has been diagnosed with asthma. We will ask up to 750 people to complete this questionnaire.

Am I eligible to take part in this study?

We are asking people who have been diagnosed with asthma, are aged 18 or over and who have access to the internet to complete the questionnaire.

Do I have to take part?

You do not have to take part in this study. Participation in this research is voluntary and taking part will not affect your medical care in any way. You are free to withdraw from the study at any time without giving reasons. You can decide if you would like to take part in this study for up to four weeks after you receive this letter, after which the questionnaire will no longer be accessible online.

What will taking part in this study involve?

To take part in this study, you will need to complete an online questionnaire by going to the following web address: www.dph.ox.ac.uk/research/hsru/asthma. We will ask you for your consent to take part in the study by clicking on boxes provided at the beginning of the online questionnaire. We will ask you to take some time to complete a set of questions asking about your general attitudes towards health websites. We will then ask you to look at a health website and answer a set of questions relating to the website. We will send you an email reminder asking you to repeat this task after a period of two weeks. In order to do this we will ask you to provide an email address where we can contact you. We expect this will take 20-25 minutes of your time on two separate occasions.

What are the possible disadvantages or risks of taking part?

Taking part in this study will take 25 -25 minutes of your time on two occasions. In order to make the best use of your time, we have tried to ensure the questionnaire is as simple as possible to complete through carrying out interviews and piloting the questionnaire.

We do not consider it likely that you will come to any harm or risk through taking part in this study, although it is possible that you may have concerns about your health following reading information on the specified website. If you read something which makes you concerned about your health you should contact your GP or call NHS Direct.

What are the possible benefits of taking part?

There may be no immediate benefits to you but the information you provide may help health information providers to design and distribute information in a way that is appropriate to the needs and preferences of people like you.

Will my taking part be kept confidential?

If you choose to take part, all information you give will be anonymised and remain strictly confidential. Information will be collected in secure survey software and stored in a secure, password protected file. Where you provide your email address, this will be kept in a separate password protected file and will only be kept for the duration of the study. Only the principal investigator will have access to your email address.

Responsible members of the University of Oxford or the Oxford University Hospitals NHS Trust may be given access to data for monitoring and/or audit of the study to ensure we are complying with regulations.

What will happen if I don’t want to continue?

You are free to withdraw from the study at any time without giving reason. If you decide to withdraw during the study and prefer to withdraw data you have previously submitted, you can contact the research team to ask them to remove this.

What if there is a problem?

Given the nature of this study, it is highly unlikely that you will suffer harm by taking part. However, the University has arrangements in place to provide for harm arising from participation in the study for which the University is the Research Sponsor.

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Laura Kelly (telephone [Enter] or email [Enter]) or you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224 or the head of CTRG, email heather.house@admin.ox.ac.uk

What will happen to the results of the study?

The results of this study will be used to ensure that the questionnaire is suitable for use with people who have been diagnosed with asthma. The questionnaire will be used to test various health websites so we can best present useful health information online. Only anonymised data will be written up, published or presented at conferences, and it will not be possible to identify a participant in any publications or presentations. In order to receive the results of this study by email, you can click on a box provided in the online questionnaire.

This study is part of a DPhil (Doctor of Philosophy) study and will therefore contribute to doctoral research. The University of Oxford is committed to the dissemination of its research and has established an online archive of research materials. This research will be written up as a thesis and, upon successful submission, will be deposited both in print and online in the University archives. The thesis may be published with open access to facilitate its use in future research and be available to every internet user.

Who is organising and funding the research?

This research will be undertaken by the Departments of Public Health and Primary Health Care, University of Oxford, in collaboration with research groups in the Universities of Warwick, Northumbria, Sheffield and Glasgow. This programme presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0608-10147).

Who has ethically approved this study?

This study was given ethical approval by the NHS Research Ethics Committee (Reference number: 12/SW/0209).

Questions or help?

Please contact Laura Kelly (doctoral student) by telephone on [Enter] or by email [Enter].

Appendix 7.7 Stage Four, Phase 1

Participant reminder letter

(Smoking cessation)

[GP practice headed paper]

Validation study of the e-Health Impact Questionnaire

Dear Patient,

Approximately two weeks ago we sent you a research invitation letter for a study being carried out by the University of Oxford. As you may recall, the research team are researching the effects of patient information on the internet and they would like you to complete an online questionnaire.

If you would like to take part in this research study, you can do so by going to following web address: www.dph.ox.ac.uk/research/hsru/stopsmoking.

Please accept our apologies for contacting you again if you have already completed this questionnaire.

If you have any questions, please contact the research team (telephone on [Enter] or email [Enter].

With kind regards,
[Insert signature]

Appendix 7.8 Stage Four, Phase 1

Participant reminder letter

(Asthma)

[GP practice headed paper]

Validation study of the e-Health Impact Questionnaire

Dear Patient,

Approximately two weeks ago we sent you a research invitation letter for a study being carried out by the University of Oxford. As you may recall, the research team are researching the effects of patient information on the internet and they would like you to complete an online questionnaire.

If you would like to take part in this research study, you can do so by going to following web address: www.dph.ox.ac.uk/research/hsru/asthma

Please accept our apologies for contacting you again if you have already completed this questionnaire.

If you have any questions, please contact the research team (telephone on [Enter] or email [Enter].

With kind regards,
[Insert signature]

Appendix 7.9 Stage Four, Phase 1

Participant cover letter

(People with MS and carers of people with MS)

Health Services Research Unit
Department of Public Health

Rosemary Rue Building, Old Road Campus, Headington, Oxford OX3 7LF
Tel: +44 (0)1865 289XXX, email: laura.kelly@XXX

Validation study of the e-Health Impact Questionnaire

Dear member,

I am writing to you to as a member of Birmingham MS Society to ask for your help in a research study being conducted within the University of Oxford. We would like to invite you and (if applicable), the person you consider to be your carer to participate in this study.

We are researching the effects of patient and carer information on the internet. To do this, we are developing an online questionnaire which is based on what people say is important to them. We would like you to complete this online questionnaire.

Enclosed you will find two participant information sheets:

- The pink sheet provides further information should you as a person with multiple sclerosis wish to take part
- The green sheet provides further information for the person you consider to be your carer (if applicable). If you have several carers, please select the person you consider to be your main carer.

Please take time to read the enclosed information before you decide if you would like to take part. This research study has been approved by an NHS Research Committee 12/SW/0209. If you decide you would like to take part in this research study, you can do so by going to the web address provided on your information sheet. Before completing the questionnaire you will be asked to confirm your consent to take part in the study by clicking on the boxes provided.

Your name and address have not been made known to the research team by Birmingham MS Society. You have the right to withdraw at any time without giving reason.
If you have any questions, please contact the research team (telephone on [Enter] or email [Enter].

With kind regards,
Laura Kelly

Appendix 7.10 Stage Four, Phase 1

Participant Information Sheet

(People with MS)

People with Multiple Sclerosis

Validation study of the e-Health Impact Questionnaire

INFORMATION ABOUT THE RESEARCH

What is the purpose of the study?

Patient experiences of health and illness can be an important source of information for other people with similar health problems or concerns. The aim of this research is to find out how we should incorporate people's experiences into online health information. To do this, we have developed a questionnaire which asks people about their views of health websites. We would like to find out whether the questions are suitable for use among people who have been diagnosed with multiple sclerosis.

Why have I been asked to take part in the study?

You have been identified through Birmingham MS Society as someone who may have multiple sclerosis. We will ask up to 750 people to complete this questionnaire.

Am I eligible to take part in this study?

We are asking people (who are 18 or over) with multiple sclerosis and who have access to the internet to complete this questionnaire.

Do I have to take part?

You do not have to take part in this study. Participation in this research is voluntary and taking part will not affect your medical care in any way. You are free to withdraw from the study at any time without giving reasons. You can decide if you would like to take part in this study for up to four weeks after you receive this letter, after which the questionnaire will no longer be accessible online.

What will taking part in this study involve?

To take part in this study, you will need to complete an online questionnaire by going to the following web address: www.dph.ox.ac.uk/research/hsru/ms. We will ask you for your consent to take part in the study by clicking on boxes provided at the beginning of the online questionnaire. We will ask you to take some time to complete a set of questions asking about your general attitudes towards health websites. We will then ask you to look at a health website and answer a set of questions relating to the website. We will send you an email reminder asking you to repeat this task after a period of two weeks. In order to do this we will ask you to provide an email address where we can contact you. We expect this will take 20-25 minutes of your time on two separate occasions.

What are the possible disadvantages or risks of taking part?

Taking part in this study will take 20-25 minutes of your time on two occasions. In order to make best use of your time, we have tried to ensure the questionnaire is as simple as possible to complete through carrying out interviews and piloting the questionnaire.

We do not consider it likely that you will come to any harm or risk through taking part in this study, although it is possible that you may have concerns about your health following reading information on the specified website. If you read something which makes you concerned about your health you should contact your GP or call NHS Direct.

What are the possible benefits of taking part?

There may be no immediate benefits to you but the information you provide may help health information providers to design and distribute information in a way that is appropriate to the needs and preferences of people like you.

Will my taking part be kept confidential?

If you choose to take part, all information you give will be anonymised and remain strictly confidential. Information will be collected in secure survey software and stored in a secure, password protected file. Where you provide your email address, this will be kept in a separate password protected file and will only be kept for the duration of the study. Only the principal investigator will have access to your email address.

Responsible members of the University of Oxford or the Oxford University Hospitals NHS Trust may be given access to data for monitoring and/or audit of the study to ensure we are complying with regulations.

What will happen if I don't want to continue?

You are free to withdraw from the study at any time without giving reason. If you decide to withdraw during the study and prefer to withdraw data you have previously submitted, you can contact the research team to ask them to remove this.

What if there is a problem?

Given the nature of this study, it is highly unlikely that you will suffer harm by taking part. However, the University has arrangements in place to provide for harm arising from participation in the study for which the University is the Research Sponsor.

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Laura Kelly (telephone [Enter] or email [Enter]) or you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224 or the head of CTRG, email heather.house@admin.ox.ac.uk

What will happen to the results of the study?

The results of this study will be used to ensure that the questionnaire is suitable for use with people with multiple sclerosis. The questionnaire will be used to test various health websites so we can best present useful health information online. Only anonymised data will be written up, published or presented at conferences, and it will not be possible to identify a participant in any publications or presentations. In order to receive the results of this study by email, you can click on a box provided in the online questionnaire.

This study is part of a DPhil (Doctor of Philosophy) study and will therefore contribute to doctoral research. The University of Oxford is committed to the dissemination of its research and has established an online archive of research materials. This research will be written up as a thesis and, upon successful submission, will be deposited both in print and online in the University archives. The thesis may be published with open access to facilitate its use in future research and be available to every internet user.

Who is organising and funding the research?

This research will be undertaken by the Departments of Public Health and Primary Health Care, University of Oxford, in collaboration with research groups in the Universities of Warwick, Northumbria, Sheffield and Glasgow. This programme presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0608-10147).

Who has ethically approved this study?

All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by NRES Committee South West – Exeter (reference number 12/SW/0209).

Questions or help?

Please contact Laura Kelly (doctoral student) by telephone on [Enter] or by email [Enter].

Appendix 7.11 Stage Four, Phase 1

Participant Information Sheet

(Carers of people with MS)

Carers of people with Multiple Sclerosis

Validation study of the e-Health Impact Questionnaire

INFORMATION ABOUT THE RESEARCH

What is the purpose of the study?

People's experiences of caring can be an important source of information to other people who are caring for a person with multiple sclerosis. The aim of this research is to find out how we should incorporate people's experiences into online health information. To do this, we have developed a questionnaire which asks people about their views of health websites. We would like to find out whether the questions are suitable for use among people who care for people with multiple sclerosis.

Why have I been asked to take part in the study?

You have been identified through Birmingham MS Society as someone who may care for a person with multiple sclerosis. We will ask up to 750 people to complete this questionnaire.

Am I eligible to take part in this study?

We are asking carers (who are 18 or over) of people with multiple sclerosis and who have access to the internet to complete this questionnaire.

What is meant by 'carer'?

A 'carer' is a family member or friend who provides care in terms of help and support to a person with multiple sclerosis. Examples of care are:

- Personal care such as help with dressing or washing.
- Healthcare such as help with medications or medical equipment.
- Household duties such as cooking or shopping.
- Physical care such as lifting or helping with walking.

Do I have to take part?

You do not have to take part in this study. Participation in this research is voluntary and taking part will not affect your (or the persons' you care for) medical care in any way. You are free to withdraw from the study at any time without giving reasons. You can decide if you would like to take part in this study for up to four weeks after you receive this letter, after which the questionnaire will no longer be accessible online.

What will taking part in this study involve?

To take part in this study, you will need to complete an online questionnaire by going to the following web address: www.dph.ox.ac.uk/research/hsru/mscarer. We will ask you for your consent to take part in the study by clicking on boxes provided at the beginning of the online questionnaire. We will ask you to take some time to complete a set of questions asking about your general attitudes towards health websites. We will then ask you to look at a health website and answer a set of questions relating to the website. We will send you an email reminder asking you to repeat this task after a period of two weeks. In order to do this we will ask you to provide an email address where we can contact you. We expect this will take 20-25 minutes of your time on two separate occasions.

What are the possible disadvantages or risks of taking part?

Taking part in this study will take 20-25 minutes of your time on two occasions. In order to make best use of your time, we have tried to ensure the questionnaire is as simple as possible to complete through carrying out interviews and piloting the questionnaire.

We do not consider it likely that you will come to any harm or risk through taking part in this study, although it is possible that you may have concerns about your (or the persons' you care for) health following reading information on the specified website. If you read something which makes you concerned about your health you should contact your GP or call NHS Direct.

What are the possible benefits of taking part?

There may be no immediate benefits to you but the information you provide may help health information providers to design and distribute information in a way that is appropriate to the needs and preferences of people like you.

Will my taking part be kept confidential?

If you choose to take part, all information you give will be anonymised and remain strictly confidential. Information will be collected in secure survey software and stored in a secure, password protected file. Where you provide your email address, this will be kept in a separate password protected file and will only be kept for the duration of the study. Only the principal investigator will have access to your email address.

Responsible members of the University of Oxford or the Oxford University Hospitals NHS Trust may be given access to data for monitoring and/or audit of the study to ensure we are complying with regulations.

What will happen if I don't want to continue?

You are free to withdraw from the study at any time without giving reason. If you decide to withdraw during the study and prefer to withdraw data you have previously submitted, you can contact the research team to ask them to remove this.

What if there is a problem?
Given the nature of this study, it is highly unlikely that you will suffer harm by taking part. However, the University has arrangements in place to provide for harm arising from participation in the study for which the University is the Research Sponsor.

If you wish to complain about any aspect of the way in which you have been approached or treated during the course of this study, you should contact Laura Kelly (telephone [Enter] or email [Enter]) or you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224 or the head of CTRG, email heather.house@admin.ox.ac.uk

What will happen to the results of the study?
The results of this study will be used to ensure that the questionnaire is suitable for use with people who care for people with multiple sclerosis. The questionnaire will be used to test various health websites so we can best present useful health information online. Only anonymised data will be written up, published or presented at conferences, and it will not be possible to identify a participant in any publications or presentations. In order to receive the results of this study by email, you can click on a box provided in the online questionnaire.

This study is part of a DPhil (Doctor of Philosophy) study and will therefore contribute to doctoral research. The University of Oxford is committed to the dissemination of its research and has established an online archive of research materials. This research will be written up as a thesis and, upon successful submission, will be deposited both in print and online in the University archives. The thesis may be published with open access to facilitate its use in future research and be available to every internet user.

Who is organising and funding the research?
This research will be undertaken by the Departments of Public Health and Primary Health Care, University of Oxford, in collaboration with research groups in the Universities of Warwick, Northumbria, Sheffield and Glasgow. This programme presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0608-10147).

Who has ethically approved this study?
All research in the NHS is looked at by an independent group of people called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by NRES Committee South West - Exeter (reference number 12/SW/0209).

Questions or help?
Please contact Laura Kelly (doctoral student) by telephone on [Enter] or by email [Enter].

Appendix 7.12 Stage Four, Phase 1

Research reminder letter

(People with MS and carer)

UNIVERSITY OF
OXFORD

Health Services Research Unit
Department of Public Health

Rosemary Rue Building, Old Road Campus, Headington, Oxford OX3 7LF
Tel: +44 (0)1865 289XXX, email: laura.kelly@XXX

Validation study of the e-Health Impact Questionnaire

Dear member,

I am writing to you to as a member of Birmingham MS Society to ask for your help in a research study being conducted within the University of Oxford. We would like to invite you and (if applicable), the person you consider to be your carer to participate in this study.

We are researching the effects of patient and carer information on the internet. To do this, we are developing an online questionnaire which is based on what people say is important to them. We would like you to complete this online questionnaire.

To find out more about the study and access the online questionnaire please follow the links below:

- Should you as a person with multiple sclerosis wish to take part, please press 'Ctrl' and click on the link: www.dph.ox.ac.uk/research/hsru/ms
- If the person you consider to be your carer (if applicable), please press 'Ctrl' and click on the link: www.dph.ox.ac.uk/research/hsru/mscarer. If you have several carers, please select the person you consider to be your main carer.

Please take time to read the further information before you decide if you would like to take part. This research study has been approved by an NHS Research Committee 12/SW/0209. When you follow the link to the questionnaire you will be asked to confirm your consent to take part in the study by clicking on boxes provided.

Your name and email address have not been made known to the research team by Birmingham MS Society. You have the right to withdraw at any time without giving reason.
If you have any questions, please contact the research team (telephone on [Enter] or email [Enter].

If you have already taken part in this research, thank you for your time. Please accept our apologies for contacting you again.

With kind regards,
Laura Kelly

Appendix 7.13 Stage Four, Phase 1

Retest invitation letter (all conditions)

UNIVERSITY OF
OXFORD

Health Services Research Unit
Department of Public Health

Rosemary Rue Building, Old Road Campus, Headington, Oxford OX3 7LF
Tel: +44 (0)1865 289XXX, email: laura.kelly@XXX

Validation study of the e-Health Impact Questionnaire

Dear Participant,

Approximately two weeks ago you completed a questionnaire for a research study being carried out by the University of Oxford. As you may recall, the study involves you completing a questionnaire about your views of health information online at two separate times.

We are now emailing you to ask you to complete the second questionnaire. Completing the questionnaire twice allows us to find out whether the questionnaire is a useful way of asking people about their views of health websites.

The second questionnaire can be found by clicking on: [insert link]

This questionnaire will be linked to the questionnaire you have previously completed and your email address will be deleted from our records at the end of the study.

If you have any questions, please contact the research team (telephone on [Enter] or email [Enter].

With kind regards,
Laura Kelly

Appendix 7.14 Stage Four, Phase 2 Research invitation email

Validation study of the e-Health Impact Questionnaire

Dear participant,

A research team in the University of Oxford would like to invite you to participate in a study researching the effects of online health information.

They are developing a questionnaire which asks about the impact of using health-related websites and would like to ask you about your views regarding a website about [insert condition]. To find out more about the study and access the online questionnaire please follow this link: Click here to take the survey.

Alternatively you can copy and paste the following URL into your browser to access the questionnaire: [Insert URL]

Please take time to read the further information before you decide if you would like to take part. This project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee. If you decide to take part in this study you will be asked to confirm your consent to take part by clicking on the boxes provided.

You have the right to withdraw at any time without giving reason. There will be no penalty if you decide to withdraw from this study. If you have any questions, please contact the research team (telephone on [Enter] or email [Enter].

With kind regards,
Laura Kelly

Appendix 7.15 Stage Four, Phase 2

Research invitation advertisement

Validation study of the e-Health Impact Questionnaire

A research team in the University of Oxford would like your help in a study researching the effects of online health information. They are developing a questionnaire which asks about the impact of using health-related websites. They would like to ask you about your views regarding a website about [insert condition]. Click here to access the questionnaire and find out more: [Insert URL]

Appendix 7.16 Stage Four, Phase 2

Participant Information Sheet

(Online recruitment)

Validation study of the e-Health Impact Questionnaire

INFORMATION ABOUT THE RESEARCH

What is the purpose of the study?
Patient experiences of health can be an important source of information to other people with similar experiences. The aim of this research is to find out how we should incorporate people's experiences into online health information. To do this, we have developed a questionnaire which asks people about their views of health websites. We would like to find out whether the questions are suitable for use among people who have [insert condition].

Why have I been asked to take part in the study?
You have been identified as someone who may have [insert condition]. We would like 250 people to complete this questionnaire.

Am I eligible to take part in this study?
We are asking people who have [insert condition], are aged 18 or over and who have access to the internet to complete the questionnaire.

Do I have to take part?
You do not have to take part in this study. Participation in this research is voluntary and taking part will not affect your medical care in any way. You are free to withdraw from the study at any time without giving reasons.

What will taking part in this study involve?
To take part in this study, you will need to complete an online questionnaire by clicking on the following link: [insert]. We will ask you for your consent to take part in the study by clicking on boxes provided at the beginning of the online questionnaire. We will ask you to take some time to complete a set of questions asking about your general attitudes towards health websites. We will then ask you to look at a health website and answer a set of questions relating to the website. We will send you an email reminder asking you to repeat this task after a period of two weeks. In order to do this we will ask you to provide an email address where we can contact you. We expect this will take 20-25 minutes of your time on two separate occasions.

What are the possible disadvantages or risks of taking part?
Taking part in this study will take 20 -25 minutes of your time on two occasions. In order to make the best use of your time, we have tried to ensure the questionnaire is as simple as possible to complete through carrying out interviews and piloting the questionnaire.

We do not consider it likely that you will come to any harm or risk through taking part in this study, although it is possible that you may have concerns about your health following reading information on the specified website. If you read something which makes you concerned about your health you should contact your GP or call NHS Direct.

What are the possible benefits of taking part?
There may be no immediate benefits to you but the information you provide may help health information providers to design and distribute information in a way that is appropriate to the needs and preferences of people like you.

Will my taking part be kept confidential?
If you choose to take part, all information you give will be anonymised and remain strictly confidential. Information will be collected in secure survey software and stored in a secure, password protected file. Where you provide your email address, this will be kept in a separate password protected file and will only be kept for the duration of the study. Only the principal investigator will have access to your email address.

What will happen if I don't want to continue?
You are free to withdraw from the study at any time without giving reason. There will be no penalty if you decide to withdraw from the study. If you do decide to withdraw during the study and prefer to withdraw data you have previously submitted, you can contact the research team to ask them to remove this.

What if there is a problem?
If you have a concern about any aspect of this project, please contact Laura Kelly ([Enter] or [Enter]) who will do her best to answer your query. If you remain unhappy and wish to make a formal complaint, please contact the Research Ethics Committee at the University of Oxford (ethics@medsci.ox.ac.uk; Medical Sciences Inter-Divisional Research Ethics Committee, Medical Sciences Divisional Office, Level 3 John Radcliffe Hospital, Oxford, OX3 9DU, UK).

What will happen to the results of the study?
The results of this study will be used to ensure that the questionnaire is suitable for use with people who have [insert condition]. The questionnaire will be used to test various health websites so we can best present useful health information online. Only anonymised data will be written up, published or presented at conferences, and it will not be possible to identify a participant in any publications or presentations.

This study is part of a DPhil (Doctor of Philosophy) study and will therefore contribute to doctoral research. The University of Oxford is committed to the dissemination of its research and has established an online archive of research materials. This research will be written up as a thesis and, upon successful submission, will be deposited both in print and online in the University archives. The thesis may be published with open access to facilitate its use in future research and be available to every internet user.

Who is organising and funding the research?

The Validation study of the e-Health Impact Questionnaire is being carried out by Laura Kelly (DPhil student) under the supervision of Professor Crispin Jenkinson and Professor Sue Ziebland. This research will be undertaken by the Departments of Public Health and Primary Care Health Sciences, University of Oxford, in collaboration with research groups in the Universities of Warwick, Northumbria, Sheffield and Glasgow. This programme presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0608-10147).

Who has ethically approved this study?

This project has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee.

Questions or help?

Please contact Laura Kelly (doctoral student) by telephone on 01865 289425 or by email laura.kelly@hmc.ox.ac.uk

Appendix 7.17 Stage Four, Phase 2

Retest invitation email

Validation study of the e-Health Impact Questionnaire

Dear Participant,

Approximately two weeks ago you completed a questionnaire for a research study being carried out by the University of Oxford. As you may recall, the study involves you completing a questionnaire about your views of health information online at two separate times.

We are now emailing you to ask you to complete the second questionnaire. Completing the questionnaire twice allows us to find out whether the questionnaire is a useful way of asking people about their views of health websites.

The second questionnaire can be found by clicking on [insert url]

This questionnaire will be linked to the questionnaire you have previously completed and your email address will be deleted from our records at the end of the study.

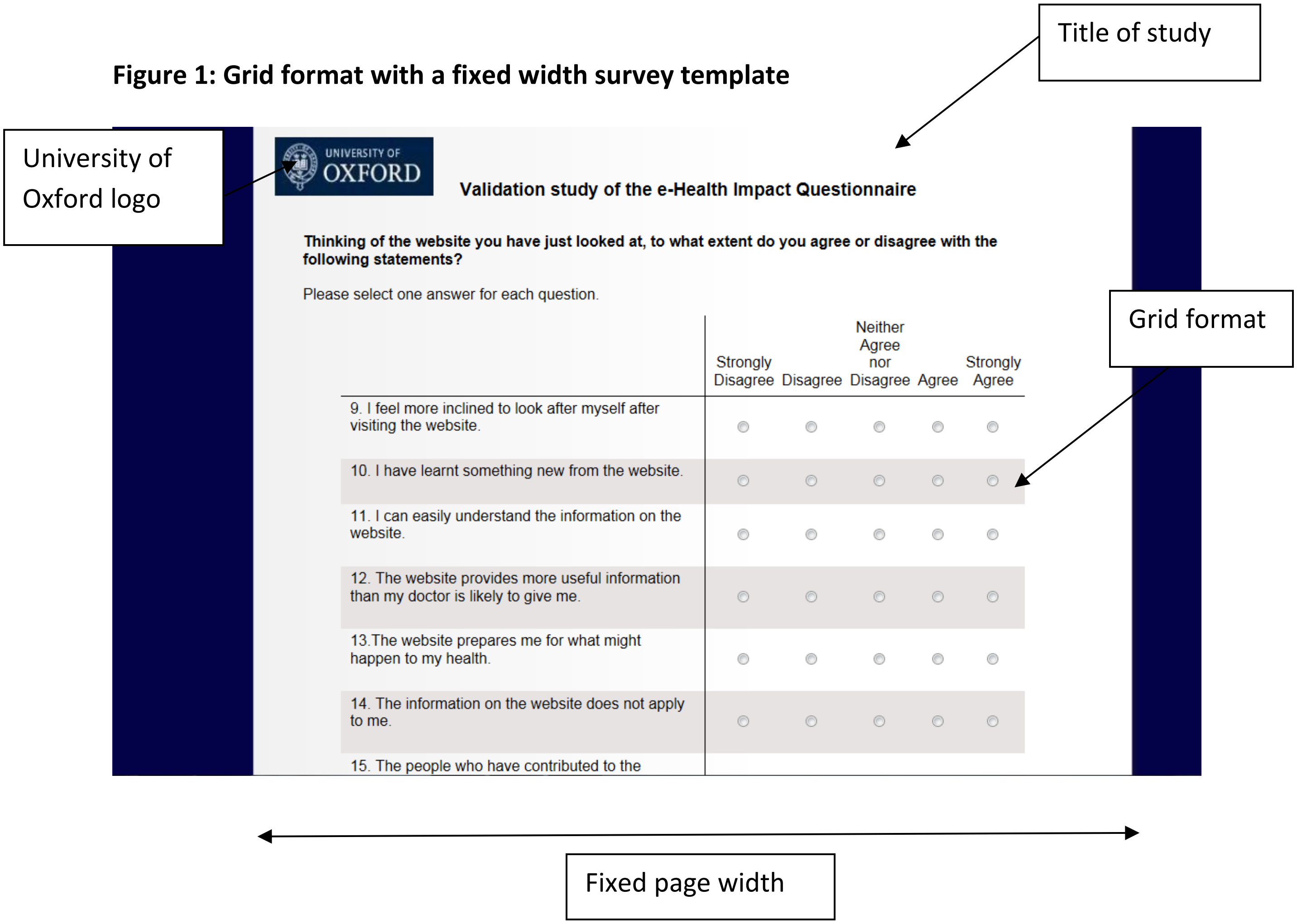
If you have any questions, please contact the research team (telephone on [Enter] or email [Enter].

With kind regards,
Laura Kelly

Appendix 7.18 Stage Four Survey design improvements

(Qualitric's survey software)

Figure 1: Grid format with a fixed width survey template



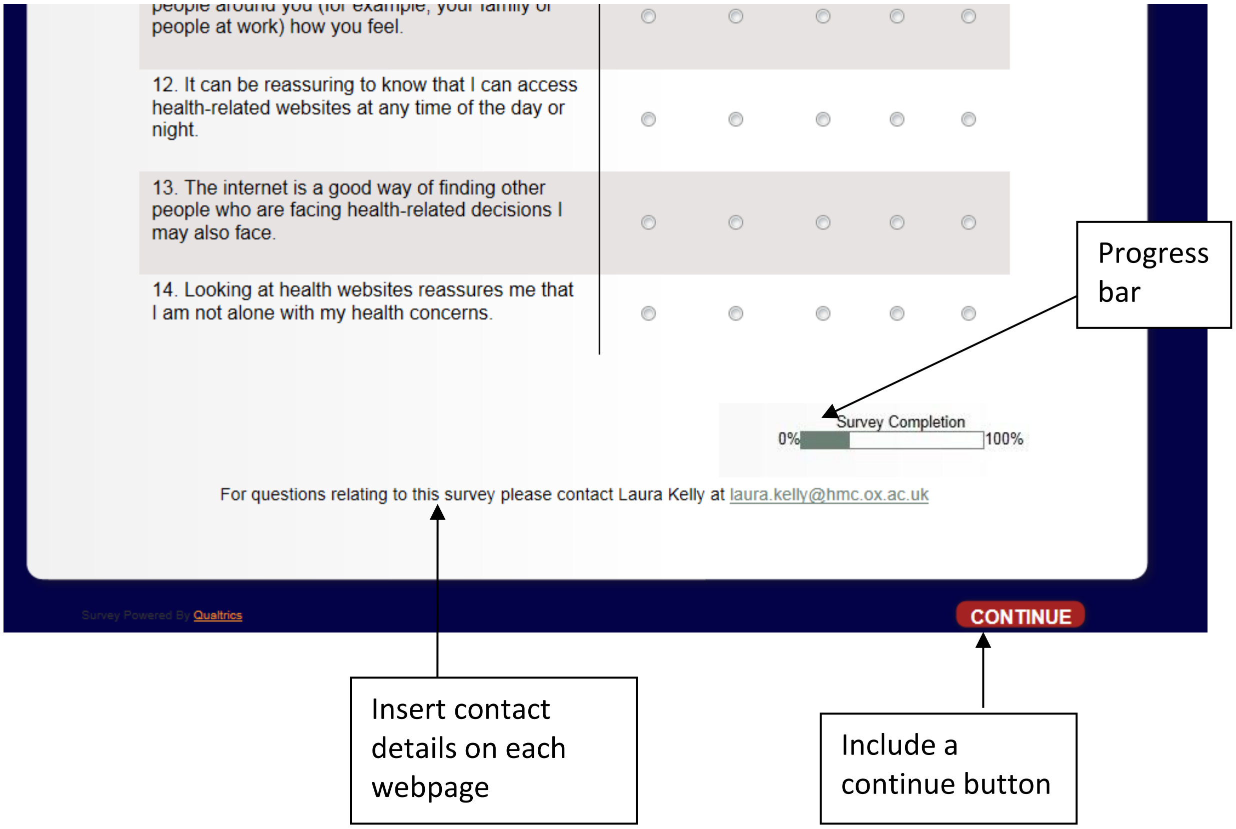
Validation study of the e-Health Impact Questionnaire

Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?

Please select one answer for each question.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
9. I feel more inclined to look after myself after visiting the website.	○	○	○	○	○
10. I have learnt something new from the website.	○	○	○	○	○
11. I can easily understand the information on the website.	○	○	○	○	○
12. The website provides more useful information than my doctor is likely to give me.	○	○	○	○	○
13.The website prepares me for what might happen to my health.	○	○	○	○	○
14. The information on the website does not apply to me.	○	○	○	○	○
15. The people who have contributed to the					

Figure 2: Progress bar and continue button using Qualtrics survey software



people around you (for example, your family or people at work) how you feel.	○	○	○	○	○
12. It can be reassuring to know that I can access health-related websites at any time of the day or night.	○	○	○	○	○
13. The internet is a good way of finding other people who are facing health-related decisions I may also face.	○	○	○	○	○
14. Looking at health websites reassures me that I am not alone with my health concerns.	○	○	○	○	○

For questions relating to this survey please contact Laura Kelly at laura.kelly@hmc.ox.ac.uk

Progress bar

Insert contact details on each webpage

Include a continue button

Appendix 7.19 Stage Four, Phase 1

Participant consent form

(NHS recruitment)

Validation study of the e-Health Impact Questionnaire

Please indicate your consent to take part in this study by ticking the boxes provided:

1. I have read and understood the information sheet (version X dated XXXX) for the above study; ☐
2. I understand that my participation is voluntary and I am free to withdraw at any time, without giving reason and without my medical care or legal rights being affected; ☐
3. I understand the data collated may be looked at by authorised individuals from the sponsor (University of Oxford) for the purposes of monitoring and auditing to ensure that the study is being conducted properly. I give permission for these individuals to have access to relevant information. ☐

Appendix 7.20 Stage Four, Phase 2

Participant consent form

(Non-NHS recruitment)

Validation study of the e-Health Impact Questionnaire

Investigators: Laura Kelly (doctoral student), Professor Crispin Jenkinson and Professor Sue Ziebland

We are asking participants to complete a questionnaire which asks people about their views of health related websites. Please indicate that you understand and give your consent to take part in this study by clicking on each box below.

I agree to participate in this study	
I have read the Participant Information Sheet	
I know who I can contact to ask questions about the study and, where applicable, have received satisfactory answers	
I understand I am free to withdraw from the study at any time, without giving any reason, and there is no penalty associated with leaving the study	
I understand personal data will not contain identifiable information (name, email address), will be accessed only by members of the research team and will be destroyed after 5 years	
I understand the results of the study will be presented in anonymous form	
I understand how to raise a complaint	
I understand this study has been approved by University of Oxford Central University Research Ethics Committee	

If you have concerns about any aspect of this project, please contact Laura Kelly ([Enter] or [Enter]) who will do her best to answer any queries. If you remain unhappy and wish to make a formal complaint, please contact the Research Ethics Committee at the University of Oxford (ethics@medsci.ox.ac.uk; Medical Sciences Inter-Divisional Research Ethics Committee, Medical Sciences Divisional Office, Level 3, John Radcliffe Hospital, Oxford, OX3 9DU, UK).

Appendix 7.21: Stage Four e-HIQ items and layout

This section asks about ***your*** *general attitudes towards health-related websites.*

In this section *'health- related websites'* can include websites that contain factual health information, stories of people's experiences of health, blogs about health or health discussion forums.

Please begin by completing the questions below.

	Select the box which applies to you.				
To what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. I know how to find relevant health information on the internet.					
2. The internet is a reliable resource to help me understand what a doctor tells me.					
3. I know which health information on the internet is trustworthy.					
4. The internet causes people to worry about their health.					
5. The internet can help the public to know what it is like to live with a health problem.					
6. The internet can be useful to help people decide if their symptoms are important enough to go to see a doctor.					
7. I would use the internet if I needed help to make a decision about my health (for example, whether I should see a doctor, take medication or seek other types of treatment).					

For questions relating to this survey please contact: [Enter]

	Select the box which applies to you.				
To what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
8. I would use the internet to check that the doctor is giving me appropriate advice.					
9. The internet is a good way of finding other people who are experiencing similar health problems.					
10. It can be helpful to see other people's health-related experiences on the internet.					
11. The internet is useful if you don't want to tell people around you (for example, your family or people at work) how you feel.					
12. It can be reassuring to know that I can access health-related websites at any time of the day or night.					
13. The internet is a good way of finding other people who are facing health-related decisions I may also face.					
14. Looking at health websites reassures me that I am not alone with my health concerns.					

For questions relating to this survey please contact: [Enter]

Continue to new page

You have completed 1 of 2 sections in this questionnaire.

Please follow the instructions below:

1. Click on the link to the health-related website below. This will **open a new page** in your browser.

2. Please take 10-15 minutes to browse the areas of this website which are of **interest to you.**

3. When you have finished browsing the website, **return to this page and click 'continue'** to complete the remaining questions.

*Health- related website: [**Insert website]***

(Please note that if you do not return to this questionnaire within 30 minutes, this session will time out)

For questions relating to this survey please contact: [Enter]

Continue to new page

Part 2

This section asks about ***your views*** *on the health-related website you have just looked at.*

	Select the box which applies to you.				
Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. The website encourages me to take actions that could be beneficial to my health.					
2. The website has a positive outlook.					
3. The information on the website left me feeling confused.					
4. The website includes useful tips on how to make life better.					
5. The website seems patronising.					
6. The website provides a wide range of information.					
7. The language on the website made it easy to understand.					
8. The website left me with a lot of unanswered questions.					

For questions relating to this survey please contact: [Enter]

Continue to new page

	Select the box which applies to you.				
Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
9. I feel more inclined to look after myself after visiting the website.					
10. I have learnt something new from the website.					
11. I can easily understand the information on the website.					
12. The website provides more useful information than my doctor is likely to give me.					
13. The website prepares me for what might happen to my health.					
14. The information on the website does not apply to me.					
15. The people who have contributed to the website understand what is important to me.					
16. It would have been useful for me to have seen the website earlier.					

For questions relating to this survey please contact: [Enter]

Continue to new page

	Select the box which applies to you.				
Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
17. I trust the information on the website.					
18. I would consult the website if I had to make a decision about my health.					
19. I feel I have a sense of solidarity with other people using the website.					
20. On the whole, I found the website depressing.					
21. I can identify with other people using the website.					
22. On the whole, I find the website reassuring.					
23. I would not want someone I care about to see the website.					
24. I value the advice given on the website.					
25. The website gives me confidence that I am able to manage my health.					
26. I feel I have a lot in common with other people using the website.					

For questions relating to this survey please contact: [Enter]

Continue to new page

	Select the box which applies to you.				
Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
27. The website gives me the confidence to explain my health concerns to others.					
28. The website helps me to have a better understanding of my personal health.					
29. The website encourages me to play a more active role in my healthcare.					
30. The website makes me more confident to discuss my health with the people around me (for example, my family or people at work).					
31. Photographs and other images were used appropriately on the website.					
32. I found the images on the website distressing.					
33. The website is attractive.					
34. The website is easy to use.					

For questions relating to this survey please contact: [Enter]

Continue to new page

Appendix 7.22 Stage Four, Phase 1

Instructions to GP practices for sampling

(Smoking cessation)

Validation study of the e-Health Impact Questionnaire

Summary of steps to follow

1. **Conduct a computerised search to identify 90 people who meet the following criteria:**

- ≥ *18years*
- Patients who have been categorised under one or more of the following read codes during the past year:
    - 8CAL- Smoking cessation advice given
    - 8H7i- Referral to smoking cessation advisor
    - 9N2k -Seen by stop smoking advisor
    - 8HTK- Referral to stop smoking clinic
- Registered at the GP practice in question

∗ *Potential participants should be ideally sampled as follows:*

Age group	***Sex***		***Total***
	Female	***Male***	
18-35	**15**	**15**	**30**
36-50	**10**	**10**	**20**
51-65	**10**	**10**	**20**
65+	**10**	**10**	**20**
Total	**45**	**45**	**90**

Sampling:
Smoking cessation read codes: We realise that patients in a practice database may be categorised by more than one of the smoking cessation read codes listed above during the last year. We therefore do not require an equal spread of patients under each of the four listed read codes. Nonetheless some care should be taken to ensure patients categorised under each of the specified read codes are represented within the sample.

Sex: In cases where a practice cannot identify a sufficient number of male or female patients in a specified age group, practices should attempt to include patients of the opposite sex so that the total number of suggested patients in each age group is reached.

- For example, if a practice can only identify 8 female patients in the 51-65 age group, they should attempt to identify 12 male patients in the 51-65 age group to reach a total of 20 patients identified in the 51-65 age group.

Age groups: In cases where a practice cannot identify the total number of suggested patients in a specified age group, a practice should attempt to identify patients in an equal spread across the remaining age groups. This can be carried out by selecting an additional patient from each age group (starting from the lowest age group first) until the required total has been reached.

- For example, where a practice can only identify a total of 18 patients from the age group 36-50, one additional patient should be selected from the 18-35 age group and one additional patient from the 51-65 age group.

2. **Review the list of 90 people to identify patients who the GP feels should be excluded due to reasons such as medical or welfare concerns. This should be carried out by a GP.**

3. **Print two address labels for each potential participant identified.**

4. **Attach one address label to a research invitation pack and one address label to a reminder letter envelope for each potential participant. Stamped research invitation packs and reminder letters will be provided by the research team.**

5. **Mail out all research invitation packs and record the postage date.**

6. **Mail out all reminder letter envelopes ten days after mailing the initial research invitation packs.**

Appendix 7.23 Stage Four, Phase 1

Instructions to GPs for sampling (Asthma)

UNIVERSITY OF
OXFORD

Validation study of the e-Health Impact Questionnaire

Summary of steps to follow

1. **Conduct a computerised search to identify 90 people who meet the following criteria:**

- *≥ 18years*
- *Diagnosed with asthma*
- *Registered at the GP practice in question*

∗ *Potential participants should ideally be sampled as follows:*

Age group	***Sex***		***Total***
	Female	***Male***	
18-35	**15**	**15**	**30**
36-50	**10**	**10**	**20**
51-65	**10**	**10**	**20**
65+	**10**	**10**	**20**
Total	**45**	**45**	**90**

Sampling:
Sex: In cases where a practice cannot identify a sufficient number of male or female patients in a specified age group, practices should attempt to include patients of the opposite sex so that the total number of suggested patients in each age group is reached.

- For example, if a practice can only identify 8 female patients in the 51-65 age group, they should attempt to identify 12 male patients in the 51-65 age group to reach a total of 20 patients identified in the 51-65 age group.

Age groups: In cases where a practice cannot identify the total number of suggested patients in a specified age group, a practice should attempt to identify patients in an equal spread across the remaining age groups. This can be carried out by selecting an additional patient from each age group (starting from the lowest age group first) until the required total has been reached.

- For example where a practice can only identify a total of 18 patients from the age group 36-50, one additional patient should be selected from the 18-35 age group and one additional patient from the 51-65 age group.

2. **Review the list of 90 people to identify patients who the GP feels should be excluded due to reasons such as medical or welfare concerns. This should be carried out by a GP.**
3. **Print two address labels for each potential participant identified.**
4. **Attach one address label to a research invitation pack and one address label to a reminder letter envelope for each potential participant. Stamped research invitation packs and reminder letters will be provided by the research team.**
5. **Mail out all research invitation packs and record the postage date.**
6. **Mail out all reminder letter envelopes ten days after mailing the initial research invitation packs.**

Appendix 7.24 Stage Four Translatability assessment changes

Table 1: eHIQ-Part 1 changes made due to Translatability Assessment (Comments summarised)

Original version	Issue	Amended version
This section asks about ***your*** *general attitudes towards health websites.*	Consistency	This section asks about ***your*** *general attitudes towards health-related websites.*
In this section *'health websites'* can include websites that contain factual health information, accounts or stories of peoples experiences of health, blogs about health or health discussion forums.	Consistency	In this section *'health- related websites'* can include websites that contain factual health information, stories of people's experiences of health, blogs about health or health discussion forums.
I know how to find relevant health information on the internet.	-	No change
The internet is a reliable resource to help me understand what a doctor tells me.	-	No change
I know when health information on the internet is trustworthy.	**PharmaQuest:** Changing 'when' to 'which' would make the sentence more fluent and understandable.	I know which health information on the internet is trustworthy.
The internet causes people to worry about their health.	-	No change
The internet can help the public to know what it is like to live with a health problem.	-	No change
The internet can be useful to help people decide if their symptoms are important enough to go and see a doctor.	-	The internet can be useful to help people decide if their symptoms are important enough to go to see a doctor.
I would use the internet if I needed help to make a decision about my health. (For example, whether I should seek medical advice or seek alternative	**PharmaQuest:** Asian languages: therapies such as acupuncture	I would use the internet if I needed help to make a decision about my health (for example, whether I should see a doctor, take medication or seek other types of treatment).

therapies).	could be regarded as standard medical practice rather than an 'alternative therapy'. Also, advice from what a Westerner may consider to be an 'alternative' practitioner may be regarded as a more mainstream form of medical advice.	
I would use the internet to check the doctor is giving me appropriate advice.	**French (France):** Perhaps write 'to check <u>that</u> the doctor…' **PharmaQuest:** We agree that this change would improve the fluency of the question.	I would use the internet to check that the doctor is giving me appropriate advice.
The internet is a good way of finding other people who are experiencing similar health problems.	-	No change
It can be helpful to see other people's health experiences on the internet.	**PharmaQuest:** For consistency we suggest changing 'health experiences' to 'health related experiences'	It can be helpful to see other people's health-related experiences on the internet.
The internet is useful if you don't want to tell people in your everyday life how you feel.	**PharmaQuest:** 'People in your everyday life' is quite a vague concept that the translators had an issue with. It could also be beneficial	The internet is useful if you don't want to tell people around you (for example, your family or people at work) how you feel.

	and clearer to change ‘people in your everyday life’ to ‘the people around you’.	
It can be reassuring to know that I can access health websites any time of the day or night.	**PharmaQuest:** For consistency we recommend making the change to ‘health related websites’.	It can be reassuring to know that I can access health-related websites at any time of the day or night.
The internet is a good way of finding other people who are facing health related decisions I may also face.	Consistency	The internet is a good way of finding other people who are facing health-related decisions I may also face.
Looking at health websites reassures me that I am not alone with my health concerns.	-	No change

Table 2: eHIQ-Part 2 changes made due to Translatability Assessment (Comments summarised)

Original version	**Issue**	**Amended version**
Insert original wording	-	This section asks about ***your views** on the health-related website you have just looked at.*
This website encourages me to take steps that could be beneficial to my health.	**PharmaQuest:** It is possible that 'take steps' will cause confusion during the translation process. 'Take actions' is still an active, positive concept that accurately conveys the meaning of 'take steps'.	The website encourages me to take actions that could be beneficial to my health.
This website has a positive outlook.	-	No change
The information on this website left me feeling confused.	-	No change
This website includes useful tips on how to make life better.	-	No change
This website seems patronising.	-	No change
This website gives a good range of information.	**Simplified Chinese (China):** No. The following wording is more idiomatic in Chinese. 'This website provides a wide range of information'.	The website provides a wide range of information.
The language on this website made it easy to understand.	-	No change

This website left me with a lot of unanswered questions.	-	No change
I feel more inclined to look after myself after visiting this website.	-	No change
I have learnt something new from this website.	-	No change
I can easily understand the information on this website.	-	No change
This website provides more useful information than my doctor is likely to give me.	-	No change
This website prepares me for what might happen to my health.	-	No change
The information on this website does not apply to me.	-	No change
The contributors to this website understand what is important to me.	**PharmaQuest:** In order to further guide the translators as to who the contributors are we will need further clarification from the developer.	The people who have contributed to the website understand what is important to me.
I wish I had seen this website at an earlier stage.	**PharmaQuest:** Please could you advise as to what time frame is meant by ‘at an earlier stage’?	It would have been useful for me to have seen the website earlier.
I trust the information on this website.	-	No change

I would consult this website if I had to make a decision about my health.	-	No change
I feel I have a sense of solidarity with other people using this website.	-	No change
On the whole, I found this website depressing.	-	No change
I can identify with other people using this website.	-	No change
On the whole, I find this website reassuring.	-	No change
I would not want someone I care for to see this website.	**PharmaQuest:** Suggest changing 'someone I care for' to 'someone I care about'.	I would not want someone I care about to see the website.
I value the advice given on this website.	-	No change
This website gives me confidence that I am able to manage my health.	-	No change
I feel I have a lot in common with other people using this website.	-	No change
This website gives me the confidence to explain my health concerns to others.	-	No change
This website helped me to develop a better understanding of my personal health.	-	No change

This website makes me want to play a more active role in my healthcare.	-	The website encourages me to play a more active role in my healthcare.
This websites gives me the confidence to discuss my health with the people in my life (For example, my family or people at work).	**PharmaQuest:** We believe that 'people around me' would be clearer than 'people in my life'.	The website makes me more confident to discuss my health with the people around me (for example, my family or people at work).
Photographs and other images were used appropriately on the website.	-	No change
I found the images on this website distressing.	-	No change
This website is attractive.	-	No change
This website is easy to use.	-	No change

7.25 Final eHIQ and scoring guide

Part 1

This section asks about ***your** general attitudes towards health-related websites.*

In this section *'health- related websites'* can include websites that contain factual health information, stories of people's experiences of health, blogs about health or health discussion forums.

Please begin by completing the questions below.

	Select the box which applies to you.				
To what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. The internet is a reliable resource to help me understand what a doctor tells me.					
2. The internet can help the public to know what it is like to live with a health problem.					
3. The internet can be useful to help people decide if their symptoms are important enough to go to see a doctor.					
4. I would use the internet if I needed help to make a decision about my health (for example, whether I should see a doctor, take medication or seek other types of treatment).					
5. I would use the internet to check that the doctor is giving me appropriate advice.					

For questions relating to this survey please contact: [Enter]

Continue to new page

	Select the box which applies to you.				
To what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
6. The internet is a good way of finding other people who are experiencing similar health problems.					
7. It can be helpful to see other people's health-related experiences on the internet.					
8. The internet is useful if you don't want to tell people around you (for example, your family or people at work) how you feel.					
9. It can be reassuring to know that I can access health-related websites at any time of the day or night.					
10. The internet is a good way of finding other people who are facing health-related decisions I may also face.					
11. Looking at health websites reassures me that I am not alone with my health concerns.					

For questions relating to this survey please contact: [Enter]

Continue to new page

Part 2

This section asks about ***your views** on the health-related website you have just looked at.*

	Select the box which applies to you.				
Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1. The website encourages me to take actions that could be beneficial to my health.					
2. The website has a positive outlook.					
3. The information on the website left me feeling confused.					
4. The website includes useful tips on how to make life better.					
5. The website provides a wide range of information.					
6. The language on the website made it easy to understand.					
7. I feel more inclined to look after myself after visiting the website.					

For questions relating to this survey please contact: [Enter]

Continue to new page

	Select the box which applies to you.				
Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
8. I have learnt something new from the website.					
9. I can easily understand the information on the website.					
10. The website prepares me for what might happen to my health.					
11. The people who have contributed to the website understand what is important to me.					
12. I trust the information on the website.					
13. I would consult the website if I had to make a decision about my health.					
14. I feel I have a sense of solidarity with other people using the website.					

For questions relating to this survey please contact: [Enter]

Continue to new page

	Select the box which applies to you.				
Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
15. I can identify with other people using the website.					
16. On the whole, I find the website reassuring.					
17. I value the advice given on the website.					
18. The website gives me confidence that I am able to manage my health.					
19. I feel I have a lot in common with other people using the website.					
20. The website gives me the confidence to explain my health concerns to others.					
21. The website helps me to have a better understanding of my personal health.					

For questions relating to this survey please contact: [Enter]

Continue to new page

	Select the box which applies to you.				
Thinking of the website you have just looked at, to what extent do you agree or disagree with the following statements?	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
22. The website encourages me to play a more active role in my healthcare.					
23. The website makes me more confident to discuss my health with the people around me (for example, my family or people at work).					
24. Photographs and other images were used appropriately on the website.					
25. I found the images on the website distressing.					
26. The website is easy to use.					

For questions relating to this survey please contact: [Enter]

Continue to new page

Scoring the eHealth Impact Questionnaire

This section provides instructions for calculating domain scores for the eHIQ-Part 1 and the eHIQ-Part 2. Each sub-scale is transformed to a 0-100 metric, where 0=lowest possible negative value and 100= highest possible positive value for each respective subscale.

Each scale is calculated as follows: sub-scale score = the sum of the final values for all the items in a given sub-scale minus the minimum raw score, divided by the range between the maximum and minimum raw score for the given sub-scale multiplied by 100. Scores can be calculated using a three step process.

Step 1: Record or enter item response

Responses for all items are exported from the data collection platform used. All items are coded the same way. It is recommended that data is recorded using the following codes:

- 1= Strongly disagree
- 2= Disagree
- 3= Neither agree nor disagree
- 4= Agree
- 5= Strongly agree

Step 2: Recode item values

Two items in eHIQ-Part 2 should be recoded to obtain their final item value as outlined in Table 3.

Table 3: Calculating final item values

Questionnaire	Item number	Original value	Final value
eHIQ-Part 2	3,25	1	5
		2	4
		3	3
		4	2
		5	1

Step 3: Determining scale scores

After item recoding, a total score for each scale can be calculated. Tables 4 and 5 provide the item numbers which belong to each scale and the minimum and maximum raw scale scores. These values should be entered into the formula below.

Table 4: eHIQ-Part 1 items per subscale and maximum scores

Sub-scale	**Sum of final <u>raw</u> values for item numbers**	**Minimum <u>raw</u> score**	**Maximum <u>raw</u> score**
1.1) Attitudes towards online health information	1+2+3+4+5	5	25
1.2) Attitudes towards sharing health experiences online	6+7+8+9+10+11	6	30

Table 5: eHIQ-Part 2 items per subscale and maximum scores

Subscale	**Sum of final <u>raw</u> values for item numbers**	**Minimum <u>raw</u> score**	**Maximum <u>raw</u> score**
2.1) Confidence and identification	10+11+14+15+17+18 +19+20+23	9	45
2.2) Information and presentation	3+5+6+9+12+24+25+26	8	40
2.3) Understanding and motivation	1+2+4+7+8+13+16+21+22	9	45

Raw scale scores can be calculated though summing the final response values for all the items in a given scale minus the minimum raw score and dividing the value by the range between the maximum and minimum raw score. The raw scale score can then be used to transform the score to a 0-100 metric by multiplying the raw domain score by 100 (See formula below).

Formula for scoring each scale=

$$\frac{Sum\ of\ scores\ of\ each\ item\ in\ scale - minimum\ raw\ score}{Maximum\ raw\ score - minimum\ raw\ score} \times 100$$

Worked example:

A person responds in the following manner for *Information and presentation* in eHIQ-Part 2 (Items included in scale: 3+5+6+9+12+24+25+26).

Table 6: Scale calculation for Scale Information and presentation

Items included	**Step 1**	**Step 2**		**Step 3**
	Exported coded response value	Original response value	Final response value	$\frac{Sum\ of\ scores\ of\ each\ item\ in\ scale - minimum\ raw\ score}{Maximum\ raw\ score - minimum\ raw\ score} \times 100$
Item 3	4	4	4	Scale score = $\frac{(4+4+5+3+3+2+5+1)-8}{40-8} \times 100$ $=\frac{27}{32} \times 100$ =0.84 x 100 =84.4
Item 5	2	2	4	
Item 6	5	5	5	
Item 9	3	3	3	
Item 12	3	3	3	
Item 24	2	2	2	
Item 25	1	1	5	
Item 26	1	1	1	

Recode items 3 and 25 (See Table 3)

Appendix 7.26 Stage Four Sub-scale score distributions

(Normal distributions)

Figure 1: eHIQ-Part 1 (Attitudes towards online health information)

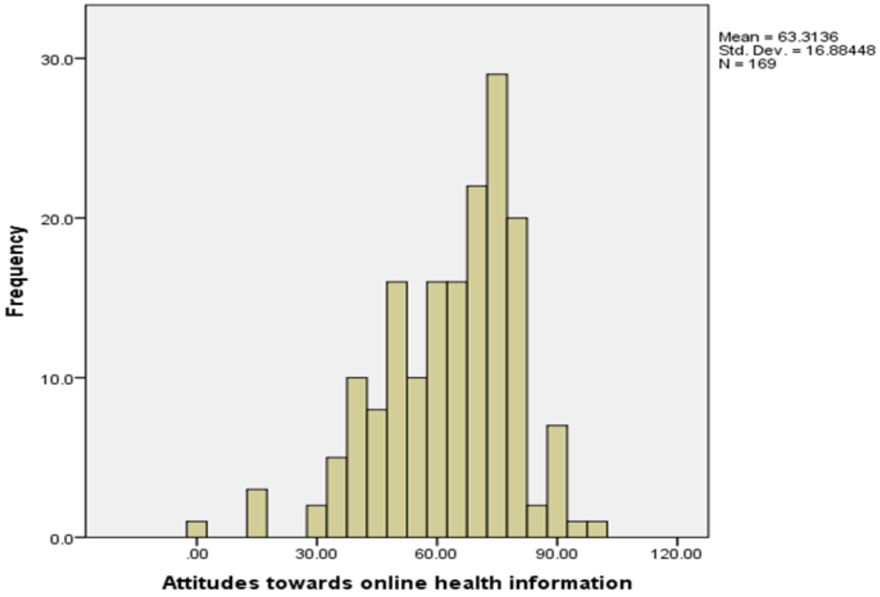


Figure 2: eHIQ-Part 1 (Attitudes towards sharing health experiences online)

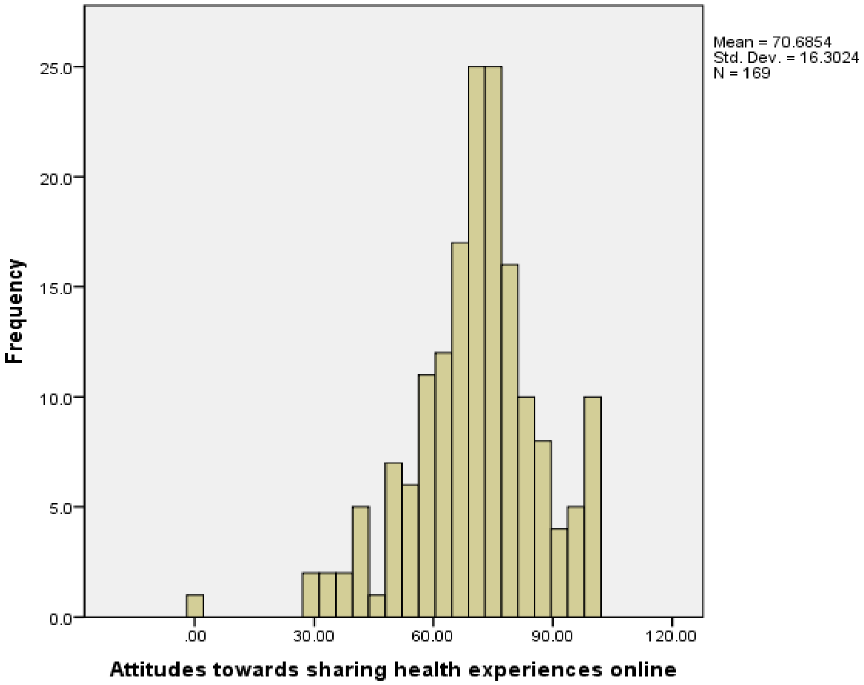


Figure 3: eHIQ-Part 2 (Confidence and identification)

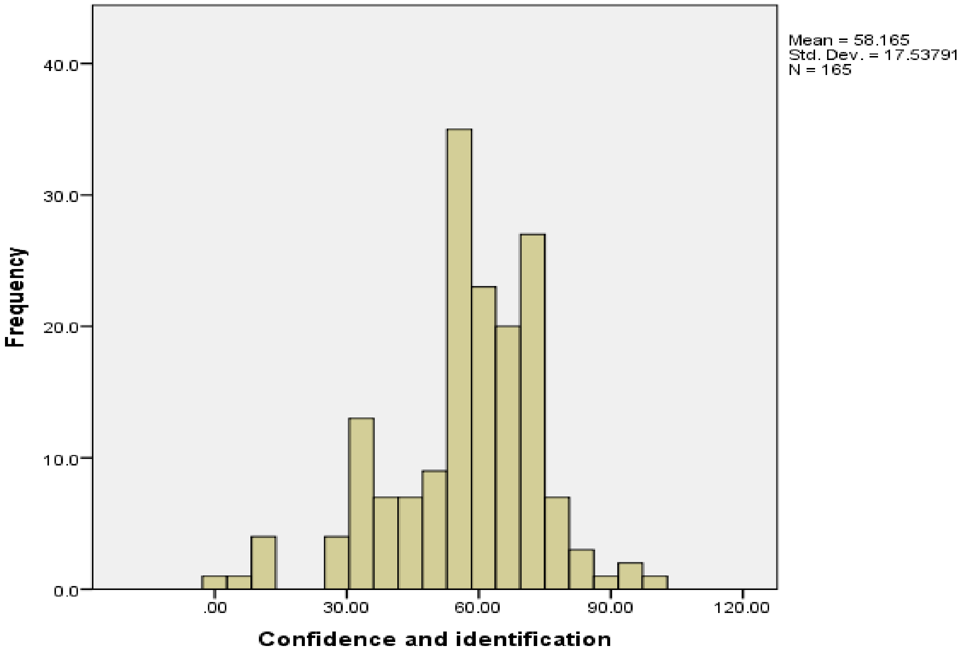


Figure 4: eHIQ-Part 2 (Understanding and motivation)

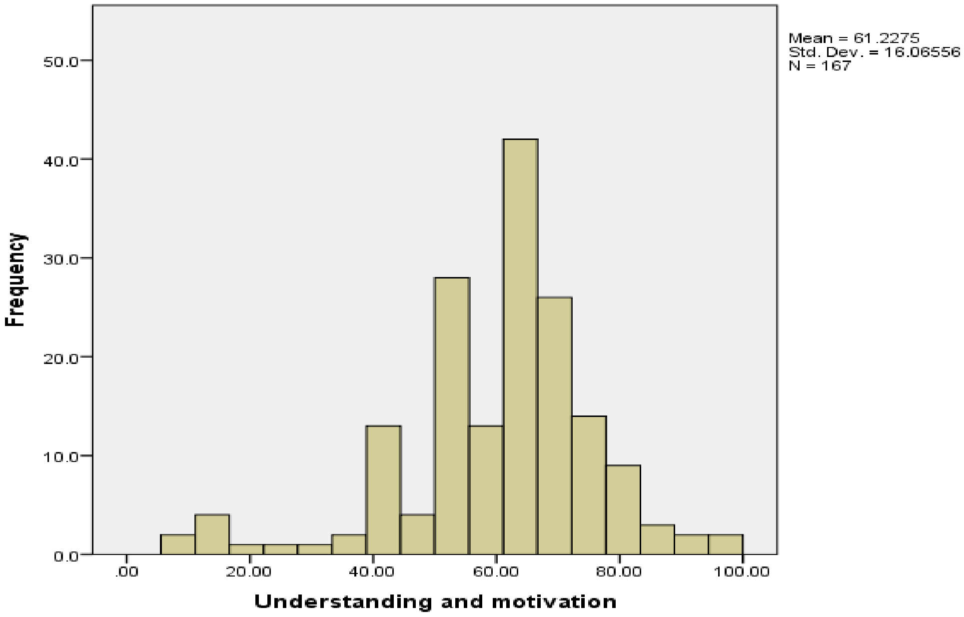


Figure 5: eHIQ-Part 1 reference measure (Health Information National Survey single item)

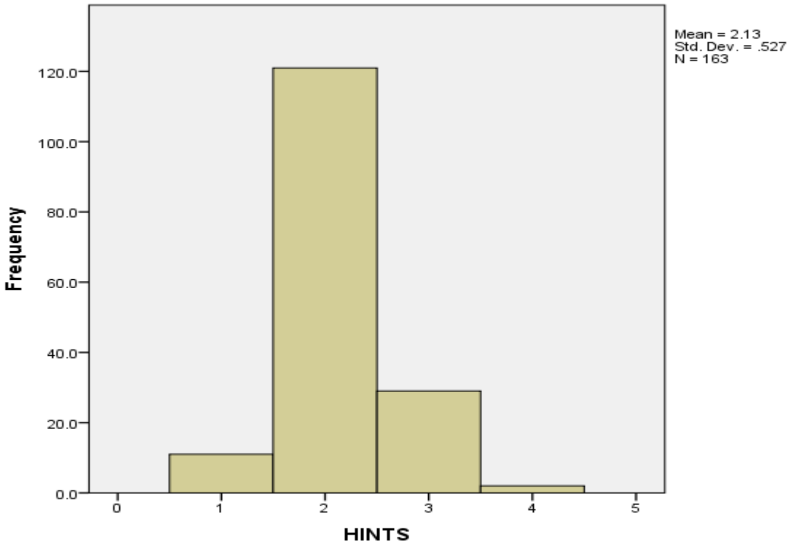
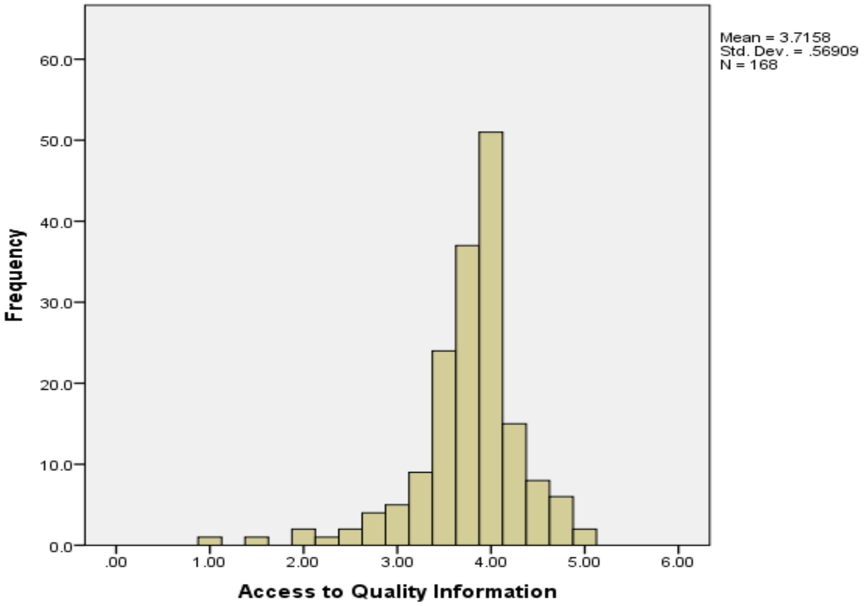


Figure 6: eHIQ-Part 2 reference measure (Access to Quality Information)



Appendix 7.27 Stage Four Descriptive statistics

(Sex)

Table 1: eHIQ Sub-scale scores and Sex

Sub-scale	Male	Female	Total
eHIQ-Part 1			
Attitudes towards sharing health experiences online (n=165)			
Mean (SD)	69.8 (17.3)	71.5 (15.7)	70.9 (16.2)
Median	70.8	70.8	70.8
Range	100	70.83	100
Attitudes towards online health information (n=165)			
Mean (SD)	61.0 (17.7)	65.7 (15.3)	64.0 (16.3)
Median	60.0	70.0	65.0
Range	90.0	85.0	100.0
eHIQ-Part 2			
Confidence and identification (n=161)			
Mean (SD)	60.3 (17.1)	57.2 (17.3)	58.4 (17.2)
Median	61.1	58.3	61.1
Range	100.0	91.7	100.0
Information and Presentation (n=163)			
Mean (SD)	73.8 (13.9)	73.3 (13.9)	73.5 (13.9)
Median	75.0	75.0	75.0
Range	100.0	90.6	100.0
Understanding and motivation (n=163)			
Mean (SD)	63.2 (14.4)	60.6 (16.5)	61.5 (15.8)
Median	63.9	61.1	63.9
Range	88.9	88.9	88.9

*Transformed scale score on 0-100 metric where 0=low perceived value of the internet (or website) for health and 100= high perceived benefit of using the internet (or website) in relation to health.

Appendix 7.28 Stage Four Descriptive statistics

(Recruitment phase)

Table 1: eHIQ Sub-scale scores and Recruitment phases

Sub-scale	Phase 1	Phase 2	Phase 3	Total
eHIQ-Part 1				
Attitudes towards sharing health experiences online (n=169)				
Mean (SD)	65.5 (14.9)	71.5 (16.7)	76.9 (15.2)	70.7 (16.3)
Median	66.7	70.8	75.0	70.8
Range	66.7	100.0	58.3	100.0
Attitudes towards online health information (n=169)				
Mean (SD)	61.2 (16.3)	62.7 (17.3)	69.1 (15.5)	63.3 (16.9)
Median	65.0	65.0	75.0	65.0
Range	75.0	100.0	60.0	100.0
eHIQ-Part 2				
Confidence and identification (n=167)				
Mean (SD)	59.2 (15.5)	56.4 (18.0)	62.8 (19.0)	58.2 (17.5)
Median	61.1	58.3	69.4	61.1
Range	88.9	94.4	86.1	100.0
Information and Presentation (n=167)				
Mean (SD)	74.5 (13.0)	72.5 (13.7)	73.4 (16.7)	73.2 (14.0)
Median	75.0	75.0	75.0	75.0
Range	59.4	96.9	87.5	100.0
Understanding and motivation (n=167)				
Mean (SD)	62.3 (15.5)	60.9 (15.8)	60.3 (18.5)	61.1 (16.1)
Median	63.9	61.1	61.1	63.9
Range	83.3	88.9	77.8	88.9

Appendix 9.1 The Rasch Model explained and worked example

Rasch Measurement Theory (RMT) literature refers to ‘person ability’ (the level of a construct a person has) and ‘item difficulty’ (the position on a hierarchal continuum where an item is located). RMT theory assumes that when a person is of higher ability than an items difficulty, the probability of them endorsing that item should be > 0.5. Equally if a person is of a lower ability than an items difficulty, the person would have < 0.5 probability of endorsing the item (Wright and Stone 1979). The probability of a person endorsing an item, $P[x_{vi} = 1]$ is shown in Equation 9.1.

Equation 9.1

$$P\{x_{vi} = 1|\beta_v, \delta_i\} = \frac{e^{(\beta_v - \delta_i)}}{1 + \ e^{(\beta_v - \delta_i)}}$$

Equation 9.1 states that the probability of a person endorsing an item, $P[x_{vi} = 1]$, given the person ability (β_v) and item difficulty (δ_i), parameters can be calculated by finding the difference between person ability and item difficulty. In practice, the difference between person ability and item difficulty ranges from plus/minus infinity and the probability of a person endorsing the item ranges from 0 to 1. The difference between ability and difficulty is therefore calculated using the exponent of the natural constant e=2.71828. The base (e) is a widely used mathematical term and is useful for describing a range of natural processes such as the rate of radioactive decay (Math_Centre, 2009, Andrich, 2013). This exponential expression (value between 0 and 1) is expressed as a ratio giving an ogive shape to find the probability of endorsing the item (Wright and Stone, 1979). The denominator serves to constrain the probability between 0 and 1.

Worked example

If a person (v) with the ability $\beta_v = 1.2$ attempts three items with difficulties $\delta_1 = -1.0,\ \delta_2 = 1.2\ and\ \delta_3 = 2.0$, the probabilities of getting a correct answer can be calculated as follows:

Table 1: Probability of a person $\boldsymbol{\beta_v = 1.2}$ getting a correct answer according to item difficulty

Item difficulty	Algorithm	Probability of endorsing item
$\delta_1 = -1.0$	$P\{x_{vi_1} = 1\|\beta_v, \delta_1\} = \frac{e^{(1.2--1.0)}}{1+e^{(1.2--1.0)}} = \frac{e^{(2.2)}}{1+e^{(2.2)}} = \frac{9.025}{10.025} = 0.90$	0.90
$\delta_2 = 1.2$	$P\{x_{vi_2} = 1\|\beta_v, \delta_2\} = \frac{e^{(1.2-1.2)}}{1+ e^{(1.2-1.2)}} = \frac{e^0}{1+ e^0} = 0.5$	0.50
$\delta_3 = 2.0$	$P\{x_{vi_3} = 1\|\beta_v, \delta_3\} = \frac{e^{(1.2-2.0)}}{1+e^{(1.2-2.0)}} = \frac{e^{-0.8}}{1+e^{-0.8}} = \frac{\frac{1}{e^{0.8}}}{1+\frac{1}{e^{0.8}}}$ $= \frac{\frac{1}{2.17}}{1+\frac{1}{2.17}} = \frac{0.46}{1.46} = 0.32$	0.32

Therefore, a person with the ability $\beta_v = 1.2$ is most likely to answer item δ_1 correctly and least likely to answer item δ_3 correctly. They are equally likely to answer item δ_2 correctly or incorrectly.

Appendix 9.2 Rasch transformation table

(eHIQ-Part 1)

Table 1: eHIQ-Part 1 Raw score interval scale transformation tables

Scale 1.1		Scale 1.2	
Raw score	Location	Raw score	Location
0	-7.195	0	-8.741
1	-4.564	1	-8.392
2	-3.319	2	-7.348
3	-2.73	3	-4.232
4	-2.315	4	-2.628
5	-1.978	5	-1.889
6	-1.68	6	-1.365
7	-1.4	7	-0.952
8	-1.123	8	-0.606
9	-0.836	9	-0.3
10	-0.53	10	-0.019
11	-0.198	11	0.248
12	0.156	12	0.51
13	0.529	13	0.775
14	0.921	14	1.052
15	1.347	15	1.351
16	1.817	16	1.683
17	2.32	17	2.061
18	2.831	18	2.49
19	3.355	19	2.955
20	3.931	20	3.436
21	4.658	21	3.935
22	5.574	22	4.488
-	-	23	5.188
-	-	24	6.075

Items scored 0 to 4 from Strongly disagree to Strongly agree.

Item 7 (Rescored: 01123- ‘Disagree’ and ‘Neither agree nor disagree’) due to disordered thresholds.

Appendix 9.3 Rasch transformation table

(eHIQ-Part 2)

Table 1: eHIQ-Part 2 Raw score interval scale transformation tables

Scale 2.1		Scale 2.2		Scale 2.3	
Raw score	Location	Raw score	Location	Raw score	location
0	-5.787	0	-6.07	0	-9.712
1	-4.94	1	-5.18	1	-6.763
2	-4.338	2	-4.508	2	-5.304
3	-3.909	3	-4.002	3	-4.582
4	-3.563	4	-3.575	4	-4.055
5	-3.266	5	-3.198	5	-3.633
6	-3.001	6	-2.861	6	-3.275
7	-2.756	7	-2.557	7	-2.958
8	-2.524	8	-2.279	8	-2.668
9	-2.3	9	-2.02	9	-2.396
10	-2.08	10	-1.774	10	-2.136
11	-1.862	11	-1.536	11	-1.884
12	-1.644	12	-1.299	12	-1.638
13	-1.424	13	-1.057	13	-1.395
14	-1.203	14	-0.803	14	-1.156
15	-0.979	15	-0.528	15	-0.917
16	-0.752	16	-0.222	16	-0.677
17	-0.522	17	0.125	17	-0.436
18	-0.287	18	0.52	18	-0.191
19	-0.048	19	0.969	19	0.061
20	0.199	20	1.475	20	0.322
21	0.456	21	2.032	21	0.599
22	0.724	22	2.592	22	0.897
23	1.005	23	3.112	23	1.224
24	1.301	24	3.598	24	1.591
25	1.612	25	4.08	25	2.004
26	1.938	26	4.588	26	2.46
27	2.275	27	5.173	27	2.936
28	2.617	28	5.929	28	3.406
29	2.961	29	6.906	29	3.862
30	3.307	-	-	30	4.311
31	3.661	-	-	31	4.769
32	4.033	-	-	32	5.269
33	4.444	-	-	33	5.865
34	4.929	-	-	34	6.683
35	5.58	-	-	35	7.807
36	6.455	-	-	-	-

Items scored 0 to 4 from Strongly disagree to Strongly agree.

Items 17, 31 and 32 have four categories after reordering to account for disordered thresholds. *Item 17 (Rescored: 01123- 'Disagree' and 'Neither agree nor disagree' collapsed), **Item 31 (Rescored: 00123- 'Strongly disagree' and 'Disagree' collapsed) and ***Item 32 (Reversed and rescored: 01123 'Agree and 'Neither agree nor disagree' collapsed)