

Appendices

Appendix 1: Search strategy

Databases: EMBASE, PsychINFO and MEDLINE

All terms were entered with *.mp*

'Mobile devices' terms

Cell* phon* OR handheld computer* OR handheld devic* OR mobile phon* OR smartphon* OR smart-phon* OR smart phon* OR iPhone* OR (Blackberry adj10 phon*) OR (Blackberry adj10 devic*) OR (Blackberry adj10 mobile*) OR Nokia OR Symbian OR (Windows adj10 mobile*) OR (Windows adj10 phon*) OR (Android adj10 mobile*) OR (Android adj10 phon*) OR Palm OS OR Palm Pre Classic OR (HTC adj10 phon*) OR HTC adj10 mobile*) OR text messag* OR short messag* OR multimedia messag* OR multi-media messag* OR ((smartphone or smart-phone or smart phone or mobile) adj10 app*) OR iPad* OR tablet devic* OR tablet computer* OR personal digital assistant* OR mHealth OR m-Health OR m Health OR mobile health

'Information needs' terms

Information need* OR informational need* OR information gathering OR Interactive health communication OR communicat* OR self-efficacy OR quality of life OR social support OR health promotion OR self-care OR self-help OR health behaviour OR health behavior OR behaviour change OR behavior change OR health education OR health competenc* OR complian* OR adher* OR noncomplian* OR non-complian* OR nonadher* OR non-adher* OR self-management OR disease management OR long term management OR long term care OR patient empowerment OR self-monitoring

'Cancer patient' terms

Neoplasm* OR cancer* OR carcinoma* OR oncolog* OR malignan* OR tumor* OR tumour* OR leukemia* OR sarcoma* OR lymphoma* OR melanoma* OR blastoma* OR radiotherapy OR chemotherapy OR palliative care

Limits:

Language – English

Human studies

(Not all limits were valid in PsychINFO)

Appendix 2: CASP checklists

Quantitative checklist:

Paper Title	Year	First Author	
Screening questions		Yes	No
Was there a clear statement of the aims of the research? - <i>was the goal stated?</i> - <i>why is this important?</i> - <i>how relevant is it?</i>			
Is a quantitative methodology appropriate?			
Is it worth continuing?			
Detailed questions		Comment	
Was the research design appropriate to address the aim of the research? - <i>Has the research design been justified?</i>			
Was the recruitment strategy appropriate to the aims of the research study? - <i>Has the researcher explained how participants were selected?</i> - <i>Has the researcher explained why the participants were appropriate to provide answers to the research question?</i> - <i>Has the research discussed non-participants and their reasons?</i> - <i>Has the researcher discussed the response rate?</i> - <i>Has the researcher discussed how the control group was selected and why (if appropriate)?</i> - <i>Were demographic variables of respondents discussed?</i>			
Were the data collected in a way that addresses the research issue? - <i>Was mode of data collection justified (medical records/questionnaires etc.)?</i> - <i>Is it clear how data was collected?</i> - <i>Has the researcher made methods explicit?</i> - <i>If a survey was used, was the survey piloted?</i> 1. <i>Were there open questions? How were they analysed?</i>			
Has the relationship between researcher and participants been adequately considered? - <i>Has the researcher considered their own role, potential bias and influence?</i> 1. <i>during formation of research questions</i> 2. <i>during recruitment and data collection (if data collected from participants through face-to-face or telephone survey)</i> - <i>Has the researcher considered the implications of any changes in the research design and events during the study?</i>			
Have ethical issues been taken into consideration?			

<ul style="list-style-type: none"> - <i>Were ethical standards maintained (if enough information provided)?</i> - <i>Has approval been sought from ethics committee?</i> 	
<p>Was the data analysis sufficiently rigorous?</p> <ul style="list-style-type: none"> - <i>Has an in-depth description of data analysis been provided?</i> - <i>Is it clear which statistical tests were used/were the tests appropriate to answer the research questions?</i> - <i>Is sufficient data presented to support the findings?</i> - <i>To what extent was contradictory data taken into account?</i> 	
<p>Is there a clear statement of findings?</p> <ul style="list-style-type: none"> - <i>Are the findings explicit?</i> - <i>Is there adequate discussion of the evidence for and against the researcher's arguments?</i> - <i>Has the researcher discussed the credibility of their findings?</i> - <i>Are findings discussed in relation to other research?</i> 	
<p>How valuable is the research?</p> <ul style="list-style-type: none"> - <i>Has the researcher discussed the contribution his study makes to existing knowledge?</i> - <i>Does the researcher identify areas for further research?</i> - <i>Has the researcher discussed whether findings can be transferred to other populations or considered ways the research can be used?</i> 	
Further comments	
Score	

Qualitative checklist:

Question	Description	Study :
1. Was there a clear statement of the aims of research?	<ul style="list-style-type: none"> • What was the goal of the research? • Why it was thought important? • Its relevance 	
2. Is a qualitative methodology appropriate?	<ul style="list-style-type: none"> • If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants • Is qualitative research the right methodology for addressing the research goal? 	
3. Was the research design appropriate to address the aims of the research?	<ul style="list-style-type: none"> • If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)? 	
4. Was the recruitment strategy appropriate to the aims of the research?	<ul style="list-style-type: none"> • If the researcher has explained how the participants were selected • If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study • If there are any discussions around recruitment (e.g. why some people chose not to take part) 	
5. Was the data collected in a way that addressed the research issue?	<ul style="list-style-type: none"> • If the setting for data collection was justified • If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) • If the researcher has justified the methods chosen • If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)? • If methods were modified during the study. If so, has the researcher explained how and why? • If the form of data is clear (e.g. tape recordings, video material, notes etc) • If the researcher has discussed saturation of data 	

6. Has the relationship between researcher and participants been adequately considered?	<ul style="list-style-type: none"> • If the researcher critically examined their own role, potential bias and influence during (a) Formulation of the research questions (b) Data collection, including sample recruitment and choice of location • How the researcher responded to events during the study and whether they considered the implications of any changes in the research design 	
7. Have ethical issues been taken into consideration?	<ul style="list-style-type: none"> • If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained • If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) • If approval has been sought from the ethics committee 	
8. Was the data analysis sufficiently rigorous?	<ul style="list-style-type: none"> • If there is an in-depth description of the analysis process • If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data? • Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process • If sufficient data are presented to support the findings • To what extent contradictory data are taken into account • Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation 	
9. Is there a clear statement of findings?	<ul style="list-style-type: none"> • If the findings are explicit • If there is adequate discussion of the evidence both for and against the researchers arguments • If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) • If the findings are discussed in relation to the original research question 	

10. How valuable is the research?	<ul style="list-style-type: none">• If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?• If they identify new areas where research is necessary• If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used.	
Score		

Appendix 3: Patient invitation letter:



Ysbyty Athrofaol Cymru University Hospital of Wales

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838

Parc Y Mynydd Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 20743838

Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs

Patient Interview Invitation Letter

Dear patient,

I would like to invite you to participate in a research study. The study is being carried out by researchers from Cardiff University who are working with Velindre NHS Trust and Cardiff & Vale University Health Board. I am inviting you to take part because they **are interested in hearing the views of patients with cancer.**

The aim of the study is to find out what patients with cancer think about using a smartphone or tablet 'app' to help to provide them with information about their illness. The information they get from this study will be used to help create the app, which will be available for cancer patients to use in the future. During the study they will also be asking doctors and nurses and relatives of patients with cancer their views on the potential of such an app.

One of the researchers, Becky Richards, would like to interview you, in your own home at a time convenient to you, to ask your views about what you think the benefits or problems of the app may be. Becky would also like to hear your views about what sort of things you would like the app to do.

I have enclosed an information sheet for you to read and help you to think about whether you would like to take part. Taking part or not is entirely up to you.

If you wish to take part in the study, please tick 'Yes, I would like to take part

in this study', fill in the contact details section on the Study Reply Form and then return the form to Becky in the envelope provided.

Becky will then contact you to arrange an interview. If you do not want to be interviewed at present, but have no objections to being contacted in the future please tick '*I do not want to be interviewed but am interested in participating in other parts of the study at some time in the future*'.

If you would like to find out more about the study before deciding whether or not to take part please contact Becky Richards, Cardiff University on 02920 687219, Email: Richardsb3@cardiff.ac.uk.

The research team are also looking to find relatives or close friends of patients with cancer to participate in the study. **If you have a close family member or friend (aged over 18) who might be interested in participating in the study the researchers would like to hear from them.** If your relative/friend might be interested please fill in the section – 'I have a close family member or friend who might be interested in participating in part of this study' and Becky will send them some further information.

Yours sincerely,

Dr Jared Torkington,

Consultant Colorectal Surgeon

Appendix 4: Patient information sheet:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs

Patient Information Sheet (v1.1, 05/08/2014)

Invitation to take part in the study

We would like to invite you to take part in a research study. Before you decide you need to understand why it is being done and what it would involve for you. Please read the following information carefully. You can talk to others about the study if you wish to help you decide if you want to take part (including your family and friends or your specialist nurse). Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of the study is to find out what patients with cancer think about using a smartphone or tablet 'app' to help to provide them with information about their illness. There has been a lot of research in the past showing that cancer patients do not have all the information that they want to have about their condition. This is because some patients find it difficult to ask questions or to remember all the information they have been told. The information we get from this study will be used to help design a mobile phone 'app', which we hope will help patients with information about their condition. During the study we will also be asking doctors and nurses and relatives of patients with cancer their views about the 'app'.

Why have you been invited to take part?

We have invited you to take part because **we are interested in hearing the views of patients with cancer.**

Do you have to take part?

No. Taking part is entirely voluntary. If you do not want to take part you do not have to give a reason. If you decide to take part but later change your mind, you can do so, and you do not have to give a reason why you no longer wish to participate. **No one will be upset if you do not wish to take part and your treatment or care would not be affected.**

What will happen to you if you take part?

If you decide to take part, a member of the study team will contact you to arrange a research interview (an informal discussion between the researcher and yourself) in your own home at a time convenient to you. If you would prefer to be interviewed at another location, such as Cardiff University, you will be reimbursed for your travel expenses. If you would like a friend or relative to be at your interview, that is fine. Interviews will take about 40 minutes. The interview will be recorded with your consent. Recordings will be stored in a secure office at Cardiff University. In the interview, you will be asked to tell us your views about what you think some of the benefits or problems of the app may be. In addition, we will also ask you what kinds of things you would like the app to be able to do. There are no right or wrong answers to the questions in this study. We want to know YOUR opinions.

What are the possible risks and disadvantages of taking part?

There are no specific risks associated with taking part in this study. You do not have to talk about any issues you do not want to discuss. If you find the interview upsetting it can be stopped at any time.

What are the possible benefits of taking part?

This research study will not directly benefit you, but it will give us a better understanding of the views and needs of patients with cancer. This should help us to conduct future studies to see if the app can help patients with cancer.

Will your taking part in the study be kept confidential?

Yes. All information that is collected about you during the course of the research will be kept strictly confidential.

What will happen to the results of the research study?

Audio-recordings and transcripts of interviews will be stored on Cardiff University password protected computers for 5 years. The data will then be securely archived and then destroyed 15 years after the study is completed. Only the research student Becky Richards and lead supervisor Fiona Wood will have access to the audio-recordings. The results of the study will be written up as a thesis and presented at conferences and published in scientific journals. A report will also be prepared for Tenovus, the Cancer Charity, who are funding

this study. Tenovus may wish to publish summaries of the study on their website. Short reports may also be prepared for interested government departments and the media. A summary of the research findings will be available to you at the end of the study if you would like it. We may use direct quotes from your interview in publications, however all information provided by participants will be anonymised. It will not be possible for anyone to identify you from any of the published results.

Who has reviewed the 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, well-being and dignity. This study has been reviewed by South East Wales Ethics Committee.

What if you are harmed or unhappy about any aspect of the study?

If you have any concerns or complaints about any aspect of the study please contact Dr Fiona Wood, Institute of Primary Care and Public Health, 3rd Floor, Neuadd Meirionnydd, Heath Park Cardiff. Telephone: 02920 687185, Email: Wood@cf.ac.uk. Alternatively, please contact Dr John Staffurth, Clinical Oncologist, Velindre Hospital, Cardiff. Telephone: 02920 196135.

If you have issues that are not related to the study, such as a complaint about your care, and wish to formally complain, you can go through the NHS Complaints Procedure. Details can be found at www.puttingthingsright.wales.nhs.uk. In the interview, it is possible that you may raise other issues of concern, such as your health. If this happens, you will be advised to consult your GP or contact the Tenovus Helpline, telephone: 0808 808 1010. If the student is very worried about your health she may consider it necessary to discuss your situation with her clinical supervisor.

Who is organising the study?

The study is being organised by researchers from Cardiff University. It has been funded by Tenovus, the cancer charity.

Contact for further information

If you would like any further information, or have any questions concerning this study, please contact Becky Richards, Institute of Primary Care and Public Health, 3rd Floor, Neuadd Meirionnydd, Heath Park Cardiff. Telephone: 02920 687219, Email: Richardsb3@cardiff.ac.uk.

Who else can take part in the study?

We are also looking to find relatives of patients with cancer to take part in the study. If you have a close family member or friend (aged over 18) who might be interested in taking part, we would like to hear from them. If your relative/friend might be

interested please fill in the section – ‘I have a close family member or friend who might be interested in participating in part of this study’ and we will send them out some further information.

What do I need to do now?

If you WISH TO take part please tick **“Yes, I would like to take part in this study”** and fill in the contact details on the Study Reply Form and return the form to Becky Richards in the envelope provided.

If you do not want to be interviewed but you may be interested in participating in other parts of the study (for example a consultation with a clinician whilst using the app) please tick **“I do not want to be interviewed but am interested in participating in other parts of the study at a later date”**. Please also fill in the contact details on the Study Reply Form and return the form in the envelope provided.

Feel free to call us with any queries you may have.

Please keep this information leaflet for future reference.

Thank you for reading this information sheet and for taking an interest in the research study.

Appendix 5: Patient reply form:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs

Patient Interview Reply form

I would like to take part in this study and I wish to be contacted by the research team.

☐

I do not want to be interviewed but I may be interested in taking part in other parts of the study at a later date.

☐

I have a close family member or friend who might be interested in participating in part of this study

☐

Name of Participant:
Telephone:
Mobile:
Email:
Preferred way to be contacted:.....

Name of relative/friend:
Telephone:
Mobile:
Email:
Preferred way to be contacted:

Appendix 6: Relatives invitation letter:



Ysbyty Athrofaol Cymru University Hospital of Wales

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838

Parc Y Mynydd Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 2074 3838

Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs

Family/Friends Interview Invitation Letter

I would like to invite you to participate in a research study. The study is being carried out by researchers from Cardiff University who are working with the team at Velindre NHS Trust and Cardiff & Vale University Health Board. We have invited you to take part because **we are interested in hearing the views of close family members and friends of patients with cancer.**

The aim of the study is to find out what patients with cancer think about using a smartphone or tablet 'app' to help to provide them with information about their illness. During the study we will also be asking patients, doctors and nurses their views on the potential of such an app. The information we get from this study will be used to help create the app, which will be available for cancer patients to use in the future.

We would like to interview you to ask your views about what you think the benefits or problems of the app may be. We would also like to hear your views about what sort of things you would like the app to do.

We have enclosed an information sheet for you to read and help you to think about whether you would like to take part. Taking part or not is entirely up to you.

If you wish to take part in the study, please tick 'Yes, I would like to take part in this study', and fill in the contact details section on the Study Reply Form and then return the form to us in the envelope provided.

Once we receive the form, a member of the research team will contact you to arrange an interview.

If you would like to find out more about the study before deciding whether or not to take part please contact Becky Richards, Cardiff University on 02920 687219, Email: Richardsb3@cardiff.ac.uk.

Professor Howard Kynaston,

Consultant Urologist.

Appendix 7: Relatives information sheet:



Exploring the potential of a mobile phone or tablet ‘app’ to help patients with cancer address their information needs

Family/Friends Information Sheet (v1.1, 05/08/2014)

Invitation to take part in the study

We would like to invite you to take part in a research study. Before you decide you need to understand why it is being done and what it would involve for you. Please read the following information carefully. You can talk to others about the study to help you decide if you wish to take part. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of the study is to find out what patients with cancer think about using a smartphone or tablet ‘app’ to help to provide them with information about their illness. There has been a lot of research in the past showing that cancer patients do not have all the information that they want to have about their condition. This is because some patients find it difficult to ask questions or to remember all the information they have been told. During the study we will also be asking patients, doctors and nurses of patients with cancer their views about the ‘app’. The information we get from this study will be used to help design a mobile phone ‘app’, which we hope will help patients with information about their condition.

Why have you been invited to take part?

We have invited you to take part because **we are interested in hearing**

the views of close family members and friends of patients with cancer.

Do you have to take part?

No. Taking part is entirely voluntary. If you do not want to take part you do not have to give a reason. If you decide to take part but later change your mind, you can do so, and you do not have to give a reason. **No one will be upset if you do not wish to take part and the treatment or care of the person you care for would not be affected.**

What will happen to you if you take part?

If you decide to take part, a member of the study team will contact you to arrange a research interview (an informal discussion between the researcher and yourself) at a time convenient to you. If possible, the interview will take place at the patient's home so that both interviews can be conducted on the same day. If you would prefer to be interviewed at another location, such as Cardiff University, you will be reimbursed for your travel expenses. Interviews will take about 40 minutes. The interview will be recorded with your consent. Recordings will be stored in a secure office at Cardiff University. In the interview, you will be asked to tell us your views about what you think some of the benefits or problems of the app may be. In addition, we will also ask you what kinds of things you would like the app to be able to do. There are no right or wrong answers to the questions in this study. We want to know YOUR opinions.

What are the possible risks and disadvantages of taking part?

There are no specific risks associated with taking part in this study. You do not have to talk about any issues you do not want to discuss. If you find the interview upsetting it can be stopped at any time.

What are the possible benefits of taking part?

This research study will not directly benefit you, but it will give us a better understanding of the views and needs of patients with cancer. This should help us to conduct future studies to see if the app can help patients with cancer.

Will your taking part in the study be kept confidential?

Yes. All information that is collected about you during the course of the research will be kept strictly confidential.

What will happen to the results of the research study?

Audio-recordings and transcripts of interviews will be stored on Cardiff University password protected computers for 5 years. The data will then be securely archived and then destroyed 15 years after the study is completed. Only the research student Becky Richards and lead supervisor Fiona Wood will have access to the audio-recordings. The results of the study will be written up as a thesis and presented at conferences and published in scientific journals. A report will also be prepared for Tenovus, the Cancer Charity, who are funding this study. Tenovus may wish to publish summaries of the study on their website. Short reports may also be prepared for interested government departments and the media. A summary of the research findings will be available to you at the end of the study if you would like it. We may use direct quotes from your interview in publications, however all information provided by participants will be anonymised. It will not be possible for anyone to identify you from any of the published results.

Who has reviewed the 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, well-being and dignity. This study has been reviewed by South East Wales Ethics Committee.

What if you are harmed or unhappy about any aspect of the study?

If you have any concerns or complaints about any aspect of the study please contact Dr Fiona Wood, Institute of Primary Care and Public Health, 3rd Floor, Neuadd Meirionnydd, Heath Park Cardiff. Telephone: 02920 687185, Email: Wood@cf.ac.uk. Alternatively, please contact Dr John Staffurth, Clinical Oncologist, Velindre Hospital, Cardiff. Telephone: 02920 196135

If you have issues that are not related to the study, such as a complaint about your care, and wish to formally complain, you can go through the NHS Complaints Procedure. Details can be found at www.puttingthingsright.wales.nhs.uk. In the interview, it is possible that you may raise other issues of concern, such as your health. If this happens, you will be advised to consult your GP or contact the Tenovus Helpline, telephone: 0808 808 1010. If the student is very worried about your health she may consider it necessary to discuss your situation with her clinical supervisor.

Who is organising the study?

The study is being organised by researchers from Cardiff University. It has been funded by the cancer charity Tenovus, the cancer charity.

Contact for further information

If you would like any further information, or have any questions concerning this study, please contact Becky Richards, Institute of Primary Care and Public Health, 3rd Floor, Neuadd Meirionnydd, Heath Park Cardiff. Telephone: 02920 687219, Email: Richardsb3@cardiff.ac.uk.

What do I need to do now?

If you WISH TO take part please tick **“Yes, I would like to take part in this study”**, and **fill in the contact details on the Study Reply Form and return the form to Becky Richards in the envelope provided.**

Feel free to call us with any queries you may have and/or talk the study over with anyone else.

Please keep this information leaflet for future reference.

Thank you for reading this information sheet and for taking an interest in the research study.

Appendix 8: Patient consent form:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs

Please initial if
you agree

Interview Consent Form

I confirm I have read and understood the information leaflet dated 05/08/2014, version 1.1 for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I give permission for the interview to be audio recorded.

I understand and agree that quotes from my interview may be used within written reports or publications, and that any quotes would be completely anonymous and could not be linked to me in any way.

I agree to take part in the above study

Name of Participant:.....

Signature:.....

Date:.....

Name of Person taking consent:.....

Signature:.....

Date:.....

Appendix 9: Relatives consent form:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs

Interview Consent Form

Please
initial if
you agree

I confirm I have read and understood the information leaflet dated 05/08/2014, version 1.1 for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

I give permission for the interview to be audio recorded.

I understand and agree that quotes from my interview may be used within written reports or publications, and that any quotes would be completely anonymous and could not be linked to me in any way.

I agree to take part in the above study.

Name of Participant:.....

Signature:.....

Date:.....

Name of Person taking consent:.....

Signature:.....

Date:.....

Appendix 10: Patient demographic questionnaire:



Patient Demographic Questionnaire

Please circle the correct responses:

Age:

- 18-25
- 26-35
- 36-45
- 46-55
- 56-65
- 66-75
- 76-85
- 85+

Gender:

- Male
- Female

Type of cancer:

- Breast
- Urological
- Gynaecological
- Colorectal
- Other

Time since diagnosis:

- Less than 1 month
- 1-3 months
- 3-6 months
- 6 months-1 year
- 1-2 years
- 2-4 years

5 years+

Highest educational qualification:

GCSE/O Levels

A Levels

NVQ/HNC/HND

Diploma

Degree

Post Graduate degree

None of the above

Would you like to be contacted about taking part in a further phase of this study?

Yes

No

Thank you for completing this questionnaire.

Appendix 11: Relatives' demographic questionnaire:



Relatives Demographic Questionnaire

Please circle the correct responses:

Age:

- 18-25
- 26-35
- 36-45
- 46-55
- 56-65
- 66-75
- 76-85
- 85+

Gender:

- Male
- Female

Highest educational qualification:

- GCSE/O Levels
- A Levels
- NVQ/HNC/HND
- Diploma
- Degree
- Post Graduate degree
- None of the above

Thank you for completing this questionnaire.

Appendix 12: Patient interview topic guide:

Phase 1 Patient Interview Schedule

Prologue

1. Introduce myself, explain where I am from, ensure they're comfortable etc.

2. Check understanding of reason for meeting, give an opportunity for questions:

"Before we start, I wonder if you have any questions about this study or about why I've come to talk with you today?"

Set the focus of the interview and explain the app. Base this around the following script:

"Thank you for agreeing to take part in this study. I want to understand what patients with cancer think of a potential smartphone/tablet app for patients with cancer. The interview will take around half hour/forty minutes.

This app would be for use *after* diagnosis and would potentially help patients with their information needs (by providing information within the app and links to external websites, etc) and help patients to communicate with their clinicians in consultations (by bringing a prepared list of questions to consultations). The app could also help with things like adherence to medication (audio medication prompts) and social support (links to support groups, telephone helplines).

I will now show you an example of an app for healthcare that is already available, just give you an idea of such an app [Demonstration of a similar app here].

At the end of this study, we aim to develop an app based on the information gathered from interviews with clinicians, cancer patients and their relatives. I am interested in your views on a potential smartphone/tablet app for cancer patients. There are no right or wrong answers to my questions, I am interested in what *you* think."

3. After establishing what is understood about the study, and answering any questions, explain that the interview will be recorded:

"I would like to record what you say as that saves me having to scribble when you're talking and means that I can concentrate on what you're saying. The recording will only be heard by people who are working on this project. The interview will be transcribed and your identity and the identity of any person you talk about today will be anonymised in any published work. Is that okay with you?"

4. Obtain consent for the interview and for the recording. If not already done, set up and switch on the recording equipment while the volunteer signs the consent form.

Opening question

- Can you tell me why you were interested in taking part in this study?

Information needs

- Do you like to have information about your illness? (prompt: why, how much information?)

- Where do you normally get information about your illness (prompts: health professionals, friends/family, book/internet etc)?
- What sources do you use? Why?
- Was there a particular point where you felt like you needed more information?

Communication with clinicians in consultations, part 1

- How do you find talking to clinicians about your illness?
- How do you feel when you ask the doctors and nurses questions about your illness? (prompts: is it easy or difficult, what makes it hard to ask them questions?)
- What makes it easier to ask doctors and nurses questions?
- Were there any barriers to communicating with your doctors/nurses?
- How do you remember all the information about your illness?
- Do you find it easy to talk to your family/ friends about your illness?

Experience with mobile technology

- Do you have experience of using a mobile/smartphone/ tablet computer?
- What was your experience of using a mobile/ smartphone/tablet computer? OR Why don't you use a mobile/smartphone/tablet computer?
- What do you use your mobile/smartphone/tablet computer for?
- Are you familiar with 'apps'?
- Have you ever, or do you currently use an app to help with your health or cancer? Why?

Perceived acceptability of an app

- Do you think you would find an app acceptable to use? (i.e. easy or difficult to use?)
- Do you think other patients who have cancer would find an app acceptable to use?
- Do you think families or friends of patients would want to use an app? Why?
- Do you think you/other patients would need initial training to use an app?
- If the app was made available, would you download it and use it?
- Would you have any concerns about using an app?

Desired app features

- What things would you like the app to do? Why?
- What sort of things do you think family and friends of patients would want the app to do?
- Is there anything that you would not want the app to do? If so, why?

Perceived benefits of the app

- What benefits do you think there might be for patients using the app?
- What benefits do you think there might be for clinicians?
- What benefits do you think there might be for the family/friends?

Communication part 2

- Do you think the app would have an impact on the way you talk to your doctors and nurses about your illness? How? Could it help? Could it make it more difficult to talk to them?
- Do you think the app might affect the way you talk to your family and friends? In what ways?

Perceived barriers of the app

- Do you think there may be problems with using the app? What do you think the problems might be of using the app?

Patient type

- Are there any particular types of patient that you think might find the app most useful? (prompt: age groups, patients at different stages of diseases). Why?
- When do you think it might be most useful for patients to use the app? (i.e. after diagnosis, after the dust has settled, pre-treatment, post-treatment and discharge)
- If any of your friends had cancer would you recommend they use it? Do you think they would use it? Why/why not?

Final question

- What was your overall experience of being involved in this study?

Appendix 13: NHS ethical approval

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



South East Wales Research Ethics
Committee B
6th Floor Churchill House
17 Churchill Way
Cardiff
CF10 2TW

Telephone : 02920 376823
E-mail : carl.phillips@wales.nhs.uk
Website : www.nres.nhs.uk

28 March 2014

Dr Fiona Wood
Senior Lecturer
Cardiff University
3rd Floor, Neuadd Meirionnydd
Heath Park, Cardiff
CF14 4YS

Dear Dr Wood

Study title:	Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs
REC reference:	14/WA/0066
Protocol number:	SPON 1275-13
IRAS project ID:	143124

Thank you for your letter of the 28 March 2014, responding to the Committee's request for further information on the above research, and for submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Carl Phillips, Carl.phillips@wales.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.
- Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.
- Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.
- Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.
- For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.
- Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

- All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).
- There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.
- To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.
- If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of insurance or indemnity	UMAL/Cardiff University	26 July 2013
Investigator CV	B Richards	31 January 2014
Investigator CV	F Wood	03 February 2014
Investigator CV	J Staffurth	26 February 2014

Investigator CV	K Brain	26 February 2014
Investigator CV	P Kinnersley	26 February 2014
Letter from Sponsor	Cardiff University	10 January 2014
Other: Confirmation of funding	Tenovus	25 March 2013
Other: Patient Invitation Letter	1.0	31 January 2014
Other: Relatives Invitation Letter	1.0	31 January 2014
Other: Health Professional Invitation Letter	1.0	31 January 2014
Other: Patient Interview Reply Form	1.0	21 March 2014
Other: Health Professionals Interview Reply Form	1.0	21 March 2014
Other: Family/Friends Interview Reply Form	1.0	21 March 2014
Other: Patient Interview Schedule	1.1	27 March 2014
Other: Relative Interview Schedule	1.1	27 March 2014
Other: Clinician Interview Schedule	1.1	27 March 2014
Participant Consent Form: Patient	1.0	31 January 2014
Participant Consent Form: Relatives	1.0	31 January 2014
Participant Consent Form: Health Professional	1.0	31 January 2014
Participant Information Sheet: Health Professional	1.1	27 March 2014
Participant Information Sheet: Patient	1.1	27 March 2014
Participant Information Sheet: Relatives	1.1	27 March 2014
Protocol	1.0	30 January 2014
REC application	3.5	10 February 2014
Response to Request for Further Information	F Wood	28 March 2014

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

14/WA/0066	Please quote this number on all correspondence
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We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



Mrs S Warrell
Vice-Chair, South East Wales Research Ethics Committee B

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copied: Dr F Wood, wood@cf.ac.uk

Ms B Richards, richardsb3@cardiff.ac.uk

R&D Office for Cardiff University,
resgov@cardiff.ac.uk

R&D Office for Cardiff & Vale UHB,
CAV_research.development@wales.nhs.uk

Appendix 14: R&D approval from UHW:



**GIG
CYMRU
NHS
WALES** | Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

**Ysbyty Athrofaol Cymru
University Hospital of Wales**

Heath Park,
Cardiff, CF14 4XW
Phone 029 2074 7747
Fax 029 2074 3838
Minicom 029 2074 3632

Parc Y Mynyddi Bychan,
Caerdydd, CF14 4XW
Ffôn 029 2074 7747
Ffacs 029 20743838
Minicom 029 2074 3632

Tel: 029 20746986
Fax: 029 20745311
CAV_Research.Development@wales.nhs.uk

From: Professor C Fegan
R&D Director
R&D Office, 2nd Floor TB2
University Hospital of Wales
Cardiff
CF14 4XW

17 April 2014

Professor Alison Fiander
Cancer and Genetics Research Institute
Cardiff University School of Medicine
University Hospital of Wales
Heath Park
CF14 4XN

Dear Professor Fiander

**Cardiff and Vale UHB Ref and Study Title : 14/DMD/5845 : Potential Of An App
To Address Cancer Patients Information Needs**

IRAS Project ID: 143124

The above project was forwarded to Cardiff and Vale University Health Board R&D Office by the NISCHR Permissions Coordinating Unit. A Governance Review has now been completed on the project.

Documents approved for use in this study are:

Document	Version	Date
NHS R&D Form	3.5	Received 13/02/14
SSI Form	3.5	Received 13/02/14
Protocol	1.0	30/01/14
Relatives Interview Information Sheet	1.1	27/03/14
Patient Interview Information Sheet	1.1	27/03/14
Health Professional Interview Information Sheet	1.1	27/03/14
Invitation Letter: Patient Interview	1.0	31/01/14
Invitation Letter: Relative	1.0	31/01/14
Invitation Letter: Health Professional	1.0	31/01/14
Patient Interview Form	1.0	21/03/14
Health Professional Interview Form	1.0	21/03/14
Family/Friends Interview Form	1.0	21/03/14

Phase 1 Patient Interview Schedule	1.1	27/03/14
Phase 1 Relative Interview Schedule	1.1	27/03/14
Phase 1 Clinician Interview Schedule	1.1	27/03/14
Relatives Consent Form: Interview	1.0	31/01/14
Patient Consent Form: Interview	1.0	31/01/14
Health Professional Consent Form: Interview	1.0	31/01/14
Patient Interview Reply Form	1.0	21/03/14
Health Professionals Interview Reply Form	1.0	21/03/14
Family/Friends Interview Reply Form	1.0	21/03/14

I am pleased to inform you that the UHB has no objection to your proposal. You have informed us that Cardiff University is willing to act as Sponsor under the Research Governance Framework for Health and Social Care.

Please accept this letter as confirmation of permission for the project to begin within this UHB.

The UHB considers that this study is likely to be suitable for adoption onto the NISCHR Clinical Research Portfolio (CRP). This is important so that the UHB can receive funding to support this study. An application for adoption should be made by the Chief Investigator before commencing the study.

If your study is adopted onto the NISCHR CRP, it will be a condition of this NHS research permission, that you will be required to regularly upload recruitment data onto the portfolio database.

To apply for adoption onto the NISCHR CRP, please go to:
<http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=31979>. Once adopted, NISCHR CRP studies may be eligible for additional support through the NISCHR Clinical Research Centre. Further information can be found at:
<http://www.wales.nhs.uk/sites3/page.cfm?orgid=580&pid=28571>

If your study is adopted onto the portfolio, please inform NISCHR PCU and the R&D Office of your portfolio ID number.

To upload recruitment data, please follow this link:
http://www.crncc.nihr.ac.uk/about_us/processes/portfolio/p_recruitment Uploading recruitment data will enable NISCHR to monitor research activity within NHS organisations, leading to NHS R&D allocations which are activity driven.

May I take this opportunity to wish you success with the project and remind you that as Principal Investigator you are required to:

- Inform the R&D Office if this project has not opened within 12 months of the date of this letter. Failure to do so may invalidate R&D approval.
- Inform NISCHR PCU and the UHB R&D Office if any external or additional funding is awarded for this project in the future
- Submit any substantial amendments relating to the study to NISCHR PCU in order that they can be reviewed and approved prior to implementation
- Ensure NISCHR PCU is notified of the study's closure

- Ensure that the study is conducted in accordance with all relevant policies, procedures and legislation
- Provide information on the project to the UHB R&D Office as requested from time to time, to include participant recruitment figures

Yours sincerely,





PP

Professor Christopher Fegan
R&D Director / Chair of the Cardiff and Vale Research Review Service (CaRRS)

CC Chief Investigator: Dr Fiona Wood
 Becky Richards, Student, Cardiff University
 Academic Supervisor: John Staffurth
 Academic Supervisor: Professor Paul Kinnersley
 Academic Supervisor: Dr Kate Brain

Appendix 15: R&D approval from Velindre NHS Trust:

		Velindre NHS Trust Ymddiriedolaeth GIG Felindre	Velindre NHS Trust Headquarters Pencadlys Ymddiriedolaeth GIG Felindre 2 Charnwood Court/ 2 Cwrt Charnwood Heol Billingsley Parc Nantgarw Cardiff/ Caerdydd CF15 7QZ Tel/Ffon : 02920 196161 www.velindre-tr.wales.nhs.uk
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Correspondence to: Mrs Sarah Townsend, Research and Development Manager
Velindre NHS Trust, Headquarters, 2 Charnwood Court, Heol Billingsley
Parc Nantgarw
Cardiff, CF15 7QZ
Email: Sarah.Townsend@wales.nhs.uk
Tel: 02920 196165 Fax: 02920 344695

Dr John Staffurth
Clinical Senior Lecturer
Velindre NHS Trust
Velindre Hospital
Cardiff
CF14 2TL

6th October 2014

Dear Dr Staffurth

2014/VCC/0021: Exploring the potential of a mobile phone or tablet 'app' to help patients with Cancer address their information needs, Phase 1

Thank you for your e-mail dated 5th August 2014, in which you responded to the issues raised by the Research Risk Sub Committee on the 29th July 2014. Your response was forwarded to the RRRSC as per Trust procedures; the Committee has confirmed the response as satisfactory.


I am therefore pleased to take Chair's action to approve this project on behalf of the Sponsor and Research Risk Review Committee (RRRSC). This decision will be reported for ratification at the next RRRSC on 28th October 2014.

Approval lapses if the project does not commence within 12 months of Trust approval. The Committee reserve the right to information on the progress of the project at any time and should receive a progress report six monthly and a written report on completion. Random audits may be carried out to ensure that projects comply with the clinical guidelines for research. Any serious adverse incidents relating to the project should be reported to the R&D office and a Clinical Incident Form completed.








On completion of the project please inform the R&D office.

All correspondence relating to this project should be forwarded to Sarah Townsend, R&D Manager, R&D Office, Velindre NHS Trust Headquarters, 2 Charnwood Court, Heol Billingsley, Parc Nantgarw, Cardiff, CF15 7QZ ext 6165.

Yours Sincerely,



Professor Jane Hopkinson
Trust Independent Member, RRRSC Chair

						
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Mae'r Ymddiriedolaeth hon yn croesawu gohebiaeth yn y Gymraeg
This trust welcomes correspondence in Welsh

1 **Appendix 16: interview transcript for P5 Pam and R5 Susan**

2

3 I – I'll put this here so I can pick you both up. Okay so I've got some
4 questions, but again if there's anything that you want to talk about or
5 feel is useful for us then please feel free, okay so could you tell me why
6 you're interested in taking part in this study?

7

8

9 DS240149.F – my background is research and development so I've always
10 been interested in helping people

11

12

13 I – okay and what about yourself?

14

15

16 Partner – been there done it, got the T-shirt

17

18

19 I – what research or?

20

21

22 Partner – yes

23

24

25 I – so when you were diagnosed and throughout your treatment, did you
26 like to have information about your illness, I know you said earlier that
27 you're very inquisitive

28

29

30 DS240149.F – when I was diagnosed I had enough information were you
31 saying?

32

33

34 I – did you like to have information, did you want it?

35

36

37 DS240149.F – oh definitely

38

39

40 I - and what about as the stage progressed then?

41

42

43 **Partner - anything and everything we could get our hands on we read**
44
45
46 DS240149.F – yeah and if I couldn't find the answers I asked people, and if I
47 couldn't find them, I'd either go online or I'd just keep asking questions you
48 know,
49
50
51 **Partner – we wanted to know the type, you know, we wanted to know**
52 **what was going to happen, how you were going to do that**
53
54
55 **I - so did you go to people first before you went on the internet, what was**
56 **your first port of call for information?**
57
58
59 DS240149.F – my very first port of call would have been the Macmillan
60 nurse. I have to say that the surgeon who operated, he answered all my
61 questions there at the time, he was very good, he had a list of things he
62 wanted to tell me and he went through that very methodically didn't he?
63
64
65 **Partner – yes**
66
67
68 **I – that's good**
69
70
71 DS240149.F – um so that was like on the Monday I was told I had cancer and
72 he spent about half an hour didn't he, and he went and left us with the
73 Macmillan nurse, the Macmillan nurse said "you know there's too much
74 going on here, I'll come out on Friday" So she came out on Friday so in that
75 time, I sort've get my head around it I suppose, so she came out and by that
76 time I had a load of questions to ask her
77
78
79 **I – right okay**
80
81
82 DS240149.F – um I think she did very well
83 **Partner – she did, absolutely, she was amazing**

84
85
86 DS240149.F – I mean she didn't know about the surgery and the prosthesis
87 and things, she knew about the cancer treatment, she could tell you about
88 the cycles you know she said down and told us "you're going to have 6
89 cycles"
90
91
92 **Partner – she didn't treat you like an imbecile, she answered your**
93 **questions openly, honestly, and yes**
94
95
96 DS240149.F – I found her very, very good...and if she didn't know something
97 she'd say "oh I don't know" but and she was great the phone in no time
98
99
100 **I – and did you feel like you could approach her?**
101
102
103 DS240149.F – oh absolutely, absolutely
104
105
106 **I - so in the cases where she wasn't sure of the answers did you go on the**
107 **internet then, or did you go back to the consultant?**
108
109
110 DS240149.F – well I have got this very good friend, um who is overseas and
111 she put me right about, I had what do you call in a seroma following surgery
112 and I didn't know why, or whatever, and it was she's qualified so
113
114
115 **I – so was that the nurse?**
116
117
118 DS240149.F – this is the nurse overseas she is, was a Macmillan nurse, I think
119 she still might be, I'm not quite sure
120
121
122 **Partner – oh <friend>'s daughter? Who is a medical consultant so we ring**
123 **her she's got this special thing that she goes into...for the medical**
124 **professionals and then she will ring us back**

125

126

127 **I – yes so there’s quite informed people around you then**

128

129

130 DS240149.F – So it was those two, if anybody and I’ve got these intellect
131 friends/neighbours who have had cancer, they tell you terrible stories, they
132 don’t know the science behind it and I don’t, I’m not one to be in a group of
133 people all talking about breast cancer and things, it’s all different for
134 everybody, so I like to have my answers, you know questions answered by
135 somebody who’s intelligent and has the knowledge you know, not guess
136 work

137

138

139 **Partner – that sounds awful**

140

141

142 DS240149.F – It does sound awful I know

143

144

145 **I – it sounds sensible**

146

147

148 DS240149.F – but anyway the only people I’d ask questions would be the
149 people I knew had a wealth of knowledge

150

151

152 **I - yeah okay. Was there a particular point where you felt you needed**
153 **more information?**

154

155

156 DS240149.F – I have to come back to that because I think, um after my first
157 chemotherapy, you wait nearly 3 weeks and you have a blood test on the
158 Monday and then on the Wednesday you have the chemo, so I had my first
159 cycle, went in Monday 3 weeks later, bloods taken on the Tuesday morning
160 I had a phone call, and it was “hi your neutrophils are 0.9” “my was what,
161 what, what are neutrophils?” sorry, okay I know what they are, but no idea
162 where they should be 900. So I said “what does that mean?” “well they have
163 to be up to 1 before we can give you chemo” “okay” and that threw me into
164 a spin actually, I mean the whole of that Tuesday I was on...

165

166

167 **Partner – you came off, you were online**

168

169

170 DS240149.F – trying to find out why my neutrophils had gone down, what I
171 could do to up it and things. I went in on the Wednesday had the bloods
172 taken, had to wait then 2 hours had no idea what was going to happen and
173 then they just said “yep okay bloods back you’re ready” so I said “what are
174 they?” “1.9” and to me that was like – what within 48 hours you know? And
175 it was that lack of knowledge, so much so that, spin on now to new year and
176 uh you have to take your temperature morning and night, so I took my
177 temperature in the morning I didn’t feel well, obviously I’d been very poorly.
178 Took my temperature and it was up 37.9 I phoned and I was asked to come
179 in immediately, um and I was shocked that I was in what they call
180 neutropenic sepsis and it’s such a serious thing, fatality rate is 20% or
181 something

182

183

184 **I - oh really**

185

186

187 DS240149.F – and I think I should’ve been told more clearly, because we had
188 an hour education chat before chemotherapy

189

190

191 **I – is that the induction, yes**

192

193

194 DS240149.F – so we all sat around, all different types of cancer sat in this
195 one room with people who had different roles, taking out our thermometers
196 and we had to show that we could use them and things like that, but I don’t
197 think anyone of us realised the significance of your temperature going up
198 and the timing of that, there’s a specific time, they call it the nadir which is
199 between 7 and 12 days where neutrophils are incredibly low and I found
200 that out by going through help and we

201

202

203 **I – that seems important stuff to be passing on**

204

205 DS240149.F – really I mean if apparently your neutrophils will drop every
206 cycle to a really, really, low level

207
208
209 **Partner – you knew that**
210
211
212 DS240149.F – and I knew that, but I didn't realise that this was, I thought it
213 was sort of going down and then would plateau and go back up, but it sort
214 of does that then suddenly it's really low and it's this real low period that
215 they should say you know "be very aware, make sure your temperature is
216 being recorded, make sure you don't go out and get a..."
217
218
219 **Partner - you did it**
220
221
222 DS240149.F – I was frightened to death when I went in
223
224
225 **Partner – I know that because you were at that stage**
226
227
228 DS240149.F – you know people around me putting drips up they were
229 panicking
230
231
232 **Partner – it's very difficult what you say and what you don't**
233
234
235 DS240149.F – so how much do you tell people? There's me, I want to know
236 everything, and there's some people who say "I don't want to know". I mean
237 there were other complications that I didn't know about it is DVT and PE's
238 um and you're not told about that
239
240
241 **Partner – yeah, but that's everything isn't it, you know you go in for a**
242 **hospital appointment, DVT, PE**
243
244
245 DS240149.F – but it's like side effects you don't want to be told all the side
246 effects because you'll, you'll have them, you know what I mean, but at the
247 same time, I was told I wouldn't vomit, categorically in this hour long....

248
249
250 **Partner – it wasn't categorically they just said "you probably won't vomit,**
251 **you'll just feel sick"**
252
253
254 DS240149.F – I'd feel very sick, so when I came home 3 hours later and I was
255 really vomiting everywhere I'm thinking this shouldn't have happened
256
257
258 **Partner – "oh they told me I wouldn't vomit! That oncologist told me I**
259 **could get on with life and be normal! I'm absolutely feeling rotten you**
260 **know" so don't say things like....they don't know do they? If you're**
261 **thinking about it, they don't know what you're going to be like in that first**
262 **cycle?**
263
264
265 DS240149.F – of course not
266
267
268 **Partner – so from the first cycle, they take it and they really have**
269
270
271 DS240149.F – they've worked really hard to help me not, and I haven't
272 vomited since then
273
274
275 **Partner – they knew what the first cycle was like, the second cycle they,**
276 **and every subsequent cycle they have worked their socks off to get it right**
277 **– you can't complain!**
278
279
280 **I – yeah well that's good, yeah**
281
282
283 DS240149.F – no I think the thing is I don't know what the percentage is, but
284 say 70% or more don't vomit, so why treat them for that, you know wait
285 until they do and then we'll.... and I think that's what they do
286
287

288 **Partner – and that’s what is happening they do they wait to see if you have**
289 **symptoms**

290

291

292 DS240149.F – they’ll wait to see, like you said, some people swan through it
293 and have no problems at all, they don’t even know they’re on
294 chemotherapy, so

295

296

297 **Partner – ha, that would be nice!**

298

299

300 DS240149.F – well I haven’t met anybody yet ((laughs)) who doesn’t have
301 any problems with chemo

302

303

304 **I – so what do you think we should put in the app? Do you think we should**
305 **put possible side effects to prepare people, or do you think we should**
306 **leave that stuff out?**

307

308

309 DS240149.F – I think something like a guide, sort of, every person is an
310 individual, depending on how much you want to know

311

312

313 **Partner – and then they could go further**

314

315

316 DS240149.F – open at A at B or at D, so each time you go in you can go
317 neutrophils are - your white cells that fight infection and the normal range
318 would be between blah de blah and blah de blah if you want more
319 information then go into another, you know what I mean, so open a
320 different window

321

322

323 **I – so they have the choice**

324

325

326 DS240149.F – some people will go “okay I know about neutrophils, but
327 people like me then, okay what’s normal? What happens if it’s abnormal,
328 do you know what I mean, so you don’t frighten everybody by saying if your

329 neutrophils drop down to 0.2 you've got a 1 in 5 chance of dying, you don't
330 want to be told that do you? I do, I think it has to be based on by stage
331 almost

332

333

334 **I – yes that's a good idea**

335

336

337 DS240149.F – you know just open that window up and when you want come
338 back and then vomiting, some patients won't get vomiting some patients
339 might be a bit nauseas, and then you can click on vomiting and go in on what
340 to do

341

342

343 **Partner – If you do have vomiting then...**

344

345

346 DS240149.F – I just think it's a way to open the windows depending on a
347 person's nosiness if you like

348

349

350 **I –tailoring it to them**

351

352

353 **Partner – yeah some people won't want to go into detail**

354

355

356 DS240149.F – yeah I mean my mother for example, you could give her a
357 tablet, she will read all the side effects and then she will have all of them
358 ((laughs)) all of them!

359

360

361 **I - yeah ((laughs))**

362

363

364 DS240149.F – and I just think yes, it's like consent you have to know the
365 basic things obviously, but every tablet starts with nausea and vomiting, so
366 my mother ((rambles in mother's voice)) no...and there are people out there
367 who will do that so no it's a tough one

368

369

370 I – yeah, that’s a good idea having a staged approach though
371
372
373 **Partner – but then you know, depending on how much a person wants to**
374 **know, you can open those windows if you want to**
375
376
377 I – yeah exactly, okay. What about communication then, how did you find
378 talking to the clinicians about the cancer?
379
380
381 DS240149.F – the surgeon and that Macmillan nurse, can’t fault them, they
382 were there and they had time, and that’s the thing I felt was special was that
383 the nurse had, she seemed to have loads of time, although I know she was
384 incredibly busy
385
386
387 **Partner – she took the time to talk to us**
388
389
390 DS240149.F – the first time, the only time I’ve met my oncologist, only once,
391 um he was running his clinic incredibly late, which I can understand because
392 when we went in that first time to discuss what time of chemotherapy I had
393 to have, he must have been 40 minutes over
394
395
396 **Partner – and he was great**
397
398 DS240149.F – I asked him lots of things and he answered as truthfully as he
399 could, I think he did measure his words, but I’ve not seen him since, so I see
400 the nurse practitioners when I go in and all they do is “how have you been?”
401 and they try to stop those things
402
403
404 **Partner – nothing like the Macmillan nurse, they haven’t supported me at**
405 **all**
406
407
408 DS240149.F – they haven’t supported me at all, I don’t feel supported at all
409
410

411 I – by the oncologist?

412

413

414 DS240149.F – by the second half the oncologist and their team

415

416

417 I – and what about asking questions have you found it easy or difficult?

418

419

420 DS240149.F – there’s no one to ask

421

422

423 I - okay and that’s the oncologist

424

425

426 Partner – but, she will ask anyway, you know she will ask

427

428

429 I – yeah you should

430

431

432 Partner – you know who ever it is that you know if the nurse practitioner
433 is there you know we’ll put her on the spot ((mobile phone rings)) sorry, if
434 this is ((candidate’s)) health and we would ask, if she doesn’t know then
435 she should get off her backside and go and find out

436

437

438 DS240149.F – for example, excuse me if I don’t do this he’ll keep on...bing,
439 bing, binging I can’t remember which cycle, I think it was the second cycle,
440 just before it was the day I was going to give my bloods to measure my
441 neutrophils so that would be a Monday, and then I go for chemo, so on the
442 Monday morning I was having a shower and I had a huge flash in my eye and
443 masses of floaters, so when I mentioned this to the nurse practitioner “no”
444 she hadn’t heard of that “no, you’re better off going to your optician” go
445 online there’s a huge connection between chemotherapy and that, but she
446 wasn’t at all concerned, not at all

447

448

449 Partner – why did she think you should see your optician?

450

451

<<15:00>

452 DS240149.F – she thought my retina had torn away from the back of my eye
453 and she sent me to the ophthalmic bod's in Bridgend but because she hadn't
454 heard it, the nurse practitioner, no connection, I've got a black mark on my
455 nail, it's pathetic I know it's pathetic but I've asked about it, "don't know"
456 look it up black stripe on your nail indicates breast cancer, um and these are
457 things I've had to find out about myself

458

459

460 **I – I would've thought that they'd be aware of that, or at least look it up**

461

462

463 DS240149.F – but when I ask them, they don't, it's not like, I don't know, I'll
464 have to find out about that, which is what my Macmillan nurse would say, it
465 was "no, it's not connected"

466

467

468 **I – I'm sorry that you experienced that**

469

470

471 **Partner – but, <hospital> have been amazing**

472

473

474 DS240149.F – no I can't, I don't want anyone, it's nobody's fault it's just
475 there not, they've got too many people, I think they go, they're
476 overwhelmed by the amount of patients

477

478 **I - What I've learned from this project so far is that there seems to be**
479 **variation in the information that some people are getting, <hospital> was**
480 **voted the best for cancer treatment I think in Wales, um and then...**

481

482

483 **Partner – it's a centre of excellence?**

484

485

486 **I – yeah, exactly and that's really been reflected in interviews and other**
487 **hospitals... the standard of care appears to be different**

488

489

490 **Partner – well when we go and have blood, she goes in she has her blood**
491 **taken then we go around a corner and we could be sitting there for 2 hours**

492

493
494 **I – really?**
495
496
497 DS240149.F – sometimes 3
498
499
500 **Partner – when she’s feeling poorly, or really, you know you’re talking**
501 **about a cancer patient here who is here, who is not up to scratch, who is**
502 **having chemo**
503
504
505 **I – yeah that’s a very long time**
506
507
508 **Partner – and it’s 2 hours before, and that is waiting for a nurse**
509 **practitioner to see us, not a consultant a nurse practitioner. I’m sorry that**
510 **is appalling**
511
512
513 DS240149.F –last Monday when we went in
514
515
516 **Partner – that is appalling**
517
518
519 DS240149.F – there was a lady and she complained to one of the nurses, not
520 the nurse practitioner, she complained to one of the nurses in the
521 outpatient clinic, excuse me my appointment is at 10 o’clock and it’s quarter
522 past 11 now “oh yes, yes, what’s your name?” so.... and I said “well actually
523 my appointment is for 10 o’clock too” “oh okay” so they are just 10 o’clock
524 appointments, you just sit there, she went in before me, so I went in after
525 her, so I didn’t get in until after 12 o’clock and I missed my lunch because
526 they give you a prescription and you’ve got to go to pharmacy and wait and
527 they’re never ready, it takes ages to do it, so I missed my lunch and when
528 you’ve had chemo you feel quite sick you have to eat little and often so I
529 don’t know what they can do about it it’s just not particularly well organised
530
531
532 **I – no it doesn’t seem to be, it seems quite manic**
533

534
535 DS240149.F – but they’re always hectic there seems loads, we went to
536 <hospital> at that time and there was hundreds of people milling around....
537
538
539 **Partner – I was about to get up and just say you know “have you forgotten**
540 **that we’re here?” and they just called us ((laughs)) and they just rush you**
541 **when they talk to you, and then you understand why actually, he was very**
542 **thorough, I asked him questions about her diet and whatever and you**
543 **know**
544
545
546 **I – yeah, if I was gonna ask were there any barriers communicating with**
547 **doctors and nurses, I’m guessing one of those then is sort of time pressure**
548 **isn’t it?**
549
550
551 **Partner – really busy well I don’t see...well you’re in there isn’t it...they do**
552 **take their time it’s just the waiting to get in to see someone**
553
554
555 **I - yeah**
556
557
558 DS240149.F – but it’s like I was given the name and number of the Macmillan
559 Nurse after I had breast surgery, I haven’t been given a name that I can
560 contract. The only number that I can contact is in an emergency. I’ve got a
561 number if my temperature goes up, or if I’ve got this, this, or this
562
563
564 **I – but no one to have...**
565
566
567 DS240149.F – but not on a day to day to say “I’m not feeling so good, blah,
568 blah” you know, and sometimes I just want to run that past them
569
570
571 **I - yeah exactly. I thought <hospital> had a Macmillan nurse, or I thought**
572 **they had someone you could call and ask?**
573
574

575 **Partner – well I thought...**
576
577
578 DS240149.F – I don't have anybody
579
580
581 **Partner – oh no you can, you could call and ask, but you don't know who**
582 **they are. You've got a phone number, that's what they want**
583
584
585 DS240149.F – that phone number is only if I have a chest infection or I have
586 this, this, or this
587
588
589 **Partner – no, they have given you a number for Tenovus and you can talk**
590 **to anybody in Tenovus**
591
592
593 DS240149.F – that's counselling, no I mean
594
595
596 **Partner – no, no, no, you can talk about treatment, or whatever with**
597 **Tenovus, there's somebody there**
598
599 DS240149.F – yes, but I don't have my own nurse
600
601
602 **Partner – no**
603
604
605 DS240149.F – like with <nurse>, I don't....
606
607
608 **I - yeah that would be really helpful if you had questions for a doctor or**
609 **nurse**
610
611
612 DS240149.F – no, I've got an emergency number that they have to bleep the
613 on call oncologist, well I'm not gonna bleep her to say that I've got a little
614 grey line on my toe nail, what do I do about it?
615

616
617 **I – yeah you must have your own nurse that you can run that past**
618
619
620 DS240149.F – and if she doesn’t know, she’ll come back to you
621
622
623 **I - yeah exactly, so do you think an app could help with something like**
624 **that then, to be able to look that up. I mean I suppose you could do it on**
625 **the internet**
626
627
628 **Partner – If you really wanted to do it, you would do it**
629
630
631 DS240149.F – well I can, it’s like sometimes just for me, to have a voice...to
632 have someone to say, “well actually I don’t know about that one I’ll come
633 back to you”
634
635
636 **I – okay**
637
638
639 DS240149.F – I suppose I’m spoilt because of <nurse>, <nurse> was
640 incredibly supportive
641
642 **Partner – she was**
643
644
645 DS240149.F - and she did look after me and I felt, I did, I felt if I wanted to I
646 could’ve rung her and said “could you come out?” you know, where it’s that
647 feeling where you’re unsure and she would have, and I don’t have the same
648 support going through oncology. Oncology in actual fact has been worse,
649 the side effects have been terrible, things that I don’t know about yes I feel
650 like I’ve been hunting both of us, even her daughter
651
652
653 **Partner – it’s been a bit learning curve for all of us**
654
655
656 DS240149.F – yes

657

658

659 **I – yes**

660

661

662 DS240149.F – I got a lot of information when I was admitted as an
663 emergency because the doctor sat with me for hours

664

665

666 **Partner – yes she was very good**

667

668

669 DS240149.F – you know she was very concerned and she sat and she
670 answered all my questions

671

672

673 **I - yeah okay, so just going back to the information, how did you**
674 **remember all the information, did you write it down or keep leaflets, or**
675 **just revisit, the resources you used?**

676

677

678 **Partner – we wrote it down, you took a little pad and paper and you wrote**
679 **it down**

680

681

682 DS240149.F – I wrote notes. I've got a booklet in here that...the other thing
683 which I had found very helpful is I've kept a very brief diary of my cycles and
684 I've found that really helpful to see a pattern and there is a definite pattern
685 and it's helpful to know I have this foul taste for example, for 5 days after
686 the chemo, it's so awful I, I have difficulty in eating anything, but I know it's
687 only going to be 5 or 6 days and then it passes

688

689

690 **I – so does that help you to cope with it?**

691

692

693 DS240149.F – absolutely, I would recommend that to people, I also put
694 down, I'll show you, it's pathetically basic, but it's been a real help to me

695

696

697 **Partner – I whisked it off the computer and just said “fill it in” and now I**
698 **say to her**

699

700

701 **I – oh so was it, it was a...?**

702

703

704 **Partner – day 5**

705

706

707 **I – ready made**

708

709

710 **Partner – I went on to a computer and...**

711

712

713 DS240149.F -

714

715

716 **I – oh and you typed it out**

717

718

719 **Partner – typed in the diary a little bit and then she writes in it every day**
720 **and then I say to her “can you put a number there from 1-10 on how you**
721 **feel?**

722

723

724 **I – this is very good yeah**

725

726

727 **Partner – so sometimes she feels like a number 3 yesterday? I’d put you**
728 **down as a 1! ((laughs))**

729

730

731 **I - ((laughs)) yeah**

732

733

734 DS240149.F – I think from my point of view I like to be doing, I like to be
735 proactive, trying to help myself you know

736

737

738 **Partner – that’s our background we are always proactive**

739

740

741 DS240149.F – well that’s as maybe, but if you look here so this is my first
742 cycle day 1 I gave myself a 2 at the time about how I actually feel, vomiting,
743 I was admitted to hospital for support, a bit nauseas and then ulcers and
744 sore eyes, ulcers have gone and then back on obviously puffy eyes, nauseas,
745 and then ulcers, ulcers and then tired, tired, dry eyes, same thing – space,
746 space, space...that’s when I was admitted, the zombie that’s beginning
747 that’s day 1 and this is yesterday okay, bowels opened cos that’s another
748 thing 6 out of 10 yesterday and I find it useful because it’s a definite pattern,
749 absolutely definite pattern

750

751

752 **I – yeah, it’s really interesting that you’ve done that because a lot of**
753 **studies are using apps now for patients do to exactly that, so they track**
754 **their main symptoms and what is interesting though and it might’ve**
755 **helped you is if the symptoms or the temperature goes up to a certain**
756 **point, the nurse looks in and suggests remedies to help it you know reduce**
757 **it at home, but if it goes so far they’ll call you into hospital so they can**
758 **treat you**

759

760

761 **Partner – wouldn’t that be a good idea?**

762

763

764 **I – yeah and you’re already doing it yeah and it’s incorporating then what**
765 **you said then having a nurse just looking over and just watching....**

766

767

768 DS240149.F – cos you do get paranoid every single thing like when my nails,
769 my cuticles were splitting you know, but you want to know also, put it this
770 way if you don’t know anything, which is how I started off, how do you know
771 what questions to ask?

772

773

774 **I – yeah, so would you suggest something like this for the app to have then,**
775 **a sort of electronic diary?**

776

777

778 **Partner – yes**

779
780
781 DS240149.F – yes, I think that’s brilliant
782
783
784 **Partner – absolutely, cos we see a pattern, I say to her now – “what day**
785 **are you 6, okay what was last time’s day 6? Oh okay”**
786
787
788 **I – and you sort of prepare**
789
790
791 **Partner – could fit then...?**
792
793
794 **I – yeah exactly**
795
796
797 DS240149.F – well somewhere in my first cycle my nose kept running, just
798 like a tap and I mentioned it to the nurse practitioner and she said yes you’ve
799 got no nose hair it’s all fallen out
800
801
802 **Partner – and we both went “oh right”**
803
804
805 DS240149.F – and I mean it grows back a little bit and then half way through
806 the second cycle and suddenly it’s like this and I’ve got no nose hair...! You
807 know it’s silly things like that, it’s having this pattern and working it out
808
809
810 **I - yes, I expect it makes it easier for you to cope with then if you know**
811 **what’s coming**
812
813
814 DS240149.F – well I know that my taste will get better, where as the first
815 time I had it, I thought I can’t be like this for 6 months I won’t be able to eat!
816
817
818 **Partner – I’ve learned now what to cook you know the first 3 or 4 days I....**
819

820
821 I – oh that’s great
822
823
824 Partner – and no salt, cos if I put a bit of salt in it, so I make her some sort
825 of butternut squash soup, so that she can eat that with bread and she’s
826 fine, no butter, butter will make her sick and no salt because the salt then
827 she’d go...I’ve got this salt in my mouth all the time so...but it’s all its trial
828 and error
829
830
831 I – yeah, that’s such a good idea. Okay, so how have you found it because
832 we’re still on communication so how have you found it, have you found it
833 easy to talk to family and friends about the cancer? Or do you prefer to
834 keep things to yourself?
835
836
837 DS240149.F – I’m selective who I talk to I would say
838
839
840 I – and for what reasons, why would you say you’re selective?
841
842
843 Partner – she wants to be a moaning minnie
844
845
846
847 DS240149.F – no I don’t mean to be, I don’t want people coming around
848 having to listen to me “oh I’ve got a bad ulcer...oh my pain” and things...I
849 just say “I’m not too good today, come tomorrow” you know
850 I – yeah, yeah
851
852
853 DS240149.F – um and like I said if I need information there are certain
854 people I will go to...so anybody who comes will just sit and they say “how
855 are you” and I go “I’m getting there” I don’t want to bore them, you know
856 because it’s quite an enjoyment sitting there talking about all you’re pains
857 and aches isn’t it....you know you become a right old moaning minnie...
858
859

860 I – yeah I expect you don’t want it to dominate you’re whole day I would
861 think talking about

862

863

864 DS240149.F – it was hard at the beginning, deciding who to tell that I had
865 breast cancer um, is it me or is it just hot suddenly?

866

867

868 **Partner – when the sun goes down it gets hot**

869

870

871 I – yeah, yeah

872

873

874 DS240149.F – oh gosh I’m like an oven, it was hard at the beginning to say
875 “I have breast cancer” I didn’t know how to tell....

876

877

878 **Partner – you didn’t want to tell anybody**

879

880

881 DS240149.F – I didn’t want to tell anybody because I didn’t want people
882 worrying about me, because when you get to the stage when you’re having
883 chemotherapy and people are going to wonder why I’m not going out, so I
884 had to tell people, but I’m still selective who I told, not everybody in my
885 friends, my close friends know, but my sort of peripheral friends...

886

<<30:00>

887

888 I – okay, so working on to technology then, do you have experience of
889 using a smart phone, or a tablet computer?

890

891 DS240149.F – yes I do

892

893

894 I - is that both or either?

895

896

897 DS240149.F – yep phone and my Ipad is joined at my hip

898

899

900 I – okay yeah so you prefer the Ipad, yeah so what do you use the devices
901 for?

902

903

904 DS240149.F – well the Ipad is for really the search engine to see Macmillan,
905 I try to go on a medical site that <partner> uses because she has access to
906 the information, I don't like these blogs where people write in you know I
907 don't like that. I much prefer to have factual information Macmillan is, it's
908 quite helpful, but it's very basic you know you go into the Macmillan site,
909 only because I need to know the ins and outs of everything, I'm not like
910 everybody I'm sure

911

912

913 I – yeah, no I think because you've come from a research background
914 you're well educated, I think you'll want the more scientific sort of medical
915 knowledge where as I think....

916

917

918 DS240149.F – well if I understand the workings of like neutrophils I now
919 understand the workings of it, I know what to look for and I know to avoid
920 things like blue cheese, or live yoghurt there's no where you'd find that
921 information, but if you're neutrophils are fighting bacteria the last thing you
922 need to be doing is eating bacteria, um which sounds logical now oh I should
923 have thought of that, but it took me, only when they told me that my
924 neutrophils were 0.9 I thought so what do you think is doing that? We were
925 having you know live yoghurt you know. I do look at American sites, the
926 American's are much more upfront with the information, much, much, more

927

928

929 Partner – yes

930

931

932 I – really

933

934

935 DS240149.F – much more, you have mucositis where all your mucosa all
936 your membranes are infected and uh the Americans have got like a herbal
937 tincture if you like, you can only get from America, I bought it from America.
938 Now why don't they have something like that you know, how many Cancer
939 patients have sore mouths?

940

941
942 I – yeah and did that help you?
943
944
945 DS240149.F - yes
946
947
948 I – and they don’t sell it over here gosh. So do you use apps for your health
949 at all?
950
951
952 DS240149.F – I don’t have an app specifically no, I just use search engines
953
954
955 I – okay so you’re just looking through google and on the databases
956
957
958 DS240149.F - yeah
959
960
961 I – and what about yourself ((referring to partner))
962
963
964 Partner – same, same
965
966
967 DS240149.F – you don’t have an app do you?
968
969
970 DS240149.F – no I go into google or ask Informed <Medic Friend> yeah we
971 ask Informed <Medic Friend> it’s good that she knows, if she doesn’t know,
972 which is very rare, if she doesn’t know, she’ll come back and find it, she will
973 go to ((both talking at once inaudible 33:03))
974 I – yes that’s brilliant the internet. Okay so the type of app we’ve talked
975 about, we’re hoping that it will help patients with appointments by
976 prompting them to ask questions, or think about the types of questions
977 they want to ask, it can be linked to reputable websites so they’re getting
978 good information, and it could also help them with social support, so links
979 to support groups, so they’re the sorts of things we’re thinking about, but
980 really it’s gonna come from what you suggest, so bearing that in mind, do
981 you think patients would use this type of app if we built it?

982
983
984 **Partner – yes I think they would**
985
986
987 DS240149.F – I actually think they would, because you are given a huge
988 amount of paperwork at the beginning you know about diet, exercise,
989 fatigue blah, blah, blah...
990
991
992 **Partner – all these leaflets....**
993
994
995 DS240149.F – masses of them, they're all in here and I have gone right now
996 I've put them in there, a lot of it because um
997
998
999 **Partner – you weren't in the right frame of mind to look at it**
1000
1001
1002 DS240149.F – I wasn't, it's all timing isn't it?
1003
1004
1005 **I – it's too much**
1006
1007
1008 DS240149.F – it's really overload. The number of appointments I had from
1009 the first time I went to a GP to my surgery, I got through 40 it was unbearable
1010 wasn't it
1011
1012
1013 **Partner – we were going to Swansea um Bridgend, <hospital>**
1014
1015
1016 DS240149.F – it was just awful
1017
1018
1019 **Partner – I just stopped doing everything okay cancel everything**
1020
1021
1022 DS240149.F – she had to give up work

1023
1024
1025 **I - wow, yeah**
1026
1027
1028 **Partner – it's you know – let's see what's going on here**
1029
1030
1031 DS240149.F – I don't know how they can avoid them, but it was overload
1032
1033
1034 **I – and so did you read half of the information, or did you sort of leave it**
1035 **and then...**
1036
1037
1038 **Partner – some of it**
1039
1040
1041 DS240149.F – I have read it, I have read it now, um yes because most of it
1042 has been quite useful, but again it was too basic. They're using it for people
1043 you know don't know, which I can understand again. I think what you need
1044 is this like open window you need oh okay that's fine, that's as much as I
1045 need to know, if you want to know more you can, but I think if they'd said
1046 you know this is the basic if you want to know more, look up blah, blah, that
1047 would've been helpful, but it stops...it doesn't...
1048
1049
1050 **I – yeah it's interesting because some of the patients I've spoken to have**
1051 **said, "actually the information leaflets are too complicated, there was too**
1052 **many big words and I can't understand it all" so the app maybe could then**
1053 **starting simple and say if you want to know more and as you progress and**
1054 **for people like yourselves who really are getting down to the science**
1055 **behind it, so maybe like we could**
1056
1057 DS240149.F – maybe stages, you could have idiot, middle and bright
1058
1059
1060 **I – yeah**
1061
1062
1063 DS240149.F – you know, that sounds dreadful doesn't it?

1064
1065
1066 I – ((laughs))
1067
1068
1069 **Partner – but we do have a medical background so we’re a bit...**
1070
1071
1072 DS240149.F – well that’s the problem...
1073
1074
1075 I – yes exactly
1076
1077
1078 **Partner – so we know what’s going on and we’re “oh okay let’s go through**
1079 **here and find this”**
1080
1081
1082 DS240149.F -
1083
1084
1085 I – or even if we link the app maybe to the internet to um a reputable
1086 scientific website
1087
1088
1089 **Partner – absolutely, a medical site that we could go and have a look at,**
1090 **now that would be ideal**
1091
1092
1093 DS240149.F – and there are going to be people who’ll say “I didn’t know
1094 that” or “I don’t understand” my mother doesn’t understand big
1095 words...you know if I said to her...
1096
1097
1098 **Partner – didn’t understand what a protein is**
1099
1100 DS240149.F – neutrophenic sepsis no idea, no idea, but if I said have you
1101 heard of white cells? “yeah” have you heard of red cells? “yes” and that’s
1102 how basic it is. That’s where have to...you have to cover it for everybody
1103 don’t you?
1104

1105
1106 I – yeah exactly
1107
1108
1109 DS240149.F – and that’s tough...
1110
1111
1112 I – that’s really, that’ll be definitely noted down
1113
1114
1115 Partner – but if I opened that you see I’d go right...close it down and go
1116 onto my...((laughs))
1117
1118
1119 DS240149.F – no I know but it’s like colour coding, you going to have to you
1120 know if you’re interested it’s green, if you’re really interested it’s amber and
1121 if you really want to know intricate details you go into red, or you could have
1122 a coloured section or something do you know what I mean?
1123
1124
1125 Partner – yeah absolutely
1126
1127
1128 DS240149.F – so I would go straight to the red and I would just be reading
1129 that
1130
1131
1132 Partner – yes absolutely
1133
1134
1135 I – yes cos that’s avoiding the sort of....
1136
1137
1138 DS240149.F – the dross that goes before it which we know and I think that
1139 is hard because you’re reading something.....
1140
1141 Partner – when the diagnosis comes, you read as much as you can you
1142 know I study the internet here, she’s on the internet here and I go “did you
1143 know” and she goes “oh yeah that sounds interesting you know”
1144
1145

1146 DS240149.F – she says things like you’ve got lobular cancer HER positive,
1147 meant nothing
1148
1149
1150 **Partner – but we logged it came home we were both on different sites and**
1151 **away we went you know**
1152
1153
1154 DS240149.F – but you can’t cover everything, but if you have links you know
1155 like you said to the higher information
1156
1157
1158 **I – yeah to do guide you onto the right information for them**
1159
1160
1161 DS240149.F – depending on where you wanted to stop
1162
1163
1164 **I – yeah okay**
1165
1166
1167 DS240149.F – some people would be petrified, I mean...that lady I shared a
1168 ward with she didn’t want to know anything, she didn’t want to know
1169 anything about anything
1170
1171
1172 **Partner – another thing is if you’re doing the surgery bit, it’s about you**
1173 **know do I go for reconstruction or not?**
1174
1175
1176 DS240149.F – that’s hard
1177
1178
1179 **Partner – you know there’s a really...**
1180
1181
1182 DS240149.F – you don’t have much time to make up your mind obviously
1183
1184
1185 **Partner – it’s a very short period to think about that**
1186

1187
1188 **I – yeah they said it’s quite**
1189
1190
1191 DS240149.F – they’re rushing you through because of the government
1192 objectives, that you have to go from uh GP visit to surgery in X amount of
1193 weeks, then you are pushed and you’ve got all these appointments in-
1194 between as well, and you’ve got so much information to take in...do I have
1195 a lumpectomy, do I have a mastectomy do I have reconstruction now, or do
1196 I have reconstruction later?
1197
1198
1199 **I - yeah exactly**
1200
1201
1202 DS240149.F – you have to say if you want it later because they have got to
1203 have the skin flap you know
1204
1205
1206 **Partner – but you don’t have to do that and my first instinct was take it**
1207 **away...I don’t care what you...just take it away and then she said “hey**
1208 **hang on, no I need to think about this you know” and it was good for her**
1209 **to sit and think about it**
1210
1211
1212 DS240149.F – I said I need an MRI, I want an MRI to see if I’ve got it in my
1213 other breast. I don’t want to have to go through this again um and that gave
1214 me time to come to terms with what I’d decided, but if they’d given me a
1215 reason I would’ve just said “you’ve got breast cancer she would’ve said “I’ll
1216 have a mastectomy on Wednesday”
1217
1218
1219 **Partner – when he said...I would’ve been on the Wednesday had it done**
1220 **and I’d be out**
1221
1222
1223 **I – really yeah**
1224
1225
1226 **Partner – so it’s a different thinking isn’t it? My sisters came around and**
1227 **my one sister said “yeah I would’ve done the same as you” and the other**

1228 **one went..."I'm not so sure, I don't know where I would've been with that**
1229 **till I'd thought about it"**

1230

1231

1232 **I – so it's really important then getting to the decision?**

1233

1234

1235 DS240149.F – it's really important but you don't have time to think about it

1236

1237

1238 **Partner – and she has a chest problem and she didn't want to be on the**
1239 **table too long, well if you have a reconstruction, you're adding on hours in**
1240 **surgery and she was petrified, you know if I'm hours and hours under**
1241 **anaesthetic, what's my chest gonna be like when I come out? And you**
1242 **know and we talked this through a lot**

1243

1244

1245 DS240149.F – and I think American women just go for the mastectomy's
1246 their very gun-hoe about it no reconstruction it is what it is. British people,
1247 British women tend to go for reconstructions or lumpectomies, it's the
1248 different culture isn't it, we are about body image and so was I, you know
1249 and the thought of it was horrendous to me, but if I had a lumpectomy, I
1250 would've had to have radiotherapy and the radiotherapy would knackered
1251 my chest and I've also got, I've already got a knackered chest. So although
1252 I wanted a lumpectomy, I couldn't have it. I....

1253

1254

1255 **Partner – you couldn't have it anyway**

1256

1257

1258 DS240149.F – I wasn't offered anything because of my lymph glands

1259

1260

1261 **Partner – her glands had gone**

1262

1263

1264 DS240149.F – but there was a point in this discussion that I could have a
1265 lumpectomy and I felt like, I should say yes you know

1266

1267

1268 **Partner – but the surgeon was very good about that wasn't he, they were**
1269 **talking about it, but there's still that...**
1270
1271
1272 DS240149.F – there's a pressure on you to make a decision
1273
1274
1275 **I - oh and it's a very big decision**
1276
1277
1278 DS240149.F – and I'm intelligent so I don't know how somebody who's just
1279 "oh my god" what are they going to base their decisions on?
1280
1281
1282 **Partner – I think they just say "go with it" I don't know**
1283
1284
1285 DS240149.F – what would you do? That's what...put it on the surgeon, what
1286 would you suggest?
1287
1288
1289
1290 **Partner – because as you come out of the, the surgeon's consulting room,**
1291 **your mind is going 19 to the dozen is it a lumpectomy is it a mastectomy**
1292 **and you come home and you immediately go online to find out...**
1293
1294
1295 DS240149.F – and the problem we had also was that I was told it was in my
1296 lymph and I was told it wasn't in my lymph and then I was told it was in my
1297 lymph...so if it wasn't in my lymph
1298
1299
1300 **Partner – it was in the lymph**
1301
1302
1303 DS240149.F – I couldthat was just
1304
1305
1306 **Partner – mind blowing**
1307
1308

1309 DS240149.F – you know I don't want chemotherapy, nobody wants
1310 chemotherapy and there was a point

1311

1312

1313 **Partner – like being on a rollercoaster**

1314

1315

1316 DS240149.F – there was a point, there was a glimmer in the middle of it all
1317 when he said “good news” he actually said “I have good news for you” and
1318 then half an hour later...? I had an ultrasound and I had a full biopsy and I
1319 thought well what are you doing a full biopsy on if it's not in my lymph you
1320 know?

1321

1322

1323 **I – I don't understand why they told you that?**

1324

1325

1326 DS240149.F – I had an MRI and the MRI showed I didn't have it in my lymph

1327

1328

1329 **I – oh when they took the biopsy**

1330

1331

1332 DS240149.F – so when I went then he said “ the MRI, I've got good news for
1333 you, you've got it in your breast, but you don't have it in your lymph, but I'll
1334 send you for an ultrasound just to be certain. I went for the ultrasound and
1335 instead of being in my armpit it's lower down here it's still lymph obviously,
1336 but for half an hour I had yes! I can remember I had that feeling...I can have
1337 a lumpectomy no chemotherapy oh my god you know that, that was just.
1338 Right at the beginnings of everything isn't it, because you've got
1339 chemotherapy and then you've got 5 years of drugs and....it's such a long
1340 haul

1341

1342 **Partner – it's a rollercoaster**

1343

1344

1345 DS240149.F – that decision I still wonder if I should've had like a silicone
1346 implant even now...you know it's too late now

1347

1348

1349 **I – okay so going back, what about**

1350
1351
1352 DS240149.F – too much information for you sorry
1353
1354
1355 I - no, no it's great it's just we'll just get through other questions these as
1356 well. So do you think other patients would find this app accessible for use?
1357
1358
1359 **Partner – yes absolutely**
1360
1361
1362 DS240149.F – definitely
1363
1364
1365 I – and what about friends, friends and family's of the patients?
1366
1367
1368 DS240149.F – yes I'm sure
1369
1370
1371 **Partner – I would've been on it**
1372
1373
1374 DS240149.F – everybody wants to help
1375
1376
1377 **Partner – absolutely**
1378
1379
1380 I – and do you think patients would need training to use it? Do you think
1381 we'd have to train patients up first of all?
1382
1383
1384 **Partner – no**
1385 DS240149.F – I think the majority of patients...are all computer literate now
1386
1387
1388 **Partner – we're all computer, even her mother at 85 can use a computer**
1389
1390

1391 DS240149.F – I think they are and they're grandchildren can show them if
1392 they're stuck

1393

1394

1395 I – yeah that's what we're hoping that there will be someone in the family

1396

1397

1398 Partner – my 4 year old...what are you doing, quick and she's away gone
1399 done everything, she's you know,

1400

1401 so computer literate ((laughs))

1402

1403

1404 I - yeah okay and if it was made available do you think it's something you'd
1405 download and recommend to friends as well?

1406

1407

1408 DS240149.F – well I would absolutely when I heard about it I thought it was
1409 a good idea

1410

1411

1412 I – okay alright I know this is hard because it depends on what the app is
1413 gonna do and we've touched on it briefly, but what benefits do you think
1414 there might be for patients using the app?

1415

1416

1417 Partner – information!

1418

1419

1420 DS240149.F – well I think there's also all sorts of reassurance, that it's not
1421 something that's unusual, you know 95% of my problem is from
1422 chemotherapy are normal if you like, so it's all about reassurance and
1423 information

1424

1425 I - and what about the clinicians do you think they'll get any benefit if
1426 patients are using this type of app?

1427

1428

1429 Partner – well they'll be asked more questions, so they will have to take
1430 time to answer them

1431

<<45:00>

1432
1433 I – so how do you think they’ll cope with that, do you think that they’ll like
1434 that? Or do you think they won’t like that very much
1435
1436
1437 DS240149.F – I know talking to my GP for example she hates me to know,
1438 because everyone knows everything and they go in and tell her what’s
1439 wrong with them, you know so there is a point, there’s a point there, too
1440 much information? I don’t know, I think it’s useful and yes there are going
1441 to patients who are going to sit and say “I have read” and they’ve got a 100
1442 questions you know. I think for the majority of people it’ll just be
1443
1444
1445 **Partner – information gathering and you know okay this is what I need to**
1446 **ask and what am I going to do..okay so I’m going to ask him thisand**
1447 **hopefully he’ll give me answers. We know they’re rushed, we know they**
1448 **are, but you know they’re not God they are people and they are dealing**
1449 **with people**
1450
1451
1452 I – and if they don’t know the answers they should definitely look them up
1453
1454
1455 **Partner – absolutely**
1456
1457
1458 I – and what about for family and friends, what benefits do you think they
1459 might get from using this app?
1460
1461
1462 DS240149.F – all my friends have said “what can I do to help you?” all of
1463 them, um they don’t know how to deal with me
1464
1465
1466 **Partner – we just say “meet us for coffee”**
1467
1468
1469 DS240149.F - I think but if they...there’s a lovely line um not another bunch
1470 of flowers.com this woman she’s had 3 breast surgery’s and uh she’s fed up
1471 of getting flowers, she wants useful gifts and I think that would be if they

1472 had some ideas about how to alleviate they might not feel so helpless are
1473 they, because they all want to help don't they?

1474

1475

1476 **Partner – and don't bring another bunch of flowers!**

1477

1478

1479 DS240149.F – I mean a friend of mine with breast cancer sent me a bra, now
1480 she obviously knew exactly

1481

1482

1483 **Partner – excellent**

1484

1485

1486 DS240149.F – what I was going through, because my bras don't fit

1487

1488

1489 **Partner – and deodorant, special deodorant, it was amazing**

1490

1491

1492 DS240149.F – it's the only bra in fact it's on my Facebook page, my profile is
1493 a picture of me sitting with on obviously smiling cos it's the only bra that's
1494 comfortable...not now this was immediately post surgery, you've got drains
1495 hanging down oh god...tried all sorts of bras

1496

1497

1498 **I - aw that's so useful isn't it?**

1499

1500

1501 DS240149.F – but she'd been there, done it so you know

1502

1503

1504 **I – so that sort of information would be helpful**

1505

1506

1507 DS240149.F – of course yes I mean how

1508

1509

1510 **Partner – with websites like not another bunch of flowers, because they've**
1511 **got lovely hats and all those sorts of things**

1512

1513

1514 **I – that’s brilliant that is yeah**

1515

1516

1517 **Partner – but they are a bit expensive, but**

1518

1519

1520 DS240149.F – it’s things like cracked lips you know I talked about the sores

1521 in your mouth...you know the basics the actual how to stop it? What can

1522 we do about constipation?

1523

1524

1525 **Partner – which is horrendous in the beginning**

1526

1527

1528 DS240149.F – people don’t, they say “make sure you don’t get constipated”

1529 that’s okay, but how do you make sure you don’t? You’re taking a drug that

1530 fluid retention is horrendous, it sucks out all the fluid from your bowel, so

1531 you don’t go to the toilet for 4 days and you feel like death

1532

1533

1534 **Partner – and we’re vegetarian so you can imagine you know**

1535

1536

1537 DS240149.F – well like it’s the bottom line you address you when you have

1538 this << inaudible everybody speaking at once 49:23>>

1539

1540

1541 **Partner – your food and your drink isn’t it ((laughs)) your basic needs**

1542

1543

1544 DS240149.F – are you warm, are you

1545

1546

1547 **Partner – basic needs**

1548 DS240149.F – it effects every one of your bodily functions chemotherapy

1549

1550

1551 **Partner – and I feel useless because sometimes I can’t help her you know**

1552 **and that’s really hard there should be a practical part of the app like what**

1553 **to do to help**

1554
1555
1556 DS240149.F – you know what to do, to help you have a cracked nose, your
1557 eyes get sore, there's a whole....
1558
1559
1560 **Partner – my remedy is “go to bed and sleep”**
1561
1562
1563 **I - yeah ((laughs))**
1564
1565
1566 **Partner – have this soup, feel the warmth, have a hot water bottle, please**
1567 **go to bed**
1568
1569
1570 DS240149.F – just go away...((laughs))
1571
1572
1573 **I – so, what about for you then what could the app help with for yourself?**
1574 **Something you said you were finding it hard...**
1575
1576
1577 **Partner – practical things you know?**
1578
1579
1580 **I – ...you don't know what to do what about supporting yourself, do you**
1581 **talk to other people or? How do you, because it's difficult for you as well,**
1582 **so how do you cope with everything?**
1583
1584
1585 **Partner – I take the dog for a walk, you know I'm not one to sit and talk to**
1586 **people, and in fact I'll tell you openly and truthfully if she hadn't said yes**
1587 **to this, if you had rung me I would've said no, because I don't do that sort**
1588 **of thing, that's not me**
1589
1590 **I – Okay. Well what about for other relatives then do you think...because**
1591 **some relatives go to support groups and things like that. Do you think that**
1592 **would be helpful for others?**
1593
1594

1595 **Partner – if the opportunity is there, then I’m sure some people would take**
1596 **that yes**
1597
1598
1599 **I – okay**
1600
1601
1602 **Partner – but I’ve had my own way of dealing with that and**
1603
1604
1605 DS240149.F – oh I’ve been offered, have been offered it.... I’ve kept it
1606
1607
1608 **Partner – there may be a time when you will need it**
1609
1610
1611 DS240149.F – it’s a very emotional thing for a woman to go through, but I’ve
1612 been able to
1613
1614
1615 **Partner – some people grab it**
1616
1617
1618 DS240149.F – I’ve talked to <partner> we talk about our problems we’re
1619 very open about it you know it definitely helps
1620
1621
1622 **I – yeah definitely**
1623
1624
1625 **Partner – I’m a psychotherapist as well, so you know**
1626
1627
1628 **I - oh there you go ((laughs))**
1629
1630
1631 DS240149.F – I would’ve said psychobabble go away and leave me alone
1632
1633
1634 **Partner – yes she does, “don’t give me that psychobabble” okay**
1635

1636
1637 DS240149.F – and she says “so I guess what you’re saying....” and I think ah,
1638 ah...no don’t, don’t....((laughs))
1639
1640
1641 I – ((laughs)) um okay so do you think the app would have an impact on
1642 the way you talk to doctors and nurses about the cancer? Do you think it
1643 could be easier or more difficult?
1644
1645
1646 DS240149.F – no, it’s going to make it easier
1647
1648
1649 **Partner – it will make it easier**
1650
1651
1652 DS240149.F – you go in with a bit more information, you feel more
1653 comfortable, you can ask them a questions and the answer won’t confuse
1654 you because you know the rudiments of it like
1655
1656
1657
1658 **Partner – or if it does, you’ll take it into your head you’ll come away and**
1659 **go and look it up ((laughs))**
1660
1661
1662 I – yeah, what about writing things down...do you think the app should
1663 have a facility for writing the answers down? Because some people have
1664 said “I don’t know if I would have time, or it’ll distract me”. What do you
1665 think about that?
1666
1667
1668 **Partner – it would distract on an app**
1669
1670
1671 DS240149.F – I think something like this that is perhaps a diary and...
1672 **Partner – you can make a recommendation to do that if they wanted to?**
1673
1674

1675 I – I mean when you're in the consultation and you've got your list of
1676 questions on the app, what about writing the answers down during the
1677 consultation?

1678

1679

1680 **Partner – no I write them on a bit of paper and I'd be then asking, I'd have**
1681 **my bit of paper in front of me...**

1682

1683

1684 DS240149.F – I wouldn't, I don't think I would be bothered to....

1685

1686

1687 **Partner – but then we're old**

1688

1689

1690 DS240149.F – fill in the detail

1691

1692

1693 **Partner – well no I take my app in there and say "hold on second, I need**
1694 **to..."**

1695

1696

1697 DS240149.F – but you see if you've got an interactive app, much more
1698 complicated then you must have some sort of scoring system or something
1699 in the end

1700

1701

1702 **Partner – yes**

1703

1704

1705 DS240149.F – and that would be too difficult you know. I think and make
1706 notes when you want to

1707

1708

1709 **I – yeah okay, and what about family and friends, do you think the app**
1710 **could affect the way you talk to family and friends, or other patients?**

1711

1712

1713 DS240149.F – the only way I could see with family and friends went into the
1714 app they had more understanding of what you're going through, because
1715 nobody knows what it's like until

1716
1717
1718 **Partner – I don't see your sister asking questions on an app, or your mother**
1719
1720
1721 DS240149.F – no I mean my family are not interested....they just want to
1722 know that I'm okay...are you alright today? "yeah I'm alright"
1723
1724
1725 **Partner – they do get on with it?**
1726
1727
1728 DS240149.F – they just want to know I'm okay
1729
1730
1731 **Partner – are you alright today? Yeah I'm alright...well that's fine**
1732
1733
1734 DS240149.F – they don't want to know the ins and outs of it you know?
1735
1736
1737 **Partner – but her family are completely different her sister wants to**
1738 **what....**
1739
1740
1741 DS240149.F – so maybe she would find some use for the app
1742
1743
1744 **Partner – oh yes absolutely so there are people who are going to and there**
1745 **are people that are not, but if the availability was there, then most people**
1746 **would use it I'm sure**
1747
1748
1749 **I – okay and what about problems what do you think the problems might**
1750 **be, the barriers in practice?**
1751
1752
1753 DS240149.F – I think sometimes not understanding the information, you
1754 misunderstanding it perhaps can lead to confusion and they may might get
1755 very frightened if as I said you opened up different pages and they've

1756 followed it through, when I found out that I could've died when I went in
1757 over the new year...I was surprised, so if I'd been told

1758

1759

1760 **Partner – you weren't frightened, you were sort of shocked, wow, in fact**
1761 **you were....**

1762

1763

1764 DS240149.F – sometimes it's maybe too intimate it's really to gain...I can't
1765 really answer then. I can't have enough information, but I know from my
1766 experience people don't want a lot of information

1767

1768

1769 **Partner – then they're not going to use the app are they? They won't**
1770 **they'll**

1771

1772

1773 **I – yes exactly**

1774

1775

1776 **Partner – you know they won't, they'll go...or they may open it they may**
1777 **see a little bit and they'll go "okay that's as far as I want to go" Now the**
1778 **people who are going to use it are the ones with a little bit of brain and**
1779 **will want the information**

1780

1781

1782 DS240149.F – I think this business of people thinking that consultants are
1783 God and you have to look up to them, I think that's moved on, I think most
1784 patients want some interaction and want to be part of the decision making

1785

1786

1787 **I – yeah, I think that's...**

1788

1789

1790 DS240149.F – they want to be more in control

1791

1792

1793 **I – yeah okay and do you think that's something that the app can help**
1794 **with?**

1795

1796

1797 **Partner – yes, absolutely**
1798
1799
1800 DS240149.F – I mean you’ve been asked to make a decision about
1801 something incredibly important, what are you basing your knowledge on,
1802 you have no knowledge of this at all
1803
1804
1805 **I – they did they give you a decision aid? So it’s like an A4 piece of paper**
1806 **with the different treatments – they’re making those at Cardiff**
1807 **Universities now they’re very helpful**
1808
1809
1810 **Partner – no, no nothing like that**
1811
1812
1813 DS240149.F – he sat, he had his notes and bit of paper, he went through
1814 them the cancer I had, what type I had, what ops blah, blah, blah...and that
1815 was it
1816
1817
1818 **I – and you had to go away and search all this information?**
1819
1820
1821 DS240149.F – at that point I had no written information at all, I said to her
1822 “can you remember what...” I was in a state of shock, cos I knew I had breast
1823 cancer
1824
1825
1826 **Partner – but you can’t take it all in though**
1827
1828
1829 DS240149.F – you know if <friend> who went through it at the same time as
1830 me, she had no idea, no idea, she went for a mammogram and the person
1831 in the unit said, she’d been shopping of all things had a mammogram in the
1832 morning, it was the first one that she’d ever had in her life and then went
1833 on shopping...and the person, the radiographer said “I’m sorry, but this isn’t
1834 looking good, you look like you’ve got breast cancer” that’s how she was
1835 told! And she went through it blindly, she was really in a bad place wasn’t
1836 she?
1837

1838
1839 **Partner – oh I know, you did this, you...**
1840
1841
1842 **I - that must've been such a shock**
1843
1844
1845 DS240149.F – you see whereas when I went it was...
1846
1847
1848 **Partner – we'd had a week talking about it because...**
1849
1850
1851 DS240149.F – well I had a mammogram, I went to the GP I found my lump,
1852 I had a mammogram and then I had another mammogram 2 days later, so I
1853 knew, on the Friday I knew, so that Monday when he said, I felt like saying...
1854
1855
1856 **Partner – I kept on saying “wait till it's said, once it's said then that'll be**
1857 **okay” but we have to wait until it comes out of his mouth to say yes, cos**
1858 **you always have...**
1859
1860
1861 DS240149.F – and I think a lot of patients hear, yes you have cancer, that's
1862 it, nothing make sense, everything else has gone over the top and that
1863 would be so useful to have something you're going to...this is what we've
1864 discussed, take this away look at it I'm here for you I'll hear for your
1865 questions and that's what you need isn't it
1866
1867
1868 **Partner – we did have that with <district nurse> I have to say she was**
1869 **amazing**
1870
1871
1872 DS240149.F – <district nurse> was the one that did that form
1873
1874
1875 **I – yeah, and at what point did <district nurse> come?**
1876
1877
1878 DS240149.F – she was there when they said to me

1879
1880
1881 **Partner – at the diagnosis**
1882
1883
1884 DS240149.F – I’m sorry you’ve got bad news
1885
1886
1887 **Partner – she was amazing**
1888
1889
1890 DS240149.F – she was sat in with him all that Monday and then he left the
1891 room and she sat with us while I cried and then she said, this is my name
1892 and number when can I come and see you? We said come on Friday you
1893 can have a coffee, she came and she sat with me for about an hour and
1894 a half on that Friday and we discussed everything
1895
1896
1897 **I – yeah, so that was from the Monday to the Friday**
1898
1899
1900 DS240149.F - hmm
1901
1902
1903 **I - so in that time did you have leaflets to take with you?**
1904
1905
1906 **Partner – no, nothing**
1907
1908
1909 **I – no**
1910
1911
1912 **Partner – we were on the internet on the settee we were away trying to**
1913 **find out**
1914
1915
1916 **I - the thing is some people don’t realise that not all the websites have**
1917 **reliable information, so within that time they could’ve found unreliable**
1918 **information**
1919

1920
1921 **Partner – and they might not have remembered correctly what was wrong**
1922 **with them you know**
1923
1924
1925 DS240149.F – yep, did he say I had to have a double mastectomy or...?
1926
1927
1928 **Partner – but you were good you had a bit of paper in your bag, or can I**
1929 **have a bit of paper and you had your pen out and you were writing things**
1930 **down all the time**
1931
1932
1933 DS240149.F – I mean for some reason I can't remember what it was but it
1934 was something about 10% of information is retained, it was something really
1935 small
1936
1937
1938 **I – yeah, yeah**
1939
1940
1941 DS240149.F – yes big words come out medical words come out they don't
1942 understand so that goes over their heads and they don't feel confident in
1943 themselves to....
1944
1945
1946 **Partner – I can remember you saying “what was that again?” and then you**
1947 **wrote it down ((laughs))**
1948
1949
1950 DS240149.F - and you said something and I said “so I don't know what I'm
1951 talking about” to initials you know like MRI
1952
1953
1954 **Partner – I know what an MRI is, but not everybody does, you know**
1955
1956
1957 **I – yes exactly**
1958
1959
1960 **Partner – well we use PRN, BD whatever...you know**

1961
1962 DS240149.F – you do it's just <<inaudible 01:01.12>> and the doctor said
1963 can you....why
1964
1965
1966 **Partner – we didn't stop for a cup of tea ((laughs))**
1967
1968
1969 DS240149.F – and she said “oh that was on the Monday afternoon it wasn't
1970 on the Monday after I tell a lie it was on the Tuesday...” I was hanging up
1971 the washing, no I wasn't hanging out the washing, it was her ((screams)) she
1972 said you just went ((strange noise)) you know that's what's happened....
1973
1974
1975 **Partner – so many people can't get their mind into that sort of order**
1976 **because of fear, not because they are stupid, it' because they are petrified**
1977
1978
1979 **I - yeah just panicking**
1980
1981
1982 **Partner – cancer - death**
1983
1984
1985 **I – Okay, so based on your experiences and everything that has happened,**
1986 **what things should we put in the app?**
1987
1988
1989 DS240149.F – most things
1990
1991
1992 **I – and I know that's a hard question, you've already mentioned things like**
1993 **a staged approach of information, and information on side effects, surgery**
1994 **and that sort of thing**
1995
1996
1997 DS240149.F – I think some of the technical jargon should be explained
1998
1999
2000 **Partner – yes absolutely, yes that would be lovely**
2001

2002

2003 DS240149.F – explaining things like secondary dysplasia, invasive, words I

2004 would use, I mean they’ve heard of

2005

2006

2007 **Partner – the different types of cancer there are, you could just put that in**

2008 **because it was the American sites that we found the explanations for the**

2009 **type of cancer that ((candidate has got))**

2010

2011

2012 **I – yeah, I’m really shocked I see huge gaps of information**

2013

2014

2015 **Partner – huge gaps, huge**

2016

2017

2018 **I – especially with the information you’ve taken away from the hospital as**

2019 **well and it’s not standardised across...**

2020

2021

2022 **Partner – it is absolutely**

2023

2024

2025 DS240149.F – I thought the sort of thing, you know like I know nurse direct,

2026 I know they’ve stopped it and they’ve got that 111 which is but that was a

2027 computer program but half way, chemotherapy, nausea, yes/no

2028 yes...vomiting, yes...and it followed on you know things to help you out, if

2029 you haven’t got vomiting do you miss that bit completely? I mean that’s

2030 quite a useful way of doing....

2031

2032

2033 **Partner – and people like doing those sorts of things don’t they?**

2034

2035

2036 DS240149.F – you know it’s like a quiz almost you know? I mean the leaflet

2037 they gave me in chemotherapy talks about painful hands and feet, I’ve never

2038 had pain in my hands and feet, so I felt much better because I was informed,

2039 but the information should be there and I know you don’t agree with this,

2040 but DVT, DVT and PE I think are so important and I’ve never been told that,

2041 it was only the doctor when I went in she was sitting on the bed talking and

2042 she said “one of the biggest problems is DVT” Patients who have

2043 chemotherapy they're very lethargic and tired they don't move
2044 around...bing...you know. Whereas all you've got to say is they're tired I
2045 know a lot of patients are, I'm lucky I don't have this exhaustion, but some
2046 of them can't get out of bed

2047

2048

2049 **Partner – saying that what were you like last week?**

2050

2051

2052 DS240149.F – oh I'm forgetting

2053

2054

2055 **I – ((laughs))**

2056

2057

2058

2059 DS240149.F – I'm not a bed person, you won't find me in my pyjamas, I'm
2060 not

2061

2062

2063 **Partner – she doesn't like a pyjama day**

2064

2065

2066 DS240149.F – (L) spent the first 5 weeks after surgery in bed! So everybody
2067 is so different, but I really think a glossary would be incredibly useful

2068

2069

2070 **I – Is there anything else can you think of, any other things?**

2071

2072

2073 **Partner – I think all the way through we've been talking about certain**
2074 **things, there isn't anything new**

2075

2076

2077 DS240149.F – I mean the things that could kill you like neutrophenic sepsis
2078 like DVT that should be made more clear

2079

2080

2081 **I – it seems essential**

2082

2083

2084 DS240149.F – have you seen what they’ve given me? this is what I’ve
2085 depended on

2086

2087

2088 **Partner – he did say to her, but if you have everything you may have**
2089 **everything you know just go with the flow and what I’ve been trying to get**
2090 **her to do is to go with the flow, okay it’s important to take your**
2091 **temperature morning and evening and if there are any deviations then**
2092 **that’s important for you to do**

2093

2094

2095 DS240149.F – that’s all the information I have

2096

2097

2098 **I – gosh**

2099

2100

2101 DS240149.F – and these are the things for neutrophenic sepsis if you have
2102 any of these you ring this number here and that’s it and that’s the
2103 information I got, and that is not enough and that the basics

2104

2105

2106 **I - yeah does it even explain neutrophenic sepsis in this**

2107

2108

2109 DS240149.F - no

2110

2111

2112 **Partner – no ((laughs))**

2113

2114

2115 DS240149.F – that was just given to us with a thermometer and told to take
2116 my temperature and they pressed 37.5, 37.5

2117

2118

2119 **Partner – they could’ve made so much more on the talk we had that**
2120 **evening, because we went to get information didn’t we and we came away**
2121 **thinking okay**

2122

2123

2124 DS240149.F – I didn’t learn anything

2125
2126
2127 **Partner – no we didn't but then I did say well that's us, maybe a lot of**
2128 **people came away from there knowing certain things, I don't know**
2129
2130
2131 DS240149.F – one lady in the car park she could hardly work she had some
2132 sort of bowel surgery and she was so ill she didn't take anything in, for her
2133 it was a complete waste of time
2134
2135
2136 **I – Some patients, if they don't understand why they should be doing**
2137 **something they often they often don't do it**
2138
2139
2140 **Partner – well we didn't, and I think she'd vomited quite a few times**
2141 **before I said ((candidate)) this isn't right, you need to ring them and then**
2142 **next thing we knew we were in casualty**
2143
2144
2145 DS240149.F – on the Sunday night when I was feeling like death I took my
2146 temperature and it was 37.5 so I took it with another thermometer and it
2147 was 37.4, because 37.5 is the magic number I went to bed, in the morning I
2148 took my temperature and it was 37.9
2149
2150
2151 **Partner – and I said it's about time now you rang**
2152
2153
2154 DS240149.F – so I was in because they've a....
2155
2156
2157 **Partner – because she wouldn't ring**
2158
2159
2160 DS240149.F – but because I didn't want to go in its 37.4 I don't want to go
2161 in, if I had understood the very important aspect of that I would've gone in
2162 that night
2163
2164
2165 **I - exactly yeah**

2166
2167
2168 DS240149.F – there’s no point in saying 37.5 you have to
2169
2170
2171 **Partner – but they have to give you a cut off don’t they, I mean it’s**
2172 **something that**
2173
2174
2175 DS240149.F – yes but that card is it, that card is all the information
2176
2177
2178 **I – you know that’s unbelievable really**
2179
2180
2181 DS240149.F – but then they’re inundated with information, I mean there’s
2182 no
2183
2184
2185 **Partner – there’s no getting is there? I mean we’ve learned by okay it’s**
2186 **about time you went in now, give them a ring and I’ll walk the dog quickly**
2187 **because I mean we can go**
2188
2189
2190 DS240149.F – and I mean how far? How far do you go? You know do you
2191 frighten everyone to death, you can’t, it’s so tough
2192
2193
2194 **Partner – I’ve just said to her we’ll pack a bag came in and you said “I’m**
2195 **packing a bag” I came in and I said “you’d better pack a bag just in case,**
2196 **we can keep it in the car**
2197
2198
2199 DS240149.F - and I said “I have, I felt poorly”
2200
2201
2202 **Partner – so we were both thinking you know they’re gonna keep her in**
2203
2204
2205 DS240149.F – but even though I felt poorly, I didn’t realise how poorly I was
2206

2207
2208 **I - What about family and friends, do you think there's anything additional**
2209 **we could include in the app for them?**
2210
2211
2212 DS240149.F – I don't think so
2213
2214
2215 **Partner – they will find what they need to find if you do that sort of**
2216 **sequence**
2217
2218
2219 DS240149.F – maybe you could have a bit on the practicalities you know,
2220 sort of try and encourage different food and drinks and...
2221
2222
2223 **Partner – I've tried everything, you name it, I've gone out and bought it**
2224 **((laughs)) try this**
2225
2226
2227 DS240149.F – oh that stuff I bought from America you know it's been a
2228 godsend
2229
2230
2231 **Partner – yes if you think about mouth ulcers we've got soothe gel bonjela**
2232 **that bonjela that stings I've got that one, I think we've got a whole**
2233 **cupboard full of just preparations for mouth ulcers so that she can use**
2234 **that. Whereas they gave you one with that jel okay it's probably**
2235 **expensive, but that helped you a lot**
2236
2237
2238 DS240149.F – that was when I was in the hospital and it was the time that
2239 my mouth ulcers were at their worst because my neutrophils were low and
2240 although I felt horrible and I had bronchitis and I felt dreadful, this mouth
2241 ulcer was driving me nuts and I said to this night nurse "have you got
2242 anything?" "hang on" she said she just popped in on the desk, she'd picked
2243 it up ready it was something like clear gel or something it's called and you
2244 paste it on and it forms a coating and takes the swelling down, I went to
2245 sleep after about 10 minutes
2246
2247

2248 I – oh brilliant
2249
2250
2251 DS240149.F – you know, why didn't you give me that before!
2252
2253
2254 **Partner – well if you knew that in the beginning, you know!**
2255
2256
2257 I – it's so frustrating
2258
2259
2260
2261 **Partner – and constipation, we went into Boots ((laughs))**
2262
2263
2264
2265 DS240149.F – I don't know what this woman though...
2266
2267
2268 **Partner – and we just filled it all, and this woman said "I hope you're not**
2269 **taking these altogether" ((laughs))**
2270
2271
2272 DS240149.F – I need a....
2273
2274
2275 **Partner – so you know you just go into boots and you put them all in....**
2276
2277
2278 DS240149.F – I think normally you don't get constipated, but normal people
2279 don't get constipated do they? But they're giving you something that will
2280 make you constipated. Instead of saying "if you're constipated, they want
2281 to say "before you get constipated, do this"
2282
2283
2284 **Partner – exactly**
2285
2286
2287 I - Is there anything you wouldn't want the app to do?
2288

2289
2290 **Partner – I wouldn't want it to frighten people**
2291
2292
2293 DS240149.F – well it's like this 111 thing they send everybody to A&E
2294 because they can't make a decision, they're not qualified people manning
2295 this line, and 60% of the people that phone in 111 are asked to go to A&E,
2296 so you wouldn't want an app that said you're in danger of dying quick get
2297 into <hospital>, you wouldn't want anything like that, you just want
2298 information, I don't think any action plan really would be good
2299
2300
2301 **Partner – but it's like the temperature of 37 if you've got a temperature**
2302 **at 37 you go in**
2303
2304
2305 DS240149.F – 37.5, 37.5!
2306
2307
2308 **Partner – then don't take another, use the same thermometer all the time.**
2309 **You see I have taken the thermometers away, she's got one thermometer**
2310 **back there**
2311
2312
2313 DS240149.F – I thought it was a cunning and devious plan actually
2314
2315
2316 **I – Okay so my last question, are there any particular types of patient you**
2317 **think would find this technology most useful, so age groups or different**
2318 **points during the cancer?**
2319
2320
2321 DS240149.F - because I'd love to ask patients how much they want to know?
2322 Some patients, they don't they just....
2323
2324
2325 **I – from those I've interviewed so far I'd say about 70-80% want the**
2326 **information and then the rest just want the minimum**
2327
2328
2329 DS240149.F – well that's the thing, you don't want to frighten them

2330
2331
2332 **Partner – and I bet they’re older?**
2333
2334
2335 **I – yeah, yeah, yeah**
2336
2337
2338 **Partner – they’re the older patients that think oh well, what will be, will**
2339 **be, whereas the younger ones want as much information as they can**
2340 **possibly have**
2341
2342
2343 **I – yeah, have a bit of control over it and to...**
2344
2345
2346 **Partner – because you lose total control of your whole lives you know it’s**
2347 **all about, you know hospital appointments, we’ve got a diary with hospital**
2348 **appointments you know, it’s....and the first couple of weeks it was just**
2349 **hospital appointments**
2350
2351
2352 DS240149.F – every other day
2353
2354
2355 **Partner – I just rang work and said “you know actually I’m not going to be**
2356 **there until end of March, put me down for the end of March and I’ll**
2357 **probably come back and do some work ((laughs)) you know**
2358
2359
2360 **I – exactly**
2361
2362
2363 DS240149.F – my concentration I’ve got chemo brain,
2364
2365
2366 **Partner – they call it chemo brain ((laughs))**
2367
2368
2369 DS240149.F - I absolutely can’t remember names, I couldn’t drive long
2370 distance, I’d crash

2371
2372
2373 **Partner – you did try once**
2374
2375
2376 DS240149.F – I came out on my own one day and I realised that I was in a
2377 bad way. I was in the slow lane about 50 mph to couldn't see very, very
2378 clearly I had the air con on cold and the music was loud
2379
2380 **Partner – and she hasn't driven since**
2381
2382
2383 DS240149.F – I was so desperate I didn't know where I was
2384
2385
2386 **Partner – that's okay I drive a BMW ((laughs))**
2387
2388
2389 **I – ((laughs))**
2390
2391
2392 DS240149.F – any excuse, who put petrol in it, I got in it today to go to the
2393 shops and there's no petrol in the car
2394
2395
2396 **I – well that's it really, is there anything else you think we need to cover?**
2397
2398
2399 DS240149.F – no I think it's a great, I think it's a brilliant idea
2400
2401
2402 **Partner – and the sooner you can do it the better**
2403
2404
2405 **I – yes definitely**
2406
2407
2408 DS240149.F – sorry I gabbed on so much
2409
2410
2411 **End of interview. Duration: 1:15:06**

1 **Appendix 17: transcript for P3 John and R3 Helen**

2
3 **I – Right okay, so I'll start with some questions. Can you tell me why you were**
4 **interested in taking part in this study?**

5
6
7 DS240157.M – well basically it's because of the treatment that I've received, it's
8 exceptional and I just feel that if I can do anything to repay in some small way uh that
9 might benefit people, basically that's it

10

11

12 **Wife – from my point of view, there were times during ((candidates)) treatment that**
13 **I felt as you said, you do look things up on the internet and some of it is conflicting,**
14 **some of it is worrying and actually especially if you're being dealt with by <hospital>**
15 **and this app is developed with <hospital> you know that you're dealing with people**
16 **that you're actually physically dealing with, so they're able to help you and I think if**
17 **people other patients, we found that when we used to go down there, other patients**
18 **with similar cancers receiving chemotherapy and you talk and that always helped to**
19 **find out their experiences how they dealt with certain site effects and if that would**
20 **be, if you could have that on an app I think it would be you know a help. I always,**
21 **sometimes I felt it would've been good**

22

23

24

25 DS240157.M – yeah you do get feedback from other people suffering with the same
26 type of illness, I mean and you have people obviously who've suffered with the illness
27 for years, and years, and years, and of course like there are different aspects when you've
28 got the illness, like some people have you know depending on what type of cancer
29 you've got, like uh, you know like people who have a stoma bag attached, some people
30 have got it lifelong, other people like myself hopefully will have it reversed, but then
31 you have other problems which like I have a hernia with it as well, and it's just finding
32 certain ways of dealing with these things, I mean when I first had it I was leaking all over
33 the place wasn't I?

34

35

36 **Wife – yeah but that was not to do with the cancer as such...you know...**

37 DS240157.M – well it's due to the cancer isn't it

38

39

40 **Wife – the app wouldn't help with that**

41

42

43 I – well I see what you mean though, that you wanted information on....
44
45
46 DS240157.M – yeah you know you talk to people oh I’ve done this and the way I dealt
47 with it is this...so you get that information that otherwise...
48
49
50 I – yeah well that was my question actually, so where did you normally get information
51 about the cancer and the side effects was it mainly from doctors?
52
53
54 DS240157.M – well doctors and patients
55
56
57 **Wife – and that was our St David’s Hospice nurse, she’s been really good, you know if**
58 **we couldn’t find something out she would, she would find out for us**
59
60
61 I - oh that’s good
62
63
64 **Wife - yeah I found her marvellous**
65
66
67 DS240157.M – yeah hospice <Nurse> yeah brilliant
68
69
70 I – so when you said you talked to patients, were they the ones that you met at
71 <hospital>?
72
73
74 DS240157.M – yeah
75
76 **Wife - yeah just other patients you’d see, going regularly you see regular faces you**
77 **would get to know people**
78
79
80 I - yeah okay and what about the internet or books or... did you get information there?
81
82

83 DS240157.M - well as we said, they're conflicting aren't they? When you look on the
84 internet
85
86
87 **Wife - I did**
88
89
90 DS240157.M – I mean not all the information on the internet is correct
91
92
93 **Wife - but in all fairness you are told at the beginning, don't look it up on the internet**
94
95
96 **I – ah okay and who told you that?**
97
98
99 **Wife - oh god I can't remember**
100
101
102 DS240157.M – well a few people because of the conflicting reports and that
103
104
105 **Wife - and they said "don't look it up on the internet because you'll consider yourself**
106 **to be....everything"**
107
108
109 DS240157.M – gone ((laughs))
110
111
112 **I – ah I see, so you did look things up <wife>?**
113
114
115 **Wife - you do, you do look things up**
116
117 **I – so did you find that helped you at all?**
118
119
120 **Wife - to some extent yeah**
121
122
123 DS240157.M – to some extent

124
125
126 **Wife - it explained certain things, so it did help in certain ways**
127
128
129 DS240157.M – yeah
130
131
132 **Wife - but I never kept to one site I'd look at a couple**
133
134
135 I – that's what I was going to ask you was there, you know did you use...?
136
137
138 **Wife - a couple of sites yeah**
139
140
141 I - which sites were they?
142
143
144 **Wife - don't ask...I've no idea**
145
146
147 I – ((laughs)) okay so they weren't like Macmillan, or Cancer Research, or...
148
149
150 **Wife - I very rarely use Macmillan to be honest, um, the NHS one basically was the**
151 **one I used more than anything, but then I would go to ones to see if they said the**
152 **same thing...for comparisons, you know**
153
154
155 DS240157.M – make comparisons
156
157
158 I – that seems a sensible way to do it
159
160
161 **Wife - well yeah, it did help, but I mean you would still, at the end of the day you**
162 **would still pick up the phone and phone <hospital> and say look can you...**
163
164

165 I – okay. So did you like to have information about the cancer then?

166

167

168 DS240157.M – well yes, yes because, I mean obviously it helps doesn't it? I mean having
169 cancer is a pretty traumatic thing, when I was first diagnosed with it I was quite blasé
170 about it, I didn't really appreciate the seriousness of having cancer like as never having
171 it before, uh, and then suddenly as time went by before the operation I realised then
172 and um, you then start asking questions, you know, it's a difficult thing, it's one of those
173 things in life that you a....it's difficult to really assess isn't it <Wife>?

174

175

176 Wife - yeah

177

178

179 DS240157.M – you know you....

180

181

182 Wife - it turns your life upside down as you can imagine. It's just uh, everything is
183 different, you know

184

185

186 I – so you like to have information?

187

188

189 Wife - I like to have information yeah because I'm one of these people I like to be
190 prepared you know, because if I want to, if I think, if I read something and they
191 suggested it would be better to have something here, then I would make sure I had
192 something here, in case he went down the route of feeling this way with certain side
193 effects. You know I'd rather him say the chemotherapy that <candidate> had, he um,
194 the drug was Oxaliplatin <candidate> side effects were numbness in his fingers

195

196 DS240157.M – ah I've heard of that yeah, yeah

197

198

199 Wife - with gloves on and sometimes he would get lockjaw as well

200

201

202 DS240157.M – oh when I, this is one of those things yeah, I couldn't understand that,
203 um, if I closed my mouth with nothing in it and I clenched my teeth nothing happened,
204 but as soon as I put food in my mouth to chew it....

205

206
207 **Wife - only initially**
208
209
210 DS240157.M – initially and I’d go...
211
212
213 **Wife - his jaw would lock**
214
215
216 **I - really?**
217
218
219 DS240157.M – yeah
220
221
222 **Wife - and when we asked them about that, now here’s an example, because this was**
223 **not one of the side effects they said that could happen, so we ended up phoning up**
224 **and they said “it is rare, but it can happen” so if you had an app there where a patient**
225 **has said this is what I experienced it would ease that worry a little bit until you manage**
226 **to see the consultant you know**
227
228
229 **I – yeah, yeah because if you’ve not been told that beforehand then I expect....**
230
231
232 DS240157.M – yeah that’s right, but they give you certain things that normally happens,
233 pins and needles uh, tiredness you know the things that normally...
234
235
236 **Wife - but if you remember <candidate> when we went up there, the <clinical nurse>**
237 **he was really good with us wasn’t he, he said about the lockjaw, he said “we’ve got**
238 **one other patient with that” he said and that’s up in <location> wasn’t it? <hospital>**
239 **he said “it is unusual, but it does happen”**
240
241
242 **I – yeah, yeah, well it makes you feel better about it already then doesn’t it?**
243
244
245 DS240157.M – see a lot of people suffer with sickness as well, well I never suffered with
246 sickness

247
248
249 **Wife - you were good you didn't**
250
251
252 DS240157.M – you know so, variables depending on one's metabolism
253
254
255 **Wife - everyone's different**
256
257
258 DS240157.M – everybody's different, well to a certain extent
259
260
261 **I – yeah, yeah, okay. So was there a particular point that you felt that you needed**
262 **more information, either of you?**
263
264
265 DS240157.M – no I think we, I gotta be honest we were kept pretty well up to date on
266 all aspects of the illness um, yeah I can't fault that
267
268
269 **I - that's good, okay**
270
271
272 DS240157.M – and you know when you talk to the surgeon you could ask any question
273 and you know, your answers were given in laymen's terms because sometimes some
274 people can answer questions can't they, and they're using words that you've got no idea
275 what they're on about, but I was given information like with <doctor> you know plain
276 language, which I understood, no messing around you know and I fully understood what
277 he was on about
278
279
280 **I - yeah that's one of the things we're thinking about doing, is putting a glossary of**
281 **medical terms in there, because some patients have said that not all doctors and**
282 **nurses have given information in layman's terms and then it makes it difficult...**
283
284
285 **Wife - that would be a very good idea**
286
287

288 I – then for the patients and family to understand what they’re saying and then
289 they’ve got even more questions then...
290
291
292 **Wife - I mean I found it last year, I, I’m not one to remember medical terms I mean**
293 **I’m on all these tablets and I can’t remember the name of them, people say what are**
294 **you on? And I say oh...**
295
296
297 **I – yeah they’re so complicated**
298
299
300 **Wife– Benzo something or other...but in the last year I know exactly what <candidate>**
301 **takes. I know exactly how many milligrams, I know the name of it what he was on,**
302 **cos now we go in and they say “well what did you have...and what are you on” and**
303 **he says “<Wife>?” ((laughs))**
304
305
306 DS240157.M – I mean you know, basically it is a form of laziness on my behalf, because
307 there’s people like me uh, I’ve got my wife who’s on the ball and she knows everything
308 you know uh in respect of my medical condition you know medication I take you know
309 and uh, yeah there’s another question I mean there’s a lot of blokes like me out there
310 who leaves it up to their partners or their wife or vice versa like you know
311
312
313 **Wife - I think you’ve got enough to contend with**
314
315
316 DS240157.M – thing is it’s a mental state isn’t it?
317
318
319 **I – yeah I expect it really helps to take some of the burden off them so they don’t have**
320 **to remember all this information**
321
322
323 DS240157.M – well that’s right I mean you know especially when you’re undergoing
324 chemo as I said it varies from people I’ve found that um, my uh, sort of um, ((sighs))
325 here we go again see....
326
327
328 **Wife - this is another side effect you get sometimes**

329
330
331 **I - yeah like the concentration**
332
333
334 DS240157.M – yeah, you’ve got a very short span
335
336
337 **I – yeah you can be in the middle of a sentence and then you just can’t remember**
338
339
340 DS240157.M – it just goes blank
341
342
343 **Wife - there’s a gentleman who lives down the road that <candidate> talks to, and**
344 **they’ve got a lot in common they were both in the army and he’s been diagnosed with**
345 **the same cancer as you hasn’t he? and he’s on the same chemo that <candidate> was**
346 **see and he finds, they compare, he says “<candidate> do you find, do uh, oh...”**
347
348
349 DS240157.M – similar yeah, yeah and it just goes, like I used to do crosswords, always
350 doing crosswords I can’t do a crossword now, because my, my... here you are...the...
351
352
353 **Wife - concentration**
354
355
356 DS240157.M – concentration... putting things into perspective as well like as well like
357 you know, in context uh, I just lose it you know it’s peculiar, I’ve never you know and
358 you thing well... you end up shrugging your shoulders and... I’ve got half way through
359 my crossword book and I haven’t touched it see
360
361
362 **I – oh yeah hopefully that, that’ll come back, yeah**
363
364
365 DS240157.M – yeah hopefully
366
367

368 **Wife - well he did say that, he said it could take you know up to 6 months to a year,**
369 **cos I mean <candidate> had 2 major operations in a year and loads of chemotherapy**
370 **so I mean he did have, and he had blood clots**

371

372

373 DS240157.M – I told <interviewer> about that and that was horrendous that was, and
374 in between that, whilst undergoing all that, I had these spasms, remember that night
375 we had to call the ambulance out, I had spasms in my shoulders in my back

376

377

378 **Wife - but they thought he was having a heart attack**

379

380

381 DS240157.M – and I tell you what the pain was horrendous, I mean they put me on a
382 drip of Panacetum and eventually it subsided and the doctor gave me valium/diazepam

383

384

385 **Wife - diazepam**

386

387

388 DS240157.M – but what I'm doing now, I'm not taking them every day, I'm uh
389 alternating you know maybe a day or 2 days off but it petrifies me to think what I went
390 through I mean I was absolutely, I was on the floor and the pain was you know, I just it
391 was peculiar, it's just one of those things, anyway

392

393

394 **I – was that related to the treatment?**

395

396

397 DS240157.M – well I don't know

398

399

400 **Wife - what the doctor said, because it was a spasm, not a muscle but a nerve spasm**
401 **and what he reckons is when he had the bowel operation, because it wasn't long after**
402 **you come home**

403

404

405 DS240157.M – that's right

406

407

408 **Wife - and he reckoned he was there in the operation for some time, he said you don't**
409 **know what position you were in on the operating table and he said "it could be that"**
410 **but because they couldn't when the paramedics come they just didn't....and they**
411 **went "it could be a heart attack let's get him to the hospital" mind you saying that we**
412 **went to <hospital> they said to him they didn't know what it was**
413
414
415 DS240157.M – this doctor was asking questions and...
416
417
418 **Wife - we told him he'd just had the operation he had cancer and basically because I**
419 **know they hoping to link up which would be a brilliant idea, to me it's ridiculous you**
420 **can't go into a hospital and they can't call up your records and see what's wrong with**
421 **you...**
422
423
424 DS240157.M – unless you're in the same NHS isn't it?
425
426
427 **I – oh I know, I....**
428
429
430 DS240157.M – it's terrible that
431
432
433 **Wife - and they didn't have a clue up in <hospital>**
434
435
436 DS240157.M – you can imagine if you're on holiday in North Wales just for example, or
437 something like that and uh, you know how would they get that information, the only
438 way is by making a telephone call and you know answering phones, hospitals are
439 inundated with them, I mean, you know, other than that it's written application isn't it?
440
441
442 **I – yeah I know, it's 2015 and we have the internet, all the things we have now...**
443
444
445 DS240157.M – I know
446
447
448 **Wife - our son in law actually works for the...**

449
450
451 DS240157.M – for the NHS on the computers
452
453
454 **I – oh okay**
455
456
457 **Wife - and he's been doing this project at the moment where what they doing they're**
458 **installing....**
459
460
461 DS240157.M – linking, linking up
462
463
464 **Wife - not the hospitals, but all the GP's**
465
466
467 DS240157.M – all the surgeries
468
469
470 **Wife - but of course now they've had the go ahead, the Welsh Assembly are going to**
471 **put all this money in to making the hospitals able to link up with the GP's**
472
473
474 DS240157.M – you'd think it would be normal wouldn't you? I mean it's...incredible...I
475 just dread to think
476
477
478 **Wife - <hospice nurse> said she can look on the < hospital 1>, but she can't go to**
479 **<hospital2>, she can't look on <hospital2> because the systems are different systems**
480
481
482 DS240157.M – different systems, different health authorities, it's ridiculous anyway
483
484
485 **I – yeah, okay. So communication... how did you find talking to the doctors and nurses**
486 **about the cancer?**
487
488
489 **Wife - good**

490
491
492 DS240157.M - good
493
494
495 **I - how did you feel when you had to ask them questions, was it easy or difficult?**
496
497
498 DS240157.M – no easy, I mean as I said...
499
500
501 **Wife - yeah, and not just the doctors but their secretary's**
502
503
504 DS240157.M – the secretary's, uh the nurses, the consultants, I've been very, very
505 fortunate, I just can't you know I know it sounds, I just can't complain
506
507
508 **I – yeah, oh that's good and what do you think made it so easy to ask them questions**
509 **then?**
510
511
512 DS240157.M – it's their demeanour, you know the way they presented themselves the
513 way they talked, um, and it basically helps a lot doesn't it, if you're taking having a
514 conversation with someone and you've got that response you know, that...it's much
515 easier to open up and ask questions and especially when you're getting the answers
516 which you understand. It's like <doctor> with the blood clots, the way you know he
517 took time to draw diagrams and explain certain things, and I said oh yeah
518
519
520 **Wife - you never felt as though you were....**
521
522
523 DS240157.M – imposing
524
525
526 **Wife - no, you never felt like you were just another one of the sheep, you were made**
527 **to feel as though, yes what you've had and they were caring for you**
528
529
530 **I – yeah oh that's brilliant**

531
532
533 DS240157.M – they were concerned about you
534
535
536 **Wife - they were concerned**
537
538
539 I – that’s really good, yeah because they see so many people every day, every week
540 and some people have said that they felt that sometimes that they were just a
541 ‘number’, so to hear about the care that you’ve had, that’s really good
542
543
544 DS240157.M – yeah I mean, yeah
545
546
547 **Wife - there’s one or two departments but I mean...**
548
549
550 DS240157.M – I’ve had one or two, but like everything else, I mean....
551
552
553 **Wife - the major...especially at <hospital> absolutely brilliant, can’t fault it**
554
555
556 I – most of the people I’ve talked to so far have been from <hospital> and have not
557 had a bad word to say
558
559
560 **Wife - they’re brilliant**
561
562
563 DS240157.M – they’re very professional, put it this way, the professionalism and as you
564 say they see countless, hundreds and thousands of patients in a year and they go
565 through this routine and you know it’s very gratifying you know they treat you...
566
567
568 **Wife - even the staff, you can be walking down the corridor going to the canteen and**
569 **the staff coming the other way and they always got a smile and a hello for you**
570
571

572 I - yeah, it makes a difference

573

574

575 **Wife - they gotta be happy in their job, I mean as far as I'm concerned**

576

577

578 DS240157.M – well they do, the thing is there, they're doing a worthwhile job aren't
579 they, not to say they get reciprocated in uh, financial terms you know in that respect,
580 they do get a lot of satisfaction

581

582

583 **Wife - I do feel sorry for the NHS staff, the actual working staff you know, because**
584 **they're under so much, you know, they are under so much pressure and they do work,**
585 **you know they work their...**

586

587

588 DS240157.M – well the nurses when I was in hospital 12 $\frac{2}{3}$ hours night shift

589

590

591 I – yeah my friend is a nurse I think she...she's on the cardiac ward so she's very busy,
592 she's really feeling pressure and she's really laid back, so for her to be feeling it...

593

594

595 DS240157.M - 12 $\frac{2}{3}$ hours! The question you've got to ask there is this, how can a nurse
596 perform to the same level after 12 $\frac{2}{3}$ hours after 1,2,3, hours that's fair enough, after
597 12 $\frac{2}{3}$ hours can that person whether male or female perform to the same standard as a
598 normal person working normal hours, normal shift. I don't think so

599

600

601 I – yeah, and it can be life threatening consequences if anything goes wrong, they're
602 exhausted coming off nightshifts then going onto dayshifts

603

604

605 **Wife - I really feel for them I do...**

606

607

608 I – yeah it's a problem at the moment isn't it

609

610

611 **Wife - I really do**

612

613
614 **I –okay, so were there any barriers communicating with the doctors and nurses at all?**
615
616
617 DS240157.M - no
618
619
620 **I - and how did you remember all the information about the cancer, did you write**
621 **things down, or rely on memory or...?**
622
623
624 DS240157.M – well sometimes, we, we
625
626
627 **Wife - you relied on me! ((laughs))**
628
629
630 DS240157.M – we did take little notes, I threw them all the way actually I was reading
631 them last night, um, and we were asked one of the things as well with <hospital> I was
632 asked to make notations of certain uh feelings whilst I was undergoing chemo, so I had
633 a little diary day to day and I used to keep notes like if, when I was on uh, medication,
634 how I felt, the side effects, uh and it was like what’s the uh...<wife> them tablets I was
635 taking to give me more energy?
636
637
638 **Wife - the steroids**
639
640
641 DS240157.M – steroids you know like obviously I had the chemo sometimes you’re on
642 a down and then I think it was once ad day, or twice a day I was taking steroids wasn’t
643 it?
644
645
646 **Wife - yeah, and of course they have their side effects**
647
648
649 DS240157.M – they have their side effects, but I noted down after taking the steroids
650 how I felt, so I kept a daily tag for a couple of months on different aspects and the way
651 I felt after taking certain medication, like the chemo medication, uh but the second time
652 I had the chemo it had adverse effects on me, I felt much worse after the second uh
653 than I did after the first sessions

654
655
656 **Wife - not the session you had 4 you were the first time, you yeah...**
657
658
659 DS240157.M – you know what I mean
660
661
662 **Wife – yeah but that was because of saturation**
663
664
665 **I – so how did the day to day diary help you?**
666
667
668 DS240157.M – well
669
670
671 **Wife - you can take that along to your consultation**
672
673
674 DS240157.M – well I could make references
675
676
677 **Wife - which is a bit like if you do react hopefully you'd be able to put it down which**
678 **will remind you to ask a question....**
679
680
681 **I – yeah well another option is to have an electronic diary then where you can put how**
682 **you're feeling on the app so I'm just wondering how did that help you by doing that**
683 **do you think it's something worth putting in the app?**
684
685
686 DS240157.M – well yes because um, whilst undergoing chemo obviously your diet is
687 different especially for people who wear stoma bags I mean there's you can eat and you
688 cannot eat, now unless you actually keep a notation of what you can't and what you can
689 you don't know do you, so by doing this I would like my wife would say we're having so
690 and so and I'd go, look well I had them last time and uh and I was very lose in the...so I
691 had to take Imodium, you know so
692
693
694 **I – you can alter your diet around how you expect to respond to it?**

695
696
697 DS240157.M – yeah
698
699
700 **I – that’s really good okay. So what about family and friends, did you find it easy to**
701 **talk to them about the cancer?**
702
703
704 DS240157.M – um, ((sighs)) yeah difficult at times didn’t I, cos I don’t like imposing uh,
705 not so much imposing but uh....
706
707
708 **Wife - it’s strange really because um, certain friends yes you could tell and they would**
709 **be concerned and they would phone to see how things were, and then you’d get other**
710 **friends you’d mention it to and you tell them and you never saw them again, and you**
711 **can understand that they don’t know how to deal with it, or they can’t face it so if you**
712 **could say to them, if you want to know more, there is an app, so they could read it**
713 **might help them as well**
714
715
716 DS240157.M – yeah it’s a question with family as well, you don’t want to, like people
717 will say “how are you today?”
718
719
720 **Wife - we’re not a big family really are we?**
721
722
723 DS240157.M – no, no we’re not. You know you don’t want to go into the depths of your
724 problem you’d say, “not too bad” when you really wasn’t too bad, you were feeling
725 pretty crappy like you know, uh so that’s part of the difficulty of answering questions,
726 it’s depending like and how one felt when they asked you as well, this is the thing, you
727 know if you felt quite buoyant uh, yeah I feel great today like you know, but when you
728 wasn’t up to that standard yeah I’m alright....which they deduced then by you saying
729 that then – yeah he’s not on top form today like they just left it as it was
730
731
732 **I - okay. So talking about the technology then, so have you used, so you’re familiar**
733 **with apps but have you used a smart phone or a tablet computer like an Ipad or Iphone**
734 **before?**
735

736
737 **Wife - yeah**
738
739
740 **I – you do have one, so what’s that?**
741
742
743 **Wife - an Ipad and an Iphone**
744
745
746 **I – okay and what about yourself <candidate>?**
747
748
749 **Wife - he’s got a fire a kindle fire**
750
751
752 **I – oh okay**
753
754
755 DS240157.M – yeah but don’t ask me anything about computers please, no I’m not
756 being ignorant or...I’m a dinosaur when it comes to...you know
757
758
759 **I – no, it’s not, they’re not for everybody, this is what is interesting... to ask... because**
760 **not everyone is going to want to use this app**
761
762
763 DS240157.M – but I mean my <daughter> my daughter and with our son in law they’re
764 all on the ball even the grandchildren they just lose me
765
766
767 **I – yeah okay, so is there any reason then that you don’t like these sorts of devices?**
768
769
770 **Wife - he’s afraid of technology, he doesn’t want to learn – it is the truth!**
771
772
773 DS240157.M – well I think it’s laziness personally
774
775
776 **Wife - you just can’t be bothered**

777
778
779 DS240157.M – well ironically when I was in the army I was a data telegraphist
780
781
782 I - wow...yeah
783
784
785 DS240157.M – ((laughs)) so we had computers the size of that armchair
786
787
788 I – yeah wow
789
790
791 DS240157.M – but I just got to the stage oh I don't know I just
792
793
794 **Wife - oh there's another one now stop it ((talking to the pet)) she's losing her teeth**
795
796
797 DS240157.M - but you do you know I don't know as I've got older I've got a bit lazy, not
798 lazy in physical things to do....
799
800
801 I – no, no I know what you mean
802
803
804 DS240157.M – in certain mental aptitude I just...I just give it to the wife
805
806
807 **Wife - it started when we got a video recorder...he didn't want to know how to use**
808 **that either**
809
810
811 DS240157.M – the what?
812
813
814 **Wife - – video recorder**
815
816
817 DS240157.M – I can't do that either

818
819
820 **Wife - we don't have them anymore**
821
822
823 **I – so what about yourself <wife> what sort of things do you use the Ipad and Iphone**
824 **for?**
825
826
827 **Wife - ooooh**
828
829
830 **DS240157.M - everything**
831
832
833 **Wife - I use it quite a lot, shopping, finance, news yeah, I do use it, games ((laughs))**
834
835
836 **DS240157.M – yeah you're brilliant at it you know I got to be honest**
837
838
839 **Wife - it's brilliant I do find it useful and my reading I can you know**
840
841
842 **I – and have you ever used an app to do with your health or <candidate> health?**
843
844
845 **Wife - yeah**
846
847
848 **I – what sort of apps have you used?**
849
850
851 **Wife - well the NHS more than anything, it was like yesterday I looked up last night I**
852 **told you because our daughter's got diabetic neuropathy and um I thought I'll have a**
853 **look, and I look it up to see on a couple of websites what they had to say about it,**
854 **compare what they say**
855
856
857 **I – yeah okay**
858

859

860 **Wife - my first port of call is normally the NHS one yeah**

861

862

863 **I – yeah it’s a pretty safe one. So the type of app we’ve talked about do you think**
864 **patients with cancer would want to use this type of app?**

865

866

867 DS240157.M – well I think the question there is

868

869

870 **Wife - yes**

871

872

873 DS240157.M – the type it’s a type of person

874

875

876 **I - yes so for yourself then <candidate> do you think if it was available do you think**
877 **you would download it and try to use it**

878

879

880 DS240157.M – yes, because if you’ve got information there which would shall we say
881 alleviate certain problems, I mean sometimes you don’t, you get this feeling and you
882 don’t know what it’s about, looking at the app and it might not turn out as bad as one
883 expects – yeah? So in that way it’s a great thing, vice versa though

884

885

886 **Wife - when you’re sat with my husband you’ll just assume by looking on the app**
887 **what you’re looking for is a safe escape, so that I feel this, or this is wrong I look on**
888 **the app and that’ll tell me everything is alright, it doesn’t always work like that**

889

890

891 DS240157.M – well no that’s what I just said vice versa

892

893

894 **Wife - but then if you have got more, you know yourself if you did have more worries**
895 **from that stage you would just phone <hospital> wouldn’t you?**

896

897

898 DS240157.M – oh yeah, yeah, yeah well that would give you some indication then
899 wouldn’t it that things weren’t as they should be

900
901
902 **Wife - I think I would use it more than ((candidate)) would**
903
904
905 **I – yeah yes so I was going to say what about family and friends, do you think they’d**
906 **use the app?**
907
908
909 **Wife - yes I think family and friends would**
910
911
912 DS240157.M – <son> yeah <son> would
913
914
915 **Wife - <son> partner would as well**
916
917
918 DS240157.M – and <son> partner yeah <son> would as well
919
920
921 **Wife - I think it’s down to the individual if you’re that way, if you’ve got as you said**
922 **the technology and you’ve got the equipment then yeah you would, cos as I said if**
923 **you’ve got that device in front of you, even though they’ve said to you “don’t look it**
924 **up on the internet” you’re going to that’s the first thing...**
925
926
927 **I – so it’s you’re saying if you can have something that you can trust?**
928
929
930 **Wife - exactly**
931
932
933 **I – okay so what about training do you think it would be useful if patients had training**
934 **to use the app? Do you think they’d need it?**
935
936
937 **Wife - now that might, well you can’t really say that until it comes out can you, you**
938 **see, but it would be....**
939
940

941 I – I mean for someone like <candidate>, so he's not as experienced as yourself do you
942 think that could help?

943

944

945 **Wife - yeah**

946

947

948 DS240157.M – well yeah I mean

949

950

951 **Wife - even when you're diagnosed as cos initially you know when you're diagnosed**
952 **are sort of bombarded with this, that and the other and different leaflets and maybe**
953 **say on your first visit to <hospital> you know there's someone there who can explain**
954 **this to you and show it to you, once the initial shock has calmed down, I think for a**
955 **patient it would be helpful yeah**

956

957

958 DS240157.M – and, and of course at the end of the day, it's the mental state of the
959 individual isn't it? You know you have positive and you have negative and you know as
960 I said like you know, if you are, and I truly believe that if you are positive in your outlook
961 it goes a long way to make you better quicker and without a doubt

962

963

964 **I – yeah it gives you a better quality of life**

965

966

967 DS240157.M – well if you want to sit on your bum all day and just think about what's
968 happening I mean, that's no good

969

970

971 **I - no exactly**

972

973

974 DS240157.M – you've got to get up you know, alleviate the old problem in the mind,
975 find something different to do and it without a doubt it helps

976

977

978 **Wife - I tell you what I think would be helpful as well is if there was something on**
979 **there for family, immediate partners where you could share experiences, or maybe**
980 **chat to other people, because if you know what I mean you're, I've been strong for**
981 **<candidate> and doing everything for <candidate> but then you get those moments**

982 when I'm on my own, and you do think down the wrong way and you get worried, and
983 have concerns and then I don't want to go to him with it
984
985
986 I – yeah, so who do you talk to?
987
988
989 Wife - exactly and I did find that was, you know
990
991
992 I – yeah so there are support groups for relatives, or chat forums, or did you ever use
993 anything like that?
994
995
996 Wife - no, no I wasn't aware that there, there was anything I mean support, going to
997 actually see someone that wouldn't have worked because I was so involved with
998 <candidate> back and forth, but to maybe pickup of an evening and talk to someone,
999 I mean it's like, I know I could talk to my daughter but I know she's going through the
1000 same thing as me
1001
1002
1003 I – yeah so perhaps having someone external to the whole situation?
1004
1005
1006 Wife - yes
1007
1008
1009 I – so yes, so you said that you know you're quite busy so you wouldn't maybe be able
1010 to get to one of those groups, so do you think that a smart phone then...the app, if we
1011 could link you with something that's online and you don't have to leave the house...
1012
1013
1014 Wife - I think it would be good yeah
1015
1016
1017 I – okay, that's a really good point. Right where am I, yes so right would you have any
1018 concerns about the app at all?
1019
1020
1021 DS240157.M – in what way?
1022

1023

1024 I - well I mean some patients have said "I don't trust that type of technology" others
1025 have said "you know I'm worried that there will be too much information and that
1026 could worry patients", or....

1027

1028

1029 **Wife - that's the chance you've got to take, that's life, you know...if you are concerned**
1030 **about what's on there if you think that there's too much information and you're**
1031 **worried by it, it's like you said if what they say on the app is not what you want to**
1032 **here, you are gonna be worried by it, so your next step is to phone your consultant,**
1033 **or phone hospital<1> they've always got time for you**

1034

1035

1036 I – well what I've been thinking from the rest of the interviews what's coming out is
1037 some patients are saying "okay, well you can avoid that problem perhaps, not by
1038 putting the information in the app", but by perhaps signposting patients to external
1039 information, so if you want information on this treatment for this type of cancer
1040 there's a good section on the Macmillan website and you can put the link, click on that
1041 and it takes you there...

1042

1043

1044 **Wife - yes but I always feel, I always feel when you go to an app and it gives you a link**
1045 **to another site, that sometimes as you said, for want of a better expression, their**
1046 **passing the buck, you want, I mean the fact that this app is gonna be something, cos**
1047 **it will be locally I take it won't it? It'll be something I would feel more inclined to trust**
1048 **that app**

1049

1050

1051 I - yeah than the website

1052

1053

1054 **Wife - than a bigger app, and if I did have any concerns I would just phone**

1055

1056

1057 DS240157.M – well yeah I mean that's right, I'm thinking with some of these apps I mean
1058 you got so many variables, so many different peoples' opinion on a particular subject
1059 haven't you I mean and that could be quite conflicted as well couldn't it? You know if
1060 you wanna go through it and you see people...well so and so says this, and you look at
1061 the next one and the other one....you know sort've says something totally different, cos
1062 that's their own opinion on a particular subject, but if you've got an app like that which
1063 is quite direct, this is what etc., et., and it's straightforward isn't it?

1064
1065
1066 I – yeah I think my other concern is that there is so many different types of cancer, so
1067 much information, how would we pack that into one app you know I mean that's
1068 another issue we've got
1069
1070
1071 **Wife - yeah there is that about it**
1072
1073
1074 DS240157.M – well, I think you'd have to well, yeah, how would you deal with it...?
1075 Other than you'd have to categorise each different type of cancer, and it's like it just
1076 asked you know on the question form bowel cancer it doesn't say bowel cancer on
1077 there, it says urological, or whatever it is....
1078
1079
1080 DS240157.M – well what I'm saying is it doesn't I want to ask the question in medical
1081 terms what type of cancer is this then like...?
1082
1083
1084 **Wife - colon**
1085
1086
1087 DS240157.M – well you know I mean you could say bowel cancer, well everybody knows
1088 then what bowel cancer is, lung cancer do you follow what I mean, that would be
1089 straightforward rather than....these medical terms related to cancer, well what type of
1090 cancer? Like you know people get lost....
1091
1092
1093 I – yeah, use like the most common names, yeah
1094
1095
1096 DS240157.M – yeah, yeah you know layman's sort of terms as we've said before
1097
1098
1099 I – so what about other concerns do you have any other concerns?
1100
1101
1102 **Wife - not really no, my personal opinion is I think it would be a good thing, it would**
1103 **be a help, it would be a tool to help you**
1104

1105
1106 **I - yeah it's not meant to replace anything, or be the be all and end all, it's just an**
1107 **extra additional tool isn't it?**
1108
1109
1110 **Wife - exactly yeah**
1111
1112
1113 **I – so what benefits do you think there might be for patients using an app like this?**
1114
1115
1116 DS240157.M – well if we look at it from the point of view that with a certain type of
1117 cancer you know, for arguments sake um, the information you're given is maybe
1118 undergoing chemo, this might last for 6 months, uh some people it might be longer,
1119 some people it might be less, you know after a period of time you might be a bit you
1120 know I'm still feeling rather lethargic ur, airy fairy and you might want to look up and
1121 see how generally a generalisation about how people feel after undergoing chemo
1122 because people feel different ways don't they? And it might, by doing that you might
1123 feel oh, well yeah it's a general thing and it could last 6-9 months whatever it takes
1124 maybe, will it eventually be eradicated? This feeling like, will it eventually go? You know
1125 I mean it does, I, in the morning in I <wife>? Even now I'm absolutely terrible in the
1126 morning and usually I used to get up and I used to annoy her to hell because I used to
1127 get up and sing and whistle, didn't I?
1128
1129
1130 **Wife - It takes me 2 hours to come around ((laughs))**
1131
1132
1133 DS240157.M – you know I, I honestly I mean totally revered to what I used to be like
1134
1135
1136 **I – so you think that app then could help to see if these sort of effects are normal, and**
1137 **how long they last?**
1138
1139
1140 DS240157.M – that's right you know
1141
1142
1143 **Wife - you know if patients share experiences and....**
1144
1145

1146 DS240157.M – like I talked to <friend> the bloke who was in the army who's got....and
1147 yeah we can talk about certain things and we understand exactly because we're sharing
1148 the same of type of feeling and I've noticed when he's talking he's like me, he's half way
1149 through a conversation and he go's boing...! it's a blank spot you know, how are you
1150 feeling <friend>? Uh you know, a bit sort of....and then the next day you see him he's a
1151 bit more buoyant, so there's a fluctuation in feelings

1152

1153

1154 **Wife - and he's only 45**

1155

1156

1157 **I – oh gosh really**

1158

1159

1160 DS240157.M – pardon?

1161

1162

1163 **Wife - he's only 45**

1164

1165

1166 DS240157.M - yeah

1167

1168

1169 **I - so what about, <wife> you mentioned that it would be good for you to talk to other,**
1170 **like immediate family of partners who've got cancer, so what about for yourself do**
1171 **you think it would be good if you were able... I mean you've met people down**
1172 **<hospital> and you said that helps, so what about having the app to maybe link to**
1173 **other patients or you know with, with similar cancers, do you think that would be a**
1174 **help to some patients?**

1175

1176

1177 DS240157.M – it might be for some patients, I like, again you're talking about the
1178 individual I mean, I don't like, I like keeping things to myself basically, can you
1179 understand that, I, I, I am not one for really sharing other than with the person I know

1180

1181

1182 **I – yeah, yeah, but what I mean is because you've got your friend who is fairly close**
1183 **by, you're able to see him face to face, some patients might not have that, so perhaps**
1184 **for them they could use the app as a way to contact someone, you know make a friend**
1185 **who has something similar**

1186

1187
1188 DS240157.M – well with some people it might, it wouldn't uh, that wouldn't apply to
1189 myself, but it might do with other people....
1190
1191
1192 **Wife - that's because that's you....**
1193
1194
1195 DS240157.M – pardon
1196
1197
1198 **Wife - that's because that's you....**
1199
1200
1201 DS240157.M – well exactly, that's what I'm saying you know we're individual aren't we,
1202 I don't like sharing you know I'm very sort of secular in my way of thinking, in I, I'm quite
1203 closed...
1204
1205
1206 **I – yea, yea. I'm thinking the app could be a way to set people up with a network of**
1207 **you know people who have the same thing, just to say "how are you feeling" you**
1208 **know the same sort of thing that, it won't be the same thing because you've known**
1209 **him a while and you see him face to face, but just to give them the opportunity if they**
1210 **wanted to**
1211
1212
1213 DS240157.M – well as I said, with certain people, yeah I mean there's people who
1214 haven't got family
1215
1216
1217 **I – yeah exactly**
1218
1219
1220 DS240157.M – there's people who haven't got you know and they're...they are basically
1221 alone, people like that I think it would be a benefit because at least they've got someone
1222 to contact
1223
1224
1225 **I – yeah exactly yeah and what about clinicians the doctors and nurses, what benefits**
1226 **do you think they could get if patients are using an app?**
1227

1228
1229 **Wife - well once again it's like um, I said about the clinical nurse<1> he was able to**
1230 **say that he, there was another patient of his up...so we can see if someone else is**
1231 **experiencing the same, um, maybe somebody isn't experiencing it, maybe it's only**
1232 **one person so then they can look into it further, I think it can help with somebody's**
1233 **recovery, somebody's treatment, if they can see how other people are feeling**
1234
1235
1236 **I – what doctors, so they'd be able to look at the app and see from the electronic diary,**
1237 **the symptoms is that what you mean?**
1238
1239
1240 **Wife - yeah it could do**
1241
1242
1243 **I - yeah so if patients are recording how they're feeling on the app and the doctors**
1244 **can have a look, yeah**
1245
1246
1247 **Wife - it could help in the future towards**
1248
1249
1250 **DS240157.M – yeah, I mean it's....**
1251
1252
1253 **I – yeah, they could collect some data and things...**
1254
1255
1256 **DS240157.M – I mean there are variables aren't there? You know in the way different**
1257 **people feel**
1258
1259
1260 **Wife - absolutely**
1261
1262
1263 **DS240157.M – you know I mean unbeknown sort've symptoms like, like giddiness I used**
1264 **to suffer with giddiness terrible and I still do, and it's a long term affect probably the**
1265 **chemo, well I suspect it's the chemo anyway, but um, yeah I mean, does anybody else**
1266 **suffer from it?**
1267
1268

1269 I – you know, symptoms just the side effects are so different, there’s so many random
1270 things that you would never think was a side effect
1271
1272
1273 **Wife - yeah I know, it’s like when you had to take the steroids, now the steroids they**
1274 **make the skin very, very fine...and he’d only have to....**
1275
1276
1277 DS240157.M – touch myself and I...
1278
1279
1280 **Wife - touch himself and**
1281
1282
1283 DS240157.M – I still got them now, I still get, but I don’t suffer with them so bad
1284
1285
1286 **Wife - I thought he was patched up to hell with plasters everywhere**
1287
1288
1289 DS240157.M – plasters all over my hands, I’d just touch something and I, the skin would
1290 break and of course you’ve then got to be careful of infection, so you know it’s
1291 germolene, uh alcohol wipes, germolene and plasters, I used to have plasters all up my
1292 arms down my legs...! You know so do other people suffer with it? Some people do
1293 some people don’t
1294
1295
1296 I – yeah. So what about family and friends how do you think they could benefit from
1297 using the app?
1298
1299
1300 **Wife - well I think as I said some friends and family find it difficult to talk to you, they**
1301 **don’t know what to say to you**
1302
1303
1304 DS240157.M – yeah that’s a....
1305
1306
1307 **Wife - and if they had the ability to look at the app, they could find out, I mean not**
1308 **reading peoples’ diaries or whatever, but...**
1309

1310
1311 I – yeah I know, that would be confidential
1312
1313
1314 **Wife - exactly yeah, they could see the general of what to expect, how the progression**
1315 **would go, what’s to be expected, or what could happen from side effects, and I think**
1316 **it would help yeah**
1317
1318
1319 I - and do you think the app could affect then the way family and friends talk to each
1320 other about it, do you think that would help?
1321
1322
1323 **Wife - yes I think it would be more open and not...**
1324
1325
1326 DS240157.M – it would give them more understanding wouldn’t it?
1327
1328
1329 **Wife - yeah more confidence, not worry about**
1330
1331
1332 DS240157.M – that’s what I think, it’s like I said when the sons, when our son’s phone
1333 us up and they say “how are you dad?” and you go...you know you don’t wanna say “oh
1334 I feel shitty today like...” and all this like, I mean it puts a worry on them doesn’t it
1335 then...you know it’s very conflicting
1336
1337
1338 I - so perhaps if they could have more of an understanding
1339
1340
1341 DS240157.M – yeah they could look and then say “ah yeah it’s not too bad” even though
1342 he feels that way, or she feels that way, uh you know things are progressing as normal
1343 like you know
1344
1345
1346 I – okay so what about doctors and nurses do you think the app could help with the
1347 way patients talk to the doctors and nurses, do you think it could help, or do you think
1348 it could make it more difficult?
1349
1350

1351 **Wife - yeah, no I think it could help**
1352
1353
1354 DS240157.M – I mean it's one of those situations like you go to the doctors and you've
1355 just read an app, looked up the app on certain, and you're talking to the doctor um, I
1356 suppose you've got to be careful what you say really, it's like you're taking over the
1357 job...((laughs)) doctors opinion like, do you follow what I mean?
1358
1359
1360 **I – yeah, yeah so...**
1361
1362
1363 DS240157.M – this is one of the things that you've got to be careful off...."well I've read
1364 on the app that so and so has said..." you know the doctor might have a different, a
1365 totally different opinion
1366
1367
1368 **Wife - yeah there is that side you know...**
1369
1370
1371 DS240157.M – that's one of the problems like you know
1372
1373
1374 **Wife - people do that now don't they, they go to the doctor and say "look I've self**
1375 **diagnosed myself, I've got this, I've looked on the net"**
1376
1377
1378 DS240157.M – and the doctor you know has got a totally different opinion exactly
1379 what's going on with the person, I mean generally the GP has got a finger on the pulse
1380 haven't they, if they are good GP's you know, they know your medical history and that's
1381 one of the things you've got to be careful of I think is passing your opinion onto them
1382
1383
1384 **I – yeah cos I think one of the things this app could do is, so for those patients who are**
1385 **not very vocal at their appointments and they tend just let the doctor do the talking,**
1386 **you know even if they've got questions, it's trying to give patients a bit of confidence**
1387 **to speak up and say well I want to ask this, but then there is, you are sort've changing**
1388 **the dynamic of the consultation then, because typically it's the doctor dictating isn't**
1389 **it?**
1390
1391

1392 DS240157.M – yeah, I mean exactly, exactly yeah
1393
1394
1395 **I - you know that's what we're trying to push for now you know in healthcare at the**
1396 **moment is to get a level playing field then, so the you know what's important to the**
1397 **patient becomes important to the doctor, but the doctor doesn't know how the**
1398 **patient is feeling if the patient doesn't tell them so...it's trying to give them a bit of**
1399 **confidence I suppose**
1400
1401
1402 DS240157.M – yeah you could take that to the extremes can't you uh, where some
1403 people by reading the app would might play on what he or she is reading and making
1404 the symptoms worse than they really are...
1405
1406
1407 **Wife - you're always going to have that though, it's going to be, I mean there's nothing**
1408 **that's a 100% useful, good and wonderful, there's always going to be that element the**
1409 **downside to something, the negative side**
1410
1411
1412 DS240157.M – yeah
1413
1414
1415 **Wife - but overall I think it would be helpful and a good thing**
1416
1417
1418 DS240157.M – I mean as I say, if you're getting information which is relevant, it's
1419 excellent
1420
1421
1422 **Wife - and these doctors I mean, well we're luck, the one's we've dealt with they**
1423 **aren't stupid, I mean they'd know if somebody was going in and....**
1424
1425
1426 DS240157.M – not in all cases <wife>, not in all cases, people can play on uh, on factors
1427 which are not really relevant to their condition and the doctor has got to take notice of
1428 that haven't they?
1429
1430
1431 **I – yeah, yeah, yeah**
1432

1433
1434 DS240157.M – this is the thing
1435
1436
1437 I – so can you think of any problems with this app in practice? Or any problems at all
1438 really, can you foresee any?
1439
1440
1441 **Wife - no, because I think whatever problems you get, I mean you're going to get from**
1442 **any app you're gonna it's....**
1443
1444
1445 DS240157.M – it's up to the individual how they determine it and how they actually
1446 read and understand what they're reading
1447
1448
1449 **Wife - as <candidate> just said you'll get these people that will read it and ooooooh...**
1450 **you know and then you'll get people who'll find it useful. I think myself that it'll be a**
1451 **high percentage of people that will find it useful, those who are used to technology**
1452 **and using things. I would trust, as I said I personally would trust an app that is local**
1453 **that comes from <hospital> more than I would trust an app from somebody who I**
1454 **didn't know, who they were apart from NHS, but even saying that sometimes the NHS**
1455 **you can, oh well you know**
1456
1457
1458 I – yeah sometimes it's a bit...
1459
1460
1461 **Wife - exactly**
1462
1463
1464 I – okay so what sort of things would you like the app to do?
1465
1466
1467 **Wife - well everything really ((laughs)) no, I mean**
1468
1469
1470 I - I mean we've covered a few things but...
1471
1472

1473 **Wife - yeah everything that we've said previously basically to be able to go through**
1474 **like a medical dictionary as you said a glossary, be able to give you a diary you could**
1475 **follow, shared experiences with other patients, um, side effects of different things you**
1476 **know like you could say you've had that and they could say well I've had that, useful**
1477 **things that are basically say what each and as you said I know it's gonna be a lot,**
1478 **there's so many different cancers, but if they could sort've dilute it down and like the**
1479 **colorectal cancer and you could have bowel cancer uh like a side effect. I read the**
1480 **side effects from uh first bowel cancer is secondary lung cancer, which is what you've**
1481 **got, and things like that I found helpful, I mean it's what they wanted to determine**
1482 **they found the bowel cancer, and when they found on the lung because of where it**
1483 **was situated they couldn't take a biopsy, so until they removed it they didn't know**
1484 **whether it was primary, or a secondary because you can get secondary's from bowel**
1485 **cancer**

1486

1487

1488 **I – oh I didn't know that**

1489

1490

1491 **Wife - no until I read the NHS app I didn't know that either, so things like that I think**
1492 **are helpful**

1493

1494

1495 DS240157.M – and that was reassuring

1496

1497

1498 **Wife - that's to make you...it's to make you basically understand what you or your**
1499 **partners condition is, and how to deal with it**

1500

1501

1502 DS240157.M – I mean anything relating to cancer in that respect, it's like the question
1503 we've got now with the surgeon concerning my blood clots, question is do I still want
1504 the reversal? You know that you suffer with blood clots, uh and this can be fatal, now
1505 using the word fatal, you know, so I know the problems or the possible problems that
1506 might occur, but I still prefer to have the stoma bag or the stoma reversed

1507

1508

1509 **Wife - but he wouldn't be a good doctor if he wasn't pointing out the risks**

1510

1511

1512 DS240157.M – no but then you know then the risks that you're taking

1513

1514

1515 **Wife - I tell you something else I used to find useful, is when we knew we were dealing**

1516 **with a new consultant or doctor I'd look them up on the app on the internet as well**

1517

1518

1519 DS240157.M – and find out peoples' opinion

1520

1521

1522 **Wife - you know and find out what they've done they're coming here I've found that**

1523 **quite reassuring**

1524

1525

1526 **I – yeah that's a really good idea**

1527

1528

1529 DS240157.M – aw when we looked up um, yeah you're right it...it's and the man is

1530 brilliant

1531

1532

1533 **Wife - I mean it's like <doctor> now, I mean alright he hasn't phoned, but you can't**

1534 **be angry at him because if you knew how busy he is, and how he treats his patients**

1535

1536

1537 DS240157.M – I was telling <interviewer> he used to come in on the weekend, on a

1538 Saturday and Sunday sit on the bed and go and he'd look at my catheter and one thing

1539 and the other I had all these things stuck in me all over the place

1540

1541

1542 **Wife - half past seven every morning he was there and he was immaculate**

1543 **absolutely....**

1544

1545

1546 DS240157.M – it's getting a nice strawberry colour now he's say with my, not my

1547 catheter, I had a catheter I had another drain thing like "yeah that's getting a nice colour

1548 that is" and then you know he came in and said "yeah we can have that one out"

1549

1550

1551 **Wife - his care and consideration was unbelievable and I mean uh, <doctor> has spent,**

1552 **he's done a lot of work abroad as well voluntary work, with prostate cancer and things**

1553 **like that, he's well respected and to be able to look at that, that gives you confidence**

1554 **as well you know**

1555
1556
1557 **I - yeah, yeah exactly**
1558
1559
1560 **Wife - well you've got a good job here <candidate> he's gonna do a good job**
1561
1562
1563 DS240157.M – yeah I mean that, that helped a lot that did
1564
1565
1566 **I – yeah no one's mentioned that, that's a really good idea**
1567
1568
1569 DS240157.M – yeah that helped a lot, it give you I mean to undergo an operation it's
1570 quite traumatic unless you know I mean it's okay going back a couple of years people
1571 talked about operations and you'd go....you know, but once you've gone and had to go
1572 through that experience you know you're thinking there like you know uh
1573
1574
1575 **I - you wanna know you've got someone good**
1576
1577
1578 DS240157.M – yeah you know am I gonna come out of this or, you know I mean things
1579 go through your mind
1580
1581
1582 **Wife - well it's just, it's just nice to know what that person, I mean at the end of the**
1583 **day you're putting your life in that person's hands, so you want to know about them...I**
1584 **did anyway you know**
1585
1586
1587 DS240157.M – it gives you confidence doesn't it? And confidence is a big part of
1588 everything you know, yeah
1589
1590
1591 **I – so what about family and friends is there anything the app can do to help them**
1592 **above what we've talked about?**
1593
1594
1595 **Wife - not really well I mean we've covered it there I think you know it's uh....**

1596
1597
1598 **I – and is there anything you wouldn't want the app to do?**
1599
1600
1601 DS240157.M – well I mean as long as it keeps confidentiality, which is I think absolutely
1602 imperative, I mean certain things slip past the old uh marker at times, um, yeah I think
1603 that's generally that's the most important thing confidentiality is not in any way
1604 breached, you know
1605
1606
1607 **I – yeah, okay. So the last question is are there any particular types of patient might**
1608 **find the app most useful so perhaps different age groups, or patients at different**
1609 **stages of the cancer, so you've got diagnosis, treatment, post-treatment, or do you**
1610 **think it could be useful throughout the whole thing?**
1611
1612
1613 DS240157.M – oh basically <interviewer> it would have to go through the whole thing,
1614 because even after you know, post operation, post cancer, I mean don't forget you're
1615 not cleared I think it's 5 years, uh so sometimes you might want to find out generally uh
1616 you might have sort've a down period 2 or 3 years later you know, um, how do people
1617 go through this, how do they deal with it?
1618
1619
1620 **I – so you've still got questions then yeah?**
1621
1622
1623 DS240157.M – yeah you know, it's always that thing, you just don't know, once you've
1624 had it you just don't know, people have been in remission for years great and then
1625 suddenly, we lost our grandson he was only 7½ years of age
1626
1627
1628 **I - oh gosh really?**
1629
1630
1631 DS240157.M – oh yeah and he was in remission
1632
1633
1634 **I – oh that's awful**
1635
1636

1637 DS240157.M – and everything was looking hunky dorey and he come back from Florida
1638 he had a relapse at 7½ years of age, and so you know, I suppose we didn't have that
1639 information this is going back, he would've been how old would he have been now
1640 mamma...21?

1641

1642

1643 **Wife - 25 this year**

1644

1645

1646 DS240157.M – 25 this year, so you're going back 20 years virtually like so I mean a lot's
1647 happened in 20 years hasn't it?

1648

1649

1650 **I – yeah, yeah it has**

1651

1652

1653 DS240157.M – you know progress you know so as I said like they didn't have, there's
1654 more people now surviving, there's well there's 50% more people surviving now than
1655 they were 20 years ago

1656

1657

1658 **I – yeah I think... It's all about catching it in time now isn't it, if you catch it in time**
1659 **you've got a great chance**

1660

1661

1662 DS240157.M – I was actually, I mean my GP I mean, brilliant and it was you know, and
1663 that was virtually operation....((laughs))

1664

1665

1666 **Wife - having the colonoscopy he had**

1667

1668

1669 **I – yeah I've heard they're not very nice...**

1670

1671

1672 DS240157.M – oooh..don't...

1673

1674

1675 **Wife - they told you there and then actually**

1676

1677

1678 DS240157.M – yeah that’s what I said I was saying to <interviewer> I was quite blasé
 1679 about it, I wouldn’t say blasé in the sense of you know, it didn’t really, it don’t really uh
 1680 register....
 1681
 1682
 1683 **I – sink in yeah**
 1684
 1685
 1686 DS240157.M – you know then afterwards after a while you start sitting down and then
 1687 you know....((talks to the dog)) dog growls back....
 1688
 1689
 1690 **I – so what about, this is the last question we’re talking about are there any particular**
 1691 **types of patient that you think might use the app, or find it most useful? So we’re**
 1692 **talking about different points of the cancer and <candidate> was saying he might still**
 1693 **want information even 5 years after**
 1694
 1695
 1696 **Wife -** well you don’t actually get the all clear do you for 5 years
 1697
 1698
 1699 DS240157.M – 5 years
 1700
 1701
 1702 **I – and are there any different age groups that you think might find it most useful?**
 1703
 1704
 1705 **Wife -** it’s alright it’s only my phone
 1706
 1707
 1708 **I – do you want to answer it I can always...**
 1709
 1710
 1711 **Wife -** no, it’s only a message it’s alright, um, ((sighs))
 1712
 1713
 1714 DS240157.M – I don’t know how to answer that question, it might benefit certain other
 1715 people I mean you know
 1716
 1717
 1718 **I – or do you think it’s something that can be used for everyone?**

1719
1720
1721 **Wife - yes I do**
1722
1723
1724 DS240157.M – yeah, yeah, yeah....I think that would, yes
1725
1726
1727 **Wife - if you want to use it, and it's there then I think anyone would use it**
1728
1729
1730 DS240157.M – yeah
1731
1732
1733 **Wife - I mean some people might choose not to use it because they don't want to**
1734 **know**
1735
1736
1737 DS240157.M – surprisingly the amount of people who do look up on the computer, or
1738 whatever like Wikipedia and stuff like that, again you've got to be careful because
1739 Wikipedia has been noted that a lot of information given, is only that person's opinion
1740
1741
1742 **I - yeah exactly yeah**
1743
1744
1745 DS240157.M – uh and it's been totally wrong you know, and I've read things on
1746 Wikipedia and about 4-5 conflicting different uh reports on certain things and your
1747 thinking which one is....?
1748
1749
1750 **I – yeah that just confused you even more**
1751
1752
1753 DS240157.M – that's right
1754
1755
1756 **I – alright, well that's it really is there anything else you think we should cover?**
1757
1758 **Wife - not really, no**
1759

1760
1761 DS240157.M – no
1762
1763
1764 I – okay let me just switch this off
1765
1766
1767 **End of Interview. Duration: 59.01**

1 **Appendix 18: transcript for P19 Paula**

2
3 **I – okay so could you tell me why you’re interested in taking part in this study?**

4

5

6 DS240141 F – well to be honest with you after being diagnosed with cancer I think I just
7 try to do my best to help other people, it’s not easy, it’s not an easy process, it’s much
8 easi...better now than it used to be, I think you know anything that I can do to help I’m
9 more than willing to do so, that’s why

10

11

12 **I – that’s great okay, so when you were first diagnosed and throughout your illness**
13 **did you like to have information about it?**

14

15

16 DS240141 F – I think I was very lucky because with the experts that I dealt with they
17 only gave me the information I needed and nothing else, because if you do go to the
18 internet and you do search you get bombarded with too many bad scenarios that might
19 not be your case, so from start I can tell you from my diagnosis I’ve never, ever tried to
20 investigate anything on the internet at all, I was given at every stage the right
21 information about what was happening, why, the type of treatment, the type of drugs
22 what was going to happen and I think it was spot on

23

24

25 **I – yeah, okay well that’s good that you recognise that there’s a lot of...**

26

27

28 DS240141 F – it’s too much, it’s too much, cancer is hard as it is, um it’s a lot going on,
29 there’s a lot of things can go wrong and I think when you’re going through, after
30 diagnosis you go so low emotion wise and you just panic so much, if you start reading
31 about everything you will lose it and for me personally I think one of the most important
32 things throughout the entire process is your attitude and if you get too much
33 information that will bring you even more... no so for me um, I can tell you I’ve never
34 done too much research, it’s not like I don’t want to know, I’ve always been the type of
35 person that you know, I’ll research this and see what this is related to, what’s that? This
36 time I didn’t actually, first time ever so as soon as I was told I had cancer I just didn’t, I
37 stopped there and then

38

39

40 **I – okay, and when you had the information from the clinicians how did you receive**
41 **it? Was it verbal or did you have leaflets as well?**

42

43

44 DS240141 F – leaflets, yeah every stage was verbal and leaflets and I had my breast care
45 nurse, that she came to the house as well before every surgery to tell me what was
46 happening, to see any questions, um, chat about the process itself every stage

47

48

49 **I – okay and did you get information from elsewhere so perhaps from your friends and**
50 **family or was it just from your doctor?**

51

52

53 DS240141 F – just from the doctors and nurses yeah

54

55

56 **I - okay and how did you find talking to the doctors and nurses about your illness did**
57 **you find you could communicate with them?**

58

59

60 DS240141 F – yeah, yeah it was awesome I’ve got a thing with me that I talk a lot and I
61 think that helped me a lot as well

62

63

64 **I – yeah, okay so you felt that you could engage with them?**

65

66

67 DS240141 F – yeah, yeah every single one of them yeah

68

69

70 **I - okay so how did you feel when you asked them questions, was it easy or difficult**
71 **to ask them something in a consultation?**

72

73

74 DS240141 F – not really, to be honest with you um, I could’ve asked anything even when
75 I was told I had cancer, I didn’t even ask what type of cancer, I was told what type of
76 cancer, but I didn’t really want to know

77

78

79 **I – you didn’t want to know?**

80

81

82 DS240141 F – no, I you know your mind, your mind plays up and you think okay I've got
83 cancer and it's the 'C' word, so I was trying just to get the information I needed and
84 nothing else

85

86

87 **I – right okay, so when you were first diagnosed how did you feel? Did you think right**
88 **you know "I'll get through this", or did you, did you worry or?**

89

90

91 DS240141 F – oh you always worry, there's no way you can avoid it, and to be honest
92 with you, we go through stages like that you've got days like, yes I'm fine, other days
93 you feel like gosh am I going to die? and especially if you've got small kids like, I don't
94 know it's even worse, I can tell my worst day actually from all the process was um when
95 I went to <hospital> to the scans and I thought it wasn't going to be anything, I was one
96 who pushed the GP to refer me there, um so I wasn't expecting anything, so when they
97 looked at me they did the scan and they said "well hmm we can see something so we're
98 going to do um the mammogram they could see it straight away, then I went for the
99 scans and biopsies and that's when I crumbled because they said "look it doesn't look
100 good, I'm glad you picked it up early but there is something there" my first thought was
101 what about my child I couldn't stop crying for the entire, the rest of the morning, and I
102 was stupid because I went on my own as well so that didn't help, you know that was my
103 worst day when I went and I was told that I actually had cancer, um I was ready, if you
104 can ever be ready, I did meltdown, uh but since then just ups and downs surgeries they
105 went really well second worse than the first but they went okay, chemo, you go through
106 a lot on chemo so you've got days when you think gosh I'm not going to cope with this,
107 yeah you just go through it

108

109

110 **I – oh okay, yes that's really interesting that you pushed the GP to refer then, then**
111 **that sounds like that you....**

112

113

114 DS240141 F – I was and when I got there to be honest with you the cancer wasn't that
115 big, but the cells still hasn't changed where <<inaudible 5:24>> hasn't really changed,
116 so when I'd got there it was just in time. I had a mastectomy, I had it taken out straight
117 away um I wasn't given the choice of reconstruction straight away because they weren't
118 sure what kind of treatment I would have to have after, I felt really lucky, angry at some
119 stage because I thought well I shouldn't need to push anyone for this and I was really
120 unwell since January and this was diagnosed in October, so what can you do?

121

122

123 I – yeah gosh okay so what about the family and friends did you find it easy to talk to
124 them about this?

125

126

127 DS240141 F – I never had any problems to speak with anyone at all, I think it's more
128 hard for them than myself because for them they have to cope with the fact that you
129 know I might die, um it's a critical illness and I think I was more upfront, but I can tell
130 you it was easier for me to speak with strangers and I did I spoke with loads and loads
131 and loads of people throughout the entire process and I found that really easy to do so

132

133

134 I – that's really good yeah, that's a really good thing to do

135

136

137 DS240141 F – patients, nurses, loads of people was really good, while for example with
138 my mum, I wouldn't speak too much about it because she would get too sensitive and
139 that would get into my nerves as well I think when it comes to people that are close to
140 you it's harder for them than yourself

141

142

143 I - okay, that's interesting so did you find that your family wanted information then
144 perhaps more than you did?

145

146

147 DS240141 F – I don't think so to be honest with you because I had information with me,
148 I think for them, like for example my partner and my mum for example, they were trying
149 to think positive they didn't want to know too much

150

151

152 I – they didn't want...

153

154

155 DS240141 F – I had my sister in law that actually she did some research on the internet
156 and she was asking me questions that I did not have the answer to, um but I think those
157 who were closer to me they didn't ask too much technical questions it was more "how
158 was I doing" if I needed anything how I was coping, symptoms, like that

159

160

161 I - okay and when you said you spoke to loads of other patients was that through a
162 charity you'd call, or through like an organisation or...?

163

164

165 DS240141 F - uh loads of things, through charities through hospital, um, Tenovus
166 they're awesome

167

168

169 **I – oh they're funding this study**

170

171

172 DS240141 F – I use Tenovus a lot for loads of things, they're really, really good I use
173 them for counselling, I use them for, what was it? Oh gosh they helped me with benefits
174 as well, I had a nurse that they call it the I think that it's the call back service, I had a
175 nurse ringing me about every 4-5 weeks to see how I was coping, if there was anything
176 she could help me with symptoms wise, she was really good. They gave me a grant as
177 well that helped me a lot about March time, they managed to give me £300 I think yes,
178 and that was to help me, cos when you go through the chemo, the treatment most
179 women, I did as well you go through flushes, um so they gave me that grant to assist me
180 with clothes that I needed, healthy eating, um things like that, it was really, really good

181

182

183 **I – aw that's good**

184

185

186 DS240141 F – and I used um here at <hospital2> I think I had the information through
187 Breast Cancer Care, where they gave me a lot of support groups so I went to a lot of
188 sessions and I met loads of women there. I went for a session of 'Looking Good Feel
189 Better' that was awesome where I met other women going through the same thing as
190 well, it was really, really, good and they give you makeup and products it was, that was
191 really good as well

192

193

194 **I – aw that's good**

195

196

197 DS240141 F – I've done loads

198

199

200 **I – yeah well it sounds like you've done all the right things, you've really sort of, you**
201 **know you haven't cut yourself off you've mixed with other patients and....**

202

203

204 DS240141 F – no, that, that’s not the attitude at all, but if you go that route you are just
205 adding to yourself and then to go through all that and not be able to let it out that makes
206 it even worse

207

208

209 **I – yeah, yeah well that’s brilliant that you did all that. So... how did you remember**
210 **the information that the doctors gave you did you remember it by sort of memory, or**
211 **did you write things down?**

212

213

214 DS240141 F – I just remembered it, the only time I started writing was when I was
215 starting was when I was starting chemo cos they do advise you when you go to the
216 infusion session that it’s good for you to have a daily record of how you feel, and it’s
217 spot on, because every cycle you get exactly the same times, because I had exactly the
218 same symptoms, it got worse, and worse and worse obviously, but more or less those
219 specific days I knew what was going to happen, so after the first and second session I
220 knew exactly when and what was going to happen

221

222

223 **I - how did that make you feel, did that make you feel better about things or worse**
224 **or...?**

225

226

227 DS240141 F – better because I knew honest I dread some of the days cos I knew what
228 was coming, but at least I knew that it would go, I knew what I was going to expect,
229 what I could do about it and then what do to next

230

231

232 **I – so you went to, they run like an educational session about the treatment, is that**
233 **what you’re talking about in <hospital 2> that you went to?**

234

235

236 DS240141 F – yep, before you start chemo you’ve got 2 meetings the very first one is a
237 personal one, one-one with the oncologist and the oncologist nurse where they explain
238 to you what’s happening, the type of treatment and everything else, then they send you
239 a letter and before you start chemo you get a group of people in and they go through
240 what’s going to happen, why you need to do, they give you a thermometer as well
241 because you have to monitor your temperature they tell you what you can have drug
242 wise, um why you can’t, or why you shouldn’t so they explain the full scenario, the cold
243 cap the different types of chemo that was really good

244

245
246 I - that's great, okay. Okay so talking about technology now, do you have experience
247 of using a mobile, a smart phone or a tablet computer or...Ipad?
248
249
250 DS240141 F - yes
251
252
253 I – yeah, so is that both or just one...?
254
255
256 DS240141 F - both
257
258
259 I – both
260
261
262 DS240141 F – uh hmm
263
264
265 I – and how do you find them, do you find them easy to use, do you like using them?
266
267
268 DS240141 F – yeah I do, yeah
269
270
271 I – yeah and what do you use, what would you use a tablet computer for?
272
273
274 DS240141 F – uh at the moment it's more for emails, to be honest with you, check your
275 bank account, do my banking, um obviously I check online shopping wise
276
277
278 I – so it's just all the sort of regular things?
279
280
281 DS240141 F – yeah, you just get....
282
283
284 I - and do you do the same things on your smart phone, or do you use it slightly
285 differently?

286
287
288 DS240141 F – uh, I don't use it as much my smart phone obviously because I don't use
289 so much data I can check Facebook to see if I've got any messages um....it gives me a
290 rest to be honest with you I could do some banking on my phone as well, but I use more
291 the tablet than actually the phone itself
292
293
294 **I – oh okay**
295
296
297 DS240141 F – that through the internet
298
299
300 **I - alright then and have you ever used an app to do with your health at all?**
301
302
303 DS240141 F - no
304
305
306 **I – no, okay and is there any particular reason you haven't used any health apps?**
307
308
309 DS240141 F – no, not really uh to be honest with you I never have enough time to
310 actually do it, I could be days without checking anything, um especially now I really don't
311 have a chance with the small one, the house, work wise fulltime, it's just too much going
312 on for me
313
314
315 **I – yeah okay**
316
317
318 DS240141 F – and I just don't have a chance to do it
319
320
321 **I – Okay. So the type of app that we talked about do you think, do you think patients**
322 **would want to use this type of app?**
323
324
325 DS240141 F – I don't know to be honest with you uh because every time it depends on
326 the range and ages as well I can tell you I'm not sure, I can easily see them using it but

327 others love them, where they're much older they wouldn't have the, the knowledge to
328 actually use it at all, now it all depends what the app itself it will do for you, because
329 you know you go through clinic every 3 weeks you discuss all the symptoms and that's
330 when they, they check the drugs that they give you to make sure that you've got the
331 right dosage and the right drugs as well, mine changed halfway through, um they are
332 really good in that sense, when you're going through chemo you shouldn't be having
333 any other drugs, you really shouldn't and they advise you not to and if you do have any
334 problems any symptom that you can't shift away, or it's persistent, or they will, you can
335 always give them a ring and they can tell you what you need to do, because I think every
336 person's different even the type of treatment you're having, so I don't know, I think it's,
337 it's it might be interesting to see, you know, using the app to see symptoms, to see
338 different stages, different phases of the process, what's going to happen, but then I
339 personally think then the app should be really specific for specific people so if I am at
340 that stage where I was going through chemo if I had any questions, then I would have,
341 personally I would think I would have to specify that I was <<inaudible 14:08> treatment
342 that my age, type of cancer and everything else, so it can filter the information that I
343 was going to have, because if it just brings up everything, it's too confusing personally.
344 I personally find so I can tell you I registered myself in McMillan's and I think I used their
345 website about twice, never again, it's too much on um it gets a bit confusing, um I don't
346 know it all depends on exactly what the app is going to do, for me personally I think it's
347 really good if, and that's my personal opinion, if before you get information you need
348 to choose, uh the type of treatment and everything else so it can give you that
349 information, I think that would be...

350

351

352 **I – so it's not giving you general information yeah**

353

354

355 DS240141 F – yeah I think that would be really good

356

357

358 **I – okay, okay and do you think patients would need training to use the app? do you**
359 **think you know they'd need to be taught to use the app beforehand?**

360

361

362 DS240141 F – I don't think so nowadays you learn it yourself, the app will actually teach
363 you what you need to do next so to be honest with you, even if you're not that IT kind've
364 person, I think uh as a normal app it just drives you through, so it should be
365 straightforward, but it all depends on the people themselves using it....and the age, I
366 met some woman love them, they were there with they're grandchildren and they

367 didn't really know what was going on...they knew they had cancer, they knew they were
368 going through treatment, but they couldn't even start a thermometer
369
370
371 **I - oh yeah, so how are they going to use an app?**
372
373
374 DS240141 F – so how are they going to use an app?
375
376
377 **I – yeah and were these patients quite elderly or...?**
378
379
380 DS240141 F – I had a mix unfortunately there was very young girls, extremely young, uh
381 the average of most of the women that I met I would say the average age was, I don't
382 know middle 40's I think
383
384
385 **I - gosh that's young isn't it?**
386
387
388 DS240141 F – a lot, a lot, um, I'd never met them, but when I went for my session on
389 the course to feel better, there were 2 kids they were 16
390
391
392 **I – oh gosh**
393
394
395 DS240141 F – and the lady that was actually running the session said "I was dreading
396 it" cos she did 2 sessions in <hospital> one in the morning, one in the afternoon and
397 mine was the afternoon one and she said "she was dreading it" because you know it's
398 teenagers isn't it, being teenage and going through that...it's, it's not easy to deal with
399 so she was a bit concerned on how they would react, but the kids were awesome, they
400 were raising funds towards research, they had a webpage, they were doing the lot,
401 awesome
402
403
404 **I – wow...it's a way of coping I suppose isn't it?**
405
406

407 DS240141 F – you need to put your mind into something and then I think, it's dreadful
408 that it happens to you, but then if you can put some sort of input to help the next one,
409 or who's coming next

410

411

412 **I – yeah, yeah then something good is coming from it, yeah, yeah**

413

414

415 DS240141 F – like chemo, it used to be dreadful and to be honest with you I'm not saying
416 it's easy because it's not, but it's so, so much lighter than what it used to be, and the
417 effects so....

418

419

420 **I – yeah, yeah okay. So what about families of patients do you think that they might**
421 **want to use the app for themselves or maybe not?**

422

423

424 DS240141 F – I think so, thinking about that I think it would be quite interesting some
425 of the women that I've met, the husbands for example, they went through a rough
426 stage, but they wouldn't speak about it, uh and Tenovus they've got an awesome service
427 that is for relatives as well and if you want to have questions, if you wanna find a specific
428 service for them there's some book groups there's a lot going on, but I think for the
429 relatives they try, I don't know, if it's just trying to stay strong for you, or what they are
430 trying to do, but the women I spoke to they, they didn't really speak much about it, it
431 really brought them down, but they wouldn't see a counsellor as well, so if you do have
432 the app then at least they can do the research without too many questions or
433 registrations or you know, without getting too much involved I would've thought

434

435

436 **I – so do you mean the patients or the families?**

437

438

439 DS240141 F – the families

440

441

442 **I - the families**

443

444

445 DS240141 F – yeah the families I remember one that she told me that her husband she
446 could see it affected him, well it affected mine as well and only just recently we finally
447 got it, out um but he refused to do counselling, he refused to do any research, he went

448 to the sessions with her and to see the oncologist, but, and I think if there's an app at
449 least they can get the information they need to without having to go through chat
450 forums, with all of that, without having to go to those specific cancer websites that it's
451 a lot on, so I think that for relatives I think that's very good, because that means that
452 they can actually search without letting you know

453

454

455 **I – yeah, yeah, okay. So if the app was made available and going back to your**
456 **diagnosis, do you think it's something that you would use, or like you said do you think**
457 **that you just wanted information from the doctor personally?**

458

459

460 DS240141 F – I don't know, I don't know if I would uh, it devastated me I was hmm...
461 would I use the app? At the beginning I can tell you I don't think I would, the surgeries...
462 until I knew what happened until I knew what type of cancer um, I don't think I would,
463 until my second surgery that I had to have my lymph nodes removed to make sure
464 because I had one affected already, um until I actually knew the type of cancer, if they
465 managed to get it out, um what was coming next I don't think I would. After the
466 surgeries and probably before the chemo time, probably yes, but not after the
467 diagnosis, not the first stages of surgeries

468

469

470 **I - because it's too hard?**

471

472

473 DS240141 F – it's too much and you know and especially because you don't know what
474 type of cancer because with breast cancer you can only specify the type of cancer
475 when it's out by result that's what I was told breast cancer that's how it works, you only
476 know the type of cancer you've got after they do the analysis, so I knew the type of
477 cancer when I went a week later after my surgery and because one of my lymph nodes
478 was affected I had 3 for the second one they had to get everything out, so until I told
479 just before Christmas that you know that it was clear it was just that lymph node, so I
480 knew exactly the type of cancer that they managed to get it out and everything then I
481 could get my mind set for the next stage, until then I don't think I would cos it's too....

482

483

484 **I – it's too much**

485

486

487 DS240141 F – yeah you know <<inaudible 20:41>>

488

489

490 **I – yeah, yeah, yeah, okay. So touch wood I mean if your friends or people that you**
491 **knew were diagnosed with cancer would you recommend something like an app to**
492 **them if we developed this?**

493

494

495 DS240141 F – it depends how it works I always tell everyone the type of help I had I
496 always say to everyone you know what's available, what's there for you where you can
497 go, systems that can help where you can get information from, I always do, and I always
498 tell people you know "don't just investigate, don't search on websites limit that, restrict
499 that because it's too much" so I always share every single experience that I had with any
500 woman who is actually willing to speak to me I have no problem at all, and I have, not
501 immediate friends, but for example, relatives of friends that unfortunately have been
502 diagnosed recently and going through treatments, and I don't know I can only talk about
503 my own experience so I do, what helped me when I struggled with, what you know

504

505

506 **I – yeah, yeah, yeah, okay so would you have any concerns about using the app?**

507

508

509 DS240141 F – concerns....? It all depends how the app runs, it all depends the basis, or
510 what it's based on, um for me when I think of the internet as a reliable source, can I
511 trust it or not? You know if it makes sense

512

513

514 **I – okay so how reliable it is**

515

516

517 DS240141 F – how reliable it is, if for example you told me that, that app had a support
518 or background from the cancer research, I would be more than happy to you know to
519 look up anything that I would read, or that I would obtain from the app was accurate
520 and that I could rely on, for me that would be 'the' thing reliability, where it comes from,
521 what's the basis, can I trust it personally?

522

523

524 **I – yeah, yeah okay. What about benefits, what sort of benefits do you think there**
525 **might be for patients using this app? I know it's tricky to think about this because we**
526 **don't know what the app is going to do, but the things that we think that it will have**
527 **is things like questions to ask the doctor, links to websites with reliable information**
528 **so they don't go off looking all over the internet and things like that...**

529

530

531 DS240141 F – If it works that way it can be extremely useful I can tell you I, I when I
532 went to some of my sessions, especially with the surgeries, I, I <husband> asked some
533 questions because I didn't and your brain just goes absolutely, it just melts, so you do
534 forget about everything and the first time they tell you, you've got cancer you won't
535 hear anything else, your mind is just set "gosh I've got cancer" I don't think I even asked
536 a question, no my question was "what's next?" okay I've got it so what's now...that was
537 my question um and then after the second one actually it was <husband> that was
538 asking the questions about losing hair, about how it would affect me and stuff like that,
539 I didn't, so I think if the app does you know what you're planning to do, I think it would
540 be really useful, uh because it will help you to set up like you said the questions to
541 doctors because you will forget and then later on you think oh gosh I should've asked
542 this, uh I know of for example my case can cos it's breast cancer you've got a breast
543 cancer nurse allocated to you and she does visit, she does give you the information
544 before the surgeries, but sometimes it's really hard to get in touch with them because
545 unfortunately the amount of women affected by this is increasing so, so much they're
546 always so, so busy at the hospital it's really hard to actually speak with one of them, so
547 if you do, I think if the app does that, you know gives you a list of questions that would
548 be useful for you to ask so you can write them down, if it gives you information about
549 the type of cancer, what could come next, the type of treatment you've got to have,
550 what's linked to it, I think it's extremely useful because at least you've got your mindset
551 to ask the questions if you've got any....cos yes I was still needing information and I think
552 it was just the right information I read when I got home but if I had any questions when
553 I got home I'd have to ring back and say "look I don't understand this" you know so I
554 think if the app does that, that's really good

555

556

557 **I – yeah, okay**

558

559

560 DS240141 F – to me that would be a good

561

562

563 **I – Okay great and what benefits do you think there might be for doctors and nurses**
564 **if patients are using this type of app?**

565

566

567 DS240141 F – I think for them it's more the case that you know they can see that the
568 patient has a bit more information, the patient is a bit more aware of what's going on
569 and you know, I hope they just don't rely on the fact that you, you, you will use the app,
570 therefore they don't need to give you that much information, I hope not, uh so I think

571 for the doctors it would be just the case that you know me as a patient I am more aware
572 of what's there and can be more productive cos I can, like you say write down questions
573 and to ask to organise myself towards whatever stage is coming. So I think for them it
574 could be the case that it is useful for the patient's side because it has my information
575 and it's more organisation and structured

576

577

578 **I - okay that's great. What about...do you think the app might have an impact on the**
579 **way you talk to the doctors and nurses about your cancer? Do you think it could...do**
580 **you think it could make it more easy or difficult to talk to them?**

581

582

583 DS240141 F – I don't know actually it depends on the person that uses the app okay uh
584 I can say for example you know for people that if they use the app they've got the
585 technical terms, they might get to the doctor or the oncologist and to ask some technical
586 questions that might be a bit to, beyond their level, I'm not sure if that would be
587 beneficial or not, it just depends on how the people use the information I don't think it
588 would hurt, uh if that would help the doctors, it depends on the patient isn't it because
589 if you, if you're the kind of person that just because you read something you think you're
590 an expert on the matter, but then start coming up with random stuff and not actually
591 listening to the experts then... or the person themselves

592

593

594 **I – okay. What about family and friends do you think the app can affect**
595 **communication with them?**

596

597

598 DS240141 F – no, why would it? No personally I don't see how

599

600

601 **I – yeah do you think it could improve at all?**

602

603

604 DS240141 F – I think personally when you go through cancer um I think it would just
605 help people to get more information, would it help with communication? Um I don't
606 know, I personally say that I don't think it would make a change because when you've
607 got a life threatening disease it's more your sensitive part you know, your emotions and
608 how you're going to organise them, having the app that will give you more information
609 on what access to whatever, it's there, it just makes you more aware of what's going to
610 happen, now if that's going to help with communication, I personally don't think it's
611 going to make any difference because it's hard communication anyway

612

613

614 I – yeah, yeah that’s what a lot of patients and doctor have said actually yeah

615

616

617 DS240141 F – personally that’s how I see it

618

619

620 I – okay great. So we’ve talked a little bit about some of the concerns that you have
621 with the app like confi..., like reliability of the information. Are there any other
622 problems that you may see with this app working in practice? I mean I know it’s hard
623 to think about, but just, just in case you think of something that we don’t, can you
624 think of any problems that might come up?

625

626

627 DS240141 F – If I use the app just to obtain information about for example my type of
628 cancer, hormone positive, HR positive, grade II, if the app was going to give me
629 information of you know, the type of cancer that would be brill, um, what kind of
630 treatment I was having the impact on myself, if the app would give me just to help a list
631 of things that you know, what I could ask just to support me in that sense I don’t see
632 any problem I can foresee. It all depends again, if the app would give you reliable and
633 the information you need to obtain for your particular case, if it’s designed that way, if
634 it works that way, and it filters and it gives you what it should give I think. I don’t foresee
635 any problem it all depends on how it’s going to work

636

637

638 I – yeah, yeah okay and what about um what sort of things do you think the app should
639 do for patients? I mean I know we’ve talked about some questions and links to
640 websites, is there anything in particular you think would be useful for us to build into
641 the app?

642

643

644 DS240141 F – hmm, ((pause)) I don’t know it’s a tricky question

645

646

647 I - yeah it’s hard because apps can do so many things now, so we’re wondering yeah,
648 what would be most useful

649

650

651 DS240141 F – I personally think the app should be, I mean this is my personal opinion,
652 it should be very positive, and even though it’s you know we all know it’s cancer, it’s a

653 serious illness and everything else that's on the back of it, we all know bad things about
654 it, but I think if it has some sort of positivity on it, if that makes sense, you know there
655 are people that do make it they get on with the rest and they're fine, yes there's a lot
656 of people that don't make it, and unfortunately you know they don't get there, but I
657 think if the app, the way it works, it gives you some sort of positivity in some way you
658 know, if it links to cases that people that actually made it, some comments from people
659 that you know, I've been there, I've done that, I've made through, I think that would be
660 extremely beneficial for whoever is going through, because you're so scared of what's
661 coming next

662

663

664 **I – I suppose there's a lot of sort of doom and gloom information out there it's, it's....**

665

666

667 DS240141 F – It just brings you even down, down, and down you know

668

669

670 **I – yeah, yeah so you don't want something that...**

671

672

673 DS240141 F – you need to know the information, it's good to have it, it's good for you
674 to be aware of, it does help a lot

675

676

677 **I – but focus on the positives?**

678

679

680 DS240141 F – but then have a bit of positivity to whoever is reading it because you know
681 if it's possible

682

683

684 **I – yeah, yeah okay that's useful. So what about for family and friends do you think**
685 **that there's anything that we could build into the app that would be useful for them?**
686 **Or do you think it would be the same stuff as for the patient?**

687

688

689 DS240141 F – It would probably would be the same stuff as for the patient, I think
690 personally you know be able to filter and get that, the right information you know have
691 connectivity, have links or whatever, to um I don't know comments from people that
692 went through different experiences of how they managed to go through

693

694

695 **I –okay and is there anything that you wouldn’t want the app to do? I know you’re**

696 **really sort of stressing that it needs to be reliable information and....**

697

698

699 DS240141 F – oh yes I can tell you I wouldn’t like that at all....

700

701

702 **I – yeah, yeah... is there anything else that you wouldn’t want the app to do, or you**

703 **would be wary of?**

704

705

706 DS240141 F – I wouldn’t want the app to bombard me with loads of stuff

707

708

709 **I – not to bombard you okay**

710

711 DS240141 F – cos that would put me off completely. McMillan did that for me, even

712 though so many people say “oh you know you’ve got the forms, you’ve got this” and, to

713 be honest with you...

714

715

716 **I - it’s just too much yeah**

717

718

719 DS240141 F – and some people are..... I always try to be very positive I always try to do

720 comments of stuff that I have read, and I was kind’ve told off by one of the patients and

721 he kindly said “well you know <<inaudible 33:15>> when he’s said “you’re new to this

722 so don’t speak about things you don’t know” and I thought well, thanks very much I

723 know it’s hard, I know you’re going through a lot but I was just trying to help

724

725

726 **I – yeah, yeah**

727

728

729 DS240141 F – and I never did it again I can tell you

730

731

732 **I - okay. Well moving on this is the last question, are there any particular types of**

733 **patient that you think might find this app most useful? So for example different age**

734 **groups, or different points in the disease, diagnosis or pre-treatment, post treatment,**

735 or throughout all of it? All patients, is there a particular group we should target do
736 you think or?

737

738

739 DS240141 F – I’m unsure if you’re talking about an app that it, it is designed to help
740 people through the cancer disease, I think it should be there for everyone, I think if you
741 target just specific range of people I find that idea unfair, I find that you know, it should
742 be there, it’s cancer, where it affects, it should be there for whoever wants to use it, I
743 think everyone should be targeted not only those of a specific age, obviously I can tell
744 you that I can easily see the younger people using it, I can’t see a 60, 70 , 80 year old
745 using the app, even though I can think of my mother in law and touch wood, if she had
746 to I can see her using it you know, it just depends on how the mentality of people, I
747 don’t think it should be targeted for a specific range, I think it should be easy access to
748 all range of ages, it’s simple information but you know

749

750

751 I – okay and what about the different stages of disease, the reason I ask these
752 questions is that some clinicians think it should be, this would be most useful for
753 around diagnosis because that’s when they feel patients have the most questions, or
754 perhaps this would be most useful after their discharge because that’s when patients
755 are out of the system and they have more questions, so what do you think? Could the
756 app be used all the way through or do you think there’s more of an information need
757 at certain points?

758

759

760 DS240141 F – yeah, you always need information and I think that it mean all the way
761 through okay, like I said at the very first beginning, until you know the type of cancer
762 you’ve got, you don’t know, isn’t it? Until you have the diagnosis you know, there’s
763 nothing that you can do, but then I think that’s when you’re diagnosed, that’s when you
764 start the process, so when you’re diagnosed you are told what type of cancer you’ve got
765 and what’s happening next, so I think from the entire process whether there’s surgeries,
766 doing chemo, radio, afterwards getting back to normal life, any questions at all and if
767 the app is designed you know if it has information for every stage to support you and
768 you know to answer the questions that you’ve got, because for example the questions
769 that I will have after my first surgery would be exactly the same questions I would ask
770 through chemo isn’t it cos I know when I had the chemo I knew the type of cancer, I
771 knew the size, the whatever else isn’t it, so my questions would be “well how is this
772 cycle going to affect me?” I know I’m going to lose all my hair, I know this is going to dry
773 me completely and it did uh how can I sort it, what should I be doing, is there any specific
774 foods I should be having, I had tips that the nurses gave me that they were absolutely
775 fab and I didn’t have a clue, if she didn’t tell me, I was very sick and unfortunately cos it

776 has to be given to you, the nurse has to administer it, manually you can't do it by... cos
777 it's 6 syringes for different stuff, her mum love her, she went through, she just finished
778 I think when I started chemo her mum was just finishing or something like that and I
779 was sat with her ((names her)) she was given the tips with her mum that was something
780 for the dryness cos after the chemo the next day you struggle is with dehydration it feels
781 like you're burning, you don't have a temperature, but your body is so, it's so toxic and
782 you need to detox and the best thing to do it is water with lemon, and I never had a
783 clue, so water with lemon and ice soothed my throat, if it gets really dry it detoxed me,
784 it helped me to hydrate because one of the things they tell you with chemo obviously
785 you need to drink a lot of water, now I struggle to drink water anyway so I would have
786 to drink about 4 litres of water I thought I'm not doing that I'll tell you know and if I
787 wanted to I would just physically sick it up, you know so I had a lot of tips I was given by
788 different women, nurses that was really, really helpful, so if you know if those, because
789 obviously I can see the app working on studies on scientific stuff, like NHS, or whatever,
790 it's extremely, extremely useful, but you can have tips on experiences as well, this
791 helped me a lot, like pineapple helped me a lot just pineapple in your mouth just suck it
792 and it soothes the throat, it hydrates you it was awesome and there was no way that I
793 would know that, that would help me the first few days and I was told actually in this
794 case

795

796

797 **I – so perhaps having some tips like that on the app would be helpful?**

798

799

800 DS240141 F – they are all, yeah really, really useful yeah I had loads

801

802

803 **I – I hadn't thought of them, yeah**

804

805

806 DS240141 F – I had those like losing hair, I would never know it would be so painful

807

808

809 **I – oh really**

810

811

812 DS240141 F – never, and I can tell you I was in agony by the 2nd and 3rd day yeah

813

814

815 **I – really, gosh**

816

817

818 DS240141 F – because I thought to shave my head, and then my partner he’s got
819 alopecia so he was struggling with the idea that I was losing my hair as well. I knew it
820 was going to happen, they wouldn’t believe it, so instead of shaving my hair like I’d
821 planned to do, so I just cut it as a bob when it started falling out, I could tell you the
822 third, I couldn’t cope with the pain on my head

823

824

825 **I - really**

826

827

828 DS240141 F – I had to cut it short I couldn’t cope with it

829

830

831 **I – and was it better when you shaved it then?**

832

833

834 DS240141 F – yeah, yeah

835

836

837 **I - yeah okay so that might be another tip for patients, yeah**

838

839

840 DS240141 F – yeah it really is if you are <<inaudible 39:16 >> and I choose not to use
841 the cold cap for several reasons but, if you’re not using the cold cap you will lose your
842 hair, I didn’t lose it a 100% I still have some resilient ones standing up but, it went, and
843 it went spot on the day they said it would start falling

844

845

846 **I - really**

847

848

849 DS240141 F – spot on a week later, yeah

850

851

852 **I – okay well that’s really interesting information especially about the tips, that hasn’t**
853 **come up yet so that’s really helpful**

854

855

856 DS240141 F – that’s a shame because it’s really, really helpful you know when the nurses
857 speak to you on the phone and I have a Tenovus and she was awesome um, what was

858 the thing she gave me? Was my throat I was struggling with my throat and she told me
859 to use...I don't know? I can't remember now...I suffered from heartburn a lot, they told
860 me about Gaviscon and I found that the little drops they told me to have, she told me
861 to have some sweets you know your throat gets so, so, so dehydrated it's painful and
862 you get prickly coughs as well, so if you've got something sweet that you keep in your
863 mouth it helps a lot

864

865

866 **I – oh okay**

867

868

869 DS240141 F – so I think you know there's a lot of tips I've learned from other women
870 that were awesome

871

872

873 **I – perhaps if they didn't get it from the nurse and they could get it from the app**

874

875

876 DS240141 F - yeah

877

878

879 **I – well that's great. Is there anything else at all that you think we might've missed**
880 **today, or anything else that would be helpful? Just to make sure we've covered**
881 **everything**

882

883

884 DS240141 F – I don't think so I think it's fine, we've covered everything it all depends on
885 how it's designed, how it's going to work, I think for me personally if it's objective, if it's
886 filtered that would be awesome, it would be a massive help if it would give you the
887 chance for example one of the things I think is really good, and I didn't think about that
888 before, excuse me, uh like I told you when you start chemo it's really good for you to
889 have a report, a detailed report of symptoms, how you feel. So throughout the cycles,
890 not only for yourself to prepare yourself for what's coming as well, for the nurses
891 because they ask you, they ask you every clinic, they ask you how you're feeling? How
892 did it go? If you don't write it I can tell you, you will forget. If the app has um a way so
893 that you could personalise your own link and then you can actually have a diary, so
894 instead of writing, I got to the stage where I'd forgotten completely I thought oh I'll
895 remember, I'll remember, well if you've got because cos it's much easier with
896 technology so instead of writing having an agenda or whatever, it's much easier if you've
897 got it there so when you do go to the nurse you can easily pop it up and say "look that

898 day I went though that, this was a different symptom, or this one might've been a bit
899 more graphic than the other time you know" that would be, that would be quite useful

900

901

902 **I - yeah well that's great thank you very much**

903

904

905 DS240141 F – you're welcome

906

907

908 **I – let's turn this off**

909

910

911 **End of Interview. Duration 42:05**

912

913

1 **Appendix 19: transcript for P13 Lynne**

2
3 **I – right okay, so could you first tell me why you’re so interested in why you’re so**
4 **interested in taking part in this study?**

5

6

7 DS240148.F – um well I think anything that helps to inform medical professionals and
8 patients, you know as an ex teacher I’m all about education, so

9

10

11 **I – okay yeah, okay so talking about information then, did you like to have information**
12 **about your cancer you know when you were diagnosed, and throughout?**

13

14

15 DS240148.F - yes

16

17

18 **I – where did you normally get information about your illness?**

19

20

21 DS240148.F – um well mainly from the doctor I’d get it. I didn’t really, I would sort of
22 look at websites, but I didn’t really trust you know? I wanted it from the mouths of the
23 professionals

24

25

26 **I – yeah, and what sort of websites did you look at?**

27

28

29 DS240148.F – well I looked at things like the McMillan and um I can’t tell you, but I
30 would google things like cancer of the womb...you know

31

32

33 **I – yeah, yeah, yeah**

34

35

36 DS240148.F – but to be honest it was mainly, I did like mainly get information from the
37 hospital in the form of leaflets and booklets

38

39

40 **I - OKAY and did you read those?**

41

42 DS240148.F – yes, yeah

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I – because I know, I’ve heard that you get quite a lot of those if you’re diagnosed and then....

DS240148.F – yes it is overwhelming at first

I - yeah, so did you search for information straight away or sort of...staggered along?

DS240148.F – no it was later on really, cos of course initially you are quite shocked and I really just wanted, I was more concerned about my own personal case and wanting to know what the doctors thought

I – yeah so you searched for information at a later point

DS240148.F - yeah

I – okay and you said that you went on the McMillan website which are quite, you know is quite trustworthy, did you trust them or did you....

DS240148.F – oh yeah, yes I did, um I did trust them, but I still wanted, I suppose everybody’s got their own personal....

I – you still wanted your own, yeah it’s all individual isn’t it? Okay, so when we talk about then, would you say that the information from McMillan wasn’t specific enough, and that’s why you got it from the doctors?

DS240148.F – yeah, no it was, uh I think like in my particular case, I had particular concern because I had a weight problem and there was so many risks with the operation you know and I had to weigh up the risks, so I think maybe I was perhaps more dependent on the actual, my surgeon, um...

84
85 **I – yeah okay. So what about other sources? Did you consult with other family and**
86 **friends? Or was it just over the internet and the health professionals that you used?**
87
88
89 DS240148.F – um, I certainly didn't consult with family
90
91
92 **I – okay, I'm just wondering because some patients get information from friends who**
93 **have had similar, I'm just wondering if you got any information from them at all**
94
95
96 DS240148.F – not really, I mean only in terms of maybe chatting to somebody... I didn't
97 really know anybody who had, I knew people who'd had problems with periods and
98 things like that, but not anybody who had had womb cancer
99
100
101 **I - okay. So was there a particular point that you can remember where you felt like**
102 **you needed more information?**
103
104
105 DS240148.F – funnily enough, after my operation
106
107
108 **I – okay yeah, and was that due to sort of side effects or recovery?**
109
110
111 DS240148.F – it was, it was because ((sighs)) nobody spoke to me at all, because um it's
112 a bit sort of I suppose it might sound a bit personal you know when you've had your
113 womb removed it's stupid ((laughs)) things like, cos I had everything removed, I know
114 this is very specific to womb cancer, but womb, cervix and you think stupid things like
115 well okay, so is there just a big hole there now? Um, has it been sewn up? Um....
116
117
118 **I - yes, so you had questions**
119
120
121 DS240148.F – yeah, but very sort of you know....not even specifically related to the
122 disease, but what had happened to my body?
123
124

125 I – yeah, yeah, which is fair. So no one spoke to you about that sort of thing?
126
127
128 DS240148.F – no, no one mentioned um sex, and you know, was it okay? And how long
129 and....
130
131
132 I – yeah, yeah and so when you had these questions, how did you get them answered?
133
134
135 DS240148.F – well funnily enough I was having the district nurses in um, because of my
136 wound which wouldn't heal, and there was a trainee nurse that had a whole load of
137 leaflets...well I just got on well with her and she'd um, and she'd done some work on
138 that area and she had a whole load of stuff that she gave to me, but that was just pure
139 coincidence
140
141
142 I – yeah so was that like leaflets and booklets and things?
143
144
145 DS240148.F - yes
146
147
148 I – okay so you, did you look on the internet at all for that sort of stuff?
149
150
151 DS240148.F - yeah
152
153
154 I – okay, and did you find that helpful?
155
156
157 DS240148.F – a little bit...when I say leaflets, they weren't commercially produced
158 leaflets for general distribution, they were things that she'd had because she'd done an
159 academic study
160
161
162 I - ah really, okay
163
164
165 DS240148.F – so I don't think there was anything produced, you know

166
167
168 **I – that’s interesting**
169
170
171 DS240148.F – I don’t know if there’s anything produced? But I certainly didn’t get
172 anything
173
174
175 **I – yeah, yeah you would have thought that you would’ve had something explained**
176 **to....**
177
178
179 DS240148.F – nobody ever mentioned it, and then of course you know you start feeling,
180 is it me you know, it’s embarrassing in a way to sort of....
181
182
183 **I – yes, so how did it make you feel not having this information, you mentioned you**
184 **felt embarrassed at times?**
185
186
187 DS240148.F – well I’m just a bit insecure really, um ((pause)) you know it’s a very integral
188 thing for a woman isn’t it? Your womb and...you know? And suddenly you haven’t got
189 it anymore ((laughs))
190
191
192 **I – yeah, and no information on it either**
193
194
195 DS240148.F – and no information and with the best will in the world I’m not criticising
196 the nurses, and the doctors, they’ve got so much to do
197
198
199 **I – yeah but it is a big operation isn’t it?**
200
201
202 DS240148.F – it’s a huge operation yes
203
204
205 **I - okay. So moving on then to the clinicians how did you find talking to them about**
206 **the cancer and the operation and everything else?**

207
208
209 DS240148.F – they were very, very good, brilliant, the only thing is, again not their fault,
210 but I always felt a little bit rushed because there was so many patients and so much to
211 do
212
213
214 **I – yeah, was it down at <hospital> or <hospital2>?**
215
216
217 DS240148.F – it was <hospital 3>
218
219
220 **I – okay, so you felt a little bit rushed, you were aware of....**
221
222
223 DS240148.F – yes I mean, they were brilliant, perhaps it was my own you know....
224
225
226 **I – there have been other patients who have said that they’re aware that it’s a very**
227 **busy clinic....**
228
229
230 DS240148.F – it’s so busy and I mean you know with the best will in the world, I mean,
231 the surgery itself was marvellous because I needed a lot of reassurance um, because I
232 mean I suppose they have to, but again they were really sort of you know ((sighs)) risk
233 of death and all the rest of it...and there were specialist nurses and I was assigned a
234 specialist nurse and she was lovely, um and it was “oh ring up at anytime you know”
235 bless them, again, they’ve got so many people you ring up and you’ve got an answer
236 phone message, they would get back to you eventually, but I must, I have to admit I did
237 feel a bit isolated you know
238
239
240 **I – so sorry, you rang that number when you had questions?**
241
242
243 DS240148.F - yeah
244
245
246 **I - yeah, okay and they’d get back to you?**
247

248
249 DS240148.F – they would get back to you eventually, but again they had so much to do
250 ((laughs))
251
252
253 I – so when you had those questions and they didn't get back to you straight away,
254 what did you do then? Did you wait, or did you go and find the information
255 elsewhere?
256
257
258 DS240148.F – no, I just waited
259
260
261 I - waited okay, and how was that for you?
262
263
264 DS240148.F – frightening sometimes
265
266
267 I – and what sorts of questions did you have for them?
268
269
270 DS240148.F – um, oh gosh it's hard to remember now uh
271
272
273 I – I mean were they about side effects, or psychological worries you know...?
274
275
276 DS240148.F – there were some about um medication I needed to take different
277 medication, I was worried about...
278
279
280 I – yeah that's quite important isn't it yeah
281
282
283 DS240148.F – yeah because you know again uh I didn't know whether I'd have to take
284 hormones? Um and I had, nobody seemed to volunteer information like that
285
286
287 I – yeah, so did they tell you this before you were discharged then about what to take,
288 or did you tend to forget or...? Or it's complicated?

289
290
291 DS240148.F – they didn't tell me anything
292
293
294 **I – oh really?**
295
296
297 DS240148.F – yes you do tend, until you, you know at first I was, all I was worried about
298 was getting through the operation um surviving the operation and so you're not worried
299 then about whether you are gonna have to take hormones ((laughs)) and then after a
300 while you start worrying about that sort of thing you know
301
302
303 **I – yeah, yeah cos it's the sort of next step**
304
305
306 DS240148.F – because I wasn't of the age where I knew definitely whether I'd been on
307 the change or not? Um and I didn't know and nobody seemed to, you get the feeling
308 because they're all so busy, um and again it's not a criticism, I think that basically they
309 need more staff don't they?
310
311
312 **I – yeah definitely**
313
314
315 DS240148.F – but because they're all so busy, um they, you get the feeling that perhaps
316 things have been forgotten, you know?
317
318
319 **I - okay yeah which I'm sure does happen**
320
321
322 DS240148.F – and also there's this feeling of one had not knowing what the other hand
323 is doing
324
325
326 **I – yeah, yeah, okay. So then you called up then with the questions and then**
327 **eventually they got back to you about how to take the medication**
328
329

330 DS240148.F – oh yes they always got back to me
331
332
333 **I – yeah it’s just the waiting in between isn’t it?**
334
335
336 DS240148.F – it’s the waiting and the knowing I think that they’re under pressure you
337 know
338
339
340 **I – yeah, yeah and how did you feel when you contacted them? Were you happy to**
341 **phone them, or did you dislike phoning them?**
342
343
344 DS240148.F – well I was happy to phone them, I didn’t dislike phoning them, but I did
345 feel oh is this wasting their time?
346
347
348 **I – okay yeah and I think that’s a common feeling amongst patients, but you’re**
349 **definitely not wasting their time so...yeah**
350
351
352 DS240148.F – no, no and they never gave me the impression that they felt that, you
353 know they were wonderful
354
355
356 **I – it was just that sort of delay, yeah**
357
358
359 DS240148.F - yeah
360
361
362 **I – okay. So, so we talked about how you felt when you asked some questions and**
363 **you were happy to ask them. Was there anything that made it easier to ask doctors**
364 **and nurses questions, or did you find it more difficult to ask questions?**
365
366
367 DS240148.F – um, no, no I think they were all very approachable to ask them
368
369
370 **I – okay**

371
372
373 DS240148.F – the only difficulty was feeling all the time that there was so little time,
374 you always felt rushed and a bit of time constraint and again it wasn't them making you
375 feel like that, it's just the whole atmosphere of the place ((laughs))
376
377
378 **I - yeah, yeah I know, I visited some of the nurses in the clinics down in <hospital 2>**
379 **and <hospital 3> and it's just crazy**
380
381
382 DS240148.F – it's just ridiculous. I mean you know I just felt so sorry for them because
383 they weren't going around feeling sorry for themselves, but you could see the pressure
384 they were under you know
385
386
387 **I – yes exactly, I think the patients definitely pick up on that then**
388
389
390 DS240148.F – they do, and of course to be told you've got cancer you know, your whole
391 world crashes around you and uh you really want to be able to sit down and talk to
392 somebody, or at least have like you say like an app or something
393
394
395 **I – yeah to just have time to take it in yeah**
396
397
398 DS240148.F – yeah, yeah
399
400
401 **I – okay. So the next question here is were there any barriers to communicating with**
402 **doctors and nurses? I mean you said you know it was fairly easy apart from the time**
403 **pressure, but were there any other barriers to communicating with the doctors and**
404 **nurses in general?**
405
406
407 DS240148.F – well um, not really, I mean, you did feel as if you wouldn't....my main, it's
408 funny it's a strange thing to say, but my main point of contact for me felt like it was the
409 surgeon's secretary, she was always there, she always picked up the phone. Although I
410 wouldn't talk to her necessarily about the medical stuff, at least with her I felt that she
411 would get a message through, that she had her hand on everything that was happening,

412 it was simply you know, you didn't feel, like you could pick up the phone to the nurse,
413 but you'd get an answer message and sometimes you want the reassurance there and
414 then

415

416

417 **I – yeah and do you think that's something an app could help with potentially?**

418

419

420 DS240148.F – I think so, especially if it's one that when you go to the hospital the nurse
421 and the doctor says to you look, you know, they'd tell you about the app and then you'd
422 feel that it's something that they endorsed, you know what I mean?

423

424

425 **I – okay, yeah so you'd want it t feel supported by the clinicians?**

426

427

428 DS240148.F – by them, yeah

429

430

431 **I - okay. So why would you want them to endorse the app then? Why is that**
432 **important?**

433

434

435 DS240148.F – not endorse it...I didn't mean...

436

437

438 **I – yeah I know what you mean like, sort of get behind it and say this is...you know**
439 **use this...**

440

441

442 DS240148.F – well because you'd feel, well for me personally, I'd feel that it was um,
443 you know if the medical professionals were recommending it then if you like

444

445

446 **I – yeah, yeah**

447

448

449 DS240148.F – then they must feel that it's worthy and reliable and a useful source of
450 information, I mean there's so much out there isn't there?

451

452

453 I – yeah, exactly

454

455

456 DS240148.F – not in terms of apps, but...you know

457

458

459 I – yeah, yeah so many different sorts of resources of information. Okay well we'll
460 come on to the app a little bit later. So how did you remember all the information
461 about the cancer? Did you write it down, rely on memory, or use any other ways to
462 remember it?

463

464

465 DS240148.F – um, when it, when it came to my personal situation, the things that the
466 surgeon was saying to me I wrote things down and I went in with a list of things

467

468

469 I – oh okay

470

471

472 DS240148.F – I had to because otherwise I'd forget, you know

473

474

475 I – and did you take anyone into the consultation with you, or did you go alone?

476

477

478 DS240148.F – initially I took my mother but then I ended...I went on my own after that
479 cos I felt it was too upsetting for her you know?

480

481

482 I – yeah and how did you find using the list of questions, did you find that helped?

483

484

485 DS240148.F – yes he was, I mean he was very accommodating and I, you know me being
486 me I kept apologising and he said "it's alright, I understand, you know" because you
487 know there is the white coat syndrome as well isn't there? Where you go in and
488 everything in your mind goes blank

489

490

491 I - yeah, so what, what do you mean by the white coat syndrome? Just so that I've
492 got it on tape

493

494

495 DS240148.F – the whole thing of you know, as soon as you go into a medical professional
496 setting, maybe more someone of my age who is used to, I mean I’m still surprised when
497 a doctor comes up to me in hospital and says “I’m Luke I’m one of the doctors” I expect
498 it to be “I’m Dr so, and so” ((laughs)) and there’s that sort of you know, it’s a doctor...!
499 and I know it’s silly, but uh and I and when I go to the GP I take a list with me because
500 um you do you’ve got that sort of, again, you’re afraid of wasting time, and you’ve got
501 that oh it’s a doctor, I don’t know whether I’m explaining?

502

503

504 **I – yeah, yeah I know what you mean, I have to ask the obvious questions really for**
505 **the purpose of the tape, yeah so we’ve got it on paper, because I can’t um just assume**
506 **what you’re saying you know?**

507

508

509 DS240148.F - hmm

510

511

512 **I - yeah okay, so that’s good you take a list of questions in then and that. So do you**
513 **find that helps the communication between you?**

514

515

516 DS240148.F - yeah

517

518

519 **I – and do you find that you get your answers then? compared to if you didn’t take the**
520 **list in**

521

522

523 DS240148.F - yeah

524

525

526 **I – okay and you said the doctors were accommodating?**

527

528

529 DS240148.F – very much so yeah

530

531

532 **I – okay then so did you find it easy to talk to your family and friends about when you**
533 **had cancer?**

534

535
536 DS240148.F - no
537
538
539 **I – and is there any...is there any...**
540
541
542 DS240148.F – friends yes, well no, no actually I didn't cos I, I remember not wanting to
543 ring particular friends because I'd have to say
544
545
546 **I – okay and why did you feel like you didn't want to tell them?**
547
548
549 DS240148.F – because I felt it was such bad news, uh and also I, I don't like, I've got a
550 thing about, I don't like the phrase I've got cancer, not because I don't want to face it or
551 anything, but it seems to me, I in fact, I never, ever said it, I never said it to anybody
552 "look I've got cancer" I would say they've found some cancerous cells in my womb,
553 because I had cancer in my womb, I wasn't my whole person, it wasn't my whole body....
554
555
556 **I - yeah, yeah that's exactly, that's a really good attitude to have towards it, because**
557 **I think when people say, "I've got cancer" it's like...there's a stigma attached to it**
558
559
560 DS240148.F - yeah
561
562
563 **I – that it's um you know life, always life threatening**
564
565
566 DS240148.F – always life threatening, and you know okay you've got perhaps you've got
567 cancer in some part of your body, cancer's not like you know...
568
569
570 **I – it doesn't have to define you**
571
572
573 DS240148.F – it doesn't have to define you as a whole person you know
574
575

576 I – okay, so would you say then did you prefer not to talk about for that reason?

577

578

579 DS240148.F – well for the family it was certainly more, I didn't want to accept it

580

581

582 I – okay

583

584

585 DS240148.F – because my mother is 80 and she's very um, she's not a strong person in
586 terms of coping with stress and worry and she's absolutely, well you know me and her
587 are really close so I felt I had to protect her a bit, and the same with my son, my son was
588 21, 22 at the time and brilliant, he was absolutely marvellous, but I felt I had to protect
589 him a bit, I mean I did talk to him about it, but only what I had to say and then only really
590 to reassure him you know ((laughs))

591

592

593 I – yeah, okay. So looking at the technology then, so you have an Ipad so you have
594 experience of using that. So what do you use the Ipad for?

595

596

597 DS240148.F – what do I use the Ipad for?

598

599

600 I – what sort of things?

601

602

603 DS240148.F – everything ((laughs)) um I do my shopping on it, I do my banking on it, um
604 I do research things, you know if I want to find out about anything, I'll use it. I play
605 games on it, ((laughs))

606

607

608 I - yeah, have you ever used an app to do with your health?

609

610

611 DS240148.F – I've used my fitness pal

612

613

614 I – oh I use that yeah

615

616

617 DS240148.F - yeah
618
619
620 **I – and that’s to track sort of diet and things like that**
621
622
623 DS240148.F – diet and things like that yeah
624
625
626 **I – okay how do you find using apps, when did you start using apps, is this something**
627 **that you’ve used since the beginning or?**
628
629
630 DS240148.F – yeah I’ve been using them because I used to use them on my phone as
631 well you know yeah
632
633
634 **I – okay so have you got a smart phone, or is it a regular...?**
635
636
637 DS240148.F – no a smart phone
638
639
640 **I – yeah and do you use apps on there as well?**
641
642
643 DS240148.F – yeah
644
645
646 **I – do you prefer one device over the other?**
647
648
649 DS240148.F – I’d prefer the Ipad, um but obviously then I’d prefer, but you know it
650 depends on whether I’m in or out really you know when I’m out and about I use my
651 phone, when I’m in, I use my Ipad
652
653
654 **I - yeah okay. Right well that’s great, so the type of app we talked about, do you think**
655 **patients would find this type of app acceptable to use?**
656
657

658 DS240148.F - yeah

659

660

661 **I – and do you think they would use it?**

662

663

664 DS240148.F - yeah

665

666

667 **I – okay. Can you think of any friends of yours, or you know if they had diagnosis of**
668 **cancer, are there any that you think wouldn't use it?**

669

670

671 DS240148.F – um, only the odd one or two friends I've got who don't do technology,
672 those who do I'm sure would use it. There's not many that don't do technology but
673 there are still some

674

675

676 **I – and do you know the reasons why they don't use that technology?**

677

678

679 DS240148.F – well usually it's to do with their age and generation

680

681

682 **I – yeah. Okay, so what about family and friends of patients, do you think that they**
683 **would want to use an app, for the patient or for themselves?**

684

685

686 DS240148.F – I think they might want to use one for themselves, to find out information
687 about things for themselves and it could be I suppose, it might be useful, right say my
688 mother had it, which hopefully she won't, she wouldn't use an app, but I might use it,
689 to find out for her

690

691

692 **I – yeah so you'd use it on behalf yeah. Okay and what sort of information would you**
693 **hope to get off it, would it be stuff to learn about your mother's illness, you know if**
694 **she had cancer, to learn about her, or would it be things to help you, so perhaps**
695 **relative's support groups?**

696

697

698 DS240148.F – oh both I think really, yeah

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I – okay, so that’s one of our concerns that there will be a group of people who won’t like this sort of technology and won’t use it and like you said yeah, we are hoping that maybe there would be a relative in the family, which there usually is, who are familiar with apps, and might use it for the patient. Okay so do you think patients would need initial training to use the app?

DS240148.F – um well I think some might possibly, probably not most people know, but there might be some who um might benefit from maybe you know somebody just showing them it look this is what it can do and....

I – and what sort of person would that be?

DS240148.F – well again, people who don’t particularly use technology and if you said to me there’s this app called such and such then I’d just go and look at it and find it out for myself, like my dad bless him who’s 82 and he plays around with his laptop um he wouldn’t know like to look at the little words and to click on them and things and explore an app you know

I - yeah, yeah...so someone to teach them how to sort of navigate, okay

DS240148.F – and also just to tell them the things that they can look at, because the word app not very few people these days now I should think you know when somebody of your generation finds it, oh that sounds patronising – but imagine that um you know there are some people they still don’t know what an app is, I’m sure you know that

I – yeah, yeah exactly. Do you know my mum and dad are not very good at using computers it’s taken them ages to learn, I mean they’re in their fifties which is young, but my dad started using an Ipad now and he finds that a lot easier than using a computer, but he had no concept of what an app was before...

DS240148.F – no, no...

740
741 I – so
742
743
744 DS240148.F – well my dad is 82 bless, cos I’m 57 um I think having a son, because my
745 son is 24 now, I think having him and also I worked in schools so you had to get a bit
746 savvy, but my dad bless him he’s 82 but he does really well, you know he sends emails,
747 and he googles, but to us you know it’s the air we breathe, but to them it’s you know
748
749
750 I – my grandmother then, she uses her laptop now to, for booking her golf
751 competitions and things and the only reason she’s learned because it’s all gone online
752 and she’s had to learn
753
754
755 DS240148.F – she’s had to learn
756
757
758 I – yeah, or she’ll be missing the games, but to sit down and do it it’s quite a task for
759 her, where as for us we just sort of do it by second nature. Okay so we’ve talked about
760 training then, do you think some patients would be able to use the app after some
761 training, do you think they’d get on with it?
762
763
764 DS240148.F – oh yes, yeah
765
766
767 I – okay, and if the app was made available would you download and use it and do
768 you think...
769
770
771 DS240148.F – I would yes
772
773
774 I – would you recommend it to other patients?
775
776
777 DS240148.F – definitely, I’ve been looking it up now, even though it’s you know
778
779
780 I – yeah, would you have any concerns about using the app?

781
782
783 DS240148.F – I wouldn't personally, but I would've had concerns about I wouldn't have
784 just said to my son "there's this app have a look at it" I would've wanted to look at it
785 first, but that's just me probably being over protective
786
787
788 **I – yeah, no I understand that yeah, in case there's too much information, okay. So**
789 **this question is a bit difficult because it depends on what the app is going to do, but**
790 **the type of app we've talked about, so for example, looking at helping with questions**
791 **before consultations, and reliable information where there is some sort of link, or to**
792 **social support, what benefits do you think there would be for patients using an app**
793 **like this?**
794
795
796 DS240148.F – well I think that perhaps it would help then to prepare for consultations
797 because I think it can be a bit of a shock how much information you are given and you
798 end up going from a consultation thinking oh my god, you know what was I told there
799 sort of thing, so I think it might help to prepare people, um....
800
801
802 **I - what about taking information away, how could, do you think the app could help**
803 **with actually writing the information, or recording or...typing it in?**
804
805
806 DS240148.F – yeah I think it could
807
808
809 **I – do you think that would be a good idea because I'm not sure whether that would**
810 **distract from the consultation, I'm just wondering what you think about it?**
811
812
813 DS240148.F – I don't know whether you would want to be messing about you know, I
814 think that's an individual thing, I think...I don't think it be, I don't think there would be
815 any harm in providing that facility if people wanted to use it they could, it would be up
816 to them wouldn't it?
817
818
819 **I – yeah that's a good idea yeah. When you took in the question list did you write the**
820 **answer down, or did you just use it as a prompt?**
821

822

823 DS240148.F – I just wrote them down ((laughs))

824

825

826 **I – and did you find that impacted on communication at all?**

827

828

829 DS240148.F – I think it improved it, certainly from my point of view. Oh I see what you
830 mean, no I think it did improve it, and you know from, it's helpful from the doctor
831 because they can see exactly what the patient's concerns are then, you know

832

833

834 **I – so anymore benefits for the patients, can you think of any more for the patients?**

835

836

837 DS240148.F – um ((pause))

838

839

840 **I – I mean preparing for the consultation, that is perhaps a short term benefit, can you**
841 **think of any longer term benefits from a patient just using this app throughout their**
842 **cancer?**

843

844

845 DS240148.F – well certainly it would provide, I think some sort of reassurance and some
846 support and certainly a source of information, um

847

848

849 **I - yeah and how do you think having that information would help the patient, I mean**
850 **you mentioned that it would provide reassurance, is there anything else it could help**
851 **with?**

852

853

854 DS240148.F – um, well certainly finding out things that perhaps people haven't got the
855 time to tell you, you know like side effects, like things that would happen to you after
856 the operation in terms of effects on your body and things like that you know

857

858

859 **I – okay and what about clinicians, what benefits do you think there might be for**
860 **clinicians if patients are using an app?**

861

862

863 DS240148.F – well if it would, if they could have input into it, I don't know whether an
864 app, within an app would there be um an opportunity to perhaps email, not to the
865 clinician in hospital, would there perhaps be a possibility to email a question to
866 somebody?

867

868

869 **I - yeah, yeah we could use that, maybe email questions to the nurses instead of**
870 **phoning them up, maybe it would be a bit quicker, I don't know? So how do you think**
871 **that would benefit the clinician?**

872

873

874 DS240148.F – when you're talking, how it would benefit the clinician?

875

876

877 **I – yeah, or the app in general?**

878

879

880 DS240148.F – well it would benefit the clinician in that perhaps they'd get some insight
881 into the problem before they contacted you and it would benefit the patient because
882 speaking to a machine is you know when you've got perhaps a very personal problem,
883 it's not good really, um

884

885

886 **I – so would you prefer then to email it across and perhaps them call you back?**

887

888

889 DS240148.F – yeah I think, I mean obviously in an ideal world you'd like to pick up the
890 phone and have somebody answer it, but given that, that's not the case I think it
891 probably would, yeah

892

893

894 **I – okay, and what about family and friends, what benefits if they're using an app, or**
895 **the patients are using an app?**

896

897

898 DS240148.F – well certainly obviously finding out information, finding out procedures
899 you know what are the sorts of things that happen you know what's the stages you
900 know

901

902

903 I – and how do you think that might help the patient you know if the patient knows
904 this information?

905

906

907 DS240148.F – um, well because they would perhaps have more understanding,
908 sometimes a patient is feeling too stressed and is too distressed to talk about it
909 themselves, um, certainly in, in terms of perhaps an older person being the patient it
910 enables a younger person to provide more support, more informed support and
911 obviously the same for people who are younger, you know a child or a younger person,
912 or somebody who's got learning difficulties you know

913

914

915 I – okay great. So I think we've talked about communication, well we've talked about
916 how the list impacted on communication with the doctor, do you think an app would
917 have an impact on the way you talked to doctors and nurses about cancer?

918

919

920 DS240148.F – it could do, I think you know an app could help explode the myths but uh,
921 you know it...that doctors do like to be asked questions and they don't mind you know
922 and they understand that uh your questions to them may seem very basic but they
923 understand why you are asking them

924

925

926 I - okay, – and do you think the app could affect the way you talk to family and friends?

927

928

929 DS240148.F – I think, it certainly it would help if you could say well if you want to find
930 out more about it, or if you want to um use it to help yourself you know to support
931 yourself and there is an app there could it you know?

932

933

934 I – okay so do you think there might be any problems with patients using this app?
935 Can you think of any, any barriers to this working in practice?

936

937

938 DS240148.F – well the only barrier I can think of is that some people do not have any
939 access to the internet and I suppose that's something that you just have to accept you
940 know that's not a reason for not producing something, but that's the only barrier that I
941 can see, in that people, there are people who don't have internet access, um and I
942 suppose the other barrier is....people who are not able to read and understand. I think

943 it would have to be very accessible I suppose there is a section of society where language
944 might be a...you know
945
946
947 **I - yeah, and you mentioned earlier you'd want the clinicians to support it**
948
949
950 DS240148.F – yes I would want to feel that is something that they were saying “look this
951 is good, have a look at it, it might help”
952
953
954 **I – do you think if it wasn't recommended by healthcare professionals, if they didn't**
955 **sort of mention it, what do you think the impact might be there? What would the**
956 **difference be?**
957
958
959 DS240148.F – I don't, it probably for some people it might not make any difference I
960 don't think it's a, it's not a, it's not a deal breaker you know, um I just think it would
961 make it, for me it would just make it even more supportive
962
963
964 **I – okay, would it make you feel like you trust the app more? Is that what you would**
965 **get from it?**
966
967
968 DS240148.F – yeah, I mean if I google any health issues I've always looked out, you know
969 you google and you get those things...I'll always look for any that are NHS
970
971
972 **I – okay yeah**
973
974
975 DS240148.F – I don't know why it's probably rubbish you know
976
977
978 **I – yeah, yeah but you sort of fairly know that it's up to a fairly good standard**
979
980
981 DS240148.F – being an independent thing rather than a you know
982
983

984 I – yeah, okay so what sort of things do you think the app should do to help cancer
 985 patients? I mean I know it's a broad question. We're hoping to build the app in March
 986 so we're asking patients, or past patients like yourselves, based on your experience,
 987 what could've really helped you, and you know within the means of an app?
 988
 989
 990 DS240148.F – um, I think to find out information about the particular type of cancer
 991 than you've, you've got, I suppose there could be that within an app couldn't there you
 992 know?
 993
 994
 995 I - yeah
 996
 997
 998 DS240148.F – research different types, I, I, I when I say find out about, I don't think you
 999 want to know um, the sort of scientific facts of it, but how it affects your body and what
 1000 the risks are you know and what the general um course of methods of treatment are
 1001 um....and yes with an operation what are the down sides that would...maybe some I
 1002 can't think of the word people who have had it done talking about their experience
 1003
 1004
 1005 I – so and how could we best fit that in then? Would that be perhaps a blog from a
 1006 patient, or would it be more of an interactive chatting facility?
 1007
 1008
 1009 DS240148.F – I think it could be both really, it could be you know some aspects of people
 1010 just, just telling about their experiences and there could be some sort of forum I suppose
 1011 as well
 1012
 1013
 1014 I - okay any other ideas at all?
 1015
 1016
 1017 DS240148.F – sorry I'm not very good at this sort of thing
 1018
 1019
 1020 I – no I know it's tricky because apps can do so many things and you've not had a lot
 1021 of time to think about it so I understand yes it's quite tricky. What do you think about
 1022 the question prompting idea, do you think that's something that would be useful?
 1023
 1024

1025 DS240148.F – I think that’s a very good idea, I think that’s a very good idea yeah
1026
1027
1028 **I – and what about the links to recommended websites?**
1029
1030
1031 DS240148.F – yes, yeah
1032
1033
1034 **I – how do you think that could help patients? The links to the websites?**
1035
1036
1037 DS240148.F – well it’s just another tool to find out information isn’t it and also support
1038 you know, because it wouldn’t only just be information at websites it would be people
1039 like McMillan or Tenovus
1040
1041
1042 **I – yeah, yeah so links to selective websites as well**
1043
1044
1045 DS240148.F – and with a lot of people I think money is an issue isn’t it. Like people like
1046 Tenovus and McMillan who deal with that, within the app itself it could perhaps even if
1047 it’s just that information that cancer charities will help with benefits and things like that
1048 you know
1049
1050
1051 **I – yes this has been suggested by a few patients actually, they did a survey I think in**
1052 **<hospital> and maybe a few other hospitals on what information patients with cancer**
1053 **are really missing and financial issues was number one so it’s definitely something we**
1054 **could help with**
1055
1056
1057 DS240148.F – you know for me it wasn’t an issue, because I’d been retired medically
1058 anyway, but you know if you’re going to have 6 months of work you know it’s a huge,
1059 and I mean stress is the one thing...
1060
1061
1062 **I - okay so anything else or?**
1063
1064

1065 DS240148.F – I think possibly but then again I don't know if you'd be interested or, I
1066 have a particular problem in that I've got mobility issues, so getting to appointments

1067

1068

1069 **I – yeah that's definitely that's something to think about yeah**

1070

1071

1072 DS240148.F – and I mean some people might not even be aware that you can qualify
1073 for hospital transport if you have mobility issues you know they'll come and...the
1074 ambulance you know, not an emergency ambulance a transport ambulance will come
1075 and pick you up and get you to your appointment because you know when I first started
1076 going to <hospital 2> I didn't realise I could get hospital transport and my son at the
1077 time, he was still at uni so he could take me, but again was a stress, because it meant
1078 he had to have time off missing lectures and things like that, I...and at <hospital 2> the
1079 wheelchair situation is terrible I didn't have my own wheelchair then, I've got my own
1080 wheelchair, one that folds down now and I remember cos I'm a very calm quite of laid
1081 back sort of person and not usually rude to people, but I remember getting so
1082 frustration once sitting in the reception in <hospital 2> my son had to drop me off at the
1083 main door I was crying and saying to somebody look I've got cancer and I need to get to
1084 my appointment and I haven't got a wheelchair ((laughs))

1085

1086

1087 **I – yeah oh gosh yeah**

1088

1089

1090 DS240148.F – so I know you couldn't go into specifics like that even sort of letting people
1091 know that if they talk to the ward staff or their doctor that they've got an issue, with
1092 getting to appointments you know they will help, but even things like you know I had to
1093 be in a bed on the ward that was as near as possible to the toilet because otherwise I'd
1094 be calling a nurse all the time, now I know that you wouldn't want to go into those sorts
1095 of specifics but....

1096

1097

1098 **I – but it's handy to give this information, because it could prevent you getting into a**
1099 **state where you're really upset and that's not helping anything is it so if we can**
1100 **prevent that**

1101

1102

1103 DS240148.F – you know just reassurance to people that if they do have any issues about
1104 getting to appointments, or worries about when they're in hospital you know, to talk to

1105 people about it you know to talk to them about it, because a lot of people won't they
1106 just suffer in silence

1107

1108

1109 **I – yeah, yeah okay so what about the family and friends do you think the app could**
1110 **help them with anything in particular?**

1111

1112

1113 DS240148.F – um, well again the same sorts of things I suppose information about the
1114 you know the general way of treating that cancer, how it can affect the patient, both
1115 physically and mentally and ways that they can help I suppose

1116

1117

1118 **I – yeah and what about things for the relatives themselves?**

1119

1120

1121 DS240148.F – well we could have the links to, because I mean again, people like
1122 McMillan and Tenovus, they do deal with everybody don't they it's the whole, whole
1123 person, a whole family issue really

1124

1125

1126 **I – so that's support for the support groups then?**

1127

1128

1129 DS240148.F – yeah and also just simply I think if an app gives you the information that
1130 it's normal to feel the way a relative might be feeling and they're not on their own and
1131 other people experience it as well and you know there is help to be found

1132

1133

1134 **I - and is there anything you wouldn't want the app to do?**

1135

1136

1137 DS240148.F – I don't think so, um obviously, obviously not to be too sort of, you
1138 wouldn't want it to say you know people with this type of cancer often die

1139

1140

1141 **I – yeah, yeah definitely so, don't give any sort of prognosis, or statistics?**

1142

1143

1144 DS240148.F – um, probably not no unless they're positive ones like you know 97% of
1145 people survive, or I mean even that can be dangerous can't it?

1146
1147
1148 I – okay and so not to worry the patient?
1149
1150
1151 DS240148.F – no, not to worry the patient or the relative really
1152
1153
1154 I – okay are there any particular types of patient that might find the app most useful,
1155 so we’ve talked about... do you think all age groups would find it useful, or do you
1156 think there would be a particular age group?
1157
1158
1159 DS240148.F – well I think all age groups apart from maybe the very old, but then you
1160 know I wouldn’t want them to be excluded if they wanted to be, you know that’s not
1161 what I mean
1162
1163
1164 I – yeah, yeah and what about patients at different stages of the cancer? So diagnosis,
1165 sort of treatment, post-treatment. Do you think it would be something that is sort of
1166 useful throughout the whole thing, or do you think there’s particular points...
1167
1168
1169 DS240148.F – no, I think it would be useful throughout the whole thing
1170
1171
1172 I – okay, okay so if we made this app available, how would we, how would we
1173 introduce it, how could we best get people to recognise the app as a trusted source of
1174 information, how do you think we could get people to use it? How would we get you
1175 to use it for example? Because there’s loads of websites, information leaflets, groups
1176 there’s hundreds of things so how could we make this appealing?
1177
1178
1179 DS240148.F – well I don’t know, I suppose you could have...
1180
1181
1182 I – well you said “have the clinicians endorse it”
1183
1184

1185 DS240148.F – have the clinicians endorse it, maybe advertise it through GP surgeries,
1186 um, have you know, like big posters and things like that, maybe even through television
1187 and radio um...does that make sense?
1188
1189
1190 **I – yeah, yeah**
1191
1192
1193 DS240148.F – you know advertise it cost money I know but um, um I don't know, I don't
1194 know how you would advertise an app it's all about getting it out there isn't it?
1195
1196
1197 **I - yeah, yeah**
1198
1199
1200 DS240148.F – making people aware of it and certainly for me it's this idea you know if
1201 you went to the hospital and you were diagnosed maybe they'd give you, they'd say to
1202 you "look there's this app you can use" maybe give you a leaflet with the web, you know
1203 have it written down
1204
1205
1206 **I – yeah, okay so do you think it would be helpful then to have a leaflet on how to use**
1207 **it?**
1208
1209
1210 DS240148.F – yes, yeah I do
1211
1212
1213 **I - okay, well that's it so is there anything else that you think would be helpful or we**
1214 **should know?**
1215
1216
1217 DS240148.F – no I think we've just about covered it really haven't we?
1218
1219
1220 **I – yeah lovely okay thank you, I'll just switch this off**
1221
1222 **End of Interview. Duration 54:07**

Appendix 20: Clinician invitation letter:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs

Health Professional Interview Invitation Letter

We would like to invite you to participate in a research study. The study is being carried out by researchers from Cardiff University who are working with the team at Velindre NHS Trust and Cardiff & Vale University Health Board. We have invited you to take part because **we are interested in hearing the views of clinicians (consultants, nurses and trainees) of patients with cancer.**

The aim of the study is to find out the views of cancer patients, their clinicians and relatives on a smartphone/tablet 'app' that aims to address the information needs of cancer patients. The information we get from this study will be used to help create the app which will be available for cancer patients to use in the future.

We would like to interview you, at a time and place convenient to you, to ask your views on the subject.

We have enclosed an information sheet for you to read and help you to think about whether you would like to take part. Taking part or not is entirely up to you.

If you wish to take part in the study please contact Becky Richards using the contact details below and she will send you an information sheet about the study.

If you decide to take part, Becky will contact you to arrange an interview. If you do not want to be interviewed at present, but may be interested in other parts of the study please tick '*I do not want to be interviewed but am interested in participating in other parts of the study at some time in the future*'.

If you would like to find out more about the study before deciding whether or not to take part please contact Becky Richards, Cardiff University on 02920 687219, Email: Richardsb3@cardiff.ac.uk.

Yours sincerely,

Dr John Staffurth
Consultant Urologist

Appendix 21: Clinician information sheet:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs

Health Professional Information Sheet (v1.1, 27/03/2014)

Invitation to participate in the study

We would like to invite you to take part in a research study. Before you decide you need to understand why it is being done and what it would involve for you. Please read the following information carefully.

What is the purpose of the study?

The aim of the study is to find out the views of cancer patients, their clinicians and relatives on a smartphone/tablet 'app' that aims to address the information needs of cancer patients. There has been a lot of research in the past showing that cancer patients have unmet information needs. There has been limited, if any, research on the potential usefulness of a smartphone/tablet app in addressing cancer patients information needs. The information we get from this study will be used to help create the app, which will be available for cancer patients to use in the future.

Why have you been invited to take part?

We have invited you to take part because **we are interested in hearing the views of clinicians of cancer patients.**

Do you have to take part?

No. Taking part is entirely voluntary. If you do not want to take part you do not have to give a reason. If you decide to take part but later change your mind, you can do so, and you do not have to give a reason why you no longer wish to participate.

What will happen to you if you take part?

If you decide to take part, a member of the study team will contact you to arrange a research interview at a time and place convenient to you. Interviews will take about 30 minutes. The interview will be recorded with your consent. Recordings will be stored in a secure office at Cardiff University. In the interview, you will be asked to tell us your views on the potential benefits, barriers to, and desired features of such an app.

What are the possible risks and disadvantages of taking part?

There are no specific risks associated with taking part in this study. You do not have to talk about any issues you don't want to discuss.

What are the possible benefits of taking part?

This research study will not directly benefit you, but it will give us a better understanding of the views and information needs of cancer patients. This should help us to conduct a short trial of the app, in the hope of the app being available to cancer patients in the future.

Will your taking part in the study be kept confidential?

Yes. All information that is collected about you during the course of the research will be kept strictly confidential.

What will happen to the results of the research study?

Audio-recordings and transcripts of interviews will be stored on Cardiff University password protected computers for 5 years. The data will then be securely archived and then destroyed 15 years after the study is completed. Only the research student Becky Richards and lead supervisor Fiona Wood will have access to the audio-recordings. The results of the study will be written up in the form of a thesis and presented at conferences and published in scientific journals. A report will also be prepared for Tenovus, the cancer charity, who are funding this study. Tenovus may wish to publish summaries of the study on their website. Short reports may also be prepared for interested government departments and the media. A summary of the research findings will be available to you at the end of the study if you would like it. We may use direct quotes from your interview in publications, however all information provided by participants will be anonymised. It will not be possible for anyone to identify you from any of the published results.

Who has reviewed the study?

This study has been reviewed by South East Wales Ethics Committee.

What if you are harmed or unhappy about any aspect of the study?

If you have any concerns or complaints about any aspect of the study please contact Dr Fiona Wood, Institute of Primary Care and Public Health, 3rd Floor, Neuadd Meirionnydd, Heath Park Cardiff. Telephone: 02920 687185, Email: WOOD@cf.ac.uk. Alternatively, please contact Dr John Staffurth, Clinical Oncologist, Velindre Hospital, Cardiff. Telephone: 029 2019 6135.

Who is organising the study?

The study is being organised by researchers from Cardiff University. It has been funded by Tenovus.

Contact for further information

If you would like any further information, or have any questions concerning this study, please contact Becky Richards, Institute of Primary Care and Public Health, 3rd Floor, Neuadd Meirionnydd, Heath Park Cardiff. Telephone: 02920 687219, Email: Richardsb3@cardiff.ac.uk.

What do I need to do now?

If you WISH TO take part please tick **“Yes, I would like to take part in this study”** and fill in the contact details on the Study Reply Form and return the form to Becky Richards via email.

If you do not want to be interviewed but you may be interested in participating in other parts of the study (for example, a consultation with patients who will be using the app) please tick **“I do not want to be interviewed but am interested in participating in other parts of the study at a later date”**. Please also fill in the contact details on the Study Reply Form and return the form via email.

Feel free to call us with any queries you may have and/or talk the study over with anyone else.

Please keep this information leaflet for future reference.

Thank you for reading this information sheet and for taking an interest in the research study.

Appendix 22: Clinician reply form:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs

Health Professionals Interview Reply form

I would like to take part in this study and I wish to be contacted by the research team.

☐

I do not want to be interviewed but I may be interested in participating in other parts of the study at a later date.

☐

Name of Participant:
Telephone:
Mobile:
Email:
Preferred way to be contacted:.....

Appendix 23: Clinician consent form:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address their information needs

Interview Consent Form

Please
initial if
you agree

I confirm I have read and understood the information leaflet dated 27/03/2014, version 1.1 for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.

I give permission for the interview to be audio recorded.

I understand and agree that quotes from my interview may be used within written reports or publications, and that any quotes would be completely anonymous and could not be linked to me in any way.

I agree to take part in the above study.

Name of Participant:.....

Signature:.....

Date:.....

Name of Person taking consent:.....

Signature:.....

Date:.....

Appendix 24: Clinician demographic questionnaire:

Clinician demographic questionnaire

Gender: male/female (please circle)

Occupation:.....

Cancer clinic:

Stage of disease that you usually deal with:.....

Time since graduated:.....

Thank you for completing this questionnaire.

Appendix 25: Clinician interview topic guide:

Phase 1 Clinician Interview Schedule

Prologue

1. Introduce myself, explain where I am from, ensure they're comfortable etc.

2. Check understanding of reason for meeting, give an opportunity for questions:

"Before we start, I wonder if you have any questions about this study or about why I've come to talk with you today?"

Set the focus of the interview and explain the app. Base this around the following script:

"Thank you for agreeing to take part in this study. I want to understand what clinicians of cancer patients think of a potential smartphone/tablet app for patients with cancer. The interview will take around half an hour.

This app would be for use *after* diagnosis and would potentially help patients with their information needs (e.g. by providing information within the app and links to external websites, etc) and help patients to communicate with their clinicians in consultations (e.g. by bringing a prepared list of questions to consultations). The app could also help with things like adherence to medications (e.g. audio medication prompts) and social support (e.g. links to support groups, telephone helplines).

At the end of this study, we aim to develop an app based on the information gathered from interviews with clinicians, cancer patients and their relatives. I am interested in your views on a potential smartphone/tablet app for cancer patients. There are no right or wrong answers to my questions, I am interested in what *you* think."

3. After establishing what is understood about the study, and answering any questions, explain that the interview will be recorded:

"I would like to record what you say as that saves me having to scribble when you're talking and means that I can concentrate on what you're saying. The recording will only be heard by people who are working on this project. The interview will be transcribed and your identity and the identity of any person you talk about today will be anonymised in any published work. Is that okay with you?"

4. Obtain consent for the interview and for the recording. If not already done, set up and switch on the recording equipment while the volunteer signs the consent form.

5. Explain how the interview will work:

"I've planned some ideas about the sorts of things I'd like us to talk about today, and if it's okay with you we'll try and base our conversation around those points. Having said that, if you want to tell me about anything that I don't ask about, please just tell me. Also, if you find a question difficult to answer, please say and we can move on or I could try to ask it in a different way. Of course, if you'd prefer not to answer any question, that is absolutely fine. There aren't any right or wrong answers to anything

I ask you, we're just interested in your own opinions and experiences. Does that all sound alright to you?"

6. Obtain demographic information.

Opening question

- Can you tell me why you were interested in taking part in this study?

Information provision

Rationale: establish amount and source of information provision

- How do you decide how much information you give to patients about their illness?
- How do you provide information to patients about their illness? (prompt: verbally, written information, combination]
- Do you recommend any sources of information for patients and family/friends? (Prompt: websites, helplines, and charities. What sources?)

Communication in consultations

Rationale: barriers to doctor-patient communication in consultations

- What kinds of issues do you think clinicians are faced with when talking to patients about their illness?
- Do you think there are any barriers to communicating with patients in consultations?

Experience with Smart technology

Rationale: to establish clinician's personal/professional experience with mobile technology and apps

- What experience do you have of using a smartphone/tablet computer?
- What do you use your smartphone/tablet computer for?
- Are you familiar with 'apps'?
- Do you currently use any apps for work-related purposes? Why/why not?

Perceived ease of use and acceptability

Rationale: to anticipate ease of use and clinician's support and acceptability of patient app use

- Do you think patients and their relatives would want to use it?
- Do you think patients and their relatives would find this kind of app easy to use?
- Do you think clinicians would be happy for patients to use this kind of app during their consultations?
- Do you think clinicians would be happy for patients to use this kind of app at home?

Perceived benefits of app

Rationale: perceived benefits of an app for cancer patients

- What benefits do you think there might be for *patients* using the app?
- What kinds of benefits do you think there might be for *clinicians*?
- Do you think families or friends of patients would want to use this kind of app? Why?
- Do you think the app would have an impact on communication with your patients? How would it affect communication?
- Do you think the app would have an impact on how patients and their family and friends talk about their illness and share information about their illness?

Perceived barriers of the app

Rationale: perceived barriers of app

- Do you think there may be problems with patients using this app? What do you think the problems might be?

Training needs

- Due to the app, do you feel that clinicians would require training in how to deal with more active patients/changing communication?

Desired app features

Rationale: establish what clinicians would like a cancer app to do/not do

- What sort of app features do you think would be most useful for patients?
- What sort of app features do you think would be most useful for relatives/friends?
- Is there anything that you would want the app to do? If so, why?
- Is there anything that you would not want the app to do? If so, why?

Patient type

Rationale: anticipate what type of patient might find an app most useful

- Are there any particular types of patient that you think might find this mobile technology most useful? (prompt: age groups, patients at different stages of diseases). Why?

1 **Appendix 26: transcript for C19 (Sur) (urological cancer)**
2

3 INT: Okay. So could you tell me why you are interested in taking part in the
4 study?

5 RES: Um, er, I guess, I have got two reasons; one is to, um, one one side... I'd
6 always, um, supported initiatives at the medical school, and make sure
7 students have opportunities to do, um, er, to do projects and things like
8 that... that's one reason of course. And the other reason is that if it does,
9 um, result in improvements in information giving for the patients, it provides
10 an overall benefit, so ...

11 INT: Okay.

12 RES: ... so I think those are the two main reasons.

13 INT: Okay. Um, so how do you decide how much information you give to patients
14 about their cancer, within a consultation?

15 RES: Er, I think that depends on a few things; one is whether it's the first time
16 they have heard they've got cancer. So it's at the time of diagnosis. It may
17 be the time of staging, so whereby the patient already knows they have
18 cancer. Or it may be at a later stage, a later time, so you are trying to, um,
19 modify what you say, and how much you say, depending on when you see
20 them in their particular, er, pathway, if you like. So ...at the outset it's
21 probably best not to say too much, and try and be fairly reassuring.

22 INT: Mhm.

23 RES: It's important both to get the diagnosis across, um, and then outline other
24 tests, if you need them, before you make a decision about what should be
25 done. Er, because patients often find if you tell them they've got cancer,
26 they often will take in very little subsequently during that consultation,
27 because there's a, sort of, element of shock. I guess in terms of giving
28 information, that may depend on, again, which time point we are seeing
29 them, but at the outset it's probably best to give them a small amount of
30 information which is quite general. So if it was prostate cancer it would be
31 a little bit of information about prostate cancer, and a little bit about PSA
32 tests, what the staging tests often involve, and then how, the sorts of
33 principles of treatment rather than detail. Because if you give them a lot of
34 detail and a lot of leaflets they probably won't read any of them. Whereas

35 if you give them a small amount of information at that point in time they
36 may well read through it, or their partner will read through it.

37 INT: Okay.

38 RES: Of course, if you then see them at a later date when you have got all your
39 staging information, and you are deciding between a relatively small number
40 of treatment options, you may then give them, during the consultation, a lot
41 of information verbally about that. And then you may give them written
42 information about that, er, specific treatment option; so maybe two or three
43 different options. So in localised prostate cancer we often talk about
44 surveillance, external [unclear] radiotherapy [unclear] therapy and surgery
45 is the main, sort of, treatment option, so we may well give them information
46 about that. There is very little point in giving them a lot of information about
47 palliative care, and permanent hormone therapy which we give to men as
48 mainly a palliative treatment.

49 INT: Mhm.

50 RES: So you cater the information needs for the stage of the patient at subsequent
51 points. The other thing that you can do, which we don't, we are probably
52 not very good at, is, er, is addressing the information on the internet with
53 the patient in the room.

54 INT: Mhm.

55 RES: We might give them information booklets which describe ... Prostate Cancer
56 UK website, is very good. So we are, sort of, signposting reasonably reliable
57 sources of good information for them. But in some appointments, er, we
58 might, if we have got a reasonable screen, we might show them, "this is the
59 Prostate Cancer UK website, this is the, sort, of localised treatment section
60 that tells you a little bit about them there", and, um, and I see it with that
61 sort of thing.

62 INT: Yeah.

63 RES: But we don't do that very often I don't think, and obviously there are issues
64 around availability of computer screens and showing patients, er, it's not
65 straightforward.

66 INT: Yeah.

67 RES: I think. So I think that probably sums up ...information giving at that point,
68 at those points in time.

69 INT: Yeah. Okay then, um, so what kinds of issues do you think clinicians are
70 faced with when talking to patients about their illness, during a consultation?

71 RES: I think they are faced with different issues at different time points. So at
72 diagnosis, the issues you face are that a) you have got to give someone very
73 bad news, because no matter how aggressive or not the cancer is patients
74 will take that very badly usually.

75 INT: Mhm.

76 RES: And they also will then, as I said, will take in very little information
77 afterwards, so it's challenging (phone ringing) them to get over the, um ...
78 do you want to pause that?

79 INT: Yeah, yes.

80 RES: Just in case.

81 INT: Okay. [Recording is paused].

82 RES: [Recording resumes]. So it at the diagnosis appointment, the challenges are
83 to give them bad news but don't be too gloomy. The challenges are to give
84 them information when they are not actually taking it in very easily.

85 INT: Right.

86 RES: You are trying to give them some encouragement, or some, to give them,
87 er, a steer as to... well actually, although it is cancer, actually there is
88 something we can do about it. Getting those informations across to the
89 patient so that they can remember it. And the other challenge is not to give
90 them too much information; if you say well you have got cancer and then
91 you go into a convoluted story around the principles of staging they are not
92 going to remember anything about that. And you haven't helped them
93 much. You've just given them some bad news and then you have confused
94 them. So, you know, you've got to be giving them the news, try and be
95 accurate, give them some positive encouragement. And tell them about the
96 next steps, but not go into a lot of detail.

97 INT: Mhm.

98 RES: For most patients I think that's the challenge in that appointment. If that's
99 done well, and they have the right information, their next appointment,
100 hopefully with the same person would be much better, because you had met
101 before. They haven't got to get over that cancer issue of diagnosis. If the
102 staging tests have shown its localised disease you have got quite positive
103 views because their worry is that it's spread.

104 INT: Yeah.

105 RES: Every patient who has been diagnosed with cancer, well if it's spread that's
106 the end. I think that's the way many people would probably think. Whereas
107 if it hasn't spread that's great news for patients, and then, er, and then
108 you've got to go through a lot of information at that point, and that's much
109 easier if they've had good information before and not been confused. You
110 know, they can relax a bit, and you've got a bit more time, and hopefully
111 they've read some information. And you can often ask them well what have
112 you, you know, they've seen the, you know, the cancer nurses in between
113 seeing the doctors often. They are on the telephone if they want to ask
114 questions. So it's quite good at the outset then to say well, you know, what
115 do you think of the information? And once you've got the, er, the staging
116 sorted out you know roughly where the treatment options lie, and you can
117 then start to get the patient to tell you what they, what they think about
118 treatment options.

119 INT: Mhm.

120 RES: Maybe when we know it's going to be in that group where the decisions may
121 be around surgery/radiotherapy, or a surveillance programme, so ...

122 INT: Okay. Um, in terms of communicating with the patients in consultations, do
123 you think there are any barriers there?

124 RES: Sorry?

125 INT: Um, do you think there are any barriers when communicating with the
126 patients?

127 RES: Yeah, and I think not all ...

128 INT: In terms of what type of patient you have, or ...?

129 RES: Well I think doctors are nurses, not all of them are very good at
130 communicating anyway. And that's, that is a clear issue.

131 INT: Yeah.

132 RES: Um, and no matter how, maybe, senior they are... some the communications
133 skills is not a given. That's one issue. And some, I don't think some people
134 actually like giving bad news to patients, um, feel it's, sort of, maybe letting
135 them down, or, you know, in some way they would rather give people good
136 news all the time. Rather than apologise that things are so bad.

137 INT: Yeah, yeah.

138 RES: But that, I guess that's human nature. But in terms of receipt of information
139 patients are very different. Some patients don't want any information on
140 treatment options if it's complex, um, and, um, but they will vary a lot. And
141 individuals may have read a lot in the intervening appointment if they've
142 been told before what they've got, they may read a lot about it, and
143 therefore they may have a lot of questions, and very, um, enthusiastic to
144 know precisely what their stage is, precisely what are the treatment options,
145 might ask you well if it's an operation, how many have you done, are you
146 any good at it, in other words. Um, a huge variation.

147 INT: Okay.

148 RES: So I guess there's a, sort of, level of information giving appropriate to what
149 the patient actually wants. Um, so you have to think on your feet a little bit,
150 and yeah you want to give information, basic information, then a bit more
151 complicated, until at some point you have given enough in order to make
152 decisions to the patient, so they are part of the decision making.

153 INT: Mhm.

154 RES: And that can vary a lot between patients. So if you are converting that
155 concept into an app you might say well this is the basic information; it's a
156 bit like the levels in Nintendo II or something. This is your basic level, right
157 we are okay with that now, let's move on a bit more to this if you want to.

158 INT: Yeah, yeah.

159 RES: And then, yeah, and then you can go off to different treatment options with
160 the basic information, then that's a bit more. And you have to judge how

161 soon you can move between those levels of information with patients. And
162 in the clinic, doctors have to think about that on the spot. So actually I think
163 that's a bit much, that's enough now, I am going to step back a bit, and let's
164 look at it again once you've had time to have a think.

165 INT: Yeah.

166 RES: So, you know, of course that's just a judgement thing during consultation.

167 INT: Yeah okay, great. Um, so do you have any experience of using a smartphone
168 or a tablet computer, personally and professionally?

169 RES: Um, I use standard computers to show patients illustrations on websites but
170 not a smartphone or a tablet.

171 INT: Okay, so not professionally?

172 RES: No.

173 INT: Um, and what about personally, do you use any, sort of, smart technology
174 outside of work?

175 RES: I have got a phone.

176 INT: Yeah so you are using, so you are familiar with apps?

177 RES: Not really.

178 INT: Okay yeah, alright then.

179 RES: I phone mainly and text.

180 INT: Okay, okay. Um, so do you think patients, the type of app we are talking
181 about, um, do you think patients would want to use this sort of app?

182 RES: I think many would, um, er, if you look at the, sort of, if you can imagine in
183 your own mind the, sort of, age of the patients with different cancers. So
184 testes cancer would be affecting quite a young male population, um, peak
185 incidence in the late teens, early twenties. So that group would probably be
186 quite familiar with smart phones and apps. Er, many cancers, of course,
187 affect the elderly population.

188 INT: Yeah.

189 RES: And, er, prostate cancer, bowel cancer, a proportion of patients who are
190 using apps on a smartphone, and it's probably worth a survey of that
191 actually.

192 INT: Mm, yeah.

193 RES: I mean, if you, if you said well actually I want to survey the urology clinic
194 for a couple of weeks, and ask the patients how many at this point in time
195 compared to their age would be familiar with an app, that would be quite
196 interesting. Er, I expect, I would be surprised if it was than 50% use an
197 app, currently anyway. But, er, I guess at the end of the day, thinking of
198 the future ...

199 INT: Mhm.

200 RES: ... the men who are 50 now are going to be 60 and they will be using the
201 mobile at home I suspect.

202 INT: Yeah.

203 RES: So there is element of future-proofing in that, in this kind of work, I guess.

204 INT: Yeah, yeah okay. And do you think patients would find it easy to use, or do
205 you think they might require some training beforehand?

206 RES: I think a minority would probably benefit from training within the
207 environment that they are working in. I suspect if they are using the phone
208 apps they are, they will know how to work their way around it.

209 INT: Uh-huh.

210 RES: If they are not using it I expect what they will do is speak to their kids and
211 say ...I've got this app thing, I want to ...can you help me with it. Let's look
212 at your phone ...and let's show me. And then that may be a way of doing
213 it. Running training of apps within the clinic for patients might be difficult.
214 Unless there is an inherent willingness for them to do it on a personal level.
215 Because, you know, if they are shown how to use an app at the clinic, and
216 they haven't got a smartphone ...

217 INT: Yeah.

218 RES: ... er, that's going to be difficult isn't it?

219 INT: Yeah, yeah.

220 INT: Okay, um, do you think clinicians would be happy for patients to use this
221 kind of app during a consultation?

222 RES: Oh yeah, I mean, patients bring bits of paper, articles, all sorts of things. I
223 mean, I think the patient population is changing.

224 INT: Yeah.

225 RES: You know, we are probably 10 years behind America, maybe longer, in terms
226 of what patients want to know in an appointment. And as time goes on
227 patients will bring more and more things in to say I read this, I saw this,
228 um. And if there was a, you know, when we give them written information
229 they come back and say well the information said this ... what does that
230 mean? And there is no reason, if all that was app driven, why they wouldn't
231 do that with an app.

232 INT: Yeah.

233 RES: Um, because, you know, it's just a screen with information on it really isn't
234 it? Or a diagram.

235 INT: Yeah.

236 RES: So I think, you know, the delivery is not critical...in terms of what the
237 response would be to them bringing it in and discussing it.

238 INT: Yeah. And do you think clinicians would be happy for patients to use app at
239 home, sort of, um, not under the supervision of the clinician?

240 RES: Oh yeah, as long as it was, you know, the information on it was accurate
241 and... you know, reliable and, you know... validated, agreed etc. Yeah I can't
242 ...I mean, they are doing it now aren't they?

243 INT: Yeah.

244 RES: You know on computers and things, so ...

245 INT: Yeah. Um, okay so what benefits do you think there might be for the
246 patients using the app? So I know it's a tricky question, because it sort of
247 depends on what the app will do, but what sort of benefits do you think there
248 could be from an intervention like this, for the patients?

249 RES: Of information, so it's an information...app...

250 INT: And, sort of perhaps, helping to improve communication and social support,
251 and so on ...

252 RES: Um, yeah I guess there's information giving at the level which is patient led
253 ...patient driven, so you've got those levels of information.

254 INT: Yeah, so, sort of, at their convenience?

255 RES: Yes, they say right let's just talk a little bit about prostate cancer and PSA,
256 which is a small module, if you like. And then if they want to move onto
257 other things ...they can do at their own pace. So that's good.

258 INT: Yeah.

259 RES: Um, so other things, well if you are going to link in with other resources, of
260 course it could do that. Prostate Cancer UK website ...etc., etc., so we could
261 do that. Linking into other support, well, for example, there is a patient
262 support group we have here, they come to the clinic, you could link into that
263 group, or give contact details, you know, could use, could it allow them to
264 get into a blog?

265 INT: Mm.

266 RES: It could do, you've got to be terribly careful, of course, in that patient data
267 and confidentiality ...not all patients want to tell ...their partners they've got
268 prostate cancer, never mind someone they don't know. So ...in terms of
269 the confidentiality issues, yeah the patient could look outside the box and
270 see what's there for support.

271 INT: Yeah.

272 RES: But you'd have to make sure no-one could look back and say, yeah he has
273 contacted us, he must have prostate cancer. Oh in fact he lives three doors
274 down. He never knew I had it, even though I am a patient support group
275 person. And now I know my neighbour has got it. In fact he hasn't told his
276 wife yet ...or his children, so you can imagine the problems that would
277 cause.

278 INT: Yeah, yeah.

279 RES: So that confidentiality issue, and accessing support, great but you've got to
280 be very careful about the direction of flow of information.

281 INT: Yeah.

282 RES: Er, because they can, that can be ...very difficult of course. So yeah in
283 principle I can see how the link into things can help, but, again, there has
284 got to be an ability to protect the patient from anybody saying, by inference,
285 because they got it through this way, and that means they must have this
286 disease.

287 INT: Yeah. Okay, um, so you talked a little bit about just some of the short-term
288 benefits of an app for patients, can you think of any long-term benefits, um,
289 to patients of something like this?

290 RES: Yeah, I guess it could hold patient information. Um, so say, for example, if
291 a cancer has got, um, a tumour marker we could add in their tumour marker
292 every time they come to the clinic. And then when they come back to the
293 clinic they can say to the doctor that's my record. I had treatment in 2007
294 using my tumour markers ever since...isn't it great, um, I've done very well.
295 Or they could actually complete, um, some quality of life studies on, um, for
296 use, or they could engage in research. So there are other potential benefits
297 to help with their care. So if there were things like tumour markers, or
298 whatever within one cancer site.

299 INT: Yeah.

300 RES: And prostate, of course, is the PSA. So whilst PSA is not very reliable at low
301 levels, plus we get levels of type of diagnosis and staging, it's very reliable
302 after treatment. And therefore, you know, we would like, it would be nice
303 to, you know, those PSA members who are recorded, and then we could look
304 at a graph maybe and then you would see them, if there are changes, what
305 were the rate of changes.

306 INT: Yeah.

307 RES: That would be very helpful. Both for the patient and their doctor.

308 INT: Okay, yeah. Um, you mentioned quality of life studies, do you think an app
309 like this might have any impact on the patient's quality of life, from using
310 this throughout their treatment and throughout their cancer?

311 RES: I mean, it might be helpful, but whether it'll, it would, you know, you would
 312 be able to demonstrate an objective improvement in health related quality
 313 of life, that's a big ask I think to prove it. Um, that's difficult to say.

314 INT: Okay, alright then. And do you think, um, families and friends of patients
 315 would want to use this sort of app themselves, or on behalf of the patient?
 316 Because some patients might be, sort of, elderly, but perhaps they have a
 317 daughter or son who might want to use the app?

318 RES: I am sure some will yeah.

319 INT: Yeah.

320 RES: I am sure some would.

321 INT: Yeah okay. And what kinds of benefits do you think this app might bring for
 322 clinicians?

323 RES: Um, well, as I said before, I think if they've got, um, er, information that
 324 they can retrieve from it with tumour markers, example, so urology,
 325 prostate cancer has got a tumour marker, testes cancer has got a tumour
 326 marker, um and other cancers have got a signature mark, so if you had
 327 those ...that would be helpful. If you were engaging in a project that they
 328 could use to help bring data back for you ...um, that would help for the
 329 clinician.

330 INT: Yeah. And do you think the app would have an impact on communication
 331 with your patients?

332 RES: Um, you might communicate appointments, but I think communicating
 333 medical information about the individual, because of the issues of
 334 confidentiality, that would be quite difficult. You know, at the moment it's
 335 actually not appropriate to e-mail patients ... to non-secure websites, to
 336 non-secure e-mail addresses.

337 INT: Yeah.

338 RES: So if you had to, if I e-mailed a patient and said actually you are due in my
 339 clinic tomorrow, so, er, that doesn't give anything away does it. But if you
 340 said I will see you in my clinic tomorrow and it says my name, cancer
 341 specialist ... and then the e-mail is not secure, the patient's mother reads
 342 it, son reads it ... catastrophe. Um, so, you know, if you bear that in mind,

343 whilst you may be able to give some, or help with organisational things
 344 having a communication with an app, which might then breach
 345 confidentiality, would require a lot of thought.

346 INT: And what about in the consultation, so say a patient has gone away and
 347 used the app to gather information um, and comes back to the consultation,
 348 do you think that might affect the consultation in any way, sort of, improve
 349 it, or hinder it, or ...?

350 RES: No. The patients write things down quite a lot now. If they, I think if they
 351 did something on the app as opposed to the writing it down, I don't think it
 352 makes any difference.

353 INT: Okay. Um, and what about the patient's communication with their family,
 354 and how they talk about, and share information with them, do you think the
 355 app might, sort of, facilitate or hinder information then?

356 RES: I think it probably would help if they had a clear understanding themselves.
 357 And maybe, you know, if you were able to make it interactive in the clinic,
 358 to say right with this app I am going to sum up the staging. So I am going
 359 to do T2, N0, M0, these are the treatment options that I am going to press
 360 the button, that will save on the app, I can take that home and say this is
 361 what the doctor said, this is my stage, this is my recent grade, this is my
 362 PSA, these are highlighted that I've got three or four options, and I can
 363 expand those options up and it will tell you a bit more about them.

364 INT: Okay.

365 RES: So then they are recording the information in a much more presentable,
 366 communicable way to their families. That may be an option.

367 INT: Okay. And do you think there might be any problems with patients using
 368 this app; what sort of barriers do you think there might be to this type of
 369 intervention?

370 RES: Um, the main barrier will be using it. If the, if the ...new, you know, access
 371 to a smartphone, or whatever, a tablet, I think if they are familiar with that
 372 I can't really see there would be any particular difficulties. Providing the
 373 information was logged in, you know, provided the information was in a
 374 logical format and the patient was able to step up the complexity of the
 375 information in an easy way. If the first time you went in and you were told

376 about the complexities of, a, you know, a drug that we don't often use, as
377 opposed to the basics, patients will get confused. So I think, provided it was
378 set up well I don't think I probably envisage any major problems.

379 INT: Yeah okay. Um, and just going back, you mentioned earlier that, you said
380 some clinicians don't particularly like giving bad news. Do you think an app
381 that might, sort of, facilitate question asking on the patients part, do you
382 think that might help difficult conversations like that? Do you think you
383 might, or the patient, um, the patient might be more informed, and would
384 be able, would be more quick to bring up difficult conversations, do you think
385 it might help with something?...

386 RES: Yeah, it may help if the app was ...

387 INT: So I don't think it will come at the diagnosis stage, but in terms of talking
388 about prognosis perhaps, do you think it might help with ...

389 RES: Oh that would help ...

390 INT: ... difficult conversations?

391 RES: ... yes, yeah, yeah, it would help with that. Not at the diagnostic phase, I
392 think that ...

393 INT: Yeah, yeah.

394 RES: ... you know, yeah, but ...

395 INT: Yeah.

396 RES: ... decisions about treatment stage yeah.

397 INT: Yeah, yeah, mm.

398 RES: I think it would help.

399 INT: Okay. And, er, do you think that patients using this app would affect your
400 workload anyway? Because I know you mentioned that you think that the
401 mode of delivery, they bring in paper clippings and things anyway, um, but
402 do you think it would affect your workload if patients brought the app in?

403 RES: Not really no, no not really.

404 INT: And you said that some patients might be more informed, and perhaps
405 become more, um, involved in decision making. Er, do you feel that
406 clinicians would require training in how to deal with the more active patients
407 as a result of the app?

408 RES: Well I think the clinicians would have to have some training on the app, um,
409 because if I, if I am giving any patient information, say Prostate Cancer UK
410 website. And I am showing it to them, I need to know what bits I am
411 going to show them. And what, anything on there that I haven't seen
412 because you don't want ... you know, when you are in with a patient you
413 don't want to be trying to take in information and then you look, er, it's very
414 messy then, it's not not good for the patient. So you ...the clinicians would
415 have to be fully familiar with what is on the app.

416 INT: Okay.

417 RES: Like any, anything you give the patients you have got to know what you are
418 giving them.

419 INT: Yeah, yeah okay. Um, and so you mentioned a few features that you think
420 would be useful, such as the, um, sort of, tumour markers and things like
421 that. Is there anything else that you could think would be useful for patients
422 for the app to do, other than what we have talked?

423 RES: Scheduling appointments maybe. Giving them a reminder to get their PSA
424 tests done, the tumour marker before their appointment.

425 INT: yeah.

426 RES: Um, it might be particularly helpful in that system to, um, er, trigger a
427 telephone appointment with...Because patients often don't need to come to
428 the clinic if they are well. But you need to touch base with them to just make
429 sure their PSA is okay.

430 INT: Yeah.

431 RES: Maybe if you build in a trigger that will set, say, for example, in some
432 patients we don't need to see you unless your tumour marker goes above
433 X.

434 INT: Yeah, yeah.

435 RES: So if it was plugged in and the PSA was X it would say you need to go see
436 your GP.

437 INT: Yeah.

438 RES: And go back to for a hospital appointment. So you could build in something
439 which would be tumour specific to say, mm, that doesn't sound quite right,
440 I think you need advice on that. So you could build in triggers as well.

441 INT: Yeah okay. And, um, do you think there's any features that would be useful
442 for the relatives or friends?

443 RES: I'm not sure there's anything over and above that would be unique for their
444 purposes ...as opposed to over and above what would be helpful for the
445 patient. And the only times at which I am giving information to a relative
446 more than the patients, is where the patient is very sick ...or they are
447 terminally ill and you, you know, they are in the ...er, you know, in the
448 terminal stages of cancer, then you are obviously giving information to
449 relatives in a certain way, rather than directly to the patient.

450 INT: Yeah, yeah.

451 RES: So in this context I am not sure there is anything. Apart from encouraging
452 the patient to share it with their partners/next of kin.

453 INT: Yeah okay. And is there anything that you would want the app to do, other
454 than what we've talked about?

455 RES: Tell me the lottery numbers every Friday night.

456 INT: ((Laughs)) Um, is there anything that you wouldn't want the app to do, that
457 you wouldn't feel comfortable with?

458 RES: Yeah I think the, you know, the confidentiality thing is an issue. Um, I can't
459 think of anything I wouldn't want it to do without probably looking at what
460 it's going to look like, and can do. Um, I can't think of anything immediately,
461 off the top of my head, that I wouldn't... want it to do.

462 INT: Okay. And the last question, um, do you think there's any particular types
463 of patient that might be most suited to something like this? So, sort of, age
464 groups, or patients at different stages throughout their cancer journey, do

465 you think there's a particular, er, niche for this type of intervention within
466 your clinic?

467 RES: Um, I guess it's around the diagnostic stage, and the decision making stage.
468 Because I think there probably is a benefit there, er, because I guess that's
469 what it's targeted at really, isn't it, the information giving around ...?

470 INT: Yeah, yeah.

471 RES: You know, not the follow-up stuff particularly. So I think, er, yeah I think it
472 would have a place in that, yeah.

473 INT: Yeah okay. Alright well that's great, thank you.

474 **End of Interview. Duration 32:00.**

1 **Appendix 27: transcript for C12 (Onc) (colorectal cancer)**
2

3 INT: Okay, um, so could you tell me why you were interested in taking part in
4 this study?

5 RES: Um, I think, er, very important to get the right information to patients, er,
6 it reduces anxieties, it improves, er, that communication link, it improves
7 the understanding between clinicians and the patients. Help in terms of, er,
8 choosing the right treatment for patients, help in terms of not choosing
9 treatment for patients, which is obviously a technically difficult, er, thing as
10 well. Allows that communication probably to expand more appropriately to
11 other members of the family; relations that are obviously important in that
12 also. So I think knowledge is a good thing, um, I think it should aid the
13 interaction between clinician... and demystify a lot of what actually happens.

14 INT: Yeah.

15 RES: And I think the complexity of treatment is what is often the fear, er, for the
16 patients, because it's very much the unknown. So if we can remove that
17 fear then that will improve things.

18 INT: Yeah, okay, er, and so how do you decide how much information to give the
19 patients about their cancer at the consultation?

20 RES: Er, so I think some of it is, it's fairly easy to say oh we should give them
21 everything, but actually I think there are two issues; one there is a pace at
22 what information should be given, so certain bits of information will be given
23 at a different time. Now that varies from person to person.

24 INT: Yeah.

25 RES: So I think you do assess the individual, and you see what their responses
26 are to your initial, er, introduction of information, and then decide what that
27 pace is. You will also decide how far you go with that information.

28 INT: Yeah.

29 RES: So some patients don't want to know everything, some patients do want to
30 know everything, and some ... everyone else is a spectrum in the middle.
31 Um, and there's a bit of clinical judgement there; and that's the challenge
32 in terms of an app, er, in terms of how you deal with that. So that I think
33 that's a key component as to how this should be worked.

34 INT: Yeah.

35 RES: Um, I suppose there some cues that we use, obviously there are various
36 non-verbal cues as well as verbal cues. But, er, on app I think you probably
37 have the ability to double-ask certain questions where you know there are
38 some sensitivities, and that's often what we do as clinicians.

39 INT: Yeah.

40 RES: So if somebody asks me how long have I got to live, I don't instantly blurt
41 out you have got six months. One, because I don't know, er, and two
42 because actually sometimes people ask the question without thinking,
43 because they think it's just a question they should ask. So actually, in a
44 clinical scenario, you can actually say do you, you know, do you really want
45 to know that, what are you going to do with the information.

46 INT: Yeah.

47 RES: Um, er, will it make a difference to you. Er, and sometimes people in this
48 situation, if they are given that information, then assuming it's bad, i.e. they
49 perceive things very negatively. Um, so within an app I think you need to
50 build in that pause, almost to, particularly with more sensitive information,
51 um, and obviously it's more difficult to be very specific for the individual on
52 an app ...but there are certain sensitive items that are more generic that
53 they may not want to know about.

54 INT: Right okay. And do you, well how do you provide that information, is it, sort
55 of, verbal, written information or ...?

56 RES: So, um, verbal initially, but followed up with written information.

57 INT: Okay.

58 RES: Um, certainly when their therapy is going to be ongoing, um, er, or general
59 cancer information leaflets [inaudible – 03.03] situation, bowel cancer
60 leaflets and other cancers that I'm dealing with then.

61 INT: Yeah. And do you recommend any sources of information to patients?

62 RES: MacMillan Back-up, um, is generally the first port of call, I know it's well
63 worked, I get to review some of the stuff myself, so, um before it goes out.

64 Um, then we have, from Velindre, we have specific ones around the types of
65 treatment, er that we would deliver in sometimes non-surgical cancer care.

66 INT: Yeah.

67 RES: So that's radiotherapy, chemotherapy etc. Um, so those are the probably
68 the core components yeah.

69 INT: Okay. Um, alright then, um, so what kinds of issues do you think clinicians
70 are faced with when talking to patients about their cancer?

71 RES: Um, the clinicians, er, they have to deal with, um, I think, er, giving
72 information in a clear, understandable fashion, that is delivered in a timely
73 fashion to the patient, at a place that they can cope with.

74 INT: Yeah.

75 RES: And then tailoring that into information to the individual. So you are dealing
76 with very sensitive, very emotional, times for the patient, and knowing that,
77 er, individuals can take in that information in very different ways. Knowing
78 that when you are giving information, that actually the majority of what you
79 are saying is not going to be taken in first time around, and actually
80 repeating and going over things is, can be a very, er, important part of that.

81 INT: Yeah.

82 RES: But that's where you'd see an app as support, that sort of, that component
83 for patients, I think. Or as written information can do for certain patients.

84 INT: Okay and what about in terms of the patient, um, do you think there's any
85 barriers to communication, um, within the consultation, on the patients...

86 RES: Yes, I mean, I think certainly initially, er, the first barrier to communication
87 is the anxiety ...

88 INT: Yeah, and you've mentioned ...

89 RES: ... that the patient has.

90 INT: ... that they, sort of, don't take it in.

91 RES: Yeah. Um, I think, er, we know through previous experience of interviews,
92 that most of what they take in, as soon as you mention the, and particularly
93 a new diagnosis, cancer, then that's pretty much where the information

94 stops. And after that they get very little more from that initial consultation.
 95 That's not to say you shouldn't try and give them some more information;
 96 obviously other family members, and things, are often present and can take
 97 in a little bit more. Um, but I think, er, you know, that's a huge issue to bear
 98 in mind.

99 INT: Yeah okay. Um, so do you have experience of using a smartphone or a
 100 tablet, um, personally or professionally?

101 RES: Um, personally, I mean, I have a smartphone, er, I have a tablet, I use them
 102 frequently for gaining information. I will even ...

103 INT: Is that personally?

104 RES: Personally and ...

105 INT: Yeah, ah both ...

106 RES: ... professionally.

107 INT: Yeah.

108 RES: Um, so personally definitely, professionally at certain times I do. Er, I think
 109 there are, er, certain apps I am not using at the moment that I have used
 110 before, er, which can give you information in terms of prognostic information
 111 that can stratify patients into different groups.

112 INT: Yeah.

113 RES: So you can, you can plug in certain, er non, er, named data for a patient
 114 and actually it will tell you what their risk of cancer recurrence is.

115 INT: Right okay.

116 RES: That sort of thing. So there are scoring systems for that which can be quite
 117 useful. And some of those produce images which can be quite useful for
 118 discussing with a patient as well. So you can actually look at the, er, at the
 119 survival, let's say, of a patient if they don't receive an agilent chemotherapy. Er, and then you see what impact the agilent chemotherapy
 120 would have in terms of increasing that survival, and that will then, it can
 121 visually help discussing with the patient um, how that's used. Again, I don't
 122 use them at the moment, that's because I don't have a tablet like they use
 123 in clinic.
 124

125 INT: Right okay.

126 RES: Um, but in theory there's things that the clinician could certainly use quite
127 effectively.

128 INT: Okay. So do you think if clinicians had access that this is something they
129 might take up?

130 RES: Yeah, no I think it, I think they would do, yeah.

131 INT: Okay, um, alright then. Um, do you think patients would want to use, um,
132 an app, um, the type of app we talked about?

133 RES: Definitely a proportion of patients. I think there is, er, and I think it will
134 increase as well. I think this is why it's timely, and you look at the, er, for
135 want of a better word, younger generation, er, and they will almost
136 inevitably, by the time they get to the median of where cancer's occurring
137 ... obviously it can happen young, but the majority of cancers happen as you
138 get older.

139 INT: Yeah.

140 RES: Er, will be in the scenario, in the technology world, where the app is
141 standard, or an equivalent, there may be something beyond the app that
142 will occur, where they will look to the app to try and answer questions. They
143 will look to their smartphone to try and answer questions. Um, I think that
144 having said that there is an older population at the moment who have
145 adapted apps very effectively.

146 INT: Yeah.

147 RES: Er, and it is, they are generally very user friendly. There is a cohort of
148 individuals, particularly the more mature group, who don't know what an
149 app is. Er, and so I think there is a spectrum obviously.

150 INT: Yeah. So would you say age is a barrier, or do you think [inaudible – 07:36]
151 ...

152 RES: Not age specifically. I think you've got this trend across the different ages
153 which will, if you wanted to, sort of, put it statistically then they are less
154 likely, er, than the younger group to use the app, yeah.

155 INT: Okay, alright then. Um, and what about clinicians, do you think they'd mind
156 patients using this app during a consultation?

157 RES: Um, I think, er, there would a variety.

158 INT: Yeah.

159 RES: I think there are clinicians are wary of things ...that break up this scenario.
160 There are, um, there were, there are, very sensibly I think, concerns about
161 what information is on there, and the speed at which that information is
162 given. Um, and the, and the utility for the individual. Um, so I think there
163 are some sensible concerns, there are some blocking concerns, just because
164 ...because people don't want to change things. Um, they can potentially,
165 obviously, slow down consultations, so then ...you make them longer.

166 INT: Yeah.

167 RES: Er, we have to bear that in mind. But I think in the end of you have a quality
168 consultation, in the end it probably speeds things up overall. As well as
169 improves the quality of that consultation.

170 INT: Yeah okay. And what about outside of the consultation; do you think
171 clinicians would mind patients using an app, sort of, without their
172 supervision?

173 RES: Um, I think, well I think if you are going to have an, er, then I think you
174 have to be prepared for that. I mean, they can get this information off the
175 internet generally speaking anyway. Um, what you have, the ability with an
176 app is to give some control over that, because if you go to the internet and
177 do a random search you will come up with a lot of misleading information
178 ...a disinformation. Er, which patients find scary, because they are then
179 confused by, er, the information given by the clinician, and they haven't, er,
180 and it's not necessarily true for their case.

181 INT: Yeah.

182 RES: Um, so I think we are, we are aware that happens anyway. If you have an
183 app in which that information is more effectively controlled; both in terms of
184 the type of information available but the speed at which that information will
185 come through, er, then I think you have got a greater utility for that app to
186 work.

187 INT: Yeah okay. Um, and what about, um, relatives, because we are thinking
 188 perhaps the patient, um, isn't keen to use the app, they may have a son or
 189 a daughter that might use it on behalf of them, do you think this is something
 190 they would like to use?

191 RES: Yeah, no I think that would be a very, very good way of doing it, yeah.

192 INT: Okay. And what benefits do you think there might be for patients using this
 193 type of app? I know this, sort of, depends on what features the app will
 194 have, but, um ... in general?

195 RES: I think ...I mean, it does depend on the feature, I mean, I think there are,
 196 er, in one of the, er, a common scenario, let's say, is when I see a patient,
 197 particularly in a new situation, or a changing situation, I am aware the
 198 information I will give, and the limited, sometimes limited information they
 199 will retain. But I encourage people to go away and think of questions and
 200 bring them back and write them down.

201 INT: Right.

202 RES: This will help augment that, so you could have things on an app that trace
 203 the sorts of things they wanted to look up. So that then when they go away,
 204 and they say right well I, when I got away from you I couldn't quite
 205 remember what you said about this or you said this, and I was worried about
 206 that, so I looked it up.

207 INT: Yeah.

208 RES: And you can almost go back through the history of what they looked up, and
 209 actually retrace some of those questions.

210 INT: Yeah.

211 RES: And make sure the information on the app was clear, whether it related to
 212 them specifically or not.

213 INT: Mm.

214 RES: So you have an ability to use the app to track and store the information that
 215 the patient has actually tried to utilise and guide that then once they've
 216 actually looked it up, and see if it's appropriate to them.

217 INT: Yeah okay. And, um, what about clinicians; what kinds of benefits do you
218 think there might be for clinicians?

219 RES: Um, I mean, although the initial impression is that it will probably slow things
220 down, I think overall it will speed things up. Um, I think overall it will create
221 a much better relationship between the clinician and the patient and
222 relatives. Er, I think communi... you know, the biggest problem in medical
223 healthcare, generally speaking, is poor communication. It's where
224 something has been miscommunicated, or not effectively communicated,
225 um, that leads then to anxiety, to medico-legal issues etc. So I think if you
226 are clear about that information I think it will be a very positive outcome ...

227 INT: Yeah.

228 RES: ... for clinicians as well.

229 INT: Exactly. Um, and just going back to the patients, we touched on some of
230 the short-term benefits, do you think there are any longer term benefits, do
231 you think this could affect patient outcomes...So you mentioned that perhaps
232 it could reduce anxiety?

233 RES: Mm. So I think reducing anxiety is obviously a very clear one. I think you've
234 got, you have a lot of patients now who have been cured with their
235 treatment, whatever treatment that is. And actually they are then put into
236 follow-up regimens. Now you could build in an app that did multiple different
237 things; one, you could build in so that that patient understands what their
238 standard follow-up pathway would be.

239 INT: Yeah.

240 RES: You could even build in things that go onto their calendar and say you will
241 be due a colonoscopy in three years' time, a follow-up appointment in three
242 months' time. So that they take a bit of responsibility for their own care.

243 INT: Yeah.

244 RES: The NHS is, has got all its imperfections, and actually if the patient is in
245 charge of their own care and is able to augment that by saying actually I
246 should have been this, that or the other, and for some reason it's gone
247 missing, they can really help.

248 INT: Yeah.

249 RES: Um, it also has the ability to link in then with, you know, making sure you
250 come to appointments even.

251 INT: Yeah, yeah.

252 RES: Making them understand why that happens. I know in other hospitals, not
253 on an app, so to say, but actually people have the availability in certain
254 hospitals in the UK to actually access online their actual clinical data. So they
255 can look up their tumour marker result, for instance if that's part of their
256 follow-up.

257 INT: Yeah.

258 RES: And actually they can then flag any issues if they are concerned about it.
259 Now as long as they are well informed as far as that's concerned I don't have
260 any fears about that. They will know, they might even get their CT scan
261 result that they can get downloaded from the computer. So an app could
262 actually, potentially, be integrated with that in the long-term as well. So
263 very much personalising their information. Which over a longer period of
264 time, er, will help engage their, them as an individual in the process of their
265 care.

266 INT: So do you think this app has a place, um, sort of, post-treatment then?

267 RES: Yeah.

268 INT: Do you think it could help them?

269 RES: I think so, yeah.

270 INT: Okay, um, alright then. And we talked about, you said, um, perhaps it could
271 improve the relationship with the clinicians.

272 RES: Mm.

273 INT: Um, so do you think the app would have an impact on communication with
274 your patients?

275 RES: Yeah. So I think there may be, the app, um, can be introduced, obviously,
276 at various different stages, but certainly prior to the second visit, if they
277 download the app and they have been on to answer those, ask those
278 questions, they will be able to, you know, certain things might be, common
279 questions that are asked. The frequent, you know, the facts, the frequently

280 asked questions, they may want to go through those before they then come
281 back and see you second time, or even, or the first time.

282 INT: Yeah, yeah.

283 RES: Because if it's a well-known app then the carer, the relative, the son, the
284 daughter or the individual may well have downloaded it. And said right I am
285 going to see them, I know it's going to be something about bowel cancer,
286 because they had a look and they said there was a lump, and they thought
287 it was going to be a cancer. Well look, I have looked up these questions,
288 and actually that will, like, help guide them when they actually come to that
289 assessment.

290 INT: Yeah.

291 RES: And help aid them in that process.

292 INT: Yeah okay. And do you think the app would have an impact on how patients
293 and their family share information?

294 RES: Yeah, well I think again, if there is more commonality in terms of the
295 information that's given then actually if son A in Australia has the app, and,
296 um, the individual has the app also then they have looked up the same
297 consistent information. And the consistency of information is important, as
298 I say, the difficulty is you have one family member that looks it up on the
299 internet, has slightly the wrong information, and gets a very differently
300 outlook the disease. Compared to people looking up on the same information
301 sites, and therefore being consistent in terms of how they are discussing
302 things and that will improve family communication, which is a very positive
303 outcome.

304 INT: Yeah okay. And do you see any problems with patients using this app; were
305 there any barriers that you can see?

306 RES: Those who don't want to engage in technology.

307 INT: Yeah.

308 RES: So you miss a cohort of people as far as that's concerned. I think it's
309 technically a very difficult thing to do well. Um, it's, it can be done, er, very
310 superficially, or it can be done in-depth. Um, there could be potentially a
311 huge amount of work engaged in it, if you want to take it and build on it,

312 but I, you know, the first steps I think you need to take are fairly simple
313 and that's things like frequently asked questions, things that lead them to
314 websites that would actually give them additional information. Um, things
315 that lead them to, er, places or persons that actually can be of help to them.
316 Um, whether that be ensuring that somebody with an incurable disease is
317 referred through palliative care, and what palliative care consists of, and
318 what local facilities for palliative care there are.

319 INT: Yeah.

320 RES: Um, or, er, more specific information about treatment that's going to be
321 potentially required.

322 INT: Yeah okay. Um, and do you feel that patients using this app would affect
323 your workload in any way?

324 RES: Um, I think, er, it does depend; I think there are certain patients who will
325 want to scroll through the app consistently through the, um, through the
326 consultation and you have got to be a little bit cautious of that. One, that
327 they are actually paying attention to the answers you are giving, rather than
328 just the app. But I think it could be a support, certainly a supporting tool.
329 Um, I think overall it's got potential to improve the time management, as
330 opposed to be detrimental to it.

331 INT: Yeah.

332 RES: But I think there are probably some short-term losses and some long-term
333 gains.

334 INT: Yeah okay. Um, do you feel that clinicians might require extra training in
335 how to deal with perhaps more active patients as a result of the app, if they
336 are asking questions?

337 RES: Um, I think, I think we should, I think it's not specific to the app, I think,
338 um, we are getting increasingly, without necessarily any training,
339 increasingly aware of the cohort patients who will go out, look up everything
340 on the internet, bring in the information to you in reams of documents and
341 things.

342 INT: Yeah.

343 RES: Or say do you know about this or this, etc., etc. So we are getting used to
344 that anyway. Having said that, I don't think it's a bad idea that clinicians
345 are continually updated in terms of what's available, er, and how individual
346 patients are managing this. So I think there is very limited research to say
347 how we should deal with it, we deal with it because we are used to dealing
348 with communication with a, with a broad spectrum of patients but actually
349 there may be specifics, er, related to patients who are very proactive in
350 seeking things on the internet, alternative therapies, for instance, as well,
351 for which better training for doctors would be useful. But we haven't got the
352 evidence base to say whether that would help or not. But you, you could ...
353 certainly another piece of research would be to look at that sort of issue.

354 INT: And what about, um, training on the app, do you think it might be a good
355 idea, um, to have clinicians just trained in, you know, this is what the app
356 ...

357 RES: Yeah.

358 INT: ... does, do you think ...

359 RES: I think ...

360 INT: ... that would be useful?

361 RES: ... I think that's very, very useful. And, er, cancer clinicians, I think,
362 particularly oncologists, are aware of things like websites such as MacMillan
363 Back-up and things like that, Cancer Research UK. Um, not all are, and I
364 think if an app was to become fairly standard, then actually knowing about
365 that information would be good.

366 INT: Yeah.

367 RES: We are generally used to what's contained in our information leaflets. Er,
368 but actually this would expand beyond that and, er, it would be helpful to
369 have some sort of training in it absolutely. Most of it hopefully would be fairly
370 simple, so it maybe the app itself you can train just by downloading the app
371 and having a look at it.

372 INT: Yeah, yeah.

373 RES: And it would tell you what it's about, the sort of information ...

374 INT: A tutorial.

375 RES: ... that's on it. Absolutely.

376 INT: Yeah okay. Alright so what sorts of app features do you think would be most
377 useful for patients? I mean, other than the ones we've talked about.

378 RES: Um, again it depends on the spectrum that you wish this app to, sort of, link
379 into in the end.

380 INT: Yeah, yeah.

381 RES: So you've got everything from the, er, the more generic information about
382 what, er, what the cancer is, that particular cancer type, what it means,
383 what the types of treatment are, um, down to things that are local level, so
384 bring them as local as possible. So you might say, you know, your treatment
385 is likely to be given in Velindre, if it's this type of cancer. Or it might be, it
386 might be it is likely to be given in your local hospital, er, down to that whole
387 specific information. It links, as I say, with palliative care.

388 INT: Yeah.

389 RES: Contact, er, financial support that's locally available, for instance. Transport
390 links, and how you ...

391 INT: Sort of, addressing ...

392 RES: ... what if there's an ambulance issue and you haven't got a car, how do you
393 go about doing that, so logistical things which are a bit more specific, and
394 then you can move on all the way down to the other end of the spectrum,
395 which again, as I said before, is you could use the app, potentially, to link
396 to their personal information in a secure fashion. That actually they would
397 log on to their computer notes, they would log on to their results. Er, they
398 would, er, download specific timetabling of when their appointments should
399 be.

400 INT: Yeah, yeah.

401 RES: Um, and I think those could take it, you know, to that extreme, I would say.

402 INT: Okay. And what about, um, for relatives and friends, do you think there are
403 any app features that would be useful for them, if they're any different from
404 the patient?

405 RES: Yeah I think there are, I think there are; I think the relatives' perspective is
406 often very different to the individual. Um, relatives will often feel that,
407 strangely enough, relatives often feel more stressed than some of the
408 patients, because they feel useless, they feel they can't do anything. I think
409 where one, an appreciation of the perspective of the relative, um, an
410 appreciation of their optimal interaction with the patient, generally speaking,
411 so actually talking about things is not necessarily a bad thing. Things like,
412 particularly with more advanced disease, where things like appetite become
413 an issue.

414 INT: Mhm.

415 RES: Often things, family get very stressed about how much the individual is
416 eating. Whereas the person with the anorexia just doesn't feel like eating
417 anything, and the anxieties that raise then between family members, both
418 meaning very well but actually not fully appreciating or understanding where
419 the other person is coming from, and information like that would probably
420 help with their interaction much more effectively.

421 INT: Yeah.

422 RES: I think there are support networks which, er, could be more specific to
423 patients as well, so the ability, the knowledge that as a relative or a carer
424 they are actually talking with things like palliative care teams is actually still
425 very relevant.

426 INT: Yeah.

427 RES: The palliative care team is for the whole unit and if your palliative care team
428 can help, er, the carer that will help the individual, and that's the whole
429 process which is important. So I think that will, that it can certainly help.

430 INT: Yeah.

431 RES: Um, I thought of something else for relatives as well, but they are probably
432 the main things I can think of at the moment.

433 INT: Yeah okay. Um, and is there anything that you would want the app to do,
434 as a clinician?

435 RES: Um, I think it would be nice to know if it, if the patient wishes you to do so,
436 um, the sorts of things that patients are looking up.

437 INT: Yeah right.

438 RES: I think it would be nice to have feedback from the app, to say right what
439 sorts of things are happening, I think, er, you could also use the app more
440 effectively in the future. I mean, in Wales as a whole, but in Velindre
441 probably more specifically, we do a lot of trying to get patient feedback.

442 INT: Yeah, yeah.

443 RES: So there may be questionnaires about satisfaction, er there may be them
444 being able to raise issues that they are concerned about. Um, that could be
445 hugely powerful in terms of us trying to adapt our service to a more effective
446 system in the future. So I think that's, you know, it adds potentially great
447 value to that sort of thing.

448 INT: Okay, that's interesting. Um, and is there anything that you wouldn't want
449 the app to do, that you wouldn't feel comfortable with it doing?

450 RES: Um, no I think, I think in the right context you can deal with most things. I
451 think there are, I can see how some clinicians would have concerns. So you
452 look at the situation in England at the moment with regard to surgical
453 outcomes, and, sort of, this slightly, er, which you can do anywhere on the
454 web, is try and find out what, you know, how many operations your surgeon
455 has done of that particular type, etc. I think they are still good things to do,
456 but I can see there are anxieties, um, from clinicians that may be, er, slightly
457 problematic in terms of the depth at which such an app would go to.

458 INT: Yeah okay. Um, and so the last question, er, are there any particular types
459 of patient that you think might find this app useful; do you think there is a
460 niche, perhaps, along the cancer pathway for this app? Or do you think that
461 it could be suitable ...?

462 RES: I think it could be suitable for all; I don't think there is any ...

463 INT: Because you mentioned that ...

464 RES: ... routes.

465 INT: ... with treatment it could be, so ...

466 RES: Yeah.

467 INT: ... do you think that ...?

468 RES: So I don't think there are any groups that it shouldn't be considered for.

469 INT: Yeah, okay that's great. Do you have anything else you would like to add?

470 RES: Um, so the only other thing I would add is just in terms of what other things
 471 are happening elsewhere for ... you develop an app, and you have basically
 472 got to pool things together. So I know there is work going on, er, for
 473 instance, for toxicity assessment apps. So, um, let's say we are routinely
 474 giving a course of chemotherapy, let's say over six months.

475 INT: Yeah.

476 RES: Then each week, every second week, or third week, somebody has to come
 477 in, and then they are seen by the clinician or the non-medical prescriber.
 478 They go over their list of side effects from previous treatment, then, er, then
 479 adaptations are made. You would have the potential facility within this to,
 480 er, link to the same app there, where what is actually happening, patients,
 481 before they come to clinic, are answering a fairly standard group of
 482 questions, which is then available to be recorded on their notes. You could
 483 then look at the trend in changes of toxicity; so if you can see certain things
 484 are accumulating in terms of significant problems, it might be much more
 485 effective in terms of raising concerns about the next cycle of treatment.

486 INT: Yeah.

487 RES: And therefore reduce, not only morbidity, but potentially mortalities,
 488 because patients can die of treatment. But if you can flag things at an earlier
 489 time point by tracking them in detail, using the... the patient, then I think
 490 that's got potential ...

491 INT: Has that ...

492 RES: ... safety issues.

493 INT: ... [Inaudible – 25:25] evaluations of, um, toxicity actually? Are they the
 494 ones you are referring to, have you come across them?

495 RES: Yeah.

496 INT: Yeah, yeah. So I am aware of this, it's really interesting, yeah.

497 RES: You can also look at toxicities, sort of, late outputs as well; so when we give,
 498 I mean, I give radiotherapy to the pelvis, and radio... to the pelvis, when we

499 use it it can be palliative, but for a lot of the patients it's for curative
500 treatment.

501 INT: Oh yeah.

502 RES: And we follow up people for a period of time. But some toxicities can come
503 quite late, so actually the ability to link into some of those other things from
504 patients, even when they are discharged and see where help can be sought,
505 whether their symptoms are expected, whether there's anything can be done
506 about them. Those ...those sorts of things might be helpful in the future as
507 well. So survivorship issues I think are important.

508 INT: Yeah.

509 RES: One of the important things we are beginning to look at in terms of clinical
510 research, and clinical care, is a think called patient reported outcome
511 measures, or PROMs.

512 INT: Yeah, yeah.

513 RES: And so you would have some ability to look at those more effectively as well.

514 INT: Yeah. And what sort of PROMs would you suggest might be helpful for us...

515 RES: Well that's the whole difficulty about PROMs, so to get a good PROMs data-
516 set you need a, you know, quite an extensive analysis to actually hone those
517 down which consists of interviewing numbers of patients and clinicians, and,
518 um, er, nurse specialists etc. So, er, and certainly it comes down to be fairly
519 disease specific, fairly treatment specific.

520 INT: Yeah.

521 RES: But in the context of, let's say, pelvic disease it's going to be things like
522 incontinence, urinary incontinence, bowel incontinence, pelvic pain, buttock
523 pain, er, these are things that are commonly flagged by patients as a
524 concern. Um, and ...

525 INT: And what about psychological PROMs?

526 RES: Yeah, and they are important as well; so emotional anxieties ...all of those
527 issues, the ability to interact socially, er ...a very important patient reported
528 outcome measure potentially as well.

529 INT: Okay. Um, and I just quickly wanted to ask you, because you are an
530 oncologist, do you think you have any, sort of, different perspective on this
531 app compared to a surgeon? Do you think there is anything that you would
532 want the app to do that ...?

533 RES: I think we are, we are becoming increasingly multi-disciplinary in terms of
534 understanding what one another do. But I am sure we will have different
535 contexts in terms of what we would expect it to do. I suspect, as an
536 oncologist, we are probably more broad reaching than some of our other
537 colleagues in terms of what we would anticipate from it. Um, but no, I mean,
538 I think it's, er ...

539 INT: You seem to have touched onto ...

540 RES: ... generic [unclear – 27:44] (speaking together)

541 INT: ... the same issues. I am just, I am just trying to pick up if there is anything
542 that you, sort of, view differently to a surgeon, as an oncologist?

543 RES: I think my, er, I suppose you could flag there are things, er, and the instant
544 thing is that ability to track somebody's toxicity over the period of treatment.

545 INT: Right, okay yeah.

546 RES: You know, most surgical treatments are as treatment would cover. Um, you
547 do want some follow-up data, or you want some data that says actually
548 you've got chronic abdominal pain after your surgery then that's useful.

549 INT: So perhaps we could incorporate, you know, a feature that it might be useful
550 to incorporate.

551 RES: Yeah.

552 INT: Okay that's great, thank you.

553 RES: Thanks.

554 **End of Interview. Duration 29:00.**

Appendix 28: C2 (Onc) (breast cancer)

1 **I – okay, so firstly could you tell me why you’re interested in taking**
2 **part in this study?**

3

4

5 DS230135.M – always happy to help with research and I think any
6 patient information is under studied, probably not that well
7 addressed with a lot of new technology we should be able to use it
8 better and there’s lots of sources that we should be able to put
9 together to help people ask the right questions, not just rely on
10 what’s said during consultation perhaps be supported better with
11 other media that would be good

12

13

14 **I – okay and so in your consultations how do you decide how much**
15 **information you give to patients about their illness?**

16

17

18 DS230135.M – um, mainly it’s led by the patient um, sometimes by
19 the relative, the family whoever is attending with them as well

20

21

22 **I – so they could decide how much they’d like?**

23

24

25 DS230135.M – yeah I mean in general our patient group, breast
26 cancer um, is most patients want most information so we go with the
27 premise that we’ve got to have time to give information, if the
28 balance you know um, is not overwhelming important information

29

30

31 **I – okay**

32

33

34 DS230135.M – we have to answer questions that people want
35 answered not just, some of it you’ve got there is information that you
36 have to give, you’ve got to give for safety reasons and stuff, but
37 mainly it’s let by the patient

38

39

40 **I – by the patient, okay and how do you provide that information is**
41 **it verbal, written or a combination?**

42

43 DS230135.M – a combination

44

45

46 **I - and do you recommend any sources of information to patients**
47 **like helplines, or charities?**

48

49

50 DS230135.M – yes, I mean we have, so I think the information that we
51 give does have some....I think some of the recent information sheets
52 to recommend, do mention that you can get extra information from
53 the <hospital> intranet which has recently re-launched, um
54 and we, I know that patients come because we're not seeing patients
55 we're not the first people to see them, so they've had information,
56 they've had sorts of information, often breast cancer care, and
57 information sheets and we have 2 sources that we generally say to
58 trust because they're relevant they're proportional, they quite well
59 written that's Breast Cancer Care and McMillan but we offer, like we
60 do give people information about Tenovus, but that's more um, but
61 that's more for counselling and help with benefits and stuff like that

62

63

64 **I – okay**

65

66

67 DS230135.M – and we're aware that a lot, you know some
68 information out there, sometimes that's daunting rather than helpful
69 we signpost generally to McMillan or Breast Cancer Care and a lot of
70 information in all the places is quite similar it's been adapted, people
71 have shared it around and adapted it

72

73

74 **I – yeah, alright then and what kind of issues do you think that**
75 **clinicians are faced with when talking to patients about their illness**
76 **in consultations?**

77

78

79 DS230135.M – well um, well I guess there are, there are different
80 agendas there's what the patient wants to know and there are things
81 that you feel that need to be said, that maybe as we said for safety,
82 also for moving the treatment plan forward, so there's a bit of
83 pressure of time to get it all, to get it all done in the time that you've
84 got and, and not spend too much time, that you've got too much
85 information and they can't take it in

86 **I – yeah**

87

88

89 DS230135.M – and what's the bit I'm not sure I've answered your
90 question?

91

92

93 **I – uh yeah, yeah what kinds of issues do you think clinicians are**
94 **facing, so other things that clinicians have said, or you know there's**
95 **too much information patients hear the word cancer and then they**
96 **you know it goes over their head, or they're in an anxious state**
97 **coming in...**

98

99

100 DS230135.M – yeah, so yeah and often there's also the complex, or
101 differences between what the patient may want, the amount that
102 the patient may want to know and can take in, and there's the needs
103 of the partner, there which may be quite different, and though one is
104 there for the patient primarily obviously the family have an impact
105 and that can drive you as a clinician, it's unfair to leave them without
106 some guidance, I mean we do a lot of it by staging because we can do
107 a certain amount and then we tend to reinforce, we have multiple
108 visits usually

109

110

111 **I – right okay**

112

113

114 DS230135.M – so we can reinforce it and then there's multi-
115 professional teams there's usually a nurse specialist involved who
116 may not, maybe more than one and then maybe in, in each of the
117 times, but they're always there for, there's other people you know to
118 ask questions

119

120

121 **I – okay and what about experience of these sorts of devices. Do**
122 **you have any experience of using a Smartphone or a Tablet**
123 **computer personally or professionally?**

124

125

126 DS230135.M – personally yeah, yes very

127

128

129 **I - and is it a mobile or a tablet or both**

130

131

132 DS230135.M - both

133

134

135 **I – both yeah**

136

137

138 DS230135.M – as little as possible

139

140

141 **I - okay ((laughs))**

142

143

144 DS230135.M – professionally....hmm with patients, no but I've
145 considered trying to get hold and I think if there was better
146 information um, especially visual information, perhaps I think tablets
147 would be excellent, but I haven't pursued that much because the
148 visual information isn't great, the provision of information out there
149 isn't great, so a lot of people like to, often a picture is better than...

150

151

152 **I – right okay yes, so that's what I was going to say what would you**
153 **use the tablet for with the patients?**

154

155

156 DS230135.M – well I think in a consultation you could use it to show
157 things, ((rummages in bag)) things like this, and this is not really
158 relevant to us cos it's from an app this is from bowel cancer type
159 things, but um you can show anatomy which is, for some things it's
160 quite helpful, um, and you might be able to show imaging, if you
161 know if you could show their scans and stuff on a tablet it might be a
162 lot easier, because we do often try to show it on the screen on the
163 desktop screen, but that's a bit cumbersome and it's not, I feel it's
164 not great, it's nothing to point at...

165

166

167 **I – yeah, yeah**

168

169

170 DS230135.M – so that would be quite useful um, and you could show
171 figures like survivor and risk information. I do show that to people

172 that might, that might be friendlier if it's in front of them like that
173 and then potentially if you could take that away in an electronic form
174 and then the patients could sit and think about it, rather than having
175 it flash up on the screen and then take a slightly black and white
176 dodgy printed version of it if they really wanted to

177

178

179 **I – so you've mentioned that it might be friendlier, can you just**
180 **explain what you mean by that? It could be friendlier on a tablet**
181 **for the patient compared to looking at a computer?**

182

183

184 DS230135.M – well um, because if you've got it on your lap you've
185 got control of it, and you, it's I don't know ((laughs))

186

187

188 **I – ((laughs))**

189

190

191 DS230135.M – I don't know, it's just, yeah what's the word the
192 ergonomics of it, you can see it better and you can focus in, because
193 if you're leaning over somebody's desk it's, it can be, you might find it
194 difficult to see, let alone feel that it's yours, and then you could take
195 it away couldn't you into another room and have a look at it and have
196 it on in the car

197

198

199 **I – hmm that's brilliant that's a good point. Okay so that's**
200 **interesting. So you are familiar with apps and you don't use any for**
201 **work, okay**

202

203

204 DS230135.M – no, not for....

205

206

207 **I - patients?**

208

209

210 DS230135.M – yeah not for patients, educational and stuff

211

212

213 **I – educational and stuff, and what sorts of things have you used?**

214

215 DS230135.M – well sometimes at the meetings, I'll tape stuff and
216 that, but I do look at journals and stuff. I do use apps for practical
217 stuff like converting weights and stuff like that...and they're very
218 useful for managing diaries and stuff like that uh..if you're looking at
219 protocols sometimes and you can just surf, just looking on the
220 internet sometimes, but not actually showing to patients I don't, no, I
221 don't

222

223

224 **I - okay alright so the type of app we've talked about, do you think**
225 **patients would want to use that type of app?**

226

227

228 DS230135.M - well obviously some would, and some wouldn't yeah

229

230

231 **I – okay so could you just elaborate a bit on that**

232

233

234 DS230135.M - I mean there's

235

236

237 **I – who could you imagine would use it, and who might not use it?**

238

239

240 DS230135.M – I mean sweeping statements like that, I imagine that
241 younger people who and we do have quite a significant uh
242 percentage of our patients maybe under 50 um, I imagine that they
243 generally most people would have a smart phone and they would be
244 used to using apps, um, I think those people would want that kind of
245 information but it's whether the technology would be something that
246 they would be able to use comfortable with, but maybe, you know if
247 you took in people and their families then that would probably be
248 lots of people, most people would come with somebody because you
249 know at that sort of age

250

251

252 **I – okay so you think maybe...relatives and friends could use it?**

253

254

255 DS230135.M – yeah

256

257

258 **I – well that was my next question ((laughs))**
259
260
261 DS230135.M – you know I hadn't thought
262
263
264 **I – yeah, if they have a younger daughter or son**
265
266
267 DS230135.M – yeah I mean most people would come with somebody
268 who's in an age group who's comfortable with technology
269
270
271 **I - yeah, yeah okay and what about clinicians, do you think they**
272 **would mind patients using the app during consultations?**
273
274
275 DS230135.M – I would be happy, I can't...yeah
276
277
278 **I – yeah, and what about other clinicians can you see any concerns?**
279
280
281 DS230135.M – I think er, I mean it's a bit irritating when people are
282 using their phones and texting and stuff, but I think as long
283 as...people realise, it's for, it's just like having it written on a piece of
284 paper isn't it?
285
286
287 **I - okay and do patients come in with a list of questions?**
288
289
290 DS230135.M – yeah, yeah
291
292
293 **I – and how do you find...**
294
295
296 DS230135.M – they come in with their spiral notebooks and things
297 like that
298
299

300 **I – ((laughs)) how do you find that in terms of communication? Do**
301 **you find that, that can be a bit distracting for them, or do you feel**
302 **okay with that?**

303

304

305 DS230135.M – no I think that’s usually healthy and helpful because it
306 means that you know they, they remember the things that they
307 wanted to ask and get a chance to go through...

308

309

310 **I – okay, so you might think that there might be a different attitude**
311 **if someone was doing that on a mobile?**

312

313

314 DS230135.M – no because as long as that, it was if they only did
315 that....

316

317

318 **I – and they weren’t calling people up**

319

320

321 DS230135.M – yeah okay, getting multiple texts during the
322 consultation, it’s more likely to be people, like sat next to the patient
323 rather than them themselves, it can be you know it’s a bit distracting
324 and the boundaries, peoples’ boundaries are quite different aren’t
325 they?

326

327

328 **I – yeah, and what about....**

329

330

331 DS230135.M – it’s a generational thing isn’t it...

332

333

334 **I - and what about at home do you think clinicians would be happy**
335 **for patients to use it at home?**

336

337

338 DS230135.M – yes of course

339

340

341 **I – okay, so what benefits do you think there might be for patients**
342 **using this sort of app, I know it’s difficult because we don’t know**
343 **exactly what the app will to do at the moment**

344

345

346 DS230135.M – it’ll give a framework wouldn’t it for helping um
347 helping people to cover the right sort of domains and questions, um,
348 and to give um, help people to consider all the things that they might
349 want information about, and um, and obviously then to prioritise and
350 personalise things that they want to know and things they specifically
351 want to know and then, you know like bits of paper is to me to help
352 them to remember and to recall. I don’t know how easy it would be
353 to record the answers that you’ve got, but that’s a disadvantage isn’t
354 it? I think it’s you know probably quicker for me anyway it’s quicker
355 to write it on a piece of paper than it is to try and type something in

356

357

358 **I - yeah, yeah that’s true**

359

360

361 DS230135.M – but I mean would this be personal an app on their
362 personal device?

363

364

365 **I – yes I think so yes**

366

367

368 DS230135.M – so

369

370

371 **I – so maybe it might be easier for them to record it**

372

373

374 DS230135.M – yeah you could record, but I mean in the other way, I
375 don’t know, a bit like you can do with apps that children have,
376 whether it would help for it to explore, or maybe to be probed to see
377 what information has been looked at you know what I mean?

378

379

380 **I – yes so...**

381

382

383 DS230135.M – so the clinician or the team could see what
384 information the patients have been, not to sort of spy on them, you
385 know to

386

387

388 **I –ah okay, yeah to get a feel for what information the patients**
389 **want**

390

391

392 DS230135.M – yeah and maybe how much they’ve accessed and...um
393 yeah cos word, yeah I guess the main benefit from anything
394 electronic you can link, you can link to, it’s easier to signpost and link
395 to other electronic resources then rather than....and that might break
396 down the barriers for some people who, you know aren’t used to
397 that kind of thing, if it’s got an easy interface and they go well you
398 know click on this bit here to find out about information about
399 McMillan then that’s quite, if it’s quite simple and accessible then
400 that’s...

401

402

403 **I – okay, and what about the long, do you think there would be any**
404 **long term benefits?**

405

406

407 DS230135.M – well generally if people are better informed then
408 usually it’s better for everybody, if they want to be, as informed as
409 they want to, it usually makes communication much better and
410 people ask about questions and yeah...

411

412

413 **I - okay, you just mentioned a lot of similarities that people**
414 **bringing in pieces of paper, can you think of any advantages that**
415 **this app might have over patients bringing in bits of paper or...**

416

417

418 DS230135.M – well it would be hard,...you should be able to
419 safeguard the information better because it could get lost, and you
420 could share it eas...more easily couldn’t you with your um, with your
421 relatives and yeah, if you could, yeah

422

423

424 **I – would you be able to share, do you think it’s more accessible or?**

425

426 DS230135.M – yeah I would imagine it is...

427

428

429 **I - what they could download the app, I'm not sure**

430

431

432 DS230135.M – yeah I don't know, I know from personal experience
433 you know when your family go to see somebody it's quite common
434 now for them they'll send you the information about it in an email
435 you know or something like that....so you're sending out you know
436 give you the option and you could share it with your family without
437 having to....

438

439

440 **I – so they get**

441

442

443 DS230135.M – and they could get the details from the information,
444 rather than having to...yes so direct rather than to be um, sort of
445 translated from the patient and they don't want to keep talking
446 about it and they can sent that

447

448

449 **I – yeah okay**

450

451

452 DS230135.M – but that's if what the information is personalised to
453 them you know exactly rather than just more general information
454 about their condition

455

456

457 **I – okay and what about, yes and we said that family and friends**
458 **might want to use this kind of app, but what benefits do you think**
459 **there might be for clinicians if patients are using an app?**

460

461

462 DS230135.M – well yeah I think, it would help people to focus about
463 what they want, they could do some preparation for consultation
464 um, because it could guide people, I mean there is information for
465 people out there, I know McMillan do a good leaflet about questions
466 you should ask your cancer specialist, something like that but you
467 know if we gave everybody all these leaflets....

468

469 **I – we’d just have...**

470

471

472 DS230135.M – you’d have to have a suitcase for some, where as if
473 they had a bit more, if bits of those were taken into the app so it’s a
474 bit more personalised, it’s got the relevant bits of each thing I
475 suppose clinicians could set up you know an information prescription
476 I mean you could have a set prescription for each of your types of
477 patients I think that could go onto the apps that could be quite
478 adaptable you know some could have the basic bits and then bits
479 tailored for this, bits tailored for that uh you could tailor it for your
480 patient

481

482

483 **I – and what about communication, you said earlier you think “it**
484 **could improve communication”**

485

486

487 DS230135.M – ((interview interrupted with someone walking into the
488 room))

489

490 ***End of part 1 of recording***

491

1 ***Part two of recording***

2 DS240136.P2.M - I mean what we found from and this is anecdotally
3 um, with any qualitative research but when we done a pilot here in
4 our team of doing copy letters, so copying clinical letters to the
5 patient, so that, I mean in my experience doing that I found was very
6 helpful in uh, improving the accuracy of what was in them and also
7 helping people to focus on sort of the information they wanted and
8 asking about peer questions, some of it was already answered, you
9 know some of it didn’t need to be questioned because the reminders
10 or prompts were in the letter cos I think that this could work really
11 well if it, if you could tailor it exactly, you know to that person and
12 their condition and you could um, yeah, then it would be such good
13 backup so they wouldn’t have to remember everything, it would take
14 some of the pressure of as well so you could have a more, the
15 consultation is, can be overwhelmed by information giving, it can be
16 more of an exchange then if they haven’t got that pressure thinking
17 they’ve got to try and remember everything

17

18

19 **I – okay, yeah so they can sort of focus more on the discussion**
20 **rather than try to take everything down?**

21

22

23 DS240136.P2.M - yeah

24

25

26 **I – okay, and what about communication and their families? Do you**
27 **think an app would have an impact on how they talk about their**
28 **illness and share information? I mean you’ve already said “it’s**
29 **easier to sort of send the information to your family” So do you**
30 **think it might improve it, or hinder it?**

31

32

33 DS240136.P2.M – yeah I think it might, yeah I think it could be much
34 more open then

35

36

37 **I – okay**

38

39

40 DS240136.P2.M – I’m sure it won’t... it’ll have downsides for some
41 people but it would be much, it would be much more open...

42

43

44 **I – and what do you mean?**

45

46

47 DS240136.P2.M – ...and accurate, and then the information that the
48 relatives, second hand information would be more accurate wouldn’t
49 it? Because that’s where some of the...

50

51

52 **I - okay, what about for some people, you said, “it might not be**
53 **useful”**

54

55

56 DS240136.P2.M – well I think it’s, it’s good for transparency and
57 openness and if you’re um, if you’ve got difficulty accepting some of
58 what you’re told and you don’t believe it applies to you exactly and
59 then you, and then you want um, then you might, say you disagree
60 with the information, then I guess you might feel that you don’t want
61 to pass it on to your family and then.. “don’t pass any of it on,
62 because I don’t want them to see that because that says stuff I don’t
63 want them to know” it would be much more complicated wouldn’t it
64 to, to sort of partition information rather than, you would have less
65 control over what information they’ve got potentially. I think that
66 would worry some people, some people don’t like electronic
67 transmissions cos they think it can be got at, also that kind’ve...it’s
68 like sending one of those emails you accidentally send it to somebody
69 and you realise that you’ve put somebody in, you’ve copied in and
70 you didn’t really, you know once it’s out there it’s sort of....

71

72

73 **I – yeah, so the confidentiality of freedom of information is**
74 **something...**

75

76

77 DS240136.P2.M – yeah, it's more about sharing things you didn't
78 necessarily authorise, if you wanted more control over saying it and
79 you end up just sending it out

80

81

82 **I – yeah, okay and what about the barriers of the app, do you think there**
83 **maybe any barriers to patients using this, what do you think the**
84 **problems might be?**

85

86

87 DS240136.P2.M – well I think some people just won't, it won't, it just
88 won't um appeal to them

89

90

91 **I – yeah and you mentioned like the older, people who are less...**

92

93

94 DS240136.P2.M – yeah I think if people who aren't used to that sort
95 of technology will take a lot of persuading um, I think that would be
96 the main barrier, obviously assuming it's, it's, well designed and easy
97 to use, and it's, you know it depends on the quality of the info and
98 stuff won't it?

99

100

101 **I – yeah, yeah of course yeah. Okay then do you feel that clinicians**
102 **would need extra training on how to deal with more active patients,**
103 **or the change in communication because of the app?**

104

105 **((door opens interrupted by a female))**

106

107

108 DS240136.P2.M – I'm quite used to, I think we're very used to active
109 participation that's what, yeah, I think although it's easy to be a bit
110 nervous of it, generally...

111

112

113 **I – and you mentioned that patient bringing sort of paper....**

114

115

116 DS240136.P2.M – it's actually better yeah, yeah

117

118

119 **I – and what about app features, so what sort of app features would**
120 **be most useful for patients. I mean you've already mentioned**
121 **diagrams and scans and things like that, is there anything else that**

122 **you think the app could do? Apart from like the question prompt**
123 **list that we mentioned?**

124

125

126 DS240136.P2.M – well I think good links, linking it well to other, to
127 other sources um, I think I'd want to see it before...

128

129

130 **I – I know it's hard to imagine isn't it because they can do so many**
131 **things**

132

133

134 DS240136.P2.M – yeah I think if you're tempted to try and do a lot, it
135 might be better to not, stay fairly simple

136

137

138 **I - yeah and concentrate on one or two things**

139

140

141 DS240136.P2.M – yeah um, yeah I think that would be better to start
142 with, that would be wise, otherwise it might be a bit daunting

143

144

145 **I – yeah, and what about the relatives and friends are there**
146 **anything, any features for them that would be useful for them?**

147

149

150 DS240136.P2.M – well I supp... there might be some information you
151 can signpost I would say, like um, I don't know, because there will be
152 support, there's a lot of support for patients, that's sort of embedded
153 in the system, but whether, it's more difficult to support the families
154 and stuff uh, you know there is such specific support from various
155 places and the information for people you know, young people
156 affected by cancer and their relatives and stuff like that and um, like I
157 guess that would be generic that would be... unless the apps could be
158 how old you are and stuff like that couldn't it... so it could be tailored
159 from some of those, whether you're a man or a woman and anything
160 else, you'd need to know really, yeah so it could help with the more,
161 broader stuff that's available

162

163

164 **I - okay well... and then tailor it...**

165

166

167 DS240136.P2.M – ...so the relatives could have a broader menu, for
168 more general support whereas the patient would be more focused
169 on exactly on what's going on, it's got to be better than going to, just
170 having the information essentially in leaflets people don't really like
171 going into and....it's so much readily available isn't it? You can carry

172 it around with you and you can sit doing it when you're in the waiting
173 room which is, you know hours and hours and hours patients journey
174 is waiting in the waiting area which you could, and people don't get
175 up and look at leaflets it's just...

176

177

178 **I – if it's already...**

179

180

181 DS240136.P2.M – especially younger people they could be just
182 looking at their phone, it would be, I think it's an opportunity to do that

183

184

185 **I – okay and what about.....**

186

187

188 DS240136.P2.M – I'm sure if you ask other people they'd say stuff
189 like "we should think of fundraising" and do other things on the
190 website and forums and stuff like that

191

192

193 **I – yeah okay, and what about as a clinician, is there anything that**
194 **you would like the app to do? I mean apart from the diagrams and**
195 **things....**

196

197

198 DS240136.P2.M – I think it would be good to...

199

200

201 **I – you know is there anything....**

202

203

204 DS240136.P2.M – it would be really good if you could you know add
205 extra things for this patient and stuff like that

206

207

208 **I – yeah, it could really tailor it**

209

210

211 DS240136.P2.M – you'd really be able to tailor it, I don't know how
212 you'd do that ((laughs))

213

214

215 **I - okay, yes**

216 DS240136.P2.M – um, you could send information to it

217

218

219 **I – yeah, so you could link it to the computers**

220

221

222 DS240136.P2.M – yeah, and as I said I think it would be quite
223 interesting to see if you could, with permission, pull out how much it
224 had been used and in what way, so you could have an idea of how
225 much of the information needs to be covered

226

227

228 **I - and is there anything you wouldn't like the app to do? That you**
229 **wouldn't feel comfortable with?**

230

231

232 DS240136.P2.M – um, well I don't know how it's being partnered and
233 that, but I think um, I think, I don't know whether, I suspect the
234 patients wouldn't like, I don't think it should have any
235 advertising

236

237

238 **I – oh yeah, yeah**

239

240

241 DS240136.P2.M – and it shouldn't, you need to be um, definitely try
242 to avoid, um, uh industry sponsored information, cos a lot, you know
243 there's a lot of armoured sponsored information out there which
244 may not be that independent, so I would say stuff like that

245

246

247 **I – yeah, yeah okay**

248

249

250 DS240136.P2.M – having said, they're often the best looking
251 information cos it's um, it's where the money is. You know, some
252 of the information, it can't hurt, information is power, it can't hurt,
253 it's all out there anyway isn't it...it's not...yeah, what could it have?
254 Things like...you could do a lot couldn't you, you could have things
255 like um, uh ((whispers to himself)) I mean because people have been
256 trying to work on things, apps like to capture stuff like diaries for
257 digitising your treatment, what would the side effects be and stuff
258 like that, there is a study that we're trying to run that does have a
259 tablet and stuff on that, we haven't got any patients, uh but I think
260 that's a different thing I think that would be confusing, trying to do
261 too much at once. I mean what about having a....I don't know you
262 could always have like a diary, but I think that's getting a bit to, trying
263 to do too much isn't it? Yeah but it would be good if it had a little
264 place where patients could add little, could add free text so you
265 know...you could have remember to do such and such a thing and
266 that sort of thing

267

268

269 **I – yeah okay, so like a diary option**

270

271

272 DS240136.P2.M – and maybe, you know if we were doing copy
273 letters there's gonna be this portal at sometime my clinical, where
274 you would be able to log on and look at your own information but
275 whether you could, with all the permissions and the nightmare of all
276 that sort of stuff, email information to, you know send information to
277 the app for that page, for the letters, and stuff, whether that's
278 possible, that might, that would be really, that would be really
279 powerful at some point, probably not in the first generation

280

281

282 **I – yeah, yeah okay and what about, the last question is are there**
283 **any particular types of patient that you think might find this most**
284 **useful and at what sort of stage along the cancer pathway do you**
285 **think it would be useful, if there was one specific? I mean you**
286 **already said sort of "those who are more familiar with the**
287 **technology a bit younger"**

288

289

290 DS240136.P2.M – I don't see why it couldn't start really, you know
291 right, really, really early, I mean that's not...imagine if you've got a
292 breast lump you go to your breast clinic....

293

294

295 **I – ... thinking you know this app would be after diagnosis,**
296 **you know so they can get their head around it and then they could**
297 **start using the app**

298

299

300 DS240136.P2.M – before, it would be good, yeah, I don't know, I
301 think it could work, it could be used as early as possible

302 **I - really?**

303

304

305 DS240136.P2.M – yeah, it would have to be you'd have to open up
306 new stages, keep opening up new parts of the information as you
307 went along, you know download, a download could be

308

309

310 **I – so a staged approach?**

311

312

313 DS240136.P2.M – I have a breast cancer, a bit of information, and
314 Then, that would be a good thing about it, it could be chunks rather
315 than having too much at once

316

317

318 **I - so sort of paced you know**

319

320

321 DS240136.P2.M - yeah

322

323

324 **I – okay and what about the follow-up? Do you think it would be**
325 **useful for patients who have been treated?**

326

327

328 DS240136.P2.M – yeah...

329

330

331 **I – and then they're discharged**

332

333

334 DS240136.P2.M – or if they're being followed-up which is not very
335 you know, yeah I think that would be excel....that would be
336 particularly helpful actually I hadn't thought about that, um, yeah so
337 there's lifestyle, lots of patient type stuff that you can pick up, but
338 also then uh, yeah how to, what things to be concerned about. So I
339 think as a reference it would be really helpful really to have a
340 reference, so if it could, you know if it could send stuff like a
341 document of your personalised treatment plan which could mirror
342 your developing....and they're doing work in this area?

343

345 **I – McMillan? Yeah there is a well, I'm not sure if there's an app,**
346 **there's a follow-up project going on in <hospital>**

347

348

349 DS240136.P2.M – yes that's what I was thinking, that's an app isn't
350 it?

351

352

353 **I – yeah well I think it's the same one**

354

355

356 DS240136.P2.M – that would be the sort of follow-up

357

358

359 **I – yeah and they do like a holistic needs assessment and that sort**
360 **of thing so yeah**

361

362

363 DS240136.P2.M – I know McMillan are very keen on this information
364 prescriptions, I don't know, I mean this was, that was quite a few
365 years ago, that was a few years ago I don't know if....

366

367

368 **I - okay is there anything else you'd like to add?**

369

370

371 DS240136.P2.M – it would have to, yeah, I mean it would be great
372 thing to have um, but obviously it would have to be ongoing...it would
373 have to have an ongoing management of it...wouldn't it?

374

375

376 **I – yes, sort of keeping it up to date, keeping it relevant you know**

377

378

379 DS240136.P2.M – cos that's always an issue isn't it?

380

381

382 **I - yeah, yeah, yeah okay well that's great thank you**

383

384 **End of Interview. Duration 34:00.**

1 **I – okay, so firstly could you tell me why you’re interested in taking**
2 **part in this study**

3
4

5 DS240139.F – well I think anything that um gives a patient more
6 information in an understandable format is helpful because some of
7 them come to clinic with very little understanding of what’s being
8 said and I think for some patients a lot of them I don’t think would
9 engage with much information even before they come to see us,
10 certainly some of the older patients, but a lot of the younger ones are
11 more motivated to try and find out as much as they can, or their
12 families are motivated to find out as much as they can, so if there
13 was something that would signpost them, to help them guide
14 through all of the evidence that is out there, which is not all helpful
15 on the internet I think that’s worthwhile

16
17

18 **I – yeah, yeah okay and with your patients do you see mainly**
19 **younger or older patients, or is it a mix?**

20
21

22 DS240139.F – It’s a mix, you know it’s an absolute mix

23
24

25 **I – yeah okay, okay so in terms of information how do you decide**
26 **on how much information you give to patients about their illness?**

27
28

29 DS240139.F – I always start with new patients by first asking them
30 what they understand about coming to see us in <hospital> so that,
31 I give the opportunity to say even if they understand that they’ve got
32 cancer because some of them turn up and deny all knowledge of
33 even been told that they’ve got cancer

34
35

36 **I – oh really**

37
38

39 DS240139.F – so therefore you have to always gauge the
40 conversation by what they know before they even come in so if you
41 have somebody who comes in and says “I know I’ve got cancer and
42 it’s affecting this, this and this, and I’m looking at chemotherapy”

43 then obviously you can have quite a detailed discussion about what,
44 you know the stage of the diagnosis, the type of cancer, um the
45 treatment – whether surgery would be an option and you can have
46 quite a detailed discussion you know, or the clinical trials that are
47 available, but if you’ve got someone who either hasn’t taken onboard
48 their diagnosis, or says they didn’t know their diagnosis then you’re
49 starting from a much lower level and you have to kind’ve simplify it,
50 and some patients don’t want to know everything and they, straight
51 away they say “I don’t want to know, I just want to keep it basic” and
52 other patients you know want a lot of detail, so as I say I always start
53 by asking what they understand before, and then you know tailor it
54 to what they seem to want

55

56

57 **I – yeah, it’s funny that you said that because when I interviewed**
58 **some other nurses they said that some of the patients, they’re**
59 **surprised that, some of the patients come in and they don’t**
60 **know that they’ve got cancer, or that’s what they say...**

62

63

64 DS240139.F – absolutely and, but we get them referred from
65 <nurse1> and <nurse2>

66

67

68 **I - okay yeah**

69

70

71 DS240139.F – so cos, all 90% of my patients come from <Health
72 Authority1> so they’ll have gone through that clinic with < nurse1>
73 with <nurse2> and the gynae oncologist and would’ve gone to see a
74 gynae oncologist and they still come to me and say “they didn’t know
75 they had cancer”

76

77

78 **I – wow**

79

80

81 DS240139.F – so a lot of it is, some people it’s genuine, some people
82 it’s just denial they can’t take it in

83

84

85 **I - so they are referred from the cancer nurses then, so where do**
86 **they come from prior to that, is it from the GP**

87

88

89 DS240139.F – usually it would be either through the GP or they may
90 have been admitted to hospital with something non-specific, but
91 what we deal with in ovarian cancer, the symptoms a very non-
92 specific, abdominal distension, bloating, nausea, off their food, that
93 can be so many things that they often go in under a general medical
94 team and then if they're...or a surgical team and then referred on, or
95 come through the GP

96

97

98 **I – yeah okay, okay then so how would you provide that**
99 **information to patients, is it verbal or written information, or a**
100 **combination?**

101

102

103 DS240139.F – the information about stage, diagnosis is all verbal, the
104 information about chemotherapy is both we go through it in clinic
105 and then we give them written information leaflets on a general
106 chemotherapy booklet and then the specific chemotherapy that
107 we're offering to them and if they then are patients who are going to
108 need you know, suffer hair loss we give them a hair loss booklet as
109 well

110

111

112 **I – yeah, yeah okay, and are there any other resources that you**
113 **recommend to patients, like charities or helplines and such?**

114

115

116 DS240139.F – I don't routinely recommend patients, we have 2
117 excellent specialist nurses specialist <nurse1> and <nurse2> and they
118 will often speak to them as well <nurse2> is McMillan funded so
119 they will often signpost them to, not always, but if it's appropriate
120 you know we, I usually say if somebody asks me, I say to go to the
121 Cancer Research, or McMillan websites

122

123

124 **I – okay yeah**

125

126

127 DS240139.F - UK, McMillan

128 **I – so you wouldn’t routinely recommend it, you’d wait until they**
129 **ask for the information**
130
131
132 DS240139.F – no, yes
133
134
135 **I – okay, so what kind of issues do you think clinicians are faced**
136 **with when talking to patients about their illness in a consultation?**
137
138
139 DS240139.F – I think it’s at what stage the patient is in accepting their
140 diagnosis
141
142
143 **I - okay**
144
145
146 DS240139.F – because if they’ve accepted the diagnosis they just
147 want to know everything about all the treatment options and you can
148 have a very detailed discussion about the pros and cons and clinical
149 trials and what’s available, if they’re even still struggling with the fact
150 they’ve got cancer they’re not going to take any of that in
151
152
153 **I – yeah and how do you deal with that because I expect there’s**
154 **time pressure, how long are the consultations usually?**
155
156
157 DS240139.F – we usually, for a new patient we try to give them about
158 half an hour, um but we don’t, I don’t consent them for
159 chemotherapy at that same appointment, so what I always say to
160 them usually at the end is you know “obviously we’ve given you lots
161 of information, go away have a think about it” um, I usually get an
162 answer out of them, whether or not they even want to consider
163 chemotherapy so which one, so then we put that in the system and
164 then we usually start the chemotherapy you know 10 days later um,
165 and so they come and see us again in clinic before then and that’s
166 when we consent for the chemotherapy but we always say to them
167 “well look we’ll see you again before the chemotherapy starts, if
168 you’ve got any questions write them down and we can go through
169 them again”
170

171 **I - oh that's good**

172

173

174 DS240139.F – and when we see them at the second appointment
175 prior to their chemotherapy starting, some of them it's a quick 5
176 minutes, yes happy with everything no questions sign the consent
177 form, and other patients maybe another you know 10-15 minutes
178 going through things again because they just need to get things into
179 their head

180

181

182 **I – yeah okay so there's sort of 3 appointments then, well including**
183 **the treatment**

184

185

186 DS240139.F – 3 including the treatment yeah and the nurses, when
187 they turn up for the treatment the nurses will go through the
188 practicalities of the chemotherapy again with them as well and they
189 also get offered here now, or they, not all attend, they get offered a
190 patient education session on chemotherapy um where they actually
191 come to <hospital> and one of the chemo nurses, it's a general one,
192 but then she tries to talk about the individual chemotherapies that
193 they're going to have, so they have that as well, education session,
194 and not all of them go to it but the ones who do often find it quite
195 helpful and you can usually tell the ones who've gone to it because
196 when you start going through the toxicities on the consent form they
197 say "oh yeah, yeah we know about that" so you can see that it's gone
198 in

199

200

201 **I – ah that's great, okay do you think there are any barriers in**
202 **communicating with patients during consultations?**

203

204

205 DS240139.F – well there's always a time pressure

206

207

208 **I – yes and you mentioned patient understanding earlier**

209

210

211 DS240139.F – and yeah, the time pressure, what they can take in,
212 how much they can take in

213

214 **I – and do you find they come with pieces of paper to write down**
215 **questions, or do they bring anything with them into consultations**

216

217

218 DS240139.F – completely varies, sometimes they do, or sometimes
219 they somebody else comes in with them to do the writing, I've found
220 that quite a few times, rather than the patient themselves doing it,
221 they bring somebody else with them who'll make notes

222

223

224 **I – okay that's useful, okay so in terms of experience with smart**
225 **phones, do you have a smart phone or a tablet computer, do you**
226 **use it personally or professionally...**

227

228

229 DS240139.F – I have a smart phone personally and I use the
230 computer um at work just because we can't really use the tablets at
231 work

232

233

234 **I - yeah, okay and are you, obviously you're familiar with apps and**
235 **things, would you ever use any for work at all or do you know of**
236 **anybody who does?**

237

238

239 DS240139.F – yeah, no I have a couple of apps that I use some of the
240 medical calculators, I often use the NICE um there's sort of FIGO
241 staging app which stages the cancer and gives pictures as well which
242 is quite a good one

243

244

245 **I – what, to share with patients?**

246

247

248 DS240139.F – well I don't usually um, I don't usually show it to the
249 patients but it, I can if they're really struggling and they do...I also
250 have a paper copy of that if they're really struggling with the pictures
251 that I can show them, um most of my apps have been superseded by
252 my children's so I have more peppa pig than medical apps on my
253 phone now, um, no I ((laughs)) they've all been superseded, the
254 NICE one you can get things like for clinical guidelines ESMO um,
255 NCCN those types of things

256

257 **I - yeah, okay, so the type of app we've talked about, do you**
258 **think patients would find that kind of app, do you think they'd want**
259 **to use it?**

260

261

262 DS240139.F – I think some would, some are very electronically based
263 and therefore would find that helpful, there are some patients who
264 do not engage at all, either because they're older patients, um and
265 they're not interested in that side of things, or they just don't want to
266 know they have that very almost old fashioned kind of paternalistic
267 approach that what the doctor tells them is all they want to know
268 type thing um, but....

269

270

271 **I – would you say they're in the minority of patients, or are there**
272 **quite a number...?**

273

274

275 DS240139.F – no, no, no I'd say there's quite a number that is like
276 that, but what you usually find in that situation their relatives, their
277 children, their sons and daughters who want to find the information,
278 so you can give them a signpost

279

280

281 **I – okay, and what about, yes family and friends do you think they**
282 **would want to use an app like that?**

283

284

285 DS240139.F – yes, yes, yeah I think a lot of the family and friends,
286 families certainly are wanting to get more information

287

288

289 **I – okay and what about clinicians, do you think they'd be happy if a**
290 **patient brought an app into a consultation, or was using it**
291 **throughout their illness?**

292

293

294 DS240139.F – throughout their illness, I'd have no problems with
295 them using it throughout their illness, it could be quite difficult in a
296 consultation if they're kind've going through everything that's on an
297 app just because of time pressure

298

299

300 **I – yep okay**

301

302

303 DS240139.F – um but certainly as a guide to support them and point
304 them in the direction of information I think that's a really good thing

305

306

307 **I – yeah okay so what benefits do you think they're might be for**
308 **patients using an app like this, I know it's sort of dependent on**
309 **what the app is actually going to do, but it general can you think of**
310 **any benefits?**

311

312

313 DS240139.F – well I think it just gives them a better understanding of
314 their illness and what you know what kind of thing is, you know a
315 question we get asked a lot is "why don't you give radiotherapy in
316 ovarian cancer" you know why....and you kind've try to describe the
317 difference between chemotherapy and radiotherapy and because
318 they're given the information leaflet on chemotherapy sometimes
319 say by the gynae team and <hospital2> they're not given information
320 on radiotherapy because we don't use it, and they're saying "why
321 don't you use it?" just having something where they can get a bit
322 more information, and know about different treatments that are
323 available, say sign posting for clinical trials and things like that, the
324 concept of clinical trials even if you can't....on an app probably can't
325 cover every trial because it changes so much, but the concept of
326 them 'why you might be asked to do research, what's the importance
327 of that?' you know all of those kind've things you know I think would
328 be quite helpful for them and if they have dipped in and dipped out
329 you know the gene...for us I think it's a kind've thing like the genetics
330 guidelines as well you know when you pick up when you have a
331 significant family history, because that's what a lot of them ask with
332 the ovarian cancer. So yeah you could see the potential for quite a
333 few helpful things

334

335

336 **I - and what do you think, if they have a better understanding, what**
337 **do you think the benefits would be in the long term for the**
338 **patients?**

339

340

341 DS240139.F – it just gives them more control, um I think when they
342 have more control, feel more control that helps them because it's

343 their lack of control, their lack of being able to plan, their lack of,
344 things just happening around them and at least if you know what's
345 happening, so many patients come in and say, "even though you
346 kind've given me bad news I feel better leaving than I did coming
347 because I know what's happening and I know you've got a plan" so
348 you kind've think actually as long as it's not an information overload
349 and it's not sign posting them to inappropriate sites um, I think, you
350 know the kind of information you get from McMillan or CRUK where
351 it puts things quite well is, is useful

352

353

354 **I – okay and what about for the family do you think there's any**
355 **benefits for them, and for the clinicians as well?**

356

357

358 DS240139.F – well for the family I think the same thing, it gives them
359 more information and it points them in the right direction if they're
360 trying to get more information, for clinicians well if patients are
361 better informed um, it, it enables you to have a better discussion
362 with the patient because you can discuss treatments it can make it
363 more challenging for the clinician ((laughs)) when they're very well
364 informed! Sometimes they know things you don't know, so make
365 sure we have the app as well ((laughs)) so we know what they're sign
366 posting to, but no it's good, it's good and I think I, I'd much rather be
367 able to go through things with patients and you know when they
368 come in with all the cuttings from the Daily Mail and all their
369 questions because at least you feel that you've answered everything
370 as best you can

371

372

373 **I - yeah, yeah okay and what about communication, do you think it**
374 **would have an impact on the way you communicate with patients?**

375

376

377 DS240139.F – it would probably be a more fluid conversation
378 between us, rather than you talking to the patient because if they've
379 already got a general understanding before you've even started

380

381 Then it allows you to have more of a discussion rather than you just
382 imparting information to them

383

384 **I – okay and what about with their family do you think like an app**
385 **would help patients to communicate with their families or do you**
386 **think there would be no difference?**

387

388

389 DS240139.F – I’m not sure if it would help the patient communicate
390 with their families any better, but it you know they can sign post their
391 families to that information if they don’t want to keep repeating it so
392 at least then you know that the family are getting reasonable sensible
393 advice

394

395

396 **I – yeah, yeah okay, so what about barriers to the app, do you**
397 **think there would be any problems with patients using this app or**
398 **general barriers to this working in practice?**

399

400

401 DS240139.F – I think you will have a cohort of patients who just
402 won’t engage with it, you know they’re not into mobile phones and
403 on smart phones you can’t say that’s an age thing, because I know a
404 lot of older patients are very you know IT savvy and you get a lot of
405 others who aren’t, so I think you’ll always have a group, a cohort of
406 patients who just won’t engage with it. I suppose the other thing if
407 anything with that, it depends how you’re going to do it because I
408 think it’s updating it, is, is the because you know oncology changes so
409 quickly and even if you’re trying to do just 3 or 4 sites, you know
410 making sure things aren’t out of date and they’re not being told out
411 of date information, or being led to kind’ve sites which may not be
412 that helpful to them and might just confuse them

413

414

415 **I – yeah okay. So do you feel that patients using this app could**
416 **affect your workload in anyway?**

417

418

419 DS240139.F – um you could argue it both ways I don’t think so
420 because you say consultations might be shorter because they’re
421 better informed before they come, consultations could be longer
422 because they are better informed you end up having more in-depth
423 discussions about smaller details so I’m not sure, it could go either
424 way

425

426

427 **I – okay and do you feel like clinicians, if patients are better**
428 **informed and sort of more active in the consultation, do you think**
429 **clinicians would require extra training on how to deal with the**
430 **change in communication?**

431

432

433 DS240139.F – no I don’t think so

434

435

436 **I – and what about for the app, do you think clinicians would need**
437 **training on how to use the app and patients would they need**
438 **training?**

439

440

441 DS240139.F – well most apps are pretty straightforward I have to say
442 I mean certainly the apps that we use when you download you just
443 download the information and do it, I think most clinicians are pretty
444 IT savvy, yeah as long as you know it's highlighted that it's there and
445 what it does, I think most clinicians are pretty IT savvy and would be
446 able to cope with it and I think if patients are engaging with it then as
447 long as it's a well sign posted app, you know I'm quite used to apps so
448 for me I wouldn't see that I'd need...

449

450

451 **I - so do you think patients would benefit then if the nurse, or**
452 **someone on site were to go through the app with the patient, do**
453 **you think that would be helpful or do you think that, that's not**
454 **needed that they would...?**

455

456

457 DS240139.F – I don't, I think a lot of the role of the apps, potentially
458 will be them looking at it at home

459

460

461 **I – right okay**

462

463

464 DS240139.F – just going through it in their own time, um you know
465 an information leaflet about the app saying what it is, what it does
466 and maybe you know a flow diagram on how to use it kind've thing,
467 or signposting you know maybe helpful rather than an indiv...because
468 you can't be, one person can't be in all the clinics at all the sites at all
469 the centres so I think even if you have an information, or posters up,
470 because if you're going to advertise it, which presumably is what you
471 would do is advertise it as an app, then probably you'd need to have
472 that as a poster '*this is how you do it, this is how you download it*' a
473 simple guide as to how you use the site

474

475

476 **I - okay, great, and what features do you think would be most useful for**
477 **patients, so what should we put in the app do you think?**

478

479

480 DS240139.F – from a gynae, from an ovarian point of view
481 particularly? Are you talking generally and....?

482

483

484 **I – yeah both really, generally and specific**

485

486

487 DS240139.F – I mean I think you need to, I think I, I'm not sure how
488 much you're planning to build in to your app in terms of information,
489 or whether you are using it more as to a sign posting to other sites?

490

491

492 **I – we're not sure yet, we want to know what you think**

493

494

495 DS240139.F – I mean for me, for patients I suppose it would be the
496 types of cancer they can get

497

498

499 **I – so information on...**

500

501

502 DS240139.F – yeah you know the type of cancer, staging, so you
503 know the app that I used to use which isn't on my phone anymore,
504 um which is the FIGO one which was really good because it gave you
505 the FIGO staging which you could push on the, you know push on it
506 and it would flip over and it would give a picture of where it was so it
507 did both, words and pictures, but you know that kind've thing makes
508 it more obvious to them and they can get their head around it, um so
509 be kind've information on staging, information of types of the cancer,
510 what symptoms they could get because you will find some patients
511 will look at it to look for symptoms whether you're going to give it
512 kind've presenting symptoms or red flag signs or whatever, um and
513 then the treatment options, um you know that they might have
514 chemotherapy, for us it would be chemotherapy, or chemotherapy
515 plus surgery um and there's no clear role for radiotherapy so they
516 know that because that's often a question that I hear and then also
517 kind've who they would expect to meet in their journey, so you know
518 you'll meet a surgeon and then a specialist nurse, oncologist you
519 know oncologists work as a team, so you may not always meet the
520 same person you know it's that kind've information. I think it would
521 be really good to get something in on clinical trials that you know, if
522 you were looking at this from oncology from Wales, in the first
523 instance, or even in south Wales, I don't know, you'd say <hospital>
524 you know does clinical trials you may be asked to participate you
525 know either to donate a blood sample or tissue that's already been
526 taken, or to actually participate in a treatment trial, just because a lot
527 of them, I mean then there's not always trials available for them, but
528 you know there was a study funded by McMillan recently um, I think

529 it was McMillan and they looked at, kind've they had secret shoppers
530 going around various centres around the UK, to say you know if you
531 walked into...would you think that this is a site for research and trials
532 and how were you asked about it and actually the patients were
533 saying, the majority of patients it wasn't even mentioned they
534 weren't aware of clinical trials, they didn't see it...I think that's really
535 good just to float an idea to them, they may be asked I think the
536 clinical trial side. Um, support, so you know support sites, um you
537 know the role of palliative care, getting it across that palliative care
538 does not mean you're dying, it just means you know symptom
539 support, um so you're kind've looking at all the layers that would
540 then would be built up as they come in to the system you know side
541 effects of chemotherapy, you could always then link them to you
542 know who to contact, but that becomes a very detailed, I mean if you
543 were doing it for <hospital> that's easy cos it's one person for that,
544 you know one number for the whole of all the cancer sites but it
545 becomes a bit harder if you are trying to generalise it a bit more. Um
546 if you were then going into more detail you could link to some of the
547 websites where they do list the cancer trials, you know list what's
548 happening, what's new, um I'm not sure if you want to be, you know
549 sort of, patients want to know about prognosis, not everyone does,
550 even if you just signpost them, but the thing is, is you don't want to
551 re-invent all of this, because all of this is put quite well on like
552 McMillan sites and the Cancer Research UK site and it is how much
553 do you link in with them and just sign post them, or how much are
554 you planning?

555

556

557 **I – Yeah I think, from the interviews, I think we may, mainly**
558 **concentrate on the question list to prepare them for**
559 **consultations rather than sort of reinventing information,**
560 **so probably signpost them to reliable web-sites and have some,**
561 **you know, you can click on diagnosis or treatment or follow-up,**
562 **what stage you're at and then the relevant, relevant links then**
563 **really**

563

564

565 DS240139.F – yeah I think once you get past that first initial
566 consultation how are they followed up, so for us in ovarian cancer,
567 whether we use the tumour marker, there's lots of evidence and
568 discussion about that, you know we don't regularly do CT scans in
569 ovarian cancer because it's symptom led follow-up and so, so they
570 know that kind've thing you could use to give them more information
571 but it becomes very specific because it's very different for breast
572 cancer and very different for colorectal cancer, so how much um you
573 know whether you're saying you know, make sure you know how you
574 will be followed up, or whether you're saying in gynaecological

575 cancers you're likely to be followed up 3 monthly with an
576 examination and the doctor will discuss with you. I, I don't know how
577 much information you are planning to put in so it's a bit hard to

578

579

580 **I –yeah, okay and do you think there are any other features that would**
581 **be useful for relatives or friends, or do you think it's the same**
582 **information the patients will want?**

583

584

585 DS240139.F – I think it's the same information because the
586 information needs, you don't want to put more information, you
587 could, uh you have a link to a support or carer's forum, which the
588 patient can click on if they want, or the, the, the family can click on,
589 um you kind've don't want the patient to feel that they're getting
590 information that, someone else is getting information that they're
591 not getting

592

593

594 **I - and what about as a clinician is there anything you'd want the**
595 **app to do, other than what we've talked about?**

596

597

598 DS240139.F – no because it's hard isn't it because until you actually
599 kind've see it, a kind've a mocked up version it's hard to know
600 how it's going to work, and whether...the other thing I'm
thinking there are some for breast you know putting in the
genetics guidelines, because a lot of people get very concerned
about genetics and I mean that page up there, I know it's a bit
old now, but that's...the referral, do you see what I mean it's only
1 side of A4 and it's all of the cancers and that who will accept
referrals with the following criteria met and that comes from
genetics I mean they change a little bit, it's probably a little bit
old, but it's the kind've thing when they say "oh you know" and
that's the kind've thing families and daughters are concerned
about ovarian cancer "am I at high risk?" you know so a link for
them being able to look at something to see whether they need
to be concerned and do something, or whether actually because
their mum's 65 they really don't need to be concerned as a
genetic thing

614

615

616 **I – and is there anything you wouldn't want the app to do?**

617

618

619 DS240139.F – you wouldn't want them to be signposting
them to the more conflicting information, some patients get

themselves really caught up about diets and you know and supplements and things like that and I'm not saying that they can't gain the information, but if you're trying to, if it's something you want us to promote, probably wouldn't over, you know make, I wouldn't over try to promote that side of it as much because I think patients get really confused

626

627

628 **I - okay yeah, so last question is there any particular type of patient that you think might find this app most useful, or any particular stage of their illness, or there...I mean we've talked about age groups, but what about the different stages do you think....?**

632

633

634 DS240139.F – In ovarian cancer 80% of patients are at advanced
635 stage, so the majority are going to be at advanced stage anyway

636

637

638 **I – yeah, yeah that's quite a lot isn't it gosh**

639

640

641 DS240139.F – it's ovarian cancer that's why it's called the '*silent killer*'

642

643 **I – so what's the prognosis with that then? If they come at an
644 advance stage?**

645

646

647 DS240139.F – maybe about 25% long term survival, but for the
648 majority they will relapse within 2 years

649

650

651 **I – oh really**

652

653

654 DS240139.F – but they can still go for 3 or 4 years even once they've
655 relapsed so it's, it's still years rather than months

656

657

658 **I – hmm gosh, okay is there anything else that you want to add that
659 we might have missed?**

660

661

662 DS240139.F – I don't think so

663

664

665 **I – okay thank you**

666

667

668 DS240139.F – that’s alright, we’re dead on

669

670

671 **End of Interview. Duration: 28:03**

Appendix 30: Information sheet for informal user-testing session:



Exploring the potential of a mobile phone or tablet ‘app’ to help patients with cancer address their information needs: focus group

Information Sheet (V1.0, 30/07/2015)

I recently spoke to you about taking part in a study. The study is funded by Tenovus Cancer Care. The aim is to conduct user-testing for an app that aims to help patients with cancer prepare for consultations with their doctors and nurses.

The study involves a focus group to find out what people think about the app that we have developed. This sheet will tell you more about the study.

Invitation to take part in the study

We would like to invite you to take part in a research study. Before you decide you need to understand why it is being done and what it would involve for you. Please read the following information carefully. You can talk to others about the study if you wish to help you decide if you want to take part. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of the study is to find out what previous patients with cancer think about using a smartphone or tablet ‘app’ to help to help them to prepare for consultations with their clinicians. There has been a lot of research in the past showing that cancer patients do not have all the information that they want to have about their condition. This is because

some patients find it difficult to ask questions or to remember all the information they have been told. The information we get from this study will be used to further develop and improve the 'app', which we hope will help patients with information about their condition.

Do you have to take part?

No. Taking part is entirely voluntary. If you do not want to take part you do not have to give a reason. If you decide to take part but later change your mind, you can do so, and you do not have to give a reason why you no longer wish to participate. **No one will be upset if you do not wish to take part.**

What will happen to you if you take part?

You will take part in a focus group with up to 6 other members where you will be shown the app and asked a series of questions.

What are the possible risks and disadvantages of taking part?

There are no specific risks associated with taking part in this study. You do not have to talk about any issues you do not want to discuss. If you find the focus group upsetting it can be stopped at any time.

What are the possible benefits of taking part?

This research study will not directly benefit you, but it will give us a better understanding of the views and needs of patients with cancer.

Will your taking part in the study be kept confidential?

Yes. All information that is collected about you during the course of the research will be kept strictly confidential.

What will happen to the results of the research study?

The results of the study will be written up as a thesis and presented at conferences and published in scientific journals. A report will also be prepared for Tenovus, the Cancer Charity, who are funding this study. Tenovus may wish to publish summaries of the study on their website. We may use comments from the focus group in publications, however all information provided by participants will be anonymised. It will not be possible for anyone to identify you from any of the published results.

What if you are unhappy about any aspect of the study?

If you have any concerns or complaints about any aspect of the study please contact Dr Fiona Wood, Institute of Primary Care and Public Health, 3rd Floor, Neuadd Meirionnydd, Heath Park Cardiff. Telephone: 02920 687185, Email: Wood@cf.ac.uk. Alternatively, please contact Dr John Staffurth, Clinical Oncologist, Velindre Hospital, Cardiff. Telephone: 02920 196135.

Who is organising the study?

The study is being organised by researchers from Cardiff University. It has been funded by Tenovus, the cancer charity.

Contact for further information

If you would like any further information, or have any questions concerning this study, please contact Becky Richards, Institute of Primary Care and Public Health, 3rd Floor, Neuadd Meirionnydd, Heath Park Cardiff. Telephone: 02920 687219, Email: Richardsb3@cardiff.ac.uk.

Thank you for reading this information sheet and for taking an interest in the research study.

Appendix 31: Consent form for informal user-testing session:

CONSENT FORM

Please complete and return this consent form if you are happy to take part in the study

	<i>Please initial each box</i>
I have read and understood the information sheet dated 30.07.2015, (version 1.0) for the study, and have had the chance to ask questions.	
I understand that taking part in the study is up to me, and that I can stop at any time without giving a reason.	
I agree that the researcher can take notes of any comments that I make during the user-testing session.	
I understand that the focus groups will be typed and may be used in a written report of the study. My name will <u>not</u> be typed, so that the report cannot be linked back to me in any way.	
I agree to take part in the study.	

Your name (BLOCK CAPITALS): _____

Your signature: _____ Date: _____

Name of Researcher: _____

Researcher's signature: _____ Date: _____

Appendix 32: Demographic questionnaire for user-testing discussion group:



User-testing discussion group

Demographic questionnaire

Participant type: Patient/relative (please circle)

Age:

18-25

26-35

36-45

46-55

56-65

66-75

76-85

85+

Gender:

Male

Female

Highest educational qualification:

GCSE/O Levels

A Levels

NVQ/HNC/HND

Diploma

Degree

Post Graduate degree

None of the above

Type of cancer (for patients only):

Breast

Urological

Gynaecological

Colorectal

Other

Time since diagnosis (for patients only):

Less than 1 month

1-3 months

3-6 months

6 months-1 year

1-2 years

2-4 years

5 years+

Thank you for completing this questionnaire.

Appendix 33: User-testing session topic guide:

User-testing session topic guide

Design

What do you think of the overall design of the app?
What do you think of the colours?
Is the font size large enough to read easily?
What do you like about the design?
What do you dislike about the design?
Do you think there is anyway that we could improve it?

Usability

Is the app easy to use/navigate around or difficult?
Is there anything that we could change to make it easier to use?
Can you understand the language used in the app?
Do you think patients would need training in how to use this app?
Do you think we could improve the user-friendliness of the app in any way?

Content

What do you think about the features of the app?

Introductory text

Do you think the introductory text explains the purpose of the app well enough? How could we improve it?

QPL

Do you think the introductory text explains the purpose of the QPL well enough? How could we improve it?
Can you understand the questions?
Are there important questions that you think should be added to the list?
Are there any questions that you particularly like?
Are there any questions that you dislike?
Are there any questions that you think should be reworded?
Do you think we could improve this feature in any way?

Glossary

What do you think about this feature of the app?
Are there any important terms that we may have missed?
Can you understand the definitions of terms?
Do you think we could improve this feature in anyway?

Resources

What do you think of this feature of the app?

Are there any important resources that we may have missed?

Do you think we could improve this feature in any way?

Contacts

What do you think of this feature of the app?

Do you think we could improve this feature in any way?

Additional questions

Is there anything else that you think we should add to the app?

Appendix 34: Screen shots of the final version of the ‘Ask Us’ cancer app

Figure 1. Disclaimer

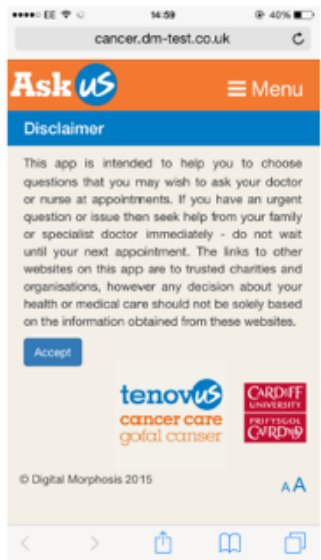


Figure 2. Main menu

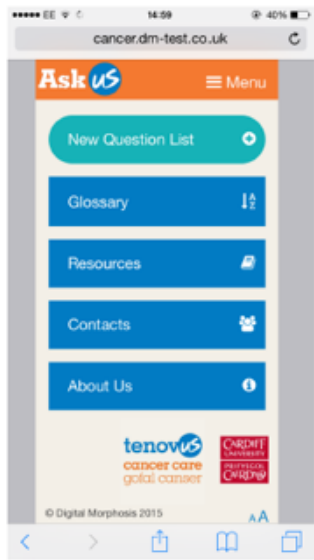
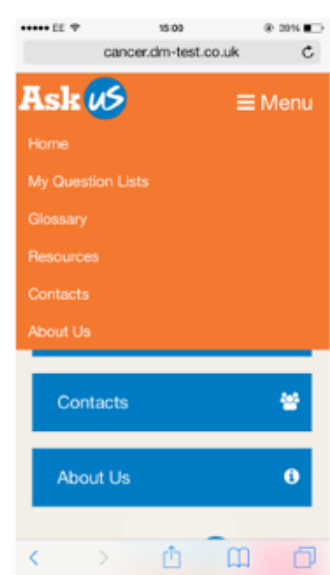
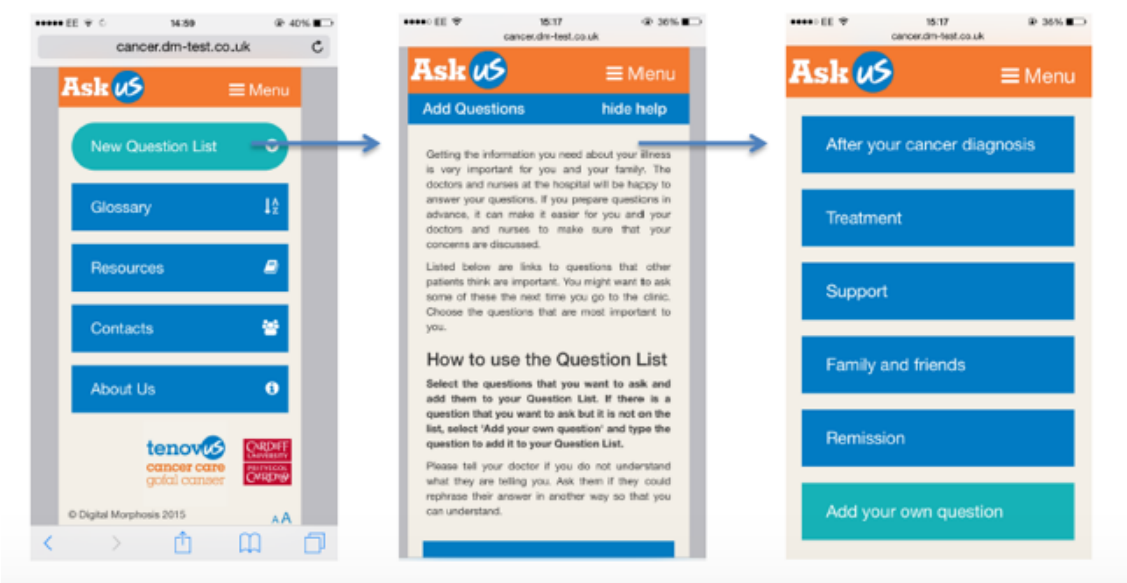
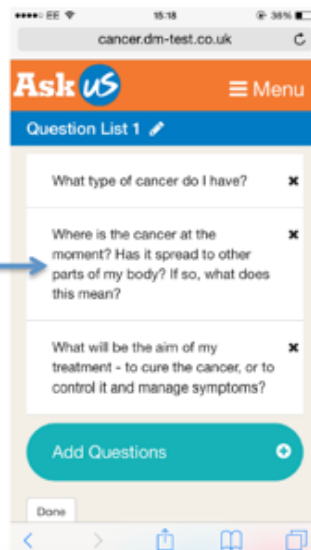
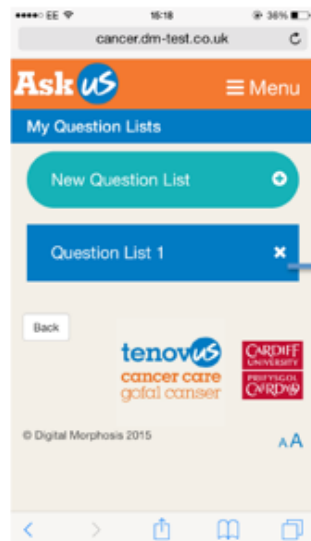
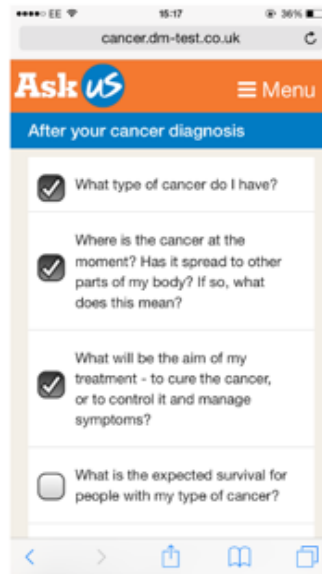
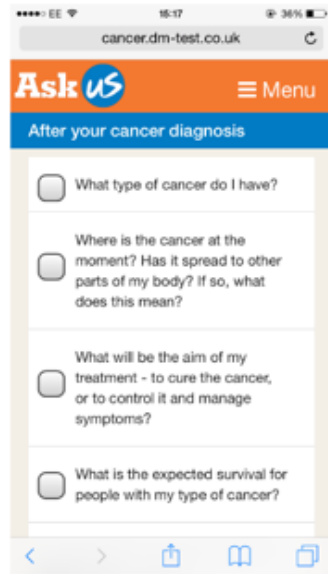


Figure 3. In-feature menu

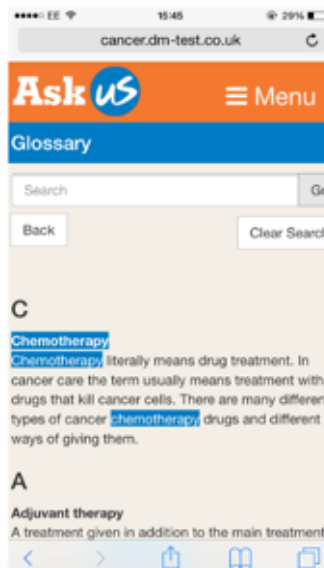
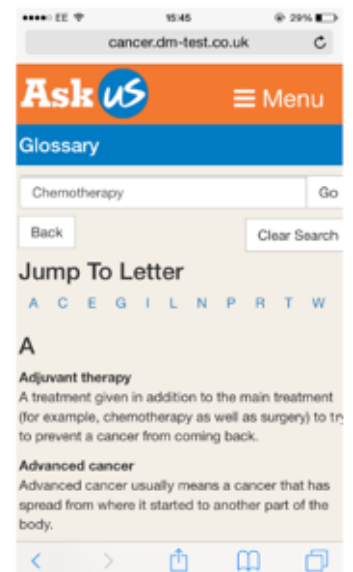
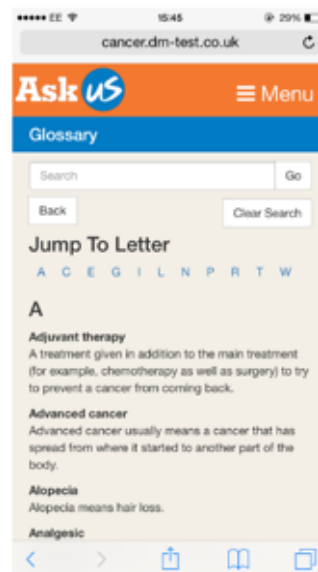
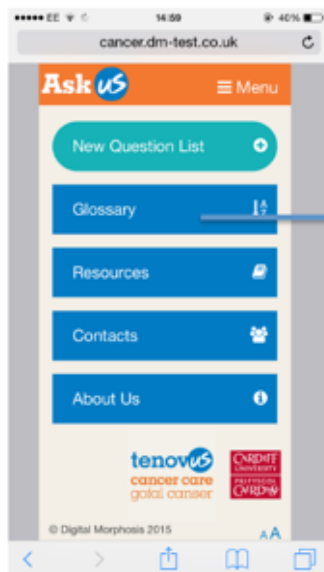


Figures 4-11. Question prompt list feature

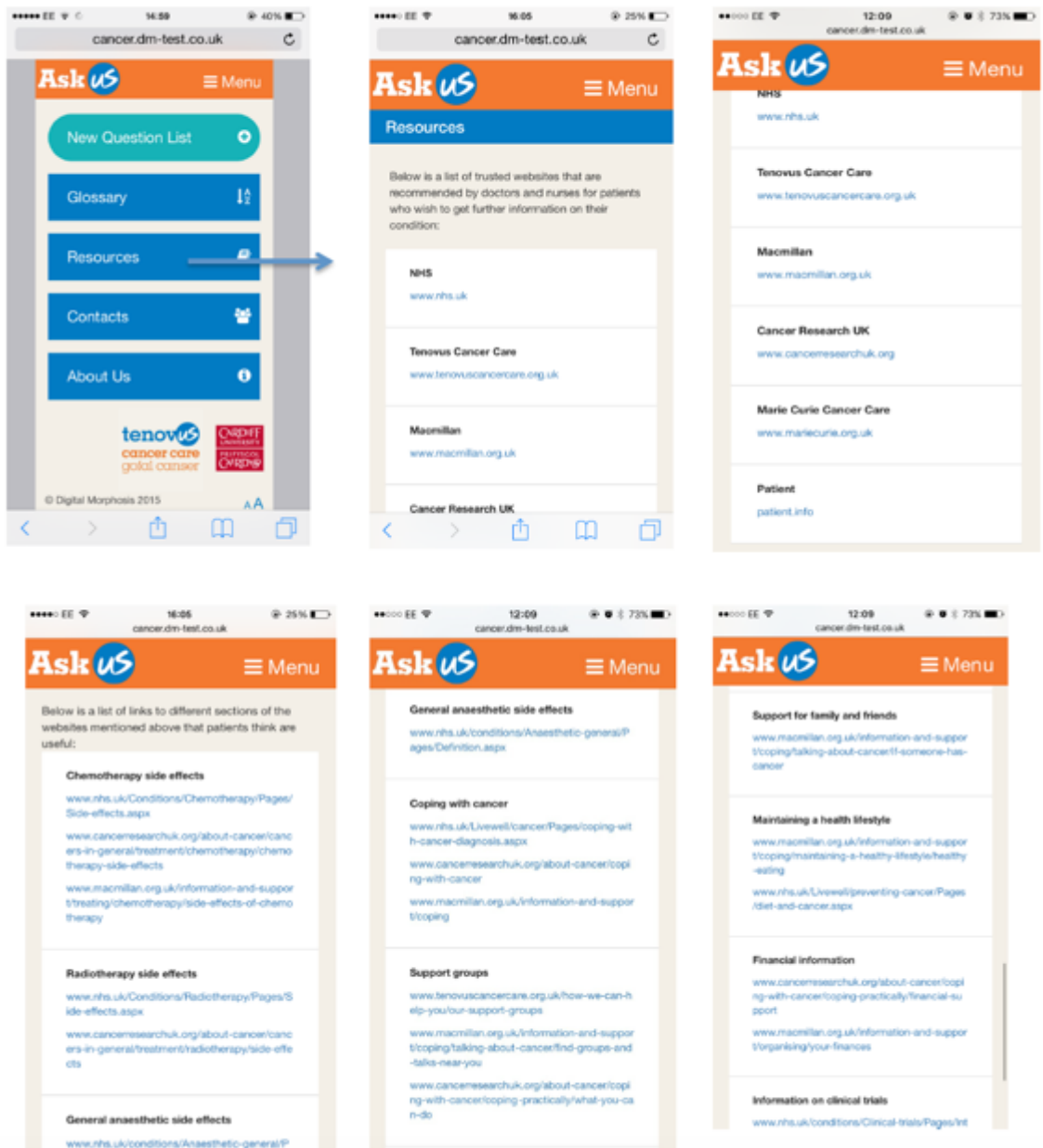




Figures 12-15. Glossary of cancer terms



Figures 16-21. Resources feature



Figures. 22- 27. Contacts feature

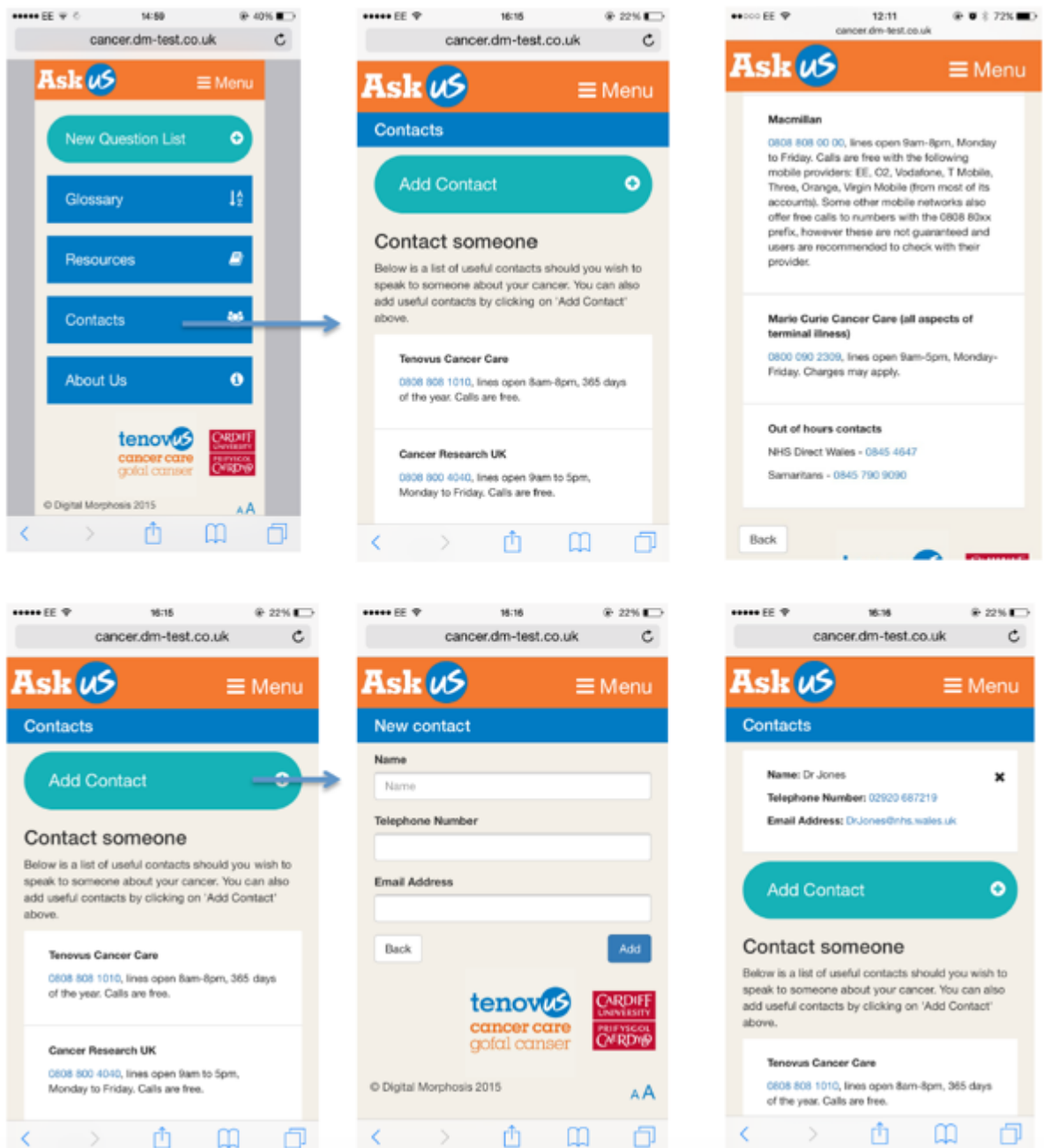
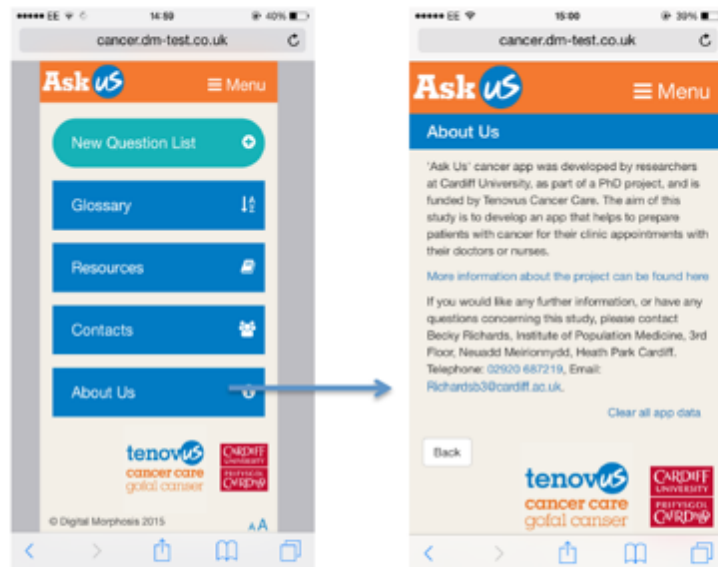


Figure 28-29. 'About us' page



Appendix 35: Feasibility study invitation letter:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer prepare for consultations

Patient Invitation Letter

Dear patient,

I would like to invite you to participate in a research study. The study is being carried out by researchers from Cardiff University who are working with Velindre NHS Trust and Cardiff & Vale University Health Board. We have invited you to take part because **we are interested in finding out whether a Smartphone or tablet 'app' would be useful for cancer patients.**

The aim of the study is to find out what patients with cancer think about using a Smartphone or tablet 'app' to help to provide them with information about their illness. The information we get from this study will be used to help create the app, which will be available for cancer patients to use in the future. **As you will be using an app, you will need to have access to a Smartphone or tablet device to take part in this study.**

Once you have used the app, we would like to interview you in your own home at a time convenient to you to ask about your experiences of using the app.

We have enclosed an information sheet for you to read and help you to think about whether you would like to take part. Taking part or not is entirely up to you.

If you wish to take part in the study, please tick 'Yes, I would like to take part in this study', fill in the contact details section on the Study Reply Form and then return the form to us in the envelope provided.

Once we receive the form, a member of the research team will contact

you to arrange to meet you and download the app to your Smartphone or tablet and then arrange an interview once you have used it. Please note that your name and contact details have not been given to any researchers at Cardiff University.

If you would like to find out more about the study before deciding whether or not to take part please contact Becky Richards, Cardiff University on 02920 687219, Email: Richardsb3@cardiff.ac.uk.

Yours sincerely,

Dr John Staffurth
Clinical oncologist

Tel: 029 2019 6135

Appendix 36: Feasibility study information sheet



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address prepare for consultations

Patient Information Sheet (v2.1, 18.01.2016)

Invitation to participate in the study

We would like to invite you to take part in a research study. Before you decide you need to understand why it is being done and what it would involve for you. Please read the following information carefully. You can talk to others about the study if you wish to help you decide if you want to take part (including your family and friends or your specialist nurse). Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The aim of the study is to find out what patients with cancer think about using a Smartphone or tablet 'app' to help to provide them with information about their illness. There has been a lot of research in the past showing that cancer patients do not have all the information that they want to have about their condition. This is because some patients find it difficult to ask questions or to remember all the information they have been told. The information we get from this study will be used to improve the 'app', which we hope will help patients with information about their condition in the future. As you will be using an app, you will need to have access to a Smartphone or tablet device to take part in this study. **You will need to bring your Smartphone or tablet device with you to your next clinic appointment, where a researcher will meet with you to download the app onto your device so that you can use it at home.**

Why have you been invited to take part?

We have invited you to take part because we are interested in finding out whether a mobile phone or tablet 'app' would be useful for cancer

patients.

Do you have to take part?

No. Taking part is entirely voluntary. If you do not want to take part you do not have to give a reason. If you decide to take part but later change your mind, you can do so, and you do not have to give a reason why you no longer wish to participate. **No one will be upset if you do not wish to take part and your treatment or care would not be affected.**

What will happen to you if you take part?

If you decide to take part, a member of the study team will contact you to arrange a time to show you how to use the app on Smartphone or tablet device. This will take place either at your next clinic appointment or in your own home and will take approximately 30 minutes. If you choose to meet the researcher at your next clinic appointment, please remember to bring your Smartphone or tablet device with you. If you would prefer to meet the researcher at another location, such as Cardiff University, you will be reimbursed for your travel expenses. The researcher will also call you one week later to answer any further questions you may have about using the app. You will be asked to use the app running up to an appointment with your cancer doctor. Once you have had the appointment, you will be asked to be interviewed to tell us what you think of the app, what sort of things you may have found useful and what sort of things you think could be improved. Researchers will also download data from the app to look at how and when you used it. The interview will be at a time convenient for you and will take place in your own home but if you would prefer to be interviewed at another location, such as Cardiff University, you will be reimbursed for your travel expenses. If you would like a friend or relative to be at your interview, that is fine. Interviews will take about 40 minutes. The interview will be recorded with your consent. Recordings will be stored in a secure place. There are no right or wrong answers to the questions in this study. We want to know YOUR opinions.

What are the possible risks and disadvantages of taking part?

There are no specific risks associated with taking part in this study and you may withdraw from the study at any time. If you find the interview upsetting it can be stopped at any time.

What are the possible benefits of taking part?

This research study will not directly benefit you but it will give us an understanding of the potential usefulness of the app for cancer patients. This should help us to improve the app, in the hope of the app being available to cancer patients in the future.

Will your taking part in the study be kept confidential?

Yes. All information that is collected about you during the course of the research will be kept strictly confidential.

What will happen to the results of the research study?

Audio-recordings and transcripts of interviews will be stored on Cardiff University password protected computers for 5 years. The data will then be securely archived and then destroyed 15 years after the study is completed. Only the research student Becky Richards and lead supervisor Fiona Wood will have access to the audio-recordings. The results of the study will be written up as a thesis and presented at conferences and published in scientific journals. Direct quotations from parts of your interview may be used in the thesis and publications, but these will be anonymised and will not be linked back to you in any way. A report will also be prepared for Tenovus Cancer care, the cancer charity, who are funding this study. Tenovus Cancer Care may wish to publish summaries of the study on their website. Short reports may also be prepared for interested government departments and the media. A summary of the research findings will be available to you at the end of the study if you would like it. All information provided by participants will be anonymised in any publications. It will not be possible for anyone to identify you from any of the published results.

Who has reviewed the 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, well-being and dignity. This study has been reviewed by the Wales REC 2 committee.

What if you are harmed or unhappy about any aspect of the study?

If you have any concerns or complaints about any aspect of the study please contact Dr Fiona Wood, Institute of Primary Care and Public Health, 3rd Floor, Neuadd Meirionnydd, Heath Park Cardiff. Telephone: 02920 687192, Email: Wood@cf.ac.uk. Alternatively, please contact Dr

John Staffurth, Clinical Oncologist, Velindre Hospital, Cardiff. Telephone: 029 2019 6135.

If you remain unhappy and wish to complain formally, you can go through the NHS Complaints Procedure. Details can be found at www.puttingthingsright.wales.nhs.uk. In the interview, it is possible that you may raise other issues of concern, such as your health. If this happens, you will be advised to consult your GP or contact the Tenovus Cancer Care Helpline, telephone: 0808 808 1010. If the student is very worried about your health or other issues that you may disclose (e.g. a complaint about medical treatment), she may consider it necessary to discuss your situation with her clinical supervisor.

Who is organising the study?

The study is being organised by researchers from Cardiff University. It has been funded by Tenovus Cancer Care, the cancer charity.

Contact for further information

If you would like any further information, or have any questions concerning this study, please contact Becky Richards, Institute of Primary Care and Public Health, 3rd Floor, Neuadd Meirionnydd, Heath Park Cardiff. Telephone: 02920 687219, Email: Richardsb3@cardiff.ac.uk.

What do I need to do now?

If you WISH TO take part please tick **“Yes, I would like to take part in this study”** and **fill in the contact details on the Study Reply Form and return the form to Becky Richards in the envelope provided.**

Feel free to call us with any queries you may have and/or talk the study over with anyone else.

Please keep this information leaflet for future reference.

Thank you for reading this information sheet and for taking an interest in the research study.

Appendix 37: Feasibility study reply form:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer address prepare for consultations

Patient Reply form

I would like to take part in this study and I wish to be contacted by the research team

☐

Name of Participant:

Telephone:

Mobile:

Email:

Preferred way to be contacted:.....

Appendix 38: Feasibility study consent form 1:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer prepare for consultations

Feasibility study Consent Form 1

Please
initial if
you agree

I confirm I have read and understood the information leaflet dated 18.01.2016 v2.1 for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I give researchers permission to download data from the app to look at how and when I used it

Name of Participant:.....

Signature:.....

Date:.....

Name of Person taking consent:.....

Signature:.....
Date:.....

Appendix 39: Feasibility study demographic questionnaire:



Patient Demographic Questionnaire

Please circle the correct responses:

Age:

18-25
26-35
36-45
46-55
56-65
66-75
76-85
85+

Gender:

Male
Female

Type of cancer:

Breast
Urological
Gynaecological
Colorectal
Other

Time since diagnosis:

Less than 1 month
1-3 months
3-6 months
6 months-1 year
1-2 years
2-4 years
5 years+

Are you currently having treatment?

Yes

No

Highest educational qualification:

GCSE/O Levels

A Levels

NVQ/HNC/HND

Diploma

Degree

Post Graduate degree

None of the above

Smart device:

Smartphone

Tablet computer

Thank you for completing this questionnaire.

Appendix 40: Feasibility study consent form 2:



Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer prepare for consultations

Pilot Evaluation Interview Consent Form

Please
initial if
you agree

I confirm I have read and understood the information leaflet dated 18.01.2016 v2.1 for the above study. I have had the opportunity to consider the information and ask questions, and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I give permission for the interview to be audio recorded.

I understand and agree that quotes from my interview may be used within written reports or publications, and that any quotes would be completely anonymous and could not be linked to me in any way.

I agree to take part in the above study.

Name of Participant:.....

Signature:.....

Date:.....

Name of Person taking
consent:.....

Signature:.....

Date:.....

Appendix 41: Feasibility study interview topic guide:

Feasibility study Interview Schedule

Opening question

- How did you find using the app?

Training

- Did you feel comfortable using the app after the training session?
- Did you feel comfortable using the app in general over the last few months?

Acceptability of the app

- Did you find the app easy to use? Or did you find it difficult?
- Did your relatives/friends use the app with you? Did they find it easy to use/understand?
- Do you think other patients with cancer would find this app acceptable to use?
- Did you experience any technical problems?

Actual use of app

- How often did you use the app?
- When did you use the app? (e.g. daily, weekly... / around consultations, treatments)
- Where did you use the app? (e.g. in your home, in the clinic, other community settings?)
- Was there a point where you found the app most useful?
- Was there a point where your relatives/friends found the app most useful?
- Was there a point where you found the app least useful?
- Was there a point where your relatives/friends found the app least useful?

Use of app content

- What were the most useful features on the app?
- What were the least useful features on the app?

Benefits of and barriers to app

- What sorts of benefits did you get from using the app? (knowledge, confidence, communication with clinicians/family)
- Did you find any problems with the app?

Communication in consultations

- Did you use the app leading up to/in a consultation with a doctor or nurse? If not, why not?
- What benefits did you get from using the app leading up to/in a consultation?
- Were there any problems with using the app leading up to/in a consultation?
- Do you think the app made a difference to how you talked to the doctors and nurses? (For example did it help you clarify your questions). How?
- Do you think the app made a difference to how you talked to your relatives/friends? How?

App development

- Now that you have used the app, are there any features that you would like added to the app? Why?
- Are there any features that you think should be removed from the app? Why?
- How else might the app be improved? (navigation, understanding etc)

Closing question

- Overall, how did you find being involved in the study?

Appendix 42: Ethical approval for the feasibility study:

Part of the research infrastructure for Wales funded by the National Institute for Social Care and Health Research, Welsh Government.
Yn rhan o seilwaith ymchwil Cymru a ariannir gan y Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru



Wales Research Ethics Committee 2
6th Floor Churchill House
17 Churchill Way
Cardiff
CF10 2TW

Telephone : 02920 376823
E-mail : carl.phillips@wales.nhs.uk
Website : www.nres.nhs.uk

4 June 2015

Dr Fiona Wood
3rd floor, Neuadd Meirionnydd
Cardiff University
Heath Park
CF14 4YS

Dear Dr Wood

Study title:	Exploring the potential of a mobile phone or tablet 'app' to help patients with cancer prepare for consultations: Phase 3 pilot evaluation
REC reference:	15/WA/0161
Protocol number:	SPON 1412-15
IRAS project ID:	172524

Thank you for your letter of the 3 June 2015, responding to the Committee's request for further information on the above research, and for submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair..

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details.

Publication will be no earlier than three months from the date of this favourable opinion letter.

The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager, Carl Phillips, carl.phillips@wales.nhs.uk.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.
- Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.
- Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.
- Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.
- For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.
- Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant. There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net.

The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from NRES. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering letter on headed paper [Cover letter]		23 April 2015
Covering letter on headed paper [Ethics reply covering letter]	1.0	26 May 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	UMAL	01 August 2014
Interview schedules or topic guides for participants [Patient interview schedule]	1.0	10 February 2015
IRAS Checklist XML [Checklist_29042015]		29 April 2015
IRAS Checklist XML [Checklist_03062015]		03 June 2015
Letter from sponsor [Letter from sponsor]		10 April 2015
Letters of invitation to participant [Patient invitation letter]	1.1	26 May 2015
Other [Patient Reply Form]	1.0	10 February 2015
Other [App Summary document]		
Participant consent form [Patient consent form (1of2)]	1.0	26 May 2015
Participant consent form [Patient consent form (2of2)]	1.1	26 May 2015
Participant information sheet (PIS) [Patient information sheet]	1.1	26 May 2015
REC Application Form [REC_Form_29042015]		29 April 2015
Referee's report or other scientific critique report [Evidence of scientific review]		25 March 2013
Research protocol or project proposal [Study protocol]	1.0	23 April 2015
Summary CV for Chief Investigator (CI) [Fiona Wood CV]		29 April 2015
Summary CV for student [Becky Richards CV]		25 April 2015
Summary CV for supervisor (student research) [Fiona Wood CV]		29 April 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors.

You are invited to give your view of the service you have received and the application procedure.

If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

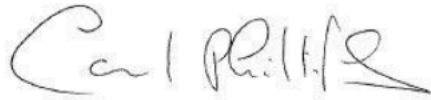
HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

15/WA/0161	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project.

Yours sincerely



p.p.

Dr I Doull

Chair, Wales Research Ethics Committee 2

Email: carl.phillips@wales.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copied: Dr F Wood, wood@cf.ac.uk

Ms B Richards, richardsb3@cardiff.ac.uk

R&D Office for Cardiff University,
resgov@cardiff.ac.uk

R&D Office Velindre, Sarah.Townsend@wales.nhs.uk

Appendix 43: R&D approval for the feasibility study:



GIG
CYMRU
NHS
WALES

Ymddiriedolaeth
GIG Felindre
Velindre NHS Trust



Welsh Blood Service
Gwasanaeth Gwaed Cymru



Velindre NHS Trust Headquarters
Pencadlys Ymddiriedolaeth GIG Felindre

2 Charnwood Court
Heol Billingsley
Parc Nantgarw
Cardiff
CF15 7QZ

Tel/Ffon : (029) 2061588
www.velindre-tr.wales.nhs.uk

*Correspondence to: Mrs Sarah Townsend, Research and Development Manager, Velindre NHS Trust,
Research & Development Office, Velindre Cancer Centre, Velindre Road, Whitchurch,
Cardiff, CF14 2TL*

*Email: Sarah.Townsend@wales.nhs.uk
Tel: 029 20 615888 ext: 4670*

Dr John Staffurth
Consultant Oncologist
Velindre NHS Trust
Velindre Cancer Centre
Whitchurch
Cardiff
CF14 2TL

24th August 2015

Dear Dr Staffurth

2015/VCC/0031 Exploring the potential of a mobile phone or table "app" to help patients with cancer prepare for consultations; Phase 3 pilot evaluation

Thank you for your mail dated 10th August 2015, in which you responded to the issues raised by the Research Risk Sub Committee on the 30th June 2015. Your response was forwarded to the RRRSC as per Trust procedures; the Committee has confirmed the response as satisfactory.

I am therefore pleased to take Chair's action to approve this project on behalf of the Sponsor and Research Risk Review Committee (RRRC). This decision will be reported for ratification at the next RRRSC on 29th September 2015.

Approval lapses if the project does not commence within 12 months of Trust approval. The Committee reserve the right to information on the progress of the project at any time and should receive a progress report six monthly and a written report on completion. Random audits may be carried out to ensure that projects comply with the clinical guidelines for research. Any serious adverse incidents relating to the project should be reported to the R&D office and a Clinical Incident Form completed.

On completion of the project please inform the R&D office.

All correspondence should be forwarded to Sarah Townsend, R&D Manager, R&D Office, Velindre NHS Trust, Velindre Cancer Centre, Cardiff CF14 2TL ext 4670.

Yours sincerely

Professor Jane Hopkinson
Trust Independent Member, RRRC Chair

Mae'r Ymddiriedolaeth hon yn croesawu gohebiaeth yn y Gymraeg
This Trust welcomes correspondence in Welsh

