Appendices

Appendix 1: Search strategy

Databases: EMBASE, PsychINFO and MEDLINE

All terms were entered with .mp

'Mobile devices' terms
Cell* phon* OR handheld devic* OR mobile phon* OR smartphone* 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-compliant* OR non-adher* OR non-adherence 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:

<table>
<thead>
<tr>
<th>Paper Title</th>
<th>Year</th>
<th>First Author</th>
<th>Screening questions</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
</table>

Was there a clear statement of the aims of the research?
- was the goal stated?
- why is this important?
- how relevant is it?

Is a quantitative methodology appropriate?

Is it worth continuing?

<table>
<thead>
<tr>
<th>Detailed questions</th>
<th>Comment</th>
</tr>
</thead>
</table>

Was the research design appropriate to address the aim of the research?
- Has the research design been justified?

Was the recruitment strategy appropriate to the aims of the research study?
- Has the researcher explained how participants were selected?
- Has the researcher explained why the participants were appropriate to provide answers to the research question?
- Has the research discussed non-participants and their reasons?
- Has the researcher discussed the response rate?
- Has the researcher discussed how the control group was selected and why (if appropriate)?
- Were demographic variables of respondents discussed?

Were the data collected in a way that addresses the research issue?
- Was mode of data collection justified (medical records/questionnaires etc.)?
- Is it clear how data was collected?
- Has the researcher made methods explicit?
- If a survey was used, was the survey piloted?
  1. Were there open questions? How were they analysed?

Has the relationship between researcher and participants been adequately considered?
- Has the researcher considered their own role, potential bias and influence?
  1. during formation of research questions
  2. during recruitment and data collection (if data collected from participants through face-to-face or telephone survey)
- Has the researcher considered the implications of any changes in the research design and events during the study?

Have ethical issues been taken into consideration?
<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Were ethical standards maintained (if enough information provided)?</td>
<td></td>
</tr>
<tr>
<td>Has approval been sought from ethics committee?</td>
<td></td>
</tr>
<tr>
<td>Was the data analysis sufficiently rigorous?</td>
<td></td>
</tr>
<tr>
<td>Has an in-depth description of data analysis been provided?</td>
<td></td>
</tr>
<tr>
<td>Is it clear which statistical tests were used/were the tests appropriate to answer the research questions?</td>
<td></td>
</tr>
<tr>
<td>Is sufficient data presented to support the findings?</td>
<td></td>
</tr>
<tr>
<td>To what extent was contradictory data taken into account?</td>
<td></td>
</tr>
<tr>
<td>Is there a clear statement of findings?</td>
<td></td>
</tr>
<tr>
<td>Are the findings explicit?</td>
<td></td>
</tr>
<tr>
<td>Is there adequate discussion of the evidence for and against the researcher’s arguments?</td>
<td></td>
</tr>
<tr>
<td>Has the researcher discussed the credibility of their findings?</td>
<td></td>
</tr>
<tr>
<td>Are findings discussed in relation to other research?</td>
<td></td>
</tr>
<tr>
<td>How valuable is the research?</td>
<td></td>
</tr>
<tr>
<td>Has the researcher discussed the contribution his study makes to existing knowledge?</td>
<td></td>
</tr>
<tr>
<td>Does the researcher identify areas for further research?</td>
<td></td>
</tr>
<tr>
<td>Has the researcher discussed whether findings can be transferred to other populations or considered ways the research can be used?</td>
<td></td>
</tr>
<tr>
<td>Further comments</td>
<td></td>
</tr>
<tr>
<td>Score</td>
<td></td>
</tr>
<tr>
<td>Question</td>
<td>Description</td>
</tr>
<tr>
<td>----------</td>
<td>-------------</td>
</tr>
</tbody>
</table>
| **1. Was there a clear statement of the aims of research?** | • What was the goal of the research?  
• Why it was thought important?  
• Its relevance | |
| **2. Is a qualitative methodology appropriate?** | • 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?** | • 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?** | • 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?** | • 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 | |
<table>
<thead>
<tr>
<th>6. Has the relationship between researcher and participants been adequately considered?</th>
</tr>
</thead>
</table>
| • 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 |

<table>
<thead>
<tr>
<th>7. Have ethical issues been taken into consideration?</th>
</tr>
</thead>
</table>
| • 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 |

<table>
<thead>
<tr>
<th>8. Was the data analysis sufficiently rigorous?</th>
</tr>
</thead>
</table>
| • 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 |

<table>
<thead>
<tr>
<th>9. Is there a clear statement of findings?</th>
</tr>
</thead>
</table>
| • 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? | • 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:

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
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:

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.
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

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: ....................................................................................


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

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.

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

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.rsforum.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:

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**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

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

Ma B Richards, richardsb3@cardiff.ac.uk

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

R&D Office for Cardiff & Vale UHB, CAY research.development@wales.nhs.uk
Appendix 14: R&D approval from UHW:

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:

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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.


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.crmec.nhs.ac.uk/about_us/processes/portfolio/p_recruitment](http://www.crmec.nhs.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.

Page 2 of 3
• 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,

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 Stafford
Academic Supervisor: Professor Paul Kinnersley
Academic Supervisor: Dr Kate Brain
Appendix 15: R&D approval from Velindre NHS Trust:

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,

[Signature]

Professor Jane Hopkinson
Trust Independent Member, RRRSC Chair
Appendix 16: interview transcript for P5 Pam and R5 Susan

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

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

I – okay and what about yourself?

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

I – what research or?

Partner – yes

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

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

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

DS240149.F – oh definitely

I - and what about as the stage progressed then?
Partner - anything and everything we could get our hands on we read

DS240149.F – yeah and if I couldn’t find the answers I asked people, and if I couldn’t find them, I’d either go online or I’d just keep asking questions you know,

Partner – we wanted to know the type, you know, we wanted to know what was going to happen, how you were going to do that

I - so did you go to people first before you went on the internet, what was your first port of call for information?

DS240149.F – my very first port of call would have been the Macmillan nurse. I have to say that the surgeon who operated, he answered all my questions there at the time, he was very good, he had a list of things he wanted to tell me and he went through that very methodically didn’t he?

Partner – yes

I – that’s good

DS240149.F – um so that was like on the Monday I was told I had cancer and he spent about half an hour didn’t he, and he went and left us with the Macmillan nurse, the Macmillan nurse said “you know there’s too much going on here, I’ll come out on Friday” So she came out on Friday so in that time, I sort’ve get my head around it I suppose, so she came out and by that time I had a load of questions to ask her

I – right okay

DS240149.F – um I think she did very well

Partner – she did, absolutely, she was amazing
DS240149.F – I mean she didn’t know about the surgery and the prosthesis and things, she knew about the cancer treatment, she could tell you about the cycles you know she said down and told us “you’re going to have 6 cycles”

Partner – she didn’t treat you like an imbecile, she answered your questions openly, honestly, and yes

DS240149.F – I found her very, very good...and if she didn’t know something she’d say “oh I don’t know” but and she was great the phone in no time

I – and did you feel like you could approach her?

DS240149.F – oh absolutely, absolutely

I - so in the cases where she wasn’t sure of the answers did you go on the internet then, or did you go back to the consultant?

DS240149.F – well I have got this very good friend, um who is overseas and she put me right about, I had what do you call in a seroma following surgery and I didn’t know why, or whatever, and it was she’s qualified so

I – so was that the nurse?

DS240149.F – this is the nurse overseas she is, was a Macmillan nurse, I think she still might be, I’m not quite sure

Partner – oh <friend>’s daughter? Who is a medical consultant so we ring her she’s got this special thing that she goes into...for the medical professionals and then she will ring us back
I – yes so there’s quite informed people around you then

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

Partner – that sounds awful

DS240149.F – It does sound awful I know

I – it sounds sensible

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

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

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

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

I – oh really

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

I – is that the induction, yes

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

I – that seems important stuff to be passing on

DS240149.F – really I mean if apparently your nuetrophils will drop every 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....
Partner – it wasn’t categorically they just said “you probably won’t vomit, you’ll just feel sick”

DS240149.F – I’d feel very sick, so when I came home 3 hours later and I was really vomiting everywhere I’m thinking this shouldn’t have happened

Partner – “oh they told me I wouldn’t vomit! That oncologist told me I could get on with life and be normal! I’m absolutely feeling rotten you know” so don’t say things like....they don’t know do they? If you’re thinking about it, they don’t know what you’re going to be like in that first cycle?

DS240149.F – of course not

Partner – so from the first cycle, they take it and they really have

DS240149.F – they’ve worked really hard to help me not, and I haven’t vomited since then

Partner – they knew what the first cycle was like, the second cycle they, and every subsequent cycle they have worked their socks off to get it right – you can’t complain!

I – yeah well that’s good, yeah

DS240149.F – no I think the thing is I don’t know what the percentage is, but say 70% or more don’t vomit, so why treat them for that, you know wait until they do and then we’ll.... and I think that’s what they do
Partner – and that’s what is happening they do they wait to see if you have symptoms

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

Partner – ha, that would be nice!

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

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

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

Partner – and then they could go further

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

I – so they have the choice

DS240149.F – some people will go “okay I know about neutrophils, but people like me then, okay what’s normal? What happens if it’s abnormal, do you know what I mean, so you don’t frighten everybody by saying if your
nuetrophils drop down to 0.2 you’ve got a 1 in 5 chance of dying, you don’t want to be told that do you? I do, I think it has to be based on by stage almost

I – yes that’s a good idea

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

Partner – If you do have vomiting then...

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

I – tailoring it to them

Partner – yeah some people won’t want to go into detail

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

I - yeah ((laughs))

DS240149.F – and I just think yes, it’s like consent you have to know the basic things obviously, but every tablet starts with nausea and vomiting, so my mother ((rambles in mother’s voice)) no...and there are people out there who will do that so no it’s a tough one
I – yeah, that’s a good idea having a staged approach though

Partner – but then you know, depending on how much a person wants to know, you can open those windows if you want to

I – yeah exactly, okay. What about communication then, how did you find talking to the clinicians about the cancer?

DS240149.F – the surgeon and that Macmillan nurse, can’t fault them, they were there and they had time, and that’s the thing I felt was special was that the nurse had, she seemed to have loads of time, although I know she was incredibly busy

Partner – she took the time to talk to us

DS240149.F – the first time, the only time I’ve met my oncologist, only once, um he was running his clinic incredibly late, which I can understand because when we went in that first time to discuss what time of chemotherapy I had to have, he must have been 40 minutes over

Partner – and he was great

DS240149.F – I asked him lots of things and he answered as truthfully as he could, I think he did measure his words, but I’ve not seen him since, so I see the nurse practitioners when I go in and all they do is “how have you been?” and they try to stop those things

Partner – nothing like the Macmillan nurse, they haven’t supported me at all

DS240149.F – they haven’t supported me at all, I don’t feel supported at all
I – by the oncologist?

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

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

DS240149.F – there’s no one to ask

I - okay and that’s the oncologist

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

I – yeah you should

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

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

Partner – why did she think you should see your optician?
DS240149.F – she thought my retina had torn away from the back of my eye
and she sent me to the ophthalmic bod’s in Bridgend but because she hadn’t
heard it, the nurse practitioner, no connection, I’ve got a black mark on my
nail, it’s pathetic I know it’s pathetic but I’ve asked about it, “don’t know”
look it up black stripe on your nail indicates breast cancer, um and these are
things I’ve had to find out about myself

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

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

I – I’m sorry that you experienced that

Partner – but, <hospital> have been amazing

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

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

Partner – it’s a centre of excellence?

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

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

DS240149.F – sometimes 3

Partner – when she’s feeling poorly, or really, you know you’re talking about a cancer patient here who is here, who is not up to scratch, who is having chemo

I – yeah that’s a very long time

Partner – and it’s 2 hours before, and that is waiting for a nurse practitioner to see us, not a consultant a nurse practitioner. I’m sorry that is appalling

DS240149.F – last Monday when we went in

Partner – that is appalling

DS240149.F – there was a lady and she complained to one of the nurses, not the nurse practitioner, she complained to one of the nurses in the outpatient clinic, excuse me my appointment is at 10 o’clock and it’s quarter past 11 now “oh yes, yes, what’s your name?” so.... and I said “well actually my appointment is for 10 o’clock too” “oh okay” so they are just 10 o’clock appointments, you just sit there, she went in before me, so I went in after her, so I didn’t get in until after 12 o’clock and I missed my lunch because they give you a prescription and you’ve got to go to pharmacy and wait and they’re never ready, it takes ages to do it, so I missed my lunch and when you’ve had chemo you feel quite sick you have to eat little and often so I don’t know what they can do about it it’s just not particularly well organised

I – no it doesn’t seem to be, it seems quite manic
DS240149.F – but they’re always hectic there seems loads, we went to <hospital> at that time and there was hundreds of people milling around....

Partner – I was about to get up and just say you know “have you forgotten that we’re here?” and they just called us ((laughs)) and they just rush you when they talk to you, and then you understand why actually, he was very thorough, I asked him questions about her diet and whatever and you know

I – yeah, if I was gonna ask were there any barriers communicating with doctors and nurses, I’m guessing one of those then is sort of time pressure isn’t it?

Partner – really busy well I don’t see...well you’re in there isn’t it...they do take their time it’s just the waiting to get in to see someone

I – yeah

DS240149.F – but it’s like I was given the name and number of the Macmillan Nurse after I had breast surgery, I haven’t been given a name that I can contract. The only number that I can contact is in an emergency. I’ve got a number if my temperature goes up, or if I’ve got this, this, or this

I – but no one to have...

DS240149.F – but not on a day to day to say “I’m not feeling so good, blah, blah” you know, and sometimes I just want to run that past them

I -  yeah exactly.  I thought <hospital> had a Macmillan nurse, or I thought they had someone you could call and ask?
Partner – well I thought...

DS240149.F – I don’t have anybody

Partner – oh no you can, you could call and ask, but you don’t know who they are. You’ve got a phone number, that’s what they want

DS240149.F – that phone number is only if I have a chest infection or I have this, this, or this

Partner – no, they have given you a number for Tenovus and you can talk to anybody in Tenovus

DS240149.F – that’s counselling, no I mean

Partner – no, no, no, you can talk about treatment, or whatever with Tenovus, there’s somebody there

DS240149.F – yes, but I don’t have my own nurse

Partner – no

DS240149.F – like with <nurse>, I don’t....

I - yeah that would be really helpful if you had questions for a doctor or nurse

DS240149.F – no, I’ve got an emergency number that they have to bleep the on call oncologist, well I’m not gonna bleep her to say that I’ve got a little grey line on my toe nail, what do I do about it?
I – yeah you must have your own nurse that you can run that past

DS240149.F – and if she doesn’t know, she’ll come back to you

I - yeah exactly, so do you think an app could help with something like that then, to be able to look that up. I mean I suppose you could do it on the internet

Partner – If you really wanted to do it, you would do it

DS240149.F – well I can, it’s like sometimes just for me, to have a voice...to have someone to say, “well actually I don’t know about that one I’ll come back to you”

I – okay

DS240149.F – I suppose I’m spoilt because of <nurse>, <nurse> was incredibly supportive

Partner – she was

DS240149.F - and she did look after me and I felt, I did, I felt if I wanted to I could’ve rung her and said “could you come out?” you know, where it’s that feeling where you’re unsure and she would have, and I don’t have the same support going through oncology. Oncology in actual fact has been worse, the side effects have been terrible, things that I don’t know about yes I feel like I’ve been hunting both of us, even her daughter

Partner – it’s been a bit learning curve for all of us

DS240149.F – yes
I – yes

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

Partner – yes she was very good

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

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

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

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

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

DS240149.F – absolutely, I would recommend that to people, I also put down, I’ll show you, it’s pathetically basic, but it’s been a real help to me
Partner – I whisked it off the computer and just said “fill it in” and now I say to her

I – oh so was it, it was a...?

Partner – day 5

I – ready made

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

DS240149.F -

I – oh and you typed it out

I – this is very good yeah

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

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

I - ((laughs)) yeah

DS240149.F – I think from my point of view I like to be doing, I like to be proactive, trying to help myself you know
Partner – that’s our background we are always proactive

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

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

Partner – wouldn’t that be a good idea?

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

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

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

Partner – yes
DS240149.F – yes, I think that’s brilliant

Partner – absolutely, cos we see a pattern, I say to her now – “what day are you 6, okay what was last time’s day 6? Oh okay”

I – and you sort of prepare

Partner – could fit then...

I – yeah exactly

DS240149.F – well somewhere in my first cycle my nose kept running, just like a tap and I mentioned it to the nurse practitioner and she said yes you’ve got no nose hair it’s all fallen out

Partner – and we both went “oh right”

DS240149.F – and I mean it grows back a little bit and then halfway through the second cycle and suddenly it’s like this and I’ve got no nose hair...! You know it’s silly things like that, it’s having this pattern and working it out

I - yes, I expect it makes it easier for you to cope with then if you know what’s coming

DS240149.F – well I know that my taste will get better, where as the first time I had it, I thought I can’t be like this for 6 months I won’t be able to eat!

Partner – I’ve learned now what to cook you know the first 3 or 4 days I...
I – oh that’s great

Partner – and no salt, cos if I put a bit of salt in it, so I make her some sort of butternut squash soup, so that she can eat that with bread and she’s fine, no butter, butter will make her sick and no salt because the salt then she’d go...I’ve got this salt in my mouth all the time so...but it’s all its trial and error

I – yeah, that’s such a good idea. Okay, so how have you found it because we’re still on communication so how have you found it, have you found it easy to talk to family and friends about the cancer? Or do you prefer to keep things to yourself?

DS240149.F – I’m selective who I talk to I would say

I – and for what reasons, why would you say you’re selective?

Partner – she wants to be a moaning minnie

DS240149.F – no I don’t mean to be, I don’t want people coming around having to listen to me “oh I’ve got a bad ulcer...oh my pain” and things...I just say “I’m not too good today, come tomorrow” you know

I – yeah, yeah

DS240149.F – um and like I said if I need information there are certain people I will go to...so anybody who comes will just sit and they say “how are you” and I go “I’m getting there” I don’t want to bore them, you know because it’s quite an enjoyment sitting there talking about all you’re pains and aches isn’t it....you know you become a right old moaning minnie...
I – yeah I expect you don’t want it to dominate you’re whole day I would think talking about

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

Partner – when the sun goes down it gets hot

I – yeah, yeah

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

Partner – you didn’t want to tell anybody

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

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

DS240149.F – yes I do

I - is that both or either?

DS240149.F – yep phone and my Ipad is joined at my hip
I – okay yeah so you prefer the Ipad, yeah so what do you use the devices for?

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

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

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

Partner – yes

I – really

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

DS240149.F – yes

I – and they don’t sell it over here gosh. So do you use apps for your health at all?

DS240149.F – I don’t have an app specifically no, I just use search engines

I – okay so you’re just looking through google and on the databases

DS240149.F - yeah

I – and what about yourself ((referring to partner))

Partner – same, same

DS240149.F – you don’t have an app do you?

DS240149.F – no I go into google or ask Informed <Medic Friend> yeah we ask Informed <Medic Friend> it’s good that she knows, if she doesn’t know, which is very rare, if she doesn’t know, she’ll come back and find it, she will go to ((both talking at once inaudible 33:03))

I – yes that’s brilliant the internet. Okay so the type of app we’ve talked about, we’re hoping that it will help patients with appointments by prompting them to ask questions, or think about the types of questions they want to ask, it can be linked to reputable websites so they’re getting good information, and it could also help them with social support, so links to support groups, so they’re the sorts of things we’re thinking about, but really it’s gonna come from what you suggest, so bearing that in mind, do you think patients would use this type of app if we built it?
Partner – yes I think they would

DS240149.F – I actually think they would, because you are given a huge amount of paperwork at the beginning you know about diet, exercise, fatigue blah, blah, blah...

Partner – all these leaflets....

DS240149.F – masses of them, they’re all in here and I have gone right now I’ve put them in there, a lot of it because um

Partner – you weren’t in the right frame of mind to look at it

DS240149.F – I wasn’t, it’s all timing isn’t it?

I – it’s too much

DS240149.F – it’s really overload. The number of appointments I had from the first time I went to a GP to my surgery, I got through 40 it was unbearable wasn’t it

Partner – we were going to Swansea um Bridgend, <hospital>

DS240149.F – it was just awful

Partner – I just stopped doing everything okay cancel everything

DS240149.F – she had to give up work
I - wow, yeah

Partner – it’s you know – let’s see what’s going on here

DS240149.F – I don’t know how they can avoid them, but it was overload

I – and so did you read half of the information, or did you sort of leave it and then...

Partner – some of it

DS240149.F – I have read it, I have read it now, um yes because most of it has been quite useful, but again it was too basic. They’re using it for people you know don’t know, which I can understand again. I think what you need is this like open window you need oh okay that’s fine, that’s as much as I need to know, if you want to know more you can, but I think if they’d said you know this is the basic if you want to know more, look up blah, blah, that would’ve been helpful, but it stops...it doesn’t...

I – yeah it’s interesting because some of the patients I’ve spoken to have said, “actually the information leaflets are too complicated, there was too many big words and I can’t understand it all” so the app maybe could then starting simple and say if you want to know more and as you progress and for people like yourselves who really are getting down to the science behind it, so maybe like we could

DS240149.F – maybe stages, you could have idiot, middle and bright

I – yeah

DS240149.F – you know, that sounds dreadful doesn’t it?
I – ((laughs))

Partner – but we do have a medical background so we’re a bit...

DS240149.F – well that’s the problem...

I – yes exactly

Partner – so we know what’s going on and we’re “oh okay let’s go through here and find this”

DS240149.F -

I – or even if we link the app maybe to the internet to um a reputable scientific website

Partner – absolutely, a medical site that we could go and have a look at, now that would be ideal

DS240149.F – and there are going to be people who’ll say “I didn’t know that” or “I don’t understand” my mother doesn’t understand big words...you know if I said to her...

Partner – didn’t understand what a protein is

DS240149.F – nuetrophenic sepsis no idea, no idea, but if I said have you heard of white cells? “yeah” have you heard of red cells? “yes” and that’s how basic it is. That’s where have to...you have to cover it for everybody don’t you?
I – yeah exactly

DS240149.F – and that’s tough...

I – that’s really, that’ll be definitely noted down

Partner – but if I opened that you see I’d go right...close it down and go onto my...((laughs))

DS240149.F – no I know but it’s like colour coding, you going to have to you know if you’re interested it’s green, if you’re really interested it’s amber and if you really want to know intricate details you go into red, or you could have a coloured section or something do you know what I mean?

Partner – yeah absolutely

DS240149.F – so I would go straight to the red and I would just be reading that

Partner – yes absolutely

I – yes cos that’s avoiding the sort of....

DS240149.F – the dross that goes before it which we know and I think that is hard because you’re reading something.....

Partner – when the diagnosis comes, you read as much as you can you know I study the internet here, she’s on the internet here and I go “did you know” and she goes “oh yeah that sounds interesting you know”
she says things like you’ve got lobular cancer HER positive, meant nothing

Partner – but we logged it came home we were both on different sites and away we went you know

DS240149.F – but you can’t cover everything, but if you have links you know like you said to the higher information

I – yeah to do guide you onto the right information for them

DS240149.F – depending on where you wanted to stop

I – yeah okay

DS240149.F – some people would be petrified, I mean...that lady I shared a ward with she didn’t want to know anything, she didn’t want to know anything about anything

Partner – another thing is if you’re doing the surgery bit, it’s about you know do I go for reconstruction or not?

DS240149.F – that’s hard

Partner – you know there’s a really...

DS240149.F – you don’t have much time to make up your mind obviously

Partner – it’s a very short period to think about that
I – yeah they said it’s quite

d DS240149.F – they’re rushing you through because of the government objectives, that you have to go from uh GP visit to surgery in X amount of weeks, then you are pushed and you’ve got all these appointments in-between as well, and you’ve got so much information to take in...do I have a lumpectomy, do I have a mastectomy do I have reconstruction now, or do I have reconstruction later?

I - yeah exactly

DS240149.F – you have to say if you want it later because they have got to have the skin flap you know

Partner – but you don’t have to do that and my first instinct was take it away...I don’t care what you...just take it away and then she said “hey hang on, no I need to think about this you know” and it was good for her to sit and think about it

DS240149.F – I said I need an MRI, I want an MRI to see if I’ve got it in my other breast. I don’t want to have to go through this again um and that gave me time to come to terms with what I’d decided, but if they’d given me a reason I would’ve just said “you’ve got breast cancer she would’ve said “I’ll have a mastectomy on Wednesday”

Partner – when he said...I would’ve been on the Wednesday had it done and I’d be out

I – really yeah

Partner – so it’s a different thinking isn’t it? My sisters came around and my one sister said “yeah I would’ve done the same as you” and the other
one went...“I’m not so sure, I don’t know where I would’ve been with that
till I’d thought about it”

I – so it’s really important then getting to the decision?

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

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

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

Partner – you couldn’t have it anyway

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

Partner – her glands had gone

DS240149.F – but there was a point in this discussion that I could have a
lumpectomy and I felt like, I should say yes you know
Partner – but the surgeon was very good about that wasn’t he, they were talking about it, but there’s still that...

DS240149.F – there’s a pressure on you to make a decision

I - oh and it’s a very big decision

DS240149.F – and I’m intelligent so I don’t know how somebody who’s just “oh my god” what are they going to base their decisions on?

Partner – I think they just say “go with it” I don’t know

DS240149.F – what would you do? That’s what...put it on the surgeon, what would you suggest?

Partner – because as you come out of the, the surgeon’s consulting room, your mind is going 19 to the dozen is it a lumpectomy is it a mastectomy and you come home and you immediately go online to find out...

DS240149.F – and the problem we had also was that I was told it was in my lymph and I was told it wasn’t in my lymph and then I was told it was in my lymph...so if it wasn’t in my lymph

Partner – it was in the lymph

DS240149.F – I could ....that was just

Partner – mind blowing
DS240149.F – you know I don’t want chemotherapy, nobody wants chemotherapy and there was a point

Partner – like being on a rollercoaster

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

I – I don’t understand why they told you that?

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

I – oh when they took the biopsy

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

Partner – it’s a rollercoaster

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

I – okay so going back, what about
I - no, no it's great it's just we'll just get through other questions these as well. So do you think other patients would find this app accessible for use?

Partner – yes absolutely

I – and what about friends, friends and family's of the patients?

Partner – I would've been on it

Partner – absolutely

I – and do you think patients would need training to use it? Do you think we’d have to train patients up first of all?

Partner – no

Partner – we’re all computer, even her mother at 85 can use a computer
I think they are and they’re grandchildren can show them if they’re stuck.

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

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

so computer literate ((laughs))

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

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

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

Partner – information!

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

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

Partner – well they’ll be asked more questions, so they will have to take
time to answer them
I – so how do you think they’ll cope with that, do you think that they’ll like that? Or do you think they won’t like that very much?

DS240149.F – I know talking to my GP for example she hates me to know, because everyone knows everything and they go in and tell her what’s wrong with them, you know so there is a point, there’s a point there, too much information? I don’t know, I think it’s useful and yes there are going to patients who are going to sit and say “I have read” and they’ve got a 100 questions you know. I think for the majority of people it’ll just be

Partner – information gathering and you know okay this is what I need to ask and what am I going to do...okay so I’m going to ask him this ....and hopefully he’ll give me answers. We know they’re rushed, we know they are, but you know they’re not God they are people and they are dealing with people

I – and if they don’t know the answers they should definitely look them up

Partner – absolutely

I – and what about for family and friends, what benefits do you think they might get from using this app?

DS240149.F – all my friends have said “what can I do to help you?” all of them, um they don’t know how to deal with me

Partner – we just say “meet us for coffee”

DS240149.F - I think but if they...there’s a lovely line um not another bunch of flowers.com this woman she’s had 3 breast surgery’s and uh she’s fed up of getting flowers, she wants useful gifts and I think that would be if they
had some ideas about how to alleviate they might not feel so helpless are they, because they all want to help don’t they?

Partner – and don’t bring another bunch of flowers!

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

Partner – excellent

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

Partner – and deodorant, special deodorant, it was amazing

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

I - aw that’s so useful isn’t it?

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

I – so that sort of information would be helpful

DS240149.F – of course yes I mean how

Partner – with websites like not another bunch of flowers, because they’ve got lovely hats and all those sorts of things
I – that’s brilliant that is yeah

Partner – but they are a bit expensive, but

DS240149.F – it’s things like cracked lips you know I talked about the sores in your mouth...you know the basics the actual how to stop it? What can we do about constipation?

Partner – which is horrendous in the beginning

DS240149.F – people don’t, they say “make sure you don’t get constipated” that’s okay, but how do you make sure you don’t? You’re taking a drug that fluid retention is horrendous, it sucks out all the fluid from your bowel, so you don’t go to the toilet for 4 days and you feel like death

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

DS240149.F – well like it’s the bottom line you address you when you have this << inaudible everybody speaking at once 49:23>>

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

DS240149.F – are you warm, are you

Partner – basic needs

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

Partner – and I feel useless because sometimes I can’t help her you know and that’s really hard there should be a practical part of the app like what to do to help
DS240149.F – you know what to do, to help you have a cracked nose, your
eyes get sore, there’s a whole....

Partner – my remedy is “go to bed and sleep”

I - yeah ((laughs))

Partner – have this soup, feel the warmth, have a hot water bottle, please
go to bed

I – so, what about for you then what could the app help with for yourself?
Something you said you were finding it hard...

Partner – practical things you know?

I – ...you don’t know what to do what about supporting yourself, do you
talk to other people or? How do you, because it’s difficult for you as well,
so how do you cope with everything?

Partner – I take the dog for a walk, you know I’m not one to sit and talk to
people, and in fact I’ll tell you openly and truthfully if she hadn’t said yes
to this, if you had rung me I would’ve said no, because I don’t do that sort
of thing, that’s not me

I – Okay. Well what about for other relatives then do you think...because
some relatives go to support groups and things like that. Do you think that
would be helpful for others?
Partner – if the opportunity is there, then I’m sure some people would take that yes

I – okay

Partner – but I’ve had my own way of dealing with that and

DS240149.F – oh I’ve been offered, have been offered it…. I’ve kept it

Partner – there may be a time when you will need it

DS240149.F – it’s a very emotional thing for a woman to go through, but I’ve been able to

Partner – some people grab it

DS240149.F – I’ve talked to <partner> we talk about our problems we’re very open about it you know it definitely helps

I – yeah definitely

Partner – I’m a psychotherapist as well, so you know

I - oh there you go ((laughs))

DS240149.F – I would’ve said psychobabble go away and leave me alone

Partner – yes she does, “don’t give me that psychobabble” okay
and she says “so I guess what you’re saying....” and I think ah, ah...no don’t, don’t.((laughs))

I – ((laughs)) um okay so do you think the app would have an impact on the way you talk to doctors and nurses about the cancer? Do you think it could be easier or more difficult?

DS240149.F – no, it’s going to make it easier

Partner – it will make it easier

DS240149.F – you go in with a bit more information, you feel more comfortable, you can ask them a questions and the answer won’t confuse you because you know the rudiments of it like

Partner – or if it does, you’ll take it into your head you’ll come away and go and look it up ((laughs))

I – yeah, what about writing things down...do you think the app should have a facility for writing the answers down? Because some people have said “I don’t know if I would have time, or it’ll distract me”. What do you think about that?

Partner – it would distract on an app

DS240149.F – I think something like this that is perhaps a diary and...

Partner – you can make a recommendation to do that if they wanted to?
I – I mean when you’re in the consultation and you’ve got your list of questions on the app, what about writing the answers down during the consultation?

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

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

Partner – but then we’re old

DS240149.F – fill in the detail

Partner – well no I take my app in there and say “hold on second, I need to...”

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

Partner – yes

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

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

DS240149.F – the only way I could see with family and friends went into the app they had more understanding of what you’re going through, because nobody knows what it’s like until
Partner – I don’t see your sister asking questions on an app, or your mother

DS240149.F – no I mean my family are not interested....they just want to
know that I’m okay...are you alright today? “yeah I’m alright”

Partner – they do get on with it?

DS240149.F – they just want to know I’m okay

Partner – are you alright today? Yeah I’m alright...well that’s fine

DS240149.F – they don’t want to know the ins and outs of it you know?

Partner – but her family are completely different her sister wants to
what....

DS240149.F – so maybe she would find some use for the app

Partner – oh yes absolutely so there are people who are going to and there
are people that are not, but if the availability was there, then most people
would use it I’m sure

I – okay and what about problems what do you think the problems might
be, the barriers in practice?

DS240149.F – I think sometimes not understanding the information, you
misunderstanding it perhaps can lead to confusion and they may might get
very frightened if as I said you opened up different pages and they’ve
followed it through, when I found out that I could’ve died when I went in over the new year...I was surprised, so if I’d been told

Partner – you weren’t frightened, you were sort of shocked, wow, in fact you were....

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

Partner – then they’re not going to use the app are they? They won’t they’ll

I – yes exactly

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

I – yeah, I think that’s...

DS240149.F – they want to be more in control

I – yeah okay and do you think that’s something that the app can help with?
Partner – yes, absolutely

DS240149.F – I mean you’ve been asked to make a decision about something incredibly important, what are you basing your knowledge on, you have no knowledge of this at all

I – they did they give you a decision aid? So it’s like an A4 piece of paper with the different treatments – they’re making those at Cardiff Universities now they’re very helpful

Partner – no, no nothing like that

DS240149.F – he sat, he had his notes and bit of paper, he went through them the cancer I had, what type I had, what ops blah, blah, blah...and that was it

I – and you had to go away and search all this information?

DS240149.F – at that point I had no written information at all, I said to her “can you remember what...” I was in a state of shock, cos I knew I had breast cancer

Partner – but you can’t take it all in though

DS240149.F – you know if <friend> who went through it at the same time as me, she had no idea, no idea, she went for a mammogram and the person in the unit said, she’d been shopping of all things had a mammogram in the morning, it was the first one that she’d ever had in her life and then went on shopping...and the person, the radiographer said “I’m sorry, but this isn’t looking good, you look like you’ve got breast cancer” that’s how she was told! And she went through it blindly, she was really in a bad place wasn’t she?
Partner – oh I know, you did this, you...

I - that must’ve been such a shock

DS240149.F – you see whereas when I went it was...

Partner – we’d had a week talking about it because...

DS240149.F – well I had a mammogram, I went to the GP I found my lump,
I had a mammogram and then I had another mammogram 2 days later, so I
knew, on the Friday I knew, so that Monday when he said, I felt like saying...

Partner – I kept on saying “wait till it’s said, once it’s said then that’ll be
okay” but we have to wait until it comes out of his mouth to say yes, cos
you always have...

DS240149.F – and I think a lot of patients hear, yes you have cancer, that’s
it, nothing make sense, everything else has gone over the top and that
would be so useful to have something you’re going to...this is what we’ve
discussed, take this away look at it I’m here for you I’ll hear for your
questions and that’s what you need isn’t it

Partner – we did have that with <district nurse> I have to say she was
amazing

DS240149.F – <district nurse> was the one that did that form

I – yeah, and at what point did <district nurse> come?

DS240149.F – she was there when they said to me
Partner – at the diagnosis

DS240149.F – I’m sorry you’ve got bad news

Partner – she was amazing

DS240149.F – she was sat in with him all that Monday and then he left the room and she sat with us while I cried and then she said, this is my name and number when can I come and see you? We said come on Friday you can have a coffee, she came and she sat with me for about and an hour and a half on that Friday and we discussed everything

I – yeah, so that was from the Monday to the Friday

DS240149.F - hmm

I - so in that time did you have leaflets to take with you?

Partner – no, nothing

I – no

Partner – we were on the internet on the settee we were away trying to find out

I - the thing is some people don’t realise that not all the websites have reliable information, so within that time they could’ve found unreliable information
Partner – and they might not have remembered correctly what was wrong with them you know

Partner – but you were good you had a bit of paper in your bag, or can I have a bit of paper and you had your pen out and you were writing things down all the time

Partner – I mean for some reason I can’t remember what it was but it was something about 10% of information is retained, it was something really small

I – yeah, yeah

Partner – I can remember you saying “what was that again?” and then you wrote it down ((laughs))

Partner – I know what an MRI is, but not everybody does, you know

I – yes exactly

Partner – well we use PRN, BD whatever...you know
DS240149.F – you do it’s just <<inaudible 01:01.12>> and the doctor said can you....why

Partner – we didn’t stop for a cup of tea ((laughs))

DS240149.F – and she said “oh that was on the Monday afternoon it wasn’t on the Monday after I tell a lie it was on the Tuesday...” I was hanging up the washing, no I wasn’t hanging out the washing, it was her ((screams)) she said you just went ((strange noise)) you know that’s what’s happened....

Partner – so many people can’t get their mind into that sort of order because of fear, not because they are stupid, it’ because they are petrified

I - yeah just panicking

Partner – cancer - death

I – Okay, so based on your experiences and everything that has happened, what things should we put in the app?

DS240149.F – most things

I – and I know that’s a hard question, you’ve already mentioned things like a staged approach of information, and information on side effects, surgery and that sort of thing

DS240149.F – I think some of the technical jargon should be explained

Partner – yes absolutely, yes that would be lovely
DS240149.F – explaining things like secondary dysplasia, invasive, words I would use, I mean they’ve heard of

Partner – the different types of cancer there are, you could just put that in because it was the American sites that we found the explanations for the type of cancer that ((candidate has got))

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

Partner – huge gaps, huge

I – especially with the information you’ve taken away from the hospital as well and it’s not standardised across...

Partner – it is absolutely

DS240149.F – I thought the sort of thing, you know like I know nurse direct, I know they’ve stopped it and they’ve got that 111 which is but that was a computer program but half way, chemotherapy, nausea, yes/no yes...vomiting, yes...and it followed on you know things to help you out, if you haven’t got vomiting do you miss that bit completely? I mean that’s quite a useful way of doing....

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

DS240149.F – you know it’s like a quiz almost you know? I mean the leaflet they gave me in chemotherapy talks about painful hands and feet, I’ve never had pain in my hands and feet, so I felt much better because I was informed, but the information should be there and I know you don’t agree with this, but DVT, DVT and PE I think are so important and I’ve never been told that, it was only the doctor when I went in she was sitting on the bed talking and she said “one of the biggest problems is DVT” Patients who have
chemotherapy they’re very lethargic and tired they don’t move around...bing...you know. Whereas all you’ve got to say is they’re tired I know a lot of patients are, I’m lucky I don’t have this exhaustion, but some of them can’t get out of bed

Partner – saying that what were you like last week?

DS240149.F – oh I’m forgetting

I – ((laughs))

I – I’m not a bed person, you won’t find me in my pyjamas, I’m not

Partner – she doesn’t like a pyjama day

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

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

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

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

I – it seems essential
DS240149.F – have you seen what they’ve given me? this is what I’ve depended on

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

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

I – gosh

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

I - yeah does it even explain nuetrophenic sepsis in this

DS240149.F - no

Partner – no ((laughs))

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

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

DS240149.F – I didn’t learn anything
Partner – no we didn’t but then I did say well that’s us, maybe a lot of people came away from there knowing certain things, I don’t know

DS240149.F – one lady in the car park she could hardly work she had some sort of bowel surgery and she was so ill she didn’t take anything in, for her it was a complete waste of time

I – Some patients, if they don’t understand why they should be doing something they often they often don’t do it

Partner – well we didn’t, and I think she’d vomited quite a few times before I said ((candidate)) this isn’t right, you need to ring them and then next thing we knew we were in casualty

DS240149.F – on the Sunday night when I was feeling like death I took my temperature and it was 37.5 so I took it with another thermometer and it was 37.4, because 37.5 is the magic number I went to bed, in the morning I took my temperature and it was 37.9

Partner – and I said it’s about time now you rang

DS240149.F – so I was in because they’ve a....

Partner – because she wouldn’t ring

DS240149.F – but because I didn’t want to go in its 37.4 I don’t want to go in, if I had understood the very important aspect of that I would’ve gone in that night

I - exactly yeah
DS240149.F – there’s no point in saying 37.5 you have to
Partner – but they have to give you a cut off don’t they, I mean it’s something that
DS240149.F – yes but that card is it, that card is all the information
I – you know that’s unbelievable really
DS240149.F – but then they’re inundated with information, I mean there’s no
Partner – there’s no getting is there? I mean we’ve learned by okay it’s about time you went in now, give them a ring and I’ll walk the dog quickly because I mean we can go
DS240149.F – and I mean how far? How far do you go? You know do you frighten everyone to death, you can’t, it’s so tough
Partner – I’ve just said to her we’ll pack a bag came in and you said “I’m packing a bag” I came in and I said “you’d better pack a bag just in case, we can keep it in the car
DS240149.F - and I said “I have, I felt poorly”
Partner – so we were both thinking you know they’re gonna keep her in
DS240149.F – but even though I felt poorly, I didn’t realise how poorly I was
I - What about family and friends, do you think there’s anything additional we could include in the app for them?

Partner – they will find what they need to find if you do that sort of sequence

Partner – I don’t think so

Partner – I’ve tried everything, you name it, I’ve gone out and bought it ((laughs)) try this

Partner – they will find what they need to find if you do that sort of sequence

Partner – I’ve tried everything, you name it, I’ve gone out and bought it ((laughs)) try this

Partner – yes if you think about mouth ulcers we’ve got soothe gel bonjela that bonjela that stings I’ve got that one, I think we’ve got a whole cupboard full of just preparations for mouth ulcers so that she can use that. Whereas they gave you one with that jel okay it’s probably expensive, but that helped you a lot

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I – oh brilliant
DS240149.F – you know, why didn’t you give me that before!

Partner – well if you knew that in the beginning, you know!

I – it’s so frustrating

Partner – and constipation, we went into Boots ((laughs))

DS240149.F – I don’t know what this woman though...

Partner – and we just filled it all, and this woman said “I hope you’re not taking these altogether” ((laughs))

DS240149.F – I need a....

Partner – so you know you just go into boots and you put them all in....

DS240149.F – I think normally you don’t get constipated, but normal people don’t get constipated do they? But they’re giving you something that will make you constipated. Instead of saying “if you’re constipated, they want to say “before you get constipated, do this”

Partner – exactly

I - Is there anything you wouldn’t want the app to do?
Partner – I wouldn’t want it to frighten people

DS240149.F – well it’s like this 111 thing they send everybody to A&E because they can’t make a decision, they’re not qualified people manning this line, and 60% of the people that phone in 111 are asked to go to A&E, so you wouldn’t want an app that said you’re in danger of dying quick get into <hospital>, you wouldn’t want anything like that, you just want information, I don’t think any action plan really would be good

Partner – but it’s like the temperature of 37 if you’ve got a temperature at 37 you go in

DS240149.F – 37.5, 37.5!

Partner – then don’t take another, use the same thermometer all the time.
You see I have taken the thermometers away, she’s got one thermometer back there

DS240149.F – I thought it was a cunning and devious plan actually

I – Okay so my last question, are there any particular types of patient you think would find this technology most useful, so age groups or different points during the cancer?

DS240149.F - because I’d love to ask patients how much they want to know?
Some patients, they don’t they just....

I – from those I’ve interviewed so far I’d say about 70-80% want the information and then the rest just want the minimum

DS240149.F – well that’s the thing, you don’t want to frighten them
Partner – and I bet they’re older?

I – yeah, yeah, yeah

Partner – they’re the older patients that think oh well, what will be, will be, whereas the younger ones want as much information as they can possibly have

I – yeah, have a bit of control over it and to...

Partner – because you lose total control of your whole lives you know it’s all about, you know hospital appointments, we’ve got a diary with hospital appointments you know, it’s....and the first couple of weeks it was just hospital appointments

DS240149.F – every other day

Partner – I just rang work and said “you know actually I’m not going to be there until end of March, put me down for the end of March and I’ll probably come back and do some work (laughs) you know

I – exactly

DS240149.F – my concentration I’ve got chemo brain,

Partner – they call it chemo brain (laughs))

DS240149.F - I absolutely can’t remember names, I couldn’t drive long distance, I’d crash
Partner – you did try once

DS240149.F – I came out on my own one day and I realised that I was in a bad way. I was in the slow lane about 50 mph to couldn’t see very, very clearly I had the air con on cold and the music was loud

Partner – and she hasn’t driven since

DS240149.F – I was so desperate I didn’t know where I was

Partner – that’s okay I drive a BMW (laughs)

I – (laughs)

DS240149.F – any excuse, who put petrol in it, I got in it today to go to the shops and there’s no petrol in the car

I – well that’s it really, is there anything else you think we need to cover?

DS240149.F – no I think it’s a great, I think it’s a brilliant idea

Partner – and the sooner you can do it the better

I – yes definitely

DS240149.F – sorry I gabbed on so much

End of interview. Duration: 1:15:06
Appendix 17: transcript for P3 John and R3 Helen

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

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

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

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

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

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

Wife – the app wouldn’t help with that
I – well I see what you mean though, that you wanted information on....

DS240157.M – yeah you know you talk to people oh I’ve done this and the way I dealt with it is this...so you get that information that otherwise...

I – yeah well that was my question actually, so where did you normally get information about the cancer and the side effects was it mainly from doctors?

DS240157.M – well doctors and patients

Wife – and that was our St David’s Hospice nurse, she’s been really good, you know if we couldn’t find something out she would, she would find out for us

I - oh that’s good

Wife - yeah I found her marvellous

DS240157.M – yeah hospice <Nurse> yeah brilliant

I – so when you said you talked to patients, were they the ones that you met at <hospital>?

DS240157.M – yeah

Wife - yeah just other patients you’d see, going regularly you see regular faces you would get to know people

I - yeah okay and what about the internet or books or... did you get information there?
DS240157.M - well as we said, they’re conflicting aren’t they? When you look on the internet

Wife - I did

DS240157.M – I mean not all the information on the internet is correct

Wife - but in all fairness you are told at the beginning, don’t look it up on the internet

I – ah okay and who told you that?

Wife - oh god I can’t remember

DS240157.M – well a few people because of the conflicting reports and that

Wife - and they said “don’t look it up on the internet because you’ll consider yourself to be....everything”

DS240157.M – gone ((laughs))

I – ah I see, so you did look things up <wife>?

Wife - you do, you do look things up

I – so did you find that helped you at all?

Wife - to some extent yeah

DS240157.M – to some extent
Wife - it explained certain things, so it did help in certain ways

DS240157.M – yeah

Wife - but I never kept to one site I’d look at a couple

I – that’s what I was going to ask you was there, you know did you use...?

Wife - a couple of sites yeah

I - which sites were they?

Wife - don’t ask...I’ve no idea

I – ((laughs)) okay so they weren’t like Macmillan, or Cancer Research, or...

Wife - I very rarely use Macmillan to be honest, um, the NHS one basically was the one I used more than anything, but then I would go to ones to see if they said the same thing...for comparisons, you know

DS240157.M – make comparisons

I – that seems a sensible way to do it

Wife - well yeah, it did help, but I mean you would still, at the end of the day you would still pick up the phone and phone <hospital> and say look can you...
I – okay. So did you like to have information about the cancer then?

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

Wife - yeah

DS240157.M – you know you....

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

I – so you like to have information?

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

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

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

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

DS240157.M – initially and I’d go...

Wife - his jaw would lock

I - really?

DS240157.M – yeah

Wife - and when we asked them about that, now here’s an example, because this was not one of the side effects they said that could happen, so we ended up phoning up and they said “it is rare, but it can happen” so if you had an app there where a patient has said this is what I experienced it would ease that worry a little bit until you manage to see the consultant you know

I – yeah, yeah because if you’ve not been told that beforehand then I expect....

DS240157.M – yeah that’s right, but they give you certain things that normally happens, pins and needles uh, tiredness you know the things that normally...

Wife - but if you remember <candidate> when we went up there, the <clinical nurse> he was really good with us wasn’t he, he said about the lockjaw, he said “we’ve got one other patient with that” he said and that’s up in <location> wasn’t it? <hospital> he said “it is unusual, but it does happen”

I – yeah, yeah, well it makes you feel better about it already then doesn’t it?

DS240157.M – see a lot of people suffer with sickness as well, well I never suffered with sickness
Wife - you were good you didn’t

DS240157.M – you know so, variables depending on one’s metabolism

Wife - everyone’s different

DS240157.M – everybody’s different, well to a certain extent

I – yeah, yeah, okay. So was there a particular point that you felt that you needed more information, either of you?

DS240157.M – no I think we, I gotta be honest we were kept pretty well up to date on all aspects of the illness um, yeah I can’t fault that

I - that’s good, okay

DS240157.M – and you know when you talk to the surgeon you could ask any question and you know, your answers were given in laymen’s terms because sometimes some people can answer questions can’t they, and they’re using words that you’ve got no idea what they’re on about, but I was given information like with <doctor> you know plain language, which I understood, no messing around you know and I fully understood what he was on about

I - yeah that’s one of the things we’re thinking about doing, is putting a glossary of medical terms in there, because some patients have said that not all doctors and nurses have given information in layman’s terms and then it makes it difficult...

Wife - that would be a very good idea
I – then for the patients and family to understand what they’re saying and then they’ve got even more questions then...

Wife - I mean I found it last year, I, I’m not one to remember medical terms I mean I’m on all these tablets and I can’t remember the name of them, people say what are you on? And I say oh...

I – yeah they’re so complicated

Wife – Benzo something or other...but in the last year I know exactly what <candidate> takes. I know exactly how many milligrams, I know the name of it what he was on, cos now we go in and they say “well what did you have...and what are you on” and he says “<Wife>?" ((laughs))

DS240157.M – I mean you know, basically it is a form of laziness on my behalf, because there’s people like me uh, I’ve got my wife who’s on the ball and she knows everything you know uh in respect of my medical condition you know medication I take you know and uh, yeah there’s another question I mean there’s a lot of blokes like me out there who leaves it up to their partners or their wife or vice versa like you know

Wife - I think you’ve got enough to contend with

DS240157.M – thing is it’s a mental state isn’t it?

I – yeah I expect it really helps to take some of the burden off them so they don’t have to remember all this information

DS240157.M – well that’s right I mean you know especially when you’re undergoing chemo as I said it varies from people I’ve found that um, my uh, sort of um, ((sighs)) here we go again see....

Wife - this is another side effect you get sometimes
I - yeah like the concentration

DS240157.M – yeah, you’ve got a very short span

I – yeah you can be in the middle of a sentence and then you just can’t remember

DS240157.M – it just goes blank

Wife - there’s a gentleman who lives down the road that <candidate> talks to, and they’ve got a lot in common they were both in the army and he’s been diagnosed with the same cancer as you hasn’t he? and he’s on the same chemo that <candidate> was see and he finds, they compare, he says “<candidate> do you find, do uh, oh...”

DS240157.M – similar yeah, yeah and it just goes, like I used to do crosswords, always doing crosswords I can’t do a crossword now, because my, my... here you are...the...

Wife - concentration

DS240157.M – concentration... putting things into perspective as well like as well like you know, in context uh, I just lose it you know it’s peculiar, I’ve never you know and you thing well... you end up shrugging your shoulders and... I’ve got half way through my crossword book and I haven’t touched it see

I – oh yeah hopefully that, that’ll come back, yeah

DS240157.M – yeah hopefully
Wife - well he did say that, he said it could take you know up to 6 months to a year, cos I mean <candidate> had 2 major operations in a year and loads of chemotherapy so I mean he did have, and he had blood clots

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

Wife - but they thought he was having a heart attack

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

Wife - diazepam

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

I – was that related to the treatment?

DS240157.M – well I don’t know

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

DS240157.M – that’s right
Wife - and he reckoned he was there in the operation for some time, he said you don’t know what position you were in on the operating table and he said “it could be that” but because they couldn’t when the paramedics come they just didn’t....and they went “it could be a heart attack let’s get him to the hospital” mind you saying that we went to <hospital> they said to him they didn’t know what it was

DS240157.M – this doctor was asking questions and...

Wife - we told him he’d just had the operation he had cancer and basically because I know they hoping to link up which would be a brilliant idea, to me it’s ridiculous you can’t go into a hospital and they can’t call up your records and see what’s wrong with you...

DS240157.M – unless you’re in the same NHS isn’t it?

I – oh I know, I....

DS240157.M – it’s terrible that

Wife - and they didn’t have a clue up in <hospital>

DS240157.M – you can imagine if you’re on holiday in North Wales just for example, or something like that and uh, you know how would they get that information, the only way is by making a telephone call and you know answering phones, hospitals are inundated with them, I mean, you know, other than that it’s written application isn’t it?

I – yeah I know, it’s 2015 and we have the internet, all the things we have now...

DS240157.M – I know

Wife - our son in law actually works for the...
DS240157.M – for the NHS on the computers

I – oh okay

Wife - and he’s been doing this project at the moment where what they doing they’re installing....

DS240157.M – linking, linking up

Wife - not the hospitals, but all the GP’s

DS240157.M – all the surgeries

Wife - but of course now they’ve had the go ahead, the Welsh Assembly are going to put all this money in to making the hospitals able to link up with the GP’s

DS240157.M – you’d think it would be normal wouldn’t you? I mean it’s...incredible...I just dread to think

Wife - <hospice nurse> said she can look on the < hospital 1>, but she can’t go to <hospital2>, she can’t look on <hospital2> because the systems are different systems

DS240157.M – different systems, different health authorities, it’s ridiculous anyway

I – yeah, okay. So communication... how did you find talking to the doctors and nurses about the cancer?

Wife - good
DS240157.M - good

I - how did you feel when you had to ask them questions, was it easy or difficult?

DS240157.M – no easy, I mean as I said...

Wife - yeah, and not just the doctors but their secretary’s

DS240157.M – the secretary’s, uh the nurses, the consultants, I’ve been very, very fortunate, I just can’t you know I know it sounds, I just can’t complain

I – yeah, oh that’s good and what do you think made it so easy to ask them questions then?

DS240157.M – it’s their demeanour, you know they way they presented themselves the way they talked, um, and it basically helps a lot doesn’t it, if you’re taking having a conversation with someone and you’ve got that response you know, that...it’s much easier to open up and ask questions and especially when you’re getting the answers which you understand. It’s like <doctor> with the blood clots, the way you know he took time to draw diagrams and explain certain things, and I said oh yeah

Wife - you never felt as though you were....

DS240157.M – imposing

Wife - no, you never felt like you were just another one of the sheep, you were made to feel as though, yes what you’ve had and they were caring for you

I – yeah oh that’s brilliant
DS240157.M – they were concerned about you

Wife - they were concerned

I – that’s really good, yeah because they see so many people every day, every week and some people have said that they felt that sometimes that they were just a ‘number’, so to hear about the care that you’ve had, that’s really good

DS240157.M – yeah I mean, yeah

Wife - there’s one or two departments but I mean...

DS240157.M – I’ve had one or two, but like everything else, I mean....

Wife - the major...especially at <hospital> absolutely brilliant, can’t fault it

I – most of the people I’ve talked to so far have been from <hospital> and have not had a bad word to say

Wife - they’re brilliant

DS240157.M – they’re very professional, put it this way, the professionalism and as you say they see countless, hundreds and thousands of patients in a year and they go through this routine and you know it’s very gratifying you know they treat you...

Wife - even the staff, you can be walking down the corridor going to the canteen and the staff coming the other way and they always got a smile and a hello for you
I - yeah, it makes a difference

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

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

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

DS240157.M – well the nurses when I was in hospital 12¾ hours night shift

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

DS240157.M - 12¾ hours! The question you’ve got to ask there is this, how can a nurse perform to the same level after 12¾ hours after 1,2,3, hours that’s fair enough, after 12¾ hours can that person whether male or female perform to the same standard as a normal person working normal hours, normal shift. I don’t think so

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

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

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

Wife - I really do
I—okay, so were there any barriers communicating with the doctors and nurses at all?

DS240157.M - no

I - and how did you remember all the information about the cancer, did you write things down, or rely on memory or...?

DS240157.M – well sometimes, we, we

Wife - you relied on me! ((laughs))

DS240157.M – we did take little notes, I threw them all the way actually I was reading them last night, um, and we were asked one of the things as well with <hospital> I was asked to make notations of certain uh feelings whilst I was undergoing chemo, so I had a little diary day to day and I used to keep notes like if, when I was on uh, medication, how I felt, the side effects, uh and it was like what’s the uh...<wife> them tablets I was taking to give me more energy?

Wife - the steroids

DS240157.M – steroids you know like obviously I had the chemo sometimes you’re on a down and then I think it was once ad day, or twice a day I was taking steroids wasn’t it?

Wife - yeah, and of course they have their side effects

DS240157.M – they have their side effects, but I noted down after taking the steroids how I felt, so I kept a daily tag for a couple of months on different aspects and the way I felt after taking certain medication, like the chemo medication, uh but the second time I had the chemo it had adverse effects on me, I felt much worse after the second uh than I did after the first sessions
Wife - not the session you had 4 you were the first time, you yeah...

DS240157.M – you know what I mean

Wife – yeah but that was because of saturation

I – so how did the day to day diary help you?

DS240157.M – well

Wife - you can take that along to your consultation

DS240157.M – well I could make references

Wife - which is a bit like if you do react hopefully you’d be able to put it down which will remind you to ask a question....

I – yeah well another option is to have an electronic diary then where you can put how you’re feeling on the app so I’m just wondering how did that help you by doing that do you think it’s something worth putting in the app?

DS240157.M – well yes because um, whilst undergoing chemo obviously your diet is different especially for people who wear stoma bags I mean there’s you can eat and you cannot eat, now unless you actually keep a notation of what you can’t and what you can you don’t know do you, so by doing this I would like my wife would say we’re having so and so and I’d go, look well I had them last time and uh and I was very lose in the...so I had to take Imodium, you know so

I – you can alter your diet around how you expect to respond to it?
I – that’s really good okay. So what about family and friends, did you find it easy to talk to them about the cancer?

DS240157.M – um, ((sighs)) yeah difficult at times didn’t I, cos I don’t like imposing uh, not so much imposing but uh....

Wife - it’s strange really because um, certain friends yes you could tell and they would be concerned and they would phone to see how things were, and then you’d get other friends you’d mention it to and you tell them and you never saw them again, and you can understand that they don’t know how to deal with it, or they can’t face it so if you could say to them, if you want to know more, there is an app, so they could read it might help them as well.

DS240157.M – yeah it’s a question with family as well, you don’t want to, like people will say “how are you today?”

Wife - we’re not a big family really are we?

DS240157.M – no, no we’re not. You know you don’t want to go into the depths of your problem you’d say, “not too bad” when you really wasn’t too bad, you were feeling pretty crappy like you know, uh so that’s part of the difficulty of answering questions, it’s depending like and how one felt when they asked you as well, this is the thing, you know if you felt quite buoyant uh, yeah I feel great today like you know, but when you wasn’t up to that standard yeah I’m alright....which they deduced then by you saying that then – yeah he’s not on top form today like they just left it as it was

I - okay. So talking about the technology then, so have you used, so you’re familiar with apps but have you used a smart phone or a tablet computer like an Ipad or Iphone before?
Wife - yeah

I – you do have one, so what’s that?

Wife - an Ipad and an Iphone

I – okay and what about yourself <candidate>?

Wife - he’s got a fire a kindle fire

I – oh okay

DS240157.M – yeah but don’t ask me anything about computers please, no I’m not being ignorant or...I’m a dinosaur when it comes to...you know

I – no, it’s not, they’re not for everybody, this is what is interesting... to ask... because not everyone is going to want to use this app

DS240157.M – but I mean my <daughter> my daughter and with our son in law they’re all on the ball even the grandchildren they just lose me

I – yeah okay, so is there any reason then that you don’t like these sorts of devices?

Wife - he’s afraid of technology, he doesn’t want to learn – it is the truth!

DS240157.M – well I think it’s laziness personally

Wife - you just can’t be bothered
well ironically when I was in the army I was a data telegraphist

I - wow...yeah

((laughs)) so we had computers the size of that armchair

I – yeah wow

but I just got to the stage oh I don’t know I just

Wife - oh there’s another one now stop it ((talking to the pet)) she’s losing her teeth

but you do you know I don’t know as I’ve got older I’ve got a bit lazy, not

I – no, no I know what you mean

in certain mental aptitude I just...I just give it to the wife

Wife - it started when we got a video recorder...he didn’t want to know how to use

that either

Wife - – video recorder

I can’t do that either
Wife - we don’t have them anymore

I – so what about yourself <wife> what sort of things do you use the Ipad and Iphone for?

Wife - ooooh

DS240157.M - everything

Wife - I use it quite a lot, shopping, finance, news yeah, I do use it, games ((laughs))

DS240157.M – yeah you’re brilliant at it you know I got to be honest

Wife - it’s brilliant I do find it useful and my reading I can you know

I – and have you ever used an app to do with your health or <candidate> health?

Wife - yeah

I – what sort of apps have you used?

Wife - well the NHS more than anything, it was like yesterday I looked up last night I told you because our daughter’s got diabetic neuropathy and um I thought I’ll have a look, and I look it up to see on a couple of websites what they had to say about it, compare what they say

I – yeah okay
Wife - my first port of call is normally the NHS one yeah

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

DS240157.M – well I think the question there is

Wife - yes

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

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

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

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

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

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

DS240157.M – oh yeah, yeah, yeah well that would give you some indication then wouldn’t it that things weren’t as they should be
Wife - I think I would use it more than ((candidate)) would

I – yeah yes so I was going to say what about family and friends, do you think they’d use the app?

Wife - yes I think family and friends would

DS240157.M – <son> yeah <son> would

Wife - <son> partner would as well

DS240157.M – and <son> partner yeah <son> would as well

Wife - I think it’s down to the individual if you’re that way, if you’ve got as you said the technology and you’ve got the equipment then yeah you would, cos as I said if you’ve got that device in front of you, even though they’ve said to you “don’t look it up on the internet” you’re going to that’s the first thing...

I – so it’s you’re saying if you can have something that you can trust?

Wife - exactly

I – okay so what about training do you think it would be useful if patients had training to use the app? Do you think they’d need it?

Wife - now that might, well you can’t really say that until it comes out can you, you see, but it would be....
I – I mean for someone like <candidate>, so he’s not as experienced as yourself do you think that could help?

Wife - yeah

DS240157.M – well yeah I mean

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

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

I – yeah it gives you a better quality of life

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

I - no exactly

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

Wife - I tell you what I think would be helpful as well is if there was something on there for family, immediate partners where you could share experiences, or maybe chat to other people, because if you know what I mean you’re, I’ve been strong for <candidate> and doing everything for <candidate> but then you get those moments
when I’m on my own, and you do think down the wrong way and you get worried, and have concerns and then I don’t want to go to him with it

I – yeah, so who do you talk to?

Wife - exactly and I did find that was, you know

I – yeah so there are support groups for relatives, or chat forums, or did you ever use anything like that?

Wife - no, no I wasn’t aware that there, there was anything I mean support, going to actually see someone that wouldn’t have worked because I was so involved with <candidate> back and forth, but to maybe pickup of an evening and talk to someone, I mean it’s like, I know I could talk to my daughter but I know she’s going through the same thing as me

I – yeah so perhaps having someone external to the whole situation?

Wife - yes

I – so yes, so you said that you know you’re quite busy so you wouldn’t maybe be able to get to one of those groups, so do you think that a smart phone then...the app, if we could link you with something that’s online and you don’t have to leave the house...

Wife - I think it would be good yeah

I – okay, that’s a really good point. Right where am I, yes so right would you have any concerns about the app at all?

DS240157.M – in what way?
I - well I mean some patients have said “I don’t trust that type of technology” others have said “you know I’m worried that there will be too much information and that could worry patients”, or....

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

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

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

I - yeah than the website

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

DS240157.M – well yeah I mean that’s right, I’m thinking with some of these apps I mean you got so many variables, so many different peoples’ opinion on a particular subject haven’t you I mean and that could be quite conflicted as well couldn’t it? You know if you wanna go through it and you see people...well so and so says this, and you look at the next one and the other one....you know sort’ve says something totally different, cos that’s their own opinion on a particular subject, but if you’ve got an app like that which is quite direct, this is what etc., et., and it’s straightforward isn’t it?
I – yeah I think my other concern is that there is so many different types of cancer, so much information, how would we pack that into one app you know I mean that’s another issue we’ve got

Wife - yeah there is that about it

DS240157.M – well, I think you’d have to well, yeah, how would you deal with it...? Other than you’d have to categorise each different type of cancer, and it’s like it just asked you know on the question form bowel cancer it doesn’t say bowel cancer on there, it says urological, or whatever it is....

DS240157.M – well what I’m saying is it doesn’t I want to ask the question in medical terms what type of cancer is this then like...?

Wife - colon

DS240157.M – well you know I mean you could say bowel cancer, well everybody knows then what bowel cancer is, lung cancer do you follow what I mean, that would be straightforward rather than....these medical terms related to cancer, well what type of cancer? Like you know people get lost....

I – yeah, use like the most common names, yeah

DS240157.M – yeah, yeah you know layman’s sort of terms as we’ve said before

I – so what about other concerns do you have any other concerns?

Wife - not really no, my personal opinion is I think it would be a good thing, it would be a help, it would be a tool to help you
I - yeah it’s not meant to replace anything, or be the be all end all, it’s just an extra additional tool isn’t it?

Wife - exactly yeah

I – so what benefits do you think there might be for patients using an app like this?

DS240157.M – well if we look at it from the point of view that with a certain type of cancer you know, for arguments sake um, the information you’re given is maybe undergoing chemo, this might last for 6 months, uh some people it might be longer, some people it might be less, you know after a period of time you might be a bit you know I’m still feeling rather lethargic ur, airy fairy and you might want to look up and see how generally a generalisation about how people feel after undergoing chemo because people feel different ways don’t they? And it might, by doing that you might feel oh, well yeah it’s a general thing and it could last 6-9 months whatever it takes maybe, will it eventually be eradicated? This feeling like, will it eventually go? You know I mean it does, I, in the morning in I <wife>? Even now I’m absolutely terrible in the morning and usually I used to get up and I used to annoy her to hell because I used to get up and sing and whistle, didn’t I?

Wife - It takes me 2 hours to come around ((laughs))

DS240157.M – you know I, I honestly I mean totally revered to what I used to be like

I – so you think that app then could help to see if these sort of effects are normal, and how long they last?

DS240157.M – that’s right you know

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

Wife - and he’s only 45

I – oh gosh really

Wife - he’s only 45

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

I - yeah, yeah, but what I mean is because you’ve got your friend who is fairly close by, you’re able to see him face to face, some patients might not have that, so perhaps for them they could use the app as a way to contact someone, you know make a friend who has something similar
DS240157.M – well with some people it might, it wouldn’t uh, that wouldn’t apply to myself, but it might do with other people....

Wife - that’s because that’s you....

DS240157.M – pardon

Wife - that’s because that’s you....

DS240157.M – well exactly, that’s what I’m saying you know we’re individual aren’t we, I don’t like sharing you know I’m very sort of secular in my way of thinking, in I, I’m quite closed...

I – yea, yeah. I’m thinking the app could be a way to set people up with a network of you know people who have the same thing, just to say “how are you feeling” you know the same sort of thing that, it won’t be the same thing because you’ve known him a while and you see him face to face, but just to give them the opportunity if they wanted to

DS240157.M – well as I said, with certain people, yeah I mean there’s people who haven’t got family

I – yeah exactly

DS240157.M – there’s people who haven’t got you know and they’re...they are basically alone, people like that I think it would be a benefit because at least they’ve got someone to contact

I – yeah exactly yeah and what about clinicians the doctors and nurses, what benefits do you think they could get if patients are using an app?
Wife - well once again it’s like um, I said about the clinical nurse<1> he was able to say that he, there was another patient of his up... so we can see if someone else is experiencing the same, um, maybe somebody isn’t experiencing it, maybe it’s only one person so then they can look into it further, I think it can help with somebody’s recovery, somebody’s treatment, if they can see how other people are feeling

I – what doctors, so they’d be able to look at the app and see from the electronic diary, the symptoms is that what you mean?

Wife - yeah it could do

I - yeah so if patients are recording how they’re feeling on the app and the doctors can have a look, yeah

Wife - it could help in the future towards

DS240157.M – yeah, I mean it’s....

I – yeah, they could collect some data and things...

DS240157.M – I mean there are variables aren’t there? You know in the way different people feel

Wife - absolutely

DS240157.M – you know I mean unbeknown sort’ve symptoms like, like giddiness I used to suffer with giddiness terrible and I still do, and it’s a long term affect probably the chemo, well I suspect it’s the chemo anyway, but um, yeah I mean, does anybody else suffer from it?
I – you know, symptoms just the side effects are so different, there’s so many random things that you would never think was a side effect

Wife - yeah I know, it’s like when you had to take the steroids, now the steroids they make the skin very, very fine...and he’d only have to....

DS240157.M – touch myself and I...

Wife - touch himself and

DS240157.M – I still got them now, I still get, but I don’t suffer with them so bad

Wife - I thought he was patched up to hell with plasters everywhere

DS240157.M – plasters all over my hands, I’d just touch something and I, the skin would break and of course you’ve then got to be careful of infection, so you know it’s germolene, uh alcohol wipes, germolene and plasters, I used to have plasters all up my arms down my legs...! You know so do other people suffer with it? Some people do some people don’t

I – yeah. So what about family and friends how do you think they could benefit from using the app?

Wife - well I think as I said some friends and family find it difficult to talk to you, they don’t know what to say to you

DS240157.M – yeah that’s a....

Wife - and if they had the ability to look at the app, they could find out, I mean not reading peoples’ diaries or whatever, but...
I – yeah I know, that would be confidential

Wife - exactly yeah, they could see the general of what to expect, how the progression would go, what’s to be expected, or what could happen from side effects, and I think it would help yeah

I - and do you think the app could affect then the way family and friends talk to each other about it, do you think that would help?

Wife - yes I think it would be more open and not...

DS240157.M – it would give them more understanding wouldn’t it?

Wife - yeah more confidence, not worry about

DS240157.M – that’s what I think, it’s like I said when the sons, when our son’s phone us up and they say “how are you dad?” and you go...you know you don’t wanna say “oh I feel shitty today like...” and all this like, I mean it puts a worry on them doesn’t it then...you know it’s very conflicting

I - so perhaps if they could have more of an understanding

DS240157.M – yeah they could look and then say “ah yeah it’s not too bad” even though he feels that way, or she feels that way, uh you know things are progressing as normal like you know

I – okay so what about doctors and nurses do you think the app could help with the way patients talk to the doctors and nurses, do you think it could help, or do you think it could make it more difficult?
Wife - yeah, no I think it could help

DS240157.M – I mean it’s one of those situations like you go to the doctors and you’ve just read an app, looked up the app on certain, and you’re talking to the doctor um, I suppose you’ve got to be careful what you say really, it’s like you’re taking over the job...((laughs)) doctors opinion like, do you follow what I mean?

I – yeah, yeah so...

DS240157.M – this is one of the things that you’ve got to be careful off....“well I’ve read on the app that so and so has said...” you know the doctor might have a different, a totally different opinion

Wife - yeah there is that side you know...

DS240157.M – that’s one of the problems like you know

Wife - people do that now don’t they, they go to the doctor and say “look I’ve self diagnosed myself, I’ve got this, I’ve looked on the net”

DS240157.M – and the doctor you know has got a totally different opinion exactly what’s going on with the person, I mean generally the GP has got a finger on the pulse haven’t they, if they are good GP’s you know, they know your medical history and that’s one of the things you’ve got to be careful of I think is passing your opinion onto them

I – yeah cos I think one of the things this app could do is, so for those patients who are not very vocal at their appointments and they tend just let the doctor do the talking, you know even if they’ve got questions, it’s trying to give patients a bit of confidence to speak up and say well I want to ask this, but then there is, you are sort’ve changing the dynamic of the consultation then, because typically it’s the doctor dictating isn’t it?
DS240157.M – yeah, I mean exactly, exactly yeah

I - you know that’s what we’re trying to push for now you know in healthcare at the moment is to get a level playing field then, so the you know what’s important to the patient becomes important to the doctor, but the doctor doesn’t know how the patient is feeling if the patient doesn’t tell them so...it’s trying to give them a bit of confidence I suppose

DS240157.M – yeah you could take that to the extremes can’t you uh, where some people by reading the app would might play on what he or she is reading and making the symptoms worse than they really are...

Wife - you’re always going to have that though, it’s going to be, I mean there’s nothing that’s a 100% useful, good and wonderful, there’s always going to be that element the downside to something, the negative side

DS240157.M – yeah

Wife - but overall I think it would be helpful and a good thing

DS240157.M – I mean as I say, if you’re getting information which is relevant, it’s excellent

Wife - and these doctors I mean, well we’re luck, the one’s we’ve dealt with they aren’t stupid, I mean they’d know if somebody was going in and....

DS240157.M – not in all cases <wife>, not in all cases, people can play on uh, on factors which are not really relevant to their condition and the doctor has got to take notice of that haven’t they?

I – yeah, yeah, yeah
I – so can you think of any problems with this app in practice? Or any problems at all really, can you foresee any?

Wife - no, because I think whatever problems you get, I mean you’re going to get from any app you’re gonna it’s....

DS240157.M – it’s up to the individual how they determine it and how they actually read and understand what they’re reading

Wife - as <candidate> just said you’ll get these people that will read it and ooooooh... you know and then you’ll get people who’ll find it useful. I think myself that it’ll be a high percentage of people that will find it useful, those who are used to technology and using things. I would trust, as I said I personally would trust an app that is local that comes from <hospital> more than I would trust an app from somebody who I didn’t know, who they were apart from NHS, but even saying that sometimes the NHS you can, oh well you know

I – yeah sometimes it’s a bit...

Wife - exactly

I – okay so what sort of things would you like the app to do?

Wife - well everything really ((laughs)) no, I mean

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

I – oh I didn’t know that

DS240157.M – and that was reassuring

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

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

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

DS240157.M – no but then you know then the risks that you’re taking
Wife - I tell you something else I used to find useful, is when we knew we were dealing with a new consultant or doctor I’d look them up on the app on the internet as well

DS240157.M – and find out peoples’ opinion

Wife - you know and find out what they’ve done they’re coming here I’ve found that quite reassuring

I – yeah that’s a really good idea

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

Wife - I mean it’s like <doctor> now, I mean alright he hasn’t phoned, but you can’t be angry at him because if you knew how busy he is, and how he treats his patients

DS240157.M – I was telling <interviewer> he used to come in on the weekend, on a Saturday and Sunday sit on the bed and go and he’d look at my catheter and one thing and the other I had all these things stuck in me all over the place

Wife - half past seven every morning he was there and he was immaculate absolutely....

DS240157.M – it’s getting a nice strawberry colour now he’s say with my, not my catheter, I had a catheter I had another drain thing like “yeah that’s getting a nice colour that is” and then you know he came in and said “yeah we can have that one out”

Wife - his care and consideration was unbelievable and I mean uh, <doctor> has spent, he’s done a lot of work abroad as well voluntary work, with prostate cancer and things like that, he’s well respected and to be able to look at that, that gives you confidence as well you know
I - yeah, yeah exactly

Wife - well you've got a good job here <candidate> he's gonna do a good job

DS240157.M – yeah I mean that, that helped a lot that did

I – yeah no one’s mentioned that, that’s a really good idea

DS240157.M – yeah that helped a lot, it give you I mean to undergo an operation it’s quite traumatic unless you know I mean it’s okay going back a couple of years people talked about operations and you’d go...you know, but once you’ve gone and had to go through that experience you know you’re thinking there like you know uh

I - you wanna know you’ve got someone good

DS240157.M – yeah you know am I gonna come out of this or, you know I mean things go through your mind

Wife - well it’s just, it’s just nice to know what that person, I mean at the end of the day you’re putting your life in that person’s hands, so you want to know about them...I did anyway you know

DS240157.M – it gives you confidence doesn’t it? And confidence is a big part of everything you know, yeah

I – so what about family and friends is there anything the app can do to help them above what we’ve talked about?

Wife - not really well I mean we’ve covered it there I think you know it’s uh....
I – and is there anything you wouldn’t want the app to do?

DS240157.M – well I mean as long as it keeps confidentiality, which is I think absolutely imperative, I mean certain things slip past the old uh marker at times, um, yeah I think that’s generally that’s the most important thing confidentiality is not in any way breached, you know

I – yeah, okay. So the last question is are there any particular types of patient might find the app most useful so perhaps different age groups, or patients at different stages of the cancer, so you’ve got diagnosis, treatment, post-treatment, or do you think it could be useful throughout the whole thing?

DS240157.M – oh basically <interviewer> it would have to go through the whole thing, because even after you know, post operation, post cancer, I mean don’t forget you’re not cleared I think it’s 5 years, uh so sometimes you might want to find out generally uh you might have sort’ve a down period 2 or 3 years later you know, um, how do people go through this, how do they deal with it?

I – so you’ve still got questions then yeah?

DS240157.M – yeah you know, it’s always that thing, you just don’t know, once you’ve had it you just don’t know, people have been in remission for years great and then suddenly, we lost our grandson he was only 7½ years of age

I - oh gosh really?

DS240157.M – oh yeah and he was in remission

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

Wife - 25 this year

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

I – yeah, yeah it has

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

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

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

Wife - having the colonoscopy he had

I – yeah I’ve heard they’re not very nice...

DS240157.M – oooh...don’t...

Wife - they told you there and then actually
yeah that’s what I said I was saying to <interviewer> I was quite blasé about it, I wouldn’t say blasé in the sense of you know, it didn’t really, it don’t really uh register....

I – sink in yeah

DS240157.M – you know then afterwards after a while you start sitting down and then you know....((talks to the dog)) dog growls back....

I – so what about, this is the last question we’re talking about are there any particular types of patient that you think might use the app, or find it most useful? So we’re talking about different points of the cancer and <candidate> was saying he might still want information even 5 years after

Wife - well you don’t actually get the all clear do you for 5 years

DS240157.M – 5 years

I – and are there any different age groups that you think might find it most useful?

Wife - it’s alright it’s only my phone

I – do you want to answer it I can always...

Wife - no, it’s only a message it’s alright, um, ((sighs))

DS240157.M – I don’t know how to answer that question, it might benefit certain other people I mean you know

I – or do you think it’s something that can be used for everyone?
Wife - yes I do

DS240157.M – yeah, yeah, yeah....I think that would, yes

Wife - if you want to use it, and it’s there then I think anyone would use it

DS240157.M – yeah

Wife - I mean some people might choose not to use it because they don’t want to know

DS240157.M – surprisingly the amount of people who do look up on the computer, or whatever like Wikipedia and stuff like that, again you’ve got to be careful because Wikipedia has been noted that a lot of information given, is only that person’s opinion

I - yeah exactly yeah

DS240157.M – uh and it’s been totally wrong you know, and I’ve read things on Wikipedia and about 4-5 conflicting different uh reports on certain things and your thinking which one is....?

I – yeah that just confused you even more

DS240157.M – that’s right

I – alright, well that’s it really is there anything else you think we should cover?

Wife - not really, no
I – okay let me just switch this off

End of Interview. Duration: 59.01
Appendix 18: transcript for P19 Paula

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

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

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

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

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

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

I – okay, and when you had the information from the clinicians how did you receive it? Was it verbal or did you have leaflets as well?
DS240141 F – leaflets, yeah every stage was verbal and leaflets and I had my breast care nurse, that she came to the house as well before every surgery to tell me what was happening, to see any questions, um, chat about the process itself every stage

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

DS240141 F – just from the doctors and nurses yeah

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

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

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

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

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

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

I – you didn’t want to know?
DS240141 F – no, I know your mind, your mind plays up and you think okay I’ve got cancer and it’s the ‘C’ word, so I was trying just to get the information I needed and nothing else

I – right okay, so when you were first diagnosed how did you feel? Did you think right you know “I’ll get through this”, or did you, did you worry or?

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

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

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

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

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

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

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

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

I – they didn’t want...

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

I - okay and when you said you spoke to loads of other patients was that through a charity you’d call, or through like an organisation or...?
DS240141 F - uh loads of things, through charities through hospital, um, Tenovus they're awesome

I – oh they're funding this study

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

I – aw that's good

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

I – aw that's good

DS240141 F – I’ve done loads

I – yeah well it sounds like you’ve done all the right things, you’ve really sort of, you know you haven’t cut yourself off you’ve mixed with other patients and....
DS240141 F – no, that’s not the attitude at all, but if you go that route you are just adding to yourself and then to go through all that and not be able to let it out that makes it even worse

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

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

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

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

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

DS240141 F – yep, before you start chemo you’ve got 2 meetings the very first one is a personal one, one-one with the oncologist and the oncologist nurse where they explain to you what’s happening, the type of treatment and everything else, then they send you a letter and before you start chemo you get a group of people in and they go through what’s going to happen, why you need to do, they give you a thermometer as well because you have to monitor your temperature they tell you what you can have drug wise, um why you can’t, or why you shouldn’t so they explain the full scenario, the cold cap the different types of chemo that was really good
I - that’s great, okay. Okay so talking about technology now, do you have experience of using a mobile, a smart phone or a tablet computer or...Ipad?

I - yeah, so is that both or just one...

I - both

I - and how do you find them, do you find them easy to use, do you like using them?

I - yeah I do, yeah

I - yeah and what do you use, what would you use a tablet computer for?

I - uh at the moment it’s more for emails, to be honest with you, check your bank account, do my banking, um obviously I check online shopping wise

I - so it’s just all the sort of regular things?

I - yeah, you just get....

I - and do you do the same things on your smart phone, or do you use it slightly differently?
DS240141 F – uh, I don’t use it as much my smart phone obviously because I don’t use so much data I can check Facebook to see if I’ve got any messages um….it gives me a rest to be honest with you I could do some banking on my phone as well, but I use more the tablet than actually the phone itself

I – oh okay

DS240141 F – that through the internet

I - alright then and have you ever used an app to do with your health at all?

DS240141 F - no

I – no, okay and is there any particular reason you haven’t used any health apps?

DS240141 F – no, not really uh to be honest with you I never have enough time to actually do it, I could be days without checking anything, um especially now I really don’t have a chance with the small one, the house, work wise fulltime, it’s just too much going on for me

I – yeah okay

DS240141 F – and I just don’t have a chance to do it

I – Okay. So the type of app that we talked about do you think, do you think patients would want to use this type of app?

DS240141 F – I don’t know to be honest with you uh because every time it depends on the range and ages as well I can tell you I’m not sure, I can easily see them using it but
others love them, where they’re much older they wouldn’t have the, the knowledge to
actually use it at all, now it all depends what the app itself it will do for you, because
you know you go through clinic every 3 weeks you discuss all the symptoms and that’s
when they, they check the drugs that they give you to make sure that you’ve got the
right dosage and the right drugs as well, mine changed halfway through, um they are
really good in that sense, when you’re going through chemo you shouldn’t be having
any other drugs, you really shouldn’t and they advise you not to and if you do have any
problems any symptom that you can’t shift away, or it’s persistent, or they will, you can
always give them a ring and they can tell you what you need to do, because I thing every
person’s different even the type of treatment you’re having, so I don’t know, I think it’s,
it’s it might be interesting to see, you know, using the app to see symptoms, to see
different stages, different phases of the process, what’s going to happen, but then I
personally think then the app should be really specific for specific people so if I am at
that stage where I was going through chemo if I had any questions, then I would have,
personally I would think I would have to specify that I was <<inaudible 14:08> treatment
that my age, type of cancer and everything else, so it can filter the information that I
was going to have, because if it just brings up everything, it’s too confusing personally.
I personally find so I can tell you I registered myself in McMillan’s and I think I used their
website about twice, never again, it’s too much on um it gets a bit confusing, um I don’t
know it all depends on exactly what the app is going to do, for me personally I think it’s
really good if, and that’s my personal opinion, if before you get information you need
to choose, uh the type of treatment and everything else so it can give you that
information, I think that would be...

I – so it’s not giving you general information yeah

DS240141 F – yeah I think that would be really good

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

DS240141 F – I don’t think so nowadays you learn it yourself, the app will actually teach
you what you need to do next so to be honest with you, even if you’re not that IT kind’ve
person, I think uh as a normal app it just drives you through, so it should be
straightforward, but it all depends on the people themselves using it....and the age, I
met some woman love them, they were there with they’re grandchildren and they
didn’t really know what was going on...they knew they had cancer, they knew they were going through treatment, but they couldn’t even start a thermometer

I - oh yeah, so how are they going to use an app?

DS240141 F – so how are they going to use an app?

I – yeah and were these patients quite elderly or...?

DS240141 F – I had a mix unfortunately there was very young girls, extremely young, uh the average of most of the women that I met I would say the average age was, I don’t know middle 40’s I think

I - gosh that’s young isn’t it?

DS240141 F – a lot, a lot, um, I’d never met them, but when I went for my session on the course to feel better, there were 2 kids they were 16

I – oh gosh

DS240141 F – and the lady that was actually running the session said “I was dreading it” cos she did 2 sessions in <hospital> one in the morning, one in the afternoon and mine was the afternoon one and she said “she was dreading it” because you know it’s teenagers isn’t it, being teenage and going through that...it’s, it’s not easy to deal with so she was a bit concerned on how they would react, but the kids were awesome, they were raising funds towards research, they had a webpage, they were doing the lot, awesome

I – wow...it’s a way of coping I suppose isn’t it?
DS240141 F – you need to put your mind into something and then I think, it’s dreadful that it happens to you, but then if you can put some sort of input to help the next one, or who’s coming next

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

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

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

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

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

DS240141 F – the families

I - the families

DS240141 F – yeah the families I remember one that she told me that her husband she could see it affected him, well it affected mine as well and only just recently we finally got it, out um but he refused to do counselling, he refused to do any research, he went
to the sessions with her and to see the oncologist, but, and I think if there’s an app at least they can get the information they need to without having to go through chat forums, with all of that, without having to go to those specific cancer websites that it’s a lot on, so I think that for relatives I think that’s very good, because that means that they can actually search without letting you know

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

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

I - because it’s too hard?

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

I – it’s too much

DS240141 F – yeah you know <<inaudible 20:41>>
I – yeah, yeah, okay. So touch wood I mean if your friends or people that you knew were diagnosed with cancer would you recommend something like an app to them if we developed this?

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

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

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

I – okay so how reliable it is

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

I – yeah, okay. What about benefits, what sort of benefits do you think there might be for patients using this app? I know it’s tricky to think about this because we don’t know what the app is going to do, but the things that we think that it will have is things like questions to ask the doctor, links to websites with reliable information so they don’t go off looking all over the internet and things like that...
DS240141 F – If it works that way it can be extremely useful I can tell you I, I when I went to some of my sessions, especially with the surgeries, I, I <husband> asked some questions because I didn’t and your brain just goes absolutely, it just melts, so you do forget about everything and the first time they tell you, you’ve got cancer you won’t hear anything else, your mind is just set “gosh I’ve got cancer” I don’t think I even asked a question, no my question was “what’s next?” okay I’ve got it so what’s now...that was my question um and then after the second one actually it was <husband> that was asking the questions about losing hair, about how it would affect me and stuff like that, I didn’t, so I think if the app does you know what you’re planning to do, I think it would be really useful, uh because it will help you to set up like you said the questions to doctors because you will forget and then later on you think oh gosh I should’ve asked this, uh I know of for example my case can cos it’s breast cancer you’ve got a breast cancer nurse allocated to you and she does visit, she does give you the information before the surgeries, but sometimes it’s really hard to get in touch with them because unfortunately the amount of women affected by this is increasing so, so much they’re always so, so busy at the hospital it’s really hard to actually speak with one of them, so if you do, I think if the app does that, you know gives you a list of questions that would be useful for you to ask so you can write them down, if it gives you information about the type of cancer, what could come next, the type of treatment you’ve got to have, what’s linked to it, I think it’s extremely useful because at least you’ve got your mindset to ask the questions if you’ve got any....cos yes I was still needing information and I think it was just the right information I read when I got home but if I had any questions when I got home I’d have to ring back and say “look I don’t understand this” you know so I think if the app does that, that’s really good

I – yeah, okay

DS240141 F – to me that would be a good

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

DS240141 F – I think for them it’s more the case that you know they can see that the patient has a bit more information, the patient is a bit more aware of what’s going on and you know, I hope they just don’t rely on the fact that you, you, you will use the app, therefore they don’t need to give you that much information, I hope not, uh so I think
for the doctors it would be just the case that you know me as a patient I am more aware of what’s there and can be more productive cos I can, like you say write down questions and to ask to organise myself towards whatever stage is coming. So I think for them it could be the case that it is useful for the patient’s side because it has my information and it’s more organisation and structured

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

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

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

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

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

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

DS240141 F – personally that’s how I see it

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

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

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

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

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

DS240141 F – I personally think the app should be, I mean this is my personal opinion, it should be very positive, and even though it’s you know we all know it’s cancer, it’s a
serious illness and everything else that’s on the back of it, we all know bad things about
it, but I think if it has some sort of positivity on it, if that makes sense, you know there
are people that do make it they get on with the rest and they’re fine, yes there’s a lot
of people that don’t make it, and unfortunately you know they don’t get there, but I
think if the app, the way it works, it gives you some sort of positivity in some way you
know, if it links to cases that people that actually made it, some comments from people
that you know, I’ve been there, I’ve done that, I’ve made through, I think that would be
extremely beneficial for whoever is going through, because you’re so scared of what’s
coming next.

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

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

I – yeah, yeah so you don’t want something that...

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

I – but focus on the positives?

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

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

DS240141 F – It would probably would be the same stuff as for the patient, I think
personally you know be able to filter and get that, the right information you know have
connectivity, have links or whatever, to um I don’t know comments from people that
went through different experiences of how they managed to go through
I – okay and is there anything that you wouldn’t want the app to do? I know you’re really sort of stressing that it needs to be reliable information and....

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

I – yeah, yeah... is there anything else that you wouldn’t want the app to do, or you would be wary of?

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

I – not to bombard you okay

DS240141 F – cos that would put me off completely. McMillan did that for me, even though so many people say “oh you know you’ve got the forms, you’ve got this” and, to be honest with you...

I - it’s just too much yeah

DS240141 F – and some people are..... I always try to be very positive I always try to do comments of stuff that I have read, and I was kind’ve told off by one of the patients and he kindly said “well you know <<inaudible 33:15>> when he’s said “you’re new to this so don’t speak about things you don’t know” and I thought well, thanks very much I know it’s hard, I know you’re going through a lot but I was just trying to help

I – yeah, yeah

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

I - okay. Well moving on this is the last question, are there any particular types of patient that you think might find this app most useful? So for example different age groups, or different points in the disease, diagnosis or pre-treatment, post treatment,
or throughout all of it? All patients, is there a particular group we should target do you think or?

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

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

DS240141 F – yeah, you always need information and I think that it mean all the way through okay, like I said at the very first beginning, until you know the type of cancer you’ve got, you don’t know, isn’t it? Until you have the diagnosis you know, there’s nothing that you can do, but then I think that’s when you’re diagnosed, that’s when you start the process, so when you’re diagnosed you are told what type of cancer you’ve got and what’s happening next, so I think from the entire process whether there’s surgeries, doing chemo, radio, afterwards getting back to normal life, any questions at all and if the app is designed you know if it has information for every stage to support you and you know to answer the questions that you’ve got, because for example the questions that I will have after my first surgery would be exactly the same questions I would ask through chemo isn’t it cos I know when I had the chemo I knew the type of cancer, I knew the size, the whatever else isn’t it, so my questions would be “well how is this cycle going to affect me?” I know I’m going to lose all my hair, I know this is going to dry me completely and it did uh how can I sort it, what should I be doing, is there any specific foods I should be having, I had tips that the nurses gave me that they were absolutely fab and I didn’t have a clue, if she didn’t tell me, I was very sick and unfortunately cos it
has to be given to you, the nurse has to administer it, manually you can’t do it by... cos it’s 6 syringes for different stuff, her mum love her, she went through, she just finished I think when I started chemo her mum was just finishing or something like that and I was sat with her ((names her)) she was given the tips with her mum that was something for the dryness cos after the chemo the next day you struggle is with dehydration it feels like you’re burning, you don’t have a temperature, but your body is so, it’s so toxic and you need to detox and the best thing to do it is water with lemon, and I never had a clue, so water with lemon and ice soothed my throat, if it gets really dry it detoxed me, it helped me to hydrate because one of the things they tell you with chemo obviously you need to drink a lot of water, now I struggle to drink water anyway so I would have to drink about 4 litres of water I thought I’m not doing that I’ll tell you know and if I wanted to I would just physically sick it up, you know so I had a lot of tips I was given by different women, nurses that was really, really helpful, so if you know if those, because obviously I can see the app working on studies on scientific stuff, like NHS, or whatever, it’s extremely, extremely useful, but you can have tips on experiences as well, this helped me a lot, like pineapple helped me a lot just pineapple in your mouth just suck it and it soothes the throat, it hydrates you it was awesome and there was no way that I would know that, that would help me the first few days and I was told actually in this case

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

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

I – I hadn’t thought of them, yeah

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

I – oh really

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

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

I – really

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

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

DS240141 F – yeah, yeah

I – yeah okay so that might be another tip for patients, yeah

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

I – really

DS240141 F – spot on a week later, yeah

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

DS240141 F – that’s a shame because it’s really, really helpful you know when the nurses speak to you on the phone and I have a Tenovus and she was awesome um, what was
the thing she gave me? Was my throat I was struggling with my throat and she told me
to use...I don’t know? I can’t remember now...I suffered from heartburn a lot, they told
me about Gaviscon and I found that the little drops they told me to have, she told me
to have some sweets you know your throat gets so, so, so dehydrated it’s painful and
you get prickly coughs as well, so if you've got something sweet that you keep in your
mouth it helps a lot

I – oh okay

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

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

DS240141 F - yeah

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

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

I - yeah well that’s great thank you very much

DS240141 F – you’re welcome

I – let’s turn this off

End of Interview. Duration 42:05
Appendix 19: transcript for P13 Lynne

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

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

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

DS240148.F - yes

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

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

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

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

I – yeah, yeah, yeah

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

I - OKAY and did you read those?

DS240148.F – yes, yeah
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...
I - yeah okay. So what about other sources? Did you consult with other family and friends? Or was it just over the internet and the health professionals that you used?

DS240148.F – um, I certainly didn’t consult with family

I – okay, I’m just wondering because some patients get information from friends who have had similar, I’m just wondering if you got any information from them at all

DS240148.F – not really, I mean only in terms of maybe chatting to somebody... I didn’t really know anybody who had, I knew people who’d had problems with periods and things like that, but not anybody who had had womb cancer

I - okay. So was there a particular point that you can remember where you felt like you needed more information?

DS240148.F – funnily enough, after my operation

I – okay yeah, and was that due to sort of side effects or recovery?

DS240148.F – it was, it was because ((sighs)) nobody spoke to me at all, because um it’s a bit sort of I suppose it might sound a bit personal you know when you’ve had your womb removed it’s stupid ((laughs)) things like, cos I had everything removed, I know this is very specific to womb cancer, but womb, cervix and you think stupid things like well okay, so is there just a big hole there now? Um, has it been sewn up? Um....

I - yes, so you had questions

DS240148.F – yeah, but very sort of you know....not even specifically related to the disease, but what had happened to my body?
I – yeah, yeah, which is fair. So no one spoke to you about that sort of thing?

DS240148.F – no, no one mentioned um sex, and you know, was it okay? And how long and....

I – yeah, yeah and so when you had these questions, how did you get them answered?

DS240148.F – well funnily enough I was having the district nurses in um, because of my wound which wouldn’t heal, and there was a trainee nurse that had a whole load of leaflets...well I just got on well with her and she’d um, and she’d done some work on that area and she had a whole load of stuff that she gave to me, but that was just pure coincidence

I – yeah so was that like leaflets and booklets and things?

DS240148.F - yes

I – okay so you, did you look on the internet at all for that sort of stuff?

DS240148.F - yeah

I – okay, and did you find that helpful?

DS240148.F – a little bit...when I say leaflets, they weren’t commercially produced leaflets for general distribution, they were things that she’d had because she’d done an academic study

I - ah really, okay

DS240148.F – so I don’t think there was anything produced, you know
I – that’s interesting

DS240148.F – I don’t know if there’s anything produced? But I certainly didn’t get anything

I – yeah, yeah you would have thought that you would’ve had something explained to....

DS240148.F – nobody ever mentioned it, and then of course you know you start feeling, is it me you know, it’s embarrassing in a way to sort of....

I – yes, so how did it make you feel not having this information, you mentioned you felt embarrassed at times?

DS240148.F – well I’m just a bit insecure really, um ((pause)) you know it’s a very integral thing for a woman isn’t it? Your womb and...you know? And suddenly you haven’t got it anymore ((laughs))

I – yeah, and no information on it either

DS240148.F – and no information and with the best will in the world I’m not criticising the nurses, and the doctors, they’ve go so much to do

I – yeah but it is a big operation isn’t it?

DS240148.F – it’s a huge operation yes

I - okay. So moving on then to the clinicians how did you find talking to them about the cancer and the operation and everything else?
DS240148.F – they were very, very good, brilliant, the only thing is, again not their fault, but I always felt a little bit rushed because there was so many patients and so much to do

I – yeah, was it down at <hospital> or <hospital2>?

DS240148.F – it was <hospital 3>

I – okay, so you felt a little bit rushed, you were aware of....

DS240148.F – yes I mean, they were brilliant, perhaps it was my own you know....

I – there have been other patients who have said that they’re aware that it’s a very busy clinic....

DS240148.F – it’s so busy and I mean you know with the best will in the world, I mean, the surgery itself was marvellous because I needed a lot of reassurance um, because I mean I suppose they have to, but again they were really sort of you know ((sighs)) risk of death and all the rest of it...and there were specialist nurses and I was assigned a specialist nurse and she was lovely, um and it was “oh ring up at anytime you know” bless them, again, they’ve got so many people you ring up and you’ve got an answer phone message, they would get back to you eventually, but I must, I have to admit I did feel a bit isolated you know

I – so sorry, you rang that number when you had questions?

DS240148.F - yeah

I - yeah, okay and they’d get back to you?
DS240148.F – they would get back to you eventually, but again they had so much to do
((laughs))

I – so when you had those questions and they didn’t get back to you straight away, what did you do then? Did you wait, or did you go and find the information elsewhere?

DS240148.F – no, I just waited

I - waited okay, and how was that for you?

DS240148.F – frightening sometimes

I – and what sorts of questions did you have for them?

DS240148.F – um, oh gosh it’s hard to remember now uh

I – I mean were they about side effects, or psychological worries you know...?

DS240148.F – there were some about um medication I needed to take different medication, I was worried about...

I – yeah that’s quite important isn’t it yeah

DS240148.F – yeah because you know again uh I didn’t know whether I’d have to take hormones? Um and I had, nobody seemed to volunteer information like that

I – yeah, so did they tell you this before you were discharged then about what to take, or did you tend to forget or...? Or it’s complicated?
DS240148.F – they didn’t tell me anything

I – oh really?

DS240148.F – yes you do tend, until you, you know at first I was, all I was worried about was getting through the operation um surviving the operation and so you’re not worried then about whether you are gonna have to take hormones ((laughs)) and then after a while you start worrying about that sort of thing you know

I – yeah, yeah cos it’s the sort of next step

DS240148.F – because I wasn’t of the age where I knew definitely whether I’d been on the change or not? Um and I didn’t know and nobody seemed to, you get the feeling because they’re all so busy, um and again it’s not a criticism, I think that basically they need more staff don’t they?

I – yeah definitely

DS240148.F – but because they’re all so busy, um they, you get the feeling that perhaps things have been forgotten, you know?

I - okay yeah which I’m sure does happen

DS240148.F – and also there’s this feeling of one had not knowing what the other hand is doing

I – yeah, yeah, okay. So then you called up then with the questions and then eventually they got back to you about how to take the medication
DS240148.F – oh yes they always got back to me

I – yeah it’s just the waiting in between isn’t it?

DS240148.F – it’s the waiting and the knowing I think that they’re under pressure you know

I – yeah, yeah and how did you feel when you contacted them? Were you happy to phone them, or did you dislike phoning them?

DS240148.F – well I was happy to phone them, I didn’t dislike phoning them, but I did feel oh is this wasting their time?

I – okay yeah and I think that’s a common feeling amongst patients, but you’re definitely not wasting their time so...yeah

DS240148.F – no, no and they never gave me the impression that they felt that, you know they were wonderful

I – it was just that sort of delay, yeah

DS240148.F - yeah

I – okay. So, so we talked about how you felt when you asked some questions and you were happy to ask them. Was there anything that made it easier to ask doctors and nurses questions, or did you find it more difficult to ask questions?

DS240148.F – um, no, no I think they were all very approachable to ask them

I – okay
the only difficulty was feeling all the time that there was so little time, you always felt rushed and a bit of time constraint and again it wasn’t them making you feel like that, it’s just the whole atmosphere of the place ((laughs))

I - yeah, yeah I know, I visited some of the nurses in the clinics down in <hospital 2> and <hospital 3> and it’s just crazy

DS240148.F – it’s just ridiculous. I mean you know I just felt so sorry for them because they weren’t going around feeling sorry for themselves, but you could see the pressure they were under you know

I – yes exactly, I think the patients definitely pick up on that then

DS240148.F – they do, and of course to be told you’ve got cancer you know, your whole world crashes around you and uh you really want to be able to sit down and talk to somebody, or at least have like you say like an app or something

I – yeah to just have time to take it in yeah

DS240148.F – yeah, yeah

I – okay. So the next question here is were there any barriers to communicating with doctors and nurses? I mean you said you know it was fairly easy apart from the time pressure, but were there any other barriers to communicating with the doctors and nurses in general?

DS240148.F – well um, not really, I mean, you did feel as if you wouldn’t…..my main, it’s funny it’s a strange thing to say, but my main point of contact for me felt like it was the surgeon’s secretary, she was always there, she always picked up the phone. Although I wouldn’t talk to her necessarily about the medical stuff, at least with her I felt that she would get a message through, that she had her hand on everything that was happening,
it was simply you know, you didn’t feel, like you could pick up the phone to the nurse, but you’d get an answer message and sometimes you want the reassurance there and then

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

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

I – okay, yeah so you’d want it to feel supported by the clinicians?

DS240148.F – by them, yeah

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

DS240148.F – not endorse it...I didn’t mean...

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

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

I – yeah, yeah

DS240148.F – then they must feel that it’s worthy and reliable and a useful source of information, I mean there’s so much out there isn’t there?
DS240148.F – not in terms of apps, but...you know

I – yeah, exactly

DS240148.F – I – yeah, yeah so many different sorts of resources of information. Okay well we’ll come on to the app a little bit later. So how did you remember all the information about the cancer? Did you write it down, rely on memory, or use any other ways to remember it?

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

I – oh okay

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

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

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

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

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

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

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

DS240148.F - hmm

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

DS240148.F - yeah

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

DS240148.F - yeah

I – okay and you said the doctors were accommodating?

DS240148.F – very much so yeah

I – okay then so did you find it easy to talk to your family and friends about when you had cancer?
I – and is there any...is there any...

DS240148.F – friends yes, well no, no actually I didn’t cos I, I remember not wanting to ring particular friends because I’d have to say

I – okay and why did you feel like you didn’t want to tell them?

DS240148.F – because I felt it was such bad news, uh and also I, I don’t like, I’ve got a thing about, I don’t like the phrase I’ve got cancer, not because I don’t want to face it or anything, but it seems to me, I in fact, I never, ever said it, I never said it to anybody “look I’ve got cancer” I would say they’ve found some cancerous cells in my womb, because I had cancer in my womb, I wasn’t my whole person, it wasn’t my whole body....

I - yeah, yeah that’s exactly, that’s a really good attitude to have towards it, because I think when people say, “I’ve got cancer” it’s like...there’s a stigma attached to it

DS240148.F - yeah

I – that it’s um you know life, always life threatening

DS240148.F – always life threatening, and you know okay you’ve got perhaps you’ve got cancer in some part of your body, cancer’s not like you know...

I – it doesn’t have to define you

DS240148.F – it doesn’t have to define you as a whole person you know
I – okay, so would you say then did you prefer not to talk about for that reason?

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

I – okay

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

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

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

I – what sort of things?

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

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

DS240148.F – I’ve used my fitness pal

I – oh I use that yeah
I – and that’s to track sort of diet and things like that

DS240148.F – diet and things like that yeah

I – okay how do you find using apps, when did you start using apps, is this something that you’ve used since the beginning or?

DS240148.F – yeah I’ve been using them because I used to use them on my phone as well you know yeah

I – okay so have you got a smart phone, or is it a regular...?

DS240148.F – no a smart phone

I – yeah and do you use apps on there as well?

DS240148.F – yeah

I – do you prefer one device over the other?

DS240148.F – I’d prefer the Ipad, um but obviously then I’d prefer, but you know it depends on whether I’m in or out really you know when I’m out and about I use my phone, when I’m in, I use my Ipad

I - yeah okay. Right well that’s great, so the type of app we talked about, do you think patients would find this type of app acceptable to use?
I – and do you think they would use it?

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

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

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

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

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

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

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

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

DS240148.F – well my dad is 82 bless, cos I’m 57 um I think having a son, because my son is 24 now, I think having him and also I worked in schools so you had to get a bit savvy, but my dad bless him he’s 82 but he does really well, you know he sends emails, and he googles, but to us you know it’s the air we breathe, but to them it’s you know

I – my grandmother then, she uses her laptop now to, for booking her golf competitions and things and the only reason she’s learned because it’s all gone online and she’s had to learn

DS240148.F – she’s had to learn

I – yeah, or she’ll be missing the games, but to sit down and do it it’s quite a task for her, where as for us we just sort of do it by second nature. Okay so we’ve talked about training then, do you think some patients would be able to use the app after some training, do you think they’d get on with it?

DS240148.F – oh yes, yeah

I – okay, and if the app was made available would you download and use it and do you think...

DS240148.F – I would yes

I – would you recommend it to other patients?

DS240148.F – definitely, I’ve been looking it up now, even though it’s you know

I – yeah, would you have any concerns about using the app?
DS240148.F – I wouldn’t personally, but I would’ve had concerns about I wouldn’t have just said to my son “there’s this app have a look at it” I would’ve wanted to look at it first, but that’s just me probably being over protective

I – yeah, no I understand that yeah, in case there’s too much information, okay. So this question is a bit difficult because it depends on what the app is going to do, but the type of app we’ve talked about, so for example, looking at helping with questions before consultations, and reliable information where there is some sort of link, or to social support, what benefits do you think there would be for patients using an app like this?

DS240148.F – well I think that perhaps it would help then to prepare for consultations because I think it can be a bit of a shock how much information you are given and you end up going from a consultation thinking oh my god, you know what was I told there sort of thing, so I think it might help to prepare people, um....

I - what about taking information away, how could, do you think the app could help with actually writing the information, or recording or...typing it in?

DS240148.F – yeah I think it could

I – do you think that would be a good idea because I’m not sure whether that would distract from the consultation, I’m just wondering what you think about it?

DS240148.F – I don’t know whether you would want to be messing about you know, I think that’s an individual thing, I think...I don’t think it be, I don’t think there would be any harm in providing that facility if people wanted to use it they could, it would be up to them wouldn’t it?

I – yeah that’s a good idea yeah. When you took in the question list did you write the answer down, or did you just use it as a prompt?
I – and did you find that impacted on communication at all?

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

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

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

well certainly it would provide, I think some sort of reassurance and some support and certainly a source of information, um

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

um, well certainly finding out things that perhaps people haven’t got the time to tell you, you know like side effects, like things that would happen to you after the operation in terms of effects on your body and things like that you know

I – okay and what about clinicians, what benefits do you think there might be for clinicians if patients are using an app?
DS240148.F – well if it would, if they could have input into it, I don’t know whether an app, within an app would there be um an opportunity to perhaps email, not to the clinician in hospital, would there perhaps be a possibility to email a question to somebody?

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

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

I –  yeah, or the app in general?

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

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

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

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

DS240148.F – well certainly obviously finding out information, finding out procedures you know what are the sorts of things that happen you know what’s the stages you know
I — and how do you think that might help the patient you know if the patient knows this information?

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

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

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

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

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

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

DS240148.F — well the only barrier I can think of is that some people do not have any access to the internet and I suppose that’s something that you just have to accept you know that’s not a reason for not producing something, but that’s the only barrier that I can see, in that people, there are people who don’t have internet access, um and I suppose the other barrier is....people who are not able to read and understand. I think
it would have to be very accessible I suppose there is a section of society where language might be a...you know

I -  yeah, and you mentioned earlier you’d want the clinicians to support it

DS240148.F – yes I would want to feel that is something that they were saying “look this is good, have a look at it, it might help”

I – do you think if it wasn’t recommended by healthcare professionals, if they didn’t sort of mention it, what do you think the impact might be there? What would the difference be?

DS240148.F – I don’t, it probably for some people it might not make any difference I don’t think it’s a, it’s not a, it’s not a deal breaker you know, um I just think it would make it, for me it would just make it even more supportive

I – okay, would it make you feel like you trust the app more? Is that what you would get from it?

DS240148.F – yeah, I mean if I google any health issues I’ve always looked out, you know you google and you get those things...I’ll always look for any that are NHS

I – okay yeah

DS240148.F – I don’t know why it’s probably rubbish you know

I – yeah, yeah but you sort of fairly know that it’s up to a fairly good standard

DS240148.F – being an independent thing rather than a you know
I – yeah, okay so what sort of things do you think the app should do to help cancer patients? I mean I know it’s a broad question. We’re hoping to build the app in March so we’re asking patients, or past patients like yourselves, based on your experience, what could’ve really helped you, and you know within the means of an app?

DS240148.F – um, I think to find out information about the particular type of cancer than you’ve, you’ve got, I suppose there could be that within an app couldn’t there you know?

I - yeah

DS240148.F – research different types, I, I, I when I say find out about, I don’t think you want to know um, the sort of scientific facts of it, but how it affects your body and what the risks are you know and what the general um course of methods of treatment are um....and yes with an operation what are the down sides that would...maybe some I can’t think of the word people who have had it done talking about their experience

I – so and how could we best fit that in then? Would that be perhaps a blog from a patient, or would it be more of an interactive chatting facility?

DS240148.F – I think it could be both really, it could be you know some aspects of people just, just telling about their experiences and there could be some sort of forum I suppose as well

I - okay any other ideas at all?

DS240148.F – sorry I’m not very good at this sort of thing

I – no I know it’s tricky because apps can do so many things and you’ve not had a lot of time to think about it so I understand yes it’s quite tricky. What do you think about the question prompting idea, do you think that’s something that would be useful?
I think that’s a very good idea, I think that’s a very good idea yeah

I – and what about the links to recommended websites?

DS240148.F – yes, yeah

I – how do you think that could help patients? The links to the websites?

DS240148.F – well it’s just another tool to find out information isn’t it and also support you know, because it wouldn’t only just be information at websites it would be people like McMillan or Tenovus

I – yeah, yeah so links to selective websites as well

DS240148.F – and with a lot of people I think money is an issue isn’t it. Like people like Tenovus and McMillan who deal with that, within the app itself it could perhaps even if it’s just that information that cancer charities will help with benefits and things like that you know

I – yes this has been suggested by a few patients actually, they did a survey I think in <hospital> and maybe a few other hospitals on what information patients with cancer are really missing and financial issues was number one so it’s definitely something we could help with

DS240148.F – you know for me it wasn’t an issue, because I’d been retired medically anyway, but you know if you’re going to have 6 months of work you know it’s a huge, and I mean stress is the one thing...

I – okay so anything else or?
I think possibly but then again I don’t know if you’d be interested or, I have a particular problem in that I’ve got mobility issues, so getting to appointments, I think that’s definitely that’s something to think about yeah

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

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

but it’s handy to give this information, because it could prevent you getting into a state where you’re really upset and that’s not helping anything is it so if we can prevent that

you know just reassurance to people that if they do have any issues about getting to appointments, or worries about when they’re in hospital you know, to talk to
people about it you know to talk to them about it, because a lot of people won’t they just suffer in silence

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

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

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

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

I – so that’s support for the support groups then?

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

I - and is there anything you wouldn’t want the app to do?

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

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

DS240148.F – um, probably not no unless they’re positive ones like you know 97% of people survive, or I mean even that can be dangerous can’t it?
I – okay and so not to worry the patient?

DS240148.F – no, not to worry the patient or the relative really

I – okay are there any particular types of patient that might find the app most useful, so we’ve talked about... do you think all age groups would find it useful, or do you think there would be a particular age group?

DS240148.F – well I think all age groups apart from maybe the very old, but then you know I wouldn’t want them to be excluded if they wanted to be, you know that’s not what I mean

DS240148.F – well I think all age groups apart from maybe the very old, but then you know I wouldn’t want them to be excluded if they wanted to be, you know that’s not what I mean

I – yeah, yeah and what about patients at different stages of the cancer? So diagnosis, sort of treatment, post-treatment. Do you think it would be something that is sort of useful throughout the whole thing, or do you think there’s particular points...

DS240148.F – no, I think it would be useful throughout the whole thing

I – okay, okay so if we made this app available, how would we, how would we introduce it, how could we best get people to recognise the app as a trusted source of information, how do you think we could get people to use it? How would we get you to use it for example? Because there’s loads of websites, information leaflets, groups there’s hundreds of things so how could we make this appealing?

DS240148.F – well I don’t know, I suppose you could have...

I – well you said “have the clinicians endorse it”
DS240148.F – have the clinicians endorse it, maybe advertise it through GP surgeries, um, have you know, like big posters and things like that, maybe even through television and radio um...does that make sense?

I – yeah, yeah

DS240148.F – you know advertise it cost money I know but um, um I don’t know, I don’t know how you would advertise an app it’s all about getting it out there isn’t it?

I - yeah, yeah

DS240148.F – making people aware of it and certainly for me it’s this idea you know if you went to the hospital and you were diagnosed maybe they’d give you, they’d say to you “look there’s this app you can use” maybe give you a leaflet with the web, you know have it written down

I – yeah, okay so do you think it would be helpful then to have a leaflet on how to use it?

DS240148.F – yes, yeah I do

I - okay, well that’s it so is there anything else that you think would be helpful or we should know?

DS240148.F – no I think we’ve just about covered it really haven’t we?

I – yeah lovely okay thank you, I’ll just switch this off

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
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.
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

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?
Appendix 26: transcript for C19 (Sur) (urological cancer)

INT: Okay. So could you tell me why you are interested in taking part in the study?

RES: Um, er, I guess, I have got two reasons; one is to, um, one one side... I’d always, um, supported initiatives at the medical school, and make sure students have opportunities to do, um, er, to do projects and things like that... that’s one reason of course. And the other reason is that if it does, um, result in improvements in information giving for the patients, it provides an overall benefit, so ...

INT: Okay.

RES: ... so I think those are the two main reasons.

INT: Okay. Um, so how do you decide how much information you give to patients about their cancer, within a consultation?

RES: Er, I think that depends on a few things; one is whether it’s the first time they have heard they’ve got cancer. So it’s at the time of diagnosis. It may be the time of staging, so whereby the patient already knows they have cancer. Or it may be at a later stage, a later time, so you are trying to, um, modify what you say, and how much you say, depending on when you see them in their particular, er, pathway, if you like. So ...at the outset it’s probably best not to say too much, and try and be fairly reassuring.

INT: Mhm.

RES: It’s important both to get the diagnosis across, um, and then outline other tests, if you need them, before you make a decision about what should be done. Er, because patients often find if you tell them they’ve got cancer, they often will take in very little subsequently during that consultation, because there’s a, sort of, element of shock. I guess in terms of giving information, that may depend on, again, which time point we are seeing them, but at the outset it’s probably best to give them a small amount of information which is quite general. So if it was prostate cancer it would be a little bit of information about prostate cancer, and a little bit about PSA tests, what the staging tests often involve, and then how, the sorts of principles of treatment rather than detail. Because if you give them a lot of detail and a lot of leaflets they probably won’t read any of them. Whereas
if you give them a small amount of information at that point in time they may well read through it, or their partner will read through it.

INT: Okay.

RES: Of course, if you then see them at a later date when you have got all your staging information, and you are deciding between a relatively small number of treatment options, you may then give them, during the consultation, a lot of information verbally about that. And then you may give them written information about that, er, specific treatment option; so maybe two or three different options. So in localised prostate cancer we often talk about surveillance, external [unclear] radiotherapy [unclear] therapy and surgery is the main, sort of, treatment option, so we may well give them information about that. There is very little point in giving them a lot of information about palliative care, and permanent hormone therapy which we give to men as mainly a palliative treatment.

INT: Mhm.

RES: So you cater the information needs for the stage of the patient at subsequent points. The other thing that you can do, which we don’t, we are probably not very good at, is, er, is addressing the information on the internet with the patient in the room.

INT: Mhm.

RES: We might give them information booklets which describe ... Prostate Cancer UK website, is very good. So we are, sort of, signposting reasonably reliable sources of good information for them. But in some appointments, er, we might, if we have got a reasonable screen, we might show them, “this is the Prostate Cancer UK website, this is the, sort, of localised treatment section that tells you a little bit about them there”, and, um, and I see it with that sort of thing.

INT: Yeah.

RES: But we don’t do that very often I don’t think, and obviously there are issues around availability of computer screens and showing patients, er, it’s not straightforward.

INT: Yeah.
I think. So I think that probably sums up ...information giving at that point, at those points in time.

Yeah. Okay then, um, so what kinds of issues do you think clinicians are faced with when talking to patients about their illness, during a consultation?

I think they are faced with different issues at different time points. So at diagnosis, the issues you face are that a) you have got to give someone very bad news, because no matter how aggressive or not the cancer is patients will take that very badly usually.

Yeah. Okay then, um, so what kinds of issues do you think clinicians are faced with when talking to patients about their illness, during a consultation?

And they also will then, as I said, will take in very little information afterwards, so it’s challenging (phone ringing) them to get over the, um ...

do you want to pause that?

Yeah, yes.

Just in case.

Okay. [Recording is paused].

[Recording resumes]. So it at the diagnosis appointment, the challenges are to give them bad news but don’t be too gloomy. The challenges are to give them information when they are not actually taking it in very easily.

Right.

You are trying to give them some encouragement, or some, to give them, er, a steer as to... well actually, although it is cancer, actually there is something we can do about it. Getting those informations across to the patient so that they can remember it. And the other challenge is not to give them too much information; if you say well you have got cancer and then you go into a convoluted story around the principles of staging they are not going to remember anything about that. And you haven’t helped them much. You’ve just given them some bad news and then you have confused them. So, you know, you’ve got to be giving them the news, try and be accurate, give them some positive encouragement. And tell them about the next steps, but not go into a lot of detail.

Mhm.
For most patients I think that’s the challenge in that appointment. If that’s done well, and they have the right information, their next appointment, hopefully with the same person would be much better, because you had met before. They haven’t got to get over that cancer issue of diagnosis. If the staging tests have shown its localised disease you have got quite positive views because their worry is that it’s spread.

Every patient who has been diagnosed with cancer, well if it’s spread that’s the end. I think that’s the way many people would probably think. Whereas if it hasn’t spread that’s great news for patients, and then, er, and then you’ve got to go through a lot of information at that point, and that’s much easier if they’ve had good information before and not been confused. You know, they can relax a bit, and you’ve got a bit more time, and hopefully they’ve read some information. And you can often ask them well what have you, you know, they’ve seen the, you know, the cancer nurses in between seeing the doctors often. They are on the telephone if they want to ask questions. So it’s quite good at the outset then to say well, you know, what do you think of the information? And once you’ve got the, er, the staging sorted out you know roughly where the treatment options lie, and you can then start to get the patient to tell you what they, what they think about treatment options.

Maybe when we know it’s going to be in that group where the decisions may be around surgery/radiotherapy, or a surveillance programme, so ...

Okay. Um, in terms of communicating with the patients in consultations, do you think there are any barriers there?

Sorry?

Um, do you think there are any barriers when communicating with the patients?

Yeah, and I think not all ...

In terms of what type of patient you have, or ...?
Well I think doctors are nurses, not all of them are very good at communicating anyway. And that’s, that is a clear issue.

Yeah.

Um, and no matter how, maybe, senior they are... some the communications skills is not a given. That’s one issue. And some, I don’t think some people actually like giving bad news to patients, um, feel it’s, sort of, maybe letting them down, or, you know, in some way they would rather give people good news all the time. Rather than apologise that things are so bad.

Yeah, yeah.

But that, I guess that’s human nature. But in terms of receipt of information patients are very different. Some patients don’t want any information on treatment options if it’s complex, um, and, um, but they will vary a lot. And individuals may have read a lot in the intervening appointment if they’ve been told before what they’ve got, they may read a lot about it, and therefore they may have a lot of questions, and very, um, enthusiastic to know precisely what their stage is, precisely what are the treatment options, might ask you well if it’s an operation, how many have you done, are you any good at it, in other words. Um, a huge variation.

Okay.

So I guess there’s a, sort of, level of information giving appropriate to what the patient actually wants. Um, so you have to think on your feet a little bit, and yeah you want to give information, basic information, then a bit more complicated, until at some point you have given enough in order to make decisions to the patient, so they are part of the decision making.

Mhm.

And that can vary a lot between patients. So if you are converting that concept into an app you might say well this is the basic information; it’s a bit like the levels in Nintendo II or something. This is your basic level, right we are okay with that now, let’s move on a bit more to this if you want to.

Yeah, yeah.

And then, yeah, and then you can go off to different treatment options with the basic information, then that’s a bit more. And you have to judge how
soon you can move between those levels of information with patients. And in
the clinic, doctors have to think about that on the spot. So actually I think
that’s a bit much, that’s enough now, I am going to step back a bit, and let’s
look at it again once you’ve had time to have a think.

INT: Yeah.

RES: So, you know, of course that’s just a judgement thing during consultation.

INT: Yeah okay, great. Um, so do you have any experience of using a smartphone
or a tablet computer, personally and professionally?

RES: Um, I use standard computers to show patients illustrations on websites but
not a smartphone or a tablet.

INT: Okay, so not professionally?

RES: No.

INT: Um, and what about personally, do you use any, sort of, smart technology
outside of work?

RES: I have got a phone.

INT: Yeah so you are using, so you are familiar with apps?

RES: Not really.

INT: Okay yeah, alright then.

RES: I phone mainly and text.

INT: Okay, okay. Um, so do you think patients, the type of app we are talking
about, um, do you think patients would want to use this sort of app?

RES: I think many would, um, er, if you look at the, sort of, if you can imagine in
your own mind the, sort of, age of the patients with different cancers. So
testes cancer would be affecting quite a young male population, um, peak
incidence in the late teens, early twenties. So that group would probably be
quite familiar with smart phones and apps. Er, many cancers, of course,
affect the elderly population.

INT: Yeah.
And, er, prostate cancer, bowel cancer, a proportion of patients who are using apps on a smartphone, and it’s probably worth a survey of that actually.

Mm, yeah.

I mean, if you, if you said well actually I want to survey the urology clinic for a couple of weeks, and ask the patients how many at this point in time compared to their age would be familiar with an app, that would be quite interesting. Er, I expect, I would be surprised if it was than 50% use an app, currently anyway. But, er, I guess at the end of the day, thinking of the future ...

Mhm.

... the men who are 50 now are going to be 60 and they will be using the mobile at home I suspect.

Yeah.

So there is element of future-proofing in that, in this kind of work, I guess.

Yeah, yeah okay. And do you think patients would find it easy to use, or do you think they might require some training beforehand?

I think a minority would probably benefit from training within the environment that they are working in. I suspect if they are using the phone apps they are, they will know how to work their way around it.

Uh-huh.

If they are not using it I expect what they will do is speak to their kids and say ...I've got this app thing, I want to ...can you help me with it. Let's look at your phone ...and let's show me. And then that may be a way of doing it. Running training of apps within the clinic for patients might be difficult. Unless there is an inherent willingness for them to do it on a personal level. Because, you know, if they are shown how to use an app at the clinic, and they haven't got a smartphone ...

Yeah.

... er, that’s going to be difficult isn't it?
Okay, um, do you think clinicians would be happy for patients to use this kind of app during a consultation?

Oh yeah, I mean, patients bring bits of paper, articles, all sorts of things. I mean, I think the patient population is changing.

You know, we are probably 10 years behind America, maybe longer, in terms of what patients want to know in an appointment. And as time goes on patients will bring more and more things in to say I read this, I saw this, um. And if there was a, you know, when we give them written information they come back and say well the information said this ... what does that mean? And there is no reason, if all that was app driven, why they wouldn’t do that with an app.

Um, because, you know, it’s just a screen with information on it really isn’t it? Or a diagram.

So I think, you know, the delivery is not critical...in terms of what the response would be to them bringing it in and discussing it.

Yeah. And do you think clinicians would be happy for patients to use app at home, sort of, um, not under the supervision of the clinician?

Oh yeah, as long as it was, you know, the information on it was accurate and... you know, reliable and, you know... validated, agreed etc. Yeah I can’t ...I mean, they are doing it now aren’t they?

You know on computers and things, so ...

Yeah. Um, okay so what benefits do you think there might be for the patients using the app? So I know it’s a tricky question, because it sort of depends on what the app will do, but what sort of benefits do you think there could be from an intervention like this, for the patients?
Of information, so it’s an information…app...

And, sort of perhaps, helping to improve communication and social support, and so on ...

Um, yeah I guess there’s information giving at the level which is patient led ...patient driven, so you’ve got those levels of information.

Yeah, so, sort of, at their convenience?

Yes, they say right let’s just talk a little bit about prostate cancer and PSA, which is a small module, if you like. And then if they want to move onto other things …they can do at their own pace. So that’s good.

Yeah.

Um, so other things, well if you are going to link in with other resources, of course it could do that. Prostate Cancer UK website …etc., etc., so we could do that. Linking into other support, well, for example, there is a patient support group we have here, they come to the clinic, you could link into that group, or give contact details, you know, could use, could it allow them to get into a blog?

Yeah.

It could do, you’ve got to be terribly careful, of course, in that patient data and confidentiality …not all patients want to tell …their partners they’ve got prostate cancer, never mind someone they don’t know. So …in terms of the confidentiality issues, yeah the patient could look outside the box and see what’s there for support.

Yeah.

But you’d have to make sure no-one could look back and say, yeah he has contacted us, he must have prostate cancer. Oh in fact he lives three doors down. He never knew I had it, even though I am a patient support group person. And now I know my neighbour has got it. In fact he hasn’t told his wife yet …or his children, so you can imagine the problems that would cause.

Yeah, yeah.
RES: So that confidentiality issue, and accessing support, great but you’ve got to be very careful about the direction of flow of information.

INT: Yeah.

RES: Er, because they can, that can be ...very difficult of course. So yeah in principle I can see how the link into things can help, but, again, there has got to be an ability to protect the patient from anybody saying, by inference, because they got it through this way, and that means they must have this disease.

INT: Yeah. Okay, um, so you talked a little bit about just some of the short-term benefits of an app for patients, can you think of any long-term benefits, um, to patients of something like this?

RES: Yeah, I guess it could hold patient information. Um, so say, for example, if a cancer has got, um, a tumour marker we could add in their tumour marker every time they come to the clinic. And then when they come back to the clinic they can say to the doctor that’s my record. I had treatment in 2007 using my tumour markers ever since...isn't it great, um, I've done very well. Or they could actually complete, um, some quality of life studies on, um, for use, or they could engage in research. So there are other potential benefits to help with their care. So if there were things like tumour markers, or whatever within one cancer site.

INT: Yeah.

RES: And prostate, of course, is the PSA. So whilst PSA is not very reliable at low levels, plus we get levels of type of diagnosis and staging, it’s very reliable after treatment. And therefore, you know, we would like, it would be nice to, you know, those PSA members who are recorded, and then we could look at a graph maybe and then you would see them, if there are changes, what were the rate of changes.

INT: Yeah.

RES: That would be very helpful. Both for the patient and their doctor.

INT: Okay, yeah. Um, you mentioned quality of life studies, do you think an app like this might have any impact on the patient’s quality of life, from using this throughout their treatment and throughout their cancer?
I mean, it might be helpful, but whether it'll, it would, you know, you would be able to demonstrate an objective improvement in health related quality of life, that's a big ask I think to prove it. Um, that's difficult to say.

Okay, alright then. And do you think, um, families and friends of patients would want to use this sort of app themselves, or on behalf of the patient? Because some patients might be, sort of, elderly, but perhaps they have a daughter or son who might want to use the app?

I am sure some will yeah.

Okay okay. And what kinds of benefits do you think this app might bring for clinicians?

Um, well, as I said before, I think if they've got, um, er, information that they can retrieve from it with tumour markers, example, so urology, prostate cancer has got a tumour marker, testes cancer has got a tumour marker, um and other cancers have got a signature mark, so if you had those ...that would be helpful. If you were engaging in a project that they could use to help bring data back for you ...um, that would help for the clinician.

Yeah. And do you think the app would have an impact on communication with your patients?

Um, you might communicate appointments, but I think communicating medical information about the individual, because of the issues of confidentiality, that would be quite difficult. You know, at the moment it’s actually not appropriate to e-mail patients ... to non-secure websites, to non-secure e-mail addresses.

Yeah.

So if you had to, if I e-mailed a patient and said actually you are due in my clinic tomorrow, so, er, that doesn't give anything away does it. But if you said I will see you in my clinic tomorrow and it says my name, cancer specialist ... and then the e-mail is not secure, the patient's mother reads it, son reads it ... catastrophe. Um, so, you know, if you bear that in mind,
whilst you may be able to give some, or help with organisational things
having a communication with an app, which might then breach
confidentiality, would require a lot of thought.

INT: And what about in the consultation, so say a patient has gone away and
used the app to gather information um, and comes back to the consultation,
do you think that might affect the consultation in any way, sort of, improve it, or hinder it, or …?

RES: No. The patients write things down quite a lot now. If they, I think if they
did something on the app as opposed to the writing it down, I don’t think it makes any difference.

INT: Okay. Um, and what about the patient’s communication with their family,
and how they talk about, and share information with them, do you think the app might, sort of, facilitate or hinder information then?

RES: I think it probably would help if they had a clear understanding themselves.
And maybe, you know, if you were able to make it interactive in the clinic,
to say right with this app I am going to sum up the staging. So I am going
to do T2, N0, M0, these are the treatment options that I am going to press the button, that will save on the app, I can take that home and say this is what the doctor said, this is my stage, this is my recent grade, this is my PSA, these are highlighted that I’ve got three or four options, and I can expand those options up and it will tell you a bit more about them.

INT: Okay.

RES: So then they are recording the information in a much more presentable,
communicable way to their families. That may be an option.

INT: Okay. And do you think there might be any problems with patients using
this app; what sort of barriers do you think there might be to this type of intervention?

RES: Um, the main barrier will be using it. If the, if the …new, you know, access
to a smartphone, or whatever, a tablet, I think if they are familiar with that I can’t really see there would be any particular difficulties. Providing the information was logged in, you know, provided the information was in a logical format and the patient was able to step up the complexity of the information in an easy way. If the first time you went in and you were told
about the complexities of, a, you know, a drug that we don’t often use, as
opposed to the basics, patients will get confused. So I think, provided it was
set up well I don’t think I probably envisage any major problems.

INT: Yeah okay. Um, and just going back, you mentioned earlier that, you said
some clinicians don’t particularly like giving bad news. Do you think an app
that might, sort of, facilitate question asking on the patients part, do you
think that might help difficult conversations like that? Do you think you
might, or the patient, um, the patient might be more informed, and would
be able, would be more quick to bring up difficult conversations, do you think
it might help with something?...

RES: Yeah, it may help if the app was ...

INT: So I don’t think it will come at the diagnosis stage, but in terms of talking
about prognosis perhaps, do you think it might help with ...

RES: Oh that would help ...

INT: ... difficult conversations?

RES: ... yes, yeah, yeah, it would help with that. Not at the diagnostic phase, I
think that ...

INT: Yeah, yeah.

RES: ... you know, yeah, but ...

INT: Yeah.

RES: ... decisions about treatment stage yeah.

INT: Yeah, yeah, mm.

RES: I think it would help.

INT: Okay. And, er, do you think that patients using this app would affect your
workload anyway? Because I know you mentioned that you think that the
mode of delivery, they bring in paper clippings and things anyway, um, but
do you think it would affect your workload if patients brought the app in?

RES: Not really no, no not really.
And you said that some patients might be more informed, and perhaps become more, um, involved in decision making. Er, do you feel that clinicians would require training in how to deal with the more active patients as a result of the app?

Well I think the clinicians would have to have some training on the app, um, because if I, if I am giving any patient information, say Prostate Cancer UK website. And I am showing it to them, I need to know what bits I am going to show them. And what, anything on there that I haven't seen because you don’t want ... you know, when you are in with a patient you don’t want to be trying to take in information and then you look, er, it’s very messy then, it's not not good for the patient. So you ...the clinicians would have to be fully familiar with what is on the app.

Okay.

Like any, anything you give the patients you have got to know what you are giving them.

Yeah, yeah okay. Um, and so you mentioned a few features that you think would be useful, such as the, um, sort of, tumour markets and things like that. Is there anything else that you could think would be useful for patients for the app to do, other than what we have talked?

Scheduling appointments maybe. Giving them a reminder to get their PSA tests done, the tumour marker before their appointment.

yeah.

Um, it might be particularly helpful in that system to, um, er, trigger a telephone appointment with...Because patients often don’t need to come to the clinic if they are well. But you need to touch base with them to just make sure their PSA is okay.

Yeah.

Maybe if you build in a trigger that will set, say, for example, in some patients we don’t need to see you unless your tumour marker goes above X.

Yeah, yeah.
RES: So if it was plugged in and the PSA was X it would say you need to go see your GP.

INT: Yeah.

RES: And go back to for a hospital appointment. So you could build in something which would be tumour specific to say, mm, that doesn’t sound quite right, I think you need advice on that. So you could build in triggers as well.

INT: Yeah okay. And, um, do you think there's any features that would be useful for the relatives or friends?

RES: I'm not sure there's anything over and above that would be unique for their purposes ...as opposed to over and above what would be helpful for the patient. And the only times at which I am giving information to a relative more than the patients, is where the patient is very sick ...or they are terminally ill and you, you know, they are in the ...er, you know, in the terminal stages of cancer, then you are obviously giving information to relatives in a certain way, rather than directly to the patient.

INT: Yeah, yeah.

RES: So in this context I am not sure there is anything. Apart from encouraging the patient to share it with their partners/next of kin.

INT: Yeah okay. And is there anything that you would want the app to do, other than what we’ve talked about?

RES: Tell me the lottery numbers every Friday night.

INT: ((Laughs)) Um, is there anything that you wouldn’t want the app to do, that you wouldn’t feel comfortable with?

RES: Yeah I think the, you know, the confidentiality thing is an issue. Um, I can’t think of anything I wouldn’t want it to do without probably looking at what it’s going to look like, and can do. Um, I can’t think of anything immediately, off the top of my head, that I wouldn’t... want it to do.

INT: Okay. And the last question, um, do you think there's any particular types of patient that might be most suited to something like this? So, sort of, age groups, or patients at different stages throughout their cancer journey, do
you think there's a particular, er, niche for this type of intervention within
your clinic?

RES: Um, I guess it’s around the diagnostic stage, and the decision making stage. Because I think there probably is a benefit there, er, because I guess that’s what it's targeted at really, isn't it, the information giving around …?

INT: Yeah, yeah.

RES: You know, not the follow-up stuff particularly. So I think, er, yeah I think it would have a place in that, yeah.

INT: Yeah okay. Alright well that’s great, thank you.

End of Interview. Duration 32:00.
Appendix 27: transcript for C12 (Onc) (colorectal cancer)

INT: Okay, um, so could you tell me why you were interested in taking part in this study?

RES: Um, I think, er, very important to get the right information to patients, er, it reduces anxieties, it improves, er, that communication link, it improves the understanding between clinicians and the patients. Help in terms of, er, choosing the right treatment for patients, help in terms of not choosing treatment for patients, which is obviously a technically difficult, er, thing as well. Allows that communication probably to expand more appropriately to other members of the family; relations that are obviously important in that also. So I think knowledge is a good thing, um, I think it should aid the interaction between clinician... and demystify a lot of what actually happens.

INT: Yeah.

RES: And I think the complexity of treatment is what is often the fear, er, for the patients, because it’s very much the unknown. So if we can remove that fear then that will improve things.

INT: Yeah, okay, er, and so how do you decide how much information to give the patients about their cancer at the consultation?

RES: Er, so I think some of it is, it’s fairly easy to say oh we should give them everything, but actually I think there are two issues; one there is a pace at what information should be given, so certain bits of information will be given at a different time. Now that varies from person to person.

INT: Yeah.

RES: So I think you do assess the individual, and you see what their responses are to your initial, er, introduction of information, and then decide what that pace is. You will also decide how far you go with that information.

INT: Yeah.

RES: So some patients don’t want to know everything, some patients do want to know everything, and some ... everyone else is a spectrum in the middle. Um, and there’s a bit of clinical judgement there; and that’s the challenge in terms of an app, er, in terms of how you deal with that. So that I think that’s a key component as to how this should be worked.
INT: Yeah.

RES: Um, I suppose there some cues that we use, obviously there are various non-verbal cues as well as verbal cues. But, er, on app I think you probably have the ability to double-ask certain questions where you know there are some sensitivities, and that’s often what we do as clinicians.

INT: Yeah.

RES: So if somebody asks me how long have I got to live, I don’t instantly blurt out you have got six months. One, because I don’t know, er, and two because actually sometimes people ask the question without thinking, because they think it’s just a question they should ask. So actually, in a clinical scenario, you can actually say do you, you know, do you really want to know that, what are you going to do with the information.

INT: Yeah.

RES: Um, er, will it make a difference to you. Er, and sometimes people in this situation, if they are given that information, then assuming it’s bad, i.e. they perceive things very negatively. Um, so within an app I think you need to build in that pause, almost to, particularly with more sensitive information, um, and obviously it’s more difficult to be very specific for the individual on an app ...but there are certain sensitive items that are more generic that they may not want to know about.

INT: Right okay. And do you, well how do you provide that information, is it, sort of, verbal, written information or ...

RES: So, um, verbal initially, but followed up with written information.

INT: Okay.

RES: Um, certainly when their therapy is going to be ongoing, um, er, or general cancer information leaflets [inaudible – 03.03] situation, bowel cancer leaflets and other cancers that I’m dealing with then.

INT: Yeah. And do you recommend any sources of information to patients?

RES: MacMillan Back-up, um, is generally the first port of call, I know it’s well worked, I get to review some of the stuff myself, so, um before it goes out.
Um, then we have, from Velindre, we have specific ones around the types of
treatment, er that we would deliver in sometimes non-surgical cancer care.

INT: Yeah.

RES: So that’s radiotherapy, chemotherapy etc. Um, so those are the probably
the core components yeah.

INT: Okay. Um, alright then, um, so what kinds of issues do you think clinicians
are faced with when talking to patients about their cancer?

RES: Um, the clinicians, er, they have to deal with, um, I think, er, giving
information in a clear, understandable fashion, that is delivered in a timely
fashion to the patient, at a place that they can cope with.

INT: Yeah.

RES: And then tailoring that into information to the individual. So you are dealing
with very sensitive, very emotional, times for the patient, and knowing that,
er, individuals can take in that information in very different ways. Knowing
that when you are giving information, that actually the majority of what you
are saying is not going to be taken in first time around, and actually
repeating and going over things is, can be a very, er, important part of that.

INT: Yeah.

RES: But that’s where you’d see an app as support, that sort of, that component
for patients, I think. Or as written information can do for certain patients.

INT: Okay and what about in terms of the patient, um, do you think there’s any
barriers to communication, um, within the consultation, on the patients...

RES: Yes, I mean, I think certainly initially, er, the first barrier to communication
is the anxiety ...

INT: Yeah, and you’ve mentioned ...

RES: ... that the patient has.

INT: ... that they, sort of, don’t take it in.

RES: Yeah. Um, I think, er, we know through previous experience of interviews,
that most of what they take in, as soon as you mention the, and particularly
a new diagnosis, cancer, then that’s pretty much where the information
stops. And after that they get very little more from that initial consultation. That’s not to say you shouldn’t try and give them some more information; obviously other family members, and things, are often present and can take in a little bit more. Um, but I think, er, you know, that’s a huge issue to bear in mind.

INT: Yeah okay. Um, so do you have experience of using a smartphone or a tablet, um, personally or professionally?

RES: Um, personally, I mean, I have a smartphone, er, I have a tablet, I use them frequently for gaining information. I will even ...

INT: Is that personally?

RES: Personally and ...

INT: Yeah, ah both ...

RES: ... professionally.

INT: Yeah.

RES: Um, so personally definitely, professionally at certain times I do. Er, I think there are, er, certain apps I am not using at the moment that I have used before, er, which can give you information in terms of prognostic information that can stratify patients into different groups.

INT: Yeah.

RES: So you can, you can plug in certain, er non, er, named data for a patient and actually it will tell you what their risk of cancer recurrence is.

INT: Right okay.

RES: That sort of thing. So there are scoring systems for that which can be quite useful. And some of those produce images which can be quite useful for discussing with a patient as well. So you can actually look at the, er, at the 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 would have in terms of increasing that survival, and that will then, it can visually help discussing with the patient um, how that’s used. Again, I don’t use them at the moment, that’s because I don’t have a tablet like they use in clinic.
Right okay.

Um, but in theory there's things that the clinician could certainly use quite effectively.

Okay. So do you think if clinicians had access that this is something they might take up?

Yeah, no I think it, I think they would do, yeah.

Okay, um, alright then. Um, do you think patients would want to use, um, an app, um, the type of app we talked about?

Definitely a proportion of patients. I think there is, er, and I think it will increase as well. I think this is why it's timely, and you look at the, er, for want of a better word, younger generation, er, and they will almost inevitably, by the time they get to the median of where cancer's occurring ... obviously it can happen young, but the majority of cancers happen as you get older.

Yeah.

Er, will be in the scenario, in the technology world, where the app is standard, or an equivalent, there may be something beyond the app that will occur, where they will look to the app to try and answer questions. They will look to their smartphone to try and answer questions. Um, I think that having said that there is an older population at the moment who have adapted apps very effectively.

Yeah.

Er, and it is, they are generally very user friendly. There is a cohort of individuals, particularly the more mature group, who don't know what an app is. Er, and so I think there is a spectrum obviously.

Yeah. So would you say age is a barrier, or do you think [inaudible – 07:36] ...

Not age specifically. I think you've got this trend across the different ages which will, if you wanted to, sort of, put it statistically then they are less likely, er, than the younger group to use the app, yeah.
Okay, alright then. Um, and what about clinicians, do you think they'd mind patients using this app during a consultation?

Um, I think, er, there would a variety.

Yeah.

I think there are clinicians are wary of things ...that break up this scenario. There are, um, there were, there are, very sensibly I think, concerns about what information is on there, and the speed at which that information is given. Um, and the, and the utility for the individual. Um, so I think there are some sensible concerns, there are some blocking concerns, just because ...because people don’t want to change things. Um, they can potentially, obviously, slow down consultations, so then ...you make them longer.

Yeah.

Er, we have to bear that in mind. But I think in the end of you have a quality consultation, in the end it probably speeds things up overall. As well as improves the quality of that consultation.

Yeah okay. And what about outside of the consultation; do you think clinicians would mind patients using an app, sort of, without their supervision?

Um, I think, well I think if you are going to have an, er, then I think you have to be prepared for that. I mean, they can get this information off the internet generally speaking anyway. Um, what you have, the ability with an app is to give some control over that, because if you go to the internet and do a random search you will come up with a lot of misleading information ...a disinformation. Er, which patients find scary, because they are then confused by, er, the information given by the clinician, and they haven't, er, and it’s not necessarily true for their case.

Yeah.

Um, so I think we are, we are aware that happens anyway. If you have an app in which that information is more effectively controlled; both in terms of the type of information available but the speed at which that information will come through, er, then I think you have got a greater utility for that app to work.
Yeah okay. Um, and what about, um, relatives, because we are thinking perhaps the patient, um, isn’t keen to use the app, they may have a son or a daughter that might use it on behalf of them, do you think this is something they would like to use?

Yeah, no I think that would be a very, very good way of doing it, yeah.

Okay. And what benefits do you think there might be for patients using this type of app? I know this, sort of, depends on what features the app will have, but, um ... in general?

I think ...I mean, it does depend on the feature, I mean, I think there are, er, in one of the, er, a common scenario, let’s say, is when I see a patient, particularly in a new situation, or a changing situation, I am aware the information I will give, and the limited, sometimes limited information they will retain. But I encourage people to go away and think of questions and bring them back and write them down.

Right.

This will help augment that, so you could have things on an app that trace the sorts of things they wanted to look up. So that then when they go away, and they say right well I, when I got away from you I couldn’t quite remember what you said about this or you said this, and I was worried about that, so I looked it up.

Yeah.

And you can almost go back through the history of what they looked up, and actually retrace some of those questions.

Yeah.

And make sure the information on the app was clear, whether it related to them specifically or not.

Mm.

So you have an ability to use the app to track and store the information that the patient has actually tried to utilise and guide that then once they’ve actually looked it up, and see if it’s appropriate to them.
INT: Yeah okay. And, um, what about clinicians; what kinds of benefits do you think there might be for clinicians?

RES: Um, I mean, although the initial impression is that it will probably slow things down, I think overall it will speed things up. Um, I think overall it will create a much better relationship between the clinician and the patient and relatives. Er, I think communi… you know, the biggest problem in medical healthcare, generally speaking, is poor communication. It’s where something has been miscommunicated, or not effectively communicated, um, that leads then to anxiety, to medico-legal issues etc. So I think if you are clear about that information I think it will be a very positive outcome ...

INT: Yeah.

RES: … for clinicians as well.

INT: Exactly. Um, and just going back to the patients, we touched on some of the short-term benefits, do you think there are any longer term benefits, do you think this could affect patient outcomes...So you mentioned that perhaps it could reduce anxiety?

RES: Mm. So I think reducing anxiety is obviously a very clear one. I think you’ve got, you have a lot of patients now who have been cured with their treatment, whatever treatment that is. And actually they are then put into follow-up regimens. Now you could build in an app that did multiple different things; one, you could build in so that that patient understands what their standard follow-up pathway would be.

INT: Yeah.

RES: You could even build in things that go onto their calendar and say you will be due a colonoscopy in three years' time, a follow-up appointment in three months’ time. So that they take a bit of responsibility for their own care.

INT: Yeah.

RES: The NHS is, has got all its imperfections, and actually if the patient is in charge of their own care and is able to augment that by saying actually I should have been this, that or the other, and for some reason it’s gone missing, they can really help.

INT: Yeah.
Um, it also has the ability to link in then with, you know, making sure you come to appointments even.

Yeah, yeah.

Making them understand why that happens. I know in other hospitals, not on an app, so to say, but actually people have the availability in certain hospitals in the UK to actually access online their actual clinical data. So they can look up their tumour marker result, for instance if that’s part of their follow-up.

Yeah.

And actually they can then flag any issues if they are concerned about it. Now as long as they are well informed as far as that’s concerned I don’t have any fears about that. They will know, they might even get their CT scan result that they can get downloaded from the computer. So an app could actually, potentially, be integrated with that in the long-term as well. So very much personalising their information. Which over a longer period of time, er, will help engage their, them as an individual in the process of their care.

So do you think this app has a place, um, sort of, post-treatment then?

Yeah.

Do you think it could help them?

I think so, yeah.

Okay, um, alright then. And we talked about, you said, um, perhaps it could improve the relationship with the clinicians.

Mm.

Um, so do you think the app would have an impact on communication with your patients?

Yeah. So I think there may be, the app, um, can be introduced, obviously, at various different stages, but certainly prior to the second visit, if they download the app and they have been on to answer those, ask those questions, they will be able to, you know, certain things might be, common questions that are asked. The frequent, you know, the facts, the frequently
asked questions, they may want to go through those before they then come back and see you second time, or even, or the first time.

INT: Yeah, yeah.

RES: Because if it’s a well-known app then the carer, the relative, the son, the daughter or the individual may well have downloaded it. And said right I am going to see them, I know it’s going to be something about bowel cancer, because they had a look and they said there was a lump, and they thought it was going to be a cancer. Well look, I have looked up these questions, and actually that will, like, help guide them when they actually come to that assessment.

INT: Yeah.

RES: And help aid them in that process.

INT: Yeah okay. And do you think the app would have an impact on how patients and their family share information?

RES: Yeah, well I think again, if there is more commonality in terms of the information that’s given then actually if son A in Australia has the app, and, um, the individual has the app also then they have looked up the same consistent information. And the consistency of information is important, as I say, the difficulty is you have one family member that looks it up on the internet, has slightly the wrong information, and gets a very differently outlook the disease. Compared to people looking up on the same information sites, and therefore being consistent in terms of how they are discussing things and that will improve family communication, which is a very positive outcome.

INT: Yeah okay. And do you see any problems with patients using this app; were there any barriers that you can see?

RES: Those who don’t want to engage in technology.

INT: Yeah.

RES: So you miss a cohort of people as far as that’s concerned. I think it’s technically a very difficult thing to do well. Um, it’s, it can be done, er, very superficially, or it can be done in-depth. Um, there could be potentially a huge amount of work engaged in it, if you want to take it and build on it,
but I, you know, the first steps I think you need to take are fairly simple
and that's things like frequently asked questions, things that lead them to
websites that would actually give them additional information. Um, things
that lead them to, er, places or persons that actually can be of help to them.
Um, whether that be ensuring that somebody with an incurable disease is
referred through palliative care, and what palliative care consists of, and
what local facilities for palliative care there are.

INT: Yeah.

RES: Um, or, er, more specific information about treatment that's going to be
potentially required.

INT: Yeah okay. Um, and do you feel that patients using this app would affect
your workload in any way?

RES: Um, I think, er, it does depend; I think there are certain patients who will
want to scroll through the app consistently through the, um, through the
consultation and you have got to be a little bit cautious of that. One, that
they are actually paying attention to the answers you are giving, rather than
just the app. But I think it could be a support, certainly a supporting tool.
Um, I think overall it’s got potential to improve the time management, as
opposed to be detrimental to it.

INT: Yeah.

RES: But I think there are probably some short-term losses and some long-term
gains.

INT: Yeah okay. Um, do you feel that clinicians might require extra training in
how to deal with perhaps more active patients as a result of the app, if they
are asking questions?

RES: Um, I think, I think we should, I think it’s not specific to the app, I think,
um, we are getting increasingly, without necessarily any training,
increasingly aware of the cohort patients who will go out, look up everything
on the internet, bring in the information to you in reams of documents and
things.

INT: Yeah.
Or say do you know about this or this, etc., etc. So we are getting used to that anyway. Having said that, I don’t think it’s a bad idea that clinicians are continually updated in terms of what’s available, er, and how individual patients are managing this. So I think there is very limited research to say how we should deal with it, we deal with it because we are used to dealing with communication with a, with a broad spectrum of patients but actually there may be specifics, er, related to patients who are very proactive in seeking things on the internet, alternative therapies, for instance, as well, for which better training for doctors would be useful. But we haven’t got the evidence base to say whether that would help or not. But you, you could certainly another piece of research would be to look at that sort of issue.

And what about, um, training on the app, do you think it might be a good idea, um, to have clinicians just trained in, you know, this is what the app...

Yeah.

... does, do you think ...

I think ...

... that would be useful?

... I think that’s very, very useful. And, er, cancer clinicians, I think, particularly oncologists, are aware of things like websites such as MacMillan Back-up and things like that, Cancer Research UK. Um, not all are, and I think if an app was to become fairly standard, then actually knowing about that information would be good.

Yeah.

We are generally used to what's contained in our information leaflets. Er, but actually this would expand beyond that and, er, it would be helpful to have some sort of training in it absolutely. Most of it hopefully would be fairly simple, so it maybe the app itself you can train just by downloading the app and having a look at it.

Yeah, yeah.

And it would tell you what it’s about, the sort of information ...
A tutorial.

... that's on it. Absolutely.

Yeah okay. Alright so what sorts of app features do you think would be most useful for patients? I mean, other than the ones we've talked about.

Um, again it depends on the spectrum that you wish this app to, sort of, link into in the end.

Yeah, yeah.

So you’ve got everything from the, er, the more generic information about what, er, what the cancer is, that particular cancer type, what it means, what the types of treatment are, um, down to things that are local level, so bring them as local as possible. So you might say, you know, your treatment is likely to be given in Velindre, if it's this type of cancer. Or it might be, it might be it is likely to be given in your local hospital, er, down to that whole specific information. It links, as I say, with palliative care.

Yeah.

Contact, er, financial support that’s locally available, for instance. Transport links, and how you ...

Sort of, addressing ...

... what if there's an ambulance issue and you haven't got a car, how do you go about doing that, so logistical things which are a bit more specific, and then you can move on all the way down to the other end of the spectrum, which again, as I said before, is you could use the app, potentially, to link to their personal information in a secure fashion. That actually they would log on to their computer notes, they would log on to their results. Er, they would, er, download specific timetabling of when their appointments should be.

Yeah, yeah.

Um, and I think those could take it, you know, to that extreme, I would say.

Okay. And what about, um, for relatives and friends, do you think there are any app features that would be useful for them, if they're any different from the patient?
Yeah I think there are, I think there are; I think the relatives' perspective is often very different to the individual. Um, relatives will often feel that, strangely enough, relatives often feel more stressed than some of the patients, because they feel useless, they feel they can’t do anything. I think where one, an appreciation of the perspective of the relative, um, an appreciation of their optimal interaction with the patient, generally speaking, so actually talking about things is not necessarily a bad thing. Things like, particularly with more advanced disease, where things like appetite become an issue.

Mhm.

Often things, family get very stressed about how much the individual is eating. Whereas the person with the anorexia just doesn't feel like eating anything, and the anxieties that raise then between family members, both meaning very well but actually not fully appreciating or understanding where the other person is coming from, and information like that would probably help with their interaction much more effectively.

Yeah.

I think there are support networks which, er, could be more specific to patients as well, so the ability, the knowledge that as a relative or a carer they are actually talking with things like palliative care teams is actually still very relevant.

Yeah.

The palliative care team is for the whole unit and if your palliative care team can help, er, the carer that will help the individual, and that’s the whole process which is important. So I think that will, that it can certainly help.

Yeah.

Um, I thought of something else for relatives as well, but they are probably the main things I can think of at the moment.

Yeah okay. Um, and is there anything that you would want the app to do, as a clinician?

Um, I think it would be nice to know if it, if the patient wishes you to do so, um, the sorts of things that patients are looking up.
INT: Yeah right.

RES: I think it would be nice to have feedback from the app, to say right what sorts of things are happening, I think, er, you could also use the app more effectively in the future. I mean, in Wales as a whole, but in Velindre probably more specifically, we do a lot of trying to get patient feedback.

INT: Yeah, yeah.

RES: So there may be questionnaires about satisfaction, er there may be them being able to raise issues that they are concerned about. Um, that could be hugely powerful in terms of us trying to adapt our service to a more effective system in the future. So I think that’s, you know, it adds potentially great value to that sort of thing.

INT: Okay, that’s interesting. Um, and is there anything that you wouldn’t want the app to do, that you wouldn’t feel comfortable with it doing?

RES: Um, no I think, I think in the right context you can deal with most things. I think there are, I can see how some clinicians would have concerns. So you look at the situation in England at the moment with regard to surgical outcomes, and, sort of, this slightly, er, which you can do anywhere on the web, is try and find out what, you know, how many operations your surgeon has done of that particular type, etc. I think they are still good things to do, but I can see there are anxieties, um, from clinicians that may be, er, slightly problematic in terms of the depth at which such an app would go to.

INT: Yeah okay. Um, and so the last question, er, are there any particular types of patient that you think might find this app useful; do you think there is a niche, perhaps, along the cancer pathway for this app? Or do you think that it could be suitable ...

RES: I think it could be suitable for all; I don’t think there is any ...

INT: Because you mentioned that ...

RES: ... routes.

INT: ... with treatment it could be, so ...

RES: Yeah.

INT: ... do you think that ...?
So I don’t think there are any groups that it shouldn’t be considered for.

Yeah, okay that’s great. Do you have anything else you would like to add?

Um, so the only other thing I would add is just in terms of what other things are happening elsewhere for ... you develop an app, and you have basically got to pool things together. So I know there is work going on, er, for instance, for toxicity assessment apps. So, um, let’s say we are routinely giving a course of chemotherapy, let’s say over six months.

Then each week, every second week, or third week, somebody has to come in, and then they are seen by the clinician or the non-medical prescriber. They go over their list of side effects from previous treatment, then, er, then adaptations are made. You would have the potential facility within this to, er, link to the same app there, where what is actually happening, patients, before they come to clinic, are answering a fairly standard group of questions, which is then available to be recorded on their notes. You could then look at the trend in changes of toxicity; so if you can see certain things are accumulating in terms of significant problems, it might be much more effective in terms of raising concerns about the next cycle of treatment.

And therefore reduce, not only morbidity, but potentially mortalities, because patients can die of treatment. But if you can flag things at an earlier time point by tracking them in detail, using the... the patient, then I think that’s got potential ...

Has that ...

... safety issues.

... [Inaudible – 25:25] evaluations of, um, toxicity actually? Are they the ones you are referring to, have you come across them?

Yeah.

Yeah, yeah. So I am aware of this, it’s really interesting, yeah.

You can also look at toxicities, sort of, late outputs as well; so when we give, I mean, I give radiotherapy to the pelvis, and radio... to the pelvis, when we
use it it can be palliative, but for a lot of the patients it’s for curative treatment.

INT: Oh yeah.

RES: And we follow up people for a period of time. But some toxicities can come quite late, so actually the ability to link into some of those other things from patients, even when they are discharged and see where help can be sought, whether their symptoms are expected, whether there’s anything can be done about them. Those ...those sorts of things might be helpful in the future as well. So survivorship issues I think are important.

INT: Yeah.

RES: One of the important things we are beginning to look at in terms of clinical research, and clinical care, is a think called patient reported outcome measures, or PROMs.

INT: Yeah, yeah.

RES: And so you would have some ability to look at those more effectively as well.

INT: Yeah. And what sort of PROMs would you suggest might be helpful for us...

RES: Well that’s the whole difficulty about PROMs, so to get a good PROMs data-set you need a, you know, quite an extensive analysis to actually hone those down which consists of interviewing numbers of patients and clinicians, and, um, er, nurse specialists etc. So, er, and certainly it comes down to be fairly disease specific, fairly treatment specific.

INT: Yeah.

RES: But in the context of, let’s say, pelvic disease it’s going to be things like incontinence, urinary incontinence, bowel incontinence, pelvic pain, buttok pain, er, these are things that are commonly flagged by patients as a concern. Um, and ...

INT: And what about psychological PROMs?

RES: Yeah, and they are important as well; so emotional anxieties ...all of those issues, the ability to interact socially, er ...a very important patient reported outcome measure potentially as well.
Okay. Um, and I just quickly wanted to ask you, because you are an oncologist, do you think you have any, sort of, different perspective on this app compared to a surgeon? Do you think there is anything that you would want the app to do that ...?

I think we are, we are becoming increasingly multi-disciplinary in terms of understanding what one another do. But I am sure we will have different contexts in terms of what we would expect it to do. I suspect, as an oncologist, we are probably more broad reaching than some of our other colleagues in terms of what we would anticipate from it. Um, but no, I mean, I think it's, er ...

You seem to have touched onto ...

... generic [unclear – 27:44] (speaking together)

... the same issues. I am just, I am just trying to pick up if there is anything that you, sort of, view differently to a surgeon, as an oncologist?

I think my, er, I suppose you could flag there are things, er, and the instant thing is that ability to track somebody's toxicity over the period of treatment.

Right, okay yeah.

You know, most surgical treatments are as treatment would cover. Um, you do want some follow-up data, or you want some data that says actually you've got chronic abdominal pain after your surgery then that's useful.

So perhaps we could incorporate, you know, a feature that it might be useful to incorporate.

Yeah.

Okay that's great, thank you.

Thanks.

End of Interview. Duration 29:00.
I – okay, so firstly could you tell me why you’re interested in taking part in this study?

DS230135.M – always happy to help with research and I think any patient information is under studied, probably not that well addressed with a lot of new technology we should be able to use it better and there’s lots of sources that we should be able to put together to help people ask the right questions, not just rely on what’s said during consultation perhaps be supported better with other media that would be good

I – okay and so in your consultations how do you decide how much information you give to patients about their illness?

DS230135.M – um, mainly it’s led by the patient um, sometimes by the relative, the family whoever is attending with them as well

I – so they could decide how much they’d like?

DS230135.M – yeah I mean in general our patient group, breast cancer um, is most patients want most information so we go with the premise that we’ve got to have time to give information, if the balance you know um, is not overwhelming important information

I – okay

DS230135.M – we have to answer questions that people want answered not just, some of it you’ve got there is information that you have to give, you’ve got to give for safety reasons and stuff, but mainly it’s let by the patient

I – by the patient, okay and how do you provide that information is it verbal, written or a combination?
I - and do you recommend any sources of information to patients like helplines, or charities?

DS230135.M – yes, I mean we have, so I think the information that we give does have some....I think some of the recent information sheets to recommend, do mention that you can get extra information from the <hospital> intranet which has recently re-launched, um and we, I know that patients come because we’re not seeing patients we’re not the first people to see them, so they’ve had information, they’ve had sorts of information, often breast cancer care, and information sheets and we have 2 sources that we generally say to trust because they’re relevant they’re proportional, they quite well written that’s Breast Cancer Care and McMillan but we offer, like we do give people information about Tenovus, but that’s more um, but that’s more for counselling and help with benefits and stuff like that

I – okay

DS230135.M – and we’re aware that a lot, you know some information out there, sometimes that’s daunting rather than helpful we signpost generally to McMillan or Breast Cancer Care and a lot of information in all the places is quite similar it’s been adapted, people have shared it around and adapted it

I – yeah, alright then and what kind of issues do you think that clinicians are faced with when talking to patients about their illness in consultations?

DS230135.M – well um, well I guess there are, there are different agendas there’s what the patient wants to know and there are things that you feel that need to be said, that maybe as we said for safety, also for moving the treatment plan forward, so there’s a bit of pressure of time to get it all, to get it all done in the time that you’ve got and, and not spend too much time, that you’ve got too much information and they can’t take it in
I – yeah

DS230135.M – and what’s the bit I’m not sure I’ve answered your question?

I – uh yeah, yeah what kinds of issues do you think clinicians are facing, so other things that clinicians have said, or you know there’s too much information patients hear the word cancer and then they you know it goes over their head, or they’re in an anxious state coming in...

DS230135.M – yeah, so yeah and often there’s also the complex, or differences between what the patient may want, the amount that the patient may want to know and can take in, and there’s the needs of the partner, there which may be quite different, and though one is there for the patient primarily obviously the family have an impact and that can drive you as a clinician, it’s unfair to leave them without some guidance, I mean we do a lot of it by staging because we can do a certain amount and then we tend to reinforce, we have multiple visits usually

I – right okay

DS230135.M – so we can reinforce it and then there’s multi-professional teams there’s usually a nurse specialist involved who may not, maybe more than one and then maybe in, in each of the times, but they’re always there for, there’s other people you know to ask questions

I – okay and what about experience of these sorts of devices. Do you have any experience of using a Smartphone or a Tablet or computer personally or professionally?

DS230135.M – personally yeah, yes very
I - and is it a mobile or a tablet or both

DS230135.M - both

I - both yeah

DS230135.M – as little as possible

I - okay ((laughs))

DS230135.M – professionally….hmm with patients, no but I’ve considered trying to get hold and I think if there was better information um, especially visual information, perhaps I think tablets would be excellent, but I haven’t pursued that much because the visual information isn’t great, the provision of information out there isn’t great, so a lot of people like to, often a picture is better than…

I – right okay yes, so that’s what I was going to say what would you use the tablet for with the patients?

DS230135.M – well I think in a consultation you could use it to show things, ((rummages in bag)) things like this, and this is not really relevant to us cos it’s from an app this is from bowel cancer type things, but um you can show anatomy which is, for some things it’s quite helpful, um, and you might be able to show imaging, if you know if you could show their scans and stuff on a tablet it might be a lot easier, because we do often try to show it on the screen on the desktop screen, but that’s a bit cumbersome and it’s not, I feel it’s not great, it’s nothing to point at…

I – yeah, yeah

DS230135.M – so that would be quite useful um, and you could show figures like survivor and risk information. I do show that to people
that might, that might be friendlier if it’s in front of them like that
and then potentially if you could take that away in an electronic form
and then the patients could sit and think about it, rather than having
it flash up on the screen and then take a slightly black and white
dodgy printed version of it if they really wanted to

I – so you’ve mentioned that it might be friendlier, can you just
explain what you mean by that? It could be friendlier on a tablet
for the patient compared to looking at a computer?

DS230135.M – well um, because if you’ve got it on your lap you’ve
got control of it, and you, it’s I don’t know ((laughs))

I – ((laughs))

DS230135.M – I don’t know, it’s just, yeah what’s the word the
ergonomics of it, you can see it better and you can focus in, because
if you’re leaning over somebody’s desk it’s, it can be, you might find it
difficult to see, let alone feel that it’s yours, and then you could take
it away couldn’t you into another room and have a look at it and have
it on in the car

I – hmm that’s brilliant that’s a good point. Okay so that’s
interesting. So you are familiar with apps and you don’t use any for
work, okay

DS230135.M – no, not for....

I - patients?

DS230135.M – yeah not for patients, educational and stuff

I – educational and stuff, and what sorts of things have you used?
DS230135.M – well sometimes at the meetings, I’ll tape stuff and that, but I do look at journals and stuff. I do use apps for practical stuff like converting weights and stuff like that...and they’re very useful for managing diaries and stuff like that um...if you’re looking at protocols sometimes and you can just surf, just looking on the internet sometimes, but not actually showing to patients I don’t, no, I don’t.

I - okay alright so the type of app we’ve talked about, do you think patients would want to use that type of app?

DS230135.M - well obviously some would, and some wouldn’t yeah

I – okay so could you just elaborate a bit on that

DS230135.M - I mean there’s

I – who could you imagine would use it, and who might not use it?

DS230135.M – I mean sweeping statements like that, I imagine that younger people who and we do have quite a significant uh percentage of our patients maybe under 50 um, I imagine that they generally most people would have a smart phone and they would be used to using apps, um, I think those people would want that kind of information but it’s whether the technology would be something that they would be able to use comfortable with, but maybe, you know if you took in people and their families then that would probably be lots of people, most people would come with somebody because you know at that sort of age

I – okay so you think maybe...relatives and friends could use it?

DS230135.M – yeah
I – well that was my next question ((laughs))

I – yeah, if they have a younger daughter or son

DS230135.M – you know I hadn’t thought

DS230135.M – yeah I mean most people would come with somebody who’s in an age group who’s comfortable with technology

DS230135.M – yeah, if they have a younger daughter or son

DS230135.M – yeah I mean most people would come with somebody who’s in an age group who’s comfortable with technology

DS230135.M – yeah okay and what about clinicians, do you think they would mind patients using the app during consultations?

DS230135.M – I would be happy, I can’t…yeah

DS230135.M – I would be happy, I can’t…yeah

DS230135.M – I think er, I mean it’s a bit irritating when people are using their phones and texting and stuff, but I think as long as people realise, it’s for, it’s just like having it written on a piece of paper isn’t it?

DS230135.M – I think er, I mean it’s a bit irritating when people are using their phones and texting and stuff, but I think as long as people realise, it’s for, it’s just like having it written on a piece of paper isn’t it?

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I – okay and do patients come in with a list of questions?

DS230135.M –yeah, yeah

DS230135.M – yeah, yeah

DS230135.M – they come in with their spiral notebooks and things like that

DS230135.M – they come in with their spiral notebooks and things like that

DS230135.M – they come in with their spiral notebooks and things like that
I – ((laughs)) how do you find that in terms of communication? Do you find that, that can be a bit distracting for them, or do you feel okay with that?

DS230135.M – no I think that’s usually healthy and helpful because it means that you know they, they remember the things that they wanted to ask and get a chance to go through...

I – okay, so you might think that there might be a different attitude if someone was doing that on a mobile?

DS230135.M – no because as long as that, it was if they only did that....

I – and they weren’t calling people up

DS230135.M – yeah okay, getting multiple texts during the consultation, it’s more likely to be people, like sat next to the patient rather than themselves, it can be you know it’s a bit distracting and the boundaries, peoples’ boundaries are quite different aren’t they?

I – yeah, and what about....

DS230135.M – it’s a generational thing isn’t it...

I - and what about at home do you think clinicians would be happy for patients to use it at home?

DS230135.M – yes of course
I – okay, so what benefits do you think there might be for patients using this sort of app, I know it’s difficult because we don’t know exactly what the app will to do at the moment.

DS230135.M – it’ll give a framework wouldn’t it for helping um helping people to cover the right sort of domains and questions, um, and to give um, help people to consider all the things that they might want information about, and um, and obviously then to prioritise and personalise things that they want to know and things they specifically want to know and then, you know like bits of paper is to me to help them to remember and to recall. I don’t know how easy it would be to record the answers that you’ve got, but that’s a disadvantage isn’t it? I think it’s you know probably quicker for me anyway it’s quicker to write it on a piece of paper than it is to try and type something in.

I - yeah, yeah that’s true.

DS230135.M – but I mean would this be personal an app on their personal device?

I – yes I think so yes.

DS230135.M – so.

I – so maybe it might be easier for them to record it.

DS230135.M – yeah you could record, but I mean in the other way, I don’t know, a bit like you can do with apps that children have, whether it would help for it to explore, or maybe to be probed to see what information has been looked at you know what I mean?

I – yes so...
DS230135.M – so the clinician or the team could see what information the patients have been, not to sort of spy on them, you know to

I –ah okay, yeah to get a feel for what information the patients want

DS230135.M – yeah and maybe how much they’ve accessed and...um yeah cos word, yeah I guess the main benefit from anything electronic you can link, you can link to, it’s easier to signpost and link to other electronic resources then rather than....and that might break down the barriers for some people who, you know aren’t used to that kind of thing, if it’s got an easy interface and they go well you know click on this bit here to find out about information about McMillan then that’s quite, if it’s quite simple and accessible then that’s...

I – okay, and what about the long, do you think there would be any long term benefits?

DS230135.M – well generally if people are better informed then usually it’s better for everybody, if they want to be, as informed as they want to, it usually makes communication much better and people ask about questions and yeah...

I – okay, you just mentioned a lot of similarities that people bringing in pieces of paper, can you think of any advantages that this app might have over patients bringing in bits of paper or...

DS230135.M – well it would be hard,...you should be able to safeguard the information better because it could get lost, and you could share it eas...more easily couldn’t you with your um, with your relatives and yeah, if you could, yeah

I – would you be able to share, do you think it’s more accessible or?
DS230135.M – yeah I would imagine it is...

I - what they could download the app, I’m not sure

DS230135.M – yeah I don’t know, I know from personal experience you know when your family go to see somebody it’s quite common now for them they’ll send you the information about it in an email you know or something like that...so you’re sending out you know give you the option and you could share it with your family without having to....

I – so they get

DS230135.M – and they could get the details from the information, rather than having to...yes so direct rather than to be um, sort of translated from the patient and they don’t want to keep talking about it and they can sent that

I – yeah okay

DS230135.M – but that’s if what the information is personalised to them you know exactly rather than just more general information about their condition

I – okay and what about, yes and we said that family and friends might want to use this kind of app, but what benefits do you think there might be for clinicians if patients are using an app?

DS230135.M – well yeah I think, it would help people to focus about what they want, they could do some preparation for consultation um, because it could guide people, I mean there is information for people out there, I know McMillan do a good leaflet about questions you should ask your cancer specialist, something like that but you know if we gave everybody all these leaflets....
I – we’d just have...

DS230135.M – you’d have to have a suitcase for some, where as if they had a bit more, if bits of those were taken into the app so it’s a bit more personalised, it’s got the relevant bits of each thing I suppose clinicians could set up you know an information prescription I mean you could have a set prescription for each of your types of patients I think that could go onto the apps that could be quite adaptable you know some could have the basic bits and then bits tailored for this, bits tailored for that uh you could tailor it for your patient

I – and what about communication, you said earlier you think “it could improve communication”

*End of part 1 of recording*

*Part two of recording*

DS240136.P2.M - I mean what we found from and this is anecdotally um, with any qualitative research but when we done a pilot here in our team of doing copy letters, so copying clinical letters to the patient, so that, I mean in my experience doing that I found was very helpful in uh, improving the accuracy of what was in them and also helping people to focus on sort of the information they wanted and asking about peer questions, some of it was already answered, you know some of it didn’t need to be questioned because the reminders or prompts were in the letter cos I think that this could work really well if it, if you could tailor it exactly, you know to that person and their condition and you could um, yeah, then it would be such good backup so they wouldn’t have to remember everything, it would take some of the pressure of as well so you could have a more, the consultation is, can be overwhelmed by information giving, it can be more of an exchange then if they haven’t got that pressure thinking they’ve got to try and remember everything

I – okay, yeah so they can sort of focus more on the discussion rather than try to take everything down?

DS240136.P2.M - yeah
I – okay, and what about communication and their families? Do you think an app would have an impact on how they talk about their illness and share information? I mean you’ve already said “it’s easier to sort of send the information to your family” So do you think it might improve, or hinder it?

DS240136.P2.M – yeah I think it might, yeah I think it could be much more open then

I – okay

DS240136.P2.M – I’m sure it won’t... it’ll have downsides for some people but it would be much, it would be much more open...

I – and what do you mean?

DS240136.P2.M – ...and accurate, and then the information that the relatives, second hand information would be more accurate wouldn’t it? Because that’s where some of the...

I - okay, what about for some people, you said, “it might not be useful”

DS240136.P2.M – well I think it’s, it’s good for transparency and openness and if you’re um, if you’ve got difficulty accepting some of what you’re told and you don’t believe it applies to you exactly and then you, and then you want um, then you might, say you disagree with the information, then I guess you might feel that you don’t want to pass it on to your family and then... “don’t pass any of it on, because I don’t want them to see that because that says stuff I don’t want them to know” it would be much more complicated wouldn’t it to, to sort of partition information rather than, you would have less control over what information they’ve got potentially. I think that would worry some people, some people don’t like electronic transmissions cos they think it can be got at, also that kind’ve...it’s like sending one of those emails you accidently send it to somebody and you realise that you’ve put somebody in, you’ve copied in and you didn’t really, you know once it’s out there it’s sort of....
I – yeah, so the confidentiality of freedom of information is something...

DS240136.P2.M – yeah, it’s more about sharing things you didn’t necessarily authorise, if you wanted more control over saying it and you end up just sending it out

I – yeah, okay and what about the barriers of the app, do you think there maybe any barriers to patients using this, what do you think the problems might be?

DS240136.P2.M – well I think some people just won’t, it won’t, it just won’t um appeal to them

I – yeah and you mentioned like the older, people who are less...

DS240136.P2.M – yeah I think if people who aren’t used to that sort of technology will take a lot of persuading um, I think that would be the main barrier, obviously assuming it’s, it’s, well designed and easy to use, and it’s, you know it depends on the quality of the info and stuff won’t it?

I – yeah, yeah of course yeah. Okay then do you feel that clinicians would need extra training on how to deal with more active patients, or the change in communication because of the app?

((door opens interrupted by a female))

DS240136.P2.M – I’m quite used to, I think we’re very used to active participation that’s what, yeah, I think although it’s easy to be a bit nervous of it, generally...

I – and you mentioned that patient bringing sort of paper....

DS240136.P2.M – it’s actually better yeah, yeah

I – and what about app features, so what sort of app features would be most useful for patients. I mean you’ve already mentioned diagrams and scans and things like that, is there anything else that
you think the app could do? Apart from like the question prompt list that we mentioned?

DS240136.P2.M – well I think good links, linking it well to other, to other sources um, I think I’d want to see it before...

I – I know it’s hard to imagine isn’t it because they can do so many things

DS240136.P2.M – yeah I think if you’re tempted to try and do a lot, it might be better to not, stay fairly simple

I - yeah and concentrate on one or two things

DS240136.P2.M – yeah um, yeah I think that would be better to start with, that would be wise, otherwise it might be a bit daunting

I – yeah, and what about the relatives and friends are there anything, any features for them that would be useful for them?

DS240136.P2.M – well I supp… there might be some information you can signpost I would say, like um, I don’t know, because there will be support, there’s a lot of support for patients, that’s sort of embedded in the system, but whether, it’s more difficult to support the families and stuff uh, you know there is such specific support from various places and the information for people you know, young people affected by cancer and their relatives and stuff like that and um, like I guess that would be generic that would be… unless the apps could be how old you are and stuff like that couldn’t it… so it could be tailored from some of those, whether you’re a man or a woman and anything else, you’d need to know really, yeah so it could help with the more, broader stuff that’s available

I - okay well… and then tailor it...

DS240136.P2.M – …so the relatives could have a broader menu, for more general support whereas the patient would be more focused on exactly on what’s going on, it’s got to be better than going to, just having the information essentially in leaflets people don’t really like going into and….it’s so much readily available isn’t it? You can carry
it around with you and you can sit doing it when you’re in the waiting room which is, you know hours and hours and hours patients journey is waiting in the waiting area which you could, and people don’t get up and look at leaflets it’s just...

I – if it’s already...

DS240136.P2.M – especially younger people they could be just looking at their phone, it would be, I think it’s an opportunity to do that

I – okay and what about.....

DS240136.P2.M – I’m sure if you ask other people they’d say stuff like “we should think of fundraising” and do other things on the website and forums and stuff like that

I – yeah okay, and what about as a clinician, is there anything that you would like the app to do? I mean apart from the diagrams and things....

DS240136.P2.M – I think it would be good to...

I – you know is there anything....

DS240136.P2.M – it would be really good if you could you know add extra things for this patient and stuff like that

I – yeah, it could really tailor it

DS240136.P2.M – you’d really be able to tailor it, I don’t know how you’d do that (laughs))

I - okay, yes

DS240136.P2.M – um, you could send information to it

I – yeah, so you could link it to the computers
DS240136.P2.M – yeah, and as I said I think it would be quite interesting to see if you could, with permission, pull out how much it had been used and in what way, so you could have an idea of how much of the information needs to be covered.

I - and is there anything you wouldn’t like the app to do? That you wouldn’t feel comfortable with?

DS240136.P2.M – um, well I don’t know how it’s being partnered and that, but I think um, I think, I don’t know whether, I suspect the patients wouldn’t like, I don’t think it should have any advertising.

I – oh yeah, yeah

DS240136.P2.M – and it shouldn’t, you need to be um, definitely try to avoid, um, uh industry sponsored information, cos a lot, you know there’s a lot of armoured sponsored information out there which may not be that independent, so I would say stuff like that.

I – yeah, yeah okay

DS240136.P2.M – having said, they’re often the best looking information cos it’s um, it’s where the money is. You know, some of the information, it can’t hurt, information is power, it can’t hurt, it’s all out there anyway isn’t it...it’s not...yeah, what could it have? Things like...you could do a lot couldn’t you, you could have things like um, uh ((whispers to himself)) I mean because people have been trying to work on things, apps like to capture stuff like diaries for digitising your treatment, what would the side effects be and stuff like that there is a study that we’re trying to run that does have a tablet and stuff on that, we haven’t got any patients, uh but I think that’s a different thing I think that would be confusing, trying to do too much at once. I mean what about having a....I don’t know you could always have like a diary, but I think that’s getting a bit to, trying to do too much isn’t it? Yeah but it would be good if it had a little place where patients could add little, could add free text so you know...you could have remember to do such and such a thing and that sort of thing.
I – yeah okay, so like a diary option

DS240136.P2.M – and maybe, you know if we were doing copy letters there’s gonna be this portal at sometime my clinical, where you would be able to log on and look at your own information but whether you could, with all the permissions and the nightmare of all that sort of stuff, email information to, you know send information to the app for that page, for the letters, and stuff, whether that’s possible, that might, that would be really, that would be really powerful at some point, probably not in the first generation

I – yeah, yeah okay and what about, the last question is are there any particular types of patient that you think might find this most useful and at what sort of stage along the cancer pathway do you think it would be useful, if there was one specific? I mean you already said sort of “those who are more familiar with the technology a bit younger”

DS240136.P2.M – I don’t see why it couldn’t start really, you know right, really, really early, I mean that’s not...imagine if you’ve got a breast lump you go to your breast clinic....

I – ... thinking you know this app would be after diagnosis, you know so they can get their head around it and then they could start using the app

DS240136.P2.M – before, it would be good, yeah, I don’t know, I think it could work, it could be used as early as possible

I - really?

DS240136.P2.M – yeah, it would have to be you’d have to open up new stages, keep opening up new parts of the information as you went along, you know download, a download could be

I – so a staged approach?

DS240136.P2.M – I have a breast cancer, a bit of information, and Then, that would be a good thing about it, it could be chunks rather than having too much at once
I - so sort of paced you know

DS240136.P2.M - yeah

I – okay and what about the follow-up? Do you think it would be useful for patients who have been treated?

DS240136.P2.M – yeah...

I – and then they’re discharged

DS240136.P2.M – or if they’re being followed-up which is not very you know, yeah I think that would be excel....that would be particularly helpful actually I hadn’t thought about that, um, yeah so there’s lifestyle, lots of patient type stuff that you can pick up, but also then uh, yeah how to, what things to be concerned about. So I think as a reference it would be really helpful really to have a reference, so if it could, you know if it could send stuff like a document of your personalised treatment plan which could mirror your developing....and they’re doing work in this area?

I – McMillan? Yeah there is a well, I’m not sure if there’s an app, there’s a follow-up project going on in <hospital>

DS240136.P2.M – yes that’s what I was thinking, that’s an app isn’t it?

I – yeah well I think it’s the same one

DS240136.P2.M – that would be the sort of follow-up

I – yeah and they do like a holistic needs assessment and that sort of thing so yeah

DS240136.P2.M – I know McMillan are very keen on this information prescriptions, I don't know, I mean this was, that was quite a few years ago, that was a few years ago I don't know if....
I - okay is there anything else you’d like to add?

DS240136.P2.M – it would have to, yeah, I mean it would be great thing to have um, but obviously it would have to be ongo...it would have to have an ongoing management of it...wouldn’t it?

I – yes, sort of keeping it up to date, keeping it relevant you know

DS240136.P2.M – cos that’s always an issue isn’t it?

I - yeah, yeah, yeah okay well that’s great thank you

End of Interview. Duration 34:00.
Appendix 29: transcript for C1 (Onc) (gynaecological cancer)

1 I – okay, so firstly could you tell me why you’re interested in taking part in this study
2
3 DS240139.F – well I think anything that um gives a patient more information in an understandable format is helpful because some of them come to clinic with very little understanding of what’s being said and I think for some patients a lot of them I don’t think would engage with much information even before they come to see us, certainly some of the older patients, but a lot of the younger ones are more motivated to try and find out as much as they can, or their families are motivated to find out as much as they can, so if there was something that would signpost them, to help them guide through all of the evidence that is out there, which is not all helpful on the internet I think that’s worthwhile

18 I – yeah, yeah okay and with your patients do you see mainly younger or older patients, or is it a mix?

22 DS240139.F – It’s a mix, you know it’s an absolute mix

25 I – yeah okay, okay so in terms of information how do you decide on how much information you give to patients about their illness?

29 DS240139.F – I always start with new patients by first asking them what they understand about coming to see us in <hospital> so that, I give the opportunity to say even if they understand that they’ve got cancer because some of them turn up and deny all knowledge of even been told that they’ve got cancer

36 I – oh really

39 DS240139.F – so therefore you have to always gauge the conversation by what they know before they even come in so if you have somebody who comes in and says “I know I’ve got cancer and it’s affecting this, this and this, and I’m looking at chemotherapy”
then obviously you can have quite a detailed discussion about what, you know the stage of the diagnosis, the type of cancer, um the treatment – whether surgery would be an option and you can have quite a detailed discussion you know, or the clinical trials that are available, but if you’ve got someone who either hasn’t taken onboard their diagnosis, or says they didn’t know their diagnosis then you’re starting from a much lower level and you have to kind’ve simplify it, and some patients don’t want to know everything and they, straight away they say “I don’t want to know, I just want to keep it basic” and other patients you know want a lot of detail, so as I say I always start by asking what they understand before, and then you know tailor it to what they seem to want

I – yeah, it’s funny that you said that because when I interviewed some other nurses they said that some of the patients, they’re surprised that, some of the patients come in and they don’t know that they’ve got cancer, or that’s what they say...

DS240139.F – absolutely and, but we get them referred from <nurse1> and <nurse2>

I - okay yeah

DS240139.F – so cos, all 90% of my patients come from <Health Authority1> so they’ll have gone through that clinic with <nurse1> with <nurse2> and the gynae oncologist and would’ve gone to see a gynae oncologist and they still come to me and say “they didn’t know they had cancer”

I – wow

DS240139.F – so a lot of it is, some people it’s genuine, some people it’s just denial they can't take it in
I - so they are referred from the cancer nurses then, so where do they come from prior to that, is it from the GP

DS240139.F - usually it would be either through the GP or they may have been admitted to hospital with something non-specific, but what we deal with in ovarian cancer, the symptoms a very non-specific, abdominal distension, bloating, nausea, off their food, that can be so many things that they often go in under a general medical team and then if they’re...or a surgical team and then referred on, or come through the GP

I – yeah okay, okay then so how would you provide that information to patients, is it verbal or written information, or a combination?

DS240139.F – the information about stage, diagnosis is all verbal, the information about chemotherapy is both we go through it in clinic and then we give them written information leaflets on a general chemotherapy booklet and then the specific chemotherapy that we’re offering to them and if they then are patients who are going to need you know, suffer hair loss we give them a hair loss booklet as well

I – yeah, yeah okay, and are there any other resources that you recommend to patients, like charities or helplines and such?

DS240139.F – I don’t routinely recommend patients, we have 2 excellent specialist nurses specialist <nurse1> and <nurse2> and they will often speak to them as well <nurse2> is McMillan funded so they will often signpost them to, not always, but if it’s appropriate you know we, I usually say if somebody asks me, I say to go to the Cancer Research, or McMillan websites

I – okay yeah

DS240139.F - UK, McMillan
I – so you wouldn’t routinely recommend it, you’d wait until they ask for the information

DS240139.F – no, yes

I – okay, so what kind of issues do you think clinicians are faced with when talking to patients about their illness in a consultation?

DS240139.F – I think it’s at what stage the patient is in accepting their diagnosis

I - okay

DS240139.F – because if they’ve accepted the diagnosis they just want to know everything about all the treatment options and you can have a very detailed discussion about the pros and cons and clinical trials and what’s available, if they’re even still struggling with the fact they’ve got cancer they’re not going to take any of that in

I – yeah and how do you deal with that because I expect there’s time pressure, how long are the consultations usually?

DS240139.F – we usually, for a new patient we try to give them about half an hour, um but we don’t, I don’t consent them for chemotherapy at that same appointment, so what I always say to them usually at the end is you know “obviously we’ve given you lots of information, go away have a think about it” um, I usually get an answer out of them, whether or not they even want to consider chemotherapy so which one, so then we put that in the system and then we usually start the chemotherapy you know 10 days later um, and so they come and see us again in clinic before then and that’s when we consent for the chemotherapy but we always say to them “well look we’ll see you again before the chemotherapy starts, if you’ve got any questions write them down and we can go through them again”
I - oh that’s good

DS240139.F – and when we see them at the second appointment prior to their chemotherapy starting, some of them it’s a quick 5 minutes, yes happy with everything no questions sign the consent form, and other patients maybe another you know 10-15 minutes going through things again because they just need to get things into their head.

I - yeah okay so there’s sort of 3 appointments then, well including the treatment

DS240139.F – 3 including the treatment yeah and the nurses, when they turn up for the treatment the nurses will go through the practicalities of the chemotherapy again with them as well and they also get offered here now, or they, not all attend, they get offered a patient education session on chemotherapy um where they actually come to <hospital> and one of the chemo nurses, it’s a general one, but then she tries to talk about the individual chemotherapies that they’re going to have, so they have that as well, education session, and not all of them go to it but the ones who do often find it quite helpful and you can usually tell the ones who’ve gone to it because when you start going through the toxicities on the consent form they say “oh yeah, yeah we know about that” so you can see that it’s gone in

I – ah that’s great, okay do you think there are any barriers in communicating with patients during consultations?

DS240139.F – well there’s always a time pressure

I - yes and you mentioned patient understanding earlier

DS240139.F – and yeah, the time pressure, what they can take in, how much they can take in
I - and do you find they come with pieces of paper to write down questions, or do they bring anything with them into consultations

DS240139.F - completely varies, sometimes they do, or sometimes they somebody else comes in with them to do the writing, I’ve found that quite a few times, rather than the patient themselves doing it, they bring somebody else with them who’ll make notes

I - okay that’s useful, okay so in terms of experience with smart phones, do you have a smart phone or a tablet computer, do you use it personally or professionally...

DS240139.F - I have a smart phone personally and I use the computer um at work just because we can’t really use the tablets at work

I - yeah, okay and are you, obviously you’re familiar with apps and things, would you ever use any for work at all or do you know of anybody who does?

DS240139.F - yeah, no I have a couple of apps that I use some of the medical calculators, I often use the NICE um there’s sort of FIGO staging app which stages the cancer and gives pictures as well which is quite a good one

I – what, to share with patients?

DS240139.F - well I don’t usually um, I don’t usually show it to the patients but it, I can if they’re really struggling and they do...I also have a paper copy of that if they’re really struggling with the pictures that I can show them, um most of my apps have been superseded by my children’s so I have more peppa pig that medical apps on my phone now, um, no I ((laughs)) they’ve all been superseded, the NICE one you can get things like for clinical guidelines ESMO um, NCCN those types of things
I - yeah, okay, so the type of app we’ve talked about, do you think patients would find that kind of app, do you think they’d want to use it?

DS240139.F – I think some would, some are very electronically based and therefore would find that helpful, there are some patients who do not engage at all, either because they’re older patients, um and they’re not interested in that side of things, or they just don’t want to know they have that very almost old fashioned kind of paternalistic approach that what the doctor tells them is all they want to know type thing um, but....

I – would you say they’re in the minority of patients, or are there quite a number...?

DS240139.F – no, no, no I’d say there’s quite a number that is like that, but what you usually find in that situation their relatives, their children, their sons and daughters who want to find the information, so you can give them a signpost

I – okay, and what about, yes family and friends do you think they would want to use an app like that?

DS240139.F – yes, yes, yeah I think a lot of the family and friends, families certainly are wanting to get more information

I – okay and what about clinicians, do you think they’d be happy if a patient brought an app into a consultation, or was using it throughout their illness?

DS240139.F – throughout their illness, I’d have no problems with them using it throughout their illness, it could be quite difficult in a consultation if they’re kind’ve going through everything that’s on an app just because of time pressure
I – yep okay

DS240139.F – um but certainly as a guide to support them and point them in the direction of information I think that’s a really good thing

I – yeah okay so what benefits do you think they’re might be for patients using an app like this, I know it’s sort of dependent on what the app is actually going to do, but it general can you think of any benefits?

DS240139.F – well I think it just gives them a better understanding of their illness and what you know what kind of thing is, you know a question we get asked a lot is "why don’t you give radiotherapy in ovarian cancer" you know why....and you kind’ve try to describe the difference between chemotherapy and radiotherapy and because they’re given the information leaflet on chemotherapy sometimes say by the gynae team and <hospital2> they’re not given information on radiotherapy because we don’t use it, and they’re saying “why don’t you use it?” just having something where they can get a bit more information, and know about different treatments that are available, say sign posting for clinical trials and things like that, the concept of clinical trials even if you can’t....on an app probably can’t cover every trial because it changes so much, but the concept of them ‘why you might be asked to do research, what’s the importance of that?’ you know all of those kind’ve things you know I think would be quite helpful for them and if they have dipped in and dipped out you know the gene...for us I think it’s a kind’ve thing like the genetics guidelines as well you know when you pick up when you have a significant family history, because that’s what a lot of them ask with the ovarian cancer. So yeah you could see the potential for quite a few helpful things

I - and what do you think, if they have a better understanding, what do you think the benefits would be in the long term for the patients?

DS240139.F – it just gives them more control, um I think when they have more control, feel more control that helps them because it’s
their lack of control, their lack of being able to plan, their lack of, things just happening around them and at least if you know what’s happening, so many patients come in and say, “even though you kind’ve given me bad news I feel better leaving than I did coming because I know what’s happening and I know you’ve got a plan” so you kind’ve think actually as long as it’s not an information overload and it’s not sign posting them to inappropriate sites um, I think, you know the kind of information you get from McMillan or CRUK where it puts things quite well is, is useful

I – okay and what about for the family do you think there’s any benefits for them, and for the clinicians as well?

DS240139.F – well for the family I think the same thing, it gives them more information and it points them in the right direction if they’re trying to get more information, for clinicians well if patients are better informed um, it, it enables you to have a better discussion with the patient because you can discuss treatments it can make it more challenging for the clinician ((laughs)) when they’re very well informed! Sometimes they know things you don’t know, so make sure we have the app as well ((laughs)) so we know what they’re sign posting to, but no it’s good, it’s good and I think I, I’d much rather be able to go through things with patients and you know when they come in with all the cuttings from the Daily Mail and all their questions because at least you feel that you’ve answered everything as best you can

I – yeah, yeah okay and what about communication, do you think it would have an impact on the way you communicate with patients?

DS240139.F – it would probably be a more fluid conversation between us, rather than you talking to the patient because if they’ve already got a general understanding before you’ve even started

Then it allows you to have more of a discussion rather than you just imparting information to them

I – okay and what about with their family do you think like an app would help patients to communicate with their families or do you think there would be no difference?
DS240139.F – I’m not sure if it would help the patient communicate with their families any better, but if you know they can sign post their families to that information if they don’t want to keep repeating it so at least then you know that the family are getting reasonable sensible advice.

I – yeah, yeah okay, so what about barriers to the app, do you think there would be any problems with patients using this app or general barriers to this working in practice?

DS240139.F – I think you will have a cohort of patients who just won’t engage with it, you know they’re not into mobile phones and on smart phones you can’t say that’s an age thing, because I know a lot of older patients are very you know IT savvy and you get a lot of others who aren’t, so I think you’ll always have a group, a cohort of patients who just won’t engage with it. I suppose the other thing if anything with that, it depends how you’re going to do it because I think it’s updating it, is, is the because you know oncology changes so quickly and even if you’re trying to do just 3 or 4 sites, you know making sure things aren’t out of date and they’re not being told out of date information, or being led to kind’ve sites which may not be that helpful to them and might just confuse them.

I – yeah okay. So do you feel that patients using this app could affect your workload in anyway?

DS240139.F – um you could argue it both ways I don’t think so because you say consultations might be shorter because they’re better informed before they come, consultations could be longer because they are better informed you end up having more in-depth discussions about smaller details so I’m not sure, it could go either way.

I – okay and do you feel like clinicians, if patients are better informed and sort of more active in the consultation, do you think clinicians would require extra training on how to deal with the change in communication?

DS240139.F – no I don’t think so.
I – and what about for the app, do you think clinicians would need training on how to use the app and patients would they need training?

DS240139.F – well most apps are pretty straightforward I have to say. I mean certainly the apps that we use when you download you just download the information and do it, I think most clinicians are pretty IT savvy, yeah as long as you know it’s highlighted that it’s there and what it does, I think most clinicians are pretty IT savvy and would be able to cope with it and I think if patients are engaging with it then as long as it’s a well sign posted app, you know I’m quite used to apps so for me I wouldn’t see that I’d need...

DS240139.F – I don’t, I think a lot of the role of the apps, potentially will be them looking at it at home

I – right okay

DS240139.F – just going through it in their own time, um you know an information leaflet about the app saying what it is, what it does and maybe you know a flow diagram on how to use it kind’ve thing, or signposting you know maybe helpful rather than an indiv...because you can’t be, one person can’t be in all the clinics at all the sites at all the centres so I think even if you have an information, or posters up, because if you’re going to advertise it, which presumably is what you would do is advertise it as an app, then probably you’d need to have that as a poster ‘this is how you do it, this is how you download it’ a simple guide as to how you use the site

I – okay, great, and what features do you think would be most useful for patients, so what should we put in the app do you think?

DS240139.F – from a gynae, from an ovarian point of view particularly? Are you talking generally and....?
I – yeah both really, generally and specific

I – we’re not sure yet, we want to know what you think

I – so information on...

DS240139.F – I mean I think you need to, I think I, I’m not sure how much you’re planning to build in to your app in terms of information, or whether you are using it more as to a sign posting to other sites?

DS240139.F – I mean for me, for patients I suppose it would be the types of cancer they can get

DS240139.F – yeah you know the type of cancer, staging, so you know the app that I used to use which isn’t on my phone anymore, um which is the FIGO one which was really good because it gave you the FIGO staging which you could push on the, you know push on it and it would flip over and it would give a picture of where it was so it did both, words and pictures, but you know that kind’ve thing makes it more obvious to them and they can get their head around it, um so be kind’ve information on staging, information of types of the cancer, what symptoms they could get because you will find some patients will look at it to look for symptoms whether you’re going to give it kind’ve presenting symptoms or red flag signs or whatever, um and then the treatment options, um you know that they might have chemotherapy, for us it would be chemotherapy, or chemotherapy plus surgery um and there’s no clear role for radiotherapy so they know that because that’s often a question that I hear and then also kind’ve who they would expect to meet in their journey, so you know you’ll meet a surgeon and then a specialist nurse, oncologist you know oncologists work as a team, so you may not always meet the same person you know it’s that kind’ve information. I think it would be really good to get something in on clinical trials that you know, if you were looking at this from oncology from Wales, in the first instance, or even in south Wales, I don’t know, you’d say <hospital> you know does clinical trials you may be asked to participate you know either to donate a blood sample or tissue that’s already been taken, or to actually participate in a treatment trial, just because a lot of them, I mean then there’s not always trials available for them, but you know there was a study funded by McMillan recently um, I think
it was McMillan and they looked at, kind’ve they had secret shoppers going around various centres around the UK, to say you know if you walked into...would you think that this is a site for research and trials and how were you asked about it and actually the patients were saying, the majority of patients it wasn’t even mentioned they weren’t aware of clinical trials, they didn’t see it...I think that’s really good just to float an idea to them, they may be asked I think the clinical trial side. Um, support, so you know support sites, um you know the role of palliative care, getting it across that palliative care does not mean you’re dying, it just means you know symptom support, um so you’re kind’ve looking at all the layers that would then would be built up as they come in to the system you know side effects of chemotherapy, you could always then link them to you know who to contact, but that becomes a very detailed, I mean if you were doing it for <hospital> that’s easy cos it’s one person for that, you know one number for the whole of all the cancer sites but it becomes a bit harder if you are trying to generalise it a bit more. Um if you were then going into more detail you could link to some of the websites where they do list the cancer trials, you know list what’s happening, what’s new, um I’m not sure if you want to be, you know sort of, patients want to know about prognosis, not everyone does, even if you just signpost them, but the thing is, is you don’t want to re-invent all of this, because all of this is put quite well on like McMillan sites and the Cancer Research UK site and it is how much do you link in with them and just sign post them, or how much are you planning?

I – Yeah I think, from the interviews, I think we may, mainly concentrate on the question list to prepare them for consultations rather than sort of reinventing information, so probably signpost them to reliable web-sites and have some, you know, you can click on diagnosis or treatment or follow-up, what stage you’re at and then the relevant, relevant links then really

DS240139.F – yeah I think once you get past that first initial consultation how are they followed up, so for us in ovarian cancer, whether we use the tumour marker, there’s lots of evidence and discussion about that, you know we don’t regularly do CT scans in ovarian cancer because it’s symptom led follow-up and so, so they know that kind’ve thing you could use to give them more information but it becomes very specific because it’s very different for breast cancer and very different for colorectal cancer, so how much um you know whether you’re saying you know, make sure you know how you will be followed up, or whether you’re saying in gynaecological
cancers you’re likely to be followed up 3 monthly with an
examination and the doctor will discuss with you. I, I don’t know how
much information you are planning to put in so it's a bit hard to
I –yeah, okay and do you think there are any other features that would
be useful for relatives or friends, or do you think it’s the same
information the patients will want?
I – and what about as a clinician is there anything you’d want the app to do, other than what we’ve talked about?
I – and is there anything you wouldn’t want the app to do?
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 thing patients get really confused.

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....?

DS240139.F – In ovarian cancer 80% of patients are at advanced stage, so the majority are going to be at advanced stage anyway

I – yeah, yeah that’s quite a lot isn’t it gosh

DS240139.F – it’s ovarian cancer that’s why it’s called the ‘silent killer’

I – so what’s the prognosis with that then? If they come at an advanced stage?

DS240139.F – maybe about 25% long term survival, but for the majority they will relapse within 2 years

I – oh really

DS240139.F – but they can still go for 3 or 4 years even once they’ve relapsed so it’s, it’s still years rather than months

I – hmm gosh, okay is there anything else that you want to add that we might have missed?

DS240139.F – I don’t think so
I – okay thank you

DS240139.F – that’s alright, we’re dead on

End of Interview. Duration: 28:03
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 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

<table>
<thead>
<tr>
<th></th>
<th>Please initial each box</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td></td>
</tr>
<tr>
<td>I understand that taking part in the study is up to me, and that I can stop at any time without giving a reason.</td>
<td></td>
</tr>
<tr>
<td>I agree that the researcher can take notes of any comments that I make during the user-testing session.</td>
<td></td>
</tr>
<tr>
<td>I understand that the focus groups will be typed and may be used in a written report of the study. My name will not be typed, so that the report cannot be linked back to me in any way.</td>
<td></td>
</tr>
<tr>
<td>I agree to take part in the study.</td>
<td></td>
</tr>
</tbody>
</table>

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 any way?

**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

C
Chemotherapy
Chemotherapy usually means drug treatment. In cancer care the term usually means treatment with drugs that kill cancer cells. There are many different types of cancer drugs and different ways of giving them.

A
Adjuvant therapy
A treatment given in addition to the main treatment
Figures 16-21. Resources feature

Below is a list of trusted websites that are recommended by doctors and nurses for patients who wish to get further information on their condition:

1. NHS
   www.nhs.uk
2. Tenovus Cancer Care
   www.tenovuscancercare.org.uk
3. Macmillan
   www.macmillan.org.uk
4. Cancer Research UK
   www.cancerresearchuk.org

Support groups:
www.macmillan.org.uk/how-we-can-help-support-groups
www.cancerresearchuk.org/about-cancer/supporting-general-support
www.cancerresearchuk.org/about-cancer/supporting-practically/what-you-can-do

Financial information:
www.cancerresearchuk.org/about-cancer/supporting-financially-support
www.macmillan.org.uk/information-and-support

Information on clinical trials:
www.nhs.uk/conditions/Cancer-trials/Pages/Int
Figures 22-27. Contacts feature
Figure 28-29. 'About us' page
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
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

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.
Exploring the potential of a mobile phone or tablet ‘app’ to help patients with cancer prepare for consultations

Pilot Evaluation Interview Consent Form

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:

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](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.studyreregistration@nhs.net](mailto:hra.studyreregistration@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:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering letter on headed paper [Cover letter]</td>
<td></td>
<td>23 April 2015</td>
</tr>
<tr>
<td>Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)</td>
<td>UMal</td>
<td>01 August 2014</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants [Patient interview schedule]</td>
<td>1.0</td>
<td>10 February 2015</td>
</tr>
<tr>
<td>IRAS Checklist XML [Checklist_29042015]</td>
<td></td>
<td>29 April 2015</td>
</tr>
<tr>
<td>IRAS Checklist XML [Checklist_03062015]</td>
<td></td>
<td>03 June 2015</td>
</tr>
<tr>
<td>Letter from sponsor [Letter from sponsor]</td>
<td></td>
<td>10 April 2015</td>
</tr>
<tr>
<td>Other [Patient Reply Form]</td>
<td>1.0</td>
<td>10 February 2015</td>
</tr>
<tr>
<td>Participant consent form [Patient consent form (1of2)]</td>
<td>1.0</td>
<td>26 May 2015</td>
</tr>
<tr>
<td>Participant consent form [Patient consent form (2of2)]</td>
<td>1.1</td>
<td>26 May 2015</td>
</tr>
<tr>
<td>Participant information sheet (PIS) [Patient information sheet]</td>
<td>1.1</td>
<td>26 May 2015</td>
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<tr>
<td>REC Application Form [REC_Form_29042015]</td>
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<td>29 April 2015</td>
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<tr>
<td>Referee’s report or other scientific critique report [Evidence of scientific review]</td>
<td></td>
<td>25 March 2013</td>
</tr>
<tr>
<td>Research protocol or project proposal [Study protocol]</td>
<td>1.0</td>
<td>23 April 2015</td>
</tr>
<tr>
<td>Summary CV for Chief Investigator (CI) [Fiona Wood CV]</td>
<td></td>
<td>29 April 2015</td>
</tr>
<tr>
<td>Summary CV for student [Becky Richards CV]</td>
<td></td>
<td>25 April 2015</td>
</tr>
<tr>
<td>Summary CV for supervisor (student research) [Fiona Wood CV]</td>
<td></td>
<td>29 April 2015</td>
</tr>
</tbody>
</table>

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

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

Yours sincerely

[Signature]

D.D.
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:

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 tablet “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