



SCHOOL OF
COMPUTER SCIENCE

Information
Management Group

WEL— OSS Technical Report 1, May 2012

Personas for Lung Cancer Patients, Carers and Healthcare Professionals, developed through the Ethnographic Coding of Empirical Data.

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This report contains details of the personas and scenarios constructed during the pilot phase of the Online Social Support for Lung Cancer Patients project. The personas are all derived from empirical data, using an ethnographic coding process.

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WEL is working in partnership with Intel, Finerday and the School of Nursing, Midwifery and Social Work to determine the feasibility of developing personalised, adaptable healthcare advice and social support for people with lung cancer. <http://wel.cs.manchester.ac.uk/research/online-social-support-for-lung-cancer-patients/>.

OSS Reports

This report is in the series of WEL OSS technical reports. Other reports in this series may be found in our data repository, at <http://wel-eprints.cs.manchester.ac.uk/view/subjects/oss.html>. Reports from other Web Ergonomics Lab projects are also available at <http://wel-eprints.cs.manchester.ac.uk/>.

Acknowledgements

OSS is funded by the University of Manchester EPSRC windfall grant.

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1 Introduction

The first step towards developing a tool or system is to gain a full understanding of the target user group(s) and their requirements. Doing this for lung cancer patients is difficult, however, as the sensitive nature of data about their condition—usually collected in a confidential, clinical setting—means it cannot be used directly by software engineers or other technical experts for developing interventions.

To overcome this problem, we devised a novel, cross-disciplinary system for transforming confidential datasets so they can be used by technical experts for requirements analysis. Lung cancer experts, who had permission to perform secondary analysis with the data, followed an ethnographic coding process designed to summarise, aggregate, and anonymise the data into a number of personas and scenarios. This meant it remained representative, but no longer referred to particular individuals, and could therefore be published and used openly.

This report describes the process used to construct the personas and scenarios, and contains the results—31 patient and 17 healthcare professional (HCP) personas/scenarios—in full.

2 Method

2.1 Data Set Transformation

To develop the personas and scenarios a secondary analysis of interviews from two projects was undertaken. The first project was an interview study of patients with lung cancer and their carers and the overall objective was to understand the experiences of patients after completing their treatment. The specific aims of the original data collections were:

1. To gain insight into the meaning that patients place on follow-up after treatment, and understand why this is important.
2. To explore patient and carer need, preference and priorities at follow-up.
3. To gain an understanding of which interventions might be most useful after treatment.

The second project was an interview study of HCPs. The aims of these interviews were:

1. To explore HCPs' priorities at follow-up.
2. To gain insight into the models of follow-up currently in existence.
3. To gain some understanding of which interventions might be most useful after treatment.

Both of the projects were given a favourable ethical opinion by an National Health Service (NHS) ethics committee, South Manchester Research Ethics Committee (Ref 09 / H1003 / 72). Participants gave written informed consent to participation in the study and consent to their data being used for secondary analysis in the way we describe here.

2.2 Data Set Details

The first study comprised thirty-one participants who were lung cancer patients. Interviews were completed with the patients and their carers (SC/NSCLC all treatments and stages) from five clinical centres in the North West of England. The age range was 49–88 years, 16 men and 15 women. Eight carers were interviewed with patients – seven female and one male. Interviews lasted from 40 mins to 90 mins, equating to approximately 930 typed A4 pages of transcripts.

The second study comprised seventeen participants, all HCPs. Participants were purposively sampled from a range of professional backgrounds – clinical and medical oncologists, surgeons, general practitioners, respiratory and palliative care consultants and nurse specialists. Interviews lasted from 30 mins to 60 mins, equating to approximately 510 typed A4 pages of transcripts.

The interviews for patients were unstructured but followed a set of topic guidelines resulting in questions such as:

- Tell me about your contact with health professionals since the treatment finished: how often are appointments?; who do you see when you have appointments?; what happens at the appointment?; is there a plan of care – tell me about this?; what would you do if you had any problems?; where do you/your husband/wife/mum/dad etc. have treatment?
- What information do you think you need now your treatment is finished?
- Where would you like follow-up to occur: in the community, hospital, specialist hospital?
- Who do you think could follow-up patients?
- How would you view a structured programme of follow-up such as that which often happens with patients?
- What about using computers/the internet/ mobile phones as a way of keeping in touch with professionals?
- What support do you need as a patient/carer?
- Is there anything not provided now that you would like?
- What do you think that the most important thing is about follow-up after treatment?

For the health care professionals, discussions centred around the following topics:

- Is there a plan of follow-up for patients after treatment?
- What is the aim of the follow-up care you give?
- Are there alternative models of follow-up that might benefit patients, or professionals?
- Is there anything you don't do that you would like to?

- Is there anything you do that you would rather not?
- Who do you think could follow-up patients?
- What about using computers/the internet/ mobile phones as a way of keeping in touch with patients?
- What do you think that the most important thing is about follow-up after treatment?

Current epidemiological data¹ was also consulted to ensure that the personas developed fitted with the population profile of lung cancer patients.

2.3 Transformation process

Each interview was scrutinised individually by a lung cancer domain expert to identify data of relevance. Personas were developed iteratively, being formed initially by lung cancer experts and then referred to computer science experts to ensure that the data extracted from the interviews was relevant. Condensing such rich data was not easy but provided the opportunity to highlight a number of different aspects of participant views, so although one persona does not capture the whole experience even for one person, the personas together give a picture of what it is like to be a patient, carer or HCP.

One of the main challenges of the development of personas was to maintain anonymity of participants. The qualitative data collected for the two studies were analysed using the principles of Grounded Theory to develop a theoretical understanding of the issues. Data was thus fragmented and de-contextualised from individual experience and presented in relation to theoretical importance. Anonymity is easier to preserve when working with multiple data sources. Personas are individualised accounts and care must be taken when explaining individual circumstances and experience not to reveal any information that would make an individual recognisable. When personas were developed some details about an individual's circumstances were altered: for example, a son might become a daughter; specialist hobbies or occupations were also changed. This contextual information can easily identify patients and HCPs. However, the issues raised by patients and HCPs that formed the key aspects of the personas were preserved as much as possible. Due care and attention were taken to ensure high standards of ethical conduct were met when presenting individual stories or personas.

3 Results

31 patient/carers personas and 17 HCP personas were produced altogether. A scenario follows each persona, describing a situation in which the actor might use an online health and social support system.

¹<http://info.cancerresearchuk.org/cancerstats/types/lung/>.

3.1 Personas and scenarios: Patients and Carers

John is a 48 year old man who was diagnosed with lung cancer 3 months ago. He has never smoked and has been shocked by his diagnosis. He is married to Claire and they have 2 children Gavin aged 9 and David aged 13. John used to work in marketing and had a senior role in a small company. He played golf and kept fit and active with his children. He has had surgery for his cancer and had his right lung removed, but it is taking longer than he hoped to recover from this operation. He feels breathless and struggles to take his dog for a walk. He still has some nerve pain since the surgery and is currently on sick leave. John was a highly proficient user of technology: he has a smartphone; a PC at home and an ipad. He looks for information on the internet about new treatments but is concerned about where the information comes from, and whether it is a reputable source. John wants accurate and up to date information about lung cancer. He has not been active in any forums online since his diagnosis.

John is interested in new treatments that might be available in the near future. He has talked to his doctor about this but can't get any definite answers. He is not sure how to search for information about new treatments that are being developed and a lot of the information he has found has come from the US.

Eva is 75 and was diagnosed with lung cancer 8 months ago. She has had chemotherapy to manage her symptoms and to hopefully extend her life. She found the treatment very difficult and had lots of side effects. Her husband died 5 years ago from bowel cancer and she lives alone in social housing. Her daughter lives nearby and she sees her grandchildren often. She is an ex-smoker and quit 20 years ago. She attends church on a Sunday when she can but is otherwise limited in her social contact. She does not own a computer and feels she is too old to learn about technology. Her granddaughter sometimes brings her articles from the internet about new treatments but she finds them confusing. She telephones her cancer nurse if she has any problems but mainly gets information when she has her regular follow-up appointments.

Eva would like to find out about meeting people in her own area who have had a similar experience to her. She would like to meet face-to-face rather than online but she doesn't want to bother her cancer nurse by asking. Her granddaughter has had a look for support groups online but can't find much information.

Neil is in his late 60s and was diagnosed with lung cancer 3 years ago. He was treated with surgery and chemotherapy. He has had regular checkups since his treatment finished but not any recurrence of disease. He was treated at two different hospitals and now has follow-up at the local hospital. He is supported by his wife Glynnis who takes charge of all the household management and Neil's recovery. Neil considers himself 'computer illiterate' but Glynnis says that she couldn't have coped without the internet as this was her main source of information to help Neil's recovery.

Neil would like some information about exercise so he can start to take control of his recovery. He got some leaflets from the nurse but is still unsure of how to

start or whether it is safe for him. His next appointment at the hospital is not for 3 months and he would rather not ask for an early appointment just to ask about this.

Derek is in his early 60s and diagnosed with lung cancer 2 years ago. He didn't have any specific symptoms but was feeling run down, fatigued and had lost his appetite. His GP sent him for an x-ray and he was seen at a local hospital and then by a surgeon. He had a lobectomy and chemotherapy and was referred back to his local hospital. He felt abandoned at this point, with little interaction with health care professionals. He tried rehab sessions but these were too much for him and he stopped going. He worked in a physical building job before he was diagnosed and this was too much for him after the surgery. He could have worked in the office but he doesn't like computers. His employers were very supportive offering him flexible work but he felt he couldn't manage it. To Derek and his wife, Eva, this has meant a significant change in lifestyle. He had worked all his life and had brought up 2 sons and a daughter. He has had difficulty accessing benefits and received very little information and support about this after treatment. Derek feels he has lost his confidence since his treatment, finding it difficult to get out and about as he is worried something might happen when he is on his own. Derek's wife took over as main breadwinner and this caused a further loss of confidence for Derek. He feels if he had not had surgery maybe he would not have such severe effects and he could have gone back to work. Derek does not like computers and his wife jokes he will not even text. Eva does use the internet and she is on facebook to keep in touch with her children and grandchildren but says she would rather pick up the phone to talk to people or meet face-to-face .

Derek would like support to develop his skills in computing so he may be able to go back to work and also be able to access information and support online as well as keeping touch with his family.

Dora is 82 and was diagnosed with lung cancer less than a year ago and had chemotherapy and radiotherapy to treat it. She talks of cancer being 'rife' in her family. Her father died of lung cancer and a number of other family members have also being diagnosed with cancer. Dora talks of loss of confidence after her cancer diagnosis but knowing that clinical staff are there to support her helps to boost her. She lives alone. She is also reassured by hearing about other people's stories (such as reading about them in magazines or seeing them on the TV) of survival after cancer. However, she would not like to attend a support group as she does not want to talk about her own illness and feels that people are only there to talk about themselves. She has got a lot of benefit from complementary therapies such as aromatherapy. Dora feels she is very well supported by her lung nurse and the medical staff at the hospital and this is where she gets all her information from. She does not own a computer or mobile phone.

Dora feels isolated but does not want to attend a support group. She values hearing about other people's experiences as they give her reassurance but she doesn't know how she can learn about people's experiences without having to meet them.

Ann is in her late 50s and was diagnosed with lung cancer 2 years ago. She

was treated with surgery and chemotherapy. She stopped smoking as soon as she was given her diagnosis. She has struggled to get her life back to normal since her treatment and feels frustrated that she can't do things as she once did. She has been told by the doctors she must learn to adapt, but this has been very difficult and she has received very little advice as to how to do this. It was suggested that she try to attend a gym under the supervision of a physiotherapist but she found that too much and now swims at her local pool. She has sought benefits to help her but has been 'knocked back' as she had had surgery and was not eligible for them. Her good friend (a non smoker) recently died from lung cancer after having similar treatment so she worries about the cancer coming back; this is her biggest worry when it comes to her cancer. She has not used the internet for information although she can use a computer. She thinks she may have used it more if she were younger. She feels there is too much information out there and she can't be bothered to look though it all: a clear information booklet would be of most use to her. Her daughter and grandchildren use the internet but she feels she would not bother them to look for information.

Ann's biggest worry is about whether her cancer will come back but she is not clear what symptoms she should look out for and she doesn't want to bother her doctor unnecessarily.

Deirdre is in her late 40s and had a very traumatic year before her diagnosis, caring for her father at home who died of cancer. She was distraught after his death and suffered a lot of vague symptoms which she put down to stress. She visited her local hospital for tests and her diagnosis was broken to her in a very direct 'brutal' way which she was very upset about. She started chemotherapy and then had radiotherapy which she completed 4 months ago. She is still suffering from fatigue and other side effects from her treatment. She had mixed feelings about the end of treatment. She felt relieved she had some time to herself but a bit lost and lonely after all of the contact she had had with the hospital over several months. She feels very much on her own and very low in her mood. She lives on her own but her son lives nearby. She feels that she didn't have time to talk about her diagnosis as she was so busy during treatment but now she dwells on it. She feels she didn't get any information on finances or benefits but that could be because she only remembers being focused on medical information; her family has taken over any financial issues for her. She limits the amount of information she gets from the doctor as she thinks this does not help her. She often leaves her son to speak to the doctor and she leaves the room. She is seeing a counsellor and a community Macmillan nurse to help her rebuild her confidence, but she is very frightened about the cancer coming back. She would not seek information on the internet because she wants to control how much information she gets and her medical team are aware of this and personalise consultations to support her wishes.

To manage her worries Deirdre likes to control what information she gets. The doctors know this and can personalise information for her, but this is not possible online so she will not use the internet for cancer information.

Mark is in his 50s and was diagnosed one year ago and was treated with radical

radiotherapy (with curative intent). He has a long term ‘lady friend’ who he lived with during treatment but he has moved back home now and lives alone. He considers himself to be very independent and did not want to join any support groups or access any support services after treatment — he just tries to think that it is gone and leaves it at that. He sometimes worries if there is something on TV such as a soap opera storyline about cancer and worries he needs to have more scans and should be checked up more frequently. But on the whole he plans holidays to look forward to and tries to get on with his life. He does have a computer but doesn’t want to think about his cancer and would not look up anything about cancer on it, he wants to forget about his illness.

Mark’s focus is getting on with his life and does not want to think about cancer.

Joan is in her 60s and lives with her husband. She was treated with chemo and radiotherapy which finished 3 years ago. She recognises now that people go through different stages after cancer treatment and that their needs are different at different times. She feels she would have benefited from some encouragement to exercise after cancer and knows that some groups are run at the hospital, but is not sure if she would be eligible for them. Her husband is very sociable and has darts nights planned (games and practice) through the week but he has held off socialising. Joan would like contact with other people with cancer but not in a support groups setting. She would like to have a coffee with other people and talk about cancer if she wanted to, but also TV shows or other everyday things if she preferred. She misses social contact and it does seem to be important that this comes from other cancer patients so people understand where she is coming from, maybe with a doctor or nurse popping in to answer any questions. She is well supported by her family who look up symptoms and information on the internet if there is anything worrying her. For example, she was very cold after treatment and had the heating in the house turned up, and her children looked on the Web to see if that was a side effect of treatment. They found that it was but when she asked her consultant she was told that was wrong and it was not to do with her treatment. She has not looked for any information or support on the Web but her extended family do.

Joan wants more social contact. Although her nurse suggested a support group, she feels this has too much focus on cancer. Although she wants to meet people who understand where she is coming from she doesn’t want the focus to be talking about cancer.

Alan was a heavy smoker since his early teens. He is now in his early 40’s. Fourteen months ago he attended A&E after an episode of chest pain. The tests on his heart were inconclusive but a chest x-ray showed a ‘shadow’ and he was told in A&E he had suspected lung cancer. He had surgery and chemotherapy and found the experience of chemo worse than the removal of the lung. After treatment his follow-up was with the surgical centre, but he has an excellent relationship with his GP and can access an appointment quickly at his local surgery if need be. His GP has given him emergency antibiotics at home so he can start them quickly in case of a chest infection and then make an appointment with the doctor. He is confident he can spot the signs of a chest infection and feels reassured he has the tablets at

home. He lives with his wife and grown up son and daughter and feels he gets a lot of support from them. He would like to get back to normal after his treatment, and is learning to do this through trial and error, learning to pace himself walking his dog. He likes to travel but has had problems obtaining travel health insurance since his diagnosis. He feels the internet has more bad news than good news on it relating to lung cancer. After googling lung cancer after his diagnosis he felt he should dig his own grave! Sometimes he clicked on and then straight off a website because it was so frightening. He suggests that people look at the Macmillan site, as they will get enough information there and it warns people when, for example, mortality statistics will be presented so you don't have to read them. He would not recommend any US sites. As he has had curative treatment he no longer considers himself a patient or someone living with lung cancer but he is still living with the physical and emotional aftereffects.

Although Alan feels cured he still has some worries and symptoms he needs help and support with. At the moment he is managing these through trial and error. He has not had much support in these issues from his health care team and would welcome more information.

Jack is in his late 50s and was diagnosed 2 years ago after attending A&E with a severe chest infection. He had surgery but the surgeon was not 100% certain he had removed all of the cancer. Jack is well at the moment and has his fingers crossed that everything will be okay in the future. He says that although he has healed after the surgery he feels he will never be the same person again due to the aftereffects of the surgery. He experiences a lot of pain (he is still on analgesics) and that has an impact on, for example, picking up his grandchildren and he often feels very fatigued if he does too much. He is back at work in a manual job but finds it very hard. He feels he benefits from his regular hospital appointments which are every four months. He finds the appointment reassuring, but he feels very anxious before his appointment hoping everything will be okay. He has changed his lifestyle since his diagnosis. He is careful about what he eats and drinks and has stopped smoking. He feels he would have benefited from getting to know other patients after his treatment, so he could get some reassurance that what he was experiencing was normal. He has used the internet for information but he jokes that he has been to all the wrong sites — ones that contain information or patient stories that are very frightening. He would like to have been directed to websites created by professionals and where he can pick up tips about everyday living.

Jack still has questions about his health and wellbeing after his cancer treatment, but is not sure which websites are reliable.

Janet is in her 70s and finished her chemotherapy treatment 12 months ago. She was pleased to finish treatment and was relieved she did not have to go back to the hospital for three months. Between appointments she tries to put her illness out of her mind and think positively about everyday things, e.g. she was able to attend her granddaughter's wedding abroad. She does worry in the days before her appointments. She worries that something might be wrong but feels this is a natural concern. For Janet, the longer between appointments the better, as she feels she can

forget about her illness for longer. She didn't want information from the hospital about the diagnosis and treatment — she just wanted them to get on with what they were doing. She would not be interested in attending support groups or talking with other patients as she feels this would become quite negative, going over their diagnosis and treatment. She would rather move on positively with the life. She has not used the internet as a resource for information. She has only just learnt to use a mobile phone. Her family are users of technology but like her don't want much information about the illness, and would not look for information on the web.

Janet wants to remain positive and likes to have long periods between appointments so she can get on with life. She feels very anxious before appointments. She would like to be able to accurately monitor how she is feeling so she doesn't need to attend appointments if she is well.

Jane is 74 and was treated with surgery one year ago. Her husband died of lung cancer 5 years ago. She lives alone, but has a very supportive daughter and grandchildren who live close by and who see her on a daily basis. She was very anxious about being alone in the first few weeks after the operation and felt very frightened. If she went out of the house on her own she felt breathless and was scared she would fall. She persevered, walking a bit further every day and doing some gardening, although acknowledges that now she will probably not be able to do all the things she used to do. She has learnt to pace herself in her activities such as housework. Jane has also put on weight and stopped smoking since her diagnosis. Jane has a number of co-morbidities including heart problems that have made her treatment complex. She was given information during her illness but says she 'shut her mind to this' and let her daughter deal with everything. Jane does not own or use a computer. Her daughter is a daily user of the internet and has looked for information but feels it is a bit dangerous to know too much. Both mother and daughter would prefer to get information from healthcare professionals so it can be tailored specifically to them.

Jane does not want too much information about lung cancer but has made a number of changes to her lifestyle since her diagnosis. She'd like to be able to monitor her health without focusing on cancer.

Tony is in his 60s and lives with his wife. He was diagnosed 2 years ago and was treated with surgery. He worked in a very physical manual job, but has retired since his diagnosis. He feels very breathless since his operation and occasionally has some pain. He would have liked some further information on diet and exercise after the operation but lots of booklets or exercise programmes would have been too much for him. All of his support comes from his wife Edna. They do not have a computer at home and wouldn't know what to do with one.

Tony would like information about lifestyle after his treatment.

Norman is in his late 70s and was treated with radiotherapy 6 months ago. He focused on getting on with treatment and is not one for asking questions. His wife didn't like to interfere and take over but had some questions, particularly about prognosis, which she felt were never really answered, although she wonders if it is

too early to tell the effects of treatment. Norman feels that the treatment has left him breathless, fatigued and less able to do heavy work around the house such as gardening. He has asked the doctor about this and has been told it will get better with time, but was not offered any interventions to help with this. He prefers to accept this and manage as best he can. His wife Alison would rather be more proactive but holds back so she doesn't look too pushy. Norman feels that some written information might have been useful to support him with his recovery: for example, he is now doing regular exercise but worries that it might be doing him harm. He does not think a structured face-to-face programme would have been helpful. Norman does not use the internet but Alison has looked for specific information about treatment and tests although she has not shown these to Norman; they are for her information only. Alison feels that carers sometimes want different or more information to patients and that information specifically for carers would be very useful.

Alison needs information as a carer but realises that she may need or want different information to her husband.

Moira's cancer was found in the work up for cardiac surgery and she was told she could not have treatment for both. She had chemotherapy and radiotherapy treatment for her cancer which finished 10 months ago. She is in her late 60s and lives with her husband Raymond but his health is also very poor and he has been hospitalised since her treatment. Her son lives an hour away by car but is very supportive. She reports feeling very tired since the treatment and she has good days and bad days but it is her heart trouble that gives her most bother. She is married and her husband worries terribly about her. She has felt a bit lost since the end of her treatment and worries that no one is keeping an eye on her regularly. She does have appointments at the hospital every 2-3 months but worries in between. She feels she has lost some of the small pleasures in her life. She used to love reading and is too tired now to bother. She feels she couldn't be bothered with face-to-face rehabilitation and going to more appointments but would like further information about living after treatment and dealing with everyday problems. She has never used a computer.

Moira would value contact with HCPs between appointments to reassure her and this might encourage her to get back to activities she enjoys.

Amy is in her late 60s and lives alone in a retirement flat. She was treated 7 months ago with radiotherapy. She feels very isolated and would like to meet other people in the same situation, but doesn't know how to go about meeting other patients. She recounts stories of friends who have had breast cancer and says she feels they get more support than lung cancer patients as there are groups for women and specialist nurses. She is living with the hope that the cancer has been treated and that the future will be okay, trying not to make too much of a fuss about it, but knows the doctors and nurses can't give her an accurate prognosis. She does feel lonely and worries about burdening her friends who she doesn't feel understand her situation. She says she has wonderful friends and family but when she is left on her own she just has to get on with it, coping alone. She did meet other patients

during treatment but as everyone was scared during treatment it wasn't the time for chit chat. To get to know people, she would value a support group after treatment. She would value further information about coping with the ongoing effects of cancer and its treatment. Her son has just set up a computer for her as she has friends in Australia so she can email them. She is just learning how to search the Web and thinks she will look for information about lung cancer but hopes it won't frighten her too much.

Amy would value a way of contacting other patients now her treatment is over. This is less easy to do now as follow-up clinics are big and busy—you can't just strike up a conversation as you did during treatments when you saw the same people having treatment every week.

Andy is in his late 80s and was taken to A&E in an ambulance due to extreme shortness of breath. An x-ray showed an abnormality and he was diagnosed with lung cancer 18 months ago. He was treated with chemotherapy and is being followed up at the hospital every 2-3 months. He says he doesn't know what the future might bring. He lives in supported accommodation with a warden who looks in on him regularly, but he has no close family in the UK. He get out on his mobility scooter and manages to look after himself, and he is also supported by a home care worker. He likes to go to the hospital appointments as it gives him a change from being at home. He does not have a computer but has leaflets from the hospital that give him information.

Andy values getting out of the house to his hospital appointments as they are a change from being at home.

Irene is in her early 70s and had no symptoms of her cancer before it was diagnosed during an investigation for an unrelated illness. They tried to operate but it was unsuccessful due to complications. She was very low after the unsuccessful operation and felt she was going to die quickly. Irene started chemotherapy but found it very difficult to tolerate and had to stop the treatment (1 year ago). She lost 4 stone and felt she was falling apart. Her sister came to stay with her but after a few weeks had to go back to her own family so Irene sold her house to move somewhere more suitable for her needs. This has made a big difference and she feels much less isolated. She felt she lost all of her confidence after treatment, but in her new house she is close to shops and her family and is beginning to feel more positive. She has a huge amount of support from her family and they help her with things she feels less confident about, such as driving to appointments. She sets goals for herself to keep active such as waking to the shop each day or getting on the bus to the town centre. She values the support she gets from the hospital but would not want to join support groups or attend a cancer centre as she feels she just wants to forget about her illness and manage her everyday life. If she had any questions she would call the nurse at the hospital. Irene does not have a computer and her family have not to her knowledge looked up any information about lung cancer on the internet.

Irene has moved to a new area to be near her family and live in more suitable accommodation. She lost a lot of confidence after her treatment and has been setting

herself goals to move forward. Shed like to be able to monitor her progress in relation to the goals.

Steven is in his late 50s and was treated with chemotherapy 4 months ago; he has suffered long term lung problems related to smoking for most of his life. He felt a bit let down at the end of treatment as the doctors did not give him as much information as he wanted about whether the treatment had worked, or about the ongoing side effects of treatment. Steven felt he went from contact with the hospital every week to no support at all at home. He had expected to continue to see the doctors regularly at the end of treatment. He is being seen at his local hospital after treatment. He has felt short of breath since his treatment and managed this by walking short distances to try to maintain his independence. He did have some pulmonary rehabilitation for his chronic lung disease and sees that as a useful model for post lung cancer treatment. The rehab included sessions at a gym with nurses and physiotherapists and an opportunity to ask questions or get help with any problems. He lives on his own but has good support from the community Macmillan nurse. Steven has used the Web for information about his treatment, although he finds a lot of the information outdated and irrelevant. He has used it mainly for background information such as how radiotherapy and chemotherapy work rather than for information about specific treatments. A relative is now having treatment for lung cancer and he is trying to support them by telephone. He thinks having contact with other patients would be very beneficial, to talk through any problems or issues with someone who has been through it before.

Steven has found supporting his relative with lung cancer a positive experience and would have found it useful to have talked to someone when he was having treatment.

Ian is in his late 60s and for a few months before his diagnosis had been experiencing a number of lung symptoms, coughs and chest infections. He was diagnosed 6 months ago with lung cancer and had surgery to remove the tumour. He has had problems with his voice ever since a side effect of the surgery. He says he was not warned about the possibility of losing his voice before the surgery but is not sure if that would have made any difference anyway — he decided very quickly he wanted to have surgery. It has had an impact on his life, however, as he used to sing in a choir. Although Ian reported that his care was fantastic during and just after treatment he did feel less supported after a few weeks. He wonders if it would be possible for someone at the hospital to call just to check on people — ask how they are and if they have any questions. Some support in between 3 month appointments would be valuable. The contact would not have to be structured like a rehabilitation programme, just an informal chat to see if things are okay. Ian is well supported by his wife, June, extended family and neighbours, but was aware when he was in hospital that a lot of people did not get any visitors and wonders how they cope when they go home. June uses the internet a lot to trace her family tree but Ian is not interested in the internet. June looked up information about lung cancer treatment before Ian's surgery but not after treatment. She found some of the information very technical and not that helpful. She feels that particularly

reading other people's stories is not helpful and you have to form your own opinion about what you should be doing. Everyone's experience is different.

Ian would like a way of getting support from HCPs between appointments. He doesn't like to bother people between appointments and so would prefer to have someone contact him rather than the other way round.

Linda is in her early 60s and finished radio and chemotherapy treatment 14 months ago. She saw the treating consultant for a couple of follow-up appointments and has now been referred back to her local hospital. She is happy with this, but liked to see the treating consultant and was a bit anxious about how easy it would be to see the treating doctor again if she needed to. However, the specialist nurse who she has met before gave her some continuity when she changed services. She was told if she had any problems to phone the clinic and they would see her again, but she is a bit confused about what that means and about what problems she may encounter. She is determined to stay fit and walks a lot to keep herself going. Although she feels being positive and moving on with her life are very important she says her husband and family have seen a change in her since her diagnosis and she has noticed this herself. She can be snappy and bad tempered even though she does not mean to be and she finds this difficult. She used to work but now relies on benefits and she feels very uncomfortable about this, as she was proud that she had never relied on the state for anything. Her husband is also having a difficult time coming to terms with her diagnosis and has been off sick with stress and depression. She feels there should be further support for carers as well to support them. She values her regular appointments but admits to being terrified when she goes as she is worried that she will be told the cancer is coming back. She thinks further support in the way of information would be useful between appointments so you have something to fall back on if you need some information. She likes to talk to people one to one but would not like group support. She knows her children have used the internet for information but do not discuss this with her. She and her husband do not have a computer at home.

Linda was told to call the clinic if she had any problems, but is not sure what this means. She has had a cold but is not sure if this warrants a call to the nurse, or whether she should go to her GP.

Diane is in her 70s and was being treated for breathlessness at her local hospital in relation to an ongoing lung condition. She was x-rayed and scanned and a malignancy was found in her lung. She had surgery 2 months ago and since then has suffered with pain and a number of other complications and consequences of the operation. She was relieved that no further treatment was necessary. Her grown up children have stayed with her and her husband has been a great support and has taken over all of the household tasks. She would have appreciated further information after her diagnosis but feels she got all of the support she needed from her family, although she says she feels for people who are on their own and thinks maybe they could do with more support. She has never used the internet for further information or support.

Dianne would have appreciated further information after her diagnosis.

Bill is in his 50s and used to work in a very physical manual job and sought out his GP as he developed back pain. He was eventually sent for an x-ray and scans and 12 months ago was diagnosed with lung cancer. He was treated with chemotherapy but struggled with the side effects and spent some time in a local hospice for respite. He did not finish his treatment. He says he feels lucky to have got home from the hospice and now has medication for pain and to help him sleep. He is no longer able to work and this has had a huge financial impact. Bill and his wife now live on disability benefits. They got advice about this from Macmillan. The financial burden for his wife is a great concern to Bill. He has also been assessed by the OT and is waiting for various adjustments to his home to make life easier. His philosophy is to try to forget about the cancer and focus on him and his wife doing small things together like a day trip, but money is limiting their lifestyle. He is worried about how his wife will cope when he is gone as he is aware that that is the stage he is at now, but he is setting small goals to keep himself moving forward. He gets all of his support and information from the hospice and does not use the internet for any information or support.

Bill is worried about how his wife will cope, financially and practically when he dies. He would like to set up some services/support to help her and get his financial affairs in order.

Martin is in his late 60s and completed chemotherapy and radiotherapy 5 months ago. Before his diagnosis he was very active and had his own home decorating business. He was fatigued when he finished his treatment but saw this as a good thing: he was getting better and thought now he could look to the future and see how it goes. He says he didn't have any questions and did not need any information after treatment; he felt he would be better just to see how things went. He thinks that joining a support group or talking to other people about their experiences would be quite upsetting and would rather just get on with things himself. He does have a computer but he uses it to download music and videos. He has never searched the Web for information about cancer. His daughter has looked for information but he isn't sure that it is a good idea. He likes to get information from his doctor as he knows everything about him and can give him information specifically tailored to him. He would, however, consider looking on the Web for information that was recommended by a doctor — then he would know it was relevant to him and of good quality.

Martin wants personalised information that has been recommended by a doctor.

Brian is in his early 70s and was treated with radiotherapy 8 months ago, as although surgery would have been possible he was not well enough to cope with the operation. He lives with a number of co-morbidities. He had daily radiotherapy and spent weekdays in hospital to make it easier for him to manage. He has done well since his treatment and put on weight. He is very well supported by his wife and daughters. He is a regular user of the internet, e.g. he banks online, and his son works in IT and set up their system for them, and checks up on any new treatment of cancer and his other co-morbidities. He does find Web based information helpful

and searches on Google for the medication he is on although his wife suggests you can read too much information and reading about all the side effects of medication can be worrying. They think that the cancer information is useful but you have to take the good with the bad and reading the stories of people who are very unwell has made them realise how lucky they were that Brian's cancer was caught early. They have never used the internet for support, i.e. joining chat rooms. Neither of them think this would be useful.

Brian is a confident user of the internet and searches for information about cancer and his co-morbidities. But is not sure what a dedicated internet site would offer him as he doesn't want to interact with other people online.

Jan is in her early 60s and was not in good health before her diagnosis. She had chemotherapy and radiotherapy treatment which finished 10 months ago. Treatment was a worrying time for her and her husband as she seemed to go downhill with the side effects and stress of treatment. She was very worried that she would become unwell (it was the flu season) due to her low immune system, a side effect of treatment, so wouldn't leave the house because she was frightened and was very relieved when it finished. She felt very anxious about everything during treatment and she felt she lost her confidence and needed a lot of support from her family. Her husband Joe retired in the week she was diagnosed and took on all of the household management — something he had never done before — so he felt it was like role reversal. It was a huge change in one week. They had planned an active retirement. Jan is not keen on reading a lot of information but Joe has picked up leaflets from the local Macmillan centres. He has also been online for information although he is very wary of websites. He would not like his wife to read some of the information he has seen — he feels he can cope with it but is not sure if his wife could. As information is not targeted at the individual you can read a lot of information that is irrelevant or just really worrying. He thinks some cancer sites are like hotel recommendation sites: you either get very good or very bad stories, and there is no one just with a normal experience, so it is hard to interpret the story for you. He thinks the Macmillan/Cancerback-up website is good. Joe would go to a website if it was specially recommended to him by a professional, but no one has suggested he looks on the Web for information.

Joe is concerned about his wife reading information on the Web that might frighten her, and would prefer websites that were recommended by a professional.

Dave went to his GP with a bad cough which he put down to smoking. He was sent for an X-ray and was diagnosed with lung cancer and was treated with radiotherapy 3 months ago. He coped well with the treatment but in the last few weeks he has not felt well with a cough and worries that it could be his cancer coming back. He gets breathless when he goes out for a walk but tries to do this anyway to keep a routine going and to try to build up his exercise. He says before his treatment he was always ready to do something like the garden but now he mostly doesn't feel in the mood for anything. He has learned to pace himself and prioritise what he needs to do and not worry if he can't get things done. He doesn't really want any help at home as he would rather stay independent and try to get on with his life.

He values regular contact with the hospital and his focus for the appointments is finding out if the cancer has come back and if he can have further treatment. He is not sure about how important or useful information is to him; he says it depends on whether the news is good or not. He does not have a computer.

Dave is worried about his cancer coming back and this is his main concern. He values face-to-face appointments with the doctor to reassure him about this, as he can have test that can show if things have changed.

Matt is 80 and was diagnosed after he collapsed and was taken to A&E. He had surgery 4 months ago and now considers himself cancer-free. He feels he is slowly getting back to normal and thinks that he will be able to start getting back to playing some golf soon. His wife says that he should get back to normal and there is nothing wrong with him now but he feels that the process of diagnosis was very stressful and he still needs some time to come to terms with what happened and he will start to do things again in his own time. He feels the medical team have done their part and he now needs to work on getting better himself. He relies a lot on his wife for support and to remember his tablets. The information he got came from the hospital and he does not have a computer.

Matt feels the medical team have done their part and that he has a lot of work to do by himself now to recover from his treatment. He'd like support developing realistic goals and monitoring his progress in relation to them.

Chloe is in her late 50s and was diagnosed 2 years ago. She had surgery and chemotherapy, although she was not able to tolerate the chemo and it was stopped early. She has been struggling with breathlessness since her operation. She feels she is still recovering emotionally from her treatment. She feels you get on a conveyer belt of treatment which moves forward whether you are ready for it or not so she is still taking her time to come to terms with things. She is well supported by her husband but lost her confidence after her treatment. She had panic attacks and felt that she could not go out. Her Macmillan nurse referred her to a hospice to help her manage her anxiety and this seems to have worked. Although she has her ups and downs, she is back at work part time. One of her biggest worries is that her cancer will come back and she misses the support she got from the hospice and the people she met there. She would like a drop in facility where she could talk to other people who understand her worries. She does not use the internet.

Chloe had support to help her manage anxiety after treatment but now this is finished she misses the contact with other people and the support she had. She would like to be able to 'drop in' for support as and when she needs this.

Tom is in his 70 and was extremely fit and healthy before his diagnosis. He had no symptoms and was diagnosed after a routine check up. He is a keen runner and ran a marathon the week before his operation. He had surgery 12 months ago and he developed his own recovery plan based on exercise equipment he had at home and was running again within 8 weeks of his operation. He would not attend a support group as he feels that it would all be about who was sicker than who and his focus is on recovery. He wanted to be involved in decisions about his treatment as his main

focus was to maintain his fitness after treatment; this was really important to him. He used the internet to look at treatments and who in the UK was leading work on new types of treatment, so he could discuss this with the doctor. He has not looked up anything else related to cancer on the Web, however. He feels that it would be too negative, and regards charities such as Macmillan as being for people who are dying and not him. So he has used the Web for very specific information about new and advanced treatments.

Tom is very fit and well and no longer identifies himself as having lung cancer; he wants to focus on the positive and many charity websites have negative connotations for him such as Macmillan.

3.2 Personas and scenarios: Health Care Professionals

3.2.1 Surgeons

Surgeon 1 works in specialist surgical centre. His patients face a large operation that might have an impact on their ongoing quality of life; they may also have to go through further treatment — radio or chemotherapy — and may be moved from hospital to hospital. It is a lot for patients and their families to manage. There can be a psychological impact that can manifest itself in physical symptoms. Most people are referred back to their local hospital for follow-up so they don't have so far to travel. He thinks giving information is important, but prefers this is given in such a way that it instils hope for the patients, although if patients want to know about issues related to, say, prognosis, he will give this in a 'straight' way. There is a lack of data about quality of life after treatment and better evidence would be helpful to guide patients in making treatment choices: collecting this data as part of routine care would be very useful.

There is lack of longitudinal data about quality of life, so it is difficult to get an idea of patients' general welfare after treatment.

3.2.2 Respiratory Consultants

The respiratory consultants are chest physicians working in a local hospital, seeing patients at diagnosis and after treatment for follow-up in the local area.

Respiratory consultant 1 likes to see more isolated patients more often to keep an eye on them, as well-supported patients tend to either stay in touch themselves, or often a family member will call if there is an issue. One of the key aspects of care is the access that patients have by telephone to specialist nurses: they are a key point of contact between patients at home and medical staff. Only the minority of patients need to come back between appointments or be seen as an emergency, as issues can be dealt with by the specialist nurse by phone and liaising with other services: care is much more symptom and patient-led between appointments. Without regular appointments patients could perceive that they are being abandoned. In many appointments he will do nothing active, but simply check that things are

okay through taking a history and asking about symptoms. This represents important contact for the patient. He gets a lot of satisfaction from working with the patient group and enjoys building relationships over time. He is cautious about giving too much information to patients about signs and symptoms to look out for in case patients spend all of their time worrying about whether they are losing weight or coughing up blood; there is a balance to be had in giving information versus worrying patients about the future.

Appointments have a supporting role for patients. Although few patients need to come back early, additional support between appointments is also important. Information should be balanced and possibly tailored.

Respiratory consultant 2 thinks communication between the treating centre and the local hospital is important. She would like a clear plan of follow-up to come from the treating consultant. She highlights inconsistency in care: some treating consultants will refer back to local centres for follow-up, but others don't. She would be very happy to have nurse-led or GP-led follow-up so long as there was a clear plan for the patient. She feels that there are a lot of information leaflets on offer to the patient — usually given out by the lung specialist nurses — but again recognises that every centre has its own information, help lines etc. and feels that some sort of standard information including self management strategies would be useful. She feels that on the whole the patient groups are not very proactive or able to manage by themselves and professional input is important in follow-up care. She has some anxiety that patients without professional input might miss the opportunity for further treatment if they are not followed up carefully. Lack of research evidence in the area makes it difficult to make decisions about the best way to follow-up patients after treatment.

Standardising information for patients would be helpful so it is consistent and patients have equitable access to it.

3.2.3 Clinical oncologists

The clinical oncologists work in a cancer treatment centre specialising in radiotherapy for lung cancer treatment.

Clinical oncologist 1 understands that as most patients are referred back to local centres for follow-up after treatment, having a good and trusting relationship with local clinicians is important. He keeps some patients who may require further treatment quickly, but gives clear direction highlighting in what circumstances he would retreat patients, e.g. for symptoms, to local consultants. He acknowledges that although there have been advances in the treatment for lung cancer, for most patients palliative care is an important component from early on. Follow-up is determined on an individual basis and there are no set rules about which patients will be referred back locally, but acknowledges that the treatment centre can be 30 miles from where people live and that it is not always beneficial to ask frail elderly people with no transport of their own to come to the hospital for a regular check up. He feels communication with patients about their prognosis and the aims

and outcomes of treatment is difficult. Most patients have palliative treatment (for symptoms or to slow down the tumour growth) and many feel better after this and feel that they are getting better and think that the prognosis has changed when it has not. Again he feels that patients are not very empowered so tend not to be proactive about monitoring symptoms themselves. He does think that keeping a diary or monitoring symptoms would be useful as long as this could be translated into an action plan. Further information about what symptoms to look out for and how to contact HCPs (most likely with the GP as a first port of call) would maybe be more useful. He does not think that patients would read large amounts of information.

He has anxiety that lung cancer patients are not very proactive and to leave patients to fend for themselves would mean patients could fall through the net. Monitoring symptoms might be helpful but patients may need professional support to turn this into an action plan or to manage these.

Clinical oncologist 2 sees patients after curative therapy once to check for toxicity of treatment, and refers them back to local centres for follow-up care. Palliative patients are followed up in the specialist service only if they are fit for further treatment (this applies to up to 50% of patients) so follow-up clinics are getting very busy. Patients can deteriorate very quickly and communication between centres is very important in order for patients to be referred between clinicians as quickly as possible. He thinks that in particular there should be stronger links with the palliative care services for these patients. He highlights that choice is important to patients and they should choose which model of care would suit them best. Continuity is also important for the patient. Self-management approaches and non-HCP support would be useful for some patients who want to get some control back over their lives, but many lung cancer patients are not like that and rely on HCPs to tell them things are okay. He does not see that this could be a substitute for HCP-led care. He thinks that many patients would not report their symptoms because they do not want to bother professionals even if they know who to contact if there is a problem. He considers that there is very little data on the population to understand who might need more support after treatment so it is difficult to stratify patients and identify those who need more support.

Communication between clinicians is vital particularly if a patient needs urgent referral. It would be useful to have a means of monitoring this.

Clinical oncologist 3 sees lots of patients on clinical trials who are followed up and supported by strict trial protocol. She acknowledges that patients are often given very little information about what to expect after treatment and patients can experience, for example, long term shortness of breath that they have to live with for the rest of their lives. Many of these patients also have co-morbidities — especially lung disease related to smoking which can impact on their recovery. She thinks that patients would benefit from further information about issues that might develop in the follow-up period. Decisions about where patients are seen after treatment depends on their clinical status: if suitable for re-treatment they will be kept in the treating services; if palliative they will be referred back for local follow-up. There is

some concern that chest physicians are not up to date with new treatment options and may miss the opportunity for patients to have further treatment. The volume of work in specialist centres is growing, however. This can make clinics unmanageable, so she has to be selective about which patients she continues to see. A limitation to the supportive side of care is that there are only 2 specialist nurses (compared to 10 consultants), so they cannot see every patient to give information or support. A lack of resources therefore makes it difficult to change follow-up. The pressure on time makes it very difficult to collect routine data on patients, quality of life, symptoms etc. that would build evidence about the needs of the population and the natural history of disease after treatment. Due to lack of time in follow-up clinics issues such as managing breathlessness, cough and smoking cessation are often not addressed. She acknowledges that many patients in this group come from deprived backgrounds and have not looked after their health in the past and is uncertain about whether patients would make use of information or self-management techniques. She suggests that the key issue is for patients to know who their local contact is if they need to get in touch with the health services.

Collecting quality of life data particularly about patients have new treatments is not possible in busy clinics.

3.2.4 Medical oncologists

The medical oncologists work in specialist treatment centres specialising in chemotherapy treatment.

Medical oncologist 1 acknowledges the lack of consistency in follow-up (this is individually determined by treating consultants). He does continue to follow-up many of his patients as his experience is that if they are referred to local chest physicians they are unlikely to be referred back for further treatment. This means he needs to be proactive in his care, so that patients do not miss treatment. His experience is that even younger patients who are intelligent and articulate do not contact the hospital between regular appointments if they are having problems, and this can mean by the time they do come back they are too ill to treat. Managing communication and co-ordination between services is difficult and could be improved. It may be beneficial to run multidisciplinary clinics which would improve communication and relationships between the multidisciplinary team.

Patients do not contact HCPs between appointments, even those who are articulate.

Medical oncologist 2 tailors follow-up to the individual, taking into consideration the distance they travel, their preference and their disease status so it is difficult to be prescriptive. He highlights the difficulty of explaining the aims of treatment and follow-up to patients, and that treatment does not mean cure for most people. Patients often come with lots of little questions at follow-up — can I have my flu jab?, can I go on holiday? — which could be managed outside a clinic appointment. Another potential difficulty for the patients is uncertainty about the prognosis and what might happen in the future. Managing this needs skill and understanding of

what treatment and care is available if patients become unwell. This may be best done by specialist treatment centres. He acknowledges that information for patients is important but that professionals don't get it right all the time. He is not sure whether they do deliver information in the right way by giving leaflets as increasingly people use the internet, watch television a lot, DVDs etc. When working abroad he came across living with cancer programmes that supported patients after treatment and thought this was very useful. Planning care after treatment is complex as many patients will have a poor prognosis and will need palliative care so it is a complex decision as to whether to start being explicit with patients that this is where the plan is heading: towards end of life care. He would not want this to become a tick box form filling exercise, or having something too prescriptive when patient needs change very quickly.

Living with cancer programmes may benefit patients after treatment; this cannot always be addressed in busy clinics. A patient's condition may change very quickly and regular contact with HCPs is important.

Medical oncologist 3 feels that the transition between active treatment and follow-up is not know that is always well managed; it is not always explained clearly to patients about the outcome of treatment and what the aim of follow-up is. She feels that a care plan would be helpful in addressing these issues. She acknowledges that many patients find the end of treatment very difficult and that it is not always managed well: they go from regular intense contact to coming to the hospital every 3 months. She feels that maybe she does not focus enough on giving information at that point about what symptoms patients should call the hospital about and what the further options for treatment are. One solution would be to shorten the time between appointments but then people have to come back often but for very little purpose. She wonders whether proactive intermediate phone checks with HCPs might be helpful to bridge the gap between appointments. HCP-led care would be preferable because patients often do not contact the services even if they are having quite significant problems at home. A more multidisciplinary approach would enhance care so different professional perspectives are discussed. The focus in busy clinics is often on survival and treatment and there can be little time to address symptoms or quality of life and this is often not documented well. In particular, the outcomes for patients on new or complex treatments are not well understood.

Care plans following treatment would be useful to support patients at home, so everyone is clear on the plan of care and patients can be encouraged to get in touch if things change.

3.2.5 Palliative consultants

The palliative consultants work in specialist palliative care across the hospice, community and hospital settings.

Palliative consultant 1 offers a specialist service where patients are referred for specific issues such as pain. The aim is to resolve these issues; he does not take over a patient's care but rather offers a consultative service. This can cause

some issues as the doctor does not know the patient before they are referred, and they can be working with doctors with a number of different models of care. He thinks it is valuable for the patient to be in touch with the palliative care service as for most patients they will need the service at the end of life; then the doctor can build relationships with the patient and family. Building links for the patient with community services local to their home is important, but he considers that patients should be able to choose the patterns of follow-up and who delivers this.

Patients are referred into specialist services: these professionals do not take over care but add specialist care often for a short time. Palliative care can have negative associations for patients and care can have a different ethos to oncology services.

Palliative consultant 2 is part of a specialist service that supports patients with complex symptoms, considering their psychological, social, and spiritual support needs. The service also runs as an advisory service for other professionals who need advice about the management of a patient. She has to work with a complex team of nurses and doctors in community and secondary care services, so communication and building trust is very important. Discussing prognosis and aims of treatment is important with this group of patients; the focus is on quality of life whilst being aware prognosis is poor. She feels this is easier for a doctor to manage in the palliative care setting rather than in an active cancer treatment centre when the focus may be on treatment rather than quality of life. She gives patients copies of her letters to the GP or other HCPs so they have a record of what has been discussed but rarely gives written information booklets as there is a lot of uncertainty in palliative care. Information booklets can be very general and in fact can lead to uncertainty if they don't apply exactly to a patient's situation. In most cases she makes it clear to patients that their main point of contact is the GP not the palliative care services and she writes to GPs to update them with information. Some patients are managed very proactively and others she is happy to leave with open access if they need it. Continuity in the service is very important: this includes good communication with other parts of the service so everyone is informed about the patient's status.

Communication between HCPs and patients is very important. In particular recommendations for the care of individual patients need to be circulated to patients and the rest of the team.

Palliative consultant 3 believes the card of the nurse specialist is a prized possession: patients use the number regularly and it is often used for signposting e.g. patients may have questions about flying or the flu jab. A strategy for empowering patients or self management may be useful for 30-40% of patients, but for many patients their social and psychological makeup would make that very difficult to use. But for those people who could manage something like breathlessness themselves it might be really useful to give them some control back. Some patients who have had breathlessness training so they can manage it at home have found it very helpful, but those resources are not available in every locality. There is a danger of bringing people back to clinics unnecessarily and being too medicalised in focus.

It would be useful to have online symptom management resources that could be

used by patients to prevent extra appointments. Face-to-face interventions are not available in every locality so online resources could make care more accessible to all patients. Patients may have to be assessed for their suitability for these programmes.

3.2.6 Nurse specialists

The nurse specialists work in a supportive care clinic for lung cancer patients at a local hospital alongside medical-led clinics.

Nurse specialist 1 spends a lot of time with patients who are anxious, talking about treatments and medical issues. She also focuses on issues like how patients are doing at home and checking they have access to all the benefits they are entitled to — things that are more nursing-focused than the issues dealt with in medical clinics. She sees patients in the hospital and would like to be able to see people at home. Although logistically it would be very difficult, she would like to offer it as a choice to patients. She spends a lot of time in communication with primary care services, but she feels the hospital services get very little feedback from HCPs in the community about the status of patients. She wonders whether a patient-held record would be helpful to ease communication so that this could be brought to the hospital and also used by professionals in the community and it would have up to date annotations from HCPs. She also thinks that this would be useful for patients as they can sometimes forget things they need to ask about when they come into appointments. She thinks that patients get particular benefit from seeing specialists like nurses at the hospital as they are more attuned to the specific issues and symptoms of lung cancer and can focus on those. She ran a support group at the hospital but few patients actually attended even though they said they wanted support, so it seems that patients want tailored individual support rather than group support. She feels it is important to follow-up with information booklets for patients to take home if they have been talking about specific issues such as diet and she can refer patients out to services such as breathlessness clinics because she does not have the time to run these herself. She feels some sort of rehabilitation programme would be useful for post-surgical patients in particular. She would support better information available through self-management programmes as patients' problems do not tend to coincide with clinic appointments, and giving patients more control to manage symptoms themselves may be very useful. But she is concerned that patients often do not call and say they have problems and so care has to be very proactive from the HCPs. She thinks that family members would also benefit from further information about supporting the patients at home.

She highlights communication between primary and secondary care as a problem.

Nurse specialist 2 works in follow-up, which is adaptable and dependent on the patient's condition and preference. Her role in follow-up focuses on symptoms and everyday living with the disease and generally coping with things at home. She feels in general that the role of follow-up is to keep tabs — a check on patients — as they tend not to be proactive about coming forward with issues, and so they don't feel abandoned at the end of treatment. They do not give people information routinely

after treatment as she feels you can never anticipate what will happen but they tend to take issues as they come and address these with patients. She does feel that giving contact information to patients would be very useful, however. Ideally it would be great to have an information package that could be individualised for each person, but there is little time in the clinic to tailor things in this way. Brief information would be more useful for this patient group as they may not read it. Issues such as shortness of breath and cough would be good to give patients information on, but it is easy to overload people with information. She does not feel many patients do read the information leaflets they are given. Giving too much information might also generate worry and people might call over *potential* problems rather than issues they are *actually* facing. She thinks that telephone follow-up might be useful to check on patients and it may then be possible to increase the time between appointments as you are dealing with issues over the phone.

There is little time in clinic to personalise information for patients and nurses do not want to overload patients with information in short appointments. Telephone follow-up would also help to support patients.

Nurse specialist 3 has a flexible role that allows her to be patient-led, so she can visit patients in their home if they are struggling. She has good links with community services which she thinks are vital for the management of patients. The majority of patients do want to be seen in the hospital although the choice to be seen by the GP is there. Patients contact her by phone a lot and she spends a lot of time responding to queries and problems through that route. By calling the nurse patients have quick access back to medical consultants if the nurse can't deal with it by phone or she may refer them on to their GP depending on the problem. Lung cancer care needs a multidisciplinary focus due to the complexity of problems and models of care need to be flexible. One of the biggest issues for patients is fear of recurrence, so worry and anxiety is a problem. She is concerned that if HCP care was diluted that patients would fall through the net as patients are reluctant to call for help when they need it, although this is variable and some patients phone all the time. She feels it is better to have face-to-face appointment in the diary which can be cancelled if a patient feels well than wait for a patient to contact the hospital. She would like to offer more support to patients but is not sure of the way to do this — whether it should be through face-to-face groups or through giving more information to people.

Specialist nurses are key to the management of patients. They are often the first point of contact if patients are having difficulty and they have a gatekeeping or sign-posting role to other services. These ad hoc contacts from patients are difficult to manage for specialist nurses in terms of managing their workload, but she does not want to move away from a more traditional model of face-to-face contact in case patients slip through the net.

3.2.7 Palliative care nurses

Palliative care nurse 1 works in a lung oncology treatment team with a focus on supportive needs. She tends to see people early on and during treatment and after treatment if there are any issues. She calls patients regularly in follow-up to check everything is okay and she spends a lot of time dealing with telephone calls from patients or families. She will often phone patients after an appointment to check if the patient has understood everything or if there are any other issues. Her role is to deal with problems as they arise and refer people on to the appropriate services if there is a problem. She particularly keeps an eye on people who have less social support at home. Many patients will not ask for help or support so she tries to be proactive in her care. She does offer information to patients but many are happy to go with what professionals say to them and don't want an information leaflet; they just want to get back to normal and forget about their illness. Some patients also have poor literacy skills and don't want to highlight this by taking a leaflet. The nursing team manage information and will provide help if the patient asks, for example, about going on holiday or about finances. They are aware that patients do feel vulnerable at the end of treatment and send a letter to say they can still call the service and all the telephone numbers. Continuity and getting to know patients is important to pick up subtle changes that might indicate problems such as brain metastasis.

A good relationship is important to get to know patients and know what patients want and their preferences. Information is tailored to the patient's needs. Relationships are facilitated best by face-to-face appointments, but follow-up telephone calls are also important to check understanding.

3.2.8 GPs

GP 1 works in deprived area of Manchester and sees 3-5 patients per year in his practice — a high prevalence rate. GPs are generally not involved in follow-up but the general support and care of patients.

Patients will be sent for investigation by the GP if lung cancer is suspected and patients will be diagnosed at their local hospital. Patients are then seen by the treating centre sometimes for 3-6 months and lose contact with the GP who is not always kept in the loop about patients' progress by the treatment centre. He feels this is something that could be addressed. He feels that this could be best done by direct (telephone) contact by the treating centre to update the GP on treatment and what information has been given. GPs consider themselves gatekeepers of care and find it very difficult when that is taken away from them when they lose contact with a patient. Personal contact would be preferable, as a letter can be missed as it can be opened by other GPs in the practice. It would be useful to get an end of treatment plan from the treating centre so everyone knows what the aim of follow-up is. This could include likely survival and alternative treatments that may be considered. What should happen if things go badly? What has the patient been told? It would be nice to include these things in a document because GPs get different things from different clinics. They sometimes get annotations from the

notes but these are not always helpful to the GP as they are in oncology speak! GPs can't attend hospital-based case conferences due to their own workload in the community, so a liaison role would be useful for managing information. He feels that patients do get frustrated with the GP because they are not informed about the plan of care by the hospital and cannot answer patient's questions. He thinks that large information packs are not usable in practice; personal individualised communication is better so a GP know exactly what to do with an individual if they present with a symptom and understands whether or not they need a referral back to specialist services. He thinks patients can feel let down in the post treatment phase as they are told to come back in 6 months with little support in between.

Communication between secondary and primary care can be slow and does not always happen effectively. There is a lack of communication between services and doctors and nurses are unlikely to know each other personally.

Cancer Care Services, Royal Brisbane and Women's Hospital, Herston, Queensland, Australia. Email:

Brett.Hughes@health.qld.gov.au. Most will develop "acquired resistance", either through secondary EGFR mutations or activation of EGFR-independent pathways. Clinicians should therefore consider re-biopsy at progression to assess contemporaneous tumour biology (74-77). As with EGFR TKIs, resistance can also develop to crizotinib for ALK rearranged NSCLC. Unfortunately a wide variety of mechanisms are being discovered including; ALK amplification, EGFR/HER1, HER2 and HER3 up-regulation, cKIT amplification and various ALK mutations including L1196M (analogous to T790M for EGFR) (107-110). Lung cancer patients have been found to have a significantly higher burden of unmet psychological need compared to other cancer patients,[1] with studies quoting up to 43% of lung cancer patients experiencing psychological distress compared with approximately 35% of patients with other cancer diagnoses.[2] The psychological distress of lung cancer patients has been found to persist throughout the clinical course of. These guidelines have been developed following review of current literature, taking into account the limited number of randomised control trials, small sample sizes, heterogenous samples and high attrition rates in this population. Back to top. Psychosocial treatment of depression. Lung cancer patients also report the highest levels of psychological distress and symptom burden than any other forms of cancer (Linden, Vodermaier, MacKenzie, & Greig, 2012). 76 Background: For lung cancer patients and caregivers, navigating the healthcare system while coping with the complexities of the illness is challenging. We explored organizational barriers to receiving quality healthcare from the perspectives of these stakeholders. Interview analysis focused on patients and carers as individuals and pairs, exploring multiple dimensions of their coping experiences. People draw from pre-diagnosis coping strategies, but these develop through responding to the experience of living with advanced cancer.