

○ CANCER FOLLOW UP CARE

THE VIEWS OF PATIENTS AND CARERS
EXPRESSED IN A RANGE OF FOCUS GROUPS

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The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. We undertake a unique combination of research, development and policy activities which together work to make patients' views count. There are three key strands to our work:

- Measurement - researching and evaluating patients' experience
- Improvement - leading initiatives that make improvements happen
- Policy - building evidence to inform health policy.

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CONTENTS

Executive summary	4
Introduction	4
Introduction	8
Group 1: women with experience of follow up care for breast and gynaecological cancer	9
3.1 Participants	9
3.2 Definitions of follow up care	9
3.3 Views of aspects of follow-up care	10
3.4 Views of some alternative models of follow-up care	21
3.5 Agreements within Group 1	25
3.6 Variations within Group 1	25
Group 2: carers of patients with experience of follow up cancer care	27
4.1 Participants	27
4.2 Definitions of follow up care	27
4.3 Views of different aspects of follow up care	28
4.4 Views of some alternative models of follow-up care	36
4.5 Agreements within the carers group	40
4.6 Variations within the carers group	41
Group 3: men with experience of follow up care for prostate cancer	42
5.1 Participants	42
5.2 Definitions of follow up care	42
5.3 Views of aspects of follow up care	43
5.4 Views of different models of care	50
5.5 Agreements within the prostate cancer group	54
5.6 Variations within the prostate cancer group	56
Group 4: men and women with experience of follow up care for cancer requiring extensive monitoring including invasive procedures	57
6.1 Participants	57
6.2 Definitions of follow up care	57
6.3 Views of aspects of follow up care	60
6.4 Views of different models of care	69

6.5 Agreements within Group 4	72
6.6 Variations within Group 4	75
Group 5: men and women living with the long term side effects of treatment for cancer	78
7.1 Participants	78
7.2 Definitions of follow up care	79
7.3 Views of aspects of follow up care	84
7.4 Views of some alternative models of follow-up care	96
7.5 Agreements within Group 5	100
7.6 Variations within Group 5	104
Similarities and variations between the groups	107
Introduction	107
Definitions of follow up care	107
Views of aspects of follow up care	109
Views of different models of care	119

Executive summary

Introduction

The Picker Institute was commissioned by NHS Improvement (formerly the Cancer Services Collaborative 'Improvement Partnership') and Macmillan Cancer Support to examine patient and carer views of health and social care services following treatment for cancer.

To gather opinions, five focus groups were held with people who had direct experience of cancer follow up care. The five groups were made up of one group of carers as well as four groups of patients who had experience of one of the following aspects of cancer care:

- gynaecological and breast cancer
- prostate cancer
- invasive procedures
- long term side effects.

The views gathered were examined to identify both commonality and difference of opinion. In addition the views of each group were separately examined to establish both areas of consensus and disagreement between the groups.

Common experiences of follow up care

Findings revealed a number of similarities regarding follow up care across the groups. These were:

- most patients had their follow up appointments with a specialist at the hospital, though in the later stages of their treatment some saw their GP for part or all their follow up care. Most patients also had more informal access to a Cancer Nurse Specialist (CNS).
- patients in all groups believed the main purpose of follow up appointments was to provide reassurance, particularly around recovery and absence of symptoms of a recurrence
- most participants, except those in the side effects group, described broadly positive experiences of follow up care, but also talked of certain difficulties they'd had.
- patients living with the side effects of treatment appeared to have had particularly poor experiences of follow up care.
- Those with the 'best' access to follow up care often described 'working hard' to get it.

- the most common problems related to access to care which were caused largely by a lack of the following:
 - co-ordination
 - local provision
 - integrated and holistic care
 - specialised services either locally or, in some cases, nationally.

What participants thought of follow up care and its delivery

Rapid access to specialist medical care

Patients in all groups regarded having rapid access to specialist medical care when they had concerns as very important. They described both positive and negative experiences of accessing appropriate specialist care and there was a view that it was 'hard work'. Concern was expressed that some patients might not be able to access specialist advice if they did not have certain personal attributes and skills, such as confidence or tenacity.

Accurate information about what to expect following treatment

Many participants were critical of information provision and would like to have received more information. They appeared to have had little information provided by health professionals about what to expect during their follow up care.

There were particular gaps in the supply of written information and this was seen as a priority for improvement. It was suggested that health professionals only provided information on request and the only patients who got information were those who asked the right questions.

A lack of information was seen as potentially leading to feelings of 'frustration' and 'isolation'.

Help with returning to (and staying in) work

Returning to work after treatment for cancer was generally regarded as difficult and the ease with which it happened depended largely on support provided by the employer.

There was agreement that information to raise employers' awareness of the issues involved would be helpful.

Advice about benefits

Participants in all groups described difficulties with getting advice about benefits. Most had not received any help with obtaining financial support while they were unable to work and some had experienced financial hardship.

It was suggested that advice about benefits would be helpful as many people with cancer were at risk of financial hardship.

Psychological support

Participants identified the ongoing need for psychological support from the beginning, at diagnosis, right through to follow up care. They felt support should be provided on a range of issues tailored to individual needs.

Many of the participants were members of support groups and they quoted this as a source of psychological support. Few patients in any of the groups had received any other emotional support, though many said they would have benefited from this.

Support for carers (and/or family and friends)

Participants agreed there was a need for support for their partners, carers, family and friends. The patient groups focused predominantly on the need for emotional support, while the carers also discussed the need for help with more practical aspects of providing care.

Few participants in any of the groups had experience of psychological support for carers.

Being seen at a GP surgery

Many patients said they would prefer not to have their follow up conducted by their GP because of problems with:

- lack of specialist knowledge
- access
- continuity.

Those patients who were more receptive to GP follow up were most attracted by the potential reduction it offered in trips to hospital, particularly if the hospital was not easy for them to reach.

One suggestion made (in the gynaecological and breast cancer group) to help facilitate more GP follow up was to expand the role of the CNS, so that they went out into the community and brought their specialist knowledge to GPs.

Being seen at hospital

Most participants had a strong preference for having their follow-up care delivered by a specialist at a hospital, for similar reasons as those outlined above. Very few patients, and no carers, raised any concerns about being seen at hospital. However, practical difficulties in attending hospital appointments were often acknowledged.

Knowing who to contact

Most participants said they now knew who to contact if they had a problem, but that this was only after having made efforts to establish who their contact was.

Many people expressed the need for a single point of contact and most made initial contact by telephone when there was a concern.

Seeing the same specialist consultant/nurse

Continuity of care was generally regarded as a high priority during follow up care. It was considered very important to see the same specialist (either a consultant or nurse) at each appointment throughout treatment and follow up to ensure this continuity.

Most patients had seen the same specialist throughout their treatment and follow up. They commented favorably on the impact this had on their care and the benefit of a specialist knowing the history of their case.

A small number of participants described problems resulting from a lack of continuity of care and/or integration of care.

It was suggested that having one central contact might help improve problems with continuity of care.

Views of different models of care

Participants were also asked to comment on three alternative models for organising follow up care:

- telephone follow up (nurse led)
- patient managed follow up
- group follow up.

Participants in all but the side effects group were generally resistant to these alternatives as replacements for existing models of follow up care, and many foresaw potential problems. There was, however, some limited support for all three models as ways of supplementing gaps in current care, particularly in the areas of support provision and the exchange of information.

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Methods

During February and April 2008 focus groups were held to explore the experiences and perceptions of cancer patients and their carers about follow up care.

Patients and carers were recruited for the focus groups through local cancer support groups, voluntary agencies and community networks.

The composition of the five groups was as follows:

- women who had experience of follow up care for gynaecological and breast cancer
- men who had experience of follow up care for prostate cancer
- carers of people who had experienced follow up care for a range of cancers
- people who had experienced follow up care that included invasive procedures
- people who were living with the side effects of treatment for cancer.

Each focus group was facilitated by a researcher from the Picker Institute using a topic guide developed in collaboration with the project steering group. Groups met for approximately one and a half hours.

Group 1: women with experience of follow up care for breast and gynaecological cancer

3.1 Participants

The nine participants in Group 1 were made up as follows:

- five with gynaecological cancers (ovarian, vulva, endometrial)
- four with breast cancer
- all were members of two different support groups.

3.2 Definitions of follow up care

Most patients in Group 1 defined follow up care as the care they received after their cancer treatment was completed:

I think that mine was just surgery – I was lucky, it was clear, so I had no radiotherapy, no chemo or anything like that so as far as I am concerned everything since my surgery is follow up care

Oh yes – when the treatment is completed.

These patients specifically referred to the regular check up appointments they attended, such as the three monthly appointments set up with a specialist:

I see the skin specialist still who is trying to improve the skin in that area and also I see the oncologist surgeon... I see them both still every six months. So basically every 3 months I see one or the other.

One patient felt that physical examinations were the most important aspect of follow-up appointments. In contrast, another patient felt the opposite, that fewer examinations were necessary.

Other patients in Group 1 also talked about the more informal contact they had with their Cancer Nurse Specialist (CNS) in addition to these check up appointments:

...you have got CNS's in between that you can refer to if you have got any worries or any problems.

Three patients mentioned experiencing complications or after effects since their cancer treatment. For two of these patients, the treatment they received for these effects was distinct from the initial cancer treatment and was also defined as part of follow up care.

Because I have got lymphodema obviously I am still being followed up all the time. Trying out different things which haven't worked but it wasn't for the want of trying.

I would have said my treatment and follow up for the lymphodema was follow up as against treatment. I felt the treatment side finished, like (Name) said, sort of 3 weeks after you had finished your radiotherapy – that was the end of treatment and then you waited for six months. But during that period I was followed up because I developed lymphodema and I count that follow up work as follow up rather than treatment if you understand me.

However, for one patient, the treatment she received for the same side effect was part of treatment rather than the follow up, and only after this treatment was finished would follow up begin.

(Talking about physical side effect) I would have called that an outcome of the actual treatment which ought to have been dealt with in the treatment phase. But once you have got beyond that, that is when the follow up cycle, to me begins.

One patient commented that the definition of follow up care depends upon the individual, their situation and support from others.

It is individual – for me because I have no relatives here – but I was fortunate I had excellent friends who are not here any more.

3.3 Views of aspects of follow-up care

Rapid access to specialist medical care if I have a concern

Most patients in Group 1 had a direct contact number for their consultant or cancer nurse specialist (CNS) to call if they had a concern. This number was made available to them both during the period when they were still having regular check up appointments, and after they had been signed off. These patients who had a contact number for their specialist found it reassuring to have direct access to specialist knowledge and the continuity of speaking to the person who knew their case.

I was told that when I was signed off in September after five years – just ring me – this was the consultant – just pick the phone up and we will see you as quick as we can.

I was told don't bother with the GP phone up and speak straight to me.

I have not been signed off yet but I still feel that I could ring up (the CNS) any time that I have a problem.

I think that is the most important thing actually to know that because half of the healing is – yes I can do that – I can go in there.

Continuity is important – but also easy access to advice must be important too – not to be sort of fobbed off with – “Well I will get him to ring you back when he comes back from holiday” or something like that – it should be easy access and instant advice or if not – I can’t find out now but I will get straight back to you and mean it – get straight back with the answers.

One patient in Group 1 had not been provided with a contact number for her specialist after sign off, instead she had been told to go to her GP with any concerns. This patient felt she would have preferred the option to continue to contact her specialist directly. However this was not the opinion of two other patients who had gone to their GPs with a problem, both were satisfied they had received timely access to specialist care - in their experience, the GP was able to arrange an appointment with a specialist within hours.

I had a slight concern and I went to my doctor and they just phoned straight after and got me an appointment.

Well I had just to go the GP (and they sent me) straight to the hospital... I could even have had transport but I said no I would go myself – that was perfect.

Accurate information about what to expect following treatment

Some patients in Group 1 felt that the information they needed about what to expect following treatment had been fully available to them, when they needed it.

Well whilst undergoing treatment, there were a number of leaflets available just on stands etc. and handed out, which I felt did cover the follow up really. Maybe because once you have had your surgery, once you have had radiotherapy, chemo before all that – you just need to get back to normality so a little bit on nutrition – a couple of paragraphs maybe, and keep the exercises and get back to normal, was really all I feel, for breast cancer, is what you need.

Other patients said they would have preferred more information to be provided about side effects and how to deal with them, perhaps in advance. It was not clear, but it seemed that this difference was not simply due to variations in the amount of information provided, rather, that there were individual differences in the amount of information each patient required, depending on various factors, including the type of cancer, type of treatment and the severity of potential after effects or side effects.

Well I would say that you actually need more than that – having had a lot of side effects I needed far more information which I wasn’t given. Whether that is because people thought, oh it’s (Name), she knows. I did have a tremendous amount of trouble with joints that were swelling up with fluid and peripheral neuropathy and I couldn’t walk, I couldn’t move, my hands just seized up on me, I developed diabetes. I just wish that somebody had sat down and talked to me... but when people did start listening to me and I started getting the information that I wanted and I started on an exercise programme and the diabetic people sorted me out then my

life was transformed but I had to go through that – it was lack of communication and lack of support I think at that particular time.

When I was diagnosed and (consultant) tells you the good news and then you go out with the cancer nurse specialist in floods of tears – I don't think you take in everything. I felt that we took in as much as we needed, but I was never ever told about lymphodema and that is, I think, one of the worse things as an after thing and I never ever anticipated the problems with lymphodema.

Also of course there are long term side effects from radiotherapy – I don't know about chemo because I have never had it – (Name) and I were discussing this earlier – she is 3 ½ years on and I am 5 ½ years on – still have awful side effects with our bowels from the radiotherapy and I do with the bladder but more so with the bowels. So that can quite govern your life because it is very difficult to diet because as soon as you start eating the green vegetables and the salad stuff etc. etc. you spend all day, every day in the loo unless you take medication. Then you go back to the radiotherapy diet which is very unhealthy but it does the trick, it is all white bread, white rice, cake – you must eat cake – nobody has ever told me to do that – but it is so unhealthy and it so puts weight back on again that you are fighting a losing battle. You are on like a roller coaster – and that is long term.

Several patients had not been made aware of the reasons *why* they went to follow up appointments, the reasons they went, *when* they did and *what* the follow ups were looking for. Within this group of patients there were those who had been able to ask these questions, but another had not felt comfortable enough to ask these types of question during her follow up appointments, she felt it should be the clinicians' responsibility to provide this information, without the patient having to ask.

Then you go for your follow ups but nobody tells you what they are looking for or why you go from 3 months to 6 months. Why up to 5 years and then no more – what is to prevent anything happening after 5 years. If you are going to have follow ups, why do you stop there, what are you looking for and why six months? I think I knew but I wasn't given the information because I was also a nurse so obviously I didn't push it but nobody said "We are looking for"

I asked the oncologist why after five years it stops and how would I know? And he said it is not necessary to go back every six months or even a year because it might develop, it might not but you know your body and you will feel that there is something. That was the question – why are we not seen after 5 years?

Yes – unless you specifically ask – why should it be waiting until you ask. I know there is a theory that you only really want to know if you ask and you won't take it in unless you ask – it is too much information before you are ready for it but I didn't feel the opportunity was there to discuss the follow up and what you are looking for and why.

In addition to knowing what their follow up appointments were looking for, some patients had been told of signs and symptoms to look out for themselves, although this was largely due to patients specifically asking for this information rather than clinicians being forthcoming.

I feel that I knew why I was going back for follow up – that I am far more likely to get a second primary in the other breast than I am to get secondaries. So I know exactly where my focus is and what I am looking for and that I need to make sure I have a mammogram every two years etc.

But unless you ask – this is it. But if you are told “If you have pain – unexplained bleeding, weight loss” and a list of things “Please report them and let us know”. But you are not told how to look after your body.

The information provided on what to expect and reasons for follow up care could be described as mixed – information was available, but there was a reliance on the patient to ask questions. Almost all patients in Group 1 agreed that they would have liked more holistic information on how to improve their health and well being in general (additional to specific information on side effects etc.)

But the one issue I would have and would like to lay on the table really is that the care I had and the treatment was entirely to get me well and I am really grateful that that was the focus but there was nothing on how to lose weight, how to get fit, what sort of vitamins are useful, what alternative therapies have a scientific validity and may have helped which didn't. And I think a little bit more guidance in that line would be what I felt could have gone in to make the package perfect rather than excellent.

What I don't feel I had was how to take care of my body and that I think is a different issue. Because when I was told I was diabetic and I had to lose weight, within 3, 4 or 5 months I had lost 2 stone – I should lose another 2 but I was told to do it and I was told how to do it and I did it and I felt better for it. I was told “You are at greater risk because you are overweight of having another primary, go away and lose weight” but that was it full stop. No how to go about it and what to do. That I think is the difference that follow up involves making sure you haven't got another cancer or a secondary from the same cancer but it doesn't involve making sure you are well and fit and living life to the full. That is really where a health service ought to be coming from.

Help with returning to (and staying in work)

A couple of patients had returned to work during their treatment, while others had stayed off work until after treatment was finished. Similar issues were faced by both groups, although the patients who stayed in work during treatment perhaps found their employer had raised expectations of what they could do after treatment was finished.

Two patients had had particularly difficult transitions going back to work, both felt their difficulties were largely due to a lack of understanding by their employers, in terms of the workload they were expected to be capable of and the additional support they required.

The company that I worked with were not particularly supportive with me being unwell and having time off work because I was unwell.

It was actually getting people to listen to me because I was not feeling very well and I was struggling on certain issues and definitely with regards to returning to work

because at the time I was working as a senior nurse on the palliative care unit and I really did not feel that was addressed properly.

Inflated expectations of workload capability were a problem not just from employers expecting too much from returning employees, but also, as one patient pointed out, people not knowing what to expect from themselves.

I didn't know what to expect of me when I went back to work and my employers didn't know what to expect of me ...when I went back, which was about four weeks after I finished the Radiotherapy. I expected to do a days work and they expected me to do a days work and I wasn't ready for it. It would have been nice if there was a "How to get back to work" guide that you could take in and hand out - that would be something really positive to get out of this.

Taking time off for follow up appointments had been a problem for a number of patients, since these could not be made outside work hours, and had to be attended every few months. Again the help was needed here to improve employers understanding of the importance of these appointments.

I think it is just about the fact that you need time off work to go for follow up appointments and again we are back to the fact that some employers don't actually see that as a priority. Some of them expect you to take you doctors appointments outside of working hours which you can't because that is not offered to you. So the issue is taking the time off work and you may have to take annual leave to go and have your follow up check up, or unpaid leave. And also the pressure on - that is not a convenient day for you to go because something is happening at work. So I think it is an understanding on the employer as to why you need to go for those appointments. Again we are back to understanding what the appointments are about not just for you but for the person who is actually having to release you to go for that appointment. So yes there are issues around the fact that you do need to take time if you are going every 3 months, that is a half day every 3 months which can tot up.

Together with help to facilitate the return to work is the need for help with finances. One patient felt that due to financial pressures, she had returned to work sooner than she should have, which added to her problems with this transition. She felt information and advice on finances and how to get financial support provided early on, would have allowed her to plan her return to work better and perhaps given her more time off to recover fully.

They were not particularly supportive in a financial way either and at no point did anybody say to me "You can approach MacMillan or anybody else for financial support if you need it", which actually would have made a difference because I returned to work probably before I should have done because I was concerned about our financial situation. Then I had extra pressures put upon me through work and having had time off to go for Radiotherapy - which again doesn't help for your recovery and as we all know when you are having Radiotherapy you get immensely tired and so with going to work and having Radiotherapy and having a lot of problems and issues at work who were not happy with me having time off to go.

There was nothing that I could take to work to explain to them what was happening and why I needed the time or what would happen to me as an employee. So there were those issues as well and perhaps there should be something more readily available for employers to understand what is happening to their employees during this time and the support they might need. Also around the financial implications as well.

The things that I felt would have helped – as a younger woman – were issues around financial support and returning to work which were not addressed at all and it became quite difficult... for me... It would have been nice to have had someone to talk to around dealing with going back to work, people's perception and also having to take time out of work to go for follow up check ups and things like that and managing your work's expectations of you when you are going through an illness and when you are having to have time off for continued check ups.

Advice about benefits

One patient had received a lot of support from Social Services, who had arranged financial assistance for her care whilst she was under going treatment, until she returned to work. This patient's experience seemed to be unique within the group and is perhaps linked to the lack of support from friends and family she mentioned earlier in the discussion.

Yes – because I was by myself and I didn't have my friends with me... a lady (from Social Services) came to the hospital and we discussed it... She said "We could put you into a rest home" – she found all the financial situation – fortunately I could go private as well – to a rest home – one third was paid by the National Service – the rest of me – or by the insurance because I had company insurance. I have to say I was paid for six months for it and it seemed to work – but it is all individual. Six months full pay – but going back to work after the chemo – going to this rest home – OK I didn't pay anything because the insurance paid – social services – they paid. It was also arranged for the transport for the chemotherapy, car there and car back.

As mentioned previously (see section on 'Help with returning to (staying in) work') information and advice on financial support, such as benefits, was lacking for one patient who needed this when planning the return to work. This view was shared by another patient in Group 1 who felt more information and advice was important from the beginning, rather than during follow up, so that it was not a worry.

The other thing is probably around help with financial information and support around what you can actually receive, whether it be financial benefits and that sort of thing is very, very important for anybody. As (Name) said – she went up to a nursing home and had lots of help with that because that is where she was but it should be available to you at the point of diagnosis so that you know that you haven't got to worry about that particular issue.

Psychological support

None of the participants in Group 1 mentioned receiving (or wanting to receive) professional psychological support, for example through counselling. Several patients felt

the need for psychological support was most crucial around the time of diagnosis and that the quality of support received at this time affected their psychological support needs during follow up care.

I personally think it is what input you had from that during your treatment is how you cope in your follow up and that is where – it is missing.

Yes it is too late (at follow up) because you have no reserves and you don't know whether you are coming or going. So I would question that psychological support needs to be introduced from referral really.

Another factor said to affect the need for support during follow up was how successful the recovery process had been. A couple of patients who had had a rapid recovery did not feel they needed psychological support, but acknowledged its importance for others.

I think there probably would (be a need for psychological support) but I don't need it. I was just so thankful that everything went so well and as far as I am concerned I have had it – it has gone – and we hope it doesn't come back.

Patients mentioned a number of existing sources of psychological support including clinicians involved in the treatment of the cancer, in particular the CNS since they would have an overview of patients needs. All patients in this group were members of support groups and they mentioned this as a source of psychological support. It was thought however, that the majority of people would not want to get involved in support groups. There was a feeling that there was untapped potential within the role of the CNS to provide psychological support. As mentioned earlier, psychological support from diagnosis, throughout the cancer journey, was seen as important. This CNS's involvement with the case allows them to monitor and provide continuous support throughout this journey.

I think psychological support is the focus from my point of view. Nurse specialists are absolutely focal to everything that is happening and they are the ones who are now giving the psychological support initially and following on through and I think that is really great... Cancer now isn't something that is treated in one way – it is treated in a wide variety; and follow up – there ought to be a pattern available that you mix and match so it isn't one treatment plan for follow up for everyone. Maybe cancer nurse specialists or whoever actually putting together an individual plan and reviewing that once a year and saying well "Your psychological needs are different now. You are better cut loose now and come back to us if you need to" or "You are better if you go into a group" or whatever. But we are all individuals as had been said on many occasions.

There were a variety of reasons given by patients in Group 1 for needing support and they described the need for different types of support, such as support with the changes to everyday life resulting from cancer or cancer treatment, support coping with physical changes and support for the effects on relationships with family.

Sorry – can I come in on this (discussion about psychological issues) because... breast care patients.... need a great deal of psychological support I am talking

about people who are 3, 10, 15 years (after treatment) who are still aware and conscious of the fact that part of their body is missing and it is exactly the same with men who have prostate cancer and have sexual problems and those two things – there is definitely not enough psychological support.

It is the understanding of other people because one minute I was sitting at my desk with a case load of 30 odd patients and the next day I was a crumbling wreck being told (I had cancer)... So there was a huge transition and it doesn't matter what job you do – everybody has that transition and it is how you are shored up then – is how you cope with your follow up.

And I think psychological support – later – as a person I had a lot of distress about what I was putting on my family particularly my husband.

Support for my carer (and/or family and friends)

Participants agreed that there was a need for support for their partners, family and friends. They focused more on the need for emotional support, rather than practical support with the activities associated with being a carer.

One patient felt that support for all those involved, carers and family, was particularly important during follow up because of the shift away from care by the clinicians. She felt there was a need for information to relieve fears of 'what happens next', either through written information or a help line contact providing some opportunity to ask questions.

They have got the questions, well what happens next because they are trying to protect you and they have got no one to turn to. So there is psychological support I think all around in some form or another, whether it is just a leaflet or whether it is a phone number that they can ring up to ask questions, perhaps not even just for your carer but for your family for your parents... Those who have children – there are all those people who are involved in this and then you think what happens now – you are not being seen any more – what happens to you now.

Another patient felt her family's need for emotional support had been around the time of diagnosis:

It caused enormous pressure in my family – because sadly my husband's first wife died of breast cancer and my young daughter – she just flipped – she just went – it was horrendous.

Being seen at my GP surgery

No one in Group 1 would prefer to have been seen for follow-up appointments at their GP surgery, rather than at the hospital. Various reasons were put forward for this with some producing stronger negative feelings than others. Continuity was seen as important for all the patients in this group and some felt their GP could not provide this. The specialist knowledge of GPs was also questioned; some doubted their ability to instil patient confidence and consequently to provide reassurance.

It (the follow up appointment) is somewhere to seek that assurance and feel that it is more specialised than going to your GP because they might not have the oncology experience. They might say oh no that's nothing to do with this, then go to your GP and maybe find another route. It is just that reassurance to come out and think - well that is alright then.

The relationship with the GP was also a factor; one patient would not have felt comfortable with her GP examining her:

My GP is very much not "hands on" - so he would not want me taking my knickers off. He would go into a decline - mind you so would I!

Two patients were more receptive to the idea, saying it might be appropriate to see their GP for some appointments to reduce the number of trips to hospital, particularly when the hospital may be more difficult to get to. One reason why these two patients were more open to the idea may be that both these patients felt they did not need as many follow up appointments as they had (see section on 'Being seen at hospital').

And maybe not every appointment, you could do every other one at your GP or something so you would still see your specialist but also see the GP as well and it didn't (mean) such constant trips to the hospital.

I think some people would in the rural areas where they have got transport problems and it is difficult to get through (to the hospital). Particularly if the GP had an interest.

One related suggestion was to expand the role of the CNS to go into the community and perhaps work with GPs with the benefit of their specialist knowledge:

I think the role of the Clinical Nurse Specialist is something that should be addressed by the Government and that role... should have a lot of money invested into it. Because I think this is the team that can given effective continuity follow up and they could go out into the community, they could see people in their GP surgeries, they could travel round and I just think it is a very undermined post... The whole profile of it needs to be raised up because they have got a resource sitting there looking at them and they are not using it.

Being seen at the hospital

As discussed earlier, (see sections on 'Rapid access to specialist medical care if I have a concern' and 'Being seen at my GP surgery') many of the patients interviewed appreciated the continuity and specialist care provided to them by their consultant and CNS. Perhaps because of this none raised any problems with being seen at the hospital. That said, it was highlighted earlier (see section on 'Returning to (staying in) work') that some patients had trouble getting time off work to attend follow up appointments at the hospital, and they were unable to get appointment outside of work hours.

In general some patients did feel that they had too many appointments with their specialists, and that these follow up appointments should have come to an end sooner, these individuals could have benefited from alternative options to being seen at hospital or even being seen at all.

I found that after care in the short term was incredibly good – It was very reassuring to have 3 monthly check ups initially. After a period of time I felt that I was seen too often and in fact I have now signed off from my surgeon with her consent and I see my oncologist next month and I am telling him goodbye. Because he would follow me up for ever. So I feel that the aftercare actually went on too long as far as I am concerned.

Well from my point of view, a year was enough for follow ups - I felt well and.. the (agreed). I think also from the point of view of gynae cancer, it is such a personal check - you were checked back and front at every check up - it is undignified to say the least and painful and really if it isn't necessary to keep putting you through that I don't think you should. And I do think that the CNS's could perhaps ring for one check up and... spread them out further perhaps... in cases where people are well. Obviously if you are poorly and there is something worrying you or they are concerned about the reoccurrence of the cancer then yes you should be checked more regularly but personally,... it didn't help me to go for the last 4 years.

However this feeling was by no means universal, others in Group 1 felt that they had the right amount of appointments. One patient said she would even have more appointments if necessary, another expressed concern at her appointments being cut off after 5 years.

Now to me I don't think I could have enough follow up care because it is in an area that I can't see -and I wouldn't want to go any less - I just feel from my point of view - for the cancer that you can't see or inspect that area yourself - that as much as possible I would keep going. I would go every month if it was necessary. I don't think I could have too much follow up care but it does depend I would say on the cancer because I would feel that if I had one that was inside my body- how would they know if it was happening again - they don't know - so I can't see the purpose of going as often. But from my point of view you could never have enough just for reassurance.

I am just over 3 years down the line so it is still quite fresh that you still need the reassurance that somebody is keeping their eye on you and that you have got an outlet for somebody to talk to if you feel there is something going on; bearing in mind that you live in your body and you are the one that knows how it feels.

I think until you know - maybe with the breast patients - nearly all ladies want some form of follow up treatments and you take it for five years and that treatment carries with it side effects like thinning of the bones and all sorts of things like that. So there is an ongoing thing for five years but it does always bother me that at 5 years they say "Right that's it, on your bike".

Knowing who to contact if I have a problem

Most patients in Group 1 said they would either contact their GP or telephone their consultant or CNS if they had a concern. The initial point of contact depended on the options made available to the patient by their clinicians.

Those able to contact their specialist felt this was an advantage. One patient specifically said they preferred to go to their CNS or consultant as the first point of contact for any problems and to then be sent elsewhere if their concerns were not relevant to their treatment for cancer. Others who had gone to their GP initially seemed confident that their GP would refer them on to a specialist if necessary.

One patient had an ongoing concern which she wanted a test for, however despite raising the issue during follow up appointments, this had not been made available to her. This patient had not taken any further action other than asking at her appointments, and clearly did not know who else to go to.

I ask every time – you see my stomach it is all swollen and I say – is it that ovary – nobody has ever screened it to put my mind at rest. I would have liked that to have been done.

Seeing the same specialist consultant/nurse

Interviewees raised the importance of continuity at various stages throughout the group session in relation to a number of issues (such as access to specialist medical care and psychological support). Most patients had seen the same specialist throughout their treatment and follow ups and commented favourably on the impact this had on their care, particularly because the specialist knew their history. In contrast, one patient had not had continuity of carer, and this had a negative impact on how she viewed her follow up appointments.

I feel in my case (it) has been very fortunate for me, (that) every time I go I see the specialists themselves, I see (the same) dermatologist and (oncologist). They are the ones that know, they are the ones that did it and they see me every time, I have never seen anyone else. I do think continuity is important, because if I went and saw somebody else they wouldn't know what they were looking for because they had never seen it before.

When I had my follow ups I very rarely saw the same person twice so how were they going to know if there was a change so really I didn't feel sometimes that those checkups were particularly useful.

Only one patient commented negatively on seeing the same specialist during follow-up as had been seen during treatment. She felt that where things not been dealt with properly during treatment this could have an adverse affect on future interactions.

I think this also throws up anything that happened in your treatment which wasn't as it ought to have been, like waiting 14 weeks between surgery and commencement of radiotherapy which was far too long and it should never have happened... What I am trying to say is that I think things like that happen and so when things go wrong later on you are inclined to remember those things – you don't mean to drag them back but you think about them and you can't help it. All of us have got that to deal with.

3.4 Views of some alternative models of follow-up care

Telephone follow up (nurse led)

Telephone follow-up from nurses was something that was already in practice. Two of the patients in Group 1 had received follow up by telephone from a nurse, albeit in addition to face to face follow up appointments.

I think my CNS phoned me a couple of times when I had just come out of hospital to make sure I was OK.

The group was split in their opinion on telephone follow-up. Some felt that a telephone conversation was not 'proper' follow up and could not replace face to face appointments. Others felt that in cases where physical examinations were not required, telephone follow up would be fine, even preferable to face to face appointments.

One patient felt that although it would not be appropriate for her, telephone follow up may be suitable for other people with different types of cancer. She stressed that it should be the patient's choice whether or not to use this method of follow up. This was echoed by another patient who felt her follow up could have been done by telephone. This patient had also been self monitoring after asking what signs and symptoms to look out for.

I was going to say that I do think it is up to the individual and I wouldn't discount having (telephone) follow ups if the person would prefer to do it. I do think it should be an option for them to decide if they want to because like (Name) she wouldn't have wanted to carry on. I would want to carry on, but I wouldn't want pressure put on me not to carry on by somebody saying "Well would you mind not coming and somebody phoning you up" or discounting them completely. I do think it is a very personal thing and I think there is for and against both but I think it should be the patient who decides.

I wouldn't have minded at all... because as I said earlier in the beginning – by the consultant's own admission they don't find secondary cancers, you do! So you are the one that feels wrong or there is pain where it shouldn't be or whatever you are the one.

There were those in the group who felt that it could be dangerous to leave follow up solely to telephone conversations because physical examinations would not be possible

and they felt generally there would be a greater chance of nurses missing other signs that the patient was unwell.

You can't have a check up – you can't have an examination over the phone.

Also I think when you see someone you get a lot more out of their actual body language which you cannot see over the phone. You can see if somebody is looking not well or a bit distressed whereas on the phone and they go "Yes I am fine etc".

Others had more trust in nurses' ability to deal with this problem over the telephone.

Yes you might choose to lie to your CNS but she will see through it a mile off – an experienced qualified person would know and would ask the right question.

Patient managed follow up

As with telephone follow up, it was felt that patient managed follow up would not be appropriate for everyone, nor would it be appropriate immediately after treatment. That said, patients did see advantages in this method of follow up; both psychologically – by treating patients like any healthy individual and respecting their ability to monitor their own health rather than submitting to examinations that they may not feel necessary, and practically - saving time going to follow up appointments.

My immediate reaction is no follow up appointments would be very scary within the first year and I think for the first twelve months you really do need that one to one contact. After that then there are a lot of people who would be better told, you are probably OK – go away and this is the set of circumstances. It is a psychological trick again of saying, you are well but may have a problem, rather than you are ill but may get away with it.

I don't know about ovarian or any of the other gynae cancers but endometrial cancer, the chances of you getting a secondary are very high between 18 months and 3 years.... So probably it is quite important to be checked perhaps at 18 months and again at 3 years. But all the ones in between I think are quite a waste of everybody's time and your dignity!

Comments earlier on (see section on 'Being seen at hospital') suggest that for those patients who felt their follow up appointments went on too long, patient managed follow up might be more appropriate.

I am just coming up to 6 years and about a year ago I finished the five years Tamoxifen and they put me on something else and I don't tolerate it desperately well. I have been back twice to the oncologist since then because I have not been feeling well with it and had a number of problems and it was only when I went to see the surgeon, having done a fair amount of research for myself, including stopping taking it for 3 weeks to see if I felt better and I did, and I said well "I have not been so good and I think this is part of the problem" and she said "Stop taking it then". And that was exactly what I needed someone to say – that is why I said initially that I feel I have been over managed – that at five years I would have liked to know that the door was open if I needed to walk through but good luck. That would have been

much more reassuring and for example – one thing we have been talking about at the Partnership Panel is the difficulty of getting travel insurance and if you are on active treatment that defers when you can actually take the holiday of your choice.

Group follow up

One patient had experience of group follow up for a different condition, she felt that although in theory it had been a good idea, in practice the group had been poorly managed and therefore not particularly beneficial. Most patients thought the idea of group follow up was an appropriate way of providing support and information, but would not be suitable to address more individual follow up needs.

I don't think the individual care would be there but things like psychological support and knowledge of what to expect could be very well addressed by a follow up information session, maybe a month after finishing treatment or whatever. If it was set in part of the treatment plan then it would be appropriate.

I think the sort of things that do well and that patients ask for – if you ask them what speakers that they would like – they will come out on nutrition and alternative therapies, attractive underwear. But they will come up with the things that they can accept as a group, but only those – all the rest are individual. Because we found so often there are really never two I could say were alike. It can go on age, number of children, how old they are and the worries they have got in their other life and this sort of thing – it can play a part and it makes them all individual – so it is the individual bits.

Related to the view that certain individual needs could not be addressed in a group was the view that group follow up would not be appropriate for everyone, since individual needs were different. One patient in particular felt it would not work for her since she needed physical examinations, another felt she would not be comfortable asking questions in a group of people.

I think that is it with cancer, everybody's cancer is different and I think that is probably why it wouldn't work.

I don't think it would be (appropriate for everyone) because I think some people have to be examined – I have to be examined for them to see how the skin is going.

I don't think a group follow up though would be acceptable because we all have very personal cancers and you wouldn't want to sit in a group and ask about your particular problem with everybody else there. Personally... I know I wouldn't.

One patient felt that many of the functions provided by group follow up - support, experts available to talk to, information on general wellbeing etc - were very similar to the things provided in existing support groups. Therefore group follow up might face similar issues as support groups, in that groups are not suitable for everyone and many people would not attend them.

I think a limited number of people would go to that – I don't think it would be every follow up patient but again you are going to get a small nucleus – a lot would fall through.

You know when you are ready for a support group – if you need a support group ...So I don't know what the answer is – I can't honestly see that working because more people go to support groups wouldn't they.

The idea of an information meeting, with the opportunity to talk to a multi disciplinary team and ask questions, perhaps getting individual follow up after if required, would differentiate group follow up from traditional support groups. However one patient pointed out that in order to work, it was essential for the multi disciplinary team to attend, rather than let busy schedules get in the way. However another also raised the issue of cost effectiveness, and the problem of wasting the time of experts attending when they might not even be needed.

We are focusing in on a facilitated group support type meeting whereas my experience in diabetes and my initial thought was an information sort of meeting where perhaps there would be a questionnaire to say, "Have you had this, this or this?" "Is this an issue?" and during the first session you do those they get whisked out and anyone that has got issues that might need following up, they are given a quick five minutes later but the main thing maybe is on healthy eating, sexual problems on some gynae's or whatever it may be.

... an official follow up group where the person that facilitates it has got to be really, really good – it has got to be very cleverly managed. There is going to be sort of people – those that will speak out and those that will sit very quietly and not say anything and people can actually take over – and also I think – you say getting the multi disciplinary team together – well I have worked with multi disciplinary teams – I try to get them together once a week. I think you are looking at utopia. It just wouldn't happen and people wouldn't – whoever was meant to be at the group that week, would look in his diary and think "Oh my God, I can't go to that, I have got this, this and this to do!" They are just so, so busy.

I don't think it would be cost effective to be honest because you could have your 90 minutes there and your psychologist and you might find that nobody wants to see that psychologist so they have wasted that time there.

Another problem raised about group follow up was that discussing other peoples' problems and conditions, could be upsetting and even harmful, particularly without individual support:

And I think the other thing is that if something emotive comes up, people get upset – particularly with cancer where they could get upset and then it falls apart because they need support from somebody – they have got to have like a buddy to support them because it could be you are talking about their life in front of everybody else and the fact that their cancer is really bad – you have got to be really careful with something like that and what is discussed.

3.5 Agreements within Group 1

- Follow up care can be defined as 'care after treatment', either in the form of scheduled 'check up' appointments or informal contact with the CNS.
- 'Rapid Access to Specialist Medical Care' is very important, be it through contacting the specialist or CNS directly or getting a referral through the GP.
- It is important to know, not only what to expect following treatment, but what follow up appointments are for and in particular why they end when they do. In addition to this it is important to patients to have information on what signs to look out for themselves.
- More holistic information would be appreciated, for example on diet and alternative therapies, to help patients with their overall health and wellbeing.
- The main support required for returning to work is the need for some sort of information or booklet to give to employers, explaining patients' needs on returning to work and the fact that they may need to take time off for follow up appointments.
- Psychological support needs to be available right from the beginning at diagnosis, through to follow up and needs to be provided on a range of issues depending on the individual.
- All patients agreed that, personally, they would not like to be seen for follow up by their GP.
- Follow up appointments at hospital with the specialist are very important in the first one to two years.
- All patients knew of someone to contact if they had a problem.
- There was a strong feeling from the whole group that continuity is important, seeing the same nurse or consultant throughout treatment and follow up.
- 'Patient Managed Follow up' cannot be the only form of follow up, particularly not straight after treatment. But there are some cases where allowing patients to choose to manage their own follow up would be beneficial.
- Group follow up cannot possibly cover all the issues arising for follow up care, without the opportunity for individual follow up too.

3.6 Variations within Group 1

- Where ongoing treatment for side effects was provided, some patients felt this was distinct from their cancer treatment and therefore should be included in the definition of follow up care. However others felt their treatment for side effects was part of the cancer treatment and follow up care should be defined as the care provided after this was completed.

- Some patients had gone to their GP with concerns and had been very happy with the speed at which they were referred to a specialist. However others lacked confidence in getting rapid access to specialist care through going to their GP, and preferred to have direct access to their specialist.
- There were considerable differences in the amount of information patients had received about their follow up care, some were told all they needed to know, others had to ask why they were having their appointments and what they were looking for, and others had wanted to ask these questions but had not felt able to.
- There was disagreement on when information on what to expect after treatment should be provided, particularly in relation to possible side effects. Some would have liked more information on side effects in advance so they could be prepared, others preferred not to know until necessary (otherwise they would be worrying about it). One patient felt that although she would have liked to know in advance, during treatment, about potential side effects to expect after treatment, she doubted her ability to take it all in at a time when so much information was being given to her. The degree to which it was important to prepare in advance may depend on how much after care was needed.
- Psychological support is important for family and carers, for one patient this would have been most useful at diagnosis, but for another it was during follow up that support was most needed for the family.
- Some would have liked to have fewer appointments at hospital, either stopping earlier (e.g. after a year) or going to appointments less regularly (e.g. appointments with only one specialist rather than two), however others would have *more* hospital appointments with the specialist if necessary.
- Some were happy to contact their GP, others preferred their specialist to act as first point of contact.
- Some felt telephone follow up would be fine for certain cases although it would definitely not be appropriate for everyone, i.e. those who need physical examinations, whereas others felt that it would not be safe to have telephone follow up as the only form of follow up because things that could be would picked up in person might be missed over the telephone.
- Some patients felt group follow up would be good for support, but others felt it could be psychologically harmful.
- There were different views of how group follow up might work in practice, whether it would take a form similar to support groups, or whether it would be more like an information session.
- Many thought that a group could not address individual needs but this depended on their idea of how the group follow up would work. One patient thought that individual needs could be incorporated by allowing individual consultations after the group for those who needed it.

Group 2: carers of patients with experience of follow up cancer care

4.1 Participants

The eight participants in Group 2 were made up as follows:

- two women who were carers for their mothers with cancer
- five men who were carers for their wives with cancer, including two whose wives had died
- no one in the group knew each other.

4.2 Definitions of follow up care

Participants in Group 2 mentioned a range of things that for them, constituted follow up care, highlighting that follow up could be different for different people or at different stages. Several agreed the definition of follow up care applied to different stages of care, - following the first stage of treatment, in between treatments or after the final treatment - and all these phases should be included in the definition of follow up care.

For my own personal experience mum is still followed up after 6 and a bit years because she goes up and down a bit really but then other people have their operation and have no follow up so it depends really on their cancer.

I think follow up takes different meanings depending on the stage that you are actually at, whether it is following the first phase of treatment or following surgery or following final treatment. So there.... is not just one generic term of follow up because it depends when and for what period.

It could also cover the periods between treatments – if you are receiving chemo once a month – those months can be very lengthy so there is a need for “follow up” at that stage.

I saw follow up as being the continued monitoring and also mopping up the secondary phase of treatment.

Three of the carers had a more fixed definition of follow up care as solely the care received after the final cancer treatment, one specifically thinking of it as palliative care, rather than anything that went before (for example in between treatments).

I think follow up really is obviously once you have finished your treatment and that you aren't really left alone to your own resources. That there is contact – whatever that contact is.

I look on follow up as being proactive and finding a good team – no cancer and can give the services that my wife needs such as Lymphodema Clinic which is very good, CT follow up, MRI follow up and monitoring. But I look on it very much as a two way street.

I assumed in my mind that it was follow up following being told that it was the end of the line and the MacMillan people were involved. So I wasn't actually thinking much before that – obviously over 26 years an awful lot happened to my wife and on 3 occasions we were told that she was dying and she bounced back and then the final one. So I have actually in my mind thought in terms of from the last time they said it is the end of the treatment and on to palliative care treatment.

One carer also mentioned a separate type of follow up care for themselves as carers.

4.3 Views of different aspects of follow up care

Rapid Access to specialist medical care if I have a concern

Most of the carers interviewed in Group 2 talked about access to the CNS or consultant when discussing rapid access to specialist medical care. Many had experience of calling up the CNS with concerns, although the outcomes of these experiences were mixed. Several carers had had problems when their point of contact, the CNS, was not available. The main issue here was not knowing who or how to contact anyone else, although one carer also felt that due to lack of staff there may not always be someone else was available.

It has been mixed. We are still going through it now and yesterday I had an occasion to phone up wanting... information, only to be met with the answer phone for the specialist nurse saying that she is actually away for a week and no alternative phone numbers.

I think communication generally is very difficult... as it is in a lot of vast spheres. And back to my comment about carers that puts pressure on the carer for trying to communicate and failing and their partner is obviously in need of attention – that can be traumatic.

Can I just say that I think that probably the clinicians are there but they are not always accessible. If you do phone up and you get an answer phone then maybe the systems aren't in place. I am sure that the advice is available but it is just silly things like people not putting the phone through to someone else who can actually then say well I know who can help.

It is about people having time and understanding... what patients' needs are, I suppose. I think the Cancer Nurse Specialists have a lot put on them and I think... maybe their administrative tasks aren't quite together.

They are relatively under staffed so when they are away there is no backup

One carer who was well known at the hospital had no such problems accessing specialist advice. Another had been able to get past the stumbling block of not knowing an alternative contact because of similar familiarity and knowledge.

My experience locally... is excellent. I have been able to get rapid access to anyone in the cancer department and have no problems whatsoever.

...and it was only because I have got some inside knowledge that I have actually been able to. If my father had been left doing it I don't know what he would have done to be honest.

Few carers mentioned contacting a GP if they had a concern, although one carer did say that rapid access going via the GP could be a problem, depending on how good the GP was. Another agreed that there was considerable variation in getting rapid access to specialist care, partly depending on location.

That falls over at the GP level. It depends on your GP as to whether you get referred to good advice or not... it literally depends on who you get and I think the GP is the initial stumbling block, even if it is urgent.

But once you are in the system and having your follow up care, it depends on what tumour site you are with as well - locally - as to whether or not you have got access to anybody... I did, I was very lucky, but I know some tumour sites that have got no access for patients or carers that is easy to get to.

Accurate information about what to expect following treatment

There was a general feeling that information, both on treatment and what to expect after, had improved in recent years, but there were still problems with getting enough information on why patients needed to go to follow up appointments.

I think it has got better very recently. When mum was diagnosed 6 and a bit years ago there was no information really and we were told not to go exploring on the Internet because most of it was American so it wouldn't help. But recently I have seen quite a bit of information that is much, much better and access is much more available as well.

Just this is your appointment - but not why you are going particularly - you have got an out patients appointment - but you don't necessarily know the exact reason why you are going.

As well as needing more information on what follow up was for, there was also a need for more information on side effects and how to deal with them, as well as more information on general health and wellbeing.

I think more information about side effects in the short and long term and how you deal with them. And dietary information and the holistic approach – I really do think that could be so helpful.

A couple of carers mentioned problems getting appointments for further check ups they felt were necessary.

I had a double experience if you like. I think in recent years it is much, much better and people are at pains to advise you and tell you what to expect etc. But radiographers, often I have a problem with because they (say) 'there is nothing wrong – go away!'

I am surprised that she doesn't have a routine mammogram automatically once a year. I don't know about these sort of things, but I have to keep saying look you must go and get yourself checked up because you don't want it to return. And we have to make the running on that.

One carer felt that their problem in getting information was partly due to the rare nature of the cancer, with few people available locally having enough expertise to give advice.

And then you get a second opinion (after going locally... by) going somewhere else like the Marsden who are specialists in their field. So I think it is all about getting the right team but... I am in an awkward position because my wife's cancer is a rare cancer and often (locally) people don't know enough about it to be able to advise.

Help with returning to (staying in work)

Only one carer commented on this issue, saying that there was not much help or advice available, although it was not something they had sought out personally.

I don't think there is much advice about returning to work. Personally, I didn't get any advice. I didn't seek any from the hospital but there was none offered.

Advice about benefits

Only one carer in Group 2 said they had good access to advice about benefits, from a dedicated person at the hospital. However this did not appear to be the norm. Most carers who had wanted information and advice on benefits had found it difficult to find. The main problem was finding an accurate source of information; one carer had to go to multiple sources for information and advice and found these conflicting and difficult to understand.

On (one) ward there is... a social worker or something of that nature – who actually does tell you about benefits. She called me in to tell me. As it happened she couldn't tell me anything I didn't know so it was very brief but there was somebody there who specifically said "What about this, what about that."

I think there was a distinct lack of information about benefits – it was very difficult to get information. It has improved definitely – it is more accessible.

I found it very sketchy, very patchy – you get passed around by telephone and each person you speak to gives a different story and we just ended up totally confused. Claimed benefits for a little while but actually we were always confused so in the end we just gave up.

Experiences of assistance provided by social services were generally better; two carers had received support from social services. Although one mentioned that, as with information on benefits, there was a problem dealing with different agencies and with getting delivery of assistance that had been promised.

We have had no financial benefits, bar one which I will tell you about in a minute. But when (Name) died, Social Services were marvellous.... As he got less and less able to move, they put hand rails into the house and a mattress and a commode where we were and they also helped her bathing him which was much appreciated.

But from the benefit perspective my parents have been quite well supported between the GP and Social Services I think really – bit like your experience probably. And they have had extra aids in the home – which has been a bit patchy – things have been promised and then they don't turn up – we are still chasing the wheelchair which was offered in December as an urgent case so that is quite difficult to understand. The people you have to follow up aren't very helpful but that is not the hospital issue that is peripheral agencies that are attached.

Psychological support

Few had received psychological support, either for themselves as carers or for the patients they provided care for. Although those interviewed saw psychological support as an important part of follow up care, it was felt that the focus of doctors and nurses was only on physical health. Support groups were recognized as valuable sources of support, but they were viewed as distinct from formal psychological support.

I think in general doctors and nurses are inclined to say well right diagnosis and treatment and they have done their job and then you are out on a limb – not as a fundamental approach.

(Name) mentioned the word “holistic” – that really is the magic word isn't it – holistic treatment is covering all three sectors, mind, body and the spirit.

One carer had done a counselling course and had access to a counsellor working at the hospital as part of this, but he felt that this person was very thinly stretched. Another carer had received counselling during his wife's treatment but nothing during follow up.

My wife was mis-diagnosed 3 times – but the best counselling – well the only counselling was (at the) hospice... and that was all we got.

Several carers felt that there should be someone at the hospital to provide psychological support, either a CNS with special training or a qualified psychologist. For these carers it was important that the person providing psychological support was connected to the hospital and had an understanding or overview of the patients' case history.

I think at the moment it probably comes at its best level from the Clinical Nurse Specialists, especially those who are dual trained, say psychy trained because it gives them more insight into what you are going through and the support you may need. I think possibly that that is the best reasons –instead of a psychologist have a Clinical Nurse Specialist with an understanding of psychology because she sees both sides.

I personally think that the NHS ought to consider an actual qualified psychologist who is a psychologist in oncology in each area. I think it is absolutely vital – not only the psychology for us as carers and patients; there is also in my experience the psychology of junior doctors who should have somebody there to help them to handle difficult situations.

I said earlier, I think the answer is something to do with somebody who is a psychologist – being able to look at the thing throughout.

One carer was aware of various voluntary organizations providing psychological support and felt that independent organizations such as these should provide psychological support, rather than training nurses or having in house NHS psychologists.

(Nearby) hospital has a system where they are training senior nurses on the psychological side and they have got two psychologists as well there so there is a move towards it. But I think in some ways this is where the NHS stays within itself and there are outside agencies or therapies or whatever that could be brought in. I was watching... a DVD sent over the Internet today (produced by) University College Hospital. This was about healing but it is quite amazing that this was happening on the wards and the results were fantastic and you can spread that across all of the supportive therapies and advice. I don't see how the NHS can do it "In house".

Support for my carer (and /or family and friends)

One carer had been expressly given direct access to support herself; although this had not been formally extended to the whole family. Access to support for carers and family seemed depend on what was available in the area.

I was given a card from my mum's Cancer Nurse Specialist and told that I could ring them at any time but that wasn't for the whole family. I mean they probably would have spoken to my brother or anybody but we started a support group for that tumour site – well in the last 4 years or something... and that is for everyone, if you want to take family or friends. But at the time, there was nothing really for the outside. But I do know other tumour sites and husbands – breast cancer for example – saying there is nobody for them to talk to, nobody available. So it does depend on the site probably.

The lack of support was a concern, both in terms of access to psychological support, either formal or informal, and help with the more practical aspects of providing care.

I worry about people who have got little medical knowledge or who are elderly or maybe not too bright... because there is nothing out there for carers.

The district nurse system is fine but district nurses don't really know much about cancer so you have got to look for a specialist. And district nurses obviously haven't got time to do follow up for carers have they and they are not trained to in that sense.

Just probably more psychological support and people – specialists or your GP to be more aware that it is not just the patient involved that there are other people involved and that is becoming more and more I think. But it is improving I think, I hope it is.

A concern for one carer was where to go for support when grieving. Two others in the group had experience with this, but neither seemed to know who they could have contacted for support of this nature. There did not seem to be any consistent support available. One carer's experience was positive due to the personal attention of the GP, another, who did not have such an involved GP, had no support.

I have got a super GP and in fact my GP has knocked on my door just to see if I was alright – after about 6 weeks – now that must be unusual. I can't see that being regular. The only follow up I had was a booklet and telling me how to grieve!

I didn't have any follow up at all – nobody contacted me. The GP made a note in his system so if I went along for other things – presumably the member of staff were aware – but nothing at all – even the vicar stops coming.

Being seen at my GP surgery

GPs were not seen to have the specialist knowledge to provide follow up care. In addition, it was thought that they would neither have the equipment needed to conduct tests, nor the ability to analyse these tests on site. Carers also felt the GP would lack knowledge of the patient's case history. For some, seeing the GP merely presented an unnecessary 'middle man' between themselves and the specialist. Others felt more strongly that being seen by the GP could compromise care.

But the thing that has come out very clearly to us is how different everybody is. (For example), people on (clinical) trials, some have been cured and some have been stabilized which is what has happened to (wife), and some people have died unfortunately. But everybody reacts completely different to the situation and they do need that individual attention which I don't think a GP could provide. He wouldn't have the whole panorama of what is going on.

It's histology, radiography, CT, MRI and it is not just a matter of having the machine it is having somewhere that is ...the ability to read the information.

The thought I have got with that is I have got a good GP, a superb GP, but... the hospital will (only) tell him the result (of tests etc) and then he has to interpret it. In that process (he) may be slightly wrong, whereas if in fact you are told direct from the hospital what the situation is, there is one step of danger that you are missing out.

One carer had experience of going to their GP and expressed confidence in their ability to refer, but they felt there was a responsibility on the carer/patient to find the right GP who could do this and that not all would be suitable.

We have found with the GP, that if you go and ask him then you are right they do deal with coughs and colds but they will refer and we have found no problem with that. We have also found that if you need support then it is finding the right person, being determined because our experience (with the local hospital) is there is the support there.

Another, although confident that GPs could refer to the right specialist, felt it would be preferable to have direct access to the specialist rather than having the GP as a middle man.

The other thing is that the actual appointment, the follow up appointments they are to discuss things and you want answers, you don't want to say um OK I'll send you a few days later down to the hospital to speak to the person that really you should have spoken to in the first place. It is just another layer which I think is unnecessary and an unnecessary cost.

Some carers had found good GPs who provided personal attention, however this was not seen as a substitute for access to specialist knowledge.

In support of GP's, my mother's GP pops in regularly unasked, unannounced and un-requested so she is actually quite lucky in that respect.

My wife's GP is fabulous but it took us a while to find her in a big practice and I know this is bordering onto clinical care but the biggest - I am not sure of the words - but the biggest problem at the moment is getting past your GP into specialist care, specialist advice etc because they are busy with coughs and colds and unless you are very lucky (you don't get referred).

Being seen at the hospital

As discussed earlier (see sections on 'Rapid access to specialist medical care if I have a concern' and 'Being seen at my GP surgery', everyone interviewed in Group 2 expressed a strong preference for specialist care from the CNS or consultant.

No-one mentioned any problems with being seen at the hospital, perhaps to be expected since carers may feel it inappropriate to challenge the expediency of going to hospital.

One carer described the distress caused by the waiting room system at the hospital outpatient clinic. He felt that the layout of the waiting room which allowed those waiting to see other patients leaving their follow up appointments could have a negative psychological impact, particularly when seeing another patient had received bad news. He felt this could easily be resolved through providing a different exit.

I think one of the things that I find (with) follow up appointments, when you find that the person in front of you (comes out of their appointment) and you know that they (have been) given bad news... They come out and it really brings it back again. I think it is unnecessary – it is a bit like when they design day theatres, you start at one end and you never see the groggy one go out the other end because they are on their way. I think they ought to do something like that.

Knowing who to contact if I have a problem

As discussed earlier in the section 'Rapid Access to Specialist Medical Care', some carers had faced problems if the CNS or consultant were not available, not knowing who to contact. In the section on 'Being seen at my GP surgery' many carers expressed a lack of confidence in specialist knowledge of the GP, relying only on a referral through them if necessary.

Several carers had found it problematic when trying to navigate different procedures at different sites or organizations, particularly between hospital and community care. These carers all felt they would have preferred one point of contact to provide central support and join up all communications, rather than chasing up different agencies or having to decide who to contact for what.

I think the problem for the carers – my parents are elderly, my father is the main carer and it is quite difficult to understand all the processes and how they work. You go for your GP visits, but then you go to the hospital and then the nurse turns up and they are kind of doing different things; then you have a problem, so you ring the ward but actually you visit your GP. I think the whole process is confusing but I don't know how you could simplify it unless everybody was all under one umbrella and doctors were doctors – whether they came from GP's or hospitals.

(If everything was dealt with) centrally then it might (cause) less anxiety at times; if you felt there was one conduit that you had to deal with... If one area actually knew about that patient and you weren't continuously dealing with separate agencies or organisations.

But there is one area of weakness which I was hoping to bring up and that is the danger that the hospital staff... at all levels, find themselves divorced from the community and I quote my wife's example to show you what I mean. When my wife got to the stage where she was on palliative care, the support from the MacMillan unit, from the palliative care nurses was quite superb but she was being sick the whole of the time and they were giving her tablets which of course she was bringing back anyway and in fact because my daughter was a nurse she saw the local district nurse who she was friendly with and said "Look she wants a syringe driver" and my local GP, the district nurse and the palliative care unit that was local did not know one thing – they had not been contacted whatsoever. Consequently – in fact they then put a syringe driver in and obviously that helped and so on. But the weakness is the communication - from the hospital and the MacMillan unit superb, not a criticism but there was a break in the chain on local level. Once they knew we then got support from them as well. It is the communication.

(Continuity) of care from the hospital team right through the community team because there is this big impasse and it never seems to get passed to the community and they go to the GP, the district nurse.

Communication was generally seen as an important issue. In two cases it had been necessary to go to different sites for different aspects of care, but where patients had been treated in different places the notes were not always passed on.

With my mother the appointments have all been fairly straightforward and the information given has been very clear. It has fallen down because she has had added complications... where she does need emergency treatment from time to time (and) her notes maybe are still in the area where she was being treated, then it takes time for the processes to work around it.

We are in a very difficult situation where we are being treated by one hospital completely out of the area because that is the hospital that has got the contract with the drugs company for trying these new drugs out and we are here locally. We think that the (hospital out of area) does send letters to our doctor, but we haven't been able to prove that yet so we are somewhat isolated in that respect.

Seeing the same specialist consultant/nurse

As mentioned in the section on 'Knowing who to contact if I have a problem', going to multiple organisations and sites was a problem, particularly when notes were not passed on. It was suggested that having the same central contact would improve this.

Other advantages of seeing the same specialist or nurse was seeing someone with knowledge of the case history; in practical terms not having to repeat old ground, but also building a relationship with them for psychological support.

He died – MacMillan were very good but in that case the nurse was changed only a week before he died and we'd had a relationship with her – we missed out on that.

It is important to see someone who knows your case and has the continuity for your care, not necessarily the top guy in the chain (but) not the clerk or a duty body. (JM)

4.4 Views of some alternative models of follow-up care

Telephone follow up (nurse led)

One carer felt there would be an advantage to telephone follow up if it allowed them to speak to the top specialist rather than someone less involved in their care, with less knowledge of the case history. However this would not apply to nurse led telephone follow up.

We have had (a telephone consultation) on several occasions and I think the advantage is that you are more likely to get the specialist near the top of the tree

because he or she would have time to ring you, whereas maybe they can't spare enough time for a follow up appointment (in a hospital clinic) and if you went up (to the hospital) for an appointment you would see someone in the chain who would really tell you what they had been told to say or what the notes say. Whereas on the telephone consultation, call it that if you will, it is very much a two way thing and you normally get to speak to the top guy in the chain.

Another acknowledged that telephone follow up would reduce the time spent waiting in hospital. However no-one interviewed in Group 2 felt that telephone follow up would be acceptable as a sole method of follow up. Patients need to be examined in person, although test results could be, and were, provided over the phone, some felt even this was not acceptable – preferring to see the results for themselves and discuss things in person, particularly in the first few years.

If she has had a blood test or a scan or anything, sometimes if they don't want to see her they will say they will give her a ring and tell us the results. But I suppose she knows that if there was a problem they would phone her up and say that she had better come in. But in some ways that may not be very nice. She has never had a problem with it... it was more a follow up of the follow up, I suppose. So she would go for her follow up appointment, maybe the blood, the tumour mark had gone up so they would go back and have another look and then give her a ring or something like that.

I think a) I would want to see the scan myself or the results and b) have a physical examination which is what takes place for me; and also the opportunity... to discuss any issues. I wouldn't feel at all comfortable doing that over the phone. But I think maybe in your mum's case as she has gone past the five years and now it is ongoing blood tests to monitor the situation (telephone follow up might be acceptable).

Patient managed follow up

Several carers recognized patient managed follow up as something many patients already did, monitoring their own health in between appointments. No one felt patient managed follow up could be a substitute for follow up with the nurse or consultant; some were particularly concerned at the safety of this.

I think you will find a lot of patients do that anyway but they don't actually know that that is what it is called. But if they had a problem they could ring up the specialist nurse and say "I have just found so and so" or "I have got a lump" or whatever and I think you will find a lot of people will do that but not actually realise they are doing it. But I wouldn't want that to be the only thing.

Well you do it when you have had your 5 year sign off – that is what happens from that point onwards.

But how could it replace proper follow up and it is an abdication in a way, isn't it.

The main concern several carers had about patient managed follow up was the fear that not all patients would get help when they needed it, or that they might opt out of, or put off, making appointments.

I don't think someone like my mother - apart from the fact that she is now in a much more serious condition but in the past she wouldn't have bothered - if she didn't have an appointment she wouldn't have bothered to self refer.

If people had a problem with getting to hospitals or things like that they just wouldn't bother because it was too difficult and they didn't have an appointment.

As well as individual differences in willingness or ability to initiate appointments impacting on the feasibility of patient managed follow up, it was also thought that different types of cancer would impact on the feasibility of self management. For example, some patients would not be able to detect problems themselves, due to their hidden nature.

There are so many different types of cancer - how can you generalise on a thing like that - I don't think you can.

A breast care patient, for example, might feel a lump or something and (would know that) if you found one that would be a problem. But there are other cancers that aren't obvious. My mum never dreamt that she had bowel cancer.

She has never felt ill so if it was her feeling ill (that led her to initiate an appointment), she would never have any follow up probably. Because sometimes her tumour mark has gone up but she has never felt ill in herself and she doesn't know it is happening it is just what is going on inside so I don't think that is right (for appointments only to be patient initiated).

Group follow up

Attitudes to group follow up were on the whole negative in the carers group. A couple of participants felt that there could be benefits of group follow up, for support and information sharing, but it was regarded as an alternative to individual follow up.

It is good from an information point of view but not a clinical point of view.

I am all for the group meetings that we had, completely informally, completely unmanaged by the hospital. It just so happens that (the appointments) do take a long time. We leave at 5.30 am and we sit there and wait for the doctor to arrive at 10 am so you get to talk to people. And they do the blood and you wait for an hour and then you go off for the interview and then another hour and then you go to see the consultant and then you have to go to pharmacy and then go somewhere else. And we get to know what people's treatment has been because everybody is very open about it and it is nice to know that somebody else has got a headache or somebody else has got a rash (and to discuss) the side effects etc.

Another carer, although positive about the concept of group follow up, felt there would be a lot of irrelevant information.

That is the problem, so many cancers are different. I think the idea of a group follow up is brilliant if the MDT is there because you get to hear lots of bits that are

going on. But the trouble is how much of that 10 or 15 minutes or half an hour is actually relevant to you and your type of cancer.

The majority of carers felt that group follow up could not cover individual's needs and therefore was untenable.

I wouldn't be happy with a group follow up because everybody is so different.

Different cancers, different treatments, people's tolerance levels, different people's backgrounds and needs and aspirations, the level of support.

As well as not being able to have examinations in group sessions, several were of the opinion that things would be missed in a group situation, because some patients would not have the confidence to raise problems or would not want to disclose private information in front of other people. There was also concern that clinicians would not be able to monitor changes in patients or raise concerns in a group situation.

How many times have you been in an appointment and in the course of the conversation the doctor has said "Let me examine you" (and then) specific to that conversation, an action happens. That happens quite often. I would have thought that would be very difficult in a group situation, I would have thought nearly impossible.

No, there is nothing that springs to mind that say "yes that is really good". As we were saying, if you have had a blood test and someone phones up or they could text you, they could do anything these days – just e-mail and say "Everything was fine". But most of the things you actually need to someone who understands what your illness is, to actually monitor you.

When you get into the forum when you have clinicians, if you don't disclose certain things it would be detrimental to you because – so you are not in control in that situation.

And somebody might not say something to their specialist in a group that they would say privately. There might be something that is missed.

One carer had negative personal experience of a group follow up setting and he felt that rather than provide emotional support, it may actually put more pressure on patients emotionally, to see and discuss other people problems.

Based on my wife's experience – where we had a similar situation – she was on weekly chemotherapy and there was quite a big group of people – of course they did the blood tests and in those days it went off to Path Lab so you were an hour and a half waiting for it to come back – and you had got this group of people who chatted and one of the big psychological "no no's" was that one by one they were dying and you would come along and saw who had died. The psychological effect on you was that that was going to be my turn some time. And the group situation that I have seen is very negative.

Another carer was concerned at how often specialists would actually attend group sessions in practice, and another raised the concern that group follow up was just a cost saving exercise rather than what was best for the patient.

These suggestions, they sound as though rather than improving the service, they are looking at making it more affordable. A lot of the things that have come out – the systems that we have are not perfect but as basis they seem to be where the improvement is maybe required because a lot of these things they seem to be suggesting – I don't know whether they are serious – but they don't seem to be. Are they clinically based, are they clinically proven or American or something?

Individual patient follow up care pathways

A recurring issue throughout this group was the need to recognize individual differences; it was felt that some types of follow up are appropriate for some people but not for others. One person suggested a good way to deal with individual differences might be to try and map out future patient needs in a pathway to plan what kind of follow up care is needed and when.

I think you have a cancer pathway through the treatment and in an ideal world there should be a patient pathway where the future is mapped out in terms of progress and stages of doing things – personal to each patient. That is in an ideal world but with modern computer technology it shouldn't be too difficult to actually do that. So you are really personalising that individual but in a technical way.

Problems with choose and book system

Three of the carers in Group 2 had used the 'choose and book' system to book appointments. Although two had not had any particular problems with the system, one found the system frustrating and counter-productive because they were not given a fixed appointment straight away.

I find at the Marsden it is excellent, brilliant. But locally there is a new system called "choose and book" and I found that you get on the computer very quickly but it is just a dummy appointment to get you into the system so they can meet their stats... Then some time later you get a letter or phone call asking... (you to contact) the booking clerk (who tells you to ignore your original appointment and) in fact your appointment is some time later".

4.5 Agreements within the carers group

- Rapid access to specialist care is important and it can be very stressful if help is not available when needed.
- Information for patients is improving, but there is still a need for more. In particular it was difficult for patients to get further tests or check ups when requested.
- Having a single point of contact or single organisation providing information and support on benefits is easier to deal with.

- Psychological support is important and there is not enough on offer currently, for patients or carers.
- There is a lack of support for family and carers, particularly emotional support.
- GPs cannot replace specialist follow up care.
- Communication between different organizations providing follow up care needs to be improved, dealing with these different organizations can sometimes be difficult.
- Seeing the same specialist, and having continuity is important.
- There are strong concerns over how safe patient managed follow up would be, specifically because patients might not seek help when they need it.
- Group follow up could not address all the individual needs patients have during follow up care.

4.6 Variations within the carers group

- Some felt the definition of follow up care covers a range of care provided at various points in the patient journey. Others felt that the definition of follow up care only includes care after the final treatment has finished, excluding any care provided in between treatments.
- Some had good experiences of GPs providing referrals to specialist care, but others feel GPs cannot be relied upon to provide rapid access to specialist care and it should be possible to go direct to the specialist.
- Some have had problems getting rapid access to care when their CNS was not contactable because they had no alternative contacts. A couple of people did know who else to go to if their particular contact was not available.
- There were variations in the amount of support available for people looking for help with benefits, some had been offered information and advice, others had to search it out from multiple sources.
- Some people felt that psychological support needed to come from someone with an overview of the patient's history, i.e. someone within the NHS linked to the cancer ward. Others felt that psychological support would be better coming from external organisations.
- Many felt that telephone follow up was unacceptable, unless it was additional to face to face appointments. One person felt there were advantages to telephone follow up if it provided the continuity of speaking to the same specialist consultant rather than doctors with less knowledge of the case.
- Some felt that group follow up could be beneficial in providing support and allowing exchange of information. However others felt that far from being supportive, group follow up sessions could have a negative impact, with other people's problems adding to the patients own. It was also questioned whether sharing of information was a positive thing in all cases, since it removed control from patients over what they wanted to share.

Group 3: men with experience of follow up care for prostate cancer

5.1 Participants

The eight participants in Group 3 were made up as follows:

- all were members of the same prostate cancer support group and some had been members for many years, including two who had been attending since the group was started in 1999; the focus group including the founding members and the chair of the support group
- seven of the eight participants were retired; only one was working
- participants were all treated at the same hospital, the most recent in 2007 and the earliest in 1999 and 1990; the others were all diagnosed between two and one four years ago
- all participants were currently in remission.

5.2 Definitions of follow up care

Nature of follow up care for prostate cancer

- There was general agreement amongst the participants in this group that follow up care consisted of checks, usually a Prostate Specific Antigen (PSA) test at six monthly intervals.
- PSA checks at varying intervals were mentioned, depending on the stage in the patient pathway eg every three to four months, every six months and yearly; one participant mentioned having a PSA test every 6 months for four years; another said he had been told that eventually his PSA tests would reduce to yearly and then to five yearly
- PSA test provide a clear indicator of whether you are getting better or if cancer is controlled; also said that PSA “is not an exact science and different consultants will have different views of what constitutes a substantial increase”.
- The need for a more specific test than the PSA test was mentioned, ‘to distinguish whether the cancer is a pussy cat or a tiger’ in order to advise patients appropriately about how it is likely to impinge on their lives.
- One participant said he was signed off by his consultant about a year before and now had the PSA tests conducted at his GP surgery every six months; if a PSA rise was

detected over three tests (ie 18 months) then he would go back to the consultant either directly, or through the GP.

- One participant felt that it was “very much up to the individual... once you’re signed off... and it is your GP that is monitoring you... Sometimes you have to take care of yourself”.
- One participant mentioned how at his three month follow up after treatment he had various tests, including a CT scan that picked up some benign tumours and an aneurysm.

Purpose of follow up care

- Follow up gives “you confidence that are getting better” ; it is “important to provide reassurance when you have concerns”.
- Good aftercare was described by one participant as being, “ you are better and are signed off”.
- The importance of early detection of secondary cancers was mentioned in this group.

Perceptions of follow up care

- Most said their aftercare had been good.
- Perceptions of follow up care are linked to patient’s experiences at diagnosis.
- One participant said the when his aftercare started, “my consultant saw me every time. When he decided I was getting better I saw his deputy and I saw that as a very positive thing”.
- One participant mentioned the way the consultant’s team changed every August: “the sisters worry, but it can be a good thing, for example, in my case a new registrar came on and ordered new tests”.
- One participant said he could not fault the treatment, “but afterwards... (there was a) lack of interest from my consultant... He sends a deputy who I don’t think is totally capable”.
- Support group provided one participant with the only sources of information about prostate cancer: “the doctors don’t have time to sit and talk to you”.

5.3 Views of aspects of follow up care

Rapid access to specialist medical care if you have a concern

- One participant questioned what ‘rapid’ meant; there was general agreement that prostate cancer is not generally a rapid cancer:

So if I had a concern about something, I wouldn't want to see somebody the next day.

It doesn't have to be tomorrow, it can be next week.

- It was suggested that it was important to be able to get back into the system if you have a concern, but are no longer under a consultant.
- General agreement that specialist prostate cancer nurses provided a good first point of contact if patients were concerned; for example, one patients said,

"We have a couple of very good specialist prostate nurses and can ring them up if you have a worry... She was very good and could often put your mind at rest or she would recommend that you saw the doctor or... the consultant."

Accurate information about what to expect following treatment

- In terms of information from clinical specialists, one participant said he was told exactly what to expect during follow up and this was exactly what happened; another said he was told about the side effects of impotency from radical prostatectomy.
- All participants in this group were members of the same prostate cancer support group and identified a key role for the support group in terms of providing information about follow up care.
- One participant said he got most information off the internet and another said he had also got a lot of information from the internet.
- A prostate cancer charity had sent a lot of information through to one participant when he contacted them.
- One participant identified links between information needs and the need for psychological support; he said it would have been helpful to have a leaflet right at the beginning to provide reassurance, for example, about PSA levels. Another participant said leaflets were available and the support group provided them to patients during regular 'awareness weeks'.
- It was suggested that it would have been useful to have been given information about test results or to have been provided with a card so the patient could keep a record of test results for themselves; there was a suggestion that cards were already distributed at some units to do the latter. In contrast, another participant suggested it was the patients' responsibility to ask for information and he pointed out that the GP will give you the test results if you ask for them. Some patients described how they personally kept very detailed records of their test results.

Help with returning to (and staying in) work

- Only one of the participants in the group had been working at the time their cancer was diagnosed. He said his employers had been 'absolutely wonderful'; they gave him five months off during treatment with occupational health clearance so the absence

had not been recorded on his sick record. On his return to work his employer had moved him from physical work to a desk job, they had suggested flexible hours and they gave him time off to attend follow up appointments and time every month to attend the support group.

- He said he didn't need extra help in returning to work, but suggested that someone with less confidence would need this to return to work after an absence of six months:

I think the confidence factor as well; fortunately, I am not the sort of person who (has a problem with) confidence and that – but I can imagine if you were a timid person that you would probably need (extra help to return to work) – six months off work is a long time....

Yes because it changes so fast – even on a computer the systems have changed – you go in and it is a different job – literally after 12 months. I think that would be the main thing, confidence; and also if it is a physical job to allow for adjustments for a person to be able to (do lighter work).

- None of the other participants commented on the need for help with returning to, or staying in, work.

Advice about benefits

- One participant who was retired said he found it difficult to find out about benefits; he described how he went to the job centre. He said he did not see it as the job of the clinical team to give advice about benefits, but they could usefully signpost patients in the direction of appropriate sources of advice.
- The prostate support group had organised a benefits advisor to come and talk to them, followed by a one to one with anyone who wanted to speak to her privately.

Psychological support

- Generally, the need for psychological support was seen as highest around the time of diagnosis and initial treatment and one participant felt there was no need for psychological support in the follow up period.
- One participant said he did not expect psychological support from a consultant, who he regarded as the technical expert; he said he would be happier getting this support from a nurse; he also said he would prefer to get psychological support from a woman:

Psychological support – I don't expect that off a consultant – he is the engineer that does the job. I expect that off the nurses or whatever afterwards. If you have got a man with such a gift as the man who operated on me I don't expect him there for hours on end talking to me. He filled me with confidence, he did the job, he told me what would happen etc.... If I have a problem I can go and speak to his nurses any time – I can pick the phone up or whatever. I find it more comfortable to talk to a woman, it sounds silly, I don't know if it is a mothering thing or what, but a lot of consultants are "bish, bash, bosh" and out because it is precious time and not that

many people can do that job so I can understand that. As I said if I want an arm around me I would rather it be female than male anyway.

- Most of the discussion about psychological support focused on the prostate cancer support group that all the participants attended. The group met at the local hospital once a month and advertised details of the group in the local paper and in local hospitals and GP surgeries.
- There was general agreement that the peer support provided by the group was very important:

Personally I think the group is brilliant because somebody who hasn't got cancer can't talk to you about it ... I don't know what childbirth is like because I've never been through it. But people who have gone through it, that is the best support you can get. And (chair) has put people onto me and they have rung up and asked me questions and again I can't tell them what to do but I tell them my experience and you can feel the relief in their voices when you have a conversation. So I can't see that the professionals can do any better job than what we can with each other.

Somebody who's actually been through it....

- The support group provided a buddy system which matches patients up with someone who has been through something similar; they may just talk over the phone if someone does not want to attend the group.
- The way the group provided support for people at all sorts of levels was seen as very important; some people attended the group every month, whereas others might attend it once or twice to get information and others might just get information from the group over the phone.
- The support group was open to wives and this was seen as very important, as is described in the following section.

Support for my carer (and/or family and friends)

- There was general agreement that wives, family and friends had support needs as well as the patient:

They are going through the same thing.

They are as involved as you are because it is their future as well as yours.

- The discussion focused on carers support needs during diagnosis and treatment and there was no specific mention of support needs during follow up care.
- The support needs of carers, was seen primarily in terms of emotional support and information about the condition, treatment and the future.
- Participants described how their wives attended their appointments with the consultant with them. One said it was particularly important that someone comes with you when you get your initial diagnosis as you hear nothing but 'cancer' and they

may retain more information and ask questions that you need the answers to. The support provided by wives generally was mentioned by another participant, both in terms of emotional support and in terms of 'ferreting out information for you.'

- One participant whose wife attended his appointments with him, said she had said:

I might want to ask a few questions that you don't.
- He said he was happy with this arrangement, but could envisage that some people might prefer to attend appointments alone.
- The prostate support group provided support for the wives and friends and family of men with prostate cancer and there was general agreement that this was a good thing:
- One participant suggested that carers may also have individual needs for emotional support that needed to be met, for example, they might have fears that they do not want to share with the patient.
- It was suggested that wives draw comfort from their female friends.

Being seen at my GP surgery

- Most patients had their follow up care with their hospital consultant
- The role of the GP varied between the participants; one had not seen his GP since he was first referred to the specialist, another said he did not expect his GP to play any role in his prostate cancer care and saw this as something you went to hospital for.
- Just one participant mentioned a significant role for their GP in their follow up cancer care:

Your GP has got an IT link (to the hospital test results) and every lab factor – it is there on the screen and (if you) sit down and say "Look I want to know something"... then he has got all the information at his finger tips.

- It seemed common for patients to have their blood tests at their GP surgery, either with the doctor or nurse, but to then attend the hospital for the results, for example:

In my case if I go for my six monthly check I always go and have a blood test (at my GP surgery) first.... and a copy (of the results) goes to the specialist who I go and see. One goes to my GP and I have one myself. So he is fully conversant with what is going on. So if anything happens he notifies me or the specialist notifies me – so I am quite happy about that.

- One patient said his GP had had nothing to do with his blood tests as his surgeon had insisted he go to the hospital and have them done on the same machine every time to ensure the results were accurate

It is a pain in the backside to get there but he wants it accurate on the same machine and if he wants accuracy I am happy with that.... It is a drive... to have a blood test for 3 minutes and then come all the way back but what is that, if that is (what is necessary).

- Two participants suggested that GPs lacked the specialist knowledge to provide their cancer follow up care. One of these now had his blood tests done at the GP surgery every six months and said his GP liked to know what was going on, but that it was more a case of him telling her what was happening, rather than vice versa. The other participant described how he saw his GP to get notes for work:

Because I take notes for work I have to go and see the doctor. It is just a general chat but by his own admission, he is no specialist – “You probably know more than I do!” Which I probably do now. As a GP he is fine, he reads the notes and asks “How are you, can we do anything for you, etc”.

- Participants were asked if they experienced any difficulties with access to primary care that might influence their willingness to have their follow up care at their GP surgery. One responded that it was not always easy to get an appointment at short notice, another suggested that the NHS was under a great deal of pressure which created difficulties in terms of accessing GP services.

At the moment you can't actually pop down to your doctor generally speaking. You have to book an appointment 3 days in advance so it is a bit difficult to sort of say it is a very good service because it patently isn't. But my GP is very good and if I say I need to see you he will make a spot for me.

I think the problem we have got is a Health Service problem... (The NHS) hasn't grown with the population. I am not saying it is right or wrong but there is too many taking out and not enough putting in and that is the problem we have got.

Being seen at the hospital

- There was general agreement in the group that attending hospital appointments was necessary, even though it was often inconvenient.
- Participants explained how they prioritised hospital appointments because your health is more important than the inconvenience of waiting to be seen.

Well you make them convenient – you get an appointment and whatever is on that day, you cancel because that is the most important.

It is necessary to go, so you go!

It is your priority your own health.

- These patients did not seem to expect the health system to accommodate their needs:

I think if everybody said well I can't go then can you see me then – it would be absolute chaos.

When I used to go to see the surgeon it was like a 3 hour wait and now I go to the nurses it is a 3 minute wait – it is nice that way but I accepted the 3 hour wait because I wanted to see that surgeon and that is fine. Nobody likes to wait but the NHS is snowed under so you have to wait.

- One participant mentioned the lack of time given to him by the hospital consultant:

I get back to the lack of time basically again – I don't think they have enough time to actually sit there and talk to you. "That is the reading, very nice, thank you very much, any problems, no etc."

- The appeared to be general agreement that parking at the hospital was difficult.

Knowing who to contact if I have a problem

- There was general agreement in this group that they knew who to contact if they had a problem, however, participants mentioned different contacts including the prostate cancer specialist nurses, a national helpline and the GP:

If it is to do with prostate cancer we can contact our specialist nurses – no problem at all.

There is also a National Helpline as well which I have spoken to in the early days.

I think coming back to the GP as well if I went to a GP and said look I am worried about this, surely he would refer me.

I think I would go to the GP if I was really worried.

- One participant said the nature of the problem would determine who you would contact:

It depends on the nature of the problem – some things you would happily speak to the nurse about and take advice. She might say "Go and see your doctor".

- Another participant suggested that as patient you would be able to resolve many problems yourself:

I think when you have got something like this you become a specialist yourself!

Seeing the same specialist consultant/nurse

- There was general agreement in the group that it was very important to see the same specialist (either a consultant or nurse) at every appointment.
- It was suggested that it was preferable to have continuity of clinician in order to ensure consistency in the care provided:

And I would suggest that you stick to the same clinician because I know from experience when patients change team, treatment plans change because another person will see it in a different light, whereas if you stay with one person your treatment plan tends to be constant.

5.4 Views of different models of care

Participants in this group, on the whole, were resistant to the suggested new models of providing care. The main reason behind this appeared to be high levels of satisfaction with the current model:

I think the 3 monthly ones are ideal – they know roughly with experience what to see us for and we trust them and you get confidence in your doctor. My doctor said “We don’t need to see you every six months, everything is clear, come back in a year” and then I went back in a year and it is fine and they said “Come back next year”.

Telephone follow up (nurse led)

- In general, participants saw difficulties with telephone follow up. Even those who said they personally would not mind telephone follow up appointments, could see problems for others.
- Telephone communication was seen as ‘impersonal’ and most people felt that better understanding could be gained by communicating face to face with someone.

I think telephones would be a bit impersonal – seeing the people that are going to do the business for you – just looking at the faces you can get some idea better than telephone.

- A number of people felt that patients would be less likely to express their concerns and worries over the telephone, for example:

On a personal note, my mother hated the telephone and if anybody phoned up and said “How are you?” she would say “Fine” and that is her answer – she wouldn’t comment at all and a lot of people don’t like the telephone.

I find phones the most impersonal horrible thing... The only time I have words with my wife is over the phone because she can’t see I am joking or whatever. I just don’t like them and as for getting something over that is important I think it is a terrible form of communication.

- One patient mentioned potential problems with confidentiality because of others over-hearing what was said and lack of security of mobile phone lines; he also questioned how partners would be able to take part in the consultation. Another thought that people would be ‘wary and not very co-operative of telephone follow up.

You would have to make sure that the phone calls couldn’t be overheard and how would the partners hear what was going on anyway if you were on the phone. It is very difficult. I have no personal objection to it but I can see problems. You wouldn’t have to use a mobile phone for instance because anybody could tune into it.

- Participants also envisaged practical problems in setting the telephone appointment system up.

How would you know that they were going to ring you up?

They would ring you up to tell you!

The administration would be pretty difficult to arrange I would think.

- One participant envisaged problems with continuity with telephone follow up.
- One patient thought that telephone follow up might be appropriate, but only after you were signed off from the cancer specialist after five or so years of face to face follow up appointments. There was general agreement from the rest of the group that this would be a good arrangement.

When you are signed off from your consultant or your specialist I think after 5 years, then a phone call perhaps by a nurse.

When the consultant has finished with you after five years or whatever it is and then you are left on your own then. So perhaps a phone call once a year that might be (good).

- Some patients already received their test results over the telephone and were happy with this; others, however thought it was important to be able to see your results on the screen so you could be actively involved in monitoring your own condition.
- It was thought that telephone follow up appointments could save money in the NHS and another advantage was that it 'would clear the car parks' at the hospital.
- As an additional service to augment face to face appointments, telephone follow up was seen as a good thing, especially for those who do not want to join a support group.

I don't think it would be a bad thing as an extra thing for somebody to phone up and say "Is everything OK?" We are fortunate in so far as we have got the group and all the rest of it but somebody who is sitting out on their own through choice of not wanting to join into a group or whatever, might benefit from it.

Patient managed follow up

- The group was generally negative towards the suggestion of patient managed follow up where no appointments were booked, but contact was entirely initiated by the patient.
- One patient valued the reassurance provided by the current system of regular follow up appointments and regarded getting the all clear at an appointment as a positive experience he was reluctant to lose.
- Two patients felt that it sounded dangerous and others thought people might ignore their symptoms and avoid seeking advice when it was needed.

I think personally it sounds a bit dangerous to me.

It does to me.

I am sure there are none around this table but there are people that stick their head in the sand at medical problems and they don't seek advice until it is too late and things like that.

- Patient initiated follow up was thought to be particularly inappropriate with prostate cancer where they symptoms are often silent.

My concern is that with prostate cancer you can feel alright and men are particularly prone to saying "I am alright" and they will not do anything about it.

- There was also concern that some people might abuse the system by initiating contact when it was not really needed.

The other extreme you have got somebody who will be on the phone every 10 minutes.

- When asked directly if they saw any good things about patient initiated follow up, there was some support for the notion of patients looking after their own health.

The fact that you are looking after your own health, I think that is a good thing.

That's right as long as they are given the information what to look for and signs that if this happens contact your GP or the nurse of whatever and you can get an appointment to see the specialist in a reasonable amount of time.

- Generally, however there was a feeling that although those in the support group would be able to manage their own condition, there was a wide spectrum of patients and most would not be able to take the responsibility.

Group follow up

- Participants were generally negative about the idea of having group follow up appointments. As with the other two alternative models, although some of those in the group thought it might personally suit them, they did not feel that it would be appropriate for most patients.
- The importance of seeing health professionals about your own personal concerns was the main difficulty envisaged by some participants. The need to deliver personalised care that met the different needs of each patient was a key concern here.

Everybody wants to know their particular thing – whether it is 3 months or 6 months, or a year.

It is like this group here we have all got various, different symptoms and problems – we have all got prostate cancer but there is no one answer to any of us – everyone of us is different.

A group discussion would be alright, but I wouldn't be wild about it. I would rather feel your own particular circumstances, 10 minutes with somebody speaking directly about your own, would be far better than 2 hours in a group.

- Another difficulty with group follow up appointments was seen as problems with getting people to attend a formal group organised by health professionals.

If this meeting was a formal meeting and I had to come here every month – if I didn't have to come here every month I wouldn't do it – I like the informality and the joviality and the comradeship as well – that's a big part of it. If it became a state run thing as the saying is we would lose that.

- Although, participants were broadly negative about the suggestion of group follow up appointments, as active members of the prostate cancer support group, they all commented on the positive role of informal group sessions.

We have got the best of both worlds now, haven't we?

Bearing in mind... that we are all different and we all have different symptoms and treatments, I can't think of a better way for any follow up than through a group like (ours). To disseminate advice and information through that group I would have thought – I can't think of anything better quite frankly.

- There were suggestions that groups such as their own should be officially supported, rather than replacing them with formally organised groups organised by health professionals.

If the Health Service are looking for something like this it would probably be better to support a group like we have got or encourage groups in each hospital really – get Government support to help groups out like that.

- Participants discussed difficulties with getting clinical specialists to attend the support group; there was an implication that formal NHS support for the group could result in more effective medical input.

But as far as medical representation goes at that group, we are lucky if we get a consultant to come once a year, possibly twice if we are lucky. But it is really invaluable to have that gentleman there and... we are all quite happy to talk about our individual cases and we all learn from each other because you will answer questions in open forum... Because the pressure is on the Health Service, it is more and more difficult for the health professionals to come and talk to us.

- When asked directly if they saw any benefits with group follow up appointments, one participant mentioned the potential of the 'buddy system' and another pointed out that it would be a positive thing in areas that did not already have an informal support group like their own.

The good thing is – you can employ the buddy system again there – team people up with similar problems.

I think if it was in an area where you haven't got the facilities that we have got then it might be different mightn't it – it could be a replacement to the support group.

Seeing a nurse specialist for routine checks

- A participant in the group described a new format of care delivered in some units, thought he had not experienced it himself, where patients saw the nurse specialist for routine checks, rather than the consultant.

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- There was general agreement that this was an acceptable approach, for example:
They know more than the doctors in some cases

5.5 Agreements within the prostate cancer group

Definitions of follow up care

- Follow up care for prostate cancer centred on the PSA tests, conducted at intervals ranging from every three months to every five years, depending on the patient's condition. Follow up appointments were generally with a specialist at the hospital, though in the later stages, PSA tests were often conducted at the GP surgery. There was a positive attitude to a limited notion of self managed care in the group. The main purpose of follow up appointments was seen as reassurance of recovery
- Most patients in this group had very positive perceptions of their follow up care

Views of aspects of follow up care

1. Rapid access to specialist medical care if you have a concern

- Prostate cancer is not generally a rapid cancer and therefore there is less urgency for immediate access to a specialist; ability to get back into the system if have a concern regarded as important. Specialist prostate cancer nurses provided a good first point of contact if patients were concerned.

2. Accurate information about what to expect following treatment

- On the whole patients had good experience of information about follow up care, but the support group was the main source rather than health professionals. Gaps in information provision at diagnosis were identified. Resources to assist self-management were suggested eg card to record and monitor test results.

3. Help with returning to (and staying in) work

- Only one of the participants in the group had been working at the time their cancer was diagnosed and his experience had been entirely positive.

4. Advice about benefits

- One participant who was retired said he found it difficult to find out about benefits.

5. Psychological support

- Generally, the need for psychological support was seen as highest around the time of diagnosis and initial treatment. Most of the discussion about psychological support focused on the important role of the prostate cancer support group.

6. Support for my carer (and/or family and friends)

- There was general agreement that wives, family and friends had support needs as well as the patient, but at diagnosis and treatment, rather than during follow up care.

7. Being seen at my GP surgery

- Most patients had their follow up care with their hospital consultant and it was suggested that GPs lacked the specialist knowledge to provide this. Difficulties with access to primary care services were regarded as a barrier to more GP involvement in follow up care.

8. Being seen at the hospital

- There was general agreement in the group that attending hospital appointments was necessary, even though it was often inconvenient - your health is more important than the inconvenience of waiting to be seen.

9. Knowing who to contact if I have a problem

- There was general agreement in this group that they knew who to contact if they had a problem, however, participants mentioned different contacts including the prostate cancer specialist nurses, a national helpline and their GP.

10 Seeing the same specialist consultant / nurse

- It was thought very important to see the same specialist (either a consultant or nurse) at every appointment to ensure continuity of care.

Views of different models of care

Participants in this group, on the whole, were resistant to the suggested new models of providing care as replacements for existing models of follow up care. There was however, some limited support for all three models as additional services in addition to current care. There was also support for an enhanced role for prostate cancer nurse specialists in providing follow up care.

The main reason for resistance to the new models appeared to be high levels of satisfaction with the current model.

1. Telephone follow up (nurse led)

- In general, participants saw difficulties with telephone follow up, except in the period after discharge from specialist care; difficulties included:
 - 'impersonal'
 - face to face communication more effective
 - confidentiality and security were concerns
 - problems with administration
 - lack of continuity of care

2. Patient managed follow up

- The group was generally negative towards the suggestion of patient managed follow up where no appointments were booked, but contact was entirely initiated by the patient.

- The main concern was that people might ignore their symptoms and avoid seeking advice when it was needed. Patient initiated follow up was thought to be particularly inappropriate with prostate cancer where they symptoms are often silent.
- There was limited support for the notion of patients looking after their own health, but it was felt that most patients would not be able to take the responsibility.

3. Group follow up

- Participants were generally negative about the idea of having group follow up appointments. The need to deliver personalised care that met the different needs of each patient was a key concern here. Getting people to attend was also seen as a problem.
- There were suggestions that groups such as their own should be officially supported, rather than replacing them with formally organised groups organised by health professionals.

5.6 Variations within the prostate cancer group

There were no marked variations in the views expressed by participants in this group. This perhaps reflects the high degree of homogeneity of focus group members.

Group 4: men and women with experience of follow up care for cancer requiring extensive monitoring including invasive procedures

6.1 Participants

The six participants in Group 4 were made up as follows:

- three men and three women
- participants had experienced:
 - bowel cancer (three patients)
 - mouth/mouth neck cancer (two patients)
 - myeloma (one patient)
- those in the group had experienced a range of treatments, including:
 - radiotherapy
 - surgery
 - chemotherapy
 - stem cell transfer
 - series of new and experimental drugs.
- one participant had been diagnosed in 2000/01; two had been diagnosed in February 2004, one in 2005 and two in 2006
- participants had been treated at different hospitals in the South East of England
- all but one participant was currently in remission
- one participant worked four days a week
- one participant worked on a voluntary basis for a bowel cancer charity.

6.2 Definitions of follow up care

Nature of follow up care for those in group 4

Patients commonly talked in terms of the frequency of follow up appointments and the length of time follow up would extend for:

Well follow up care to me is that I know it has got to go on for five years. Luckily I didn't have any chemotherapy or radiotherapy and I am just seeing the consultant with a CT scan and a 3 yearly colonoscopy and I believe I go on for ever and a day – a 3 yearly colonoscopy and that is what my whole life is all about. But thankfully I don't need any more treatment.

Initially I was on 3 monthly check ups seeing the consultant. I am now on 6 monthly and I think probably fairly soon I will be yearly

I go (for follow up appointments) every month. I think I have had about 11 biopsies over the years.

My appointments were initially once a month but (now) I am going in twice a week

Some described seeing different health professionals for different aspects of their follow up care at different time intervals.

Patients described how follow-up was often linked to a side-effect of their initial cancer treatment:

I had no after effects of radiotherapy but I was left with a permanent colostomy so I had a couple of visits from the... nurse

One patient with a form of cancer that could not be cured described how for him there was no follow up care:

Well there is no follow up – in that there is no end of the treatment really – it basically stops when I die. There is just the hope that this new experiment will keep me going for some time. There are various other last ditch things that they can try but it is just delaying the inevitable so there is no point in which I can say “Ok that is end of treatment” – I now move into the post treatment phase.

Perceptions of follow up care

The two patients with mouth cancer had contrasting experiences in terms of access to follow up care:

- One said had expected more help in terms of follow up, particularly help to deal with the after effects of treatment eg:
 - dealing with changes in appearance, ie access to psychological support
 - improving speech ie access to speech therapy.
- The other talked of getting lots of help in terms of follow up care and suggests that this may have been due to the very young age at which she was diagnosed:
 - had a speech therapist and a dietician from the beginning of treatment
 - lots of contact points to get help

- very easy access to support at her local hospital mainly as they knew her so well.

I just literally go in or phone up

Three participants had had bowel cancer. One describes negative experiences, saying she has had no follow up appointment to see the consultant and feels that she has dropped out of the system somewhat. She suggests that you need the support most during the first year that you complete treatment and that although some aspects of her care was good that not all aspects were joined up enough.

Another describes a similar lack of co-ordination in her follow up care for bowel cancer, suggesting that the problems stemmed from the absence of a specific health professional who was responsible for co-ordinating different aspects of follow up care:

I had excellent care from the start until I was signed off after my reversal... (After that) nobody seemed to be on hand.... the Stoma nurses didn't really want to know so it was quite an upsetting time. I had a.... leakage, which was pumping out of my body through my naval which was quite scary actually.

She goes on to describe how this lack of co-ordination left her feeling as if she 'had dropped out of the system' and talks particularly in terms of the lack of continuity in the feedback of results of investigative tests :

I had a colonoscopy... but I didn't get a follow up appointment to see the consultant. I got a letter in the post a month later.... I went for my CT scan and wondered when I was going to get the results - I wanted to know what was going on... I had to wait 2 ½ weeks before I got hold of the Colorectal nurse and she had been on holiday..... I had established good relationships throughout my treatment at the hospital but they couldn't cross parameters to give me my scan results which I didn't think was right some how because I didn't have an appointment to go and get my results. I have now fallen back into the system but I am not given an appointment until July which was the first appointment that they had apparently. When you have finished treatment, I think the first year at least after you have finished all your treatment is when you need that little bit more support. Because it is full on and then there is nothing at all. So that has been my experience so far.

In contrast, another patient said how their follow up care had been well co-ordinated:

Well I think I have had very good care... It is really consistent of tracking the progress of the disease through the various treatments. So I last saw my consultant in January and was told to come back in 3 months time - that is the longest period I have had away from the hospital.

Some patients described different experiences with different aspects of their follow up care:

Oncology have been great because from the chemo I had an appointment six months after I had finished because I have still got neuropathy which I think is now permanent in my feet, I have still got another follow up appointment in June. So the Oncology follow up side has been absolutely wonderful but the colorectal side has fallen down.

6.3 Views of aspects of follow up care

Rapid access to specialist medical care if you have a concern

In general, the three patients with cancers other than bowel cancer, appeared to have had better experiences in terms of having rapid access to specialist medical care if they had a concern during their follow-up care:

Yes I think my experience is probably better really. There have been periods over the last 4 years where I have been signed off for several months – hospital free. And if a crisis has emerged there has been pretty immediate help on hand. Two examples – one was I had cellulitis in an arm so the arm swelled up like a Michelin Man – and I was straight through to Haematology and spoke to a consultant.... And I was impounded on the spot – and not allowed out of the hospital until I had a lot of intravenous stuff. I found out later that they had only managed to find a last minute bed and they had put me in a plastic surgery ward. The other occasion was just a couple of months ago when I was particularly ill – when I was on holiday – and I came back early and thought I ought to be seen and I thought the quickest way would be to go to the GP. Saw the GP who thought there was nothing fundamentally wrong but because of my unusual condition thought that she should check with my consultant. Phoned through to the consultant while I was still there and got hold of her in a fairly short time. Got a response and said “OK you are deemed not to be immune deficient at the moment and that is fine”. So in those two cases, I think I was dealt with very well. I do feel that if there were a crisis I would just phone the specialist Haematology Ward and I would be able to get immediate treatment. It is also quite convenient for me because I live just a mile away from the hospital.

One participant with mouth cancer described how she had very easy access to specialist care at the hospital, on the ward she had been treated on:

I don't even have to phone – I can just go to the hospital and someone will see me there and then... I go to the ward – I have done it a couple of times... Or if I couldn't get there I would try and ring. But they see me literally straight away even if it wasn't my consultant they would make sure someone sees me.

The other mouth cancer patient said he had similar experiences, describing how he could get an appointment the following day if he needed it by telephoning the hospital cancer centre reception. He points out that this would not necessarily be with his own consultant who would prefer to treat him himself.

One of the bowel cancer patients described how she had good access to the Stoma nurses at the hospital and points out that there were three of these at the hospital. Another agrees that access to the Stoma nurses was good, but that when her care was transferred to the Colorectal nurse, telephone access was problematic and she got more support from the nurses at her GP surgery:

For some reason or another every time I phoned... I could leave a message but I never got a phone call back. I would get replies to e-mails though. Because there were a few concerns in the first 3 months after the reversal – right up until Christmas – but I wouldn't say that... it was rapid access – it was kind of slow – it was a very slow response. Most of my support I got from the group practice and the group practice nurses. They were absolutely wonderful.

This patient describes feelings of 'dropping out of the system' when her treatment ended and the other bowel cancer patients agree, suggesting that A&E was the route by which they would access follow up care if they had a concern:

Yes I had much the same feeling. During my treatment, both radiotherapy and surgery, the treatment was overwhelmingly good – it was absolutely excellent. Then when I was convalescing from the surgery it all just seemed to rather fall away and there seemed a lack of follow up at that time.... On the check up before last and on the last one the consultant recommended that if I had any problems that I just go into A & E.

I had to go into A & E once after surgery because I was in horrendous pain, nobody seemed to want to know and this was like 10 days after being discharged from the hospital and A & E said to me "Well why are you here, why are you not speaking to – you should be seeing your consultant".

The third bowel cancer patient spoke in more positive care of being able to access specialist medical care outside of fixed appointments:

Well both my consultant and the specialist nurses they have always both of them said if I had any problems just ring through to their secretary and I would get an appointment straightaway. I wouldn't have to go back via the GP.... The consultant said "Any time you ever have any worries just ring up and I will fit you in".

This patient does however go on to describe a specific point in follow up care which was problematic:

There wasn't sufficient care and that was very distressing because they worked a four day week and I think if you had a problem on a Friday morning, you couldn't get to see anybody until Monday... You couldn't go back to the hospital because you had been discharged and you were in "no man's land" and.. that was the only criticism I have had over my treatment at all.

Accurate information about what to expect following treatment

Patients generally seemed to have had little information about what to expect during their follow up care provided by cancer health professionals. Some had sourced information themselves from the library, bowel cancer websites on the internet or from hospital based patient groups. Just one patient said he had been given good information about follow-up and suggested this was because his was a rare cancer which was being treated by new and experimental treatments:

(In each case) I felt that I was given good written material to tell me just what to expect after the principle treatment with that particular process had happened so I felt I was well informed. Generally I don't read it all in massive detail, I take points from it – I take the policy that this is not my specialist area – so I will do what I am told when I need to know it. But I had the information there and I picked from it as much as I felt I needed.

In contrast, another patient is critical of the information she was given about the consequences of her treatment and the problems she would experience when it had ended. She did qualify this by pointing out that the doctors themselves had limited

information about the consequences and 'they don't know what is going to happen in 10 years'.

Another patient describes how she would have liked more information, including written information, about the sort of follow-up care she would have when treatment had ended:

I would have appreciated a clearer guideline from my consultant or the team of what follow up care is after bowel cancer because it is different from every cancer and also it depends on what stage, how severe your tumour was. I have not received (any information) – it has just been kind of hearsay and it differs from one nurse to another. It would just be nice to have clear guidelines – what is really the follow up care for this particular cancer or that cancer. It would be nice to have something in writing because you can't take all the information in; you have been through so much already. They will say something but it doesn't always register. You get so much written information at the beginning of your treatment, what to expect etc. why can't we have something in writing – the guidelines for your particular cancer. I think that would benefit so many people in this country.

Patients describe specific information needs post treatment around:

- recovery
- diet
- exercise.

One patient suggests that information should be provided by the medical specialist rather than the patient having to seek it out for them-self from a patient organisation:

They tell you that you will never go back to normal – but what is normal? I don't know now – I can't remember what normal is and.... With foods – some foods I can eat, some I can't – that sort of information would be good even at this point down the line. That is why through "Beating Bowel Cancer" – I have looked on their website which gives you a lot of information but I think that really should come from the consultant or from the medical team.

There was general agreement that information was only provided by the health professionals on demand and it was pointed out that you need to ask the right questions:

You have got to know to be able to know what questions you should be asking – that is the problem.

The format in which information was provided was also criticised and it was suggested that it should be provided on DVD:

I felt quite strongly early on as I was starting treatment that in these days of sophisticated information technology, it seemed a bit strange that we were giving people information on photocopied folded sheets of A4 paper. Wouldn't it be more appropriate to give people access to much more on say a DVD which are quite cheap.

Two patients describe receiving conflicting advice about exercise and one says how the lack of accurate advice on this resulted in a hernia:

The other thing that I was particularly concerned about was exercise because even before I left hospital I had the Stoma nurses telling me how careful I had to be with

lifting and twisting so as not to cause a hernia. I was given no information as to how long that should go on. I have asked questions since then of the Stoma nurse and my GP and have got conflicting advice. The GP seems to think that it is overdone and the Stoma nurse thinks that there is not enough emphasis on that.

Now they told me in 3 months you can go back to gentle exercise etc. It was important to me to stay kind of reasonably active but I went into some exercise, nothing horrendous, I developed a hernia, actually two massive ones, one behind the sternum and one actually in my abdomen. I shouldn't have started any exercise for at least 6 – 9 months. I needed time – and I wasn't given – they said to me 3 months basically. So when I had the reversal I had to have hernia repairs as well so my recovery was a lot slower than it would have been otherwise. No information at all about that.

When asked about priorities for follow-up care at the end of the group, there was general agreement that written information was a priority. Different patients mentioned the need for guidelines and a clear care plan with detailed information about the timing of appointments and what they would consist of:

For me I think what I would like to see is more written information being available about follow up care for cancer patients. We get so much at the beginning – I think it is important to provide much clearer information that is relevant to that hospital because obviously it does vary from one area to another. But definitely written information because you cannot take everything in. It is a journey that you are going through – you don't absorb all the information and it is something that you can read later because from my experience there is not much information available from the voluntary sector about follow up care. There is loads of information on your particular cancer but not guidelines on follow up and that would just be absolutely wonderful....

"Since finishing treatment, I have been told I am going to be having scans every 6 months maybe. But there are no clear guidelines – I have been told different things – that I would have another colonoscopy again in 6 months time but when I received my letter – from the last one – it said that it was going to happen in a year's time... I receive one piece of information from one nurse and then something from another nurse....

"I would like to see clearer guidelines. Just... something that you can look at – what is going to happen. Because this is going on for 5 years, it is not just... one post op check – you have still got to go through all the screening and that is what we want information about....

"And not just for me but I have heard other patients within my hospital say it too".

I received clear information about those steps prior to treatment and after treatment – this is what happens next. But I have not received any information about follow up. I am none the wiser – is it every six months? I have got no clear guidelines – and that is the information that has not been provided to me – all the other information has but not the follow up guidelines.

I (agree) it is important... so that somebody has got a list of – at what point they would go from 6 months to a yearly check-up. It is not going to be in everybody's case because it depends on if they have recovered substantially. But at least it

would give you a guideline so that if you dropped off the system because of an administrative problem you would know yourself – hang on a minute I should have had this then – and then you could make the right noises.

Help with returning to (and staying in) work

Three patients describe difficulties staying in work during treatment. One had left work before diagnosis because the symptoms made work difficult. Another said she was sent many letters by her employer questioning when she would be returning to work at a time when she was clearly not well enough to return. She had then made the decision to apply to university and was now a student. The other said he was unable to return to his old job and had not been able to find work since, suggesting that this was because of the effect of the treatment on his speech:

I tried to go back to my job but I couldn't do it mainly because it involved talking to people and the people at work couldn't cope – my boss couldn't cope – so I couldn't do what I wanted to do and I have been trying to get something else and that is not easy when you are like this.

It is very difficult – people don't understand what you are saying.

It was suggested that staying in work during follow-up was not easy if your employer was unsympathetic because it could involve a lot of time off work for tests and appointments:

It was difficult to balance going for treatments / scans at short notice and your job, as the scans sometimes were often arranged at such short notice that you had to drop everything, including work.

In terms of finding work after cancer, it was suggested that employers were reluctant to employ someone who had had cancer because they were concerned you would fall ill again.

In contrast to the experiences of the two mouth cancer patients, the three people with bowel cancer had positive experiences of returning to work after the end of treatment. The willingness of the employer to allow them to work flexibly was suggested by two as crucial to their return:

Yes I was working at the time and I was extremely lucky because I was off for five months and then they allowed me to come back, staggered working so that over 3 months I could do whatever hours I wanted. So I was extremely lucky to be able to do that. It was a two way thing because they got me back to work earlier than they would have done, I am sure the GP wouldn't have signed me off as early if I had had to go back full-time – so we both won.

Yes I returned to work – very part-time in February. I was actually off for about 15 months altogether. I have not really had support from the medical professional but the people that I work with – we have got this sort of duty of care towards me and the whole team is aware that if I am tired I can go home. So it was very staggered, but it is going really well – because of the understanding and the support from my work colleagues and plus I work for a Government office as well.

Another participant had been semi-retired at the time of diagnosis and mentioned no difficulties keeping their job and returning to work at the end of treatment. It does however say he was not given advice, but implies that this was not a problem for him because of the nature of his work.

Advice about benefits

Two participants mentioned receiving help with applying for benefits during follow-up. One described how when her sick pay had ended she had been referred by a healthcare professional to someone who assisted her complete a application for benefits. This provided her with income during radiotherapy. The other describes receiving advice about benefits from the hospital cancer charitable trust and goes on to describe help received from statutory sources:

And before returning to work I also got a lot of advice from a Government agency called Work Directions that work very closely with Job Centre Plus. And if they hadn't give me the information they did, it wouldn't have been worth my while going back to work part-time so as a result of that advice I am certainly better off working part-time. So I have received excellent advice on all benefits and also the psychological stuff.

Another participant describes how the MacMillan nurses at the hospital she had treatment were very supportive during radiotherapy in helping people fill in benefit forms.

Psychological support

In identifying priorities for follow up care at the end of the group, one participant mentions the importance of psychological support:

Just to reiterate a point made earlier – I would say that during and after treatment – that psychological support is an important part of the treatment of my body as an entity and that everyone at every stage should have an easily accessible guardian angel – somebody who stands outside the clinical process... not necessarily a practicing medic but is (familiar) with the particular issues that arise with that type of condition.

When asked specifically about psychological support, two male participants described a lack of emotional support and suggested that they would have benefited from this. One describes how he has had to source this himself:

When I was first diagnosed I was told somebody from MacMillan would be in touch but nobody ever contacted me. So I would say there is a gap – I had no support there and the only thing that I might have had – I have had – I would have had to go out find myself. So somebody who would give a little bit of sympathy, psychological support would have been appreciated at times over the last few years but there is nobody there. That is not the doctor's role, the doctor's role is to deal with the machine which is in front of them – treat that as a purely technical exercise.

Another uses similar terms to describe how he would of benefited from more emotional support, particularly to deal with the 'after effects' of his cancer and the 'stigma' that results from the change in his appearance after treatment.

We get a lot of bad vibes from people – and people cannot understand what we are saying.... (And) people say forget about it, (but) you can't when you are living with it day after day; you go into the supermarket and you have people looking at you – and you are thinking "Am I that bad?".... There is no help (to cope) with any of that.

Four patients describe accessing psychological support. One patient describes how he paid for private counselling accessed through a cancer charity. Another describes being signposted to psychological support by the hospital cancer trust, though later mentions this was only after breaking down in tears in front of a nurse:

I had very positive advice from the Cancer (charitable) Trust within the hospital, they run the support service for cancer patients. I got a lot of support from them – I was referred to a psychologist – it was just coming to terms with the fact that I had been diagnosed with cancer.

Another mentions being given the contact details for a counsellor by a MacMillan nurse:

One of the bits of paper that I got gave the name and telephone number of a counsellor and I availed myself of her services a year ago last Christmas. That was very useful.

The fourth suggests that she only got psychological support because she 'shouted' for it whereas other patients with the same condition had not:

...and she didn't get any of what I got. So it is down to me actually chasing for things....

Support for my carer (and/or family and friends)

Just one patient commented on the support provided for friends and family. She describes how her daughters found it hard to cope with their mother's diagnosis of cancer and how they received lots of information from MacMillan, but what they really needed was emotional support:

My daughters found it very difficult coming to terms with the fact that I had cancer. They got in touch with MacMillan and they did receive a load of booklets through the post but they both needed someone to talk to. They actually got that through (a bowel cancer patient organisation) and that has helped.

She later describes how they had emotional support needs even though they were both adults because they thought their mother was going to die and that when these needs were met they were able to relate to her much better:

They just couldn't deal with that – I think it was the whole cancer thing. Because everybody – we have lost a lot of people in our family through cancer – both my parents, my grandparents on both my mum and dad's side so my girls – their experience of cancer is, you die – it didn't matter how old they were or how much they read, they really thought that I wasn't going to get as far as I have got. But

they got excellent support when they started having a one to one counsellor which they did for about 3 months and they actually understand me a lot better now and can deal with me on a one to one basis. Because sometimes they didn't know what to say to me.

Being seen at my GP surgery

It was suggested that the service available from the GP depended on the size of the practice and the way in which the appointment system worked. Some felt they benefited from attending a large practice whereas others described how the large size of their practice meant they rarely saw their own GP. Two patients appreciated the 'drop in' appointment system which operated at their practices which meant they were able to see their own GP:

I think you might find there is quite a difference though between those who go to single GP practices and those who go to large practices.

Yes there are about five doctors and two nurses at my group practice, I am quite fortunate.

It is about the same as mine. One time in four I might be seen by my own doctor... but it could just be any of them when I go there.

Each surgery is different. Mine still has a "Drop In" surgery so you know what day your doctor that you want to see is going to be there.

Some patients were positive about the ability of the health professionals at their GP surgery to provide their follow-up care, whereas others expressed a lack of confidence in the GPs ability to provide appropriate care. Difficulties with GPs providing follow up care focused on problems with access, continuity and a lack of specialist knowledge.

Two patients registered at large GP practices described difficulties getting appointments with their own GP and expressed a preference for care at the hospital, particularly as they were both able to rapidly access specialist care provided by the hospital consultants. One patient said he only saw his own GP if he 'really had to' as he felt his GP was flippant and did not understand his situation. Another describes getting conflicting advice from their GP and the Stoma nurse regarding exercise.

A number of those in this group made positive comments about the role played by their GP in their follow up care. One had recently been supported by her GP in accessing an earlier follow-up appointment at the hospital and comments on 'how supportive they are'.

One of the bowel cancer patients described poor access to the colorectal nurses at the hospital who were now responsible for her care and said she got more support from the nurses at her GP surgery:

Most of my support I got from the (GP) group practice and the group practice nurses. They were absolutely wonderful.... It is quite a big practice and they have known me for - I have been with my doctors for donkeys' years so I know them all really well and they gave me a lot of support.

Another patient described attending the GP when concerned about his condition; the GP checked with the consultant who confirmed the GPs opinion that there was not a problem:

I was on holiday – and I came back early and thought I ought to be seen and I thought the quickest way would be to go to the GP. Saw the GP who thought there was nothing fundamentally wrong but because of my unusual condition thought that she should check with my consultant. Phoned through to the consultant while I was still there and got hold of her in a fairly short time. Got a response and said “OK you are deemed not to be immune deficient at the moment and that is fine”.... I think I was dealt with very well.

Being seen at the hospital

As was suggested in the previous section, there was not a great deal of support for receiving follow up care away from the hospital. The main reasons given for this was the ‘need to be seen by specialists in your condition’ and as described above, there was also a lack of confidence that the GP could provide the level of care needed:

I have a very good GP who I trust very much but I think you have still got to have that confidence that they know exactly what they are talking about.

I think the specialist team is a very important part of our recovery that we see the specialist.

Knowing who to contact if I have a problem

Participants seemed to agree that they knew who to contact but they sometimes had difficulties getting hold of them:

I know who to contact but I can't get hold of them!

I actually found there is a slight issue actually that sometimes the nurses – there is a specialist nurse dealing with this particular type of cancer – and there are a couple of back-ups and sometimes you leave a message and they don't get back to you and that can be frustrating. So I think even if it is just a holding message, at least get back to somebody within 24 hours... If you take the trouble to ring the hospital, then it is important enough for somebody to ring you back.

It was suggested that staffing levels meant that the specialist nurses were very stretched which could impact on the ability to contact them when needed.

Seeing the same specialist consultant/nurse

When asked about priorities for follow-up care at the end of the group, three participants identified continuity of care as a priority:

I think it should be consistent.... You should be able to ring your consultant and your call should be returned

I agree.... there needs to be consistency. I think consistency and continuity is very important because since I left hospital I have not seen the consultant surgeon who dealt with my case. I have seen a series of different consultants and a series of different Stoma nurses and it makes you feel a little bit uneasy.

It was suggested that a lack of continuity wasted time as the health professional had to read your notes at every appointment before seeing you:

I feel the time is wasted on check ups where a different person has to scan as quickly as possible through your notes and waste valuable time doing that in a very busy colorectal clinic where they have got very limited time anyway. They are wasting time doing that when you could be speaking to them about the whole thing.

It was suggested that continuity of specialist was important to provide 'peace of mind' – reassurance for patients that the health care professional they saw was knowledgeable about their particular case.

One patient described with satisfaction how her consultant had made arrangements to ensure she received continuity of care in terms of being followed up in the way he wanted, even after he retired.

6.4 Views of different models of care

Telephone follow up (nurse led)

Patients' response to telephone follow up appointments was mixed. Two saw problems with it in the context of their specific form of cancer and another had concerns about the practicalities. Two others could see advantages. The consensus seemed to be that it might be appropriate for some patients at some stages in their journey as a cancer patient.

Positive responses were based on the convenience of a telephone based system. One patient talks in positive terms of the way his hospital provides telephone follow up as part of an Enhanced Recovery Programme:

My hospital already does this as part of their follow up care when you are discharged from hospital.... as part of the Enhanced Recovery Programme.... And it works very well. Because.... they are asking me a load of questions – and if there is anything wrong or if you have any concerns and they couldn't deal with it they would point you in the right direction or you would be called in.

Another patient also sees benefits with telephone follow up at certain periods in his care, particularly in terms of reducing the need for patients to make very long journeys to hospital for an appointment when they are symptom free:

I think that I can see circumstances where it would work and with my particular condition there are... many periods, where you appear to be in remission for probably a decade sometimes and in those cases you are effectively receiving post treatment follow up. If it is an unusual form of cancer, there maybe just one

hospital to cover a very large area (which means patients have to make long journeys to appointments)..... I could just see it being very helpful – people would phone up and say “I am experiencing... a particular symptom” and there would be somebody at the other end saying “That really is nothing to worry about” or “Get yourself in here quickly”. I think for those who do live a long way away, it could be particularly useful.

A patient with bowel cancer expresses uncertainties about the appropriateness of telephone follow up for her type of cancer because a patient would not be aware that anything was wrong. She does however, say that having improved access to advice over the telephone would be an advantage, but only in addition to follow up appointments in the clinic, not as a replacement for them:

I don't think that would work in my particular type of cancer because I might not know that there is something wrong so obviously – it would be nice to have if I just wanted a question answered but as an actual follow up to treatment, no it certainly wouldn't give me the confidence.

One of the patients with mouth cancer say that telephone follow up appointments would not suit them because the cancer treatment has made their speech difficult to understand and therefore communicating over the telephone is particularly difficult. The other mouth cancer patient also expressed concerns – about the limited time likely to be available for a telephone consultation and concerns about getting the input of other health professionals if needed:

And they have only got 10 minutes for that phone call.... Or if they needed to talk to another health professional, how would that work?

Patient managed follow up

There was a general negative response to the notion of patient initiated follow up. Two patients felt that there was a danger of ‘slipping through the net’ if follow up appointments were entirely patient initiated.

I think you could slip through... There should be an element of the fact that you can come in if you had a concern... It certainly wouldn't work for me and I think you can miss a lot of things.

I think when it comes to cancer follow up services, I think that there should be guidelines that you have set appointments every 3, 6 months or whatever and that they should happen. We shouldn't have to initiate them ourselves. In my case, I slipped out of the net so I have had to kind of initiate it but no I don't think that would work.

Another expressed concerns that a patient would have the knowledge to know when they had a problem which required further investigation or treatment:

Patients are not an expert on their own condition.

Group follow up

Participants in this group were generally negative about the notion of group follow up appointments. Two mouth cancer patients gave group follow up the 'thumbs down' and two others suggested that a group could inhibit you from revealing information that was important for your care and recovery:

One to one support is best as you might not want to share information within a group.

For follow up I think different people have different concerns. I think sometimes one person would have several different symptoms and another person may have one and they might not voice that one because that other person had several symptoms.

Patients with personal experience of attending cancer support groups described difficulties they had encountered. One talked of how those in the group had very different expectations from their own and as a consequence, the group lacked focus. Another described problems in a group he attended caused by the anger felt by other participants:

I go to a cancer group sometimes but the people at the group.... are older people who are mainly retired.... I am not in that category. I expected to go there and meet people like me trying to get back to work. But they just talk about the price of things in Sainsburys!

The disadvantage that I can see and that I have experienced a couple of times.... seems that occasionally a participant feels a good deal of anger for whatever reason about their cancer and they wish to vent their feelings and waste a lot of valuable time.

There was some support amongst participants for group based activity, but only in addition to one to one follow up appointments, not as a replacement. Two patients talked in positive terms of a hospital based support group held on a weekly or fortnightly basis:

So you are sharing your experiences with other patients who are actually having treatment at that hospital because it does vary from one hospital to another. So group support is good but (only if it) is voluntary, if you want to go to it. It shouldn't be in place for you to go along (for follow up care)... because everybody has different problems and different needs throughout their treatment and their follow up.

I think that support is a very important one – because at different stages people can get quite a bit of strength from people that they have seen come through the same experience – I think that is very important but I cannot see it working as a follow up to your own treatment.

Enhanced recovery nurse

One participant spoke in very positive terms of the care provided by the Enhanced Recovery Nurse who co-ordinated their care, though they appeared to have limited involvement in a patient's follow-up care:

It is a unique programme but it does work because you get to know (them), you are not seeing different people – you are establishing good relationships because you see them before your operation, they arrange all your pre op tests..... and they see you when you are actually in hospital and then they do your follow up – they do your post op assessments as well. You usually have two of those on discharge from – but it is really the same Enhanced Recovery Nurse. So it is very good.

6.5 Agreements within Group 4

Definitions of follow up care

- Participants in this group commonly defined follow-up care in terms of the frequency of appointments and the length of time follow up would extend for; most had seen or were currently seeing a range of different health professionals for different aspects of their follow up care at varying time intervals; follow-up for those in this group was often linked to a side-effect of their initial cancer treatment.
- Although most patients in this group had had generally positive experiences of follow-up care, most also described negative experiences in terms of access to follow up care, in particular stemming from a lack of co-ordination.

Views of aspects of follow up care

Rapid access to specialist medical care if you have a concern

- In general, the three patients with cancers other than bowel cancer, appeared to have had better experiences in terms of having rapid access to specialist medical care if they had a concern during their follow-up care.
- The three bowel cancer patients described good access to the Stoma nurses at the hospital but difficulties with access when their care was transferred elsewhere.

Accurate information about what to expect following treatment

- Patients generally seemed to have had little information about what to expect during their follow up care provided by cancer health professionals; it was suggested that the

latter only provided information on demand and was only provided to those patients who asked the right questions; two patients report receiving conflicting advice.

- There was general agreement that written information was a priority, particularly guidelines and a clear care plan with detailed information about the timing of appointments and what they would consist of; information needs around recovery, diet and exercise were also mentioned; it was suggested that information could usefully be provided on DVD.

Help with returning to (and staying in) work

- Three patients described difficulties staying in work during treatment or returning afterwards.
- The other three participants had had positive experiences of returning to work after the end of treatment; the willingness of the employer to allow flexible working during a phased return appeared crucial to their return.

Advice about benefits

- Two participants mentioned receiving help with applying for benefits during follow-up; none of the others had needed this help.

Psychological support

- Two male participants described a lack of emotional support and suggested that they would have benefited from this.
- Four patients describe accessing psychological support through MacMillan or other cancer charities.

Support for my carer (and/or family and friends)

- Support for friends and family was not a particular issue for participants in this group.

Being seen at my GP surgery

- Some patients were positive about the ability of the health professionals at their GP surgery to provide their follow-up care, whereas others expressed a lack of confidence in the GPs ability to provide appropriate care; difficulties with GPs providing follow up care focused on problems with access, continuity and a lack of specialist knowledge.

Being seen at the hospital

- There was little support for receiving follow up care away from the hospital. The main reasons given for this was the 'need to be seen by specialists in your condition' and a lack of confidence that the GP could provide the level of care needed.

Knowing who to contact if I have a problem

- Participants seemed to agree that they knew who to contact but they sometimes had difficulties getting hold of them; it was suggested that staffing levels meant that the specialist nurses were very stretched which could impact on the ability to contact them when needed.

Seeing the same specialist consultant/nurse

- Continuity of care was generally regarded as a high priority in order to give patients confidence that they were receiving the care they needed; it was suggested that a lack of continuity wasted time as the health professional had to read your notes at every appointment before seeing you.

Views of different models of care

Telephone follow up (nurse led)

- Patients' response to telephone follow up appointments was mixed; the consensus seemed to be that it might be appropriate for some patients at some stages in their journey as a cancer patient, but there was little support for it as a replacement for face to face appointments with a specialist at a hospital clinic.

Patient managed follow up

- There was a general negative response to the notion of patient initiated follow up; concerns centred on patients 'slipping through the net' and their lack of knowledge to know when they had a problem which required further investigation or treatment.

Group follow up

- Participants in this group were generally negative about the notion of group follow up appointments; concerns centred particularly on difficulties of getting the attention you needed to in a group context if others in the group shouted louder or had more pressing problems.

- There was some support amongst participants for group based activity, but only in addition to one to one follow up appointments, not as a replacement.

6.6 Variations within Group 4

Definitions of follow up care

- In contrast to others in the group who were in remission, one patient had a form of cancer that could not be cured and described how for him there was no follow up care.
- Only one participant talked in wholly positive terms of their follow-up care; most had difficulties with some or most aspects.
- Most patients described a lack of co-ordination in their care, and only one described their care as well co-ordinated.
- The two patients with mouth cancer had contrasting experiences in terms of access to follow up care; one said had expected more help and the other talked of getting lots of help in terms of follow up care and suggests that this may have been due to the very young age at which she was diagnosed.

Views of aspects of follow up care

Rapid access to specialist medical care if you have a concern

- In general, the three patients with cancers other than bowel cancer, appeared to have had better experiences in terms of having rapid access to specialist medical care if they had a concern during their follow-up care than those patients with bowel cancer.
- The bowel cancer patients described various difficulties with access to specialist medical care during follow up, particularly out of hours; they were more likely to access services via their GP or A&E.

Accurate information about what to expect following treatment

- Just one patient said he had been given good information about follow-up and suggested this was because his was a rare cancer which was being treated by new and experimental treatments.
- In contrast, another patient is critical of the information she was given about the consequences of her treatment and the problems she would experience when it had ended.

Help with returning to (and staying in) work

- Three patients describe difficulties staying in work during treatment or returning after; the other three had positive experiences with their employers which eased their return to work.
- In terms of finding work after cancer, it was suggested that employers were reluctant to employ someone who had had cancer because they were concerned you would fall ill again.

Advice about benefits

- Two participants mentioned receiving help with applying for benefits during follow-up; no others had needed this sort of help.

Psychological support

- Two men in the group expressed a particular lack of emotional support and suggested that they would have benefited from this.
- One patient describes paying for private counselling accessed through a cancer charity and another suggests that she only got psychological support because she 'shouted' for it whereas other patients with the same condition had not.

Support for my carer (and/or family and friends)

- Just one participant commented on the support provided for friends and family, describing how her daughters' needs for emotional support was met through a cancer charity.

Being seen at my GP surgery

- There was considerable variation in the confidence placed by patients in the ability of their GP and practice nurses to be involved in their follow-up; the absence of easy access to specialist hospital care meant one patient relied on the practice nurses.

Being seen at the hospital

- There was little variation in patients' desire to receive follow-up care from specialists at the hospital.

Seeing the same specialist consultant / nurse

- There was no disagreement that continuity of carer was a priority in follow up care

Views of different models of care

Telephone follow up (nurse led)

- Patients' response to telephone follow up appointments was mixed. Two saw problems with it in the context of their specific form of cancer and another had concerns about the practicalities. Two others could see advantages in terms of reducing unnecessary long journeys to specialist hospitals and enabling rapid access to specialist advice.

Patient managed follow up

- There was no disagreement that patient initiated follow up was inappropriate.

Group follow up

- There was no disagreement that group follow up appointments were inappropriate.

Group 5: men and women living with the long term side effects of treatment for cancer

7.1 Participants

The seven participants in Group % were made up as follows:

- three men and four women
- participants had experienced:
 - bladder cancer
 - gynaecological cancers (cervical, vaginal and endometrial)
 - brain tumours
 - prostate cancer
- those in the group had experienced a range of treatments, including:
 - radiotherapy
 - surgery
 - chemotherapy
- All participants were experiencing long term side effects as a result of their treatment for cancer, particularly from high dose radiotherapy including:
 - severe bowel and bladder problems, including incontinence
 - dietary problems including vitamin deficiency due to poor absorption
 - lymphodema
 - sensitive skin and dermatitis
- one participant had been diagnosed in 1988, one in 1994; two in 1999-2001 and two in 2004-2005
- six participants were having follow up treatment at different hospitals in the South East of England; in some cases this was at a specialist cancer centre, different from where original treatment had been provided; one patient was being treated in the north of England
- one patient was under observation for a secondary cancer; three patients reported being currently in remission
- most of those in this group were working on a part time basis

- some of those in this group were actively involved in local and/or national support groups.

7.2 Definitions of follow up care

All the participants in this group were living with long term debilitating effects of treatment for cancer. One points out that the implications of long term cancer survivorship were only just beginning to be considered and required a shift in the care provided based on regarding cancer as a chronic condition as opposed to an acute episode:

I have been thinking for some time... the treatment for cancer is very, very high. To put it crudely – they poison you at the beginning of the chemotherapy and then they burn you after. And yet here we are all the way down the line, (all) the years that this has been done – it is becoming more and more successful, but we are only just thinking about what is the long term effect of this? That I find very surprising.

People didn't survive....

It is that shift which I think has just been recognised, that cancer is a chronic condition. That it is not an episode – where you either survive or you don't survive, end of story. And that is probably more the model that used to exist. But with these sort of advances and treatment there are thousands and millions of us who are going to be more and more who are living with the long term effects which may be great or slight, vary from time to time. That has to be incorporated into the way the NHS and other organisations actually work with it. It should be a partnership shouldn't it.

The importance of recognising cancer as a chronic condition, 'that is going to affect various aspects of people's lives' was suggested by one participant as a key message to take forward from the group. It was thought that achieving this would bring about action on the key messages put forward by other patients, particularly increased funding for follow-up care that would achieve:

- improved access to specialists and effective treatment
- reminders routinely sent out to patients, like those sent out by dentists or opticians
- research to find a cure for the side effects of treatment for cancer
- more support and information for patients to improve access to follow up care
- improved information for health professionals.

Nature of follow up care for those in Group 5

Follow up care for one patient was currently dominated by care for secondary cancer. Another was having regular scans:

Since (the end of treatment) they have been scanning me every 2 or 3 months – I have had 10 MRI scans since the operation.

For the five other patients follow up was dominated by the problems that had resulted from high doses of radiotherapy used in treating their cancer. Some talked of these problems in the context of 'being lucky' or 'grateful' that the treatment had worked:

(The treatment) gave me another extra 12 years of life which I am very grateful for but the damage that the radiotherapy has caused is now catching up with me and causing quite a problem.

Luckily for me (the treatment) was successful but two or three years down the line I started to suffer side effects from the radiation which left me with incontinence problems and I was referred to the (specialist cancer centre) where I am still. I have a problem with food as well. I cannot absorb certain things.

One patient described how the treatment had resulted in lymphodema, three others described severe bowel problems and another had both lymphodema and bowel and bladder difficulties:

I have got severe radiotherapy damage of the bowel – I got it really within 6 months of finishing radiotherapy (about three years ago) which is unusual... severe faecal problems, incontinence and things like that – and vitamin problems because I cannot absorb my food.

(Radiotherapy) has resulted in double incontinence for all this time – 7 years.... If you don't mind a little bit of detail – when I was having the radiotherapy – to pass the faeces – it was like passing razor blades – and I was at screaming point – and nobody I am afraid helped me. I had the gas that they give to expectant mothers to inhale at those times..... I have another surgeon who was very keen to perform a colostomy on me which I was very keen to avoid and I don't think that the colostomy would have necessarily stopped some of the pain in my bowel even though of course it goes over to a bag. So I have managed to avoid a colostomy with the help of my Gastroenterologist and I am now encountering quite a lot of bladder problems because my bladder has shrunk and I am on tablets now to try and reduce the inflammation in the bladder.

Another described how the radiotherapy had resulted in very sensitive skin which combined with bowel problems had led to dermatitis on the bottom which caused discomfort.

Experiences of follow up care

One patient described his follow up in broadly positive terms, talking of a care plan agreed with the consultant and scan results delivered over the telephone. But he also explains that he often has to initiate appointments himself:

I agreed a plan with my consultant – and I asked “What’s the future?” He said... “what we need in the future is regular scans, every two or three months”. So we agreed a process of every two or three months. I do tend to have to ask – “When will the scan be, have we got a date now?” or “I am going on holiday for a couple of weeks, just wanted to let you know so you didn’t book a scan date whilst I was away” – but a process has been put in place. Results – it has actually been done over the phone – if everything is OK then there really is no point in wasting the consultant’s time.

The other patients in this group generally expressed dissatisfaction with the follow up care they had received. One patient describes difficulties with the outpatient appointment system, particularly in terms of the limited time available during the appointment:

(Ideally), the actual Out Patient follow up appointments (would feel) less like a kind of “Big event” on the horizon, where you know you have got an extremely limited time. You go in having prepared yourself as much as you can bear to with your list of questions. You get in there and the way it develops – something is said and you go off at another angle and you are trying to absorb perhaps new information or unexpected information and then you kind of turn immediately from what you thought you were there to find out about – and somehow deal with this within the space of probably 5 minutes with the doctor. I hate all that. It is very nerve racking and I always come away unsatisfied. I am not an inarticulate person but it just floors me every single time and I don’t think that has ever varied and I would really love it to be different from that.

Other problems relate primarily to accessing cancer follow up services once treatment is completed, particularly in terms of care relating to the side effects of treatment. The problems here seem to fall into two closely related categories: a lack of necessary services and the failure of the cancer specialists responsible for cancer follow up care to give any attention to problems relating to the side effects of treatment.

One patient talks of the need for access to a dietician and two others describe the lack of lymphoedema services:

Some of the rehab services, certainly within the NHS, are there but they are so minimal and I am thinking particularly of things like lymphoedema services which are stretched beyond imagination. I think it means a lot of people don’t get anything.

Lymphoedema... until relatively recently was completely uncatered for (locally) and it is very badly catered for in the country as a whole, although it is improving.... It was very depressing... not having any treatment available.... My GP (was) willing to fund out of area treatment, but the places that did it wouldn’t take me because of the waiting lists were already so long – they were sort of closed.

Most in the group describe difficulties resulting from a lack of holistic follow up care. For example, one describes regular follow up appointments with a Gynaecologist, but a complete lack of care relating to the problems she was experiencing with her bowel, bladder and lymphoedema:

So follow up care has been, I suppose you can say, poor.... I just feel that the Onco/Gynae didn't see the other things as being important – all he was concerned about was recurrence of the specific, spreading to the ovaries or whatever.

The lack of attention from the cancer specialists responsible for her follow up care, led to this patient receiving no treatment for the severe bowel and bladder side effects caused by radiotherapy until she 'just couldn't tolerate it any longer':

I had a very massive dose of radiotherapy.... So I suffered from bladder and bowel damage which I thought I would just put up with really because I thought it was an inevitable consequence of what I had been through. I just put up with it for years and then I just couldn't tolerate it any longer and now just in the last sort of 2 years I have got a Gastroenterologist and there is somebody who helps me to look after my bladder and I have got medication and so on. So life has got a bit better, but nevertheless I still do have that problem.

The experience of one patient seems to encapsulate both a lack of local services and a lack of holistic care. She suggests that there is local variation in the follow up cancer care available, describing her experience of a lack of follow up care and of being 'on your own'. She explains how this became a particular problem when she experienced severe bowel and bladder problems:

Well I think follow up depends on where you live in the country. For me there wasn't really anything of a follow up. I had my treatment – that was finished and then I was given a date for a follow up with my oncologist but down the line when I had the problems with the bowel and the bladder there wasn't anybody who I could speak to. There is nowhere you can go – I went to the GP – and I think personally that GP's really need more information as to the effects of radiation and they don't seem to know where to go to help you. I had to pester and it was through my Oncologist that I was referred on. But there must be thousands of people who are in similar situations and it is awful.... To me once your treatment is finished, you seem to be on your own. It is not just the physical, it is the emotional side as well... you need more support afterwards.

This patient talks in terms of having 'to pester' to get the follow up care she needed. Another expresses similar sentiments, implying that hard work is necessary to get the services you need and describing how she currently does not feel well enough to be able to do this. She later suggests a role for the cancer nurse specialist (CNS) in improving access to services:

I am just at the stage of waiting to hear whether the secondary cancer has spread or not. I am not feeling fantastic and having had to push all these people to get into this place – when you have got (debilitating side effects) or you have got a disability (is) not helpful.

(Ideally, follow up care) would be able to link up with a nurse specialist which has never ever been possible.

The role ascribed by this patient for the CNS is interesting in the context of the many common problems in this group that were attributed to a lack of co-ordination in the cancer follow up services:

I would like (follow up) to be integrated care where the information about the first cancer and the second cancer were properly integrated. Even though the treatment is at the same hospital – it doesn't seem to be.

Four of the patients with bowel problems resulting from radiotherapy describe difficulties with obtaining diagnosis and treatment for their condition. One attributes this to the lack of co-ordination in the cancer service:

I had all these toilet problems and I was referred by the... Oncologist/Gynaecologist – to the Gastroenterologist... and that was fine. But unfortunately, my pain problem was not recognised and I was at screaming point before I really got help with that and the dermatitis was missed too. It was the GP that picked that up. So I think there is a problem with a holistic approach. The specialists are good in their own area but don't necessarily pick up that you need help elsewhere and I think there could be more help with nutrition. It all gets a bit complicated because there is competing things.

Others support this view and describe similar problems with diagnosing their bowel problems and therefore a delay in receiving appropriate treatment:

I had a blockage in the small bowel... they have tried all sorts of different things – it is due to the fact that the elasticity of the intestine is now lost in certain places because of the damage by radiotherapy. But nobody seemed to be sure what to do about it. The surgeon I saw was very reluctant to operate because he said that damaged tissues by radiotherapy do not heal very well so he was wanting to put off the operation as far as he could. In desperation, because I was getting to a stage where my (partner) had called an ambulance because I was having so much pain – if you can imagine the food stuck somewhere – and other food going down – it was very, very painful – so I had been taken into hospital by an ambulance two or three times – and in desperation I wrote a letter to the oncologist who dealt with my radiation at the (specialist cancer centre) and I told him the problem. I said because you, no doubt have other people – they must have had similar problems – who could you point me to. He said “Well please come down.... see our gastroenterologist, which I did and I have seen him now for over a year. I am still having difficulties – to put it into context – I have got a huge bottle like this of Morphine which, when I need it, I have to take that to try and stop the pain. But what I noticed was that so many people don't seem to know what to do about it and yet the knowledge is there.

One patient suggested that the main problem with the bowel problems was the failure of the health professionals to acknowledge that these problems were linked to the radiotherapy treatment:

But I think the problem I have encountered is actually somebody recognising the fact that actually it is a radiotherapy problem – I have been diagnosed with all sorts of things which is very frustrating.

It is suggested that there is a need for a centre of excellence to disseminate knowledge to health providers about bowel problems resulting from radiotherapy:

What it needs is some sort of centre of excellence that can.... push this knowledge out to the hospitals and the nurses and the GP's so that they have some point of reference to go to.

There is also a suggestion that such a centre would need to interact with patients, gathering feedback from them about their condition and how they cope and also providing them with advice and support:

It seemed to me there is (a need for) some central point where they can feed out this information to other people – like the MacMillan nurses or whatever – but also to feed back information – because I might find the solution and then I could send that back and they would pick that up. You have got hundreds of people who are having this problem and some might find it successful to do one thing. It just needs all this knowledge centred somewhere and then going out and coming back.

7.3 Views of aspects of follow up care

Rapid access to specialist medical care if you have a concern

Three patients described positive experiences in accessing specialist medical care if they had a concern. One of them thought his ability to access care rapidly had been improved by participation in a hospital support group which helped him develop relationships with the health professionals and know who to contact:

*I have also been in a support group so I am actually physically at the hospital and I am networking and building up contacts and that sort of thing and that is useful....
I have always been able to go direct to my Oncologist who is a private person and to my Gastroenterologist who is NHS and also to the Pain Clinic which I attend which is NHS. I think if you have a relationship with these people they will always pick up a phone to answer you.*

Two made initial contact by telephone:

I just pick up the phone to my oncology nurse and ask the question. I did ask if it was OK for me to call them and she very much encouraged me to call.... It was very clearly encouraging – she was really encouraging you – very warm when you did pick up the phone.

Very good at the (specialist cancer centre). I had a problem with washing for a couple of days, every time I tried to dry myself I bled around my groin area. I rang up the secretary who said “Come in this afternoon”.... that is about as good as it can get.

The other was able to get an outpatient appointment with her specialist in an emergency, when growths on her leg related to the lymphodema became infected:

I knew that the doctor who was looking after me was having his outpatient day that day so I went to that clinic and I said “Look I am Mr X’s patient etc and would he fit me in?” and he did pretty quickly (and they admitted me onto a ward). So I was lucky but I would have gone to A & E if I had had to.

Others described their own positive experiences, but suggested that some patients might have difficulties accessing appropriate care when needed. For example, one described

how they initiated follow up care from a gastroenterologist, but thought that others might not be in a position to do that:

I looked through the Internet and then I decided at the last moment, yes I would write to the Oncologist that treated me... and he put me in touch with the Gastroenterologist. But it wasn't from the hospital or the surgeon or the GP or anybody else, it was just because I was fortunate enough to be able to do that - some people are too ill to even think about doing that. So a lot of people are getting missed out.

There was some agreement for the notion that a patient's ability to access the care they needed was dependent on their personality and other personal characteristics, including how ill they were. It was also suggested that rapid access to specialist medical care was available, but there was a problem in knowing how to access it:

I think... it is knowing where to go for that rapid access - it is there but it is being directed there that is such a problem.

But who would you go to? I think your only access when something is going on, you may think you know what it is, you may be very unsure, you may even think should I bother anybody with it - your only points of access are your GP or whichever consultant is alongside your name at whatever hospital who may or may not be the right person. I don't think it is even made clear whether you can directly access that consultant. So I think you are actually lost. You can hopefully find your way through but the time and the effort and the anxiety of finding your way through it maybe quite a heavy cost. So I think it is unclear.

As was suggested in the previous quote, it was felt that that some patients might not be aware if they had symptoms that they should seek treatment for, a concern that was raised elsewhere:

I think it is hard to understand what is happening to you as well. For me personally, I knew perhaps there might be some problems but nobody really tells you what those problems may be. It sort of comes on gradual - I was diagnosed with all sorts of things and given treatment for gastroenteritis, food poisoning etc. But there wasn't anybody that I spoke to and I wouldn't have known to go to anybody to sort of say what was happening to me.

A lack of medical knowledge amongst health professionals of some side effects of treatment was thought to limit patients' ability to access the specialist medical care they needed. One patient describes an unnecessary surgical intervention that resulted from a lack of understanding of their condition, when dietary intervention would have been more effective. Another agrees that there is a lack of medical expertise in some areas, but attributes their own more positive experiences with treatment of their bowel condition to the skills of their specialist in recognising where to refer them for appropriate treatment:

I think that there is two sides - it is absolutely right, your main access is your specialist but I was lucky because my specialist has a lot of experience and knows about these bowel problems from radiotherapy and he did refer me to the correct person... So if you have a good team then he will be able to do it. If it is a hospital without that good team they won't. But having said that - the pain and the dermatitis - I didn't get adequate treatment on that until I started screaming.

It was suggested that there were local variations in the extent to which patients could rapidly access specialist medical care, resulting from geographical inequalities in services, but also on current conditions at the hospital such as staffing levels:

It is the good old "post code lottery". Even smaller than that – it depends on the hospital – it depends on who they have got in – whether the post is vacant – how over burdened people are etc. A whole list of different things.

Accurate information about what to expect following treatment

One participant said he had received a great deal of information, including some of which was irrelevant:

Well I was smothered with information I think about follow up, that I might get this and I might get that – some things I can't do anything about or they can't do anything about..... *What I mean (by smothered) – such a mass of information came my way and not all of it was relevant to me.*

Generally however, patients identified shortfalls in the information they were given, particularly in terms of written information. There are suggestions that a lack of information led to feelings of 'frustration' and 'isolation'. In contrast, one patient suggests that it is the responsibility of the patient to ensure that they get the information they want from the specialists:

So it is up to us to ask the questions – I have a good consultant – but it is down to me to make sure that I get the information.

Most participants appear to have been given only verbal information and there was some agreement that written information would have been helpful. One says that the information she received was limited to a verbal communication from her oncologist at the start of her treatment about the side effects and she received no written information at all:

The only information that I was given was at the start of my treatment when my Oncologist said to me, "We are going to do radiotherapy, chemotherapy and the result of this will be you won't be able to have children and down the line you may have some bowel and bladder problems". That was it! I haven't had anything else.

It was suggested that accessing accurate information was more difficult if you had a rare cancer. One patient cited her mother's experience and another pointed to the lack of information about certain types and aspects of brain tumours. However, it was felt that accessing accurate information in a printed format was also difficult if you had a fairly common cancer. For example, one participant describes how she consulted medical books to get information:

It is more of a problem if you have got a rare cancer... The top specialist in the country only sees about 5 cases a year. (But) there is not much around for my cancer either. So I have to look at gynae cancer books really to get anything.

One participant suggests that it would have been useful to get information about what to expect when treatment had ended, such as symptoms to look out for and where to go if you have a concern:

I think one of the problems with sort of formal information like things from Backup and the pamphlets you are given when have cancer is that it is all related to the problem that exists at that time. What you don't get at all, what I haven't had at all is that 5, 6, 7 years later, something may occur which is going to cause you a problem and if that does happen, where to go.

Another gives a specific example of a difficulty she experienced which led to an emergency admission. She suggests this could have been averted had she been given information about the side effects of treatment:

The only time I have found I have needed an emergency service was connected with the lymphoedema because I had little growths on my leg, called lymphangiomas.... They became infected when I was on holiday.... They were terribly painful and I just said to my husband "We have got to go home". On the way home the pain became so bad, I said "Take me to the hospital". They were fine, they admitted me onto a ward and so on but I had never been told that this could happen to me. Subsequently, I carry antibiotics wherever I go and I have them in the house all the time.

There was general agreement that more written information would have been helpful, particularly a care plan which outlined follow up care:

The follow up I have is conversation – it is not leaflet driven. I do wonder whether there should be... I do think there should be a patient plan – "This is what we are going to do" – pull in all the different threads – speech therapist etc. – is that the end of it – I am happy with the access that I have to the Oncologist.

A care plan that is individualised – that is what the NHS is supposed to be delivering to us.

They should be able to do it yes.

The last point about the importance of personalised care plans was emphasised by one participant, who talked of patients having different needs for information at different stages of their care pathway:

The other thing is people have different needs at different stages of their treatment because my mother was one of these people who didn't want to know anything and now she is quite keen to know things. But because of the fact that she didn't want to know anything, they get a bit stroppy with her now because she starts asking questions which is absurd – she has moved on now and can actually talk about it. She was in complete denial at first, it was quite worrying, but now she is much more accepting.

Only one patient had been given a written care plan at the private cancer clinic he attended. Another had written his own record of what the consultant had told him at the start of his treatment. Others described difficulties resulting from the lack of information about their care pathway:

In my support group, the words "Care Pathway" were mentioned... I have no sense of that at all. I felt as if I was being pushed from pillar to post".... (My treatment was) 6, 7 years (ago and) obviously it may have improved since then.

Clearly not universal (to be given a care plan) – I was diagnosed with the second cancer last September – no care plan at all. I don't know why it is so impossible.

In terms of formats for delivering information, the provision of audio recordings of consultations around diagnosis was pointed to as an example of good practice, though only one participant had personally experienced this:

The brain tumour consultant in xxx.... has been fantastic in supporting patient and public involvement (locally)... including one thing that our group has been successful in getting which has been taped consultations, audio taped, because it was commonly felt a need that you go along for your first interview conversation with the consultant and get this diagnosis and inevitably it is a shock. You can't always remember what they have said. Because you go into shock and the person with you maybe also cannot remember if you are lucky enough to have somebody with you. I have actually asked my Oncologist if I could record the conversation with me – she agreed and I have taken a tape recorder with me always.

One patient suggests that a group session would have been a really useful way to share information with other patients with the same condition:

What I would really have liked though is a couple of years ago, having a talk like this because it is so nice hearing people having the same problems as me. It makes you feel not so isolated.

Help with returning to (and staying in work)

It was suggested that returning to work after treatment for cancer is difficult and the ease with which it happens depended largely on the extent to which the employer supported the person returning. One person described how the supportive approach of her employer enabled her to return to work gradually, but went on to say that she was aware of others who were not offered this flexibility:

I had a really understanding manager and they gave me the time to phase myself back in, as and when I felt I was ready and I know I was fortunate that way. A lot of people that I have spoken to – their employer – you are sort of coming to terms and you have got the fatigue and everything – it is really difficult getting back to normal life.

It was suggested that the long period off work during treatment for cancer meant that some people might lose their jobs if they worked for an unsupportive employer:

It is very difficult – I think it depends on your employer... If you are off work for a long time, some people might even lose their jobs – there is no support there for you.

Another participant agreed about the importance of the attitude of the employer, describing how he had been off work for more than six months before he went back. He talks of his experience of supporting a woman whose employer was pressurising her to return to work before she was well enough:

I was asked to speak to a lady that felt her employer was pressurising her back to work... (in) a situation where things had changed and having got back she wouldn't

be able to cope and then (they would) get rid of her. I talked her through... We talked about her employer, I told her to get her GP behind her and to keep signing her off – there was no way a company would risk the publicity of that... (I told her) that if your GP does not believe you should return to work, then don't – you go back when you are comfortable.

It was suggested that larger companies were more likely to provide employees with the necessary support:

If I were to get a diagnosis now my job would be kept open for 6 months for me minimum.... There is that support from a decent employer – it is small employers that can't tolerate the absence of people.

The nature of the job also seemed to impact on ease of return, for example two participants had jobs they were not well enough to return to at the end of treatment and two others could only return part time. It was suggested that changed employment circumstances could have a psychological affect:

I think there is an impact emotionally as well, if you had a career and you are no longer able to pursue it, that has a very big effect on your self-esteem.. I worked abroad.... and I had to give that up, it wasn't a well paid wonderful job or anything but I loved it and I could not continue with that at all. That was a very big blow to everything in the sense that I loved it, I felt useful. The whole thing around something that you had given 25 years to.....

Returning to work was also made more difficult for those without a sympathetic employer because of the need to attend regular hospital appointments, as evidenced by two NHS employers working part time at different trusts. One was given time off to attend appointments, the other was required to attend follow-up appointments in her own time and make up any time lost:

I work part-time so I am expected to see anybody and (have) the tests and things in the times when I am not working. Well that doesn't always fit in with the hospital so then I have to say "Well I have an appointment on Wednesday morning so I would like to work Tuesday afternoon instead (and) make up the time".

It was pointed out that some of the tests were very invasive and resulted in having to take more time off work to recover:

I went for one particular test – colonoscopy thing – and the day before I had all this incredible purgative fluid. Really it made me ill – it wasn't a test where you think you have got to make that time up – so I did actually say I was sick – I was off sick that morning. The nurse said "It is not a blood test, you haven't come for a quick test". I felt guilty about ringing in sick for that morning – it was my intention to go to work afterwards – but there was no way – I could hardly walk afterwards – awful fluid the day before and then the test that morning.

A woman described how the energy she should have devoted to searching for a new job had been consumed by a complaint against the hospital she was pursuing. In contrast one man described how he had continued to work while in hospital and after. It was suggested by one participant that the problems returning to work experienced by anyone with cancer were exacerbated for those, like herself, who had only been diagnosed after a long and protracted period of unexplained illness:

There is an issue before that though – the length of time it took me to get a diagnosis which was five years and the fact that I just had non specific fatigue.... It meant really I stopped working properly before I was diagnosed because I felt so ill for years, but it took years to get the diagnosis and that is not an isolated case....

All I am saying is that you may have a career problem like I have prior to diagnosis so that it makes it even more difficult to get back into work because you have got a longer gap than you should have had.

The problems of working when living with severe problems resulting from cancer treatment were discussed. The participants with bowel problems described the particular difficulties they experienced:

I think as well there is the cancer and then you have your treatment and then things start happening to you afterwards. Because of the radiotherapy and when you become incontinent, if you are trying to work and you are not sure what is happening to you it is really embarrassing and you get to a point where you are frightened to go out of the door, let alone go to work. And if you are trying to explain that to an employer it is so difficult.

Some days I just don't dare go out.

I used to get to a point where – your confidence is just down there – even if you are trying to do day to day things, like shop, it is like a race – yes I know there is a toilet there – I can reach that toilet.

We think about it all the time don't we, none stop.

Another participant talked of difficulties caused by lymphodema:

I developed a condition called Lymphoedema... That was a big burden it affected my ability to work, social life, everything.

It was suggested that there was a need to raise employers' awareness of the needs and rights of patients who have had cancer, including providing them with information about the side effects of cancer treatments that might impact on an employer in the work place for many years after treatment has ended:

I think there is a general need to raise employer awareness.... I am not ill.... but I was left with these long term side effects – and because I am not in a wheelchair or anything.... (my disability is not always taken into consideration)... I don't think my manager is a bad manager but I think work is a very difficult issue.

It was also suggested that it would be helpful if an employee returning to work could agree a "Come back timetable" with their occupational health department which sets out a phased return.

One participant talks of only being able to work part time because of the problems resulting from the treatment she had for cancer many years before. She suggests that she is fortunate to be able to work fewer hours, but points out that younger people with more financial responsibilities might encounter considerable difficulties:

I am very lucky in so far as my husband is totally aware of my situation and he was quite happy for me to work part-time but I think if I were single or if we had been a lot younger, with young children and a huge mortgage like a lot of people are, life would not have been so tolerable.

A self-employed participant describes how working for himself was an advantage in some respects, particularly in terms of being able to decide when to return to work:

I am self-employed so it is up to me as to how I feel physically as to whether I can work or not. So I suppose I am luckier in a way than an employed person who has got a company to bother about.

However, he agreed when others suggested that self-employed workers were financially more vulnerable because they were not entitled to statutory sick pay:

It must be more difficult financially in a way though Because if you are self-employed you don't even get SSP do you?

As others point out, it was not just the self employed who were not entitled to statutory sick pay. One person working part time had not been eligible. Another had not worked for their employer long enough before becoming ill to qualify for sick pay and described how this caused financial vulnerability which led to her returning to work before she was ready:

I am just in this phased building up of my hours now.... It is quite difficult to know when you feel ready... On both occasions (I have returned to work after cancer treatment it) has been really to a large extent up to me - which in many ways is positive - plus my GP, the hospital has had nothing to do with it whatsoever. But this time now I have been with this particular employer a relatively short time so I ran out completely of any sick pay. So I got to the point that there was no income and really... I couldn't not feel ready (to return to work).... So there was definitely that pressure and it has been quite difficult going back.

Advice about benefits

This group did not explicitly discuss the issue of accessing benefits, but as was seen in the previous section, difficulties regarding staying in and returning to work had caused financial difficulties for some. One participant said they had been living on their savings and another said he had been completely reliant on his pension. One woman who earlier described how she had been unable to work following her treatment referred to how she had been unable to discuss her need for financial support with her GP:

The GP... was a very nice woman, very middle class, dressed very prettily and everything but goodness she used to be make me so angry.... I have got a new (counsellor) and he seems a lot more sensible and much more down to earth. He cottoned on immediately to the fact that I had probably got financial problems whereas money was something that we didn't talk about with middle-class nice lady!

Two others described difficulties access financial support when they were caring for other family members.

Nobody ever said 'Because you are dying you are entitled to some money to help you die in dignity'. It was only because I worked for the NHS that I knew such things existed - nobody told us.

It was suggested that advice about benefits would be helpful as the majority of people with cancer would suffer financially:

I just think the financial impact does need to be really emphasised because I think it would be a rare person in a particularly fortunate situation who was not financially impacted by having cancer.

Psychological support

Patients described high needs for emotional support during and after cancer treatment:

I am on anti-depressives too – and possibly other people are.

It appeared that little emotional support had been available to these patients without them demanding it when things got too difficult to cope with:

In the end the whole thing, I just started to be so depressed about it all a long time afterwards, putting up with it all. I went to the GP and I just said “I am so depressed, if it weren’t for my grand children I think I would go mad”. And then they treated me for depression but there wasn’t anything built in to try and stop me getting depressed and nobody ever told me that the bowel and bladder thing might happen or else I might have sought some help with that earlier – I don’t know. There didn’t seem to be anything built in.

I had to pester (to see someone when I experienced severe bowel and bladder problems as a side effect of radiotherapy)... and it was through my Oncologist that I was referred on. But there must be thousands of people who are in similar situations and it is awful.... To me once your treatment is finished, you seem to be on your own. It is not just the physical, it is the emotional side as well... you need more support afterwards.

There was a suggestion that access to emotional support depended on the type of cancer you had:

I didn’t have any built in support – it was partly because I had a gynaecological cancer – but I got over that

One participant described how she benefited from emotional support provided by the cancer centre after her treatment for cancer, but felt this was for too short a time and then had to rely on her GP who was not helpful:

Yes I went to the (specialist cancer centre). They have a very nice person there who gives you twelve sessions and (he) got me on the road to not being quite so negative about hospitals and doctors and he was really good. But the trouble is I only had him for 12 sessions and then I went to the GP and she was a very nice woman, very middle class, dressed very prettily and everything but goodness she used to be make me so angry you could have been writhing on the floor in agony and she would have said “Oh you are coping well!” so she drove me round the bend, so I am glad I haven’t got her any more. I have got a new man who is American and he seems a lot more sensible and much more down to earth.

There was general agreement about the benefits offered by peer support:

I found that more helpful – actually speaking to another person who had gone through the same treatment and it is just – you can’t explain – your relatives and

friends – but until you speak to someone else that has gone through it – I found that really, really helpful.

For some, peer support schemes seemed to provide much needed psychological support that was not available professionally; some had been involved in setting up support groups locally:

Now I am running a Lymphoedema support group – we talk to one another and help one another. It is just too embarrassing to (talk about these bowel problems with family and friends)... We have all got this condition in common and I just kept that to myself

One of the men in the group described how he provided peer support to other cancer patients both on a one to one basis and at the support group at the hospital and someone else said a similar scheme operated at her hospital, organised by the oncology nurse:

There is a Brain Tumour Support Group at xxx – it is a real boost – not just to attend but to make appointments and speak to people.

There is something like that at xxx as well – this is during the treatment though – the Oncology Nurse actually asks you if you want your telephone number to be given out to other patients. Also there are contact names for you to contact.

A scheme where peer support was provided by email through charities was also described:

There are a couple of charities, organisations – trying to get money for research but also support – there is one very good one in the South West, on the Internet – My Story – and if you want you can put your e-mail address and people will e-mail you and I have had people coming to me. The bottom line is that it is very satisfying – you have to do something positive. Brain Tumours UK are also encouraging people to register with them and that is a very small cancer.

Provision for peer support appeared to be good during treatment, however it seemed that little was available for some patients in the follow-up period after treatment:

But there wasn't anything there for what happens when you finish and I think that perhaps that is what is needed.

I haven't had it but I would have liked it.

Support for my carer (and/or family and friends)

One participant had been caring for her elderly father and sick mother during her treatment, describing it as 'very stressful' and 'a nightmare' and going on to talk about the problems it caused in relationships within her family. She says they received no help at all, 'absolutely nothing':

We were completely left under our own devices – all three of us... all having to cope as best we could. It was dreadful.

One woman talked of her husband's need for information:

My husband poor soul – when my legs started to swell – we had no idea that I had got Lymphoedema or that Lymphoedema existed. I think he was frightened it was some other kind of cancer in my legs or something. The fatigue and so on – we have supported one another... I think it is poor for carers – very poor – I think it is only just beginning to be recognised... It is awful and in some ways it is easier to be the other person because you have got to get on with it – you have got to go and have your treatment, do what the doctor says. The other person has to stand and watch and I know my husband – nobody ever said to my husband “How are you coping?” and I think that is awful.

One of the men in the group said he had given his wife a list of useful contact numbers of people who could help in an emergency, but adds that it would be helpful if these were given to patients at the end of their treatment:

I have given her numbers to get on to because I know there will be a sympathetic answer and guidance. If at the end of your initial treatment, there could be a simple leaflet – these are your contacts.

He explains that he has put this list of names together himself, but it is something that should be provided. Another man in the group reinforces this point:

What we keep coming back to all the time is this lack of information because whether it be for the patient or for the carer, there isn't the information there. The information should not only tell you the sorts of things that can happen to you but it should also tell you where to go or who to speak to if it does happen.

Being seen at my GP surgery

Most participants were having follow-up care at the hospital. Some services were accessed through the GP surgery and participants described difficulties with certain aspects of this. For example, obtaining prescriptions for emergencies:

You have to go to the GP for your pharmaceutical products and that can be a problem because they are not necessarily au fait with things. I had an argument with my GP because I wanted antibiotics for emergencies and he wouldn't give it to me and I lost my temper and then he did. So it depends on your GP a bit. I get on better with the GP now – he has admitted that he is out of his depth with me so I like him now because he has been so honest. Out of depth – because it is a difficult and unusual cancer and with difficult side effects and he is quite young. So I am glad he said that – I thought that was nice.

The participants with bowel problems resulting from radiotherapy were generally not happy that their GPs were able to properly care for this aspect of their condition:

I have confidence in my GP, except the bladder and bowel thing.... I have this chronic diarrhoea and they... they didn't seem to take on board what it meant to me at all. I really had to go and sort of say “What am I going to do”.

That is exactly the point, because they are what they are called “General Practitioners”... They are our first port of call but you can't expect them to know everything about every problem. The bowel one – they don't quite understand it because the knowledge isn't out there – it is not freely available. They will say “You

have got to see a specialist". What sort of specialist? Is it a surgeon that you see or is it a gastroenterologist? They might say to go and see the dietician – it is very hit and miss.

I got referred by accident because I went to a different GP and when I said I had this chronic diarrhoea she referred me straight to the Gastroenterology Department. If I hadn't gone to – because it is a big practice – I suppose I would still be feeling that life wasn't worth living.

Down the line when I had the problems with the bowel and the bladder there wasn't anybody who I could speak to. There is nowhere you can go (if you have problems after treatment has finished). I went to the GP – and I think personally that GP's really need more information as to the effects of radiation and they don't seem to know where to go to help you.

Others were happy with the service provided by their GP in relation to all or some aspects of their cancer follow-up care:

Mine wants to see me every 6 weeks or sooner if I want to come in – so definitely 6 weeks. So I would have no problem – when we moved I asked my old GP for tips on getting a new GP – went down and saw him – very good dialogue – flu jabs – I have got confidence there.

Yes I have got confidence in my GP.... With the Lymphoedema because there wasn't anything.... He did refer me – I went to a private dermatologist about these growth things and they did take on board what the private dermatologist said and continued to prescribe the ointments and what have you. They kept saying we are in the hands of the dermatologist here – but they did take on board – and I had to keep going back to her as well.

One talks of the care provided by their GP as being a very important supplement to the specialist cancer care, but emphasises the importance of recognising that this care is generalist and therefore has certain limitations. They specifically mention the help provided by their GP in understanding letters from the consultant:

Well I mean – in that you are not necessarily dealing with cancer or the direct effects of that in isolation – you may have other ongoing medical issues. I think the GP is really important. Also sometimes I have talked to the GP about what the letter from the consultant has said and what it actually means and that has been quite helpful. So I think, for me, it feels like it is definitely a combination. I go to the GP when I need to rather than on a fixed basis – I think they do play quite an important role – I think as long as you recognise their limitations and like you were saying they are generalist, they know a bit about a lot of things and in terms of what they think they know it probably relies on what they have done before with other patients. So you are not going to get the kind of front line, this is the latest – whatever.

Being seen at the hospital

Connected to the discussion about the follow-up care provided by the GP it was suggested that care at the hospital was superior, but the time and travel involved in attending hospital appointments did provide another obstacle to returning to work:

*There is another obstacle to work, the amount of appointments we all have.
Yes and the travel as well because you cannot always be seen local can you.*

Knowing who to contact if I have a problem

This aspect was covered earlier in the group and it was clear that some patients experienced problems in knowing who to contact if they had a concern.

Seeing the same specialist consultant/nurse

Continuity was said to be important, but not always available in a large complex organisation like the NHS. It was suggested that there was a certain degree of luck in whether continuity was provided:

I think that is important, that you are lucky if you get it.

I have had real issues with lack of continuity.

We are at the same hospital but I have been much more lucky than you.

7.4 Views of some alternative models of follow-up care

Telephone follow up (nurse led)

There was general support in this group for telephone follow up appointments, but only if certain practical concerns were addressed and on the whole only in addition to face to face appointments at the hospital, not as a replacement for them. One participant suggested that technology needed to be used more effectively in developing cancer services.

One participant who had personal experience of telephone follow-up spoke in positive terms of this approach, particularly emphasising the time and cost advantages to both the NHS and to patients:

I find telephone follow up fine - and if there is no change - and faxes me through a copy of the analysis notes - that is economical on all parties...

Speed - it is cost sensible on both parties.

He felt this approach worked well as long as there was a system in place for a face to face appointment to take place if either party felt it was necessary. Another participant who had experienced telephone follow up spoke of it positively, particularly in terms of the reassurance it offered:

I had my initial surgery in Australia because I was living in South East Asia when I was diagnosed. The system that I experienced - after I was discharged I was given a

mobile phone number that I could ring at any time. I found that immensely reassuring and I did use it on several occasions. They told me that I could have that for a year.

She goes on to describe the system in some detail:

It was either the consultant himself (I spoke to) if he was available or somebody on that team, including the sister on the ward where I was treated. I got through to somebody who knew me very well. I found that was fantastic. What was interesting was that I did ring it just after the year was up and it was dead! But it was there for a year – it was their system.

Others saw advantages in telephone follow-up appointments, but only if certain other criteria were met. In the context of experiences of using NHS Direct, it was thought crucial that the telephone appointment was with the patients' specialist team rather than with a generalist or someone with no knowledge of their case or condition.

My experience was that it was a waste of time because by the time you have gone through all the questions they are asking and in the end the person you are speaking to is not a specialist – they put all this down and then passes it on to a nurse who rings you back perhaps an hour afterwards. I always ended up with “Well I think you ought to go and see your GP” or “Go to A & E”. So if you do have that I think it would be very useful in many cases but it would have to be more specialised. It would have to be – you ring this number if you have got a bowel problem or if you have got some other sort of problem. Because if it was just general you would end up with the sort of service that I had.

Another patient saw advantages in telephone follow up appointments, but only if they knew the health professional on the other end of the phone and as long as there were some face to face appointments as well:

Can I say I wouldn't have any great problem with it, provided I had met the person first. I would not be happy to have a kind of “telephone only” situation.

Although positive about the notion of telephone appointments herself, one participant suggested that others might have concerns that it was ‘a way of palming people off, downgrading the expertise and the quality of care’:

I think.... that this sort of thing has to be so very, very carefully introduced to people if it is to have any mileage in the future.

Others were less happy with the idea of telephone follow up appointments as a replacement to face to face appointments. The main concern seemed to be the need for the doctor to be able to check if there were symptoms of which the patient was not aware:

I wasn't happy with the telephone model for the regular appointments. I don't mind ringing up if something suddenly develops and I am worried about something but I would prefer face to face because I think that the doctor can spot things when he looks at your body and how you are walking and what you look like, that you can't detect.

Yes I am happy with it in addition but not as a replacement, because of the fact that you can see things face to face that you cannot see over the phone.

Other concerns about telephone follow up centred on beliefs that some patients would have difficulties with it:

I think a lot of people wouldn't have the confidence to pick up the phone that is the trouble and make that direct contact. M

And it is personality – my mum won't do it – she is “old school” – she suffers in silence.

Patient managed follow up

Views about patient managed follow up were generally positive amongst those in this group. It was regarded as a particularly effective approach to delivering care for those living with the long term side effects of cancer treatment and appropriate in the context of the increasing numbers of people living with cancer as a chronic condition.

It was suggested that such a system would only work in the context of detailed accurate information for patients about signs and symptoms to be aware of and arrangements to be able to rapidly access expert specialist advice if needed:

That would be good as long as you were given the knowledge and information as to what to look out for in the future if you develop any symptoms. I think the problem perhaps with everybody is that you may be sent away and you are not sure what is happening. If you were aware that 5 years down the line that this might happen, it might not happen to you but these are the symptoms to watch out for and here is a telephone number you can speak to somebody who knows about it, rather than go to your GP. Then that might be good.

One patient felt the follow-up care he had received had largely been at his initiation and he had been happy with this arrangement, suggesting that its success has been partly due to the good relationship he has built with his gastroenterologist:

I have been happy – my private Oncologist – because I can ring her at any time and I can also ring my NHS Gastroenterologist at any time. I think certainly with the NHS man, I think I have struck up a very good personal relationship with him.

It was suggested that patient initiated follow-up would be more appropriate for patients experiencing side effects some years on from the end of treatment, particularly in the context of more people surviving cancer for many more years where the long term implications of treatment were currently unknown:

I think you should be able to access your team five or even ten years down the line and... have some kind of classification whereby if you are known to have had surgery, radiotherapy and chemotherapy, then it is possible that you may develop some symptoms related to that in 10 years time and you should be able to go back without having to go through, re- referral, maybe with a six month wait or whatever. That is the problem and it is a very new thing this long term survivorship isn't it.

It was thought that such a service would improve access for patients to specialist care, and eliminate the difficulties described by some in this group of accessing this through their GP:

So that you don't have to go through going to the GP and saying "I have got a pain in my left shoulder blade, is it because I had cancer of the bone when I was 7" – "Oh maybe it is perhaps we ought to refer you" and then you wait 6 months again. They say "Oh yes this is a person who could develop something and should be fast tracked".

It was pointed out that the importance of such a service for those who experience childhood cancers was already recognised in some quarters:

At the Children's Hospital in Sheffield there is a collaboration between the Children's Hospital, Weston Park and the Hallamshire for long term effects for children who have cancer before they are five. (They) may suddenly have symptoms when they are 30 that relate to the fact that they had chemotherapy and radiotherapy when they were five. It is unique apparently in Europe this collaboration – it is elsewhere in the World.

Some participants thought that patient initiated follow up would not work for some patients and they could fall out of the system; it was suggested that such patients needed to be seen on a regular routine basis to ensure that any symptoms were not missed:

Would there be a danger that some patients would never bother to go back or would get missed from the system. I do know of some people – well I know one person who should have had radiotherapy after a cancer operation and the hospital had lost her records and never bothered. It just makes you wonder how many more mistakes there might be – I don't want to be negative but I can see there could be problems with patient referral.

This patient needs to be seen every 6 months.

I think you would have to – at least every year or something – yes with that proviso – it would be OK I suppose.

Group follow up

There was some support for the notion of group follow up appointments, though no participants had direct experience of this. One said he had been invited to such a session at his specialist cancer centre, but another said he had been invited to the same session and it was to discuss setting up a patient support group, 'which is not quite the same thing. The distinction between group support and group follow up appointments dominated the discussion of this model of care.

Two of the patients with bowel problems said a group appointment would not suit people with this condition because the nature of their problems was too personal to discuss in a group:

I think it would depend on the illness. I think it would be very difficult for us all to sit round and talk about our bowel problems. I think it is a bit too personal.

The thing is.... I think with our bowel problems we all have individual needs and they all take different forms and I am quite happy talking to the doctor about it but I wonder really whether 6 or 7 people would really want to describe how often they open their bowels and what happens and what it is like.

Others disagreed and thought a group session would be helpful:

I disagree – if it is with people who are like minded.

I think it would.

It is the support that you might gain from someone else's knowledge.

There was general agreement that there were benefits to be gained from group support:

The support group I would love – I could really do with that.

A support group I think would be good.

Someone might have the answer to your problem.

What I would really have liked... a couple of years ago, having a talk like this because it is so nice hearing people having the same problems as me. It makes you feel not so isolated.

But the function of a support group was seen by some as being very distinct from the sort of things you would want to discuss at a follow-up appointment:

Yes but that is a support (group) – I would really love a support group but I am not sure if I went in absolute agony, like I was this time last year, when one day I had to sit non stop on the toilet for an hour and a half, if not longer, whether I would really want to describe that – because I am not sure I would feel as though I was getting the one to one attention I was desperate for.

But actually getting your diagnosis for your tablets and your pain killers and things like that in a group – no I wouldn't be happy with that.

Others could see how the two activities of support and an expert medical consultation could be combined:

You would go to your group and say I am having a serious bowel problem and then you could say to the health professionals who are there, "Can I have a one to one with you?"

7.5 Agreements within Group 5

Definitions of follow up care

- All the participants in this group were living with long term debilitating effects of treatment for cancer. There was some agreement that rapidly increasing survivorship rates meant a shift was needed to recognise cancer as a chronic condition.
- Follow up care for most participants in this group was dominated by problems resulting from high doses of radiotherapy used in treating their cancer: lymphodema and severe bowel problems and bladder difficulties

- Patients in this group generally expressed dissatisfaction with the follow up care they had received, primarily related to accessing care relating to the side effects of treatment. The problems here seem to fall into two closely related categories: a lack of necessary services and the failure of the cancer specialists responsible for cancer follow up to provide holistic care for the side effects of treatment.
- Patients talked in terms of having to work hard to access care for the side effects they were experiencing, often living with severe debilitating symptoms untreated for some time before diagnosis.
- There was strong support for improving expert medical knowledge of the side effects of radiation and particularly of learning from patients living with these conditions.

Views of aspects of follow up care

Rapid access to specialist medical care if you have a concern

- The supply of specialist medical care was limited and therefore obtaining access to it was difficult.
- Once appropriate specialist care was secured patients seemed to be able to gain rapid access for advice if they had a concern.
- Telephone access for advice was common.
- There was a concern that some patients would not be able to access specialist advice because they did not have the necessary personal characteristics.

Accurate information about what to expect following treatment

- Generally patients identified shortfalls in the information they were given, particularly in terms of written information.
- There were suggestions that a lack of information led to feelings of 'frustration' and 'isolation'.
- More written information was needed about the side effects of treatment and about what to expect when treatment had ended, such as symptoms to look out for and where to go if you have a concern.
- There was general agreement that a personalised care plan which outlined follow up care would have been helpful – only one patient had been given this.

Help with returning to (and staying in work)

- Returning to work after treatment for cancer was generally regarded as difficult and the ease with which it happens depended largely on support provided by the employer.

- The need to attend regular hospital follow up appointments meant the attitude of the employer determined whether an employee could stay in work after treatment had ended.
- Most participants in this group were unable to return to their original work after treatment ended because of the severe problems resulting from cancer treatment.
- There was agreement that there was a need to raise employers' awareness of the needs and rights of patients who have had cancer, including providing them with information about the side effects of cancer treatments that might impact on an employer in the work place for many years after treatment has ended.

Advice about benefits

- Difficulties regarding staying in and returning to work had caused financial difficulties for some in this group.
- Financial support was difficult to obtain.
- It was suggested that advice about benefits would be helpful as the majority of people with cancer would suffer financially.

Psychological support

- Patients described high needs for emotional support during and after cancer treatment.
- Little emotional support had been available to these patients without them demanding it when things got too difficult to cope with.
- There was general agreement about the benefits offered by peer support.
- Peer support schemes seemed to provide much needed psychological support that was not available professionally.
- Provision for peer support appeared to be good during treatment, however it seemed that little was available for some patients in the follow-up period after treatment.

Support for my carer (and/or family and friends)

- Patients had experienced limited support for friends and family

Being seen at my GP surgery

- Most participants accessed some of their follow up care through the GP surgery and described difficulties with certain aspects of this.

- The main concern was that the GP lacked the specialist knowledge to be able to provide their follow up care.

Being seen at the hospital

- It was suggested that care at the hospital was superior, but the time and travel involved in attending hospital appointments created another obstacle to employment.

Knowing who to contact if I have a problem

- Some patients clearly experienced problems in knowing who to contact if they had a concern.

Seeing the same specialist consultant/nurse

- Continuity was said to be important, but not always available in a large complex organisation like the NHS.

Views of some alternative models of follow-up care

Telephone follow up (nurse led)

- There was general support in this group for telephone follow up appointments, but only if certain practical concerns were addressed eg appointments with the specialist team with knowledge of their case, not with a generalist.
- On the whole patients supported telephone follow up appointments only in addition to face to face appointments at the hospital, not as a replacement for them.
- There was particular concern that face to face appointments were needed for a medical specialist to check if any symptoms were present that a patient might not be aware of.
- Other concerns about telephone follow up centred on beliefs that some patients would have difficulties with it.

Patient managed follow up

- Views about patient managed follow up were generally positive amongst those in this group.
- It was regarded as a particularly effective approach to delivering care for those living with the long term side effects of cancer treatment and appropriate in the context of the increasing numbers of people living with cancer as a chronic condition.

- It was suggested that such a system would only work in the context of detailed accurate information for patients about signs and symptoms to be aware of and arrangements to be able to rapidly access expert specialist advice if needed.
- Again, there were concerns that patient initiated follow up would not work for some patients and they could fall out of the system; it was suggested that such patients needed to be seen on a regular routine basis to ensure that any symptoms were not missed.

Group follow up

- There was some support for the notion of group follow up appointments, though no participants had direct experience of this.
- There was general agreement that there were benefits to be gained from group support, but also some concern that very personal matters could only be discussed during a one to one consultation.

7.6 Variations within Group 5

Definitions of follow up care

- All the participants in this group were living with long term debilitating effects of treatment for cancer and there was little variation in their experiences of follow up.
- Just one patient described his follow up in broadly positive terms but it is clear he often has to initiate appointments himself.
- One patient described difficulties with the outpatient appointment system, particularly in terms of the limited time available during the appointment; others did not mention this as a difficulty.
- One patient had received very little in terms of follow up care following the end of their treatment.
- One patient suggested that the main problem with the bowel problems was the failure of the health professionals to acknowledge that these problems were linked to the radiotherapy treatment; this was not mentioned by others in the group.

Views of aspects of follow up care

Accurate information about what to expect following treatment

- One participant said he had received a great deal of information about follow up; all the others identified shortfalls.

- One patient suggested that it was the responsibility of the patient to ensure they received the information they needed by asking the right questions of their specialist.
- Only one patient had been given a written care plan at the private cancer clinic he attended. Another had written his own record of what the consultant had told him at the start of his treatment. Others in the group described difficulties resulting from the lack of information about their care pathway.

Help with returning to (and staying in work)

- One person described how the supportive approach of her employer enabled her to return to work gradually, but most others had experienced difficulties staying in employment.
- One participant had only been diagnosed after a long and protracted period of unexplained illness during which she had to give up work.
- One participant describes how self-employment was an advantage in some respects, particularly in terms of being able to decide when to return to work.

Advice about benefits

- One participant said they had been living on their savings and another said he had been completely reliant on his pension.

Psychological support

- One participant described how she benefited from emotional support from the cancer centre after her treatment for cancer; others had not received any professional psychological support.

Support for my carer (and/or family and friends)

- Two participants described a lack of support for their carers; this does not appear to have been a particular problem for others in this group.

Being seen at my GP surgery

- One participant talks of the care provided by their GP as being a very important supplement to the specialist cancer care they received; others were less positive about the role played by their GP.

Views of some alternative models of follow-up care

Telephone follow up (nurse led)

- Two participants who had personal experience of telephone follow-up spoke in positive terms of this approach, particularly emphasising the time and cost advantages to both the NHS and to patients.
- Others saw telephone follow-up appointments as more problematic.

Patient Managed Follow up

- One patient felt the follow-up care he had received had largely been at his initiation and he had been happy with this arrangement, suggesting that its success has been partly due to a good relationship with the specialist.

Group follow up

- Two of the patients with bowel problems said a group appointment would not suit people with this condition because the nature of their problems was too personal to discuss in a group; others were generally in favour of group follow up.

Similarities and variations between the groups

Introduction

The groups included patients with experience of follow up care for a range of different cancers. Participants in one group were recruited on the basis that their follow up includes intensive monitoring and tests and in another they had all experienced debilitating side effects. One group was made up entirely of people who had been the carer for a partner, friend or parent with cancer.

The aim of this section of the report is to identify any similarities or variations between the five groups.

Definitions of follow up care

Nature of follow up – what it consists of, when and where it happens and who with

- Follow up care for prostate cancer centred on the PSA tests and these patients spoke very specifically about their experiences around having these tests; patients with other cancers described more varied experiences of follow up appointments.
- In all groups, there was an implicit assumption that follow up was something that happened when treatment had ended; one patient perceived follow up has something that happened after your cancer was cured - he had a form of cancer that could not be cured and described how for him there was no follow up care.
- Patients in the prostate group and those in the invasive monitoring group commonly defined follow-up care in terms of the frequency of appointments and the length of time follow up would extend for.
- Most patients had their follow up appointments with a specialist at the hospital, though in the later stages some patients saw their GP for all or some of their follow up care; PSA tests for prostate cancer were often conducted at the GP surgery, particularly in the later years of follow up.
- Follow up care for patients in the breast and gynae group included both scheduled 'check up' appointments at the hospital and informal contact with the CNS; this pattern seemed to be true of most patients in most of the groups, but there were some exceptions.
- Most participants in the invasive monitoring group and the side effects group had seen or were currently seeing a range of different health professionals for different aspects of their follow up care at varying time intervals; patients in the other groups

seemed more likely to just see one type of health professional plus in some cases a CNS.

- In addition to all the patients in the side effects group, some patients in the breast and gynae group and most of those in the invasive monitoring group were having ongoing care for side effects of their cancer treatment; in many of these cases, this dominated their follow up care.

Purpose of follow up – why

- Patients in all groups often spoke of the main purpose of follow up appointments as providing reassurance, particularly around recovery and absence of symptoms.

Quality of follow up care experiences

- Most patients in all the groups, except the side effects group, described broadly positive experiences of follow up care, though most also talked of difficulties with certain aspects; patients in the prostate cancer group were particularly positive about their experiences, though even in this group some described difficulties.
- Patients in the side effects group appeared to have had particularly poor experiences of follow up care; all but one patient in this group described their follow up in generally negative terms; problems usually related to the lack of specialised care available for the side effects of cancer treatment.
- Patients talked in terms of having to work hard to access care for the side effects they were experiencing, often living with severe debilitating symptoms untreated for some time before diagnosis (side effects group).
- it was also the patients living with the side effects of treatment in the breast and gynae and invasive monitoring groups that had experienced most difficulties.
- The most common problems with follow up care in all groups related to access, in particular stemming from:
 - a lack of co-ordination (invasive monitoring group)
 - lack of local provision (side effects group)
 - lack of integrated and holistic care (side effects group)
 - lack of specialised services either locally, or in some cases nationally (side effects group).
- In addition, one patient described difficulties with the outpatient appointment system, particularly in terms of the limited time available during the appointment and the impact this had on communication with the specialist (side effects group).
- Those with the ‘best’ access to follow up care, described themselves as only achieving this because they:

- 'shouted loudest' or 'worked hardest' to get it? (invasive monitoring and side effects groups)
- were a very young age at diagnosis (invasive monitoring group)
- were willing (and able) to initiate appointments (side effects group)

Views of aspects of follow up care

Rapid access to specialist medical care if you have a concern

- Patients in all groups regarded 'Rapid Access to Specialist Medical Care' as very important.

Defining the terms

- Participants in the prostate cancer group pointed out that prostate cancer is generally not a rapid cancer and therefore there is less urgency for immediate access to a specialist; patients in this group talked of being 'out of the system' and for them the important thing was being about to get back into it if they had a concern.
- 'Specialist' medical care was defined in the breast and gynae group as their own hospital consultant cancer specialist or a CNS; those in the prostate cancer group said specialist prostate cancer nurses provided a good first point of contact if patients were concerned.
- For patients in the invasive monitoring and side effects groups, the issue was most frequently about being able to access appropriate specialist medical care for side effects of the cancer treatment.
- Patients in the other groups talked more in terms of accessing care where they had concerns about a recurrence of their cancer.
- Telephone access for initial advice was common in all groups.

Accessing specialist care through the GP

- Some patients had gone to their GP with concerns and had been very happy with the speed at which they were referred to an appropriate specialist who could deal with their concerns (breast and gynae and carers groups).
- Others lacked confidence in getting rapid access to specialist care through their GP and preferred to have direct access to their specialist (breast and gynae and carers groups) or another appropriate specialist (invasive monitoring and side effects groups).

Experiences of gaining rapid access to specialist medical care if concerned

- Patients in all groups described both good and bad experiences of rapid access to specialist medical care.
- Problems with rapid access to specialist medical care appeared to occur particularly when patients' care was transferred from their original specialist to elsewhere.
- Patients in both the invasive monitoring and the side effects groups described various difficulties with access to specialist medical care during follow up; problems most often related to side effects of their treatment, rather than directly related to their cancer; patients in these groups were also more likely to experience problems in accessing care out of hours and they were more likely to access services via their GP or A&E.
- Once appropriate specialist care was secured patients seemed to be able to gain rapid access for advice if they had a concern (side effects group).
- There was a view that accessing appropriate specialist care was 'hard work and there were concerns that some patients would not be able to access specialist advice because they did not have the necessary personal characteristics (side effects group).
- Those in the carers group described problems contacting the CNS.
- Where rapid access to specialist care is not available when needed the results can be very stressful (carers group).

Accurate information about what to expect following treatment

- More holistic information would be appreciated, for example on diet and alternative therapies, to help patients with their overall health and wellbeing (breast and gynae group).
- There were considerable differences in the amount of information patients had received about their follow up care, some were told all they needed to know, others had to ask why they were having their appointments and what they were looking for, and others had wanted to ask these questions but had not felt able to (breast and gynae group).

Experiences of obtaining accurate information about follow up

- Patients in all the groups generally seemed to have had little information about what to expect during their follow up care provided by cancer health professionals; most were critical of information provision and would have liked more.
- There were particular gaps in terms of written information (side effects group).
- On the whole patients in the prostate cancer group had good experiences of information about follow up care, but the support group was the main source rather than health professionals.
- A small minority of patients were happy with the information they received:
 - one suggested this was because his was a rare cancer which was being treated by new and experimental treatments (invasive monitoring group)

- another implied that he got information by asking the right questions (side effects)
- one patient had been given a written care plan at the private cancer clinic he attended (side effects group)
- another had written his own record of what the consultant had told him at the start of his treatment (side effects group).
- It was suggested that health professionals only provided information on demand and the only patients who got information were those who asked the right questions (invasive monitoring and side effects groups).
- One patient suggested that it was the responsibility of the patient to ensure they received the information they needed by asking the right questions of their specialist (side effects group).
- Two patients in the invasive monitoring group reported receiving conflicting advice.
- There were suggestions that a lack of information led to feelings of 'frustration' and 'isolation' (side effects group).

Information needs

- There was general agreement that written information was a priority, particularly:
 - guidelines and a clear personalised care plan or pathway with detailed information about the timing of appointments, what they would consist of and what they were for (invasive monitoring, breast and gynae and side effects groups)
 - information about what appointments were for and why they ended when they did (breast and gynae group)
 - signs and symptoms to look out for (breast and gynae and side effects groups)
 - information about who to contact if you had a concern (side effects group)
 - information about recovery, diet and exercise (invasive monitoring group)
 - information about possible side effects of treatment (invasive monitoring and side effects groups)
 - resources to assist self-management eg card to record and monitor test results (prostate cancer group)
- It was suggested that information could usefully be provided on DVD (invasive monitoring group)

Timing of information delivery

- Some patients would have liked information about the whole cancer care pathway, including follow up, delivered at diagnosis, others were not in favour of this.
- There was particular disagreement around the timing of the delivery of information on side effects: some preferred to have this in advance so they could be prepared, others preferred not to know until necessary (too much to take in and would cause patient to worry) (breast and gynae group).

Help with returning to (and staying in) work

- Returning to work after treatment for cancer was generally regarded as difficult and the ease with which it happened depended largely on support provided by the employer.
- Many patients in three of the groups described difficulties with returning to work after cancer treatment; only one participant in the prostate cancer group had been working at the time their cancer was diagnosed and his experience had been entirely positive.
- Positive experiences of returning to work after the end of treatment were related to the willingness of the employer to allow flexible working during a phased return (invasive monitoring and side effects groups).
- The need to attend regular hospital follow up appointments meant the attitude of the employer determined whether an employee could stay in work after treatment had ended (side effects group).
- Most participants in the side effects group and some in the invasive monitoring group were unable to return to their original work after treatment ended because of the severe problems resulting from cancer treatment.
- One participant had only been diagnosed after a long and protracted period of unexplained illness during which she had to give up work; this meant that by the end of her treatment she had been out of the work place for some years (side effects group).
- One participant describes how self-employment was an advantage in some respects, particularly in terms of being able to decide when to return to work (side effects group).
- In terms of finding work after cancer, it was suggested that employers were reluctant to employ someone who had had cancer because they were concerned you would fall ill again (invasive monitoring group).

Information for employers

- There was agreement in the breast and gynae and the side effects groups that information to raise employers' awareness would be helpful, including:
 - the legal rights of patients returning to work after cancer
 - patients' needs on returning to work
 - that they may need to take time off for follow up appointments
 - information about the side effects of cancer treatments that might impact on an employee in the work place for many years after treatment has ended.

Advice about benefits

- Participants in all groups described difficulties with getting advice about benefits; most had not received any help with obtaining financial support while they were unable to work and some had experienced financial hardship during follow up.
- Even where participants had information about benefits, financial support was difficult to obtain (side effects group)
- The main problem was finding an accurate source of information; one carer had to go to multiple sources for information and advice and found these conflicting and difficult to understand.
- One carer experienced problems dealing with different agencies and with getting delivery of assistance that had been promised.
- In the absence of financial support participants had been living on their savings and pensions (side effects group).
- Some participants in each of the groups had not needed financial help because they received sick pay or were financial secure.
- A small number had been offered information and advice from a dedicated advisor at the hospital (carers and invasive monitoring groups); others had to search it out from multiple sources (carers group).
- One patient in the breast and gynae group and two people in the carers group had received financial assistance from Social Services.

Suggested improvements

- It was suggested that advice about benefits would be helpful as the majority of people with cancer would suffer financially (breast and gynae. and side effects groups).
- Information on planning the return to work was also suggested (breast and gynae. group)
- Participants in one group felt more information and advice was important from the beginning, rather than during follow up, so that it was not a worry during treatment (breast and gynae. group).

Psychological support

Psychological support needs

- Participants identified the need for psychological support from the beginning at diagnosis, through to follow up and needs to be provided on a range of issues depending on the individual (breast and gynae., carers and side effects groups)
- Some thought that psychological support needs were greatest around the time of diagnosis and initial treatment (prostate cancer group); it was suggested that the quality of support received at this time affected their psychological support needs during follow up care (breast and gynae. group).

- Another factor said to affect the need for support during follow up was how successful the recovery process had been; patients who had had a rapid recovery did not feel they needed psychological support, but acknowledged its importance for others (breast and gynae. group).
- Participants in the breast and gynae. group described the need for different types of support, such as support with the changes to everyday life resulting from cancer or cancer treatment, support coping with physical changes and support for the effects on relationships with family.

Sources of psychological support

- Patients mentioned a number of different sources of psychological support including:
 - clinicians involved in the treatment of the cancer (breast and gynae. group)
 - counsellors at the hospital
 - counsellors linked to cancer charities
 - private counsellors.
- Some were very supportive of clinicians with special training or psychologists providing emotional support (carers group).
- Some participants in the carers group felt it was important that the person providing psychological support was connected to the hospital and had an understanding or overview of the patients' case history.
- Others thought that independent organizations should provide psychological support, rather than training nurses or having in house NHS psychologists (carers group).
- There was a feeling that there was untapped potential within the role of the CNS to provide psychological support because their involvement with the case allows them to monitor and provide continuous support throughout the cancer journey (breast and gynae group).

Role of support groups in providing psychological support

- Many of the participants in all the groups were members of support groups and they mentioned this as a source of psychological support.
- There was general agreement about the benefits offered by peer support (prostate, carers and side effects groups).
- Peer support schemes seemed to provide much needed psychological support that was not available professionally (side effects group)
- The carers group viewed the sort of support available in peer support groups as distinct from formal psychological support.
- Provision for peer support appeared to be good during treatment, however it seemed that little was available for some patients in the follow-up period after treatment (side effects group)
- Some participants were concerned that the majority of people would not want to get involved in support groups (breast and gynae. group).

Experiences of psychological support

- Few patients in any of the groups had received any emotional support, though many said they would have benefited from this.
- None of the participants in the breast and gynae. group mentioned receiving (or wanting to receive) professional psychological support.
- Patients describe accessing psychological support through:
 - MacMillan or other cancer charities (invasive monitoring group)
 - paying for private counselling accessed through a cancer charity (invasive monitoring group)
 - from the cancer centre after treatment for cancer (side effects group)
 - and another suggests that she only got psychological support because she 'shouted' for it whereas other patients with the same condition had not (invasive monitoring group).
- Often support had only been available to these patients when they 'shouted for it' or 'demanded it' when things got too difficult to cope with. (invasive monitoring and side effects groups).
- It was felt that the focus of doctors and nurses was only on physical health (carers group).

Support for my carer (and/or family and friends)

Carers' need for support

- Participants in four of the groups agreed that there was a need for support for their partners, family and friends; this was not a particular issue for participants in the invasive monitoring group.
- Most felt that the carers' need for support was greatest around the time of diagnosis and treatment, rather than during follow up care (prostate and breast and gynae groups).
- A minority felt that support was particularly important during follow up because of the shift away from care by the clinicians (breast and gynae group).
- Participants in four groups generally focused more on the need for emotional support, rather than practical support with the activities associated with being a carer; those in the carers group also discussed the need for help with the more practical aspects of providing care.
- The need for information to relieve fears of 'what happens next' was also identified; either through written information or a help line contact providing some opportunity to ask questions (breast and gynae. group).

Experiences of support for carers

- Two participants in the side effects group described a lack of support for their carers as problematic and it was a concern for most of those in the carers group; but this does not appear to have been a particular problem for those in the other groups.
- One carer described a lack of support when grieving after the death of their partner.
- Few participants in any of the groups had experience of psychological support for carers.
- A number of those in the carers group had received counselling; one was linked to a counselling course, another had received counselling during his wife's treatment but nothing during follow up; two had bereavement counselling and one carer's experience was positive due to the personal attention of the GP.
- One participant described how her daughters' needs for emotional support were met through a cancer charity (invasive monitoring group).
- In the carers group it was suggested that access to support for carers and family seemed to depend on what was available in the area.

Being seen at my GP surgery

- Most patients in all groups had their follow up care with their hospital consultant.
- Many patients in all groups said that, personally, they would not like to be seen for follow up by their GP; no one in the breast and gynae. group would prefer to have been seen for follow-up appointments at their GP surgery, rather than at the hospital.
- Difficulties with GPs providing follow up care focused on problems with:
 - lack of specialist knowledge (all groups)
 - access (prostate and invasive monitoring group)
 - continuity (invasive monitoring and breast and gynae. groups).
- A small number of participants also expressed concerns about:
 - the ability of the GP to instil patient confidence and consequently to provide reassurance (breast and gynae. group)
 - not feeling comfortable having GP conduct physical examination because of because of her relationship with the GP (breast and gynae. group)
 - the GP not having the equipment needed to conduct tests, nor the ability to analyse these tests on site (carers group)
 - the ability of the GP to make an appropriate referral (carers group)
 - the GP lacking knowledge of the patient's case history (carers group)
 - the GP as an unnecessary 'middle man' between themselves and the specialist (carers group)
 - being seen by the GP could compromise care (carers group).

- A small number of patients were positive about the ability of the health professionals at their GP surgery to provide their follow-up care, at least as a first point of contact and/or as a supplement to specialist care (invasive monitoring, side effects and breast and gynae. groups).
- Patients who were more receptive to GP follow up were most attracted by the potential for reducing the number of trips to hospital, particularly when the hospital may be more difficult to get to (breast and gynae. group).
- Most participants in the side effects group accessed some of their follow up care through the GP surgery and described difficulties with certain aspects of this, similar to those outlined above.
- The absence of easy access to specialist hospital care meant one patient relied on the practice nurses (invasive monitoring group).
- One carer had experience of going to their GP and expressed confidence in their ability to refer, but they felt there was a responsibility on the carer/patient to find the right GP who could do this and that not all would be suitable; other carers had found good GPs who provided personal attention, however this was not seen as a substitute for access to specialist knowledge.
- One participant talks of the care provided by their GP as being a very important supplement to the specialist cancer care they received (side effects group).
- One suggestion to increase the potential of GP follow up was to expand the role of the CNS to go into the community and perhaps work with GPs with the benefit of their specialist knowledge (breast and gynae. group).

Being seen at the hospital

- Most participants in all groups expressed a strong preference for having follow-up care with a specialist at the hospital; the reasons for preferring hospital care were closely linked to the concerns with GP led follow up described in the previous section.
- Few patients and no carers raised any problems with being seen at the hospital.
- Preferences for follow up appointments at the hospital were frequently expressed in the context of acknowledgement of difficulties of attending hospital appointments, such as:
 - the inconvenience of waiting to be seen (prostate cancer group)
 - time and travel involved in attending hospital appointments created another obstacle to employment (breast and gynae. and side effects groups)
 - follow up appointments at hospital with the specialist are very important in the first one to two years (breast and gynae. group).
- Some patients in the breast and gynae group would have liked to have fewer appointments at hospital, either stopping earlier (e.g. after a year) or going to appointments less regularly (e.g. appointments with only one specialist rather than

two), however others would have preferred *more* hospital appointments with the specialist if necessary.

- One carer described the distress caused by the physical layout of the waiting room at the hospital outpatient clinic which meant a lack of privacy for patients who were upset.

Knowing who to contact if I have a problem

- Most participants in all the groups said they knew who to contact if they had a problem, however it was also clear that for many this had not always been the case.
- Participants mentioned different contacts including:
 - cancer specialist nurses (prostate cancer group)
 - specialist consultant (breast and gynae. group)
 - their GP (prostate and breast and gynae. groups)
 - a national helpline (prostate cancer group).
- The initial point of contact depended on the options made available to the patient by their clinicians.
- Initial contact when concerned about a problem was frequently made by telephone.
- Knowing who to contact was clearly not enough as many participants described difficulties getting hold of their preferred contacts (invasive monitoring and carers groups).
- It was suggested that staffing levels meant that the specialist nurses were very stretched which could impact on the ability to contact them when needed (invasive monitoring group)
- Some patients clearly experienced problems in knowing who to contact if they had a concern (side effects and carers groups); problems most often seemed to result from:
 - a lack of integration in the care provided
 - difficulties navigating procedures at different sites or organizations, particularly between hospital and community care
 - poor communication between different care providers eg notes not being shared.
- The need for a single point of contact was mentioned frequently.

Seeing the same specialist consultant/nurse

- Participants in all groups thought it was very important to see the same specialist (either a consultant or nurse) at every appointment throughout treatment and follow up to ensure continuity of care.
- Continuity of care was generally regarded as a high priority during follow up care in order to:
 - give patients confidence that they were receiving the care they needed (invasive monitoring group)
 - not to waste time as health professional reads notes before seeing you or covering same ground at every appointment (invasive monitoring, carers and breast and gynae. groups)
 - building a relationship with health professionals to ensure psychological support (breast and gynae. group).
- Most patients had seen the same specialist throughout their treatment and follow up and commented favourably on the impact this had on their care, particularly because the specialist knew their history (breast and gynae. group).
- Only one patient commented negatively on seeing the same specialist during follow-up as during treatment where initial relationships had been soured because of poor care during treatment (breast and gynae. group).
- A small number of participants described problems resulting from a lack of continuity of care and/or lack of integration of care (breast and gynae. and side effects groups).
- It was suggested that having the same central contact would improve problems arising from a lack of continuity of care (breast and gynae. group).
- Continuity was said to not always be available in a large complex organisation like the NHS (side effects group).

Views of different models of care

On the whole, participants in all but the side effects group, were resistant to the suggested new models of providing care as replacements for existing models of follow up care. There was however, some limited support for all three models as additional services to supplement gaps in current care.

Telephone follow up (nurse led)

- There was considerable variation within and between the five groups in terms of the extent of support for telephone follow-up appointments.
- On the whole most patients showed cautious support for telephone follow up appointments, but only in addition to face to face appointments at the hospital, not as a replacement for them and if they were:
 - acceptable to the patient and their choice (breast and gynae. group)
 - appropriate to any particular patient in terms of the stage of the care pathway (invasive monitoring group)
 - with the specialist team with knowledge of their case, not with a generalist (side effects group).
- Participants in the carers and prostate groups showed the least acceptance of telephone follow up and identified the most problems, but participants in all of the groups identified difficulties, including:
 - 'impersonal' (prostate cancer group)
 - face to face communication more effective and preferred (prostate, breast and gynae. and carers groups)
 - confidentiality and security were concerns (prostate cancer group)
 - problems with administration (prostate cancer group)
 - lack of continuity of care (prostate cancer group)
 - physical examinations were vital for some patients at some stages (breast and gynae. and carers groups)
 - concerns about safety - things that could be would picked up in person might be missed over the telephone (breast and gynae. group)
 - concern that face to face appointments were needed for a medical specialist to check if any symptoms were present that a patient might not be aware of (side effects group)
 - some patients would have difficulties with it because of personal characteristics which made them resistant to, or incapable of, communicating with a health professional on the telephone (side effects group)
- Participants in the side effects group showed the most support for telephone follow-up appointments, with a minority seeing them as problematic.
- There were participants in all groups who had personal experience of some aspects of their follow-up care being conducted by telephone; some of them spoke in very positive terms about their experiences; advantages identified included:
 - more appropriate to those patient who wished and were able to self monitor, after being provided with relevant information regarding signs and symptoms to look out for (breast and gynae. and side effects groups)
 - time and cost advantages to both the NHS and to patients (side effects and carers groups)

- could provide the continuity of speaking to the same specialist consultant rather than doctors with less knowledge of the case (carers group)
- where physical examinations were not required, telephone follow up would be preferable (breast and gynae. group)
- might be more appropriate for patients with certain cancers and/or at a certain stage in the patient pathway (breast and gynae. group)
- good for obtaining test results, especially if no problems.

Patient managed follow up

- There was limited support for patient managed follow up in all groups, except in the side effects group which favoured it.
- Amongst participants in the side effects group, views about patient managed follow up were generally positive and it was regarded as a particularly effective approach to delivering care for those living with the long term side effects of cancer treatment and appropriate in the context of the increasing numbers of people living with cancer as a chronic condition.
- It was suggested that such a system would only work in the context of detailed accurate information for patients about signs and symptoms to be aware of and arrangements to be able to rapidly access expert specialist advice if needed (side effects group).
- One patient felt the follow-up care he had received had largely been at his initiation and he had been happy with this arrangement, suggesting that its success has been partly due to a good relationship with the specialist (side effects group).
- Even in this group, there were concerns that patient initiated follow up would not work for some patients and they could fall out of the system; it was suggested that such patients needed to be seen on a regular routine basis to ensure that any symptoms were not missed (side effects group).
- Participants in the other groups were generally negative towards the suggestion of patient managed follow up where no appointments were booked, but contact was entirely initiated by the patient; all the participants in the invasive monitoring group thought that patient initiated follow up was inappropriate.
- Difficulties with patient managed care centred particularly on concerns about safety, specifically because patients might 'slip through the net' or fall out of the system, because:
 - they ignore symptoms and opt out of, or put off, initiating appointments when they have a problem (prostate and carers groups)
 - they lack the knowledge to know when they had a problem which required further investigation or treatment (invasive monitoring group)
 - most patients would not be able to take the responsibility for self-monitoring (prostate cancer group)

- they may have difficulties getting back into system (carers group).
- Other problems included concerns that patient managed care was:
 - not appropriate for everyone (breast and gynae. group)
 - not appropriate at some points in the patient pathway eg immediately after treatment (breast and gynae. group)
- It was also thought that self management would not be appropriate for patients with some types of cancer because some symptoms are often silent eg prostate cancer (prostate and carers groups)
- There was strong support for patient managed follow up in the side effects group; a small number of participants in the other groups, except the invasive monitoring groups were also able to see some advantages.
- It was felt that many patients already monitored their own health between appointments and there was some support for the notion of patients looking after their own health.
- However, even amongst those in favour of 'patient managed follow up,' it was felt it could not be the only form of follow up, particularly not straight after treatment.
- Participants in the breast and gynae. group identified the following benefits of patient managed care:
 - psychological – by treating patients like any healthy individual and respecting their ability to monitor their own health rather than submitting to examinations that they may not feel necessary (breast and gynae. group)
 - practical - saving time going to follow up appointments (breast and gynae. group)
 - for patients who felt their follow up appointments went on too long, patient managed follow up might be more appropriate (breast and gynae. group)

Group follow up

- No participants had direct experience of group follow up appointments.
- All but two of those in the side effects group were in favour of group follow up appointments; participants in the other four groups were generally negative about the idea of having group follow up appointments; all those in the invasive monitoring group thought it was inappropriate.
- The inability of group follow up appointments to deliver personalised care that met the different needs of each patient was the main concern.
- There was some support amongst participants for group based activity, but only in addition to one to one follow up appointments, not as a replacement (invasive monitoring, breast and gynae. and carers groups).
- It was suggested that individual needs could be incorporated by allowing individual consultations after the group for those who needed it (breast and gynae. group).

- The main concerns with group follow up appointments were centred on:
 - fears that it could be psychologically harmful with other people's problems added to the patients own, particularly without individual support (breast and gynae. and carers groups)
 - removed control from patients over what information they wanted to share with others (carers group)
 - could not address individual needs and difficulties of getting the attention you needed to in a group context if others in the group shouted louder or had more pressing problems (invasive monitoring group, breast and gynae. and carers groups)
 - very personal matters could only be discussed during a one to one consultation (side effects group)
 - would be difficult to get people to attend (prostate and breast and gynae. groups)
 - problems with getting specialists and the multi-disciplinary team to attend (breast and gynae. and carers groups)
 - issues of cost effectiveness, and the problem of wasting the time of experts attending when they might not even be needed (breast and gynae.)
 - would be a lot of irrelevant information (carers group).
 - would not be able to have examinations (carers group)
 - clinicians would not be able to monitor changes in patients or raise concerns in a group situation (carers group).
 - was purely a cost cutting exercise (carers group).

- The main advantages of group follow up appointments were in terms of providing support and allowing exchange of information in the presence of health professionals who could provide accurate answers to questions about common problems and concerns.

- There were suggestions that it was preferable to support existing peer support groups, rather than replacing them with formally organised groups organised by health professionals (prostate cancer group).

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