
Chemotherapy Closer to Home - Patients' Perspectives of Receiving Chemotherapy in Outpatient Clinic and/or a Unique Mobile Chemotherapy Unit

Report on the interview study

July 2011

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Executive Summary

1. Chemotherapy closer to home is described in *The NHS 2010-2015: From Good to Great* (2009) as an area in which using a different model of treatment delivery could have a positive impact upon the experience of receiving chemotherapy. *The Revision to the NHS Operating Framework for the NHS in England 2010/11* (2010a) advocates more community based services for people receiving chemotherapy and The National Cancer Advisory Group (2009) also called for discussions between Cancer Networks and community healthcare service providers to consider how chemotherapy can be provided closer to patients' homes.

2. In 2007 the first Nurse-Led Mobile Chemotherapy Unit (MCU) in the UK was launched in Gloucestershire by Sir Stirling Moss, Patron of the charity 'Hope for Tomorrow' founded by Christine Mills. The bespoke unit is furnished to cater for five patients at any one time, and is staffed by two experienced oncology nurses who are trained to administer chemotherapy and run the unit autonomously with the support of the full time driver. The MCU is operational in Cirencester, Stroud, Cinderford, Stow-on-the-Wold and Ross-on-Wye on designated days of the week. The charity more recently launched two more MCUs in the South-West and the fourth is in planning.

3. The aim of this report is to give a voice to 20 people who volunteered to be interviewed because they had received chemotherapy in the Outpatient Clinic at Cheltenham General Hospital, and/or onboard the unique Gloucestershire Nurse-Led MCU. Participants described and compared their experiences of receiving treatment in both venues. The experience of having treatment can not be divorced from the experience of having cancer, and therefore this report also attends to some of the other issues important to this participant group.

4. Interviews were conducted in the homes of nineteen participants and one in the researcher's home at the convenience of that participant. An Interpretive Phenomenological approach was employed whereby the agenda belonged to the participant and conversational engagement between researcher and participant was important. Up to three hours was spent with each participant to listen, and make efforts to understand their perspective.

Participants talked about their experiences of having cancer; symptom recognition and cancer diagnosis, interface with GPs, undergoing diagnostic tests, preparing and having surgery and then chemotherapy treatment.

5. Most GPs were efficient in referring participants in this study to secondary care for diagnostic tests. There were a couple of instances where delayed referral from GPs meant that several weeks or months elapsed which could have impacted on the nature of treatment and treatment trajectory, and indeed, patient outcomes.

6. Several participants did not actively seek information from the Internet or more formal sources. They described feeling shocked at the diagnosis and too fragile to search for information, fearing what they might read. Information was obtained from informal sources such as friends and other patients waiting in the clinic for treatment.

7. There were descriptions of situations in which bad news was conveyed in an insensitive way. Some clinicians were criticised for poor bedside manner and an abruptness that caused long term emotional upset.

8. A couple of participants used the hospital car service but said that sometimes they were forgotten or there was no service after 15.00hrs and had to arrange alternative means of transport to get home.

9. The new arrangements for car parking with a permit near the oncology centre were appreciated. This allayed some anxiety during the day of treatment.

10. Data illuminated the cancer and chemotherapy journey as being undertaken by both the patient and their significant other. Many participants talked about the togetherness that they depended upon to get through the treatment. Those who did not have a partner/spouse and who attended treatment alone reported feeling burdened and lonely.

Often partners/spouses who drove the person to have treatment in the Outpatient Clinic had to wait for the duration of tests, consultations and treatment in the sitting area in clinic.

11. The most important and distinguishing feature between receiving treatment in Outpatient Clinic and the MCU was the amount of time spent waiting. Participants reported

waiting in clinic for between 3 and 12 hours. Being in the Outpatient Department for up to 12 hours for a day every week was perceived to be a waste of remaining life for some people. Several said they believed it to be the fault of 'operational' or 'organisational' staff and did not blame the doctors or nurses. Every participant in this study complained about the length of time spent waiting in clinic. The longest wait for treatment on the MCU reported in this study was 10-15 minutes.

12. Once patients were in a treatment chair in clinic or on the MCU their anxieties about cannulation become apparent. From their accounts it is evident that participants dread the multiple efforts to insert a cannula, without local anaesthetic, into overused and fragile veins. Techniques for preparing for insertion of cannulae are inconsistent between nurses; some provide warm pads to encourage vasodilation and others do not.

13. Having treatment on the MCU was perceived to be less formal than clinic and therefore less stressful. The environment was acceptable to participants who enjoyed conversations between nurses, the driver and other patients. The clinic environment was criticised for not having natural light through windows, for being cold due to air conditioning, and not having the personal touch afforded them on the MCU. There were no particular issues regarding privacy and dignity on either the MCU or in clinic.

14. Distance travelled and time taken to get to Cheltenham General Hospital (CGH) for treatment was important to participants. Some reported a round trip of over 50 miles and 2 hours travel each way. Those who went to the MCU at the various locations said it took them between 10 and 20 minutes to get there.

15. Participants tended to drive themselves to the MCU for treatment because it was a much shorter distance and they had more confidence that they would not be ill on the way home. This meant that partners/spouses were not inconvenienced (ie. taken out of work) to take the patient for their treatment. Costs to patients were significantly reduced in terms of time spent travelling, having to wait, treatment time, expenditure on fuel and companion costs.

16. A couple of participants stated that they had their appointments on the MCU cancelled because not enough patients had been booked on it for that session and it was not viable for

the Unit to go out, or it could not be staffed adequately. This is disruptive for the individual who then has to organise transport, and possibly a companion, to go to CGH. They also need to cancel other activities planned for the day.

17. Pharmacy in CGH was criticised for closing at lunchtime when patients required prescriptions to take home. This resulted in extended waits for patients who had already been delayed in the clinic. There were no issues raised at interview about medications on the MCU.

18. There was some frustration about the appointments system in clinic. Participants were frustrated when they did not receive appointments or had difficulty in changing inappropriate appointment times. Previously appointments had been made face to face with administrative staff and this was valued.

Key Recommendations

1. GPs will receive further training associated with diagnosing cancer, in particular rare cancers, as part of the Coalition Government's agenda for improved healthcare and reduced times to referral. Findings from this small study suggest that there is a need for GPs to be updated about, and more responsive to, symptoms that might not initially be indicative of malignancy but that patients report as insidious and abnormal to them.
2. Nurses should always use heat pads for vasodilation when patients report being cold or specifically request for them to be applied. Those patients who frequently experience difficulty being cannulated could be encouraged to purchase their own hand warming devices from chemists or other healthcare outlets.
3. There should be a protocol that recommends the use of EMLA cream when patients have previously experienced multiple attempts to cannulate and/or have overused and fragile veins. This will promote consistency between nurses when inserting cannulae.
4. Because some participants in this study found information confusing and overwhelming, the amount of information and timeliness of imparting it to patients should be revisited, or at least reconsidered on an individual basis.
5. Further consideration and sensitivity should be employed when breaking bad news to patients throughout the cancer and chemotherapy trajectory.
6. Waiting times were reported as being the most problematic aspect of receiving chemotherapy in clinic. The complexity of administering, staffing, and maintaining routines and order in clinic is acknowledged, however, there is a need to invest in major discussions about how the experience of patients and their significant others could be improved when receiving chemotherapy in clinic. These should be initiated at a strategic level and include medical and nursing staff, and also public involvement.
7. The environment in the clinic waiting area should be audited with the aim of improving the comfort of patients. Public views should be sought regarding, amongst other aspects, lack of natural light and over-active air conditioning.
8. Opening hours in Pharmacy at CGH must be reconsidered for the benefit of patients who require medications to take home during lunchtime hours, and indeed, in the evening.
9. Because the MCU was considered to be a desirable alternative by participants in this research, further discussions should be encouraged to identify any other chemotherapy regimes that might be appropriate to include in the criteria for treatment on the MCU.
10. Whilst it is difficult to anticipate if patients might be too ill to have their treatment on the MCU (therefore reducing the numbers for that day), or if a nurse might be off sick preventing the Unit from going to the planned destination, all efforts should be made to inform, as early as possible, other patients expecting to have their chemotherapy onboard for that session.
11. In order to make full use of the MCU and for it to be a financially viable alternative to receiving treatment in clinic it must be used to capacity at all times.
12. With the launch of the 4th MCU due in early 2012 there should be further research to assess staff satisfaction with the working environment of MCUs in comparison to clinics. In addition, a randomised controlled trial should be conducted to measure cost effectiveness of MCUs in comparison to clinics, and also to measure patient satisfaction and outcomes on MCUs. A team of researchers from Bristol University and The University of the West of England, in collaboration with the originators of the Gloucestershire MCU have been convened to plan large scale research informed by the study reported here.

1 Introduction

During the last 11 years there has been a drive to expand the geographical distribution of cancer services through the development of National Cancer Standards (Department of Health, 2000), improvement in access to palliative care by setting out recommendations within National Supportive and Palliative Care Guidelines (NICE, 2004), and development of pathways between primary and secondary care through introduction of initiatives such as the Liverpool Care Pathway (Marie Curie, 2005) and the Gold Standards Framework (Macmillan Cancer Relief, 2005). These initiatives were implemented with the intention of improving services in the future and broadening choices for people with cancer. Providing choices implies that there are options from which to choose, and undoubtedly if adequate resources across both primary and secondary care are in place then it follows that choices are extended. The Department of Health (DH) issued a White Paper in January 2006 entitled *"Our Health, Our Care, Our Say: A New Direction for Community Services"*. This set a new direction for health and social care confirming the required changes set out in the DH (2005) green paper 'Independence, Well-being and Choice'. It requires a sustained shift in the way that services are delivered, ensuring that they are more personalised and that they fit into peoples' busy lives.

At an away day in February 2006 to discuss chemotherapy services within The 3 Counties Cancer Network (3CCN, 2006) it was agreed that wherever possible chemotherapy should be delivered as close to peoples' homes within the acknowledged constraints of patient safety and affordability. The 3CCN encompasses cancer services across Gloucestershire, Herefordshire (extending into Powys) and South Worcestershire, serving a population of approximately 1.1 million people. All Primary Care Trusts within the 3CCN repeatedly expressed their desire for chemotherapy services to be provided as locally as possible.

The majority of patients having chemotherapy receive treatment as a day case and follow a pathway which includes a blood test, assessment by a nurse or doctor and then administration of treatment by nurses.

Historically chemotherapy services are located at hospital sites at which these specialist personnel and facilities are based. This often requires

patients to travel quite lengthy distances to receive treatment.

An expanding number of indications for chemotherapy, the development of new drugs approved for use in the NHS and increasing numbers of referrals to oncology services have seen workload rise exponentially over the last decade and inevitably will continue to do so for the foreseeable future. In the 3CCN chemotherapy day case episodes have increased from 20,124 in 2006/7 to 30,000 in 2010/11 (statistics taken in April of every year and reflect activity across all sites in the Network). Twenty thousand of these were at Cheltenham. Day case episodes on the MCU for that period are recorded as 1,254.

To inform this research at the outset a systematic review of the literature associated with 'mobile units', 'nurse led initiatives' 'chemotherapy at home' and 'community chemotherapy' was undertaken using databases British Nursing Index (BNI), Cumulative Index for Nursing and Allied Health Literature (CINAHL), EMBASE, PsycINFO and Medline. No research was found that described a nurse-led mobile chemotherapy administration unit. No research was detected that detailed evaluation of effectiveness of any mobile 'health' unit. Literature relating to 'mobile health units' included Wolff et al. (2005), mobile endoscopy (www.vanguardhealthcare.co.uk), mobile operating theatres (www.vanguardhealthcare.co.uk), mobile mammography (Rikiya et al., 1987), mobile digital breast screening (Baldwin, 2005), mobile medical unit in the USA (www.Whittier.org/pages/mmu.html), mobile HIV/AIDS counselling and testing unit (O'Connor et al., 2000), modular mobile health care unit for disaster areas and third world countries (www.lifeit.com/telelab/modular.htm), children's hospital mobile healthcare van (www.uchicagokidshospital.org/fact/van), and a fleet of mobile units offering a range of healthcare services contracted by the Department of Health UK through Vanguard Healthcare to serve the West Midlands Strategic Health Authority.

Although parallels can be drawn between the blood donor sessions run by NHS Blood and Transplant (NHSBT) and the MCU, for example safety issues (Brown et al., 2005; Larkin, 2000), there are many differences. Most importantly the NHSBT does not administer treatment or cater for individual treatment regimes (Green and Pirie, 2006; Singer and Shvartzman, 1998; Mancini, 1999).

The Gloucestershire Mobile Chemotherapy Unit (MCU) (Appendix 1) was launched in 2007 by Sir Stirling Moss, a patron of the charity 'Hope for Tomorrow', which donated the money to build the Mercedes Benz cab and bespoke trailer unit. The Unit was designed to provide 5 patients with chemotherapy treatment at any one time. In a day, 2 nurses administer chemotherapy to up to fifteen patients. The Unit parks in the grounds of community hospitals in Cirencester, Stroud, Cinderford, Stow-on-the-Wold and Ross-on-Wye, each on different days of the week. Patients travel directly from their home to one of these venues nearest to their home. Although parked in the grounds of community hospitals, the Unit is independent of the hospital unless there is a medical emergency in which case a GP or nurse from the practice might assist the nurses on board. However, the chemotherapy nurses are experienced oncology nurses and they have undertaken specialist chemotherapy administration courses.

Logistically, the driver picks up the Unit from the grounds of Cheltenham General Hospital (CGH) and collects the chemotherapy and nurses for that particular day. He drives to the destination, stays on board and assists with tasks to help the nurses and patients. The charity takes responsibility for the maintenance of the Unit whilst the NHS pays for the nurses, driver and fuel. There is an assumption that the Unit is more environmentally friendly because of the number of journeys saved that would otherwise have been made by patients to the more distant Outpatient Clinic in CGH.

The Unit is the first nurse-led chemotherapy unit in the UK, and as far as we know, the first worldwide.

2 Aims of the Research

1. To provide an opportunity for people receiving chemotherapy to give their perspectives on treatment.
2. To explore experiences of people receiving chemotherapy who received treatment in the Outpatient Clinic (CGH), and on the Mobile Chemotherapy Unit.
3. To identify good practice and areas for improvement.

The aims were developed to respond to the research question: "What are the experiences of patients receiving chemotherapy in the outpatient clinic and/or the mobile chemotherapy unit?"

3 Research Context

A plethora of research studies demonstrate how important quality of life is for people with cancer receiving chemotherapy (Bakker et al., 2001). The treatment period is perceived as an indicator of survival in people receiving chemotherapy with an intention to cure, and as pain relief and symptom control in those given chemotherapy for palliation. Chemotherapy is cumulative; that is, effects increase so that by the last cycle the body is toxic and at its most vulnerable, and the patient is often weak and exhausted (Kuuppelomaki & Lauri 1998). Any development or change in a service delivering chemotherapy will impact, either positively or negatively, upon ways in which patients experience chemotherapy treatment and cope with it. Toxicity that manifests through nausea, vomiting, diarrhoea and fatigue often dictates if people can travel in a car or on a bus, walk, or be comfortable being a distance away from a toilet. Convenience is of utmost importance. The intention of the interview part of the project reported in this document is to describe patients' experiences comparing the MCU service with the existing out-patient clinic service to assess if the MCU is an equitable, acceptable, desirable option for people receiving chemotherapy.

All patients who are prescribed chemotherapy treatment are firstly assessed in the Outpatient Clinic. They all have the first treatment in clinic so that any adverse reactions can be observed. After this, patients who meet the criteria for treatment on the MCU are considered by the MCU coordinator and nurses for their appropriateness to receive treatment onboard the MCU. To be eligible to have treatment on the nurse-led MCU patients have to meet specific criteria. These include the following chemotherapy regimes;

Carboplatin	GemCarbo
Trastuzumab	Zoledronic Acid
FEC	Gemcitabine
GemCap	ECF (day 8 & 15 only)
Capecitabine	Vinorelbine
VinCarbo	Pemetrexed
FF	GemCis (day 8 & 15 only)

In addition, the person would not have had a reaction to the first chemotherapy treatment; would live more than 15 miles from Cheltenham General Hospital; and their chemotherapy treatment would take less than 3 hours to administer.

4 Research Methodology

The full evaluation comprised a satisfaction survey and interviews.

For the purpose of the interviews an interpretive phenomenological (Heidegger, 1962) approach was used. This philosophical orientation acknowledges that the researcher is instrumental in co creating the data at the point of conversation with the participant and during the analysis stages.

Interpretive Phenomenology is a philosophy that provides direction for methodology and principles for the conduct of research. Because the relatively small sample can not represent larger populations there is no intention to generalise findings. However, the findings are likely to resonate with others who receive chemotherapy in the locality. There is also value in the depth of data to other oncology centres who might also consider providing chemotherapy closer to home.

It was important to capture participants' experiences of receiving chemotherapy as part of a sequence of events including symptom recognition, seeing the GP and diagnosis. The experience of receiving chemotherapy could not be divorced from having cancer.

4.1 Sampling

A questionnaire which aimed to measure service satisfaction, cost of the journey, mode of travel, time taken to travel, companion costs, costs of childcare or other dependants and time lost from paid work was given to patients after their fourth treatment on either the MCU or in Clinic. An accompanying letter of explanation from the PPI Department, and 2 stamped addressed return envelopes were inserted into the patient's notes by the Consultant Nurse or Clinical Nurse Specialists prior to the fourth treatment attendance in clinic or onboard the MCU. Patients completed and returned the questionnaire anonymously to the PPI Department in one of the SAEs.

Patients were able to indicate that they were interested in participating in an interview by returning, in the second SAE, a tear-off slip from the end of the questionnaire. The PPI Department contacted the researcher when a tear off slip had been received so that a Participant Information Sheet explaining what would be involved in the interview could be sent by post or e-mail. People had up to a month to consider whether they wanted to be interviewed. The first 20 people to

respond were interviewed. Consent to participate in an interview was obtained by the researcher after any questions arising from the participant information sheet had been answered. All participants had access to telephone numbers and an e-mail address through which the researcher could be contacted.

Participant characteristics are presented in Table 1.

Fourteen women and 6 men participated with an age range of 46 – 76 and mean age of 60 and 9 months. Ten participants presented with colorectal cancer, 5 with breast, 1 lymphoma, 1 laryngeal, 1 rare vascular and 2 with pancreatic cancer.

The sample comprised 6 teachers, 3 retired military, a retired engineer, a librarian, an office manager, a business manager, a civil servant, a retired radiotherapist, an artist and a supermarket worker. Therefore 19 participants were or had been professional/skilled. Only one was not. Three of the participants' occupations were unknown. It may be that professional/skilled workers responded to the invitation to participate in this research because they are more vocal and confident and grasped the opportunity to share their experiences with someone outside of the care environment. This is however, the researcher's conjecture.

Coincidentally, 10 participants had received treatment on the MCU and ten only had their chemotherapy in clinic.

4.2 Data collection

The researcher aimed to understand the perspective of the participants through in depth conversations (Denzin & Lincoln, 2005) and mindful absorption in the context of the participant. Nineteen interviews were conducted in the participants' homes; one occurred in the researcher's home as it was more convenient for the participant. Interviewing in participants' homes had impact upon the researcher and the data in a very positive way. Interviews were relaxed, informative and reciprocal – often involving a spouse or partner also creating data and contributing to the researcher's overall understanding of their experience of chemotherapy services. Being a guest in participants' homes contributed to them having some control over the interview agenda. This was important because the intention was to access experience as it is lived and perceived. (see Appendix 2 for the interview guide).

Table 1 Participant Characteristics

Participant Number	Age	Gender	Tumour Site	Occupation	At Interview	MCU
1	60	F	Lymphoma	Artist	Alone	NO
2	62	M	Larynx	Retired Military	With Wife	NO
3	58	F	Rare Vascular	Business Manager	Alone but met Husband	NO
4	65	M	Colorectal (Liver Mets)	Teacher	Alone but met Wife	YES
5	59	M	Colorectal	Teacher	With Wife	NO
6	55	F	Breast	Unknown	Alone	YES
7	66	F	Colorectal	Retired Radiotherapist	With Husband	NO
8	54	F	Colorectal (Ovarian Mets)	Supermarket Worker	Alone but met Partner	NO
9	49	F	Breast	Civil Servant	Alone but met Partner	YES
10	70	F	Colorectal	Unknown	With Husband	NO
11	76	M	Pancreas	Retired Military	Alone	YES
12	46	F	Breast (Bone Mets)	Office Manager	Alone	YES
13	59	F	Pancreas	Librarian	Alone	YES
14	76	M	Rectal (Abdo and Bone Mets)	Retired Engineer	With Wife	NO
15	62	F	Colorectal	Unknown	Alone	YES
16	58	F	Colorectal	Teacher	Alone, Daughter in room	YES
17	70	M	Colorectal	Retired Military	Alone	YES
18	59	F	Breast	Teacher	Alone	NO
19	50	F	Colorectal (Liver mets)	Teacher	With Husband	NO
20	61	F	Breast	Teacher	Alone	YES

All interviews were digitally recorded which was helpful during the interview when the researcher needed to focus on what the participant was saying, rather than on taking notes, and also during analysis when the interview could be revisited in order to clarify, repeat or confirm what was said. This contributed to dependability of the data; a requirement of trustworthiness in qualitative research (Koch, 1994).

The researcher also kept a journal to record post interview observations relating to the context of each individual and overall impressions of their

body language and demeanour. It was important not to suspend anticipations or presuppositions about participants' situations influencing their experience; a necessary position when using interpretive phenomenology. Seeing people in their own homes with photographs telling a family history, pets and books representing life interests and hobbies, and general homely mood were essential components of understanding others' experiences of illness and treatment. These were interpreted and recorded through the researcher's own personal and professional

frames of reference, in this instance, as a daughter, sister, partner, nurse, midwife, educationalist – but most importantly as someone who also has experience of being alongside close family members on their cancer journeys.

4.3 Analysis of Interview Data

Interviews were transcribed by an independent transcriber who had a contract with the NHS Trust and was bound by a duty of confidentiality (Data Protection Act 1998).

The first part of the analysis involved three readings of each transcript; the first to remind the researcher of the participant and highlight all the data relevant to the study aims. At this point the researcher tried to imagine being with the person during the interview. On second reading, codes were assigned to the highlighted material; sometimes to words, parts of sentences or whole paragraphs that could not be split. Sometimes the data were co constituted between the researcher, participant and their spouse, and all the relevant material was coded. The third reading facilitated the allocation of codes to new or existing categories. No new categories were generated after participant 16.

The researcher compared and contrasted data sets from different participants in order to identify unique and common experiences. A raw data pool was created to store exemplary statements to represent categories, and the researcher was able to justify to an independent colleague why any particular quote was inserted into a category. Congruent with phenomenological analysis (Jasper, 1994) all statements were seen as contextually bound, and the language of the participant in each instance was preserved. A composite list of categories from all the interviews was developed by the researcher and then themes were created from this list. During thematicizing, categories relating to each other were grouped. Sometimes the transcripts and recordings were revisited to check the context of the excerpt to make sure they had been allocated to the most appropriate theme. Undertaking the analysis manually enabled clear visibility of all the emerging themes because of the quantity of codes assigned to them, and those who contributed to the theme.

Whilst these findings are not generalisable, themes that represent this sample's experiences may be transferable to other similar populations.

4.4 Ethical considerations

Gloucestershire Research and Development Support Unit (RDSU) was involved in all discussions relating to the research. The Research and Development Coordinator and the Statistician were members of the Project Steering Group who met throughout the planning stages. Regular interim meetings were also convened between the researcher, the R&D Coordinator and Statistician with other personnel central to the research, for example, the University Finance Department, the Trust Finance Managers and the Department of Patient and Public Involvement. The Research Steering Group comprised representation from areas affected by the MCU Service; In addition to the 2 R&D members, a Trust Service Manager, 2 User Partners, 2 Consultant Oncologists (one is chair of the Chemotherapy Group, the other is Medical Director for Cancer Services and has been liaising between the MCU Research Project Team and the Oncology Clinicians with regard to project developments), a Chemotherapy Clinical Nurse Specialist and the Divisional Lead Nurse for Diagnostics and Specialities (including Oncology) were also members.

Participants' identities were protected by using a coding system that identified transcripts and records and therefore assured anonymity.

All data were kept securely in the researcher's office at UWE with only the researcher and R&D Coordinator having access. Computers are password and firewall protected and portable files have been encrypted in an effort to minimise any risk arising from loss.

5 Findings

The findings are presented as a process through 3 main themes; Pre chemotherapy experience, the process of receiving chemotherapy, and reflections upon the chemotherapy experience. Within those 3 main themes sit the 22 sub themes housing 134 categories (Appendix 3). Participants will be referred to as P1 – P20. Raw data quotes will be presented to illuminate the sub themes. Although these do not represent all participants they may provide insight into the range of views and experiences of participants.

5.1 Pre chemotherapy

5.1.1 Symptoms, seeing my GP and diagnosis

Although some participants talked at length and were descriptive about their symptoms, such as a dull ache, diarrhoea, constipation, loss of appetite, flatulence, lumps and bleeding, some had no symptoms suggestive of cancer at all. Those who did appeared reluctant to act immediately on a suspicion that they might have cancer, preferring to wait to see if and when the symptom would subside. Others went to their GP but had no idea that it might be cancer:

"Look Doc, there's something wrong here. I'm getting this pain in my solar plexus, there's definitely something wrong with me. I didn't even think of cancer at the time" (11.3).

P13 had a protracted diagnosis from the GP due to lack of detail about symptoms:

"I started feeling strange feelings in my tummy. Nothing specific and it wasn't really pain, just a strange feeling. I went to my GP and he did some blood tests and he just said that it was probably an infection as I'd had an infection about a month previously" (13.1).

For P15 the diagnosis of colorectal cancer came as a complete surprise, having had no symptoms. She was called for routine bowel cancer screening and within a week received a diagnosis of cancer and an appointment for a colonoscopy:

"It was a roller coaster of appointments. You're sort of bundled along and you don't have time to stop and think.

(TM. And you weren't feeling unwell at this time? No symptoms at all?)

Absolutely none" (15.1, 15.2, 15.14).

P9 was swift to act after finding a small lump in her breast. She decided to have a private consultation and proceeded to undergo a fine needle aspiration. She received the diagnosis of

breast cancer two days later. She had had only one episode of a sharp stabbing pain in her breast.

Others, despite having quite significant changes to normal bodily functions, denied the possibility of disease by blaming the ageing process:

"I kept having to run to the loo and I just thought it was a stomach upset or something to do with my age so I ignored it for a little while. Then I went on holiday, I was very fit and went to the gym and drank lots of water and it seemed to sort of ease a bit. Then when I went back to school I had to keep running to the loo and I was getting to the point that when I went out I wanted to know where the loo was and I thought I can't live like this, this is interfering with my life" (16 16.1).

Even those who suspected that something serious was wrong with them acknowledged that they had left it too long before seeing their GP:

"I couldn't go to the toilet and however much I strained I thought I was going to burst some blood vessels and it was that painful. Nothing was happening and I thought there's got to be something serious. I lost my appetite and it got worse and worse. I should've gone to my GP a month or more before" (17.1, 17.2, 17.3, 17.4, 17.7).

These data quotes illuminate the range of experiences regarding symptoms and participants' reactions to them.

Participants chose to consult their GPs at different times depending upon the severity of symptoms and how they affected quality of life. Participant 5 felt that his GP did not have enough knowledge about colorectal cancer and was frustrated that it took a long time for him to refer P5 to the appropriate surgical team:

"He wasn't sure whether to fast track me for bowel cancer or whether there might be another cause ... he thought it was most likely to be a swollen prostate ... he asked if I would undergo a second test with his partner GP. She began tests for prostate cancer. Neither of them seemed sure. I really feel that either there should be clearer diagnostic tests for GPs or they need more diagnostic training on those tests. ... it cost two months more time" (5.9 – 5.13).

In contrast some GPs reacted quickly to get participants on the right pathway for the suspected cancer:

"I went to the GP and explained all this to him. He thought it wasn't anything to worry about but he didn't want to be the one to quote 'miss an early breast cancer' so he put me on fast track" (20.4, 20.5, 20.6).

And personal consideration was appreciated:

"When I was diagnosed he phoned me up specifically so say if you or your partner want anything don't hesitate just make an appointment" (9.109).

Generally participants did not revisit their GP until treatment was completed because they had been under the care of surgical and oncology teams:

(TM – How was your GP throughout treatment?)

"I've never seen him. Since he diagnosed me I haven't seen him" (16.80).

"He's taken a back seat, but that wasn't a problem. I needed to be signed off work so I knew my GP was getting reports from Cheltenham and those reports were forming the basis of him signing my medical certificates. I didn't need to see him" (18.90, 18.91, 18.92).

P9 was the only participant to have commented on the continuing support of her GP:

"He's been fantastic. He was a star actually and then since then I've been going every day virtually for either a blood test or to see him. He's quite involved even though the chemotherapy has finished he's still keeping an eye on things" (9.183, 9.184, 9.185).

For the participants in this study the GP was pivotal in recognising and acting on patients' descriptions of symptoms or suspicions that there might be a tumour. Once in the referral system from the GP to surgical teams, preliminary diagnoses were confirmed by a raft of tests which appear to have taken place within days of referral:

"My GP sent me straight off to get checked out. I had a liver scan and bone scan. Yes it was cancerous. My bone scan wasn't clear so they thought probably I had secondaries in my bones" (12.4 – 12.9).

"He got me a colonoscopy within a few days because I think he picked up what it was" (5.27).

"I went to hospital but they sent me to the out of hours GP who admitted me that Saturday night. I had an xray the same night. It wasn't until the Tuesday that they put me down for a CT scan and then they found a cyst on my ovary" (8.4 – 8.9).

"He sent me direct for a blood test and the following day straight up to get a scan" (11.5, 11.6).

"I got in within 10 days and saw the surgeon who did an internal and confirmed there and then it was cancer. I was allocated a nurse, and then you have scans, I had an MRI scan and a CAT scan and a colonoscopy" (16.5, 16.6).

The time between P4 sending a specimen to the bowel screening programme and tests was considerably longer:

"I just decided to pick up the bowel screening for over 60s – from actually contacting them to going for the screening was quite a few months, and then I had 2 or 3 tests, one which showed things were clear and two that showed there was a problem and then I was sent for a colonoscopy almost on that day" (4.1 – 4.4)

And in situations where the GP did not immediately suspect a tumour and subsequent tests were negative, the diagnosis was further delayed:

"I think he tested me for gall stones and various other things, I can't remember. This went on for weeks and weeks and weeks. He sent me to a gastro specialist and they couldn't find anything and then they decided perhaps it was best to go for a scan. I had an ultrasound and that didn't show anything up. They gave me a gastroscopy and that didn't show anything either. I was already thinking I'm pretty sure that I've got cancer. I already knew. Eventually I had an MRI scan and that showed something on my pancreas and they thought there was something on my liver as well ... I had no idea what the effect of the biopsy was going to be, and I thought that I would only be off work for a couple of days and I was off for 6 weeks" (13.4 – 13.14).

Once a diagnosis of cancer had been confirmed participants conveyed their feelings of shock. For example:

"I have never felt anything like it in my life. My whole body went cold. Stone cold from the shock" (20.22).

"It was quite a bombshell" (19.43).

"I took a couple of weeks off to come to terms with the shock" (12.53, 12.54).

"I went for a colonoscopy and I mean very quickly they sort of said sorry but there is a big problem, there's a growth in your bowel, we're admitting you now. (TM – What did you think?) Just shock" (4.9).

"It was a huge shock. I mean I can't remember the doctor's name because, I mean, you're not expecting that news, you know" (8.14).

5.1.2 Consultation with medical personnel

Participants had a variety of stories to tell about their interface with medical personnel. From doctors being abrupt in their approach:

"My consultant, I'm told, is one of the best but they could do with a bit of work on bedside manner – they're a bit brutal. There were a few things that

upset me hugely. They didn't want me to have surgery ... I felt very much like they had written me off (crying). I still find it difficult to deal with" (12.109).

to feeling that they were not receiving the right attention:

"Well I went to my appointment and he was mid sentence coming through the door saying 'I don't know why you've been sent to me'. His report didn't come back to my GP for another 4 weeks" (5.21, 5.24).

Seeing different doctors caused the patient experience to be disjointed and frustrating:

"Most of the time it was one of the doctors, which I understood, but I would actually have to say, always the first five minutes of any of these meetings was me bringing the doctor up to speed because they hadn't had time to read the notes before they came in the door. They were hard pressed just running from one patient to the next and if you asked a detailed question they would say excuse me and go and consult someone else" (4.108, 4.109).

"I go to see the consultant every fortnight but you never get to see the same one. You don't get time to ask questions – they don't even look up sometimes" (8.41, 8.42, 8.43).

Participant 1 conveyed how she felt about a shocking consultation after a course of chemotherapy:

"He said 'you're not responding to the chemotherapy' and I thought oh God, you know, he said 'very few people don't respond to it, about 2%, and you're one of them'. He said 'if you don't have more chemo you could be dead within a year'. No subtlety at all, he said 'we'll have to work something out but your tumour is growing rapidly'. I went to sit in the waiting room thinking oh God. He was lucky I didn't freak out because a lot of people would have done. About half an hour later he put himself down next to me [in the waiting room] and he said, 'just looked at your MRI scan, the tumour's shrinking nicely'. What he'd done was he looked at the 2 CT scans that had been taken before I was diagnosed. He'd made a mistake – he'd looked at the wrong scans. He didn't apologise." (1.162 – 1.170).

At the point of being told their cancer diagnosis participants talked about how they received the bad news from doctors and 'being told straight'. As expected, some appreciated straight forward, clear and honest description of their condition and prognosis. Others thought that the delivery of bad news could have been better, and that more discussion about treatment should have ensued:

"He [the surgeon] is a concise man, I have a lot of respect for him" 5.37).

"He explained to me what it was; everybody was very good, very methodical, very good. They told me straight away that it was a tumour and it was cancerous" (19.7, 19.8).

"I wasn't very pleased with the way I was told, because the doctor came along, he didn't ask if I wanted anybody with me, so he told me on my own and then he gave me his mobile phone so I could ring my husband to come to the hospital – after he had told me" (8.10).

"I was put under Dr ... Nice lad, nice fella. Talked to me straight" 11.11).

"[The surgeon] didn't introduce himself he just said hello, came and sat down and looked at my notes and he said 'well we're not sure if it's so and so cancer' or whatever and I thought well you haven't even told me it was cancer (13.43). I'm sure he was a good surgeon but he didn't have, you know, how to deal with people (13.46). I thought just talk to me, I'm not a fool, I know what the odds are" (13.51).

One participant mentioned having difficulty understanding terminology:

"Some of the others had used different language to say the same things – 2 secondaries which hadn't been used before – I had been told 2 lymph nodes had been affected but I didn't actually know if it meant 2 secondaries" (5.61, 5.62).

And another was distressed about the implication of what was said:

"I said to him that the pumps don't always work and he said 'oh well it doesn't matter in the scheme of things'" (19.103).

Participant 9 challenged the decision of the surgeon who wanted to perform a mastectomy. P9 and her partner engaged in discussion with the surgeon and they came to an agreement:

"She could obviously see I was struggling with the decision; I was looking at my partner just thinking how are we going to do this? – when she said, let me have another look. And she said I'm going to try something on you – just remove the tumour, however, you must understand that if I have to take away the nipple as well I will, and at a later date if it's not successful, have a full mastectomy. So that was our plan" (9.30).

5.1.3 Information

Generally the decision to have chemotherapy was made by medical personnel with minimal choice given to patients and their partner/spouse.

Five participants mentioned the Internet as a

source of information about their particular cancer and chemotherapy. Two said they avoided looking on the Internet because it might freak them out and become depressed about what they find out:

"I did a bit of research and that was totally negative – I shouldn't have done that" (16.10).

And Participant 19 said:

"I just wondered if there was any advice or an alternative, something like nutrition, whether that would help or not. I got so confused on the Internet" (19.146).

Only one participant said anything about pre chemotherapy preparation:

"I had a talk with the preparation nurse. Everything done that week was straightforward and clear" (5.46).

Information about chemotherapy and the process of receiving it was picked up as participants progressed through treatment cycles. Some gleaned information from other patients in the waiting area of clinic, others had friends who had had cancer and chemotherapy with whom they discussed their care and treatment, others preferred to discuss issues with their spouse. Many obtained specific information from the nurses giving them treatment:

"There's a lot that was written and people had spoken a lot and I suppose in the end it's almost too much and then everyone you see who has experience of cancer give you ... they relate what's happening to them" (4.42).

"I think in the early days perhaps, information was a little bit confused, when I think about it, I think that's true isn't it?" (Husband 19.145).

A couple of participants commented on fact/information sheets available both from their GP and the hospital:

"The fact sheets, which are very good, do say possible side effects, you may get them or you may not, so I was very apprehensive about that" (3.6).

"Well one of the nurses, it was one night when I was still in clinic at half past nine and I said this you know, and she said what about the chemobus. I'd read about the bus but the leaflet wasn't that informative" (16.51).

Five participants commented about the information board in clinic. During building work in clinic the board disappeared and was a cause for concern for several patients who wanted to know how long they would have to wait for treatment. They often were unable to get any information from reception or chemotherapy administrative staff about length of wait. This

information had previously been estimated and displayed on a board in clinic:

"Before CGH was extended, we used to have electronic notice boards and they told you if clinics were running late. In April when I went there, nobody told you anything, nobody told you that the clinics were running late. So I would go to reception and I would say is the clinic running late? – they said well we don't know, so I said well can you find out for me? I asked what happened to our electronic boards, she said we still have them, I asked why they hadn't been put back up on the walls? She said I don't know but I'll find out. I wrote an official letter asking if these boards could be put back up. From a patient's perspective it has been so frustrating (3.26 – 3.37).

"There used to be this electronic thing – that again isn't good enough, we take the mickey out of it. The doctor said it's the responsibility of the nurses to do that [inform patients about delays], I don't think that should be their job. It should be someone senior, maybe the senior nurse on duty that day, someone of significance" (4.114, 4.115, 4.116).

"There used to be a sort of lit up sign above reception" (Husband 7.128).

"I expect they found it too depressing" (7.129).

"It's back up there now. Yesterday it said chemotherapy's running an hour late but it was running two hours late" (Husband 7.130, 7.131).

5.1.4 The peri operative period

All participants in this study had surgery. Participants 16 and 19 had chemotherapy or radiotherapy prior to surgery with the intention to shrink the tumour. Those who had a diagnosis of cancer without any symptoms of it were shocked by the prospect of having surgery. Post surgery chemotherapy was daunting to some of them. Participant 14 however, appeared intrigued by the whole process:

"I mean this sounds stupid I know but to me it was a new experience. I've never been in hospital before" (14.17, 14.18).

"All quite interesting" (14 Wife 14.19).

"An adventure?" (TM).

"Well almost (14.20).

"I can find better words!" (Wife 14.21).

In contrast Participant 8 found the process traumatic. She thought that surgery would remove the cancer, only to be told that it could not be contained and there was no cure. Surgery had been immediate after diagnosis of colorectal cancer and when she returned home from hospital she felt there was a lack of support:

"Coming home from hospital there was nothing in place. I had to do the stairs to get to the toilet so I had quite a few accidents obviously. I needed people to talk to. I had to go to bed before my partner went to work on nights. I couldn't get myself ... it was just too much" (8.20).

Participants clearly articulated their surgical procedures impressing upon the researcher how they were developing into 'expert patients'. Through these articulations it became clear that they had sufficient understanding of the implications of the surgery and possibilities post operatively.

"I had a partial colostomy, ileostomy. Mr ... assured me that he has cleared all the cancer out. He said you can either say yes or no to this but I would suggest that you have a session of chemo just to ensure that if there is minute particles we'll kill them. I mean I would be a fool not to take that option up. But of course, when you're having chemo you get rid of the good cells as well as the bad cells and you've got to start all over again. So I took that on board and I will say that it was explained to me in very fine detail, the pluses and minuses that could happen. So that you're fully aware of what's going on, which is very, very good. It's not the secret society like it used to be" (17.19, 17.20, 17.21).

"It was the sigmoid section – they'd taken out the sigmoid colon but it was more than they expected – it had gone beyond the colon wall and there were two lymph nodes affected and you know, the blood supply vessels were strongly in place so they removed all that as well. They took out twenty something nodes and the tumour. They did take time to be as thorough as possible and I think he was trying to tell me afterwards they do believe they've taken all the cancer out, but of course, once it's beyond the colon and it's in the blood and lymph nodes ... that's why I had to have chemotherapy" (5.41 – 5.45).

The post operative period was difficult for some participants who were trying to come to terms with altered body image;

"The lowest point for me was coming out of hospital after the mastectomy. Fitting myself with a prosthesis that didn't look right. I say fitted myself ... I was given a selection of ... and that was that, that was the only point in which I felt actually I looked like a pantomime dame, and that was a low point (18.75 – 18.78).

Participant 14 had had surgery several years previously and was used to living with an ileostomy whilst still having chemotherapy:

"It was 7 years last July since the operation. I've had the odd accident you know, but you just learn to live with it. We're going away next week for a couple of days so we just throw my bag of tricks in the back of the car. If we're going, say, on a plane then I would, you know, put lots of bags in the suitcase and then carry another shoulder bag" (14.28, 14.29, 14.30).

5.2 Receiving Chemotherapy

5.2.1 In it together

Whilst collecting data in participants' own homes the researcher observed the togetherness of participants with their partner/spouse during the cancer/chemotherapy journey. Often the partner/spouse contributed to the interview, and participants would use collective terms eg. 'we went for tests', 'we had to wait', 'we saw the consultant':

"If we did a lumpectomy what about reconstruction?" (9.56).

"That's interesting, you just said if we had a lumpectomy" (TM).

"I think that's because my partner's there, I was talking about the two of us" (9.58).

"He always says things like 'oh you've done really well' and I'll say back 'and you've done really well too'" (9.58, 9.59, 9.61).

There was evidence that when the participant was low in mood the partner/spouse would make efforts to pick them back up and vice versa:

"I think I've found myself treading on a knife edge because I don't want to encourage him to do what will be detrimental to him but on the other hand I want him ... he's the sort of person that's got to be stimulated by things. If he sits around and flops in bed he would be a miserable old git" (Wife 14.69).

"Can we have that rephrased on the tape?" (14.71).

"We'll put MOG!" (TM).

During the interview couples co created data; finishing each other's sentences, confirming or refuting what the other had just said, and using terminology familiar to both:

"You have to be together don't you?" (Wife 14.57).

"Yeah, I mean it's a joint thing – so we're just rolling on with this trial"(14.58).

"Which has been marvellous" (Wife 14.59).

"It has suited me much better than the COIN trial" (14.60).

"The combination is so good that he's normally ... eh you know at one stage even since this trial he's been on ... you had a few days during the thing

where you stay in bed and say oh God I feel awful (Wife 14.61).

"But that seems to have stopped" (14.62).

"That seems to have stopped, he just feels tired" (Wife 14.63).

Significant others can accompany their relative whilst they have the first treatment, thereafter they are asked to sit in the clinic waiting area, go home, go into town etc. Participants made decisions about whether or not it was appropriate for their partners/spouses to be with them:

"He didn't want to be involved in that bit, it would really distress him; not just seeing me being treated but seeing others. It was a joint decision really – I'm better off on my own. I don't need to worry about him – well he's been a huge support in all other areas of my life and I know it would upset him" (20.56 – 20.62).

About partners/spouses accompanying relatives to have treatment:

"She had sympathetic employers – she didn't ever have to take leave. Basically people knew why she was off, her boss knew why she was off – he was sympathetic" (18.48).

"Financially it does have a cost because I've given up working" (5.80).

"During that time I retired – I mean it was the only way, P7 wasn't well enough to look after herself so I just took early retirement" (7.29, 7.30).

Some participants commented that their families were concerned about them having chemotherapy alone:

"My family were insistent that I didn't go to chemotherapy on my own.

In turn, participants expressed concern about significant others, in particular their children;

"We told the family from the start that I had cancer – I told my daughters the day I had the diagnosis" (18.22, 18.23).

"I've been married before and my husband died of cancer 14 years ago so I had to break it to my youngest daughter that I had cancer" (8.38).

"I hope in some ways it's easier for them, you know sometimes I say something about, you know, I may not be here. They say 'oh mum' and I say well that is the reality of it and it's silly to pretend it's not going to happen even if it doesn't happen soon, at some point it will happen" (13.65, 13.66).

"The upset isn't just for yourself it's for your family, you know, the one thing I feel awful about is that my husband and my daughters have to cope with this." (20.137).

Participant 6 also conveyed her concern for her daughter and family who had recently moved in with her. P6's husband had died the year before and she had looked after him. She was worried about the impact of her cancer diagnosis on her daughter and the prospect of losing both parents within two years.

Although friends were talked about by participants, it was often to say they were either very helpful or very unhelpful. They were perceived as being unhelpful when they compared participants' experiences with other people they knew with cancer.

5.2.2 Travelling and parking

Sixteen participants talked about travelling to CGH for treatment. The cost of driving to the hospital, usually with a partner/spouse, was estimated in time and distance. Often a partner/spouse or family member would drive because participants reported sometimes feeling unwell and not fit to drive any distance home. In fact Participant 6 had two small accidents in her car involving other vehicles both times on her journey back from having chemotherapy. Another commented:

"After you've had chemo you just, I'm sure it's psychological I can't think it's physical at this stage, but psychologically you just feel very very fragile and a bit frightened" (20.91).

"My daughter took me because when I come back with the pump I'm not that comfortable driving in case I get caught and because of the chemo effect I'm not quite sure how I'm going to be" (19.74).

For these reasons ten participants in this study said that they always liked someone with them who could drive them to clinic and back.

Participants who lived in Cheltenham sometimes used public transport but were afraid of being ill on the way home. Participant 3 commented about the hospital car service finishing their day at 15.00hrs. As patients are often still receiving treatment at 21.30 this arrangement is clearly inadequate:

"My husband always takes me: I know I'm eligible for transport but they go round picking everybody up and then you have to wait until everybody has finished. The Gloucestershire Ambulance Service, their contract I think is from 8 in the morning until 3 in the afternoon. I mean the hospital paid around £90,000 in taxis last year, One of the things the PCT is looking at is getting their contract extended until 11 o'clock at night" (3.81, 3.82, 3.83).

"I had a taxi, even though I had a ticket to say I could have free parking, unfortunately by the time

I was getting there, there was no free parking at all" (17.28, 17.29). "Then of course you wait for the taxi which can be anything up to an hour or an hour and a half before they pick you up but you have to expect that. They've had one or two hiccups when they've obviously forgotten I was here" (17.40).

"It is a whole day – an hour transport from here to Cheltenham, that's by car from door to door. You can never tell with the A48 so we always leave an hour and a half. We leave here at ten and get back at half past six" (7.50 - 7.55). ... I mean transport, they do their best but you'd have to wait, I don't know how people cope I really don't" (7.135).

"It was expensive in terms of fuel" (5.91).

"It's a forty plus mile drive from here" (18.30).

"It's thirty miles to Cheltenham. Bad in the winter. He's 75 so he finds it, you know, a lot really, and then he sits up there with me, and that's another story!" (10.21, 10.22, 10.23).

Generally participants reported that if they drove to CGH they could usually get a parking space free of charge.

"Parking has improved because they have put another 20 slots in for oncology patients" (3.86).

"There was always a parking space" (5.92).

"Parking is fine (Husband 7.56).

"The parking is very good; they give you allocated parking tickets" (7.57) "for oncology" (Husband 7.58).

"You can have a patient's permit if you're having treatment, so I did manage to get that and I think it was quite well advertised" (9.166).

There were a couple of exceptions:

"Parking was an absolute wow of a problem. You're paying I think £2.80 for 2 hours, you know, when you're not keeping to your timing it's not £2.80 at all – you're talking £10 and £12" (11.17, 11.18).

"Parking was very difficult which didn't help because I thought I was going to miss my appointment. Eventually we did find a place to park but I'm not sure whether we should have parked where we did but we shoved a parking ticket on and I thought right now I don't care" (20.69, 20.70).

5.2.3 Waiting for treatment in clinic

All participants made a significant contribution to this sub theme, the largest in the study. Small excerpts of data have been extracted from each participant's data to represent the enormity of this problem. This single, most talked about irritation impacted upon participants and was

inextricably linked to requests to have treatment on the MCU. Each participant told a story around the issue of waiting in clinic but it is outside the scope of this report to present them all. Most participants said they either read, slept, did some knitting, talked to other patients or just wandered around. The voluntary helpers were appreciated.

"The main problem was the waiting – 5 hours was the longest but that was two or three times I waited 5 hours. I noticed that the people in the waiting room were as stressed as I was. I remember there was a woman crying one day with the strain of all the waiting, and any time I mentioned it to staff they said well we have too many patients and too few staff and if you want to write a complaint then we think you should" (1.12, 1.13, 1.14).

"You've got 2 or 3 hours sitting around" (2.39).

"I had my chemo the next day at 4 o'clock – except it wasn't 4 it was 6.45 and I didn't leave hospital until 9.15 at night" (3.25). "The clinic runs late 2 ½ to 3 hours regularly" (3.47). "Some days it's been fourteen hours for me" (3.51).

"I would look and see much older people there sitting around for 4 or 5 hours, without a cup of tea, without eating, those sorts of things" (4.63).

"The only part of the routine that was very disappointing was the amount of waiting ..." (5.68).

"And when you don't know how soon you're going to be called the anxiety just builds and there's an atmosphere in the room with other people in similar situations" (5.71).

"I remembered the same long waits with my husband. He died of prostate cancer last year and we had the same long waits here (6.37, 6.38).

"Two and a half hours late is the norm" (7.69)

"When I got there they were running an hour late. That went to 2 and a half hours so I did not get home until quarter to 9 for a 2 and a half hour treatment, and it's the same every week (8.58).

"So for the first session I actually waited for 4 hours and 15 minutes in Cheltenham General. I did ask twice and said have you still got me down? I was told yes it's fine. I then went to the receptionist and said is everything ok, you know I'm here, and she said yes, yes it's fine. When I went in they said I'm sorry you wouldn't normally have to wait 4 hours and 15 minutes but we didn't know you were here, which I thought was a bit strange as I asked 3 times and they said there was a bit of an administrative error" (9.118, 9.119, 9.120).

"Surely someone could ring up and say look we're running 3 hours behind don't come in at 2 o'clock come in at 4" (10.49).

"The delay in the schedule would sometimes be out by 4 or 5 hours. I mean when you're sitting in a room which is closed in, without a window, with about 50 wrinklies, 50 old people, or young people as well when you look at it – we're all dying, we're all waiting for chemo, some sort of treatment and the schedule goes to pot, which it did every week. I was never seen on time at any time during the 27 sessions of chemo" (11.18, 11.19, 11.20).

"Sometimes I just sat there but on the whole we went into Cheltenham and we window shopped. It's completely destroyed Cheltenham for me because of the associations. I don't like it. Sometimes we would get called back quickly, other times it would be hours and hours and hours. The waiting room was always heaving, absolutely packed to the guns" (12.42 – 12.48).

"We had to wait 2 hours before we saw anybody" (13.104).

"I drop P14 off and go and do some shopping and maybe meet friends for lunch, or go and visit a friend, and then when I go back he's still in the waiting room. It's just quite difficult to know so sometimes I hang around and sometimes I come straight home and just go straight back when he calls me" (Wife 14.110 – 14.114).

"The trouble with sitting in the waiting room is that it is so exhausting you're doing absolutely nothing" (15.40). "Having to sit around for hours in Cheltenham just really gets on your top note" (15.65).

"I was hanging around for 3 hours before I was called in, apart from the first session which was the quickest" (16.38).

"They're quick in you going to see the consultant; they're quick in taking your blood, and then you wait, and wait, and wait" (17.36, 17.37). "I just write off Friday, I think that's it, you can't do anything about it" (17.46).

"It might have been as much as 3 hours but I wouldn't swear to it" (18.44).

"That's what I don't understand, I don't know what time they start I don't ask them why they are running so late all the time" (19.66). "It was quite funny last time because everybody was cheesed off to have to wait so long, so we were comparing our appointments, you know, what time was yours; 2 o'clock, what time was yours 2.30 and so on. Then this lady said well surely mine has got to come up soon, anyway a nurse came and called this lady and we're all cheering hooray I'm in!!! It was like her number had come up, you know, it was quite funny" (19.140, 19.141, 19.142).

"We waited together maybe an hour and a half and then when the nurse called me through she explained to him how long I was going to be roughly, and made sure we had his mobile phone number just in case.." (20.77, 20.80).

Although some patients were offered a paging device so that they could be contacted when their treatment was ready, those who mentioned it said they were unlikely to use it because they were afraid that they would 'miss their slot'.

Four of these participants had made a formal complaint about waiting in clinic. The remaining participants had made it known at some time during their treatment journey, either to clinic staff or to reception, that the time they had waited in clinic was unacceptable.

5.2.4 Speculation about why they had to wait so long

Participant 3 was told that expensive chemotherapy treatments were only prepared the morning of the clinic because if a patient did not attend the treatment was wasted. Also that if expensive treatments were stored overnight and the refrigerator broke down the treatment would also be wasted. She replied, "Why don't you alarm the fridge?" (3.46).

Several participants, having observed the running of the clinic on many occasions, believed that it did not run to capacity or optimize the time in each chair:

"I don't feel that each day was actually working out the best use so there were lots of people maybe needing 2 hours of treatment, other people need 1 ½ hours, some people need 30 minutes and if that was mapped out in some way or other they might get better use" (4.75).

Participant 7 and her husband commented that if the treatment was not going to be ready for the patient until 10.00 then patients should not be asked to come in before 10.00. Both extolled the efforts of the nurses and the way they coped in what participants perceived to be an impossible situation:

"You couldn't fault the staff it's just that it doesn't seem to be very logistically organised at all" (7.78).

"All I can say about it is it just needs leadership. I don't call any of the nurses to task, all I say is they are not being directed, it's the operational staff" (11.78, 11.82).

Others recognised that often the day could be disrupted by adverse events:

"They might just say 'we're running late' and I can understand that because somebody decides they're

going to throw up half way through or a vein blows or something, and you're stuffed" (15.42).

"I think because they've got so little slack in the system if one patient has a blip or something ... The nurses have to attend to it and then it's all, you know, out of sync" (16.94, 16.95).

5.2.5 Feeling anxious

Participants who expressed feeling anxious, frightened, insecure and apprehensive contributed to this sub theme. The only person who appeared not to be anxious was Participant 9 who 'took it in my stride' and viewed the process as a challenge to be met and that there could only be one outcome – recovery. She did not waiver from her positive view of the future and explained how this mental attitude had carried her through the cancer and treatment trajectory.

"I only felt like a poorly person when I went to Cheltenham Hospital" (9.148).

For this participant, not feeling like a poorly person meant there was nothing to be anxious about.

Not surprisingly some participants were anxious because they might die sooner than they had anticipated and had become reflective:

"I've had a lovely life and I'm nearly 60 now, and I've had a lovely life, you can see where I live. A wonderful place. I've got a fantastic husband, I'll be crying in a minute. I've got 3 smashing kids and 2 lovely grandchildren. People say 'it's not over yet' but I feel I've only got maybe 5 years if I'm lucky. I've had a lovely life and I couldn't ask for any more, really. Sorry. A friend and me went to a wedding yesterday and there were some lovely poems – and my friend who I was at school with, and we were sitting there just crying our eyes out" (13.60 – 13.64).

Others felt the need to attend to practical issues associated with their increased vulnerability:

"Certainly this weekend after ... death who was a neighbour who had been on treatment for a couple of years, you do get bouts of umm mortality. My sister in law fixed her own funeral and pre paid her funeral not quite a year ago, and there was something she'd written to me in an e-mail I printed off as I may need to wave it under my brother's nose about the arrangements. One ought to think about what you want. We really need to update those wills" (15.72, 15.73).

For participant 13 the anxiety related to what she had heard about others with the same cancer:

"I'd heard from other people that pancreatic cancer

is not a good one to get. When I first went to the doctors I thought I'm not going to look on the Internet because, we'll just let it take its course because my mind is going overtime. I read that pancreatic cancer, it says often you get nausea which I didn't, I haven't felt sick at all. I had also heard that pancreatic cancer does sort of creep up on people and I know somebody at work whose mother had it and the first she knew she had terrible pain in her back one day and then I think, about a month later she was dead" (13.29 – 13.36).

Others were more apprehensive about the chemotherapy than their illness:

"I was apprehensive because you don't know what to expect" (3.5).

Participants 5 and 13 said they were also most anxious at the beginning of chemotherapy. Participant 20 shared her anxieties about being told about survival rates, with and without chemotherapy, by the oncologist. She also talked about feeling insecure when driving the car and apprehensive in case she got stuck in traffic or if she felt sick. She disclosed that the physical effects of chemotherapy were horrible and yet the fear of the unknown made her most anxious. Whilst she acknowledged that she did not really understand what the unknown might be her following expression clarified to some extent what she meant:

"Just a feeling of being frightened of something you've watched, all this stuff being poured into your veins – what on earth is it going to do to you?" The first time it was more in my head I was frightened and upset and I think it was more the anxiety" (20.132 – 20.135).

5.2.6 The process of having treatment in clinic

The actual administration of treatment varied between participants but appeared to range from 20 minutes to 6 hours, with some attending twice or three times a week, others once a fortnight or every three or four weeks. Administration of chemotherapy was through intravenous or peripherally inserted central catheters (PICC lines), given manually or via a pump. It seems that all participants in this study had different treatment protocols which makes each experience unique.

One of the most dreaded part of the treatment process was having the cannula inserted, particularly if they had been sitting in the waiting area for some considerable time:

"On occasions the waiting room in Cheltenham is very cold, so when you get in to have your blood taken, have your cannula inserted, your veins have

disappeared. We keep asking them to turn the air conditioning down. It is 4 or 5 times regularly before they can find a vein, and you end up with lumps and bumps and bruises, and that puts you off going, it really does, because that's very painful" (3.77 - 3.80).

It appears that preparation of the patient prior to cannulation differs between nurses:

"On one occasion after about 8 weeks, I saw people with hot, hot sort of pads out of the microwave, and I said 'what are they for?' and they said that it expands the veins and makes chemo easier. And it wasn't until my fourth chemo treatment that I was given a buzzer. Chemotherapy number 11 I said could I have a hot pad on my arm and she said 'oh the microwave's broken' and another nurse overheard the conversation and five minutes later he came back with 2 hot pads for me and said 'I've managed to fix it' but I did wonder whether it was, she didn't want to do it" (3.121, 3.123).

"There are one or two people I think oh God no, please let me have the other one. But on the whole actually, they're great, I think the most attempts there's been is 6 to get it in, by this time I was throwing it open to other patients asking if anyone else wants a go" (12.81, 12.82, 12.83).

"When you first start you don't really know and you don't really care. By the time you've gone on the one thing you fear, you look at the nurses and weigh them up who's good with needles and who's bad with needles – oh no, not her again! I know the good needlers and the bad needlers" (11.41, 11.55).

"I've had bruises that lasted a fortnight. I don't want it to go in the same hands" (15.38).

"I hate the bloody needles, (laughs) I'd rather go a round with Mike Tyson, I said to them as soon as my veins see the needle coming they say OH NO. I always look away. They're all deep seated, you know. It takes some doing to find it to get in, but there again they're very very good; there's some that are better than others" (17.69, 17.70).

Others conveyed inconveniences with their PICC lines:

"That PICC line was troublesome" (Wife 14.43)

"I've had 4 lines in and I can remember every damned detail about all 4 – you wake up as the pump stops every 30 seconds. Thirty seconds is a long time in the middle of the night" (14.45).

Yet Participant 8 said she had had her PICC line in for 18 months without trouble. Participant 16 stated:

"They hit me with the chemo and first of all they put in a PICC line and that was quite

uncomfortable. I went for about 4 when I realised it wasn't working for me" (16.34).

"What, the PICC line?" (TM).

"Not the PICC line, the waiting around!" (16.35).
(Both laugh).

Although participants recognised that chemotherapy clinic staff were under pressure and one reported that the "system is sagging" (44.59 – 4.68), they also acknowledged feeling 'looked after':

"We had complete confidence in them at Cheltenham from the start. It's a temporary inconvenience in the light of this confidence you feel and we felt that we were getting the best treatment" (18.50, 18.51).

Some of the comments from Participant 14 were in stark contrast to most of the others in terms of the mood of patients in the waiting area:

"I've been going to oncology clinic 7 years or more – everybody I know, most people just laugh and joke – I call it the chemo club" (14.73, 14.74, 14.75).

Participant 8 suggested that food for patients receiving chemotherapy treatment in clinic should be free:

"I'm always glad when the day is over. I'm always starving when I get home because there's nothing to eat unless you buy it over there. You'd think you wouldn't have to buy everything" (8.142, 8.143, 8.144).

Others were more concerned about the temperature in the waiting area:

"It's blooming cold in there – it's freezing and that big room is worse still, but a lot of people complain about that don't they? It's cold, there's a lot of air conditioning that you don't really need. I don't know if it's air conditioning or air purifying. Everywhere you sit there's like a draught; there's air conditioning or something coming down from the ceiling" (10.86).

5.2.7 About the MCU

Nineteen of the twenty participants knew about the MCU and had heard what it meant to people who were able to have their treatment on board. Participant 14 however did not want to go on the MCU and had some definite opinions about it:

"Have you had the opportunity to go to the mobile chemotherapy unit?" (TM).

"Don't want it" (Wife 14.77).

"I don't particularly want it, I mean they did advertise it but I don't think it comes to Stroud" (14.79).

"I thought well it might be convenient and I made a few enquiries. During the time I've been doing this [Having treatment in clinic] I've seen 2 ladies who had an adverse reaction to chemo. There was this crash team of doctors and it's not very pleasant you can see people are really struggling, and I said afterwards 'have they just started on this' and they said 'no it can happen at any time' " (14.81 - 14.84).

"The mobile clinics are only staffed by nurses (14.85) " ... so I thought I would rather be in the hospital" (14.86).

In addition, this participant and his wife had concerns about the cost of providing the mobile service to 'one person per outing' and also worries about standards of hygiene:

"It's just not cost effective we're going into a period of austerity, you know cut backs and all the rest of it" (14.93). "It's crazy" (Wife 14.93).

"It doesn't make any sense to me" (14.94) "and surely there's a hygiene issue in the caravan do you think?" (Wife 14.94). "I wouldn't think so I think it's cleaned as much as the ward is cleaned – that doesn't bother me at all I just think on practical grounds" (14.96). "It's a waste of NHS money" (Wife 14.96). "Total waste of money" (14.97).

Other participants had the decision for them not to have chemotherapy on the MCU made for them. Participant 5 said:

"We were told our postcode would not allow us because it's as close to go to Cheltenham as it is to go to the MCU in Cirencester (5.99). But the idea that you wouldn't have to wait if you went on the unit" (5.100).

Participant 7 was unable to have treatment on the MCU because of various technicalities:

"I wanted to go to the Dilke ... it goes there on the Tuesday of every week ... you have to have a current blood test, now the trouble is that it becomes invalid after 48 hours. Normal procedure is that you go to see a doctor and get blood tested on a Friday previous to chemo in Cheltenham on Monday, but Tuesday at the Dilke means it's out of, it doesn't count anymore" (7.45, 7.46). "There were lots of little things that came together and so I am afraid I wasn't on the list and I said what a shame because people like it local, it's lovely if you can go because it feels sort of low key" (7.48, 7.49).

And Participant 10:

"So you never had treatment on the MCU?" (TM 10.56).

"No. Because Satuximat, they said no you can't because of storage, I suppose keeping it at temperature or whatever, or making it up I'm not

sure, so no I haven't" (10.57, 10.58).

For Participant 18 it was about consistency and confidence in the treatment he had received in clinic:

"Fairly early on I was told about the mobile chemo unit and the fact that I could opt for it if I wanted umm, I was told it was exactly the same treatment as Cheltenham, same nurses delivering it and so on and I completely understand ... umm the reason I didn't opt for it, and it isn't really logical, and that was simply because I was confident with the treatment I had at Cheltenham and it was the feeling of not wanting to put that at risk in any way, do you know what I mean?" (18.64, 18.65, 18.66).

The following quote from Participant 3 is an example of the disappointment felt by those who wanted to have treatment on the MCU but did not meet the criteria:

"I did ask if I could go on the mobile chemo unit ... there's not the waiting around that you get in Cheltenham General Hospital. Unfortunately, because Paclitaxel can give anaphylactic shock, it wasn't accepted on the bus ... because they haven't got the same kind of facilities that they would in a hospital, so I wasn't able to have it on the bus and I was sad about that because all the patients I've talked to who had it on the bus rave about it" (3.13 – 3.19).

Several articulated with great delight the difference having treatment on the MCU had made to them, for example:

"I was very, very pleased to get that opportunity to go, just in terms of the drive, it means as I say, a 5 - 8 minute drive whereas going to Cheltenham is a 50 minute drive and a 50 mile round trip (4.122). It makes you feel better so I was very, very happy to take the chance to go If the number of people to go is too few it can be cancelled" (4.125).

"Has that ever happened?" (TM).

"Not to me!" (4.126).

"I was very, very pleased to get out of that [clinic] and be given the alternative and get on the mobile because the mobile unquestionably is absolutely superb. I did learn about it, it was talked about within the waiting room" (11.29, 11.30).

When asked how the MCU could be improved participant 20 informed the researcher:

I'd certainly protect it because I think it's a wonderful thing and it just takes all the stress and anxiety and worry out of the whole process" (20.166).

Participant 12 had experienced some problems with arranging appointments to attend the MCU:

"A few months, maybe 6 months ago, there was obviously a little bit of a hiccup in terms of the organisation of appointments on the chemo unit because I actually wasn't being given appointments; every time they wouldn't have a new appointment sheet for me so I would have to ring to organise the appointments myself. It became a bit tiresome, but it seems to be resolved now (12.156).

5.2.8 Advantages and disadvantages of having chemo on the MCU

Participants commented about the short travelling distance to, and quick turnaround onboard the MCU:

"It was absolutely fantastic because it's literally 15 minutes drive from here. I arrived, knocked on the door and said 'I'm here' and they said oh we're not quite ready for you yet; you can either go and have a coffee in the [community] hospital or sit outside. So I sat outside, then 5 -10 minutes later they called me over and straight away I was dealt with, in and out and back home within 2 hours. It was amazing really, so much better" (9.130, 9.131, 9.132).

"I'm now on my 32nd chemo but I go to the mobile where it's BANG come in Mr ... , sit down Mr ... bump, ¾ hour and I'm out" (11.21).

"I usually have a 10 o'clock appointment so I leave here about half 9, twenty to 10. They're usually ready for me to go on the bus as soon as I get there, I have the treatment and I'm usually left there by 11. I drive myself, it doesn't affect me, it doesn't make me feel ill" (12.73, 12.74, 12.75).

"If I go to Ross-on-Wye I can leave here quarter of an hour before my treatment and get there, my treatment takes about an hour, and then a quarter of an hour back again" (13.105). "The longest I have had to wait for treatment is about 10 minutes or quarter of an hour" (13.107).

"... the other thing is that you were seen to, you knew what time the appointment was, straight in there, seen to, I was out within half an hour" (17.49).

Clearly the reduction in travelling time and efficiency of the process of receiving treatment on the MCU was appreciated by all participants who had their treatment onboard. Quality of life on treatment days was greatly improved for these participants because they were able to plan their day around treatment; having the rest of the day to do as they please meant that treatment was less intrusive and normality and routine was more easily achieved.

In addition to these advantages, participants also enjoyed the rapport that developed between patients and nurses:

"There's quite a friendly sort of atmosphere on the mobile, I mean, you get the same nurses coming here (13.117). I find it a bit more personal on the mobile" (13.121).

"It's nicer, I mean clinic is so busy, you have more time to ask questions [on the MCU] and don't feel like you're taking their time up. So I always like asking questions (laughing) (16.62). You get to know them, you get to know them better and it's more relaxed" (16.63).

"It was all so much calmer and less intense" (20.100). The first time the nurse was there with me and I felt much more able to talk with her and ask her questions about what was happening and, you know, the whole process because I didn't feel that she needed to be away doing something else with another patient" (20.102).

And between patients and the driver of the MCU:

"... the driver has an old radio programme on old 60s or what not and sometimes there's conversations about you know, shows from our youth" (15.54).

"The driver is there as well, you can talk to him" (16.59).

"The driver makes you a cup of tea if you want one. When you arrive he meets you first and checks you in. If you're early he walks you across to the main hospital building and shows you where you can sit and then gets you when it's your turn to come in" (2.163).

Participant 13 also brought to the researcher's attention that there is no natural light in the waiting room in clinic, whereas when she looked out of the MCU windows she could see a bank of flowers on it and week by week she could see it all changing:

"And you can see the sky and you know whether it's going to rain or not" (13.162).

Two participants discovered disadvantages of having treatment onboard the MCU:

"Well I suppose the only disadvantage, it's just that sometimes it doesn't go out because either they haven't got enough staff or sometimes there's not enough people; if there's less than 4 people to have chemo then it won't go out, which is understandable obviously. So sometimes you have to suddenly change your plans" (13.123, 13.124).

"The only thing, the one thing about the chemo unit I found difficult was the loo. Because of all these drugs I needed to rush to the loo, it wasn't compatible with my [colostomy] bag (laugh). So I learnt then I had to go to the loo in the community hospital straight before I went and straight after. But sometimes it was impossible; when they made

tea I didn't have any of that and sometimes, towards the end, I mean all the drugs just went straight through me. It was my bag just burst, blew up (laugh). But apart from that it was, you know, sometimes if you want to go to the loo it can be hard to move (laughter). But they were always very accommodating (16.65 – 16.72).

5.2.9 The environment

Because the MCU is a confined space with 5 treatment chairs in close proximity the researcher asked participants about privacy and dignity issues onboard:

"What about privacy...?" (TM).

"Well there isn't any" (12.140).

"Is that an issue?" (TM).

"No, not particularly for me but there tends not to be discussion about your individual case because you've already done that by telephone triage the day before with somebody. Some people have PICC lines that need cleaning out and so on, well they've got screens, they use screens. OK you are sitting as close as I am to you to somebody else but they certainly make every effort to respect people's privacy but also I think, actually most people have been there, they've done it all so many times that nobody cares" (12.141 – 12.143).

"Are there any privacy issues?" (TM).

"Well not really. I mean I get hooked up to the 5FU, you have to go through, ... umm as a patient I get used to knowing what to wear" (16.73). "I mean once I wore a dress and realised this was never going to work (laugh) um so I didn't mind that because it was so much worth it not to wait" (16.74).

Participant 18 was one of several who said that chairs were also close together in clinic:

"You're physically close to somebody you don't know. You couldn't just sit there and read, it would be rude if someone is literally 2 feet away from you" (18.57, 18.61).

About clinic Participant 20 said:

"All the treatment chairs were full" (20.81).

"Did you talk with other people" (TM).

"Nobody did, it was ... no it's different, the contrast between the hospital and the mobile unit is just chalk and cheese" (20.82).

5.2.10 About staff

Participants generally reported feeling supported by nursing staff who they said worked hard and who were recognised as doing the best they could in a very difficult situation, in clinic in particular:

"I've got a lot of time for hospital staff" (2.46), "the nurses have a lot to put up with" (Wife 2.47).

"I feel very sorry for the staff in chemotherapy outpatients because they are very under pressure" (3.126).

"... I felt the morale of the people working there was being damaged because they looked tired a lot of the time ... a shift that didn't finish until half past eight at night and all that sort of thing. I don't think it can be very good" (4.67, 4.68).

It was evident that participants felt safe in the hands of nurses and observed good practice, for example:

"The treatment nurses I did have respect for. They seemed competent, proficient and they got on with things. They went through the routines making sure they got things in the right order; it wasn't just the two chemotherapy drugs there were the steroids, the flushes, all sorts of bits and pieces to be done in a certain order with different bags hung and come through the pumps that had to be reset and all that lot" (5.104).

"The nurses are all so positive and matter of fact – there's no hand wringing and no shilly shallying around or tiptoeing around the subject – whichever cancer you've got they're very open, very efficient and you just feel as if you're in really good hands – you're in safe hands" (20.54).

5.2.11 Side effects

Although all participants commented to some extent upon the effects chemotherapy had on them, for example; hair loss, fingertip neuropathy, nausea, and skin problems, these effects are thoroughly documented elsewhere and do not have a particular impact upon receiving chemotherapy in either the clinic or MCU. Whilst acknowledging the importance to individuals of these side effects the researcher has decided not to include these data in the report.

5.2.12 Control

Participants tried to regain some control over their lives during chemotherapy treatment and identified ways in which this might be achieved. Being positive (17.54, 19.126), self medicating with herbal remedies (91.92) and 'helping myself' (4.1, 4.34-36, 13.33-35, 19.149-152) were strategies to retain some semblance of normality. 'Keeping it under control' and 'being in control' were important factors during a period in which they reported their bodies were taken over by medical staff (10.8-11, 20.141-145). Participants 9 and 17 became aware of commercial and scientific literature concerned with suggested benefits of some foods, and invested time in

exploring how diet might reduce chemotherapy side effects and improve cancer outcomes.

Others made more political decisions either to have private care and treatment or become proactive in their contribution to local cancer policy.

The social lives of participants were significantly affected by treatment but many managed to make compromises in order to continue being with friends and family:

"Our friends know how he is 2 weeks after treatment, he's not really, you know sort of if we go out to supper we'll leave early" (Wife 14.64).

"For three years we've gone every week (to the clinic) (10.43).

"How have you managed your lives around that" (TM).

"It's a struggle, very frustrating isn't it? (10.44).

"yep" (Husband 10.45).

"Did you manage to get holidays in that time?" (TM).

"Nope" (Husband 10.46).

"We went to Cornwall for a weekend but it was on a Friday and we had to go up to the hospital before we could go. I said I wanted a 9am appointment and yes, we did get that" (10.46).

"I wasn't able to go on holiday this year, so we're going away at Christmas". I wouldn't go Theresa, because if something happened I would want to be near Cheltenham" (16.103, 16.104).

"My husband had some holiday, to go to France to see my folks and I wish I had been at home actually because I just felt so useless and hopeless. But we went to the seaside and I couldn't do the normal walks we do but I was eager to go the sea because I thought it would have healing power" (19.31).

Several participants in this study demonstrated 'expert patient' traits, that is, knowledge of systems, routines, treatments and equipment that gave them some power, control and confidence during their chemotherapy journey. Obviously this usually manifested towards the end of treatment through complaint, in this instance about a pump failing to administer chemotherapy:

"The nurses say that they are aware of the problems with the pink ones and they say they'll move you onto blue ones, they're ok" (Husband 19.105).

"I did mention it to the nurses and the nurses are not happy about it and I keep mentioning it but nothing seems to be done; it's pot luck whether you get that kind of pump really" (19.106).

"It's not actually a pump, they call it" (Husband).

"It's a little bottle" (19.107).

"So you've got like a little membrane inside which blows up like a balloon and it slowly reduces and it fits in a plastic container, but they say as the heat rises" (Husband).

"... the plastic bit, which has to be in contact with my arm, and it's the warmth of the arm that makes the pump work, so they tell me maybe you should have a wooden spoon. You try and imagine it if you had a wooden spoon with your arm straight for 2 days – that is not realistic!" (19.108).

"I was asked if I would take part in this trial drug Satuximat but for the first 12 weeks they actually said it would be chemotherapy regime which is Oxiplatin and 5FU plus Satuximat, the Oxiplatin and 5FU was fortnightly, Satuximat was weekly. They warned me of side effects with Satuximat. I did have a really quite extreme reaction in terms of skin response to Satuximat so then we had to put antibiotics and that sort of thing in place. It almost felt, the first week, as if someone had thrown acid in my face it was that vicious" (4.17 – 4.20).

"I've had chemo on and off for the past 3 years, so I've had about 6 lots I'd say – It's not something you want to be expert at (laughs)" (10.16).

"Path reports came through on 24th, one of the colorectal nurses said the tumour was at quite an early stage contained within the walls of the bowel. The lymph nodes were ok, blood vessels showed signs of cancer cells so we'll get an appointment with Dr ... in a couple of weeks to discuss reducing the risk for the future" (15.20).

5.2.13 Complications

This sub theme comprised stories of a range of physical and organisational problems not directly associated with having chemotherapy in clinic or the MCU. They included description about catching infections (7.142-146, 8.127, 9.65-102, 19.32-33), developing a deep vein thrombosis (19.35-39) and low blood count delaying treatment (1.75-77, 2.5, 9.64-181). Also with bed availability for in patient chemotherapy (2.2-40, 3.93-97) and being admitted to the Emergency Department.

5.2.14 Working whilst receiving chemo

Two participants talked about plans to continue working alongside chemotherapy but this was not possible because of timings in clinic:

"In the beginning I was working and I was quite keen to go back to my afternoon lessons. If you got an appointment at 10 o'clock I think it's quite unreasonable to see somebody at 20 past 12 for

five minutes, you know. I'm not working much now – it's a full time job being ill, I must say" (19.70, 19.71).

And because of fatigue:

"I reduced my timetable, my chairman told me not to teach but I ignored him and did my teaching (laugh). I had to give up my afternoon teaching obviously. What tired me most was waiting once I got there [clinic]" (16.23, 16.24).

Part of the need to continue working for these participants was the desire to feel normal. Those who were retired could not contemplate working at the same time as recovering from surgery and receiving chemotherapy and felt relieved that they were not having to make those decisions and sacrifices.

5.2.15 Concern for other patients

Participants showed acts of kindness and sympathy in their accounts of being with other patients in clinic waiting area whilst having treatment themselves:

"I was talking to a gentleman from ... who looked really poorly ... his wife was really worried about him. He couldn't drive to treatment, he had to have hospital transport. When I was called in I sat next to him on the next chemo chair and he looked white, I said to him 'are you feeling alright' he said actually I'm feeling lousy. I said 'you better tell the nurse – they will stop the infusion' (3.73).

"This lady who was looking really poorly sat there and sat there, and I think her son came in and said 'aren't you ready yet mum?' she said 'no I'm waiting for some medicine'. He went to the counter to ask and someone came out from there and said 'oh I'm really sorry but it's not ready yet and it won't be ready for another 2 hours because pharmacy has gone off to lunch'. I was thinking she looked so poorly they should have said well we'll get it for you" (4.136, 4.137, 4.138).

Having been admitted to the ward for observation, Participant 9 reported the reality check:

"there were a lot of really poorly people and I found it quite distressing. Then people come in and say 'oh I've been here before and once you find out how long everybody's got it sort of breaks the ice'. This is another patient and I'm thinking I don't want to be here, I don't need to hear this" (9.92, 9.93).

"It doesn't half open your eyes you see these young girls and young boys bald as a badgers coot, see I haven't even lost me hair" (17.80).

5.3 Reflections on the chemotherapy experience

5.3.1 Complaints

There were several quite serious complaints about poor communication, delayed or incorrect diagnosis and dissatisfaction with the way some medical staff had conducted themselves. Some of these issues have already been described in the previous themes. A couple of participants have been directed to appropriate departments within the Trust so that they can be advised about the complaints procedure and, if necessary, submit a formal complaint. Participants were not afraid to do this:

"I saw the nurse in charge one week and wrote about my experience to Dame Janet Trotter (4.64), and I got a letter back from Dr Harsent" (4.101).

The most common irritations for participants were doctors not being familiar with their case:

"He said, without referring to the notes, the surgeon believes he removed all traces of the cancer and the trust policy is that you will get a scan on the anniversary of your surgery, which was counter to what I had been told in the beginning" (5.54).

Poor bedside manner was alluded to several times, for example:

"I got home, having been told with a very bad bedside manner, having asked previously not to tell me, I wouldn't be strong enough whether it was good or bad news, came along, didn't pull the curtains just said 'oh yes your tumour has spread but not too badly and we'll let you home now'. I thought thank you very much" (7.23).

Some events had a lasting impact on participants:

"...he also made a few slightly unfortunate comments when I was having chemo (crying). It was something and nothing at the time but I was having an allergic reaction to chemo, it was a rash and so the next time they gave me antihistamines and whatnot before I had the treatment. But I was scared, really scared (crying) and he just made some joke and I'm sure he was trying to lighten the situation but it was ill timed I think. Well, I just erupted and burst into tears and he fled actually" (12.122-125).

"I first saw the surgeon who did the biopsy, who I must admit was very abrupt and my sister-in-law had dealings with him in the last few years because her husband died of cancer and she said to me, 'I hope you don't have because he's not very nice" (13.22, 13.23).

There was one complaint about nursing care:

"I think it might help others if we mention that when he came out of hospital he had a very, very bad bed sore – and that's bad nursing isn't it?" (Wife 14.32).

There were complaints about Pharmacy opening hours:

"Pharmacy closed for lunch between 1 – 2 and so it was likely that she would go in at 2 o'clock because her prescription wouldn't be ready, and on that occasion it wasn't ready until 4 o'clock" (3.49, 3.50).

In particular, Participant 4 expressed her anger:

"Pharmacies in hospitals are far too powerful; I mean the Pharmacy in Cheltenham shuts at lunch time. Unbelievable!! And why they couldn't actually have a rota and make sure that someone throughout the time is actually continuing to do medicines because that could be one of the reasons they would say, 'well sorry you're going to be another 2 hours because lunchtime is coming up and we have only just sent down for your chemotherapy to be prepared ...' (4.133, 4.134, 4.135).

5.3.2 Accessing other services

Only three participants talked about referral sometime during chemotherapy to other services. Participant 11 discussed pain relief needs with palliative care nurses; Participant 8 required community care, which he said he could not fault, and Participant 3 asked the consultant if she could be referred to a dietician because she was having difficulty swallowing and wanted advice about nutrition and pureed food.

5.3.3 General Comments

There were a variety of general observations and experiences that participants had disclosed in relation to receiving chemotherapy. A couple had said that the appointments process was particularly troublesome:

"[since the new clinic has been built] the appointments are worse, far worse (Husband 10.39). "You used to make appointments at reception and you could talk to somebody; they would say we can fit you in here and you could say I can't do that and they would fit you in somewhere else, but you can't do that now" (10.40). "You can't talk to anyone, they just put the cards in, or the forms, and they give you an appointment, or if it's after 4 o'clock they're closed so they send you an appointment through" (10.41). "They hadn't sent me an appointment through by Monday so it was a fortnight late and I phoned up. Nobody had let me know when" (10.42). "The appointments system

seems to be worse, it wants overhauling" (Husband 10.48).

Others conveyed that their treatment and care had been impressive (14.10, 19.7) and Participant 18 stated that:

"Right from the first meeting with the medical imager I felt complete confidence in the process I was going through. Complete confidence in the people who were dealing with me and it was a confidence that was borne, not from their obvious professionalism, but actually from the care as well – and I would say that at every stage of the process" (18.9, 18.10).

And in contrast to the complaints:

"I wrote to the umm the Chief Exec of the Health Authority to tell him about my experience because I was impressed by it – if you like, almost intellectually impressed by it as well as appreciative of it, and I just thought you people only ever hear negatives" (18.88, 18.89).

6 Discussion

Since the launch of the MCU in 2007 more recent DH documents have been published that advocate provision of chemotherapy in the home or closer to it. The National Chemotherapy Advisory Group (NCAG, 2009) recommends that each cancer network should consider, with their local PCTs, opportunities to deliver chemotherapy in facilities nearer to patients' homes.

In the publication 'Chemotherapy Services in the Community; A Guide for PCTs' (DH, 2010b) the DH Cancer Policy Team acknowledges the need to reduce investment and activity in the acute sector. This document alludes to the Gloucestershire MCU as the first nurse led unit in the UK and promotes this model of delivery as one way forward to address increased choice for patients and to improve the chemotherapy experience.

It is coincidental to this report that the major DH document 'Improving outcomes: A Strategy for Cancer' was published in January this year (DH, 2011) by the coalition government. Many of the discussion points brought forward from the findings section in this study are addressed, albeit more generally, in the DH Document.

The intention of this research was to explore experiences of people receiving chemotherapy in the locality, both in the Outpatient Clinic and on board the MCU. The Government (DH, 2011) acknowledges that there will be variations in patients' experience of care and treatment, and asks that healthcare professionals make sure that feedback on patient experience informs the design and delivery of services so that they reflect what is important to them, and this report goes some way to meet this goal.

We are fortunate in this country that cancer charities raise awareness of cancer, raise money to fund research and services, deliver some services, including information, and campaign for change (DH, 2011 p14). The charity 'Hope for Tomorrow' contributes to the coalition government's Big Society approach to healthcare. The charity is currently having their 4th Mobile Chemotherapy Unit constructed for service, and the Founder of the charity, Christine Mills, has ambition to donate ten units in ten years.

Participants had mixed experiences when interfacing with their GPs. On the whole GPs were quick to respond when symptoms were obvious, but sometimes diagnosis was delayed because the patient's clinical picture did not indicate malignancy. In such cases it was perceived to be more beneficial to patients to assume the worst and refer for diagnostic tests. It is estimated that

GPs see only 8 or 9 new patients with cancer each year. However, they see many more presenting with symptoms that could be cancer, and those symptoms are generally symptoms of many other diseases as well. This therefore makes it difficult for GPs to assess when it is appropriate to refer patients on to secondary care for investigation (DH, 2011 p44).

In addition, in the light of an exponential rise in the incidence of bowel cancer, GPs will have a centrally developed resource pack to ensure that they are fully aware of the symptoms of bowel cancer. A risk assessment tool for GPs has been developed and is about to be tested in several pilot areas (DH, 2011, p44).

Once referred, participants had appropriate tests quickly and were diagnosed, referred to a surgeon, had surgery and then oncologists planned the appropriate chemotherapy regime for that person. Many of the participants did not go early to their GP because they thought what symptoms they had could be accounted for by something less suspicious such as the aging process or stress.

It is thought that if the public is furnished with information on the symptoms and signs of cancer, they can seek help early and thereby improve their chances of cure.

Three participants commented that they had discovered they had cancer through national screening facilities such as the over 60s Bowel Cancer Screening initiative or mammography. The Revision of the Operating Framework for the NHS in England 2011/12 (2010a) states that commissioners should ensure that all local screening centres maintain the two year screening round for bowel cancer. In addition, there will be a review of the benefits of screening for other cancers. Following public and stakeholder consultation the NHS NSC recommended modelling of screening services for high risk groups is conducted, and further education of GPs through the Prostate Cancer Risk Management Programme (DH, 2011 p41.) Consideration of patients' family medical histories may indicate earlier need for screening and GPs should be observant of vulnerability to familial tendencies towards particular cancers.

There is also acknowledgement that it should be easier for employees to participate in cancer screening programmes by their employers providing flexible working arrangements for screening appointments.

The manner in which bad news was broken to participants appeared haphazard depending

upon the clinician afforded the responsibility. Participants reported being shocked, and in some instances the news was imparted in an insensitive way by a doctor who had little regard for the feelings of the patient. Being 'told straight' was appreciated by some participants but others did not want to know the prognosis (survival rates) for their particular cancer. The appropriate level of disclosure for each patient is very difficult to judge but clinicians should be receptive to non verbal and verbal cues from the patient as indicators of how the delivery of bad news might be made more acceptable. Sometimes 'throwaway' comments from doctors had harmful long term effects on patients who interpreted the implication of the comment very seriously indeed.

Participants reported receiving informal information about their cancer, treatment and expected outcomes, rather than more formal channels. Despite having access to the Internet, several participants said they preferred not to indulge in lengthy searches because they would find it too disturbing. Often the amount of information was overwhelming and people chose to opt out of the temptation to pursue cancer related literature. Informal information was obtained from other patients, and those who attended the MCU said they felt much more able to ask the nurses questions than when they were in clinic. The MCU afforded them one to one time with nurses who did not have to rush off to deal with other patients. The time spent on the MCU was perceived as quality time with nurses. Selected relevant leaflets, at significant milestones through the cancer and chemotherapy trajectory, would appear to be more helpful than a plethora of information given at diagnosis. This of course is difficult to gauge, especially if there is some urgency for surgery and subsequent treatment. In the context of healthcare reform there will be an 'information revolution in cancer' the purpose of which is to enable people to make choices about their health and treatment (DH, 2010c). However, there should be acknowledgement that not every person is able or willing to take this responsibility.

It should also be noted that although Liberating the NHS: greater choice and control (DH, 2010d) advocates patients being at the heart of decision making about treatment and where it should be provided, the opportunity to receive chemotherapy on a mobile chemotherapy unit is relatively small. The criteria for admission to the MCU are strict, and further restrictions are imposed according to day to day events in clinic, the situation for the patient, availability

of chemotherapy trained nurses, and the operational limitations of the actual unit (maintenance and testing).

There are usually two people who embark and progress through having cancer and treatment, namely the person with cancer and their significant other. The role of 'the other' became very apparent in this study. Partners/spouses supported the person with cancer at home and were alongside them at every stage; receiving bad news, anticipating surgery, through surgery, recovery from surgery, preparing for chemotherapy, taking them for chemotherapy treatment and dealing with the fallout from side effects. Partners/spouses were involved to some extent in decision making and some said they felt 'looked after'. However, they were not acknowledged as they waited in the clinic for the person having treatment and has been explored in the findings section, this meant often waiting for up to 12 hours. Some partners/spouses went home and came back again. Others went into Cheltenham or visited friends locally, some just sat and read. Some had given up work or taken early retirement to support their loved one. Perhaps this time could be better spent in a resource room/centre such as The Maggie's Centre at CGH where partners/spouses could obtain information and mix with others in similar circumstances. Only one couple in this study mentioned this resource and found it very useful and reassuring.

For those who had no family or partner support on treatment days the hospital car taxi service was often used because of the fear of after effects of treatment affecting driving. Although this service is appreciated by patients, the hours of availability were commented upon. Apparently the service is only available until 15.00hrs which means that those who have treatment up until 21.00hrs have to arrange alternative transport home. This could put them in a vulnerable situation in terms of their fragility and also incur extra expense for hire of a private taxi.

Participants were generally satisfied with the new arrangements for car parking at CGH using special permits for oncology patients. This was seen as important to people already stressed by the impending wait in clinic and process of receiving treatment. There were no issues relating to car parking for participants who had their treatment on the MCU. Participants tended to drive themselves to the MCU for treatment because it was a much shorter distance and they had more confidence that they would not be ill on the way home. This meant that partners/spouses were not inconvenienced (ie. taken out

of work) to take the patient for their treatment. Costs to patients were significantly reduced in terms of time spent travelling, having to wait, treatment time and expenditure on fuel and companion costs.

The most important and distinguishing feature of difference between receiving treatment in Outpatient Clinic and the MCU was the amount of time spent waiting. The frustration, anger, irritation and boredom experienced by participants waiting in Clinic was articulated thoroughly and repeatedly throughout the interviews. Whilst participants appreciated that delays in clinic might be caused by adverse events, staff shortages and the general pressure of throughput of patients, there was no reconciliation between what was happening behind the scenes in clinic and how long the person would have to wait their turn. Waiting more than 2 hours was just about acceptable, waiting more than 3 was not. Being in the Outpatient Department for up to 12 hours for a day every week was perceived to be a waste of remaining life for some people. Several said they believed it to be the fault of 'operational' or 'organisational' staff and did not blame the doctors or nurses.

Participants who used the MCU reported that most of the time when they arrived they would go straight in and have their treatment. A couple of participants reported having to wait 10 – 15 minutes either in the community hospital or outside, but that they did not mind this.

The Executive Summary of Waiting Times Report (DH, 2011, Annex C) states that a review of the Cancer Reform Strategy should include a review of waiting time standards. These standards are concerned with GP to secondary care referral, time to being seen by a hospital doctor, surgery waiting times etc. These are all concerned with waiting list targets. Waiting for treatment on a particular day in a clinic is not included in the statistics and yet the importance of waiting for treatment to patients should not be underestimated, particularly towards the end of a cycle when the patient is at their most vulnerable.

Participants suggested a more efficient system in clinic might include a service whereby patients are called at home or on a mobile phone to advise them of delays in clinic. This of course is more complex than it might first appear. It would involve identifying a particular member of administrative staff to make the phone calls, complete confidence in a dynamic and potentially volatile system that revised timings can be

guaranteed, the possibility of even later working hours for nurses, gaps between treatments because patients are not there to fill them, and the potential not to be able to contact patients in the first place.

Also, in relation to waiting in clinic, participants talked about an electronic board that informs those in the waiting room in Outpatients about anticipated length of time to wait for appointments. Although perceived to be inaccurate most of the time, participants used it as an indicator of how long they might wait. It was missed when the rebuilding of the Outpatient department was being undertaken and participants were curious as to its whereabouts.

Once patients get into a treatment chair in clinic or on the MCU their anxieties about cannulation become apparent. From their accounts it is evident that participants dread the multiple efforts to insert a cannula, without local anaesthetic, into overused and fragile veins. Techniques for preparing for insertion of cannula are inconsistent between nurses; some provide warm pads to encourage vasodilation and others do not. The Royal College of Radiologists (2008) recommends the use of local anaesthetic cream although this might impact upon infection control procedures in chemotherapy treatment (McGowan, 2010). EMLA (eutectic mixture of local anaesthetics) cream must remain on skin for an hour prior to the cannulation procedure and this might further complicate scheduling of a clinic.

Having treatment on the MCU was perceived to be less formal than clinic and therefore less stressful. The environment was acceptable to participants who enjoyed conversations between nurses, the driver and other patients. The clinic environment was criticised for not having natural light through windows, for being cold due to air conditioning, and not having the personal touch afforded them on the MCU. There were no particular issues regarding privacy and dignity on either the MCU or clinic.

Pharmacy was criticised for closing at lunchtime when patients required prescriptions to take home. This resulted in extended waits for patients who had already been delayed in the clinic. There were no issues discussed at interview about medications on the MCU.

Similarly some participants complained about nurses going on breaks all together, effectively depleting the service in clinic. Generally nursing staff were praised for coping under extreme pressure and caring for patients.

There was some frustration about the appointments system in clinic. Participants raised issues such as not receiving appointments and having difficulty in changing inappropriate appointment times. Previously appointments had been made face to face with administrative staff and this was valued.

Having read the DH (2010e) document reporting the results of the National Cancer Patients' Experience Programme survey, it is interesting to note the positive impact of Clinical Nurse Specialists (CNSs) on patients' experiences. In the study, patients who had contact with CNSs were more positive than those who did not; and the differences between the two groups were, in most cases, significant. "The impact of CNSs is profound and clearly very positive overall for the patient experience of cancer care". In this study only one patient commented on the excellent support she had from the CNS for rare cancers, and another who decided not to engage further with breast care nurses because she found them unhelpful. It might be assumed that all participants would have been assigned a clinical nurse specialist for their particular cancer group, yet nothing more was said about them. This may be because once people embark upon chemotherapy treatment clinical nurse specialists withdraw their support?

7 Conclusion

There are many important findings emanating from this study, not least, that having a diagnosis of cancer and undergoing subsequent surgery and treatment is abnormal and frustrating, and not only impacts upon the individual but takes its toll on those living alongside them. This is not new knowledge. However, insight into the effects upon individuals' quality of life of receiving chemotherapy on the Mobile Chemotherapy Unit is the unique contribution of this study.

Most people receiving chemotherapy report their lives revolve around treatment and they struggle to maintain any semblance of normality during this stressful time. They experience uncertainty, transitoriness and loss of control. Chemotherapy delivery closer to home assists people with cancer to regain some control and normalcy during their treatment period. Several recent Department of Health documents (DH, 2010a; DH, 2010b; DH, 2010d; DH, 2011) support service innovation that improves access to local services and chemotherapy closer to home.

Participants who had their treatment on the MCU were able to compare their experiences with those of Outpatient Clinic. They reported key differences such as the MCU being very much closer to their home so that they were able to drive there themselves without anxiety about being ill on the way home. This freed up time spent by partners/spouses driving and accompanying the person to have treatment in Cheltenham. Benefits were described in terms of a significant decrease in time and distance. There was never any difficulty parking in community hospitals. The MCU was perceived to be a much less stressful, sociable option to the clinic. Most importantly participants' quality of life was improved because they did not have to wait hours for their treatment.

Participants said that they were more likely to ask questions of the nurses on the MCU because they had more one to one time with nurses. They 'enjoyed' time spent with other people receiving chemotherapy and talking to the driver. They did not have reservations about the service being nurse-led or about dignity/privacy, cleanliness or safety issues.

Participants who did not have treatment on the MCU understood why they could not, but several had heard about what it was like to have treatment onboard and stated that they would have liked the opportunity. Two participants stated that they did not want to go on the MCU in case they had a reaction to their chemotherapy.

One did not know much about the MCU and had some inaccurate perceptions of it – that the Unit went out to treat one person at a time.

The Mobile Chemotherapy Unit has offered an alternative model for chemotherapy treatment delivery that is highly acceptable to patients who meet the criteria for receiving treatment onboard. For many patients time spent travelling, having to rely on relatives or others for transport and long waiting times on the day of treatment only adds to the burden of treatment. For many patients this burden may continue over many months or even years.

Findings from this project will contribute to the development of a template for national standards to incorporate into the cancer service peer review process. National standards for the delivery of chemotherapy treatments in a mobile unit will set quality and safety parameters for service development. Reducing travelling time is an important factor for patients who access cancer services from rural areas and therefore findings from this research will be transferable to other NHS Oncology Centres and acute Trusts.

As the Mobile Chemotherapy Unit in Gloucestershire is the first worldwide, there is likely to be international interest in these perspectives of patients receiving chemotherapy onboard.

Appendix 1 Gloucestershire Mobile Chemotherapy Unit



Appendix 2 The Interview Guide

Title of Project: Chemotherapy closer to home – An evaluation of a unique Mobile Chemotherapy Unit.

INTERVIEW GUIDE

Participants may have experience of receiving chemotherapy in the Outpatient Clinic and the Mobile Chemotherapy Unit. They will certainly have had chemotherapy in the Outpatient Clinic. The questions prefixed by a) are for patients who have had treatment in both settings, and questions prefixed by b) are for those who have only received treatment in the Outpatient Clinic.

I'd like to understand what it has been like for you since you were diagnosed with cancer – can you cast your mind back to having symptoms and then being diagnosed?

Have you received treatment in both the clinic and onboard the chemobus?

1) I would like to understand what it was like for you having treatment in the Outpatient Clinic. Could you tell me about it?

2a) I would like to understand what it was like for you having treatment onboard the chemobus. Could you tell me about it?

OR

2b) Would you have liked to have had treatment onboard the chemobus?

3a) How do your experiences of receiving chemotherapy in both settings compare?

OR

3b) Do you think it would have been different receiving your chemotherapy on the chemobus compared to Outpatient Clinic?

4a) Are there disadvantages to having chemotherapy onboard the chemobus?

OR

4b) Do you think there might be disadvantages to receiving chemotherapy onboard the chemobus?

5a) Are there advantages to having chemotherapy onboard the chemobus?

OR

5b) Do you think there might be advantages to patient's receiving chemotherapy onboard the chemobus?

6) Are there disadvantages to receiving chemotherapy in the Outpatient Clinic?

7) Are there advantages to patient's receiving chemotherapy in the Outpatient Clinic?

8a) What would you change about the service onboard the chemobus?

OR

8b) No question

9) What would you change about the service in the Outpatient Clinic?

10) Is there anything else you would like to tell me about your experiences of receiving chemotherapy?

Thank you for talking with me.

Appendix 3 Themes, Sub-themes and Categories

Theme	Sub Theme	Categories
1. Pre chemotherapy	1. Symptoms, diagnosis and seeing my GP	Pre diagnosis Symptoms Contact with GP GP very good Problems with GP's diagnosis GP not knowing enough about ... Diagnostic procedures The Shock Cancer in the family
	2. Consultation with a medic	Consultation with a medic Medical language faux pas I didn't need to hear about it Receiving bad news Being told straight No chance to ask questions Challenging the surgeon
	3. Information	General information Information sheets Information board in clinic Information overload Pre chemo information The Internet Making decisions about chemo
	4. Peri operative period	Pre surgery treatment Going for surgery Surgical procedure Post op. Aftercare issues Living with an ileostomy
2. Receiving Chemotherapy	1. In it together	Worries about spouse Spouse giving up work/trying to work In it together Togetherness on the journey Someone with you Significant others Worry for significant others Friends with cancer
	2. Travelling and Parking	Travelling for treatment Parking the car
	3. Waiting for treatment	Doing something whilst having treatment Waiting in clinic Speculation about why waiting Pager system
	4. Speculation about why they had to wait so long	Speculation about why waiting Pager system

Theme	Sub Theme	Categories
2. Receiving Chemotherapy (continued ...)	5. Feeling anxious	Feeling anxious and apprehensive Survival rates I took it in my stride It felt surreal A new experience Being frightened Feeling insecure Thinking about dying Patients who have died on the same treatment Being a poorly person
	6. The process of having treatment	Time spent having treatment Frequency of treatment Duration of treatment Recovery between chemo sessions Completing chemo PICC line Cannula insertion I feel awful so the chemo must be working Pharmacy opening hours Going into a trial The system is sagging Good things about clinic – being looked after General comments about having treatment in clinic Talking to other patients in clinic Concern for other patients Chemo club
	7. About the MCU	What people say about the MCU Asking about going on the MCU Why I can't go on the chemobus Consultants reluctant for patients to go on the MCU Perceptions of the MCU Finding out about the MCU Having treatment on the MCU Worries about having treatment on the MCU What for the future of the MCU?
	8. Advantages and disadvantages of having chemo on the MCU	Advantages Disadvantages
	9. The environment	General comments about being there Proximity of chairs Privacy issues

Theme	Sub Theme	Categories
2. Receiving Chemotherapy (continued ...)	10. About staff	Nurses in clinic Nurses on the MCU Supported all the way through Inconsistencies between nurses District nurses CNS for Rare Cancers Breast Care nurses Continuity of care Resentment from clinic nurses
	11. Side effects	Chemo effects Reactions to chemo Hair loss Chemobrain
	12. Control	Self medicating/helping self Diet Being cheerful Being positive Quality of life Social life/enjoyment Being proactive in cancer policy Give it my best shot Going without drugs Getting upset Expert patient
	13. Complications	Trouble with equipment DVT Catching infections Appointment delays and cancellations Disappointments Low blood count – neutropenia Bed availability for inpatient Being admitted to A&E
	14. Working	Working alongside chemo Returning to work
	15. Concern for other patients	Showing concern Distressed by other patients
3. Reflections on treatment	1. Complaints	Consultants not communicating They don't look at my notes Issues around diagnosis General complaints about treatment Serious events Complaints about doctors and surgeons Not receiving results by phone Discussing palliative care on the phone
	2. Accessing other services	Community care Palliative care/pain relief Counselling
	3. General	Making appointments Comments Impressive treatment Additional treatment Getting results

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