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**Riding the Melanoma Rollercoaster:
Understanding the experiences and support needs of patients with
melanoma and their carers. Charting changes over time.**

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ABSTRACT

Background: Melanoma incidence continues to rise worldwide but mortality rates remain stable, meaning ever more patients require support. However, there is currently little research on the support needs of melanoma patients and their carers.

Aim: To explore the experience/support needs of melanoma patients and their carers over time.

Methods: Using a Constructivist Grounded Theory 17 melanoma patients, 11 carers and 11 healthcare professionals (HCPS) were recruited. Concurrent data analysis, theoretical sampling and constant comparison informed a longitudinal, emergent research design capturing experiences over time. Data were collected from patients and carers using interviews and diagramming over 2 years and from HCPs on 2 occasions.

Results: A substantive theory emerged highlighting four key phases in the melanoma experience: pre-diagnosis, diagnosis and initial treatment, surveillance and advanced disease, and for some, death. The overall experience was captured by the metaphor '*Riding the Rollercoaster*' reflecting the '*ups*' and '*downs*' participants experienced at each stage in their '*roles*', '*routines*' and '*relationships*'. Changes were mediated by the ways in which patients and carers '*recognised*' and '*responded*' to their situation and the '*resources*' that they could draw upon. Key processes including '*sharing*' and '*hiding*' impacted in particular on the '*relationships*' between patients, carers and HCPs.

The *'relationships'* forged with HCPs during diagnosis were crucial as HCPs were a major *'resource'* providing expertise, information and emotional support. Some patients forged close and trusting *'relationships'* with HCPs but others had less positive experiences. The support needs of carers were given limited attention.

Conclusions: Melanoma has ongoing effects on the lives of patients and carers. HCPs play a pivotal role as part of a broader support network but not everyone received the help that they needed. If HCPs are to improve the melanoma experience they need to systematically assess patients' and carers' support needs as they change over time.

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1 CHAPTER ONE: SETTING THE SCENE

This brief introductory chapter sets the context for the thesis. It starts by highlighting my motivation to undertake the study. This is a key element of reflexivity that, as I will describe fully later, is an essential part of the methodology used (Constructivist Grounded Theory). Subsequently the structure of the thesis is presented in the form of a brief chapter by chapter account of its content.

1.1 WHAT MOTIVATED ME TO EXPLORE THE SUPPORT NEEDS OF PEOPLE LIVING WITH MELANOMA AND THEIR CARERS?

Before starting this study I worked as a Research Nurse for 9 years supporting patients taking part in clinical trials including those with melanoma. My main responsibilities were taking consent and ensuring the safety of patients taking part in clinical trials. I would record side effects and collect data on Quality of Life (QoL) and patient outcomes such as pain. During the process I spent a lot of time talking to patients and building a relationship with them. I realised that the safety data and outcomes that I was collecting did not reflect the full patient experience. This became particularly apparent when the side effects of new drug therapies began to emerge (see next chapter for more detail). For example, one young woman had developed blistering to her feet but the grading system I was using did not capture the difficulties the blisters imposed on her actively engaging with her daughter to create happy memories. She felt that these activities were a vital legacy that would comfort her daughter after her own death.

During this time I also completed a MMedSci in advanced practice, with the dissertation examining Quality of Life in patients with kidney cancer. This involved a literature review focusing primarily on measures of Health Related Quality Of Life (HRQOL), which further reinforced the inherent limitations of such approaches. I became increasingly convinced that these measures missed important dimensions of the patient experience: the potential impact of the melanoma on their family or their work. Furthermore, there was no Clinical Nurse Specialist (CNS) support available in the hospital at the time so patient concerns could not be picked up via that route.

My growing realization that melanoma patients potentially had several unmet needs led me to explore their support needs as the dissertation component of my second Master's degree (MSc Clinical Research). This was a small retrospective Grounded Theory study during which I interviewed 11 patients diagnosed with melanoma. While the participants were disease free following treatment they all had a high risk of developing further melanoma. As part of the study I worked with a member of the local consumer research panel whose wife had died from melanoma in 2005. He could still vividly recall the experience of caring for his wife, with limited professional support. Keen to improve this experience for others, he helped with the development of my questions and patient information material. While I will discuss the results of this study in more detail in the literature review chapter, a major insight to emerge was the realisation that melanoma had serious consequences, not only for the patient but also their close family. This further reinforced the narrow perspective of the trial data that I was involved in collecting as carers' needs were not considered at all.

The above factors were instrumental in motivating me to develop a research proposal for a PhD study that would explore not only the experiences of patients and their carers but also

the part played by the healthcare professionals with whom they came into contact. To achieve this it was necessary to seek funding for such a study.

1.2 FUNDING THE STUDY

Funding was obtained through a successful application for a National Institute for Health Research Clinical Doctoral Research Fellowship. The scheme, having a clinical element, enabled me both to undertake a PhD and develop my clinical role with cancer patients, with a focus on melanoma. The scheme also covered a clinical and academic training package incorporating a visit to leading melanoma treatment centres in Australia and New Zealand. The application process commenced in May 2012 and was supported by a study management group whose role was to ensure that participants' rights were met and that the study was conducted ethically. This comprised three consumer representatives from the Yorkshire and Humberside Consumer Research Panel (one being the same person involved in my Masters study) and two CNSs from different hospitals within the region. My supervisors and the study management team reviewed the application prior to submission. Following a successful application I was able to commence the Fellowship in June 2013 while continuing to work as a part-time Research Nurse.

1.3 THESIS STRUCTURE

This initial chapter has considered my motivation for undertaking the study upon which this thesis is based. I now provide a brief overview of the remaining chapters.

Chapter Two: Presents an introduction to melanoma, the biology of the disease, epidemiology and treatment options. I also describe the local clinical context, issues related to survivorship,

living with or beyond melanoma, palliative and terminal care. The chapter concludes by considering the current understanding of the support needs of melanoma patients and their carers.

Chapter Three: Discusses the role of extant knowledge within a Grounded Theory study, including my prior experience, sources of patient and carer knowledge and sources of professional knowledge/research, as well as the published literature. Analysis and synthesis of these sources identifies a number of themes: Quality of Life, psychosocial wellbeing, financial impact, information and educational need, support service use, supportive relationships, gender related differences and behavioural responses to melanoma. These themes underpin the sensitising concepts and foreshadowed questions providing initial direction for the study.

Chapter Four: Explores why Grounded Theory methods were chosen for the study, specifically Constructivist Grounded Theory. The application of Constructivist Grounded Theory methods to the study and issues related to ethics, rigour and reflexivity complete this chapter.

Chapter Five: Provides details of the participants in the form of a short biography.

Chapter Six: Introduces the results of the study and the mid-range theory produced from the data. It then focuses on the diagnostic process and how patients and carers reacted to it. This,

and subsequent chapters explore the impact of melanoma on three main areas: roles, relationships and routines.

Chapter Seven: Taking a temporal perspective the focus now turns to the stage of surveillance, where patients are monitored for new or recurrent disease and may require further surgery. The experience of patients and carers is again explored in terms of roles, relationships and routines.

Chapter Eight: Goes on to explore the experience of being diagnosed with metastatic disease and the transition to palliative care. It also provides a brief exploration of the experience of carers after the death of the patient with melanoma.

Chapter Nine: The discussion begins with a summary of the overall research then addresses its limitations as well as issues of rigour and reflexivity. It also introduces literature published since the commencement of the study. The implications of the findings for future research, practice and education are considered.

1.4 A NOTE ON NOMENCLATURE

Throughout the thesis the following terms are used:

Patient: Refers to an individual with a diagnosis of melanoma. The various interpretations of the term 'patient' are explored at differing points in the thesis.

Carer: Refers to the individual who provides the main social, psychological and /or physical support for a person with melanoma.

Participant: Refers to any individual who participated in the study, whether they are a patient, carer or healthcare professional.

The use of 'patient' and 'carer' were discussed in detail with participants and whilst they were not seen as ideal no better terms were suggested.

Healthcare Professional (HCP): Refers to Healthcare professionals as a general term whether from primary, secondary or tertiary care or voluntary organisations.

2 CHAPTER TWO: AN INTRODUCTION TO MELANOMA

2.1 WHAT IS MELANOMA?

Malignant melanoma is the deadliest form of skin cancer. Most commonly, it starts as a changing mole on the skin surface that may subsequently spread to the lymph nodes and other organs, becoming fatal if left untreated. In some instances it is easily curable whereas in others, despite rigorous treatment, it progresses to a fatal metastatic form. Patients may require multiple treatments that can include disfiguring surgery, surveillance visits and drug therapies. To have some appreciation of this diversity it is important for the non-specialist reader to have at least a broad understanding of the condition, how it manifests itself, the various treatment options and their associated outcomes.

2.2 BIOLOGY

Melanin is a substance found in different parts of the body but is most obvious as the pigment in the skin. Melanoma is a cancer of melanocytes, the cells that produce melanin. The skin is therefore the most common site for melanoma but it can also develop in the eyes and other organs. Melanocytes are found at the junction between the two layers of the skin: the epidermis and dermis. See Figure 2.1.

Figure 2.1 – Melanocytes within the structures of the skin and initial formation of a melanoma.

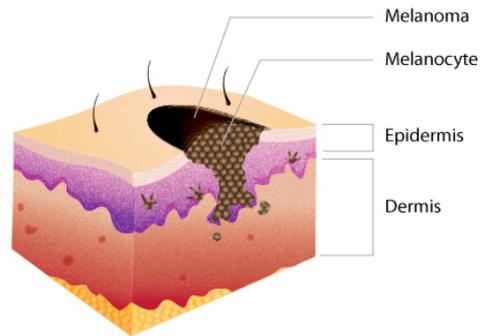


Image from: Science Learning Hub (2014)

Melanocytes produce melanin to protect the body against damage due to Ultraviolet (UV) light exposure. The development of melanoma is not fully understood but may occur when chronic exposure to growth stimuli (such as UV light) causes DNA damage to the melanocytes leading to a cancerous state where the damaged cells replicate in an uncontrolled manner (Busam, Barnhill & Piepkorn 2014). Melanoma typically grows horizontally, before spreading vertically and eventually metastasising via the lymphatic and/or vascular systems if not treated. See Figure 2.2

Figure 2.2: Melanoma development in relation to staging and image of a melanoma skin lesion

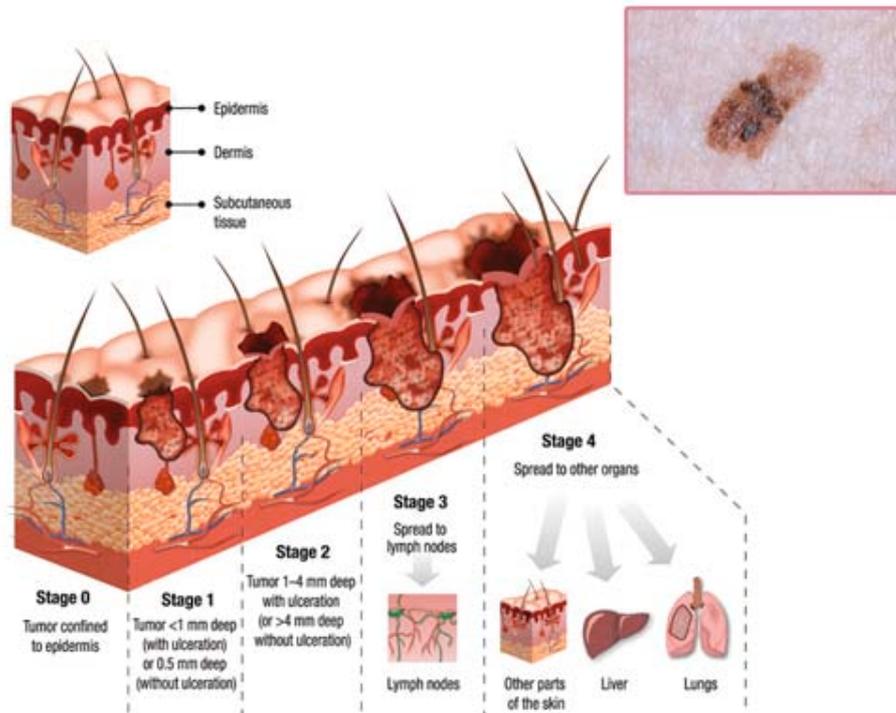


Image from: Health, Medicine & Anatomy Pictures (2013)

The stage of the disease largely determines a patient's prognosis and appropriate treatment. Melanoma occurring in the eye or mucosal tissue is considered a sub-type. The initial DNA damage leads to mutations in the BRAF gene which produces the B-RAF protein involved in cell signaling and growth. This mutation occurs in 50% of melanoma cases and influences the treatment options available, as will be described later in this chapter.

2.3 EPIDEMIOLOGY

There are over 15,000 cases of malignant melanoma per year and over 2,000 associated deaths in the UK with this incidence continuing to rise (Cancer Research UK (CRUK) 2017). Whilst melanoma is rare when compared to other cancers its incidence has increased more than any other cancer over the last 30 years across all age groups. Like many cancers, it is more common in older patients but for those aged 25-49 it is the second most common cancer in women and third most common cancer in men (CRUK 2017). In contrast to many cancers, it commonly affects younger, working-age adults. The incidence of melanoma is increasing faster in men, who are typically diagnosed in older age and more likely to die from melanoma (National Cancer Intelligence Network 2012a).

While incidence is increasing, mortality rates remain relatively stable in the UK, Australia and parts of the USA, probably due to early diagnosis and curative excision (Bataille & de Vries 2008). However such success means that more patients require follow-up and active surveillance.

Risk factors for melanoma primarily relate to skin type and exposure to the sun or UV light, which has increased due to intermittent sun exposure during foreign travel for those living in less sunny countries compared to chronic exposure in sunnier climates (Godar 2011). Exposure during childhood and teenage years when the skin is more sensitive increases risk for younger people, as does cumulative exposure for older adults (CRUK 2015a). The trunk, head and neck in men and lower and upper limbs in women are the most common sites for melanoma (National Cancer Intelligence Network 2012b).

2.4 DIAGNOSIS

The majority of patients present to their General Practitioner (GP) after noticing changes to an existing mole. CRUK (2015b) list the following changes that patients should look out for:

- getting bigger
- changing shape, particularly becoming irregular
- changing colour – getting darker, patchy or multi shaded
- loss of symmetry
- itching or pain
- bleeding or becoming crusty
- looking inflamed/red

Unfortunately patients often delay seeking help until they perceive any changes as being potentially significant (Hajdarevic et al. 2010).

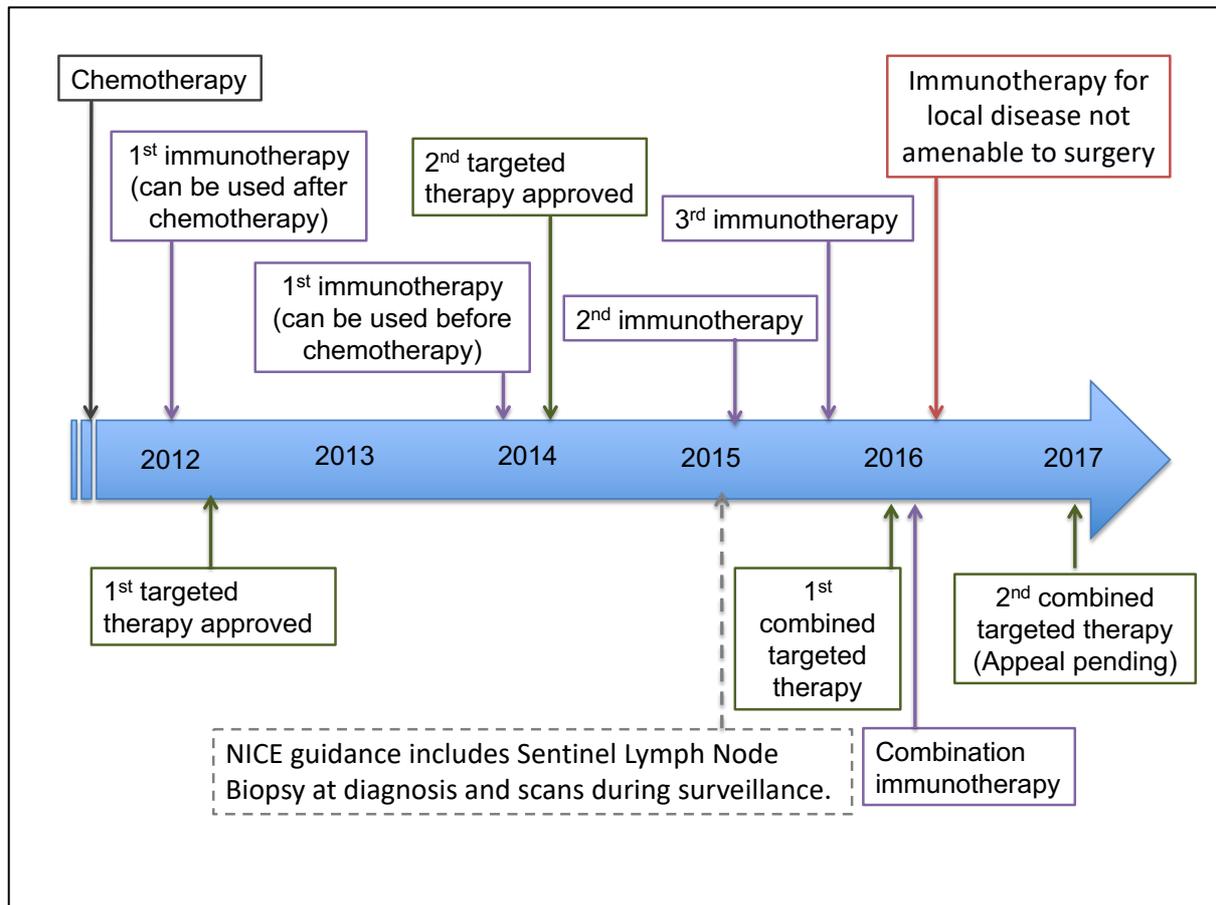
GPs should refer a suspected melanoma within two weeks to a dermatologist or plastic surgeon, who undertake a biopsy/excision to obtain a histological diagnosis if a malignancy is suspected. The clinical and histological details are then discussed by the Specialist Skin Multi-disciplinary Team (MDT) (comprising of dermatologists, plastic surgeons, oncologists, specialist nurses, radiologists and pathologists) who recommend the appropriate treatment.

2.5 TREATMENT

Treatments for melanoma have changed significantly in recent years following advances in surgical techniques and drug therapies. Patients may need multiple treatments for disease recurrence over months or years. The prognosis for metastatic disease has been historically poor. In 2010 one-year survival ranged from 33% to 62% (Balch et al. 2009), with no systemic therapy extending survival significantly (Marsden et al. 2010). Since then new targeted and immune therapies have increased survival rates but come with significant side effects (fatigue, skin reactions, diarrhoea and endocrine problems) requiring careful management (Chapman et al. 2011, Hodi et al. 2010).

These new treatments became available for some patients during the data collection period for my study as shown in Figure 2.3.

Figure 2.3: Treatments for melanoma in the UK by the National Institute for Health and Care Excellence (NICE) approval date



The available treatments are now considered in greater detail.

2.5.1 SURGERY

Surgery is the gold standard for primary melanoma as complete removal may result in cure, particularly for patients with stages 0 to 2 (Figure 2.2 above), with around 90% of patients at stage I surviving more than 10 years (Balch et al. 2009).

Tissue from every surgery is examined to ensure all the melanoma is removed with a margin of normal tissue surrounding it. Patients may therefore require further surgery to obtain a clear margin.

When melanoma spreads locally to subcutaneous tissue or lymph nodes, surgery remains the primary treatment and may also be considered in single deposit metastatic disease (NICE 2015). Patients may therefore have multiple surgeries, for example, for a primary melanoma on a limb, further surgery for melanoma on the same limb and then surgery to remove distant lymph nodes. The time between initial diagnosis and recurrent disease may be months or years.

2.5.2 SURVEILLANCE

Following potentially curative treatment for melanoma at any stage regular surveillance is offered to detect new disease early. Until 2015 this included full skin and lymph node examination but following the publication of updated guidance, imaging via CT and MRI scans were included for patients with stage IIC melanomas and above (NICE 2015). This change was driven by the approval of new drug treatments which are more effective when given earlier.

Patients with a low risk of recurrence are discharged after one year, and those with intermediate risk after five years. Some patients may have ongoing surveillance depending on personal risk factors.

2.5.3 CHEMOTHERAPY

Melanoma does not respond to chemotherapy as well as some cancers and there has been less success in treating metastatic disease or preventing recurrence after surgery. For more than thirty years the chemotherapy dacarbazine was the mainstay of metastatic melanoma treatment, with about 10% of patients experiencing a response to treatment with the average survival being 9 months (Patel et al. 2011). In rare instances chemotherapy is still used for metastatic melanoma when targeted therapy or immunotherapy are not suitable.

2.5.4 TARGETED TREATMENT

The first targeted treatment for melanoma was approved by NICE in 2012 (NICE 2012a) and works by targeting changes to the BRAF gene present in approximately 40-50% of melanomas (Eiglentler et al. 2016a). Response to targeted treatments can be dramatic with visible lesions reducing in size within days and patients living longer compared to chemotherapy (Chapman et al. 2012, Long et al. 2015, Ascierto et al. 2016). However such gains come with potentially major side-effects that require careful management. The most challenging side-effects are arthralgia, myalgia and photo-sensitivity (Chapman et al. 2011, Dummer et al. 2012, Larkin et al. 2015, Ascierto et al. 2016). Despite this the survival benefit is usually considered to outweigh the burden of side-effects, and use of targeted therapies has increased. (Hauschild et al. 2012, McGettigan 2014, Robert et al. 2015a, Grob et al. 2015).

2.5.5 IMMUNOTHERAPY

Immunotherapy has been shown to be effective for metastatic melanoma (Hodi et al. 2010, Weber et al. 2015, McDermott et al. 2014, Robert et al. 2015b) but the side-effects can be life-threatening and include diarrhoea, colitis, hepatitis, endocrinopathies as well as skin rashes

and fatigue (Ascierto et al. 2014). Experience within my clinical setting suggests that these side-effects are more severe than those reported in clinical trials (Dearden et al. 2015). Careful monitoring and early reporting of immune related side-effects are therefore required to avoid life-threatening complications (Weber et al. 2013).

Newer immunotherapies cause similar problems but these tend to be less severe (Eigentler 2016b) leading to better Health-Related Quality of Life outcome measures (Schadendorf et al. 2016), however direct comparisons between immunotherapies have not been made. Combinations of immunotherapy improve survival but at a cost, with twice as many patients experiencing severe toxicity (Postow et al. 2015). Data on long term effects is limited but some such as hypothyroidism or endocrinopathies are not reversible and require ongoing treatment.

2.5.6 RADIOTHERAPY

Radiotherapy is a localised rather than systemic treatment, recommended for the control of local disease and local recurrence (NICE 2015). Radiotherapy is administered following the removal of lymph nodes for patients with stage III melanoma with the main side effect being lymphoedema (Sanganalmath 2016). Other side-effects that patients may experience include fatigue and sore skin.

In metastatic disease radiotherapy may be used for symptomatic control in any site of the body, for example bone metastases (NICE 2015).

2.6 SURVIVORSHIP AND LIVING WITH AND BEYOND CANCER

Survivorship concerns living beyond or with cancer. Patients with melanoma may achieve a cure or may require multiple treatments and/or experience recurrent disease but continue to live with their cancer under control. Melanoma survivors may be of any age and background and therefore have varying needs which have historically not always been officially recognized, with the care pathway for all cancers including survivorship, subsequent treatments and palliative care (NHS Improvement 2010), not reflecting the complexity experienced by melanoma patients. Developments in the National Cancer Survivorship Initiative (Great Britain. Department of Health, Macmillan Cancer support & NHS Improvement 2010) promoted a change in emphasis from measuring clinical activity to capturing the patient experience to reduce the number of people reporting unmet physical or psychological support needs (Great Britain. Department of Health 2011). As a result of the National Cancer Survivorship Initiative (2013) the Recovery Package led by Macmillan Cancer Support (2013) was developed focusing on 'living with and beyond cancer'. In practice this meant that CNSs were mandated to carry out holistic needs assessment on all cancer patients. Within the local skin cancer context however, assessment tools were chosen for their brevity as CNSs were worried that in-depth tools that asked patients about financial difficulties, psychological problems, fear of dying or sexuality could cause additional worry, particularly if they had been cured. In-depth assessment therefore focused on patients with metastatic disease or additional psychological problems. The level of support available to patients taking part in the study was therefore unclear when it commenced.

Survivorship approaches however did not always take into account the growing number of people living longer with metastatic disease owing to targeted treatments and

immunotherapies. As some of the participants in the study benefited from these new treatments, the supportive relationships they experienced were explored during the study.

2.7 PALLIATIVE AND TERMINAL CARE

Historically patients with metastatic melanoma entered the terminal phase of their illness, necessitating palliative care, in a matter of months. Newer treatments have extended the time that patients live with metastatic disease and the timing of the terminal phase of disease has become harder to predict. This has created new challenges regarding the optimal point for palliative care services. Prior to 2010, patients who did not respond to chemotherapy would enter a reasonably predictable phase of decline so referrals to local palliative care services were made early to ensure a smooth transition. However, early referral became difficult for patients who were still on treatment and not deemed to be in the terminal phase. As services became busier referrals were only accepted for specific, complex care needs. A change in the transition from treatment to palliative care therefore occurred during my data collection, the effects of which I needed to consider.

2.8 THE CLINICAL PATHWAY AND LOCAL CONTEXT

Help for a suspected melanoma involves a patient pathway comprising, at a minimum their GP and local dermatology department, but may also include referral to specialist services such as plastic surgery and oncology. Patients will therefore have a combination of the following people involved in their care:

- GP for assessment of lesion and referral to hospital

- Dermatologist (at a local district general hospital or teaching hospital depending on location) for primary surgery
- CNS for support including: teaching of self-examination, coordination of hospital visits and information provision (if more than one hospital is involved then patients may have more than one CNS)
- Plastic Surgeon for larger skin surgery, skin grafts or lymph node surgery
- Oncologist for surveillance, radiotherapy and systemic therapies
- Other surgeon eg Ophthalmologist if ocular melanoma, colorectal surgeon if mucosal melanoma, head & neck surgeon for specific surgeries
- Palliative care specialists in the hospital or community setting for symptom control and complex end of life care
- Voluntary services such as those attached to hospital or hospice care. These can include information, counseling, complimentary therapy or volunteer transport services.

Patients therefore follow potentially diverse pathways and may have varied experiences. Patients within the geographical area used within this study are no exception. The specialist cancer centre receives referrals from other departments as well as five surrounding district general hospitals and from further afield for specialist care (eg mucosal or ocular melanoma). Melanoma patients with early stage disease are often treated at their local hospital but may require referral to the teaching hospital for specialist treatment.

Variation also exists within the voluntary services available depending on where patients live, for example some areas have voluntary driver services to help patients get to the cancer centre. Complementary therapies are available near the cancer centre and in some district

general hospitals or hospices but the level of service provision is not consistent across all geographical areas.

Public perceptions of melanoma are also an important consideration, with the majority of people not really being aware of what melanoma is, nor how potentially fatal it may be. Such considerations also apply within cancer services. So whilst local cancer services are improving patient pathways and care, this applies mostly to lung, breast, colorectal and prostate cancers (South Yorkshire, Bassetlaw & North Derbyshire Cancer Alliance 2017). While all areas of cancer are anticipated to benefit from additional investment, it remains the case that resources and publicity are often targeted at the most common cancers. Melanoma, although no longer considered a rare cancer still does not receive the same attention as other cancers. For example, there is no melanoma specific support group.

2.9 SUPPORT NEEDS

Supporting patients with melanoma is complex as diagnosis, curative treatment and palliative care may be required in quick succession. Such support is currently provided by CNSs based in dermatology, surgery or oncology as recommended by NICE (2006a) guidance. However there has been very little research exploring the support needs of melanoma patients (NICE 2006b). In a small qualitative study investigating the role of the Skin Cancer CNS McGarr (2008) found that the majority of time was spent with melanoma patients, who were prioritised over those with Basal Cell Carcinomas or Squamous Cell Carcinomas. For melanoma patients the CNS was seen to provide information, advice and support. However, services are inconsistent across the country, particularly the availability of Nurse Specialists (Melanoma Task Force 2011). For example, within our locality there is no defined budget for psychological

services for patients with skin cancers. Patients therefore often rely on voluntary counselling services usually funded by charities such as Macmillan. This variation in service is unfortunate as having a named CNS has been shown to make a positive difference to patient outcomes (Great Britain. Department of Health 2012).

The needs of carers of melanoma patients have received even less attention as highlighted by my own small study for my Master's degree. Whilst there is growing awareness of the needs of carers for people with cancer, support remains limited especially in areas such as melanoma. For example approximately 38% of carers for patients living with cancer reported providing more than 30 hours of care per week which can cause physical, emotional and financial burden (Macmillan Cancer Support 2008) but their needs often go unrecognised. National initiatives such as Living With and Beyond Cancer (National Cancer Action Team 2012) incorporating the National Survivorship Initiative (Great Britain. Department of Health, Macmillan Cancer support & NHS Improvement 2010) still focus primarily on the needs of the patient. At the time my study commenced very little work focused on carers, despite their need for recognition and support being great (Cancer 52 & National Cancer Survivorship Initiative 2009). Even less attention has been paid to the needs of carers of people living with melanoma.

2.10 SUMMARY

This chapter considered the nature and treatment of melanoma so that readers can better understand the condition and its potential impact on patients/carers to better appreciate the context for my study. The following chapter considers the role that the literature and other

forms of prior knowledge played in shaping the initial direction of the study and the methodology that was adopted to address its aims.

3 CHAPTER THREE: THE ROLE OF THE LITERATURE AND OTHER FORMS OF PRIOR KNOWLEDGE

3.1 INTRODUCTION

Undertaking a review of the existing literature is a widely accepted part of healthcare research. For Bryman (2012) it serves a number of useful purposes enabling the researcher to: determine what is already known about the topic, to understand what concepts/theories exist and what research methods have been used to study it, to identify any controversies about the topic, and to recognise the key contributors. Within the traditional healthcare research paradigm such '*key contributors*' are generally held to be other researchers and/or the policy/practice literatures. Moreover, methods are often viewed hierarchically, with the experiment or randomised controlled trial being at the top. Other forms of knowledge are seen as being anecdotal/lower quality, as are many other methods.

This is not necessarily the case in qualitative studies, especially those such as my own (see later for rationale) that adopt a constructivist approach, in which all forms of knowledge are equally valid (Rodwell 1998). However, the role of the literature and other extant knowledge in qualitative research is contested, especially in methodologies such as Grounded Theory. The purpose of this chapter is to explain and justify the part existing knowledge played in shaping the present study.

The role of existing knowledge, including published literature, in Grounded Theory is not universally accepted. Early advocates argued that the literature should not be consulted until

after data collection and analysis had been completed. Glaser and Strauss (1967) warned against *'forcing'* data into pre-existing categories and advised against contaminating the analysis, arguing that the literature should only be consulted after the theory had emerged. However, as Grounded Theory evolved so too did debates about the role of the literature. Corbin and Strauss (2008) acknowledged that "*Researchers bring to the inquiry a considerable background in professional and disciplinary literature*" (p134), and that the initial research question might be shaped by a variety of sources including the literature and the personal/professional experience of the researcher. Therefore, as no researcher can truly enter the field naively it is important to acknowledge anything that may have influenced the study. This was also recognised by Charmaz (2014) who concluded that an initial literature review forms part of a Constructivist Grounded Theory Study but that the purpose of this and its relationship to other forms of knowledge needs to be made clear.

Within a constructivist study the primary role of prior knowledge is to identify *'sensitising concepts'* that help to shape the initial *'foreshadowed questions'* (Rodwell 1998) that guide the study at the outset. Charmaz (2012) describes sensitising concepts as a broad term that captures the influences that inform, but not determine, the initial direction of a study. Such concepts do not provide a theoretical framework that is imposed upon the data, but they may be drawn upon in later analysis. Sensitising concepts may be derived from the published literature, but also from a wide variety of other sources, including the researcher themselves (Charmaz 2012). As her writings exerted a considerable influence on my thinking I felt it essential to make clear any role that my own prior knowledge/experience played. Furthermore, *'reflexivity'* is now widely recognised as a key component of any constructivist study (Gentles et al. 2014) and a more detailed discussion of its role within this study can be found in the methods and discussion chapters.

Moreover, in the current social and healthcare context patients and carers are not seen as passive recipients of care but rather as active players in shaping their own experience. Therefore, any patient and carer knowledge that might influence the study also needs to be considered. It was this inclusive approach to prior knowledge that informed this study.

The initial overview of the existing knowledge in this chapter therefore not only included the above sources but also the published research and professional literature. For the purposes of this study sources of professional and research knowledge were seen to emanate from published papers, textbooks, policy documents and the grey literature. Patient and carer knowledge were held to come primarily from leaflets produced by healthcare organisations or charities concerned with their condition but other potential sources such as websites, blogs and online support groups were also included. A description of the way in which these sources were identified is provided later.

Having stated my position on the definition and role of existing knowledge, attention is now turned to the various forms of knowledge that played a part in shaping the initial direction of the study, beginning with my own.

3.2 SOURCES OF MY PRIOR KNOWLEDGE AND THEIR POTENTIAL INFLUENCE

The sources of my own prior knowledge are varied and arise from both professional and personal experience. Probably the most influential were those arising from my professional background and prior studies for two Master's degrees. This was described briefly in the introductory chapter and is elaborated upon below.

My knowledge of melanoma arises primarily from my experience of working with patients. This informed me that melanoma brings uncertainty to professionals and patients alike as it may behave aggressively or be relatively benign, may respond to treatment or not. Although patients look to healthcare professionals (HCPs) for knowledge and expertise we cannot always provide the definitive answers and reassurance that patients seek. In my role as a Research Nurse I often spent time talking to patients and carers and this led me to question whether their support needs are always acknowledged. Moreover from my experience members of the skin cancer MDT often seemed to hold pre-conceived ideas about patients that may influence their views on the type and amount of support required.

Such emerging concerns influenced the development of my second Masters dissertation focussing on the support needs of melanoma patients and how these could best be met. The literature review preceding that study indicated that there was little prior work in this field with most advice being drawn from the literature on cancer generally.

At the heart of the findings from my study was the core category entitled 'Melanoma related worry'. This highlighted a number of the concerns of melanoma patients, particularly in the early stages about death and later about the possibility of recurrence. My study suggested that three factors could reduce such worries. These were:

- The extent to which patients' concerns were acknowledged and responded to, especially at the pre-diagnostic stage, with a good GP being vital
- Someone to share their worries and support them. This was most often a partner but a relationship with their CNS was also important

- Patients' efforts to try and avoid recurrence. These revolved mainly around sun-avoidance and self-examination.

Building on my professional experience and my findings I increasingly realized that melanoma was rarely a solitary experience. Rather others, especially family members and HCPs, play a key role. The extent to which patients' concerns were acknowledged and addressed seemed to turn largely on the quality of their relationships with others.

Such themes also emerged from the published literature and played an important part in shaping the initial foreshadowed questions for my study.

Whilst my professional experience clearly influenced my thinking, personal experiences of contact with the health care system, both in relation to myself and my father also played a part.

Shortly before starting my PhD I had urgent investigations and treatment for suspected thyroid cancer. A partial thyroidectomy was carried out but the worst part was awaiting the results of the biopsy and final histology. Time seemed to stand still and days felt like months, causing me considerable anxiety. To minimise concern amongst family and colleagues during this period I played down my own fears using humour. This reinforced for me the difficulties that many melanoma patients must have in fully sharing their concerns with others.

Supporting my mother caring for my father (who had a cardiac condition over a 15 year period) was far more protracted and further reinforced my increasing belief that the role and support needs of carers are not fully recognised in the current health care system.

Having highlighted the part played by my own prior knowledge/experience I now consider sources of patient and carer knowledge.

3.3 SOURCES OF PATIENT AND CARER KNOWLEDGE

Given the active role now accorded patients, and to a lesser extent carers, within the health care system, I was clear that these groups should play an active part in my study. It also seemed likely that before I interviewed them, my participants would have been exposed to various forms of knowledge that may have shaped their understanding of melanoma. I therefore wanted to explore major sources of such knowledge for potential sensitising concepts.

Patients and carers probably gain much of their knowledge from information leaflets provided by HCPs after diagnosis. Leaflets relating to melanoma from prominent UK healthcare organisations and charities were therefore seen as important. Newspapers are also a common source of information and so efforts were made to explore how melanoma is portrayed in the popular press. Patients also increasingly turn to the internet for advice and the popular search engines Google and Yahoo were searched using the term '*melanoma*'. These three searches are detailed below.

3.3.1 PATIENT INFORMATION LEAFLETS

All patient and carer information booklets produced by Cancer Research UK (CRUK), Macmillan Cancer Support (MCS), the British Association of Dermatologists (BAD) and National Health Service (NHS) Choices were included up to June 2013. Leaflets from Cancer Bacup, the leading provider of cancer patient information in the UK until 2008 when it merged with MCS, were also included. In 2011 the local teaching hospital stopped producing and updating its own patient information for cancer in favour of using the resources produced by MCS. The most prominent source of information was therefore MCS who have produced six separate guides for patients with melanoma. Information sources regarding other cancers, general effects of cancer or non-melanoma skin cancer were excluded from the search. Information from BAD may have been given to patients by Skin Cancer CNSs working in peripheral dermatology clinics. These were therefore included. Patients would most likely access CRUK and NHS choices information via the internet owing to their predominantly electronic format. These sources were therefore included in the internet search to avoid duplication. The main patient information leaflets/booklets included were therefore those produced by MCS and BAD as listed below with examples in Appendix 1.

MCS:

- Understanding melanoma
- Understanding melanoma: treatment with local surgery
- Understanding melanoma: lymph node assessment and treatment
- Understanding melanoma: adjuvant treatments after surgery
- Understanding melanoma that has come back in the same area
- Understanding advanced melanoma

BAD:

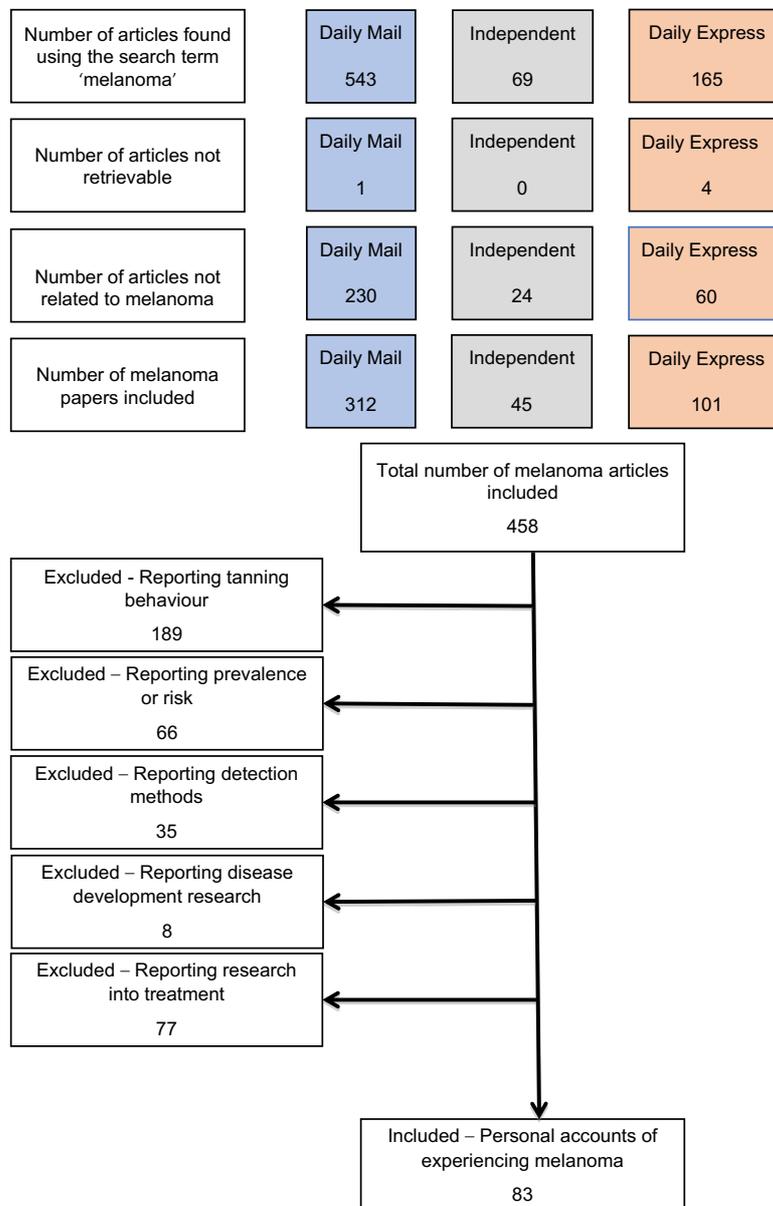
- Stage 1 melanoma
- Stage 2 melanoma
- Stage 3 melanoma
- Stage 4 melanoma

3.3.2 NEWSPAPERS

The British Newspaper Archive did not yield any results after 2000 so was not used as recent articles were not available. Individual popular national newspaper archives were therefore searched for the term '*melanoma*' for the previous 10 years (2003-2013) to see how melanoma was presented in the popular media. Publications included The Daily Mail, The Independent, The Guardian, The Sun and The Telegraph as these were the newspapers with the largest readership (Hollander 2013). Searches of individual newspaper archives using the term '*melanoma*' revealed articles from 1999. The content was scanned backwards chronologically from the most recent in 2013 to the oldest and the decision made to stop retrieval at January 2003 when no new information was forthcoming. Articles not relating to melanoma were excluded. Where the terms '*melanoma*' and '*skin cancer*' were used interchangeably articles were read carefully to determine whether melanoma or non-melanoma skin cancers were being referred to. Articles discussing both melanoma and non-melanoma skin cancer were included but those discussing non-melanoma only were excluded. Articles relating to melanoma were then screened to focus on those reporting the patient or carer experience. Those that only concerned tanning behaviour, melanoma prevalence or risk, detection methods, research into melanoma development or research into new treatments were

excluded. Data were extracted from personal accounts of having melanoma to discover themes relating to the experience. The Guardian, the Times, the Sun and the Telegraph did not have searchable archives that were free to use so articles found from the Daily Mail, the Independent and the Express were used as a representative sample of newspaper headlines during the time period chosen. The selection of newspaper articles is shown in Figure 3.1:

Figure 3.1: Selection of Newspaper Articles



3.3.3 INTERNET SEARCH

The popular search engines Google and Yahoo were searched for information published in the UK between January 2003 and June 2013 mirroring the dates of the newspaper search. While UK versions of the search engines were used and UK sources specified in the search,

some international results were returned by the search engines. These were therefore included as patients may have accessed them. To make the search manageable, results were then considered for the first two pages only as the majority of internet users do not go past the first page (Chitika 2013, Petrescu et al. 2014). Websites rather than webpages were considered as the unit of analysis for extract data. All pages relating to melanoma in humans were included with those relating to melanoma in animals being excluded. A description of the websites included can be found in Appendix 2.

How these sources were analysed is considered later in this chapter. I will now consider professional sources of knowledge.

3.4 SOURCES OF PROFESSIONAL KNOWLEDGE

Professional knowledge was held to come primarily from the published research literature, textbooks and the grey/policy literature. There is no widely accepted 'core' text on skin cancer/melanoma so the National Institute for Health and Care Excellence (NICE) guidelines were used. These are therefore considered below.

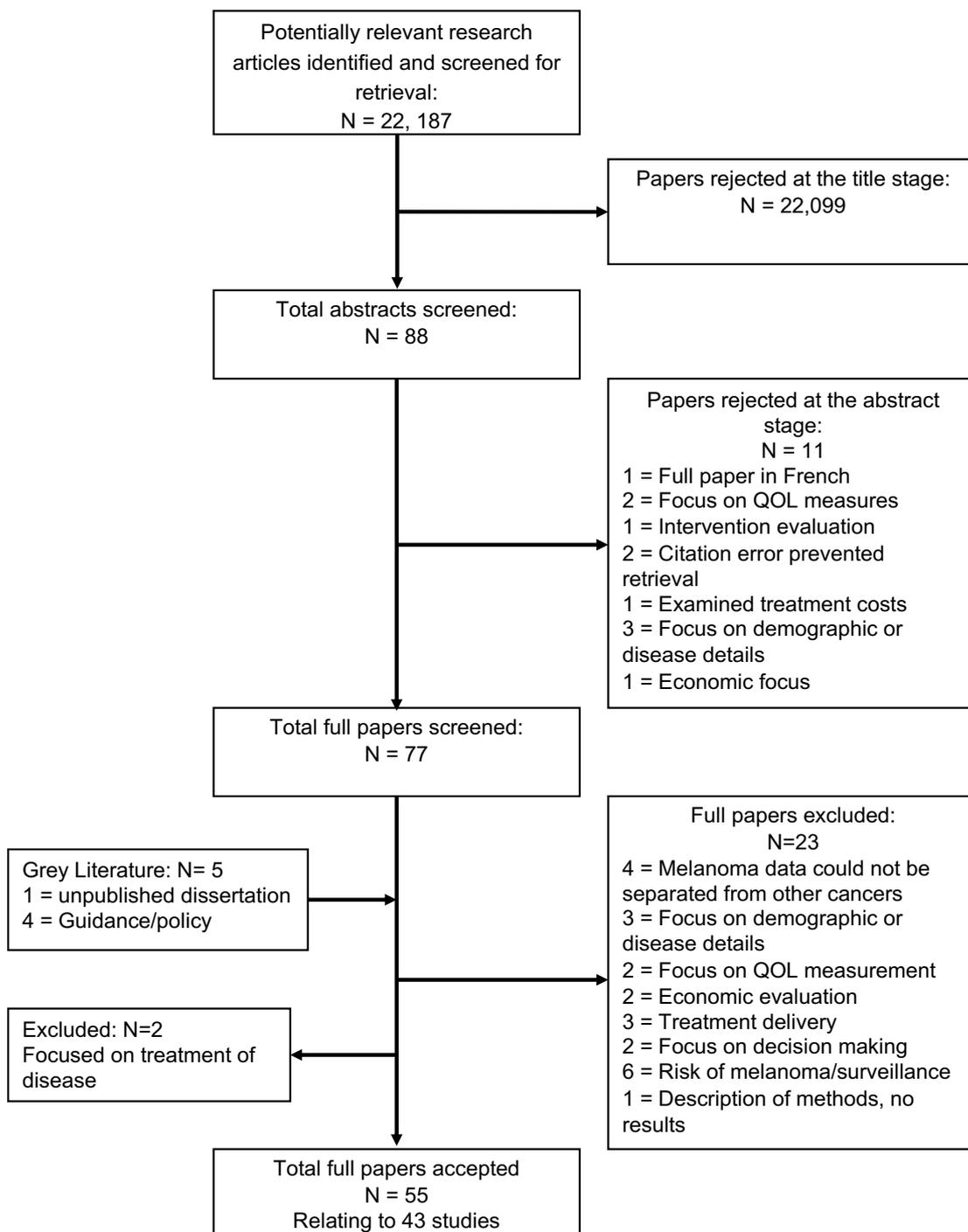
NICE published guidelines for the care of patients with skin cancer in 2006 following a review of the extant literature (NICE 2006a). This revealed a dearth of evidence on the needs of this group and a qualitative survey was therefore commissioned (NICE 2006b). The review identified twelve studies including one systematic review of good quality, nine observational studies of fair quality, one observational study of poor quality and one expert review of fair quality. Of these papers five focused on melanoma. Overall the quality of the evidence was

found to be poor, based on the presumption that RCTs provide the most robust evidence. The conclusion reached was that patients with skin cancers have diverse needs that differ from those of patients with other cancers (NICE, 2006a). However, the needs of melanoma patients were not considered separately and the needs of carers were not considered at all. Reviews on patient information needs, the needs of patients with disfigurement, psychological interventions, patient satisfaction surveys, clinical trial participation, protocol driven care and palliative and supportive care were undertaken separately, reflecting how HCPs view patients' needs individually rather than holistically.

As the above review represented a comprehensive consideration of the, admittedly limited, literature up until 2006 I only considered work after that date until the start of the study (June 2013). Separate searches were performed to find papers published on 1) the experience and needs of patients with melanoma 2) the experience and needs of the carers of patients with melanoma. Details of the databases and search terms used can be found in Appendix 3.

Studies identified were then screened via the title and those that appeared to meet the criteria detailed in Appendix 4 were screened via the abstract. Full text versions of the relevant studies were retrieved to ascertain whether they met the requirements of the review. As this was not intended to be a systematic review but rather a broad conceptual overview of the main ideas about melanoma, influential studies were not excluded on the basis of 'quality' using tools such as the Critical Appraisal Skills Programme checklists (CASP 2017). The selection of papers can be seen in Figure 3.2.

Figure 3.2: Selection of professional papers



As indicated in the figure above, on completion of the search and application of the selection criteria 55 papers were included in the review. A table of study characteristics can be found in Appendix 5.

The majority of the studies were descriptive rather than testing an intervention or determining causality. Most used a cross-sectional survey design where measurement tools were self-completed by respondents. Fifty-eight separate tools were identified, including measures of HRQOL, cancer symptoms, melanoma specific measures, psychological coping or distress and information need. The literature reviews included in the review also heavily relied on these measurement tools to capture patient outcomes. The quality of the measurement tools varied with some being validated in international melanoma populations (such as the FACT-M) to those that had not been validated in a melanoma population. Some of the original versions had been modified but not subsequently tested for internal consistency, others had been translated but not validated with the target population. Such issues limit the interpretation of the results of these studies.

Five qualitative studies provided the most detailed first-hand accounts of the experience of melanoma. Two papers based on the same study of perceptions of GP-led follow-up in Scotland considered patients' perspectives (Murchie et al. 2010) as well as those of GPs (Murchie et al. 2009). The third paper explored the risk perceptions and coping mechanisms of a high risk population after surgery for melanoma in Australia (McLoone et al. 2012). The fourth explored the experience of carers of cancer patients in France, but included 17 melanoma patients (Mancini et al. 2011) and the fifth explored the impact of non-metastatic melanoma on QOL in a British population (Burdon-Jones et al. 2010).

Overall the extant research literature when the study commenced was mainly limited to deductive approaches reducing the patient experience to quantifiable data to enable comparison between groups. Whilst this indicated the symptoms patients experience and the efficacy of interventions, it does not necessarily reflect the issues that are most important to patients and carers as all the measures used were designed by researchers.

Grey literature included NICE guidance and evidence review (NICE 2006a, NICE 2006b) and an unpublished dissertation (McGarr 2008). The NICE guidance and evidence review has been described earlier in the chapter. The dissertation (McGarr 2008) was a small qualitative study involving 11 Skin Cancer CNSs that explored their perspectives of their role. The study included a literature review on the needs of skin cancer patients concluding that despite differences to other cancers, patients diagnosed with skin cancer experience similar emotional and psychological responses to their diagnosis as patients with other cancers and have similar needs.

The searches of professional sources of knowledge also revealed two patient accounts of melanoma. One was a first person account of having melanoma written by a nurse (Griffin 2011) and the other was a book about melanoma published by a patient (Welsh 2011). Sally Welsh (2011) used her own experiences of melanoma to produce '*A Melanoma Patient's Survival Guide*'.

3.5 ANALYSIS AND SYNTHESIS

Thematic analysis of all sources retrieved was undertaken. Each source of information was read and re-read while notes were taken to identify themes. The patient information booklets available at the time focussed primarily on disease/treatment so did not greatly influence

themes related to the patient and carer experience. Web searches and a link written in a newspaper article led to first-person accounts of melanoma on the internet. These included written accounts, such as an American photographer who took daily photographs of his life including his diagnosis and treatment for melanoma and a video diary of an American man and his wife as he is treated for melanoma. The purpose of the photographs was artistic, but the purpose of the video diary was to warn people about the dangers of tanning. In examining the photographs I took notes on their meaning as I looked through them, recording what they seemed to represent. As I watched the videos I also took notes about what was being shown and its meaning. Some videos or sections were re-watched when I felt I needed to check my interpretation.

Following detailed reading/viewing initial themes were identified from these patient accounts and synthesised with those emerging from my own personal/professional knowledge. In combination these indicated that:

- Melanoma is a source of considerable worry/concern that patients want to be recognised and responded to.
- Such concerns relate primarily to fear of death, especially in the earlier stages and later to fear of recurrence. My own brush with cancer highlighted how difficult it can be to share concerns without 'burdening' those close to you.
- The desire to share concerns highlighted the importance of close and supportive relationships, often with a partner or other family member but also with a trusted health care professional.
- Both my professional and personal experience strongly suggested that living with melanoma (or other health related worry) is rarely an individual experience but that it involves and impacts on others, especially family members. The extent to which family

members for people with melanoma can be seen as 'carers' in the more widely accepted sense has not been explored and their needs had, to date, received little attention.

- Melanoma is likely to result in behavioural change by the patient, such as sun avoidance and/or self-examination.

Newspaper articles, while sometimes based on patient reports, were stylised to fit the agenda of the journalists (to sell news) often resulting in sensationalised, emotive accounts. Websites also tended to be written for specific purposes including disease information and fundraising. However, when sources were considered together clear themes emerged. These related primarily to:

- Not knowing about the dangers of tanning
- Wanting to warn others about melanoma and the dangers of sun exposure
- Avoiding sun exposure and using preventative measures
- The value of supportive relationships
- The effects on the family
- Feeling lucky having survived melanoma
- Worrying about the melanoma coming back
- Financial issues following a diagnosis of melanoma

There were notable temporal variations within the newspaper searches in that during 2006 and prior to that the articles talked about skin cancer and did not differentiate between sub-types. After 2006, however, melanoma was specifically mentioned with it being referred to as '*the most deadly/aggressive form of skin cancer*'. This change in public or journalistic perception of the disease coincided with the discovery of new treatments for melanoma, so

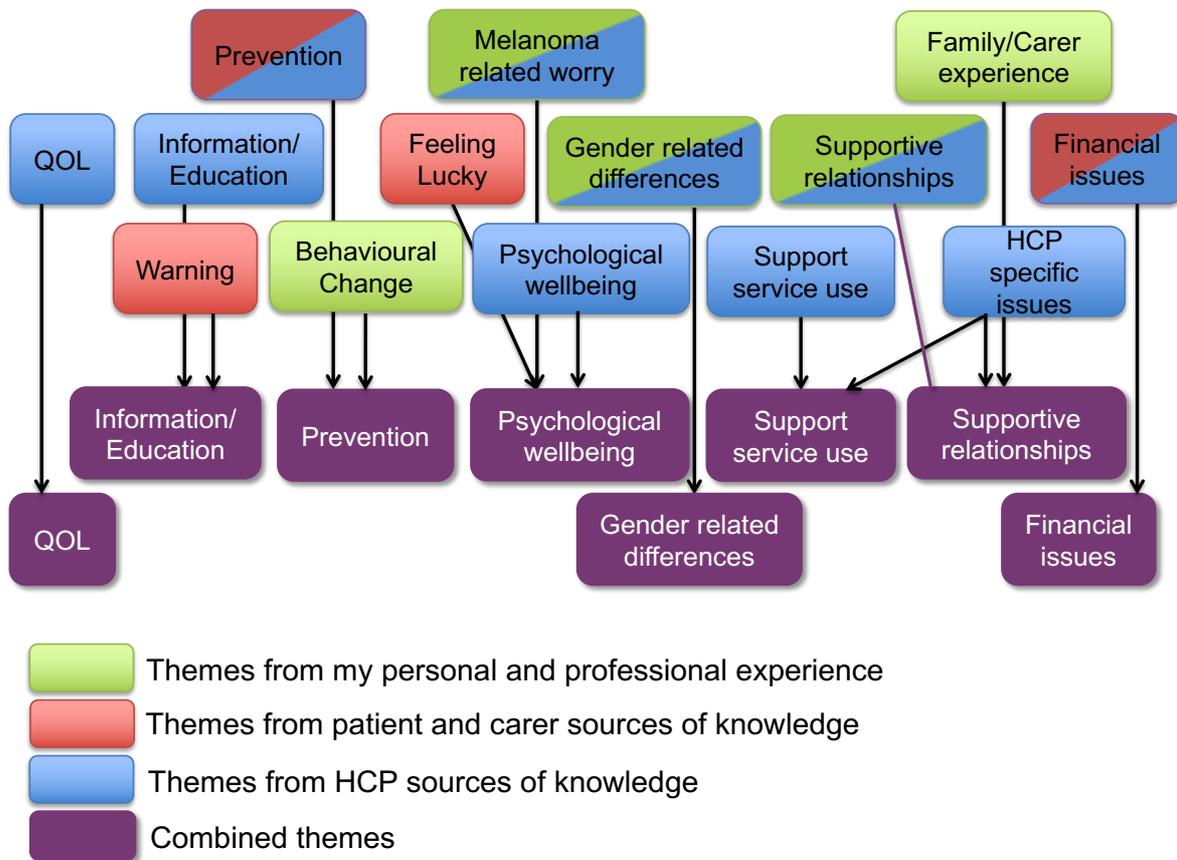
may have arisen from research related publicity, pharmaceutical publicity and/or a public need to differentiate skin cancers owing to treatment changes.

Analysis of the research and grey literature revealed several themes. These were identified as: QOL, psychological wellbeing, gender, sun avoidance, supportive relationships, information and education, financial issues, and support services.

An overview of how these were described in the research literature is provided below. Rather than describe individual studies in detail the ways in which each of these themes was '*represented*' in the research literature is the primary focus here.

Following analysis of all three forms of prior knowledge (my own personal/professional, patient and carer sources and the research literature) the themes emerging were then synthesised and these are summarised in Figure 3.3 below.

Figure 3.3: Development of themes from the existing knowledge



Each of these major themes is now described below.

3.5.1 QUALITY OF LIFE

‘Quality of life’ (QOL) or ‘Health Related Quality of Life’ (HRQOL) are terms that appeared in numerous studies concerning the impact of disease and illness and/or their treatment. More often than not these concepts are captured using measures devised primarily by researchers and intended to provide a summary score that can be used in complex multi-variate analyses. This was certainly the case in the research literature relating to melanoma with such measures being used extensively to provide an indication of, for example, the value of additional life added by new treatments or the relative cost of those treatments. Almost 60 different instruments were found in the studies I identified exploring varying dimensions of ‘Quality of

Life' such as: physical functioning, mental functioning, anxiety, depression, as well as melanoma-specific symptoms or behaviours. These were often used to compare a group of melanoma patients to a '*normal*' population or other cancer patients. There are numerous problems associated with such an approach. The most obvious of these limitations is that many of these instruments have not been validated with melanoma patients and therefore may not be sensitive enough to detect changes specific to melanoma (Cornish et al. 2009). A more fundamental question might be '*do quantitative measures devised by researchers actually capture the impact of melanoma as experienced by patients themselves?*'

Notwithstanding these limitations studies suggest that melanoma does impact on patients' QOL in varying ways at differing points in time. Al-Shakhli et al. (2006) found that patients' QOL was reduced during the diagnostic period but others found that this impact was not sustained over time (Schubert-Fritschle et al. 2013). Indeed, in some cases melanoma patients had better QOL 'scores' than the general population (Holterhues et al. 2011, Zucca et al. 2012, Noorda et al. 2007).

These findings of improved QOL reflected patient accounts of melanoma found in the newspaper reports, first-hand accounts on websites and in books written by melanoma survivors. Having one's mortality threatened through a melanoma diagnosis but surviving appears to give people a new appreciation for life. Sally Welsh (2011) states that:

"Beautiful things happen in the minds, hearts and bodies of melanoma patients. Priorities change. Words that might never have been spoken are suddenly spoken. Faith grows. Beauty that was unseen is now seen. Lived life can become life lived abundantly!!" (P1)

However in metastatic disease QOL can change dramatically. For instance, Cashin et al. (2008) found that patients' condition deteriorated quickly in almost all areas of QOL. The full emotional impact of this has not been systematically studied but website entries such as the

video diary of Eric Sizemore (Sizemore 2011) illustrates his dramatic physical deterioration over time. Most studies of QOL have focussed on the patient but the video diary of Eric Sizemore was filmed by his wife and reveals the physical and emotional effects on her.

It is clear therefore that living with melanoma is likely to impact on QOL, although this may change over time and perceived QOL can improve when treatment is successful. However, such studies have been largely quantitative and often instruments not designed to assess QOL in melanoma. There have been very few qualitative studies on patients' QOL nor has the experience of carers been explored.

A closely related concept in the research literature was psychosocial wellbeing.

3.5.2 PSYCHOSOCIAL WELLBEING

As with QOL several areas of psychosocial wellbeing can be impacted by melanoma in differing ways over time, such as anxiety and depression, especially around the time of diagnosis. Indeed the initial appointment may cause more anxiety than awaiting the results (Al-Shakhli et al. 2006). In a review of the research literature, Kasparian et al. (2013a) found the diagnostic period to be the most stressful time of all with patients expressing fears about death and suffering, as well as concerns about the emotional well-being of significant others such as family and friends. This is reflected in patient accounts. For example Rebecca Smith (2012) was '*consumed by anxiety*' worrying that she would not live to see her daughter's wedding the following year and Sally Welsh (2011) described her diagnosis as '*grief upon grief*'.

Kasparian et al. (2012a, 2009) found that melanoma has significant emotional, social, and psychological consequences, particularly anxiety and depression, with women (Vurnek et al. 2008) or younger patients with lower education, unemployment and limited social support, being most at risk (Kasparian et al. 2012a, 2009). Poor psychological well-being is compounded for those with greater physical deterioration; negative cognitive appraisals of melanoma, passive or avoidant coping styles, and a lack of confidence in one's ability to cope (Kasparian et al. 2012a, 2009).

Body image is another area of concern, but again varies, for example by personality type with Lichtenthal et al. (2005) finding that patients with compulsive personality characteristics express more concern, as do women and those with more histrionic personality features.

Whilst the time around diagnosis appears a particularly stressful period anxiety often reduces upon diagnosis (Al-Shakhli et al. 2006) as many patients experience a process of adjustment (Murchie et al. 2010, Bird 2011). However such findings are not universal and Hamama-Raz et al. (2007) found that neither the stage of the cancer at diagnosis nor time since diagnosis predict either well-being or distress, with the impact of such being contested. However, fear of recurrence or metastatic disease can last for years after treatment is completed (Kasparian et al. 2012b, McLoone et al. 2012) with uncertainty about the future being an on-going concern (White et al. 2012), irrespective of the actual risk (McLoone et al. 2012, McLoone et al. 2011).

However, in response to this uncertainty some melanoma patients can develop a more positive outlook on life (Oliveria et al. 2013) by making the most of the time they have, spending more time with family and doing the things they enjoy (Bird 2011). When compared to patients with other skin cancers those with melanoma seem significantly more likely to

mention a sense of relief/gratitude following treatment and/or a commitment to enjoy life more (Burdon-Jones et al. 2010), for example being grateful to watch their daughters grow up (Bucay 2007).

Feelings of psychological distress are likely to extend to carers and families but this was not considered in the literature.

Given the potential emotional impact of melanoma the literature indicates that many patients would like more emotional support (McLoone et al. 2012, Kasparian et al. 2009) but that this is not always provided (McLoone et al. 2012). Ironically patients with other dermatological conditions are more likely to be referred for psychological support than those with melanoma, even though melanoma has a far greater impact (Korner & Fritzsche 2012). This is despite the fact that interventions such as education, behavioural/skills training, social support and psychotherapy appear to improve psychosocial outcomes for melanoma patients (Kasparian et al. 2013a). However, to date studies have only targeted patients with a high risk of recurrence.

As with QOL it seems that melanoma can have a negative impact on psychological well-being but that this may vary depending on factors such as coping styles or personality traits, as well as gender or age. Furthermore, any negative impact may vary over time, decreasing in those who are successfully treated, although fear of relapse and/or metastatic disease may last for several years. However, the impact of melanoma need not be negative with some patients appearing to reappraise their priorities and take a different outlook on life. Again the research on QOL studies exploring psychological well-being have been nearly all quantitative.

Another area in which melanoma may have an impact is on the patient's financial situation.

3.5.3 FINANCIAL SITUATION

Melanoma patients may experience financial problems that can vary by age. Economic concerns appear far more prominent amongst younger melanoma survivors, whose ability to work may be affected (Oliveria et al. 2013). Irrespective of their employment situation patients reported difficulty in obtaining health insurance/life insurance (Holterhues et al. 2011, Oliveria et al. 2013), travel insurance (McArdle 2012), disability insurance or mortgages (Holterhues et al. 2011). For instance, McArdle (2012) found that 7 of 10 leading insurance companies would decline an application for insurance within 5 years of diagnosis, after 5 years patients faced an increased premium.

With a range of potential problems facing melanoma patients it is important to consider what support can be most helpful. The provision of education/information is one of the most frequently cited in the literature.

3.5.4 INFORMATION & EDUCATION

The literature clearly indicates that melanoma patients value information (Constantinidou et al. 2009) but frequently do not get as much as they want (Al-Shakhli et al. 2006, Husson et al. 2010. Hetz & Tomasone 2012, Schlesinger-Raab et al. 2010), especially those with metastatic disease (Passalacqua et al. 2012, White et al. 2012). Husson et al. (2010) suggest that patient-tailored information can improve satisfaction but recognise that time and resources may be barriers to this.

In a literature review Rychetnik et al. (2013) found the main sources of information patients use are: doctors, nurses and books/magazines. HCPs are therefore the primary source of information for patients and my own personal experience and observations suggest that the CNS has a central role to play in this regard.

The Internet is also increasingly used as an important source of information with Ludgate et al. (2011) finding that the majority of skin cancer patients see using the Internet as a positive experience yet were wary of some content on the available websites, with a third of melanoma patients experiencing anxiety as a result of their Internet search. My own search revealed that the majority of information for melanoma patients is produced by charities or healthcare organisations and written by HCPs for patients, carers and the public. The information booklets produced by MCS (2011a, 2011b, 2011c, 2011d, 2011e, 2011f) and CRUK (2012a, 2012b) have the most detail about melanoma and its treatment.

However, simply providing written information may not be enough. From my experience of talking to patients about melanoma, particularly during my Masters dissertation, I found that patients needed help to relate any information to their own circumstances. This is important as some groups of melanoma patients may have greater information needs than others. For example, individuals without secondary education were found to have greater information needs but were paradoxically less able to ask questions of their medical team (Hetz & Tomasone 2012). Husson et al. (2010) also discovered an association between level of education and satisfaction with the information provided. The need for information may also vary dependent on the stage of disease or risk of recurrence (McLoone et al. 2011, Husson et al. 2010) with patients who have later stage disease or low risk of recurrence being more satisfied with information provision. Gender may also be a factor with Clarke et al. (2006)

concluding that men are more likely to access written information whereas women prefer oral sources providing they have faith in the provider (Passalacqua et al. 2012).

Content of information may also be important. From my analysis of websites containing patient stories of melanoma tended to be cautionary in nature, as were some of those generated by various charities. For example while the American Cancer Society (2008, 2011, 2013) devotes one section of it's website to stories of hope, the content predominantly focuses on warnings to people who might develop melanoma. Newspaper articles also contain predominantly '*warning messages*'. Messages of encouragement, survival and feeling lucky or thankful are secondary. It therefore appears that much of the information potentially available to melanoma patients says relatively little about how to live with the condition other than avoidance or the prevention of recurrence and that an '*information gap*' about living positively with melanoma exists.

On the basis of my reviews it therefore seems that:

- Many melanoma patients have a high need for information that is not always met
- There is an informational gap about the experience of having and living with melanoma
- Subgroups may have additional information needs and those with lower educational levels are potentially less well served
- Men and women may have differing information needs

As noted above information is often obtained from HCPs and access to these and other forms of support is also an important consideration.

3.5.5 SUPPORT SERVICE USE

Access to support services is likely to vary at differing times. The diagnostic period can be a particularly stressful one but this may not run smoothly. Many patients describe experiences of missed diagnosis and being told that a mole or lesion was '*nothing to worry about*' only for it to later be diagnosed as malignant. Others describe having to make repeated visits to their GP, of not being taken seriously and of having to '*insist*' on a referral for specialist opinion. This was a major finding in my MSc dissertation (Bird 2011) where the initial contact with GPs was pivotal to subsequent trust in the system more generally.

On-going treatment often necessitates contact with several differing HCPs, including dermatologists, primary care providers and nurse practitioners (Bowen et al. 2012). In clinical practice I have observed CNSs, oncologists and plastic surgeons performing clinical examinations. Such visits can in themselves cause anxiety if there are concerns about recurrence (Oliveria et al. 2013) but may also be viewed positively if they allow patients to feel in greater control of their situation (McLoone et al. 2012). Location of follow-up may also be important with logistical difficulties such as transport inhibiting attendance (Rychetnik et al. 2013). Conversely GP-led melanoma follow-up is more convenient for some, especially if they perceive their appointment to be less rushed, the atmosphere to be more pleasant and having better continuity of care (Murchie et al. 2010).

Continuity of care enables a trusting relationship to be built between the patient and HCP. Hamama-Raz & Solomon (2006) found that melanoma survivors at high risk of recurrence particularly valued '*expert care*' that was readily accessible and delivered with continuity. Expertise of the person conducting an examination is important, particularly if patients have lost trust in a HCP (Oliveria et al. 2013, McLoone et al. 2013), with trust appearing to vary by the type of practitioner. For example, Murchie et al. (2010) found that some patients are

concerned that most GPs have less experience of melanoma than hospital specialists but also worried about the expertise of junior doctors who were perceived to have poor knowledge. Rychetnik et al. (2013) suggests that perception of expertise is a social construction, often based on the nature and quality of the relationship between patient and HCP.

Given the psychological impact of melanoma best practice should include protocols for the management of depression and anxiety, including referral to psychosocial specialists as appropriate (Hamama-Raz & Solomon 2006). However, as noted previously there is much room for improvement, with McLoone et al. (2012) finding that no patients in their study received professional emotional support. Similarly, the review conducted by Schlesinger-Raab et al. (2010) found that almost half of all study participants indicated that their doctors did not ask about their ability to cope with their disease.

Melanoma patients appear to access the majority of professional support during routine follow-up appointments rather than from additional support services. Winzer et al. (2009) found that patients who were younger, male and who had no partner were more interested in accessing a specialist support programme. There may therefore be specific sub-groups with limited pre-existing social support who would benefit from support services.

Studies exploring what HCPs think about providing support are very limited with a small qualitative study of nine CNSs by McGarr (2008) finding that they saw the provision of information and support as being a major part of their role and was something that patients valued. No other studies relating to melanoma could be found.

From a consideration of the literature on access to professional support it appears that:

- Support provision may not match patient need and that the limited amount provided is available later in the trajectory but a great deal of anxiety is experienced during diagnosis
- The majority of support for melanoma patients is given during surveillance visits making continuity of care important
- The relationship between the patients and HCP is key to enabling patients to voice their concerns
- Different types of support may be appropriate for differing groups of melanoma patients
- There appears to be no literature regarding the support needs of carers

Despite the availability of formal support much of the help that melanoma patients receive comes from their close relationships

3.5.6 SUPPORTIVE RELATIONSHIPS

Social support within close relationships is the most frequently used coping strategy amongst people with melanoma (Lehto et al. 2005, Mancini et al. 2011). Such relationships are often with family members, especially partners, but can also come from the patient's wider social network or HCPs (Lehto et al. 2005). Gender differences in the source of social support have been found with women being significantly more likely to be supported by their friends, and men by their close family (Schlesinger-Raab et al. 2010). Older patients have been found to receive less support than younger ones (Lehto et al. 2005) suggesting that there may be groups of melanoma patients with unmet needs.

Given the importance of supportive relationships it is surprising that the needs of carers are not considered in the research literature, despite the significant feelings of grief and loss that are described in the press upon the death of a patient (Sizemore 2011). Moreover carers may also have to support other family members such as children, something that often causes additional stress (Griffin 2011).

Faith is another source of support for some patients and carers and a diagnosis of melanoma may strengthen a person's relationship with their religion or spiritual beliefs. But again this is not considered in the research literature with accounts being confined largely to the popular press (Sizemore 2011, Welsh 2011).

Despite the importance of close supportive relationships being widely recognised, the nature of such relationships and the impact that melanoma has upon them has not been widely studied.

3.5.7 GENDER RELATED DIFFERENCES IN EXPERIENCING MELANOMA

As noted in a number of the themes above, gender appears to influence the ways in which people experience melanoma. However the impact of gender reported within the research literature varies depending upon the measures used. For example Ludgate et al. (2011) found no correlation between levels of anxiety and gender at initial consultation whereas Lehto et al. (2005) found that newly diagnosed females reported greater psychological symptoms and depression than males. Later in the disease trajectory Hamama-Raz (2012) found that distress was significantly higher among female than male melanoma survivors although Vurnek et al.

(2008) found no differences between men and women in QOL or coping styles. Amongst patients with advanced melanoma women want significantly more involvement in treatment decisions, clearer information, and more dialogue with HCPs (Passalacqua et al. 2012).

The nature and extent of gender differences are therefore inconsistent but on balance melanoma appears to have a more negative impact on women than men. Differences between men and women may not be specific to melanoma patients as White et al. (2012) studied a number of cancers and found that overall women had greater concerns than men about: the cancer returning, the cancer spreading, the impact of cancer on those closest to them, their lack of energy and tiredness, and not being able to do the things they used to do.

Gender differences in behavioural responses to melanoma are just as unclear, with Korner et al. (2013) finding no differences in self skin examination (SSE) and sun avoidance behaviour whereas Manne & Lessin (2006) reported that men were less likely to engage in SSE, sun avoidance or use sun protection. The reasons for this were not explored but newspaper articles suggest that this might be due to the '*macho*' attitude of men. Holterhues et al. (2011) found that women were more worried about the effects of sunlight on both their skin and on their spouses and children and so sought shade and/or used sunscreen more often than men. These findings suggest gender differences related to anxiety, perceived risk or a greater concern with body image and appearance (Lichtenthal et al. 2005).

The literature also suggests that there may be gender differences in how people seek information and support. Women have been found to be more likely than men to use the Internet to search for information about their diagnosis (Ludgate et al. 2011) while a different study found that men had significantly more interest in a support programme than women

(Winzer et al. 2009). It may be that women have social networks in place to assist coping whereas men rely more on support groups. Women express a greater willingness to talk to family members, other cancer patients, nurses or non-medical staff (Schlesinger-Raab et al. 2010). This may be because women feel more comfortable discussing their emotions with their wider social network than men, who tend to rely more on close family members (Schlesinger-Raab et al. 2010). My own study found that there may also be gender differences in people's preference for the gender of the HCP that they develop relationships with, one man stating that he could not '*pour his heart out to a woman*' (Bird 2011). This may be because men tend to rely more on their own resources with some studies suggesting that men see themselves as being better able to cope than women (Hamama-Raz 2012).

For women of childbearing age, a melanoma diagnosis can have very specific effects regarding family planning. Some women decide not to get pregnant because they have been informed that hormones may accelerate melanoma development or they are worried about passing the risk of melanoma to their children (Oliveria et al. 2013). This concern was expressed in the popular press.

Therefore whilst the picture that emerges varies it seems that gender does exert an influence on the experience of melanoma in respect of

- The degree of anxiety or worry reported
- Behavioural changes with regard to sun avoidance and protection
- Perceptions and use of social support networks
- Women of childbearing age experience specific decisions regarding family planning

3.5.8 BEHAVIOURAL RESPONSES TO MELANOMA: PREVENTION

The most commonly reported behavioural responses to a diagnosis of melanoma relate to SSE, sun avoidance and/or protection. Reports are especially prevalent in newspaper articles and patient accounts on the internet which all warn of the dangers of sun exposure and many include statements about sun protection measures (Sizemore 2011, David Cornfield Melanoma Fund 2011). 189 newspaper articles, excluding those detailing personal accounts of melanoma, were found to relate to sun protection and the dangers of tanning often using emotive headlines such as “*My TOWIE tan gave me skin cancer!*” (Satherley 2011) and “*Sunbeds almost wrecked my face*” (Donnelly 2012).

Within the research literature a diagnosis of melanoma is portrayed as a ‘teachable’ moment where patients could improve sun protection and SSE habits owing to increased perception of risk and distress (Manne & Lessin 2006) with melanoma survivors becoming more aware of sun avoidance and protection measures (Burdon-Jones et al. 2010, McLoone et al. 2012, Oliveria et al. 2013). However, the frequency of SSE has been found to increase only with perceived benefit and not perceived risk or skin cancer-worry (Kasparian et al. 2012a). Different patient subgroups seem to have varied knowledge, readiness for change, and receptiveness to medical advice regarding SSE, suggesting that an individual’s psychosocial characteristics need to be considered (Korner et al. 2013). My dissertation project (Bird 2011, Bird et al. 2015) found that some patients perform SSE for reassurance to mitigate melanoma related worry. Others have also found that worry about sun exposure can lead to lifestyle changes in some melanoma patients that may affect their daily activities and choice of leisure pursuits or holidays (McLoone et al. 2012, Mols et al. 2010). While the majority of melanoma patients continue outdoor activities while using sun protection measures, being outdoors without sun protection can be a cause of anxiety (Oliveria et al. 2013, Mcloone et al. 2012). This is not the case for all melanoma survivors though as the use of specific sun protection

behaviours within the melanoma population has been shown to vary. For example, Bowen et al. (2012) found that 59% wore long-sleeved shirts, 80% wore long trousers or skirts, 45% used sunscreen with SPF 15+, 35% wore something to cover their head, 16% wore a wide brimmed hat, 46% wore sunglasses, 36% stayed in the shade and 20% avoided peak hours of sun. However in one study of patients with primary melanoma in the USA, SSE and the use of sun protection measures (with the exception of sunscreen use) was not greater than that of the general population (Mujumdar et al. 2009). There are therefore groups of melanoma patients with differing needs relating to sun protection.

Once again women are more likely to worry about sun exposure than men (Holterhues et al. 2011) and are more likely to engage in sun protection activities such as seeking shade, wearing sunscreen, having fewer holidays to sunny destinations and wearing long sleeves and trousers (Holterhues et al. 2011 Bowen et al. 2012). However, men report nearly seven times more usage of hats, caps or scarves than women (Bowen et al. 2012).

The effect of the diagnosis on the families of melanoma patients may depend not only upon patient factors, but also the perceptions of individual family members and the interactions between patients and their families. Women have been reported to be more worried about their spouses and children being exposed to the sun than men (Holterhues et al. 2011) and caregivers of melanoma patients have reported a decrease in their own sun-related activities (Mancini et al. 2011). During my MSc dissertation some patients discussed their families adopting sun protection behaviours but this was not explored with carers themselves who were not part of the study (Bird 2011).

The professional literature strongly promotes patient education although this is not always applied in practice, which may partially explain why not all melanoma patients adopt preventive behaviours. Within my clinical experience medical consultations are short and do not leave much time for discussion about sun protection behaviours. The focus of surveillance visits is to detect new or recurrent melanoma and discussion about sun protection may not occur. Where discussion does occur it varies depending on professional background; with dermatologists holding differing views on sun protection to oncologists, plastic surgeons or CNSs.

The literature suggests that the increased use of sun protection and SSE may be driven by a combination of the perception of risk held by patients, carers and HCPs. Better understanding of the social processes involved in patient education and how perceived information is translated into behaviour is therefore needed, as is awareness of individual differences in response to melanoma. Some patients may experience excessive anxiety related to sun exposure whereas others may not engage in consistent sun protection behaviour. A balance needs to be struck to ensure that patients understand the risks related to sun exposure but do not worry excessively. Gender differences again emerge with women being more likely to engage in sun protection behaviours than men, although men are more likely to protect their head. As with most aspects of melanoma the impact on the behaviour of carers has not been widely explored.

3.6 IDENTIFYING THE SENSITISING CONCEPTS AND FORESHADOWED QUESTIONS

Despite variations in terminology, there was a strong element of overlap and consistency between the main themes emerging from my personal/professional experience, patient and carer knowledge and the varying forms of knowledge that professionals might draw upon. In seeking to develop a succinct overview that brought these various themes together it

appeared that they could be conceptualised as falling into a number of thematic categories that might serve as sensitising concepts, as outlined below:

- One relates to the potential impact that melanoma has over time on various aspects of the patient's life such as: QOL, psychological well-being, worry/concern and financial implications. Such an impact is generally described in negative terms. However, many of these concepts such as QOL and psychological well-being have, to date, been largely professionally defined and explored primarily with patients rather than patients and carers. There is clearly a need for further work that considers the impact of melanoma on both patients and carers, over time, and that focuses on their perceptions and experiences rather than the use of standardised measures
- Another relates to factors that might, in some way, improve the patient experience, such as supportive relationships, information and education and the use of formal services. Once again most of the work to date has focussed only on the patient experience with little attention having been given to carers. Nor has there been prior work that has explored what HCPs see as their role in supporting patients/carers. Another factor that might in some way differentiate the patient experience is that of gender. Whilst statistical differences may have emerged from prior work few studies have sought to explore qualitative differences between genders.
- The third sensitising concept to emerge suggests that melanoma patients might take action themselves in response to melanoma. This emerged strongly from all three forms of knowledge and to date the focus has been on behaviours such as sun avoidance and self-examination. These are important but there may well be other changes that both patients and carers might make as a result of melanoma. This is an area worthy of further exploration.

The above three areas were the primary sensitising concepts that emerged from my consideration of existing forms of knowledge and these clearly influenced the foreshadowed questions as outlined below.

From the outset my primary aim in undertaking this study was to explore the changing experiences and support needs of patients with melanoma and their carers throughout the disease trajectory. By doing so I hoped not only to add to our understanding but also to generate insights that had the potential to improve the melanoma experience especially, but not exclusively, by informing professional practice. In addition to the sensitising concepts described above two other overarching concepts lie at the heart of the study.

- Firstly that the experience of melanoma cannot be considered as a solitary one and that the nature of interactions and relationships with others, especially family members and trusted HCPs, is central to a full understanding.
- Secondly that the melanoma experience is a temporal one, likely to change over time and that these changes may not coincide with traditional medical/professionally defined pathways. It was therefore considered essential that my study actively involved patients, carers and HCPs and that it followed their experiences over time.

These two factors, together with my desire to generate insights that had potential practical application strongly influenced my methodological decisions, as will be highlighted in the next chapter. Building on all of the above the foreshadowed questions outlined below formed the initial direction for my study that will explore these questions from the point of view of all parties.

- How do patients and carers experience melanoma, and what impact does it have on various aspects of their lives such as QOL, psychological well-being, their worries and concerns and their financial situation?

- Do these experiences and impacts vary over time?
- Do patients and carers make changes to their lives as a result of melanoma?
- Are patient and carer experiences and impacts influenced by factors such as gender, information and education, the nature of supportive relationships and the support services accessed? What are their experiences of the latter?
- Do the experiences and perceptions of patients, carers and health care professionals vary?
- How can the experiences of patients and carers and the impact of melanoma be improved?

3.7 SUMMARY

This chapter has considered how my personal and professional experience motivated me to explore the experience of patients with melanoma and their carers, particularly relating to:

- Melanoma related worry
- Supportive relationships
- The impact on family members
- Behavioural change after a diagnosis of melanoma

Information from patient and public sources then revealed the following themes about the experience of having melanoma:

- Patients and their family felt that they did not know enough about melanoma and wanted to warn others about the dangers of sun exposure
- They also valued supportive relationships

- Melanoma survivors felt lucky that the melanoma had been removed but worried about it coming back and may start using preventative measures
- Patients may also experience financial difficulties as a result of their diagnosis and treatment

Examination of professional literature revealed further themes related to QOL, information/education, gender related differences, psychological well-being, support service use and HCP-specific issues.

In combination these three sources of knowledge served to identify the sensitising concepts and foreshadowed questions that informed my Constructivist Grounded Theory study.

4 CHAPTER FOUR: REFLECTIONS ON THE STUDY METHODOLOGY

4.1 INTRODUCTION

This chapter begins by describing how and why I came to choose Constructivist Grounded Theory Methods to explore the experience and support needs of melanoma patients and their carers, and considers this decision in the context of the study aims. It goes on to provide details of the study design and how it was conducted including reflections on ethical issues, rigour and reflexivity.

The preceding chapter described how the sensitising concepts and foreshadowed questions emerged and identified the relative lack of attention currently given to:

- The potential impact of melanoma over time on various aspects of patients' and carers' lives
- The actions that melanoma patients/carers might take in response to this condition
- Factors that might, in some way, improve the patient/carer experience: especially in relation to supportive relationships, information and education, and the use of formal services
- The role of HCPs in the melanoma journey

As already noted a key motivation in my intent to explore such issues was my desire to generate new insights that would reflect multiple perspectives and have the potential for practical application.

Having identified the need for further study, a key question then concerned how best to address the issues identified above.

4.2 PLANNING THE STUDY

4.2.1 THE NEED FOR A QUALITATIVE APPROACH

My consideration of the existing knowledge about melanoma drew attention to gaps in understanding about the experiences and support needs of melanoma patients and their carers. The existence of such gaps, and the over reliance on quantitative approaches within most previous studies, suggested that a qualitative methodology would be beneficial. Reaching this conclusion was helpful but still left several decisions to be made, for as Ormston et al. (2013) note qualitative methods comprise a very '*broad church*'. Despite this Denzin and Lincoln (2011) identify several shared characteristics underpinning qualitative approaches and they describe qualitative methods as:

'... a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a set of representations.....qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them.' p3

I particularly wanted to adopt an approach that would encourage participants to freely express their personal experiences and to play an active role in '*making sense*' of these experiences. This was driven by my dissatisfaction with the reliance on QOL measurement tools as a proxy for the impact of melanoma and my belief that the '*scores*' on such scales did not reflect real life experience. I therefore decided at a fairly early stage that an interpretivist stance was required. My rationale for deciding to adopt a constructivist Grounded Theory methodology is

described below. Prior to this I consider some of the ontological, epistemological and methodological debates that shaped my ultimate choice.

At the most abstract level decisions as to which research approach to adopt reflect the ontological, epistemological and methodological assumptions that underpin varying research paradigms (Lopez & Willis 2004). According to Guba and Lincoln (1994) paradigms are best understood as representing a '*world view*' that summarises the overarching beliefs upon which particular research approaches are built. A paradigm is shaped by three sets of questions. Ontological questions are concerned with the nature of '*reality*' that each paradigm holds, epistemological beliefs reflect how knowledge is perceived and methodological questions capture the ways in which each paradigm believes that such knowledge can be apprehended. Debates about paradigms are complex and numerous approaches have been identified. Table 4.1 provides an overview of one widely used classification proposed by Guba and Lincoln in 1994 and updated by Lincoln, Lynham & Guba in 2011.

Table 4.1: Basic beliefs underpinning *alternative* inquiry paradigms

Item	Positivism	Postpositivism	Critical theory	Constructivism	Participatory
Ontology	Naïve realism – “real” reality but apprehensible	Critical realism – “real” reality but only imperfectly and probablistically apprehendable	Historical realism – virtual reality shaped by social, political, cultural, economic, ethnic and gender values; crystallised over time	Relativism – local and specific co-constructed realities	Participative reality – subjective-objective reality, co-created by mind and given cosmos.
Epistemology	Dualist/ objectivist; findings true	Modified dualist/ objectivist; critical conditional/ community; findings probably true	Transactional/ subjectivist; value mediated findings	Transactional/ subjectivist; co-created findings	Critical subjectivity in participatory transaction with cosmos, extended epistemology of experiential propositional, and practical knowing; co-created findings
Methodology	Experimental/ manipulative; verification of hypotheses; chiefly quantitative methods	Modified experimental/ manipulative; critical multiplism; falsification of hypotheses; may include qualitative methods	Dialogic/ dialectical	Hermeneutical/ dialectical	Political participation in collaborative action inquiry; primacy of the practical; use of language grounded in shared experiential context.

Lincoln, Lynham & Guba (2011 p100)

Given my aims and assumptions, positivism, post-positivism and critical theory approaches were not appropriate so I came to the study from a constructivist paradigm.

According to Ormston et al (2013) constructivism involves efforts to '*construct meaning and interpretations based on those of participants where reality is affected by the research process*' (p12) therefore acknowledging interaction between participants and the researcher. This basic tenet was consistent with my own aspirations. The most influential recent exposition of the underlying assumptions of constructivism has been that provided by Guba and Lincoln (2013) who identify the following characteristics. They describe constructivism as having:

- A '*relativist*' ontology in which the world is comprised of multiple realities which are constructed by individuals in a given context
- A '*transactional subjectivist*' epistemology in which knowledge is co-created during the interactions between researcher and participants
- A '*hermeneutic*' methodology involving an iterative dialectic process between researcher and participants to uncover meaning
- A belief that the values of the inquirer, research participants and stakeholders need to be made transparent

Once again these precepts seemed consistent with both my goals and my beliefs and accepting these required me to acknowledge the following points:

- The existence of multiple realities
- That events may be interpreted in differing ways by various participants
- That understanding is constructed through interaction with participants
- That the researcher cannot adopt a neutral position but rather their own beliefs and insights influence the research process and outcomes in fundamental ways

However there are a number of methods that may, to a greater or lesser extent, claim to meet

some or all of the above conditions. The most widely used of these, especially in nursing and health care research, are phenomenology, ethnography and Grounded Theory (Parahoo 2006). In deciding upon the most appropriate method I needed to consider which of these options would best address my aims.

4.2.2 WHY I CHOSE GROUNDED THEORY

From the range of potential qualitative approaches that were available Grounded Theory was thought to have several advantages including its emphasis on exploring social processes and how these may change over time, as well as its goal of providing new theoretical insights that seek to have practical application in the real world. However, although Grounded Theory was the approach that was ultimately used, others such as phenomenology and ethnography were considered as alternative methodologies. Whilst either of these approaches could have been used I felt that they would not have necessarily been the best way to address the foreshadowed questions that this study sought to explore.

Part of the challenge in deciding which methodology to use was how to interpret what each approach claims to do. Making this decision was not helped by the ways in which various terms are used. For as Crookes and Davies (1998) note the terms Phenomenology, Ethnography and Grounded Theory are each sometimes used as synonyms for qualitative methods. In reality however each is a distinct approach with its own particular set of goals and assumptions.

Crookes and Davies (1998) describe the goal of phenomenology as being to investigate '*everyday experience from the perspective of those living that experience*'. They go on to argue that its ability to identify key issues from the perspectives of service users is

advantageous. According to Adams and van Manen (2008) phenomenology provides an interpretation of the *'lived reality'* of participants to identify the *'essence'* of that experience. At first sight these characteristics seemed consistent with my own goals but a closer look suggested otherwise.

Balls (2009) asserts that nurses are drawn to phenomenology because, like nursing, it considers the whole person and values their experience. Phenomenology could have been applied to my study as it is concerned with *'lived experience'* and may have identified different dimensions of that experience (Richards & Morse 2007). However, as Parahoo (2006) contends, the goal of phenomenology is essentially to provide an in-depth description of the *individual* experience of a specific phenomenon. As such I did not feel that it would be best suited to explore, what I already knew to be, the complex, multi-faceted and often shared experience of living with melanoma. Moreover, as Galvin & Holloway (2015) note the results generated by phenomenology often do not have the potential for direct practical application. This was central to my aims and therefore phenomenology was not considered the *'best fit'* methodology.

According to Charmaz (2014), ethnography, as a method, is primarily about:

'...recording the life of a particular group within a given milieu, requiring detailed knowledge of the multiple dimensions of life within the given milieu in order to understand taken for granted assumptions' (p35).

For Streubert (2011) ethnography is particularly suited to exploring how individual experiences are connected to, and can be understood through, membership of a given group or culture. Consequently, as Parahoo (2006) contends *'ethnographers are interested in how the behavior of individuals is influenced or mediated by the culture in which they live'* (p67). This overriding emphasis on group membership and culture did not seem particularly appropriate for my

study. From my own experience melanoma affects a diverse cross section of the population who are unlikely to be members of a specific cultural group. Therefore, as with phenomenology, ethnography was not seen to provide a 'best fit' with my own aims, therefore this left Grounded Theory.

4.2.3 THE EVOLUTION OF GROUNDED THEORY AND CONSTRUCTIVIST GROUNDED THEORY

4.2.3.1 The development of Grounded Theory

Grounded Theory was initially developed by Glaser & Strauss (1967) during their research into death and dying within an acute hospital context. In exploring this experience they wished to employ an alternative to the then dominant quantitative paradigm, which was essentially theory testing and deductive. In doing so they devised a 'new' approach to research that was theory generating, with the emerging theory being rooted in the data. Furthermore, rather than the emphasis being placed on developing a 'grand', overarching theory (which aims to explore and explain the widest set of phenomena possible) their goal was to produce a substantive 'mid-range' theory that explored a given phenomenon in a certain context (death and dying in an acute hospital in their case and melanoma amongst recently diagnosed patients and carers in mine). They called their approach 'Grounded Theory' and philosophically it was firmly rooted in Pragmatism and Symbolic Interactionism (Stern & Porr 2011). Both of these philosophies are underpinned by the idea that knowledge, rather than being universal and constant, is context related and is primarily influenced by the actions, interpretations and interactions of people in a given setting. The classic description of this belief was captured by Blumer (1969), who when describing the basis of symbolic interactionism wrote that:

"Human beings interpret or define each other's actions instead of merely reacting to each other's actions. Their response is not made directly to the actions of one another but instead is based on the meaning which they attach to such actions" (p.19)

Knowledge, and subsequent action, is therefore based on peoples' interpretations, which may change over time. Consequently Grounded Theory stresses the importance of the context in which people function and how they share and construct their social world (Holloway & Galvin 2015).

The original Grounded Theory methodology as envisaged by Glaser & Strauss (1967) had three basic precepts: theory generation; theoretical sampling; and constant comparative analysis, with these elements being considered as integral and mutually reinforcing. The descriptions of the method provided by Glaser & Strauss (1967) were intended to be a guide for systematically gathering and analyzing data to form theory. However, despite being offered as an alternative to quantitative approaches early Grounded Theory was still rooted in a largely '*objectivist*' world view in which the views and interpretations of the researcher were dominant. Paradoxically, therefore, whilst arguing that people constructed their world through their interactions with others, for Glaser and Strauss (1967) the interactions between researchers and participants were not held to be influential. Rather, the researcher was seen to be '*value neutral*' and, in order to avoid '*bias*' all forms of prior knowledge were to be put to one side. So for example Glaser and Strauss (1967) advocated ignoring any existing literature until after fieldwork had been completed. Participants were seen primarily as '*providers*' of data, having no other part to play. For Glaser and Strauss (1967) establishing rapport with participants was a time-consuming, but necessary, aspect of data collection.

As Williams and Keady (2012) note, whilst classical grounded theorists recognized the need to '*interact*' with participants, such interaction was kept to a minimum and it was the researcher's role to interpret the data and produce the theory. Glaser (Glaser & Holton 2004)

always remained true to what he described as '*Classical Grounded Theory*', emphasizing the systematic but flexible nature of its methods but still prioritising the researcher's role.

Since its original publication, however, Grounded Theory methods have been taken in differing directions including Strauss & Corbin's (Strauss and Corbin 1998, Corbin & Strauss 2008) approach that focused primarily on analytic techniques and Charmaz's (2006) Constructivist Grounded Theory. Strauss began working with Corbin to produce their own version of Grounded Theory methods (Strauss and Corbin 1998, Corbin & Strauss 2008) to clarify the analytic processes involved and make them more accessible to students. They therefore concentrated primarily on the techniques of Grounded Theory, especially data analysis. While starting from a classical, objectivist foundation, over time their methods evolved to take on a more constructivist approach with Corbin (2008) stating that her initial position as an '*authority*' on healthcare changed to that of a '*negotiator*' or co-creator of care with her patients. Eventually Charmaz (2014) recognised this change in Corbin and Strauss' (2008) standpoint with both sets of authors openly acknowledging the position of the other.

However, Charmaz (2000, 2006) had long argued for a more radical interpretation and application of Grounded Theory in which the interactions between participants and researcher were not simply acknowledged but actively encouraged. She called this '*Constructivist*' Grounded Theory.

4.2.3.2 Constructivist Grounded Theory

From the outset Charmaz (2000, 2006) challenged the objectivity advocated by Glaser & Strauss (1967), and to a lesser extent Strauss and Corbin (1998), making a clear distinction between objectivist and constructivist Grounded Theory. In proposing a new version of

Grounded theory Charmaz's (2000) goal was to develop an approach that resulted in the '*mutual creation of knowledge*' between participants and researchers, in which both parties played a full and active role. She argued that existing Grounded Theory principles could be used by researchers in many ways and that the methods employed represented a flexible '*toolkit*'. Almost in anticipation of Charmaz's arguments, Rodwell (1998), when providing an overview of objectivist methods more generally, referred to using Grounded Theory techniques as part of constructivist research (even if the end product was not a Grounded Theory, see later), and as Charmaz (2000) was to do a couple of years later, Rodwell (1998) emphasised the importance of co-construction with participants. Both Rodwell (1998) and Charmaz (2006) describe variations of Constructivist Grounded Theory research that share the same epistemological standpoints, which reflect those outlined earlier.

Therefore while the methods used in the differing iterations of Grounded Theory are often similar, it is the ways in which these methods are applied, and in particular the interactions between the researcher and the participants, that sets them apart. Mills et al. (2006) offer a methodological spiral on which all variations of Grounded Theory sit, depending upon their epistemological underpinnings, describing the constructivist paradigm as evolved Grounded Theory.

However the arguments outlined above have not been accepted uncritically and writers such as Bertero (2012) criticise those researchers who claim to have used Grounded Theory while only paying lip service to its central tenets. Bertero (2012) contends that for any approach to be called Grounded Theory it must contain the following essential elements:

- Simultaneous data collection and analysis
- Theoretical sampling leading to theoretical saturation
- Hierarchical coding processes

- The Identification of a core category

However even these elements seem to be open to interpretation with Hallberg (2006) suggesting that the following are required: simultaneous data collection & analysis; intensive interviewing, open followed by theoretical sampling, hierarchical coding processes, categories emerge from data rather than preconceptions, identification and verification of relationships between categories, identification of a core category, detailed memo writing and theoretical saturation of categories. Based on the writings of several authors (Glaser & Strauss 1967, Corbin & Strauss 2008, Charmaz 2014, Birks & Mills 2015, Bertero 2012, Hallberg 2006, Urquhart 2013) the common elements appear to be:

- Theory generation rather than verification
- Theoretical sampling
- Constant comparison
- Simultaneous data collection and analysis
- Hierarchical coding procedures
- Memo writing
- Theoretical saturation of categories and their properties

Whilst there is obvious congruence between many of these processes and a constructivist approach what sets the latter apart is the importance it accords to the relationships formed between participants and researchers and the belief that acknowledging and building on all forms of prior knowledge is central to reaching a shared understanding, in marked contrast to the position advocated by Glaser and Strauss (1967). Therefore, constructivist Grounded Theory rejects the notion of a value-free observer, and explicitly recognizes that the researcher's personal, professional and disciplinary perspectives are influential in shaping the

initial foreshadowed questions, data collection and subsequent analysis (Charmaz 2014). I have already sought to make my own influences as clear as possible. Consequently reflexivity is an essential element of any study and a fuller description of my approach to reflexivity will be provided later.

Other differences in emphasis between variants of Grounded Theory also emerge. Glaser and Strauss (1967) and Strauss and Corbin (1998) argue for the need to identify a 'Core Category' and a 'Basic Social Process' that lie at the heart of a Grounded Theory. Charmaz (2006), on the other hand, contends that this position is too reductive and that in complex social situations a number of categories and processes are likely to interact to shape the experiences of those living with, for example long term conditions.

From the above it is clear that there is no universally accepted approach to Grounded Theory and therefore it is essential that each researcher makes their own position clear. In order to provide transparency I will therefore state my own interpretation of constructivist Grounded Theory methods and how they were used to carry out this study.

4.3 THE APPLICATION OF CONSTRUCTIVIST GROUNDED THEORY TO THIS STUDY

Consistent with the central elements of Grounded Theory described above my study aimed to generate rather than test theory and the processes of data collection and analysis were to be conducted simultaneously. Therefore whilst for ease of interpretation I describe the methods I used in separate sections these were, in reality, largely undertaken simultaneously. With these caveats in mind my study was underpinned by the following principles and unfolded as described below.

4.3.1 THEORY GENERATION RATHER THAN VERIFICATION

Authors writing about Grounded Theory and constructivist research often refer to the generation of theory as being their primary goal, but this is not always the end product. The result may sometimes be largely descriptive rather than theoretical or based on data that might have been *'forced'* with the resultant theory not being adequately *'grounded'* in the data. In such cases it is questionable whether the study was truly Grounded Theory (Glaser & Strauss 1967). In constructivist research more generally, Rodwell (1998) considers that whilst Grounded Theory *'techniques'* (such as constant comparison) may be used the end result is typically a detailed *'case report'* often in the form of a case study. As noted above writers such as Charmaz (2006) highlight the importance of theorizing but do not accept that a solitary core category is always adequate to capture the complexity of real-life events and see the insistence upon identifying only one core category as a legacy of the objectivist tradition. Therefore, whilst all proponents of both Grounded Theory and constructivist research agree that the final product must be shaped by the data, universal agreement on the nature of that final product remains elusive.

My goal was to co-construct with my participants a *'theory'* of their experience of living with melanoma that, as far as possible, captured the key stages and processes that occurred over time, with particular reference to support needs. My desire to have a temporal dimension meant that a longitudinal study involving several interviews with the same participants would be required. My intent to gain as complete a picture as possible from a number of perspectives meant that I needed to include people with melanoma, their carers (where there was one) and at least one health care professional. The ultimate goal was that the insights provided would have potential practical application to improve the melanoma experience for all parties. As with all Grounded Theory studies certain essential elements were required, key to which are theoretical sampling and constant comparison.

4.3.2 THEORETICAL SAMPLING

In qualitative studies, and especially in Grounded Theory, sampling techniques differ from those applied in quantitative studies. In quantitative studies the goal is '*representation*' and random sampling is seen as the '*gold standard*'. In qualitative studies purposive or selected sampling is most frequently adopted. This may start off as a convenience sample, in which participants known to have a view on the subject of interest are selected. Sampling is usually then refined over time as new participants are identified, often by previous ones. Grounded Theory studies may start in this way but as the study unfolds theoretical sampling takes precedence. The primary purpose of this is to build the emerging theory and to do so both participants and data are selected explicitly to explore emerging ideas and maximise opportunities to refine these (Corbin & Strauss 2008).

Consequently, according to Draucker et al. (2007) theoretical sampling is central to Grounded Theory and evolves over time. Typically, at the start of the study individuals or groups who are known to have knowledge of the topic under study are selected (convenience sampling). However as data collection and analysis are concurrent early analysis helps to identify either other participants and/or ideas that can be developed in future interviews. Theoretical sampling is therefore used to identify either participants or data that will elaborate upon and refine previously identified categories until these begin to become saturated (see below).

Although sample size is not a primary consideration in qualitative research it is still a topic that is the subject of debate, therefore it is briefly considered below. When considering sample size Charmaz (2006), for example, agrees with Glaser (2002) that there is value in looking at a '*many cases*' as this will strengthen the researcher's grasp of the participants' world. Unfortunately she does not then define what she means by '*many cases*'. Rather she states that enough material is needed to both anchor the participants' experiences and identify

differences between and amongst participants with sufficient confidence to connect them to their social context. This is rather vague and instead of citing a number of participants many authors rely on the idea of '*saturation*', which is considered later. However, despite not being tied to sample size qualitative writers nevertheless ponder the question: What is too small?

Morse (2000) suggests that a Grounded Theory study with two to three unstructured interviews per person may need twenty to thirty participants (so therefore forty to ninety interviews) depending on the scope of the study, the nature of the topic and the study design. On the other hand Stern & Porr (2011) caution against collecting too much data as it can become unmanageable and for them thirty to forty interviews or hours of observation are generally adequate to reach theoretical saturation.

The situation is often further complicated for students undertaking a PhD who may be restricted as to the number of interviews they can undertake by resource and time constraints. In reviewing sample sizes across a number of published PhD studies Mason (2010) found an average of thirty-one interviews per study but her review excluded designs that were longitudinal or involved repeated interviews. As interesting as such musings are ultimately the sample size (which in this context does not just refer to the number of participants but also the number of interviews) should be enough to provide some confidence that the issues in question have been explored sufficiently to provide credible answers. Approximately twenty patients and twenty carers were estimated to sufficiently explore emerging issues through repeated interviews over three years. Along with Healthcare Professional interviews, this allowed for interactions within triads to be analysed. Previous work had shown this number to be sufficient (Hellstrom, Nolan & Lundh 2007) and thus provided an estimated number of participants required for ethical approval. Consideration of what constitutes a '*credible*' Grounded Theory will be considered later. Constant Comparison is another central element of Grounded Theory.

4.3.3 CONSTANT COMPARISON

In Grounded Theory the constant comparative method is central to the analytic process and goes hand in hand with theoretical sampling, with one informing the other. Constant comparison occurs in some form at all stages of data collection and analysis. Initially data are compared with data, within and across interviews, to help in the identification of early codes. These early codes then help to inform theoretical sampling, either of new participants and/or of additional topics, with this process occurring in an iterative fashion. Consequently Charmaz (2014) sees constant comparison as being applicable at all stages of analysis and theory generation and, as with Birks & Mills (2015), describes a number of comparisons that may be made including: statements within the same interview, between interviews, later interviews compared to earlier interviews, between participants, between codes, between incidents and codes, between codes and categories, between categories. However, it is when categories begin to emerge that constant comparison is most fully employed.

Glaser & Strauss (1967) provided detailed procedures for constant comparison and described four overlapping stages:

- comparing incidents applicable to each category
- integrating categories and their properties
- delimiting the theory
- writing the theory

These stages are not conducted in a strictly sequential way, but are often simultaneous, highlighting the interdependence between analysis, theoretical sampling and theory building as the researcher must remain open to new ideas while forming the theory. Such new ideas then inform subsequent sampling decisions, the focus of interviews and analysis. As comparisons are made throughout the analytic process, indeed until the writing of the final theory, Glaser & Strauss (1967) stress that insights may emerge late in the process. This, as

will be described below, has implications for deciding when theoretical saturation has occurred.

4.3.4 SIMULTANEOUS DATA COLLECTION AND ANALYSIS

The central role that this plays in Grounded Theory has already been considered.

4.3.5 HIERARCHICAL CODING PROCEDURES

Hierarchical coding refers to the way in which the researcher sequentially uses open, axial and selective coding to develop categories and establish links between them. Differing stages of coding have been suggested. Glaser & Strauss (1967) describe the coding of incidents, then coding for categories, by using notes and memos. Similarly Charmaz (2014) suggests using initial then focused coding, but she does not advocate axial coding as she prefers an emergent rather than a procedural approach. Theoretical coding is meant to interrelate categories and move them to a more abstract level (Charmaz 2014). The position I adopted with regard to coding will be discussed further below.

4.3.6 MEMO WRITING

Memo writing is seen as an essential part of the analytical process with memos of various types being used to record the researcher's thoughts and processes as they develop links between categories. The place that memo-writing played within my study will be discussed further below.

4.3.7 THEORETICAL SATURATION OF CATEGORIES AND THEIR PROPERTIES

As noted above theoretical saturation is taken to be the point at which data collection ceases and whilst data analysis may still continue it too is often largely complete by this stage. However, defining the point of theoretical saturation is somewhat ambiguous for as Glaser & Strauss (1967) state new insights may emerge at any point. Therefore, as the quote below suggests ultimately an element of informed judgement is required.

“Saturation is a critical concept in Grounded Theory and is based on a subjective decision: actually, you can never know if further interviewing would give more information.”

(Hallberg 2006 p144)

Given my desire to fully involve my participants I felt that the point of theoretical saturation should not be decided by myself alone but agreed with participants. Saturation would only be reached when they felt that their ‘*story*’ had been told fully. I anticipated that not everyone’s ‘*melanoma journey*’ would be complete when data collection ended, as for some participants their life with melanoma would extend beyond the duration of the study. Despite this they needed to be satisfied that a full account had been rendered up until that point in time.

Having described the main tenets underpinning the interpretation of Grounded Theory that informed my study issues of data collection are now considered.

4.3.8 DATA COLLECTION

As indicated earlier Charmaz (2006) argues that Grounded Theory methods should be seen as a set of flexible tools that can be used as suits a particular study but she also advocates that to be successful the tools selected must be the most appropriate to answer the questions posed. The choice as to ‘*how*’ the data were collected will therefore have a significant impact

on the quality of the result (Charmaz 2006). Given my desire to engage with participants over an extended period of time, and to allow them every opportunity to contribute fully to the study, interviews seemed the obvious choice of method. Indeed, Charmaz (2014) states that '*intensive*' interviews fit Grounded Theory methods well because they allow in-depth, open-ended exploration of an area in which the interviewee has substantial experience.

Whilst some researchers talk of undertaking an '*open*' interview, it has been argued that this is in fact a misnomer and that in the context of research an '*open*' interview is a meaningless concept (Whyte 1982). Whyte (1982) argues that in agreeing to take part in a study, participants have been invited to talk about *something* and have a reasonable expectation that this is what will be addressed. Furthermore, as already discussed, my study was guided by a set of sensitising concepts that gave initial direction to data collection. It therefore seemed that semi-structured, but flexible interviews were the most appropriate method to use. According to Tod (2010), semi-structured interviews have several advantages in that:

- They permit the researcher to identify a range of issues (shaped by the foreshadowed questions) to be explored. These issues are usually formed into a rough interview '*guide*'
- They are flexible and the order in which issues are addressed is not important. This allows participants a degree of freedom to explore those aspects that they feel are important
- The interview guide can evolve and change in content and emphasis as new issues emerge. This latter characteristic is essential to both theoretical sampling and constant comparison

The flexibility of semi-structured interviews is particularly valuable when participants are interviewed on more than one occasion to allow the focus of investigation to change and

evolve over time. This attribute reflected my intention to explore experiences as they emerged after a melanoma diagnosis, suggesting that longitudinal interviewing would be appropriate. This was reinforced when I considered the potential advantages and disadvantages of longitudinal interviews as shown in in Table 4.2. On the basis of these it seemed apparent that the advantages outweighed any potential disadvantages.

Table 4.2: Potential advantages & disadvantages of using longitudinal interviewing within this study

Advantages	Disadvantages
Research context	
Longitudinal qualitative research can achieve depth, quality, and variety of understandings related to the trends and processes of change Vogt (2002).	
Qualitative longitudinal methods are particularly suited to exploring many dimensions of health and illness including: symptoms, patient expectations, understanding how changes and adaptations result from particular traumas, events or interventions, the significance of timing and timeliness, the impact of health inequalities & the impact of caring (Holland <i>et al</i> 2006).	
Through repeated contact a more nuanced understanding of phenomena as they evolve through time, especially those with an unpredictable trajectory can be captured. This is particularly relevant for a better understanding the experience of illness (Carduff <i>et al</i> 2015).	
Longitudinal approaches recognise that human actions and participant perspectives might change during the course of a study, and seek to capture these (Saldana 2003). This is anticipated and the study aims to uncover these changes.	Where the aim is to observe change, the researcher must be prepared that change may not be seen during the period of study (Saldana 2003).

Data collection and quality	
Repeated contact over time may have benefits for the quality of the data, the relationship between researcher and participants and the quality of the data outputs (Holland <i>et al</i> 2006).	Continuity of researcher can lead to a loss of objectivity and an accumulation of a partial perspective (Holland <i>et al</i> 2006) but this is not a concern within a constructivist study.
Repeat interviews allow for flexibility of sampling, methods, units of analysis, and theorisation. (Holland <i>et al</i> 2006). Flexibility of the interview schedule can help to capture change as it happens over time (Carduff <i>et al</i> 2015) but the timing of data collection should be considered to anticipate changes where possible (Calman <i>et al</i> 2013).	The research focus and topic guide evolve over time so may vary from the original aim of the research (Calman <i>et al</i> 2013). This again is not a concern in a constructivist study.
	Attrition can be problematic in longitudinal research but may be countered by regular contact, good engagement with participants and efforts to maintain involvement (Carduff <i>et al</i> 2015). This proved to be the case with most of my participants.
Analytic quality	
Analytic quality requires ongoing commitment of time and contact. This is aided when there is consistency of researcher(s) which allows rapport to be built with respondents and analytic insights to be accumulated. (Holland <i>et al</i> 2006).	A small sample can give rise to a large and complex data set which can be analyzed in multiple ways from different perspectives (Calman <i>et al</i> 2013). Quality analysis of such a large amount of data is time consuming (Holland <i>et al</i> 2006).
The rich data from longitudinal interviews provide detail and density enhancing the likelihood of developing categories (Calman <i>et al</i> 2013) and enhancing analytic quality.	Analysis is often complex and multidimensional and, as noted above is usually time consuming (Calman <i>et al</i> 2013). This proved to be the case in my study but I feel that the quality and depth of the resulting product made the effort worthwhile.

There are also specific ethical concerns related to longitudinal qualitative interviewing that will be discussed later in this chapter,

Longitudinal, semi-structured interviews were therefore suited to the aims of the study and the primary method of data collection. Having made this decision I also wanted to identify the best way of enabling participants to take a full role in the process. Whilst the need to engage participants as equal partners in the research process lies at the heart of constructivist methods little is written about how best to achieve this, especially when the topic to be addressed may be sensitive or difficult. In discussing this issue with my supervisors my attention was drawn to the use of diagramming as a means of engaging with research participants over time as suggested by Keady and Williams (Keady et al. 2007a,b, Williams and Keady 2012). Diagramming in Grounded Theory is most often associated with data analysis. According to Charmaz (2014) diagrams have the advantage of being able to provide '*visual representations of categories and their relationships*' (p218) and several authors (Strauss and Corbin 1998, Clarke 2003, Corbin and Strauss 2008) see the use of diagrams as being intrinsic to Grounded Theory analysis. They suggest that a variety of diagrams including maps, figures and charts both assist in teasing out relationships in the data and in representing these relationships in the findings.

Whilst diagrams are advocated for use during analysis by Keady and Williams (Keady et al. 2007a,b, Williams and Keady 2012), these authors also see them as a key element of data collection. In using diagrams as a means of data collection the authors offered a new approach to co-constructed inquiry which facilitated engagement with people living with long-term conditions (dementia in their initial study) over time. They used diagramming as a way of working with the participants to create their own '*personal theory*' of their experience (Keady et al. 2007a,b) This new approach was based on a life story model and comprised several sequential '*stages*' which are seen as representing a series of '*acts*'. The aim was to address, amongst other things, the question of '*how*' to achieve the '*mutual creation of knowledge*' and which techniques might enable researchers to forge meaningful relationships with participants. They were particularly interested in identifying '*what*' and '*who*' participants saw as being

'centre stage' (most important to them) as things developed over time. According to Charmaz (2014) the authors:

'...offer 'center stage diagrams' as a way of advancing constructivist Grounded Theory. Over time, they co-construct these diagrams with participants about their lives through adopting participant's language and visual representation of his or her subjective experience.....Williams and Keady find that center stage diagrams enable participants to move forward with the researcher...' (p219).

The use of such diagrams seemed to offer considerable potential and was a strategy that I was keen to try. As will be explained later, I did not use diagrams in exactly the same way as the original authors nor was my goal to adopt a life story approach. However diagramming played a key role in both data collection and analysis. A consideration of how this was used in a longitudinal fashion is something that will be discussed later.

I also wanted participants to be involved in bringing their individual data together into a collective theory. To facilitate this I planned to use focus groups as a method of data collection with patients and carers towards the end of the study so as to enable them to discuss their experiences collectively. Birks & Mills (2015) view focus groups as an extension of the standard interview and see them as being useful in Grounded Theory research as a way of eliciting potentially shared perspectives. Goodman & Evans (2015) advocate that a focus group held at the end of a study allows participants to respond to findings and offer alternative interpretations, thereby allowing people to modify their initial thoughts if they wish. This was my goal in using focus groups as I wanted to provide an opportunity for participants to review the 'final' version of the theory, and to identify commonalities and differences. One limitation of focus groups is their potential susceptibility to researcher manipulation and bias (Goodman & Evans 2015). To try and avoid this reflexivity was employed as discussed later in this chapter.

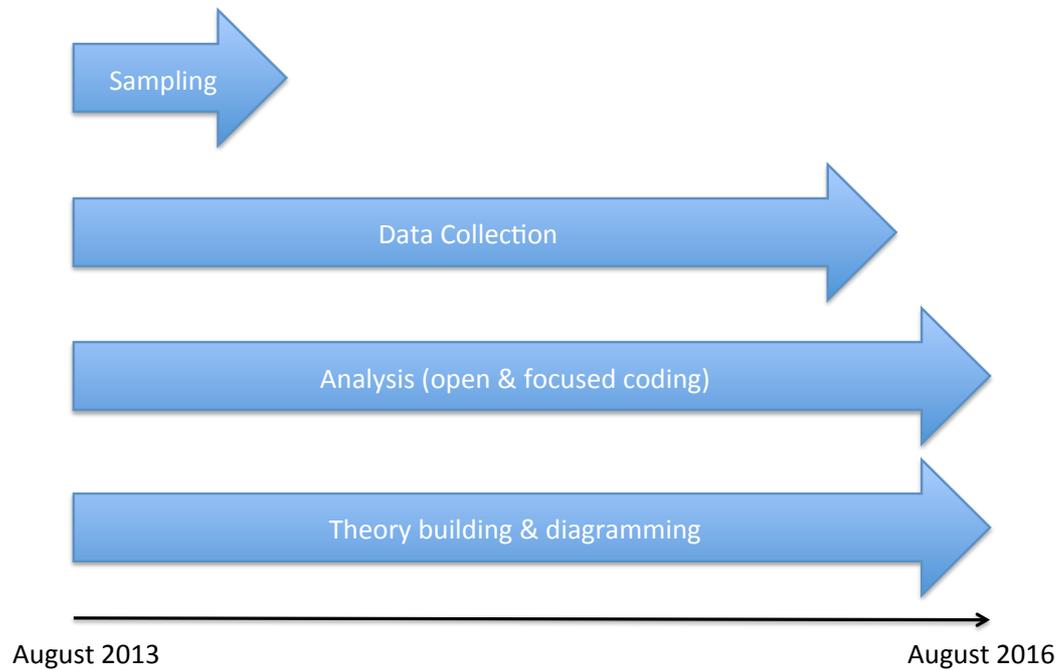
Having stated my interpretation of constructivist Grounded Theory and the methods I intended to employ, I will now provide a detailed account of how the study was conducted.

4.4 STUDY DESIGN

When planning a study there are several things to consider including the need to gain the necessary approvals to access research participants, especially within a healthcare setting. Certain actions were therefore required prior to sampling and data collection. These included selecting the study site and groups to study and deciding at what point in their melanoma journey to invite people to take part in order to capture the breadth of their experience (Corbin & Strauss 2008).

The nature of melanoma and its trajectory suggested that those patients likely to experience relapse or disease progression would do so within the first two years of diagnosis. A three-year study period was therefore planned to capture the majority of patient and carer experiences. My previous study (Bird 2011) employed a cross-sectional design, focusing on the retrospective experience of patients. The present study was designed to prospectively capture not only their experience, but also those of carers and health care practitioners to identify both short and long-term impacts in a contemporaneous way. In keeping with Grounded Theory methods, sampling, analysis and theory generation were to be conducted simultaneously. This is illustrated in Figure 4.1 below. How this timeline unfolded is now described, starting with participant recruitment.

Figure 4.1: Study timeline



4.4.1 PARTICIPANT RECRUITMENT & SELECTION CRITERIA

Initially patients were to be included if they met the following selection criteria:

- Over 16 years of age
- Able to understand what the study involved and be able to give consent
- Histological diagnosis of melanoma
- Diagnosed within the previous 3 months

The last criteria of being diagnosed within the previous three months was removed in an amendment shortly after the study opened as it became apparent that the complex referral pathway meant that not all patients could be recruited during this time frame.

Carers were included if they met the following selection criteria:

- Over 16 years of age
- Able to understand what the study involves and be able to give consent
- Were nominated as their main carer by someone with a histological diagnosis of melanoma

Healthcare and other professionals who might be nominated were eligible for inclusion as described below.

Patients were initially identified through oncology and dermatology clinics within a large, regional teaching hospital. Including oncology as well as dermatology allowed for patients with differing experiences to be recruited such as those diagnosed with metastatic disease or no known primary melanoma. Recruitment commenced by identifying patients with a new diagnosis of stage II (thicker primary melanomas) or III (lymph node involvement) melanoma, as described in Chapter 2, who were approached at outpatient appointments. As newly diagnosed melanoma patients are seen at three monthly intervals it was anticipated that several patients could be identified in a relatively short time. Later, as theoretical sampling occurred, recruitment widened to include patients diagnosed with different stages of melanoma (low risk and metastatic disease) to enable comparison of differing experiences. The low risk group are treated by dermatologists alone whereas the moderate to high risk groups are treated by a range of people including dermatologists, plastic surgeons and oncologists. Patients diagnosed with metastatic disease are often referred directly to an oncologist. The service patients receive therefore varies for these differing groups and consequently their experiences are likely to differ too.

Approximately half of all patients approached agreed to take part in the study. Patients refusing to participate stated reasons such as that they wanted to forget about the melanoma or felt that the commitment to repeat interviews was too great. This meant that the group participating was self-selected to an extent. During the latter stages of recruitment, when it became clear that the majority of patients taking part were generally older and had high-risk disease, specific efforts were made to recruit patients who were younger and/or with earlier stage disease to explore potential differences in their experiences. This was only partially successful, for a variety of reasons. For example younger patients with a new diagnosis were not available in great numbers during the recruitment period and those with earlier stage disease were only accessible through referral from a single dermatology clinic, thus limiting their participation. Reflections on the impact of such sampling limitations will be considered in the final chapter. Details of consent processes and ethical issues are provided later.

Carers were approached with patients where they were in attendance or patients passed the information sheet to the person that they identified as their main carer. Patients could participate without carers but owing to the need to maintain patient confidentiality, carers could only participate with the consent of the patient. Patients were also asked to nominate a HCP who they felt had been particularly helpful. This was done 6 months following the patient's initial recruitment to allow exposure to differing professional groups. Therefore the HCP could have come from within primary, secondary or tertiary care or voluntary sector and from any discipline. HCPs were invited to participate by letter, followed by a maximum of 2 telephone calls or emails to gain their reply.

A biographical description of each participant and those that they nominated to take part in the study, including HCPs is provided in the first results chapter.

4.4.2 DATA COLLECTION

Demographic data was collected from patients' case notes and verbally from carers and HCPs. This was used to describe the participant group as outlined in the next chapter.

In keeping with Grounded Theory methods, data collection and analysis took place in parallel (as shown in figure 1). However they are described separately here for ease of presentation. A separate reflexive account of my own part in data collection is provided later.

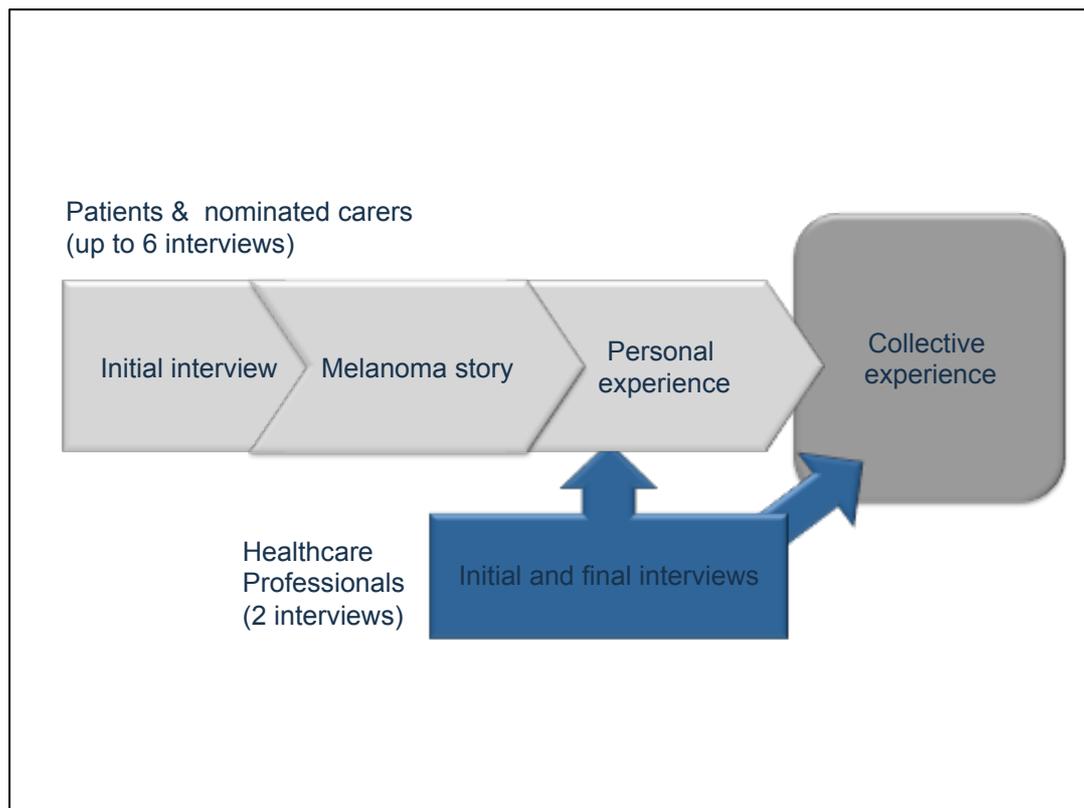
Participant Interviews

As described earlier the primary method of data collection employed in this study was in-depth interviewing augmented by the use of diagramming (see below for fuller description). Interviews were carried out face-to-face and participants were offered a choice of setting: half chose the research centre and half their home. Patients and carers were given the option of being interviewed together or separately and in almost all instances they chose to be interviewed together. Where they were interviewed separately (3 occasions) this was due to carers' work commitments. Interviews lasted between 15 and 90 minutes, with most interviews lasting around an hour.

The first interview took place as soon as possible after the participant or carer had provided their consent (see below). After the initial contact further interviews were planned to take place at months 3, 6, and 12 respectively and then six monthly, with an additional interview if there was a new cancer episode. This allowed for data to be collected for patients who experienced recurrent disease. Interviews were planned to take place over a minimum period of one year. It was anticipated that those recruited early in the study would be followed up for the full three years, but that not all subsequent participants would reach the three-year time point. A

maximum of 10 interviews with any one patient and/or carer were planned but six proved to be the maximum number. This strategy was anticipated to allow enough opportunity to clarify concepts as they emerged and generate a robust theory as shown in figure 4.2.

Figure 4.2: Using interviews to generate theory



Interviews with HCPs took place after patients nominated them (6 months after the patient was recruited) and once at the end of the patient's data collection period to explore any changes in the relationship that may have taken place.

With permission the interviews were audio recorded for accuracy and to enable me to focus my attention on my interactions with participants. Charmaz (2014) advocates recording interviews as taking notes may interfere with the flow of the interview and are likely to fail to capture subtle nuances.

The first interview usually took place within a week of information about the study being provided. At this point consent was obtained and the purpose and the structure of the study were discussed again along with related issues of confidentiality. The consent form was completed prior to the interview being undertaken. This interview was relatively unstructured and open questions were used to allow participants to freely express their experiences. No formal interview guide was used but participants were asked to talk about their experience, starting wherever they wanted to. The interview evolved from there but a list of topics I wanted to address included: how the melanoma diagnosis impacted their daily life, what the term 'support' meant to participants, who participants sought 'support' from, emotions and experiences as a result of the melanoma diagnosis and sun-related behaviours. Later in the interview probes or prompts were used to clarify issues if required. On starting the interview I would say something like "*Please start where you want to. Just say what has happened and how you have felt*" (JB, Interview with P02). Charmaz (2014) suggests that often one question may be all that is needed, and for some participants this proved to be the case. Participants naturally wanted to talk primarily about how the melanoma had affected various aspects of their life. Ultimately what emerged was therefore a '*melanoma story*' in contrast to the life story approach adopted by Keady *et al* (2007). Elaborating upon this '*melanoma story*' was aided considerably by the use of diagramming, and many participants found this very useful as described below.

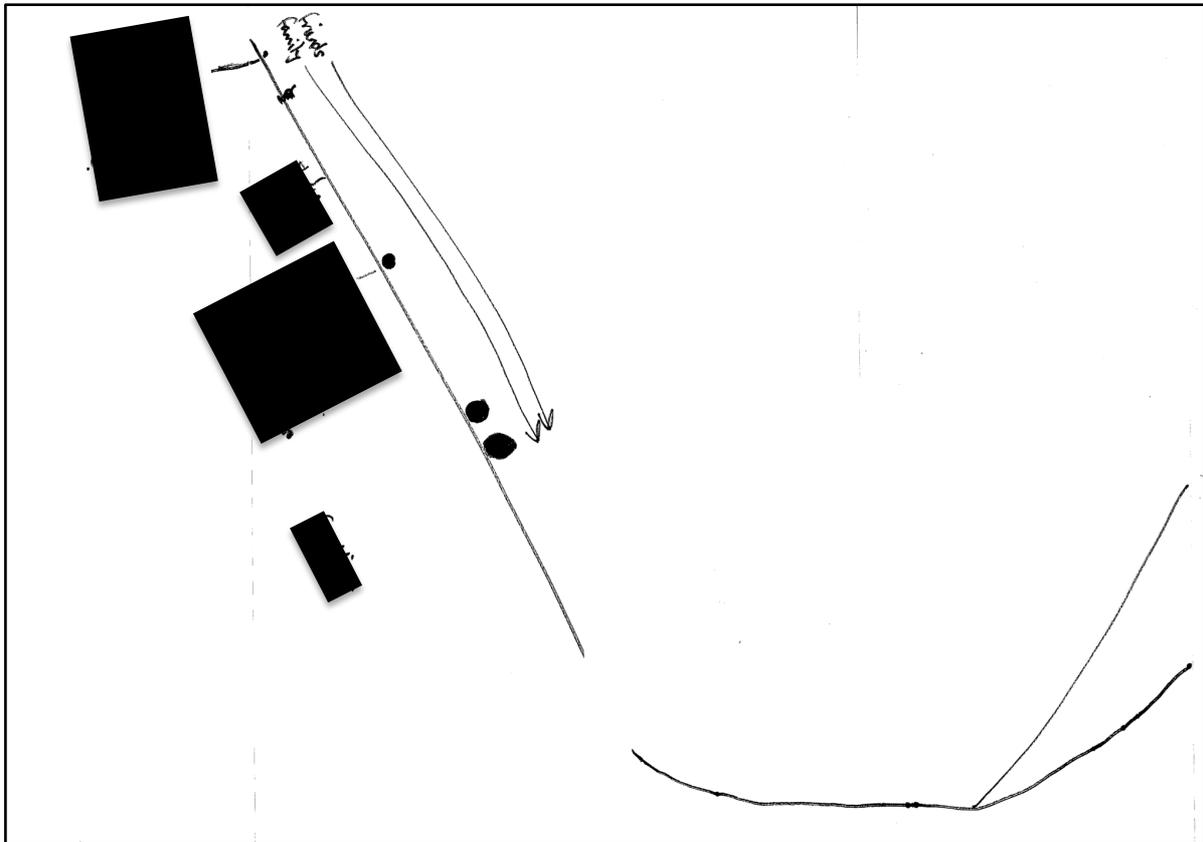
Diagramming has been used in various ways by grounded theorists to develop and elaborate their theory, but often at the stage of data analysis. As with Keady *et al* (2007) in addition to using diagrams during analysis I also used them with patients and carers during the interviews to enable them to engage more fully with the process of theory generation. Diagramming in the context of theory analysis will be discussed later, here I will discuss the data collection aspect of diagramming.

During the first, second or occasionally third interviews (owing to the staggered time frame of participant recruitment), participants were asked if thinking about their experiences in a 'visual' form, as a diagram or picture, would help. Paper and pens were available to aid exploration. I didn't suggest ways that they might do this so as not to influence them initially. Some participants were able to provide a visual representation, whereas others were not. Some participants thought this a good idea, whereas others did not. However, even those who felt that creating a diagram might be helpful did not feel confident to begin to draw one. Therefore, whilst by no means skilled myself, I offered to start the drawing off if they described what they wanted it to look like and told me where lines started and stopped. One of the participants Phil (see later) readily described his experience as being like an 'avalanche', beginning with a 'snowball' and then rapidly escalating:

"First there was the mole and then the operations and here we are on a mountainside. It was a little snowball and as it's gone downhill it's increased in size and speed. Very steep hillside. Little snowball was my mole. Under my arm, I wasn't concerned about that. And then the next one was the groin and that's quite big now. I don't want to go any further. Unless it starts going up again it's going to come to an inevitable conclusion. I want it to start going back up." Phil (Patient M06)

Based on this description we began to try and represent his experiences as a diagram, as shown in figure 4.3.

Figure 4.3: Avalanche developed by Phil, initial drawings from the interview (names blanked out for confidentiality)

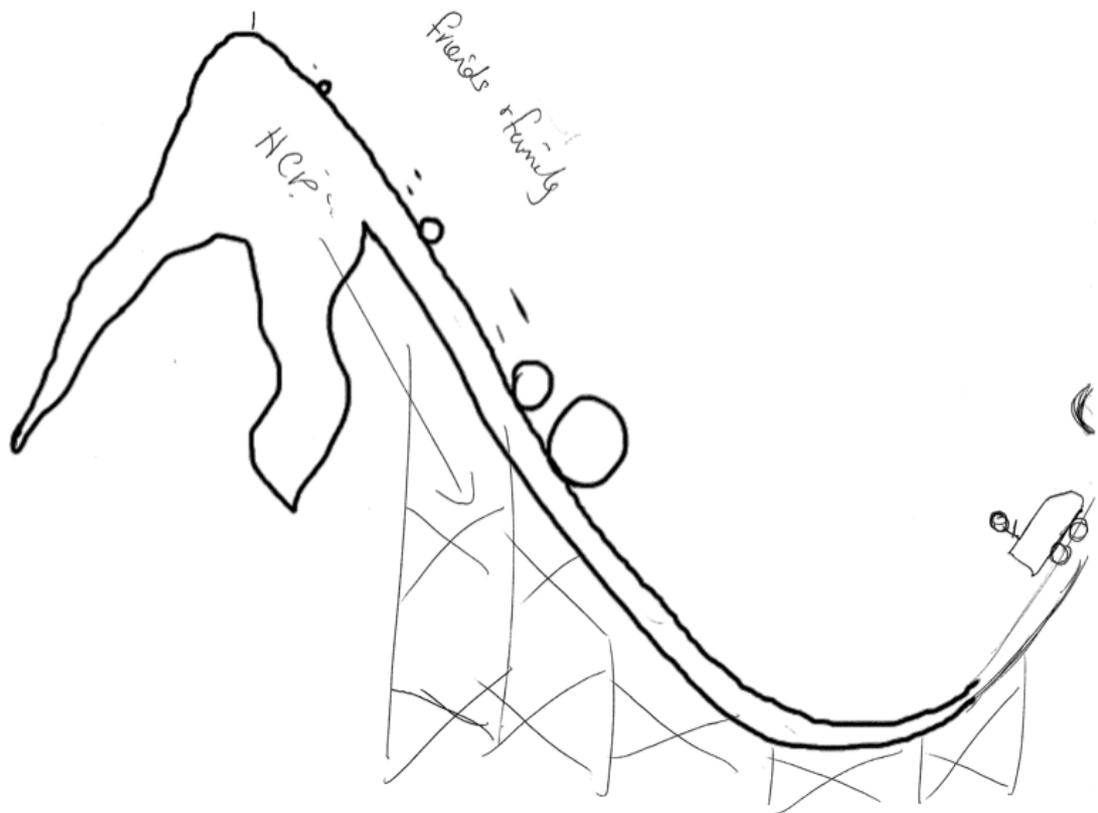


At the next interview with Phil and his wife Kate, we discussed changes that had happened since the last interview and how his avalanche analogy had developed. Things had improved so the 'avalanche' turned into a 'rollercoaster'. This was thought to be a better metaphor as a 'rollercoaster' has both ups and downs whereas an 'avalanche' only goes in one direction, downhill. Phil describes this below:

"If I equate it to a rollercoaster, obviously it's a long ride with ups and downs, I want to be on the peak not in the trough. It's a rollercoaster now because I can see the other side. I'm in a carriage because I haven't got any control. I know there will be twists and turns on my rollercoaster but I don't know what they will be. I can only say what I've experienced up to now." Phil (Patient)

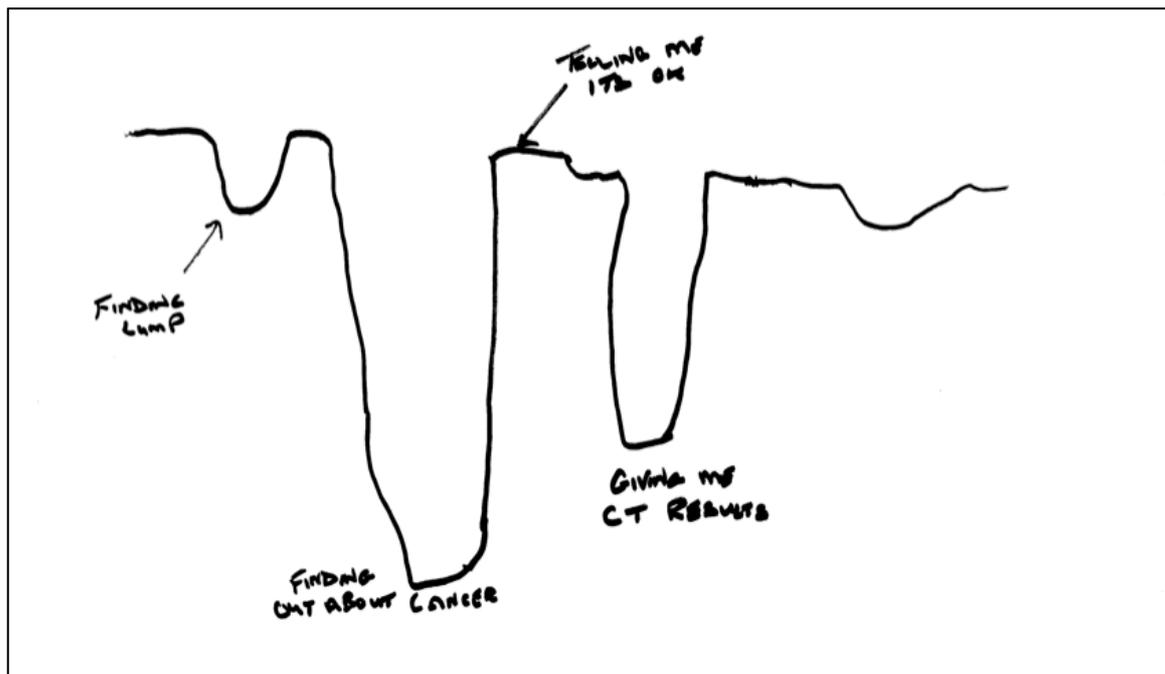
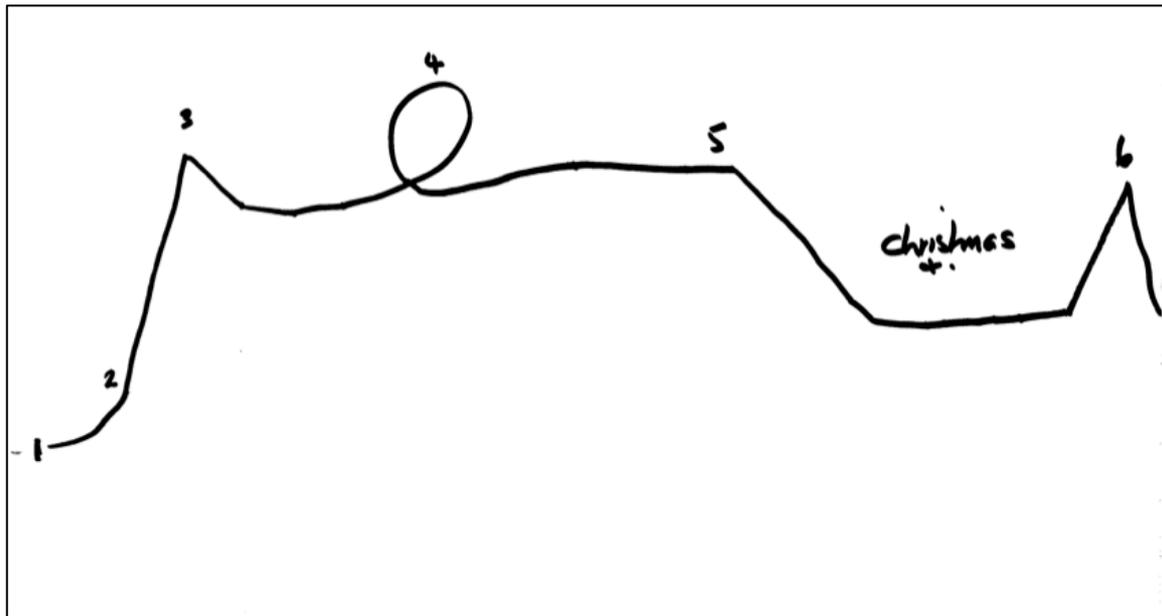
The original drawing we produced to try and capture this is presented in Figure 4.4.

Figure 4.4: Rollercoaster developed by Phil at subsequent interview



Phil was not the only participant to refer to their experiences as being like a 'rollercoaster'. , In Tony's initial interview, he had referred to an 'emotional rollercoaster' and we tried to capture this as illustrated in figure 4.5.

Figure 4.6: Rollercoasters developed by study participants once integrated into the study



Some of the initial descriptions of the melanoma experience were very powerful but neither participants nor myself possessed the talent to capture these as well as we would like visually. With participants approval I therefore commissioned an artist, Amy Martindale to create visual images from a selection of quotes. The rollercoaster she produced can be seen in Figure 4.7.

These images were then shared with participants during the focus groups and were very well received, stimulating yet more discussion and helping to create a shared visual image of their experiences.

Figure 4.7: Rollercoaster picture created from participant quotes



Having considered the process of individual data collection, I now consider the focus groups.

4.4.2.1 Focus Groups

Focus groups were initially planned for patients and carers but one also took place with HCPs. These were conducted towards the end of data collection and analysis to aid saturation of the data (which had been reached following a joint decision between myself and the participants) and refine the final version of the theory, having already presented it to participants

individually. I anticipated that group discussion might enable participants to further explore the meaning of the theory and allow possible modification following discussion with others who had been through a '*melanoma journey*'.

In July 2016, two years and nine months into data collection, remaining patients (those who had not withdrawn or died) and remaining carers (those who were continuing to take part with a patient and those who had decided to continue participation after the death of the patient) were asked if they were willing to participate in a focus group to discuss the developing theory. Nine patients and eight carers were approached to take part in a focus group. Two dates were selected at appropriate venues away from the hospital. All those who were approached agreed to take part. Logistical difficulties restricted attendance but six participants were present. Five participants (three patients and two carers) attended the first focus group for patients and carers, and unfortunately only one patient was involved in the second planned focus group owing to three patients being unable to attend on the day. The focus groups lasted 110 and 25 minutes respectively.

The interaction between participants in a focus group provides valuable data in most instances, but is somewhat dependent upon establishing rapport between the researcher and participant group (Birks & Mills 2015). Conducting focus groups at the end of the study meant that rapport had already been established with individual participants and they had already been engaged in the study and development of the theory. This meant that they were able to focus on the theory while providing additional detail to explore their experiences with each other. The discussion flowed easily with little prompting from me, as participants were keen to share their experiences with others who were living with melanoma. Prior to the discussion copies of the developing theory were made available to participants and I provided a verbal explanation of each element. Participants then began to consider the dimensions of the theory

drawing on examples from their own experience. I also used the opportunity to discuss the terminology used in the theory to ensure that they made sense to the participants.

A focus group for HCPs was not originally planned as I anticipated it being difficult for them to be released from work commitments. However, CNSs were the HCPs nominated by most patients and in February 2016, two and a half years into the study, an opportunity to hold a focus group with Skin Cancer CNSs involved in the study presented itself after one of their regular meetings. In view of this I felt that replacing the planned second individual interview with a focus group would enable me to gain data that would enrich and refine the theory (Birks & Mills 2015). Six skin cancer nurse specialists took part in the focus group over 60 minutes. As they were already known to each other and I knew them through my clinical role, rapport had already been established so discussion flowed without much prompting. Copies of the theory were provided at the beginning of the discussion with a verbal explanation. Participants were then asked to share their thoughts on the theory, which they did while providing further examples from their own experiences.

All the focus groups were recorded with permission from participants. This was particularly important to enable me to manage the meetings as having multiple participants meant that full concentration was needed to follow the conversation.

Having described how the data were collected attention is now turned to analysis.

4.4.3 DATA ANALYSIS USING THE CONSTANT COMPARATIVE METHOD TO DEVELOP THEORY

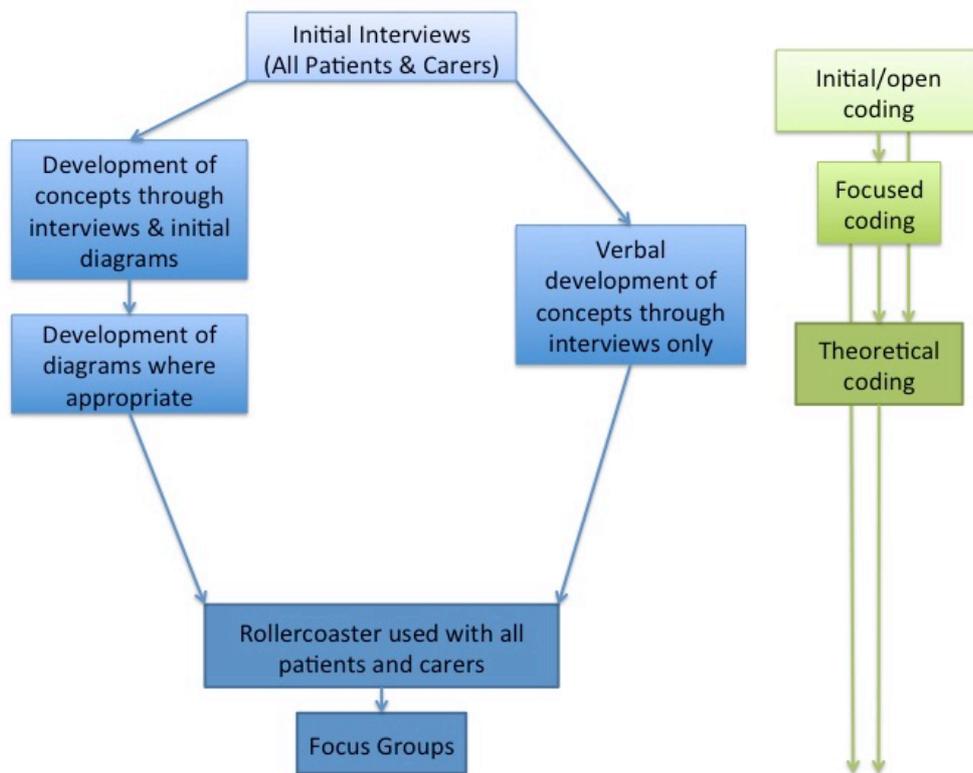
Audio recordings were transcribed and anonymised to maintain confidentiality. I transcribed the first two interviews myself to aid familiarity with the data. Subsequent interviews were then transcribed by a professional service. While transcripts were used to aid analysis, the original recordings were also listened to enabling better engagement with the data. Listening to the recordings, as Charmaz (2014) notes, helped me to get a better feel for the tone, tempo, silences, form and flow of the conversation.

Sections of data may refer to more than one category and it was anticipated that the interviews would produce large amounts of data, particularly as repeat interviews were planned. NVivo (QSR International Pty Ltd 2012) computer software was therefore initially used to aid analysis. Some authors consider it more efficient than manual analysis (Polit et al. 2001) and as data were to be analysed iteratively, in parallel with data collection, time was considered a significant issue. Urquhart (2013) cautions that a software package may have embedded in it a particular view of how the analysis should be done and so advocates familiarising oneself with the basic concepts of coding prior to using packages such as NVivo. Having used Grounded Theory methods for my Masters dissertation I was familiar with the basic techniques of coding and had prior training using Nvivo. In addition I attended a two-day course on the use of NVivo to refresh and update my skills. However, when coding the first two interviews using NVivo I found the process more time consuming than anticipated and it also generated an excessively long list of codes. An additional barrier was created through the available equipment; I worked on an Apple laptop to enable backup through the local network in my department but at the time NVivo was only developed for Windows computers. This meant connecting to a virtual computer on the departmental server to access the software. However, this method generated a large number of codes that were not leading to categories. Having coded paper transcripts in the past, I realised that carrying a large number around would be

impractical, so an electronic form was required. Driven by the need to move my analysis on and collect further data, I re-coded the transcripts in the form of a Word document which proved to be a more natural process. An example of open coding of a transcript can be found in Appendix 6, along with the steps taken through focused coding and category formation to diagramming and theory formation. Using this method there were still a large number of initial codes but not as many as previously and these were both more manageable and more conceptually dense.

Continued coding enabled new concepts to emerge through induction (Donovan & Sanders 2005). It was anticipated that coding could occur chronologically, running alongside further interviews to aid constant comparison and theoretical sampling (Polit et al. 2001). This is illustrated in Figure 4.8.

Figure 4.8: Development of coding alongside interviews



By comparing data between participants, potential categories emerged and I began to use focused coding (See example of focused coding in Appendix 6) while still allowing new ideas to emerge as changes over time experienced by participants began to unfold. Charmaz (2014) states that one goal of focused coding is to determine the adequacy and conceptual strength of the initial codes. This was true as some codes were not carried forward or were modified to reflect the ongoing data analysis. To incorporate memos into focused coding I created separate files for each focused code to include the data and memos. This enabled me to move the analysis forward. Where ideas emerged when I wasn't directly working at my computer, I would write paper notes to be included later.

Applying the constant comparative method, all data were compared: patient to patient, carer to carer, HCP to HCP, patient to carer, patient to HCP and carer to HCP. This process commenced from the first interview which contained data from both a patient and carer. By the second interview I had data from two patients and two carers to compare as well as being able to compare incidents within the interviews. Shared meanings were evident for some categories but tensions began to emerge where understandings were not shared. The first interview I conducted stood out as *'being positive'*, although it took more interviews for me to realise that this was the patient's and carer's way of giving meaning to the melanoma by trivialising it in comparison to other life events. The second patient talked at length about his roles in life, as a self-employed tradesman, a husband, a father, a friend and a brother. He related his experience of having melanoma through these roles. While there were similarities in the interviews, it wasn't until comparing the fifth interview (section available in Appendix 6) that aspects of the processes of *'hiding'* and *'sharing'* of information began to emerge. As analysis progressed and codes became categories *'hiding'* and *'sharing'* became part of the category that I termed *'relationships'*. The emergence of the category *'relationships'* is illustrated in Table 4.2 as an example of category development within the study.

Table 4.2: Example of category development

Initial Codes	Focused codes	Initial categories	Final category
Talking your mind off it Distraction Carrying on	Not thinking about it	Hiding	Relationships
Keep going for the family Withdrawing Choosing when to cry Being strong for others	Being Strong		
Talking to people Being straight with them People being there Reciprocal support Friends and family sharing cancer experiences	Support/Talking	Sharing Who do I talk to?	
HCPs support by giving information Receiving information/ Eyes open	Trusting	Trusting Who do I trust? Who is accessible?	
Being able to ask people for help Knowing who to contact A "good" HCP Belt & braces			
Expectations not met Diagnosis not immediate Having to ask for help rather than it being offered No one had the details Misdiagnosis	Not trusting	Not trusting	

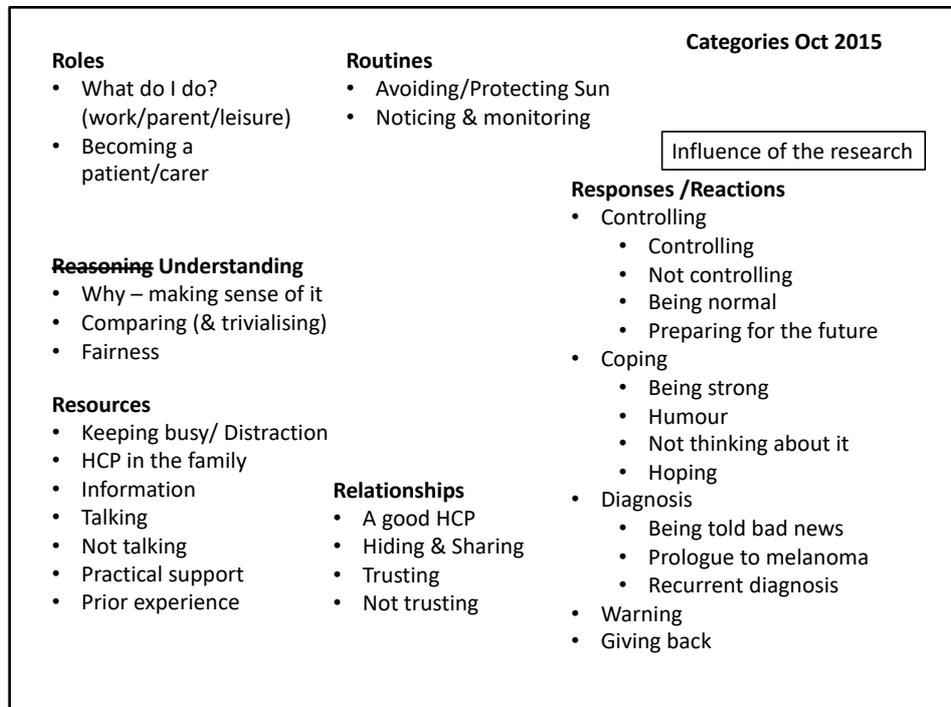
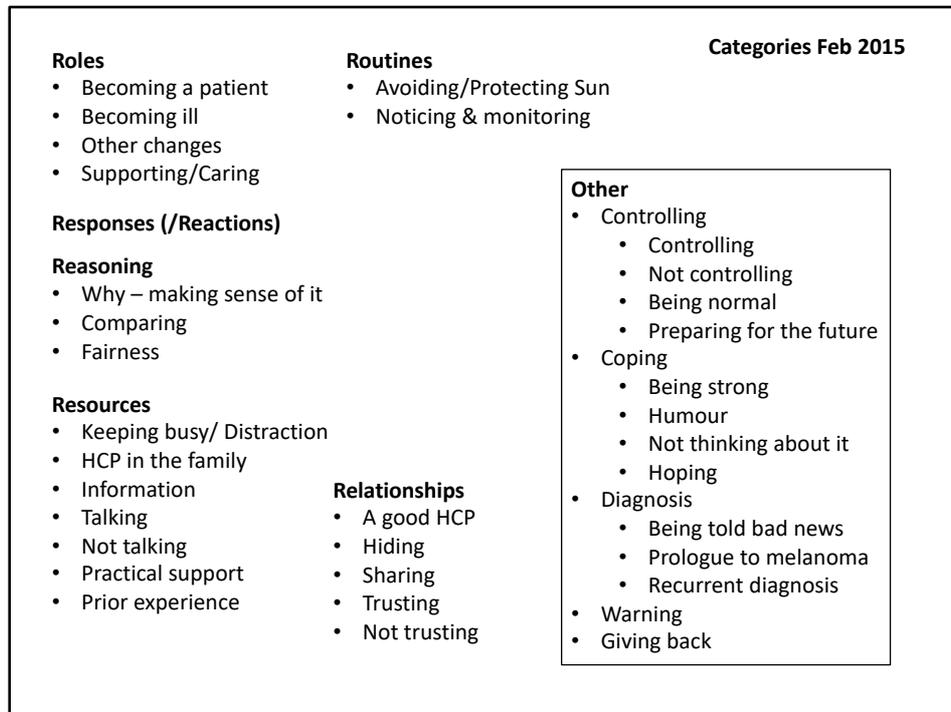
It was through the act of comparing seemingly different experiences that I began to build ideas. However, coding was not performed in isolation as there came a time where I had many categories and was still generating some open codes without moving easily to a theoretical level. Diagramming was the biggest help towards theory formation, and I will consider this next.

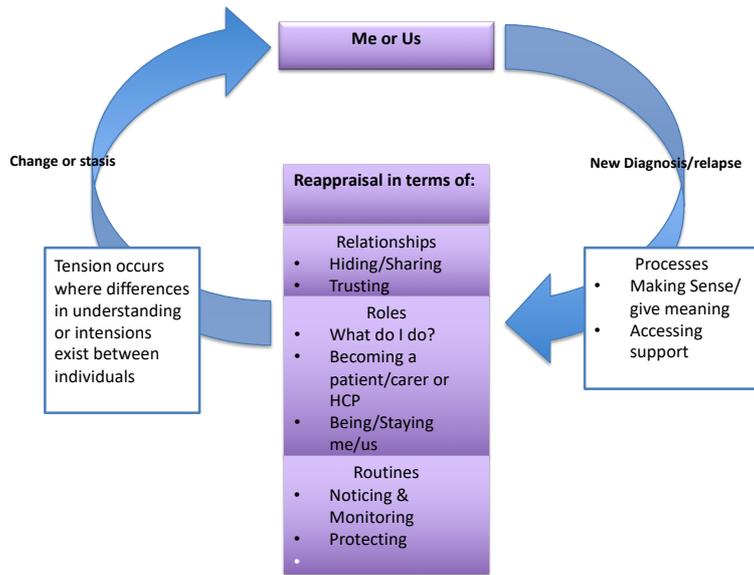
4.4.4 THEORY GENERATION THROUGH DIAGRAMMING

All authors advocating Grounded Theory and constructivist research agree that the final product must be shaped by the data, so a vision of the final product cannot be preconceived. The first step towards theory building is attaining theoretical sensitivity. I already had a degree of this owing to my previous personal and professional experiences but this was enhanced when considering the role of other forms of knowledge, as described in Chapter Three. While Glaser & Strauss (1967) advocate ignoring the literature initially, they also state that the ability to theorise will depend upon the researcher's ability to have theoretical insight into the area of research. Charmaz (2006) states that to gain theoretical sensitivity, it is important to consider the subject under study from multiple vantage points, and then use existing insights and those gathered from the data to make comparisons, follow leads and build upon ideas. Corbin & Strauss (2008) state that in essence it is the researcher's ability to compare and question the data that is central. As I was using a constructivist approach I also wanted my participants to engage in this process. Diagramming was one way to achieve this as described earlier but it also played a key role in data analysis. I found that comparing and questioning data wasn't enough to move to a more theoretical level. To explore how categories were interrelated, I used diagramming and then shared emerging theoretical relationships with the participants. An example of how the rollercoaster metaphor and diagramming process was introduced to Sarah can be seen in Appendix 6. This was the stage where, in conjunction with participants, final categories forming the final theory were determined as patients and carers drew and discussed their own '*rollercoasters*'. Patients and carers who were interviewed together were able to discuss each other's '*rollercoasters*' and in some cases drew their own visualization of the other person's '*rollercoaster*' before seeing what the other person had drawn for themselves. This led to elaboration of the key phases and transition points.

Diagramming was therefore central to theory generation and development as categories and their properties were explored. Corbin & Strauss (2008) advocate using diagramming and memos to aid conceptualization. Charmaz (2014) also promotes the use of diagrams and maps at all stages of analysis but provides few examples of how they might be used. However she argues that the boundary between data collection and data analysis becomes increasingly blurred and this was evident during my interviews where I shared various iterations of the developing theory with participants to gain their views. Those who had adopted diagramming found this very useful at that point. As I returned to participants I explored my initial categories alongside their individual quotes and provided short summaries (either textual or in diagrammatic form) to facilitate discussion and further develop ideas and the relationships between categories. Examples of the diagrams shared with participants to prompt their thoughts can be seen below in Figure 4.9. As the diagrams developed, categories and underpinning processes within the *'rollercoaster'* emerged aided by memos.

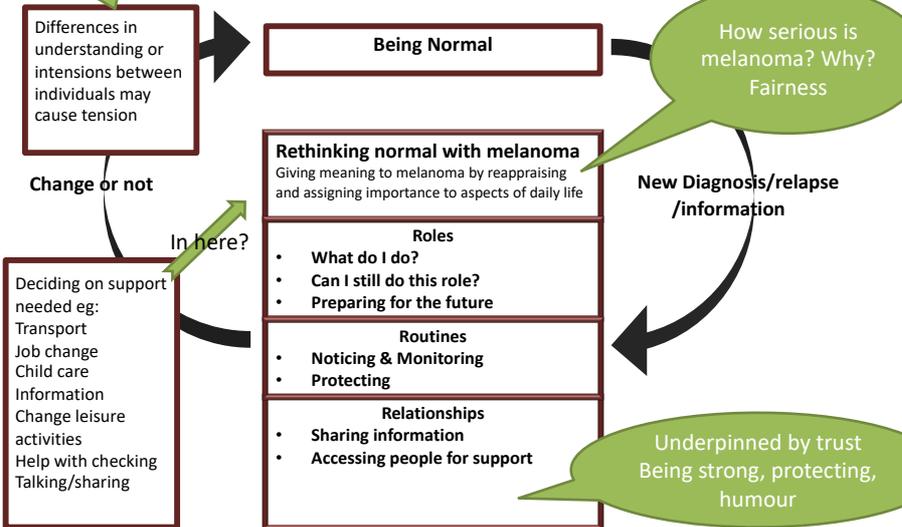
Figure 4.9: Example of category development diagrams shared with participants during interviews and focus groups.





The experience of having melanoma: Riding the Rollercoaster

3 perspectives



4.4.5 MEMOS

Charmaz (2014) describes the value of memos in the following way:

Memo-writing is the pivotal intermediate step between data collection and writing drafts of papers. Memo-writing constitutes a crucial step in Grounded Theory because it prompts you to analyse your data and codes early in the research process.

(Charmaz 2014 p162)

During my study memo writing took a number of differing forms. Charmaz (2014) suggests that a methodological journal can accomplish multiple purposes including: taking a step back from the data so as not to become too immersed, providing a means of capturing emerging ideas and feelings by reflecting on a recent interview, and bringing together potentially disparate ideas and moving them towards a higher conceptual level. Through using a reflective journal to record methodological decisions and analytic processes I was able to keep a contemporaneous account of the theory as it emerged over time. I often recorded my initial reactions to an interview immediately afterwards and returned to these later for further consideration.

Analytic memo writing also began early for me and such memos were recorded in a separate document. As the potentially more abstract and complex categories began to emerge, I then created separate documents for each category containing sections of data and accompanying theoretical insights. Through regular meetings with my supervisors, in which we discussed the analysis and emerging theory, supervision records also captured the various methodological, analytical and theoretical decisions made during the study. An examples of a theoretical memo generated during the study can be seen in Appendix 7.

4.4.6 THEORETICAL SATURATION

Data collection and analysis needed to end within the planned timeframe of the study for logistical reasons. However, it naturally came to a close as interviews were repeated and new data was not forthcoming. There came a point in the third year of interviews where participants who were likely to experience recurrent disease had done so, and those that wanted to withdraw had. Patients diagnosed with metastatic disease had died, along with others who had experienced recurrence and carers had chosen whether to continue with the study or not. Data collection was then centred around patients who were having ongoing surveillance, their carers and the carers of patients who had died. At the same time the evolving theory had been taken to participants in its various iterations and fewer changes were being made. At that point, it seemed reasonable to use the focus groups to finalise the theory. During the focus groups, the theory did not change significantly. Wording was altered slightly after discussion but the content remained the same.

4.5 ETHICAL CONSIDERATIONS

Biomedical ethics are often considered using the four sets of moral principles set out by Beauchamp & Childress (2013): respect for autonomy, non-maleficence, beneficence and justice. Within healthcare research particular attention is also given to the rights of research participants including the issue of consent as originated in the Nuremburg Code (1947). Within the UK, healthcare research is also governed by the Research Governance Framework (Great Britain. Department of Health 2005). The priorities of the Research Governance Framework include the need for ethical review, informed consent, data protection, the reduction of risk to participants and that the dignity, rights, safety and well-being of research participants are upheld at all times. The priorities of the Research Governance Framework are congruent with the moral principles of Beauchamp & Childress (2013) in that:

- Informed consent respects autonomy
- Data protection, risk reduction and safety uphold aspects of non-maleficence
- Upholding patient rights relates to justice
- The need for ethical review ensures that the research has been peer reviewed to consider ethical principles

The study was reviewed by an NHS ethics committee prior to commencement of the study. Copies of ethics and other approvals can be found in Appendix 8. The Research governance framework recommends participant involvement at all stages of the research process. Through the involvement of members of the Yorkshire and Humberside Consumer Research Panel in the development of the funding application, study protocol, related documents and ethics submission, only four questions were asked by the ethics committee at the meeting. These are detailed in the letter from the Ethics Committee found in Appendix 8. The majority of ethical issues had been addressed prior to submission.

Within this study respect for the autonomy of participants was upheld through the informed consent process. All participants were given written and verbal information during their clinic appointment and given a minimum of one day to consider the information as they were then telephoned to see if they wanted to take part and arrange an interview or to reflect further before making a decision. Participants' decisions to take part or not were respected and not questioned. The consent process was ongoing throughout the study. Participants could withdraw at any time and if they did they were given the option for their data to be withdrawn from analysis. They were assured that their treatment would not be affected whether they participated or not.

Non-maleficence with respect to upholding participants' wellbeing, safety and confidentiality were all considered. It was anticipated that patients and carers who took part might subsequently have further questions or additional support needs and concerns that were highlighted by the interviews. During the consent process, participants were advised that the research may not be of direct benefit to them personally, but might improve care for future patients. However, if any participant experienced distress as a result of this research, owing to issues that are raised, with the permission of the individual, their clinical team would be informed and two CNSs, from differing hospitals, on the advisory committee for the study were available for support. Participants were not excluded if they became terminally ill, but were reminded that they could leave the study at any point and the demands of continuing to take part in the study discussed with them. Such discussions were conducted on a case by case basis and the decisions of patients and carers respected. These occasions are detailed later, in the participant biographies. Participants could also access support from the Cancer Support Centre and were signposted there. The dignity of all participants was respected at all times and interviews were conducted sensitively. When entering patient homes, common courtesies were respected. The safety of the researcher was considered and lone-worker policies were adhered to.

The Data Protection Act (Great Britain 1998) and patient confidentiality require researchers to ensure that all patient details are kept confidential and individuals cannot be identified from the data collected. Permission was obtained from patients to access their notes to record demographic data. As the main data collected was qualitative it was especially important that confidentiality was maintained so that patients felt comfortable and happy to discuss their views, feelings and experiences and without fear of any repercussions on their treatment. Patients were therefore assured that identifiable data was not seen by anyone outside of essential members of the research team. The process of transcription and analysis was explained to them prior to consent and where an external transcribing company was used,

specific ethical approval was gained after including the company's confidentiality policy in an amendment shortly after the study opened to recruitment (See Appendix 8). In transcripts and quotes, participants were given an alias. This was felt to be in keeping with a constructivist methodology rather than providing a participant number. This also applied to healthcare professionals. Identifiable places and names were therefore removed from transcripts and quotes. Recordings of interviews were stored on a secure server and kept until the transcription and checking process was completed including the initial analysis then deleted. Recording equipment was kept in a locked cupboard in the Cancer Clinical Trials Centre (CCTC) (which can only be accessed by authorised personnel) throughout the study. Where interviews took place in the patient's home, the digital recordings were immediately returned to CCTC for appropriate storage (related risk assessment can be found in Appendix 8). Transcriptions were anonymised for analysis and stored on a secure, backed-up server, protected by a strong password and encryption.

Justice and patient rights were upheld through the other principles. Their rights to confidentiality, autonomy and access to care were respected. Patient needs were placed as more important than the study at all times. This was particularly important when patients were too physically ill to take part in interviews. Where a carer wished to continue participation this decision was respected. Patient consent for this would have been obtained where appropriate, but in the cases where carers continued participation, it was after the patient's death.

Some potential benefits of participation were anticipated as some patients and carers, or HCPs, may have found the process of talking about their experience helpful. In later interviews and focus groups with patients and carers, the effect of the research process was discussed and will be considered within the section on reflexivity.

Specific ethical issues considered during the study were those related to longitudinal interviewing and the development of the researcher-participant relationship. These include:

- Recruitment and consent shortly after significant diagnosis (Calman *et al* 2013, Yates & McLeod 1996).
- Confidentiality & anonymity (Yates & McLeod 1996),
- Developing a research relationship that can lead to blurring of boundaries potentially resulting in intrusion, dependency and distortion of life experience through repeated contact. Therefore the physical and psychological safety of the researcher and participant must be planned for, particularly where the focus of the study has an emotional element (Carduff *et al* 2015, Holland *et al* 2006, Yates & McLeod 1996).
- There may be difficulty in closing the research relationship and this must be planned for, particularly where there is the potential for patients to become unwell or die during the study (Holland *et al* 2006, Carduff *et al* 2015).
- Participant fatigue in interviews should be avoided by avoiding repetition and including emerging topics in subsequent interviews (Carduff *et al* 2015).

Table 4.4 shows the ethical issues anticipated prior to the commencement of the research, including those related to longitudinal interviewing as detailed in the section above as well as those addressed during the conduct of the study.

Table 4.4 Specific ethical issues addressed throughout the study

Timepoint	Ethical Issue	Action taken
Approach to participate following diagnosis	Participants given the choice to take part in research and not coerced at a vulnerable time after receiving bad news.	Suitability of potential participants was discussed with the medical team prior to being approached and the medical team asked if they were happy to be approached by the researcher. Participants given a verbal summary of the research and asked if they would like to hear more. If they did not want to hear more or take part then their decision was respected.
Consent	Participants should be given enough time to consider the information given to them before deciding whether to take part.	Participants were given at least 24 hours to read the study information and were provided with opportunities to ask questions over the telephone and face-to-face before the first interview.
Withdrawal/continued consent	Participants have the right to withdraw from research at any time without giving a reason or their care being affected.	Ongoing consent was gained from participants verbally prior to the start of every repeat interview. Some interviews were delayed or omitted if participants did not want to be interviewed at that particular time. One participant withdrew from the study and was given the option for data already collected to be retained or destroyed.
Confidentiality of participants and third parties identified during interviews.	Participants should feel free to talk without their care being affected and should not be identifiable from their data.	Interview recordings were kept on an encrypted laptop and transferred to a secure, encrypted server. Transcriptions were then anonymised by the researcher so that people and places could not be identified, whether interview participants or third parties discussed during interviews such as non-participating HCPs
Identification of participant support need during interviews and prevention of blurred boundaries within the research relationship.	During interviews some patients and carers asked questions about their care, but as the researcher it was not my place to answer these.	With their consent, patients and carers were referred to their allocated CNS to discuss any concerns they had. Prior to the study commencing two CNSs at differing hospitals had agreed to support study participants independently if they had issues that they did not want to discuss with their own clinical team.

		<p>This service was not utilised as the two patients requiring referral were happy to be contacted by their own team.</p>
<p>Study completion and closure of the research relationship.</p>	<p>Following repeat interviews, it was anticipated that participants and the researcher would build a relationship and the closing of this relationship would need to be mediated.</p>	<p>The Consumer Panel involved in the study were involved in discussions surrounding study completion prior to its start to ensure appropriate planning, although it was recognised that this would need to be handled on an individual basis.</p> <p>Some patients completed the study early owing to disease progression or death. Carers were given the option for further interviews, to be sent a summary of the research or to have no further contact.</p> <p>Some carers completed the study early owing to changes in their relationship with the patient and their participation/contact necessarily ended there.</p> <p>For those patients and carers completing the study, the Focus groups provided an appropriate way to end study involvement and the relationship between participants and the researcher.</p> <p>Following analysis a summary of the results was sent to all participants with my contact details, should they have any questions. Two participants (one carer and one patient) telephoned to say that they had found taking part in the study a positive experience and that it had helped them to get through a difficult time.</p>

4.6 RIGOUR

The issue of how to gauge rigour in all qualitative research, including both constructivist research and Grounded Theory is contested. In terms of Grounded Theory the original criteria proposed for judging the quality of the theory itself by Glaser and Struass (1967) were: Fit (referring to how well the theory aligns with the data), Work (considering the extent to which the theory provides a usable explanation of the topic under study), Grab (which relates to the degree to which the theory provides an explanation that readily '*grabs*' the imagination of the reader) and Modifiability (whether or not the theory provides an explanation that appears readily applicable, albeit with suitable modifications as needed, to other like contexts). As might be expected Charmaz (2006, 2014) suggested an alternative model that she thought was more relevant for constructivist Grounded Theory.

Therefore in considering the rigour of a Constructivist Grounded Theory, Charmaz (2006) advocated moving beyond the positivist stance of Glaser & Strauss (1967) and proposed an alternative set of criteria that she termed Credibility, Originality, Resonance and Usefulness. For Charmaz (2006) these address the issues listed in Table 4.5:

Table 4.5: Charmaz criteria for considering the quality of a Constructivist Grounded Theory

Credibility	<ul style="list-style-type: none"> • Is the researcher familiar with setting and topic? • Are the data sufficient to merit the claims? Have systematic observations been made between categories? Do the categories cover a wide range of observations? • Are there strong links between the gathered data and the argument and analysis? • Is there enough evidence for the claims to allow the researcher to form an independent assessment and agree with the claims?
Originality	<ul style="list-style-type: none"> • Are the categories fresh and offer new insights? • Does the analysis provide a new conceptual rendering of the data? • What is the social and theoretical significance of this work? • How does the Grounded Theory challenge, extend current ideas and practices?
Resonance	<ul style="list-style-type: none"> • Do the categories portray the fullness of the study experience? • Have taken for-granted meanings been revealed? • Where the data indicate have links been drawn between institutions and individual lives? • Does analysis offer participants deeper insights about their lives and worlds and does the theory make sense to them?
Usefulness	<ul style="list-style-type: none"> • Does analysis offer interpretations people can use in their everyday worlds? • Are there any generic processes within the categories and if so, have they been examined for tacit implications? • Does the analysis spark further research in other substantive areas? • How does the work contribute to knowledge? How does it contribute to making a better world?

Charmaz (2006)

Whilst the above framework considers the *'quality'* of the Grounded Theory that emerges from a study it does not address the extent to which the study engaged with the participants and allows them to play an active role. This is an important consideration in a constructivist study such as mine. For such studies, whether they generate a Grounded Theory or other output such as *'case report'* (as discussed earlier), Rodwell advocates the use of the authenticity criteria developed by Guba and Lincoln 1989).

With regard to constructivist studies the most widely cited, and applied, model for judging the quality of a study, is that proposed by Guba and Lincoln (1989). This framework has been adopted by many authors as an overarching one that may be applied to qualitative methods across the board.

Just as Glaser and Strauss (1967) wanted to devise a new approach to qualitative research, which they called Grounded Theory, Guba and Lincoln (1989) sought to develop and apply a new approach to the evaluation of services. They termed this *'fourth generation evaluation'*. They deemed such a development necessary in order to overcome the deficiencies that they saw within previous approaches to evaluation. They viewed existing models as being dominated by a positivist paradigm with the right to define what was *'working'* being vested in powerful interest groups, either those closely associated with the *'service'* that was being evaluated (educational initiatives in the case of Guba and Lincoln), or those conducting the evaluation or both. Their fourth generation model was based on the need to seek the views of *all* those with an interest in the service (termed *'stakeholders'*) with the aim of achieving agreement (consensus) on the criteria to be applied in determining if the service had indeed *'worked'*. If consensus could not be achieved following several interactions then multiple reports should be produced that would ensure that the voices of each stakeholder group were heard. Whilst constructivist Grounded Theory is not necessarily concerned with the evaluation of services the need to actively engage with all interested parties lies at the heart of both Fourth Generation Evaluation and Constructivist Grounded Theory.

The model advocated by Guba and Lincoln (1989) for considering the quality of their new approach was, in many ways, a radical departure from existing approaches to evaluation and they were concerned that it might be rejected by the *'scientific elite'* who largely decided which studies were funded. Guba and Lincoln (1989) therefore proposed two sets of criteria for

deciding upon the rigour or quality of a study. One was termed the '*parallel*' criteria and these they viewed as being comparable to the tradition scientific canons of generalizability, reliability and internal and external validity. They named these the '*trustworthiness*' criteria and they included dependability, confirmability and transferability.

However Guba and Lincoln (1989) were also aware that these '*parallel*' criteria did not consider the extent to which the study had been able to engage with all participants and ensure that their voices had been heard. They therefore suggested a second set of criteria that they termed the '*authenticity*' criteria which comprised: Ontological authenticity (the extent to which participants' understanding of their own position has changed as a result of taking part in the study), Educative authenticity (the extent to which participants better understand the position of other groups as a result of taking part in the study), Catalytic authenticity (the extent to which the results of the study provide a stimulus for change) , Tactical authenticity (the extent to which the results of the study provide the means to achieve change) and Fairness (the extent to which the study captured the voices of all participants). According to Guba and Lincoln (1989) it was these latter criteria that most adequately reflected the degree to which a Fourth Generation Evaluation had been true to the principles upon which it was based.

However although the '*authenticity*' criteria were developed with the aim of ensuring participants were fully engaged in the study Nolan et al. (2003) were concerned that the language used to describe them was overly complex and might not be readily understood by participants who did not have an academic background. Therefore, when building a model to engage multiple groups of participants concerned with services for older people (older people, family carers, practitioners, politicians and researchers) in Sweden, Nolan and colleagues (Nolan et al. 2003), whilst keeping the rationale underpinning the authenticity criteria renamed

them to make them more readily understandable to the wider group of participants that they were working with. This was as follows:

- Fairness became **Equal Access**
- Ontological Authenticity became **Enhanced Awareness** of our own position
- Educative Authenticity became **Enhanced Awareness** of the position of others
- Catalytic Authenticity became **Encourage Action** and
- Tactical Authenticity became **Enable Action**

Collectively these became known as the '**EA**' criteria and they have since become widely adopted by both other researchers and practitioners/service providers. In addition to renaming the criteria Nolan et al. (2003) also argued that the framework should be applied not just at the end of the study but at all stages, as illustrated in table 4.6:

Table 4.6: Modified Authenticity Criteria applied throughout the study

Criteria	Planning	Process	Product
Equal Access			
Enhanced Awareness Self Others			
Encourage Action			
Enable Action			

The extent to which my study met the criteria of Charmaz (2006, 2014) and Nolan et al. (2003) will be considered in the discussion. Attention is now turned to the question of reflexivity.

4.7 REFLEXIVITY

As noted earlier while reflexivity has been seen as an essential element of many qualitative approaches it has only recently been recognised as being central to constructivist Grounded Theory, as described by Charmaz (2014) below:

“What we bring to the study influences what we can see....Researchers and research participants make assumptions about what is real , possess stocks of knowledge, occupy social statuses and pursue purposes that influence their respective views and actions in the presence of each other. Nevertheless, researchers, not participants, are obligated to be reflexive about what we bring to the scene, what we see, and how we see it. “

Charmaz (2014) p27

The researcher’s potential influence on the research process is evident at all stages, from planning through to writing the final theory. Corbin & Strauss (2008) note that this influence is most apparent during data collection and analysis as researchers react to participants’ accounts and participants react in turn to the researcher, usually on a subconscious level. While reflexivity has become a part of Grounded Theory Methods, its exact use is hard to pinpoint within the literature. To try to achieve consensus on its use in Grounded Theory Gentles et al. (2014) reviewed the existing literature. They concluded that whilst the notion of reflexivity is widely promoted most researchers fail to explicitly define what they mean by it and which approach they are adopting. As a result of their reading they suggest that reflexivity, at least in Grounded Theory, should address four issues:

- Types of researcher interactions that may influence the research
- Researcher influence during all stages of the research process
- How researcher influence is handled
- How researcher influence is viewed.

In keeping with these suggestions I will now consider how I may have influenced the study at its various stages and how such influence was addressed.

4.7.1 RESEARCHER INFLUENCE ON RESEARCH DESIGN AND DECISIONS

My influence on the choice of research topic has been addressed in Chapters 3 and 4. As a PhD student the influence was not mine alone and the views of my supervisors also played an important part in the methodological decisions that were made. The other important influence on the design was the study advisory group which included patient representatives and specialist nurses who commented on the research protocol, associated documents and ethics submission to ensure that they were suitable for participants.

4.7.2 RESEARCHER-PARTICIPANT INTERACTIONS DURING DATA COLLECTION

The foremost influence on researcher-participant interaction was my professional role. I did not hide this from participants as I worked in the clinics that some participants attended and so they might have at least seen me in passing. To try to hide my nursing role may have inhibited the development of trust with participants, especially if they already knew of it or found out at a later point in the study.

As I had in effect a *'dual'* role for many participants (as a researcher and a nurse) this influenced my interactions with them. Some cast me in the nurse role and asked advice or questions about their melanoma and its treatment. When this happened I usually referred them to their CNS. However, I also ensured that I always checked out participants' meanings and what they understood about their condition in case they were assuming that I already knew because I was a nurse. I was also concerned that participants may not like to pass on what could be considered as potentially *'critical'* comments about their experiences in case I knew the person they were talking about. However, this did not appear to be the case. An advantage of my nursing background was that participants seemed able to talk about

potentially personal effects of their melanoma because I was unlikely to be embarrassed by their accounts.

In building rapport with participants, I capitalised on the skills gained in clinical practice where a trusting relationship needs to be built within the confines of the clinic. I observed common courtesies when visiting participants' homes and offered hospitality such as refreshments and an appropriate environment when they visited the research centre to participate in interviews. When visiting participants' homes, while dressing smartly, I would dress more casually than I would in a work environment to separate my research persona from my clinical persona and to avoid appearing in any position of power, so I quite often wore jeans and a shirt. Such attire was not possible in the research centre where I had to adhere to the appropriate dress code for the work environment. However, this did not appear to hinder the conversation, possibly because everyone else was dressed in a similar fashion. With each repeated interview, my relationship with participants became more familiar and relaxed with the majority very willing, indeed often eager, to share their story. The rapport and trust that had built up during the interviews also enabled the participants to engage readily in the focus groups.

4.7.3 RESEARCHER INFLUENCE ON THE ANALYSIS

During data analysis my potential influence on how the theory might emerge became clearer. Even though I tried to make explicit the part that my prior professional and personal experience had played in both my motivation for undertaking the study and the foreshadowed questions that I wished to study it became apparent that other, more latent, processes were at work. As a result of my clinical experience I became aware that I held some preconceived ideas about what the '*melanoma journey*' should look like. These were influenced by the traditional '*medical model*' trajectory and the clinical pathways that myself and colleagues used to frame our work. I became aware that whilst participants might use a similar framework to describe

their experiences that it should not be imposed upon them. I therefore worked hard to ensure that participants were encouraged to describe and chart their experiences over time using the milestones and key junctures that were most meaningful to them. I always checked meanings and returned to participants with my interpretation of their story at the next interview. This was a distinct advantage of repeated, longitudinal interviews.

4.7.4 RESEARCHER INFLUENCE ON THE WRITING OF THE THESIS/THEORY

The ways in which the results of research are written and presented is very important if they are to reach as wide an audience as possible. For Charmaz (2006), Constructivist Grounded Theory should be written in a style and language that can be easily understood by all the participants. For Nolan et al. (2003) this key aspect to 'equal access', as even if participants can physically access research findings they are of limited use if they cannot subsequently understand the language used. This presents something of a dilemma for a PhD student writing a thesis. The thesis has to be 'examined' and this may bring with it certain expectations as to how it is written and presented. Whilst in reality it is unlikely that many of my participants will read my thesis I still wanted the theory itself to be written in a language and to use terms that would be easily understood. I therefore always checked that participants were happy with the way that the 'theory' was describing their experiences and this was one of the main aims of the focus groups. Based on their responses I feel happy that this was achieved. However it is not just the participants that need to be able to understand the 'theory' and if it is to be of wider use other people living with melanoma, their carers and practitioners need to be able to relate to it. It will be for future readers of this thesis and subsequent publications to decide if I have achieved this.

4.7.5 INFLUENCE OF THE RESEARCH ON THE RESEARCHER

The influence of the research on me became apparent in my clinical work as I was better able to empathise with patients and carers and began to notice issues that were important to them that had also been raised in the research. I was then able to explore those issues.

The other issue was that of the relationship built with participants during the course of the research. With repeated contact over three years, a relationship was built with each participant over time. During conversations before or after interviews I would often share details about myself. For example one participant mentioned a band that they were going to see and as I had seen the same band a few years before, we shared a common interest. With another participant, I shared an interest in photography and with other participants I shared the experience of having dogs as pets.

Building ongoing relationships over time also meant that I needed to ensure that that these were brought to a close appropriately. This was firstly done while arranging the focus groups but for a final written theory to be shared with participants. These opportunities enabled me to ensure that participants were left without ongoing issues and that I had the opportunity to thank them for their participation. These opportunities also provided an end to the relationship from my perspective as relationships built over years, even in the name of research, are not one sided.

4.7.6 THE INFLUENCE OF THE RESEARCH PROCESS

Charmaz (2014) states that research participants can use interviews to make sense of their situation. This was the case in my research and the research process itself had an effect on participants' experiences. This will be discussed in detail in the results and discussion chapters.

Given the longitudinal element of the design, the influence of time on the research, researcher and participants must be considered. Saldana (2003) asserts that time should be considered as a social construction, rather than something that is experienced equally by all people at all times. In section 3.2 I have described the experience of time standing still while waiting for results and in this respect, participants may feel time differently at various points in their experience of melanoma. Saldana (2003) considers time to be data but to capture the complexities of a journey the researcher should use the concept of from-through rather than the more discrete events occurring 'from' one time point 'to' another. This is in keeping with the aim to identify social processes within Grounded Theory methods. Saldana (2003) also links the concept of change to time stating that this should be considered prior to the commencement of a study, for example change could be defined as differences, events, a process or continuous events or motion. Using Grounded Theory methods the final product or type of change identified cannot be anticipated although it can be argued that the process used to identify change is the constant comparative method whereby change is identified through differences between and within interviews and the examination of negative cases. Saldana (2003) asserts that change, like time, is contextual and may therefore change during a longitudinal study as it depends upon time and social processes that can be experienced differently. The final constructs of time and change and their influence on the researcher, research and participants within this study will be considered further in the discussion chapter.

4.8 SUMMARY

This chapter has provided insight into the methodological decisions made including why:

- Qualitative methods were chosen
- Grounded Theory was considered the most appropriate as it allows the development of mid-range theory with practical application

- A constructivist approach Grounded Theory, influenced by Charmaz (2014) was chosen

The essential elements of Grounded Theory methods have been highlighted including: theory generation rather than verification, theoretical sampling, the use of constant comparison, simultaneous data collection and analysis, hierarchical coding, memo writing and theoretical saturation of categories and their properties. It has also described how these were used in my study. In particular it has shown how diagramming was used with patients and carers to involve them in data collection and analysis to form the final theory.

While the principles of rigour and reflexivity have been explored, these will be fully elaborated on in later chapters. I now turn attention to the results, beginning with an introduction to the participants.

5 CHAPTER 5: AN INTRODUCTION TO THE PARTICIPANTS

This study adopted a Constructivist Grounded Theory approach in which an active role for the researcher and participants was integral. Using brief *'pen portraits'* this chapter introduces the primary participants in the study, people living with melanoma and where one was nominated, their carer/supporter, together with the HCP nominated as being the most influential. It is hoped that this will bring these individuals *'to life'* for the reader. Pseudonyms are used and care has been taken not to provide any information that would allow participants to be recognized by anyone else. I present the participants in the order in which they joined the study.

5.1 ANNE & ALAN

Anne and Alan were a retired couple, both in their late sixties. They had worked hard to build their farm business which they sold and retired to the local village. Their melanoma journey began when Anne *'noticed'* a *'mark'* on the back of her hand. She attributed this to a working injury but when she realized that it wasn't going away, she sought help from her GP, who referred her for a specialist opinion. Anne did not see herself as a *'sun worshipper'* and did not recognize the sun exposure as part of her occupation as a risk. She was surprised that after the *'mark'* had been removed, it was found to be melanoma. I met Anne when she was diagnosed with a further melanoma on her arm which she described as *'a different animal'*. There had been a three-month delay in her being referred to oncology as the letter hadn't arrived. Alan had also recently been diagnosed with prostate cancer so they were both familiar with the oncology department and its systems. This meant that Anne knew that she needed to *'chase up'* her appointment. Anne also had fibromyalgia, which was a greater concern to her than the melanoma.

Anne and Alan viewed the melanoma diagnosis stoically as they had overcome what they saw as greater challenges in the past. For example while visiting family their party was involved in a traffic accident that caused the deaths of three family members and friends. They had also lost contact with their grandchildren, owing to the breakdown of their son's marriage, something seen as being of far greater concern than the melanoma. When nominating a HCP for the study, Anne chose the CNS at her local hospital as she had built a relationship with her after the initial diagnosis.

Anne and Alan took part in four interviews over the course of fourteen months. The fifth planned interview was postponed as Anne had a stroke and her rehabilitation took priority. With agreement, I kept in touch with Anne and Alan via telephone and three months later Anne was diagnosed with metastatic melanoma. At this point both withdrew from the study as Anne was too unwell to continue and Alan's time was taken caring for her. She died four months later.

5.2 TONY & LIZ

Tony was a sixty-six-year-old retired fire-fighter, who was working as a plumber at the time of study entry. He was in the merchant navy in his youth and as a result of chronic sun exposure had a twelve-year dermatological history, including removal of several basal cell carcinomas. Consequently, he had built a good relationship with the Skin Cancer CNS at his local hospital and nominated her to take part in the study. The latest lesion removed from his upper back turned out to be melanoma. At that time Tony was living with his wife Liz and they both had two adult children from previous relationships who did not live with them. Liz only took part in one interview before withdrawing from the study when they separated and subsequently

divorced, although she gave permission for the data from that interview to be used as they remained friends.

Soon after the initial melanoma, Tony was diagnosed with another in his right axillary lymph nodes which required further surgery followed by radiotherapy. I met him as he was recovering from surgery, prior to having his radiotherapy.

During the interviews, Tony had further investigations but he remained disease free. The combination of surgery and radiotherapy, however, left Tony with reduced power in his dominant arm and he didn't feel able to work anymore. He decided to retire and took a job delivering medication for a pharmacy.

Tony was very sociable, being secretary to a motorcycle club and regularly arranging fund raising events for a variety of charities. He conducted a lot of the club's administration via social media, and was in regular contact with numerous people during his recovery. He therefore had good social support and he discussed his experiences with club members who had been treated for other cancers. He also had support from his brother who was a professional counsellor.

Towards the end of the study Tony became involved with a new partner and withdrew when they moved just before the focus groups started.

5.3 WITHDREW

The third patient I recruited took part in the initial interview but then withdrew from the study and did not wish the data to be used. No reason was given, as was their right.

5.4 PHIL & KATE

Phil and Kate were in their early sixties and had worked for the same company, having met when Phil replaced the light fittings in Kate's office. Kate had stopped work to have a family but at interview was working part-time having gone back to work as their children got older. Phil was now retired but passionate about his hobbies of watching football and photography.

Phil had a melanoma removed from his chest followed by a wide local excision. During his three monthly checks he found a lump under his left arm while having a shower. This required lymph node surgery and I met him just before his radiotherapy. Phil had avoided finding information about melanoma until it had spread to his lymph nodes. At this point he became very proactive, searching for all the latest information. When he was diagnosed with metastatic disease, he was keen to take part in any clinical trials available. He was supported by his CNS in oncology and regularly contacted her using email. He did not hesitate in nominating her for this study. Kate was very supportive of Phil and organised his appointments like a 'secretary'. They were also close to friends/neighbours, some of whom had experienced other cancers. This provided a good support network for them.

Phil had the opportunity to try Vemurafenib, then a new treatment for melanoma. He was keen to share his experience with the clinical team so that this knowledge might help other patients. Phil became too unwell to take part in the later interviews and died shortly after, at which point Kate ended her involvement in the study.

5.5 SARAH, PAM, LYNN & AMY

Sarah was a twenty-eight year old single parent of three children aged between twelve months and eight years old. Although her parents were divorced she saw both of them regularly along with her sister and her aunt. Sarah had a melanoma diagnosed during her most recent pregnancy so her daughter was also under surveillance. When I met Sarah she has just been diagnosed with recurrent disease to her right groin which required surgery and radiotherapy. Initially her mother, Pam, agreed to take part in the study as a carer. Unfortunately their relationship later broke down, as did her contact with many of her friends. Subsequently her Aunt Lynn took on more caring responsibilities and participated in later interviews. Sarah's sister, Amy, also took part in the final interview. While many HCPs were involved in Sarah's care she nominated her practice nurse as the most influential. They had a long standing relationship which pre-dated her melanoma and was based around her children's contact with the practice.

Sarah was always cheerful and well presented, attending to her hair and make-up throughout her treatment, possibly as a result of her having been a hairdresser prior to her illness. Maintaining her appearance was very important to Sarah, because she didn't want to '*look poorly*' for her children, who she tried to shield from her illness as much as possible.

During the first interview Sarah had asked me about whether she could get help with childcare costs while she was attending radiotherapy appointments, so I referred her to the CNS and Cancer Support Centre for advice.

The combination of surgery and radiotherapy left Sarah with lymphoedema to her right leg. This meant that she tired quickly and could not play with her children as much as she wanted

to. Having to avoid sun exposure also had an effect on their family leisure time. Towards the end of the study Sarah was diagnosed with localized but inoperable spread of the melanoma. She was faced with a choice of treatments including immunotherapy as well as the new targeted therapies. Despite such difficult choices her main concern was what would happen to her children if she died. Sarah took part in interviews to the end of data collection and wanted to take part in a focus group but problems with childcare meant she could not attend.

5.6 IRENE & SUE

Irene was an eighty-two-year-old lady with no children but was close to her niece, Sue, whose own children were now in their late teens/early twenties. Irene enjoyed gardening and spending time with friends. She went on holidays around the UK but less frequently since she had been diagnosed with angina. She now struggled when walking uphill so her small dog was now walked by a neighbour.

Investigations for 'polyps', thought to be side-effects of her heart medication led to her being diagnosed with mucosal melanoma. The diagnostic process was complicated for Irene as she was not seen via the usual dermatology route. Her case was discussed at a Gastro-intestinal multi-disciplinary team (MDT) meeting, resulting in delays in her being referred for investigation to the skin MDT. Her GP felt some responsibility for this and so acted to ensure an urgent oncology appointment was made.

Sue had been made redundant shortly before her Aunt was diagnosed with inoperable melanoma but upon hearing the news she decided to care for Irene rather than actively seek another job. Irene had always been very caring towards friends and family and Sue felt she deserved her support. Having both mucosal melanoma and angina meant that Irene's

treatment options were limited so interventions were delayed until she was symptomatic. Irene was stoical about this, with three of her sisters having died of other cancers. She spent time with Sue sorting out her affairs and passing on family history. Unfortunately, when Irene became symptomatic, she deteriorated quickly and died within 6 months of the start of the study. Sue wanted to remain involved after Irene's death to ensure that their story was complete. Sue believed in spiritualism and took comfort from the fact that Irene was going to meet her sisters who had pre-deceased her.

When nominating a HCP to take part in the study, both Irene and Sue chose Irene's GP who had been supportive throughout.

5.7 TOM & EDNA

Tom and Edna were both in their eighties. It was their second marriage, each having been widowed more than twenty years before. Tom was a retired mining engineer and Edna was a retired office worker. They enjoyed cruises and holidays and would go away for the weekend whenever they could. Their families visited regularly but Tom and Edna were very independent.

Tom's melanoma on his right heel needed several surgeries to obtain clear skin margins. Although his mobility was severely impaired they adapted their lives to accommodate this, for example by purchasing a scooter, wheelchair and crutches to minimise the impact on their lifestyle. They aimed to carry on as normal, tolerating the numerous hospital appointments.

They both had a lot of faith in the plastic surgeon as they had seen him at every appointment and if they had a problem, could easily get an appointment through his secretary. They felt that the surgeon was the person who knew all about Tom's care so nominated him for the study.

5.8 JOHN & ESTHER

John was a farmer and Esther an art teacher. They lived in a bungalow on the edge of the farm and were both in their mid sixties. They had two adult sons and grandchildren, one of whom lived in Australia. John and Esther had another house in Austria that they visited regularly. Ten years ago John had seen his GP with a mark on the right side of his face, and was reassured that it was nothing to worry about. A short time afterwards, while skiing in Austria, a friend advised him to get his mark checked as he had had something similar removed. John saw his GP again and was found to have a pre-malignant lesion.

I met John who, after investigations for a persistent cough, had recently been diagnosed with metastatic melanoma. This came as a shock and John's disease then progressed very quickly with the transition between hospital and community care not being as seamless as it should have been, so that Esther did not know who to turn to for help and information as the melanoma spread to John's brain. She was therefore glad to get support from the Macmillan nurse once they were referred. John was eventually admitted to the local hospice and he decided not to have any treatment. He found it very difficult to talk to anyone about his condition and became withdrawn, not really communicating with Esther. He only really opened up during the first interview for the research study. John's sons visited as their father's health worsened and helped Esther to care for him and supported her subsequently.

John died within three months of his interview so data from him were only collected once. Esther took a break from work while John was ill but was able to return to part-time teaching after his death. After John's death Esther continued to participate in two interviews and one of the focus groups. She felt that this helped her to deal with her, at times, overwhelming grief.

Owing to John's quick deterioration, the nomination of a HCP was made by Esther, who chose the Community Macmillan Nurse with whom she had established a strong relationship in a very short period of time.

5.9 KAREN & LAURA

Karen, forty-seven, was a nurse working as a senior clinical manager. She had three daughters and was divorced from their father. The eldest daughter, Laura, was a mental health nurse. The two younger, twin daughters were finishing college. Karen's mother also lived nearby. Karen was diagnosed with recurrent melanoma after being mis-diagnosed 10 years earlier with a benign lesion. When a 'new' lump appeared on her ear, she was busy with work and put off seeing her GP as she did not expect it to be anything sinister. Subsequently Karen had multiple surgeries and eventually her ear had to be amputated. She joined the study while under surveillance but was soon diagnosed with metastatic disease.

At this time the new therapies for melanoma were not available so Karen decided to take part in a clinical trial. She initially attended clinics alone and only passed on the information she wished to her family. Once in the trial, Karen sometimes brought Laura to her appointments. Laura was very angry about the previous mis-diagnosis. Although Karen had been offered treatment closer to home she built a trusting relationship with the oncology department and did not want to be treated elsewhere.

During the interviews, Laura felt that she was '*becoming like a Mum*' as she looked after Karen and the rest of the family. As a nurse, Laura had a better understanding of what was happening and relayed this to her sisters. While supporting her Mum, Laura re-evaluated some of her own relationships, discarding friends who did not understand why she was spending so much time with Karen. Karen and Laura planned short breaks and days out to create happy memories.

After Karen's death I had no way of contacting Laura directly as Karen had arranged the interviews and so her involvement in the study stopped and no HCP was nominated.

5.10 HELEN

Helen was forty-six and worked at a local supermarket. She had a very cheerful disposition and enjoyed interacting with her customers. She was single, but lived near her mother who she kept in close contact with. She also had a large group of friends and went out with them regularly.

Helen '*noticed*' an ulcer on her lip that was not healing and went to see her GP, who gave her some cream. When things did not improve, Helen was referred to the head and neck surgeons. Helen was surprised when she was diagnosed with melanoma and enlarged lymph nodes which required surgery. I met Helen when she was recovering from surgery and considering radiotherapy.

As her sister had died from breast cancer a few years earlier, Helen had not immediately told her mother about her diagnosis. When I met Helen, her mother still did not know.

Consequently Helen didn't name her as her carer. Neither did she want to impose on a close friend who accompanied her to appointments as she had a young family of her own.

After having radiotherapy to her neck, Helen found eating very difficult and was limited to a liquid diet. She lost a lot of weight and not wanting to impose on her family/friends had built a trusting relationship with the Head and Neck Macmillan Nurse who would telephone to check on her after treatment. This was the HCP that Helen nominated to take part in the study.

Helen slowly regained her ability to eat. Although she was still not able to eat socially she would still go out with friends, and have a drink whilst they ate. When she felt able, Helen would also still cook for her friends, but have some soup herself. Eventually she was able to eat soft foods but it was a long recovery. The radiotherapy also left Helen with a dry mouth so she carried a bottle of water with her wherever she went.

Helen decided to tell her Mum about the melanoma before she started radiotherapy and found her Mum to be supportive, helping with meal preparation. Helen stayed with her Mum for a few days after her treatment. However, her Mum did not trust Helen to tell her everything once she knew that information had initially been withheld.

Helen completed study participation, including a focus group and was being followed up by the oncologists and surgeons at the end of data collection.

5.11 LUKE

Luke was forty-two, recently divorced and living with his mother. His father had died from bowel cancer the previous year. Luke enjoyed photography, walking and growing his own vegetables. He had a manual job in a warehouse, which kept him fit, and he enjoyed being active. He did not have many friends, only mentioning a co-worker in the interviews. He didn't feel he needed a 'carer' and so did not nominate one. He was very independent and liked to deal with things himself.

After his father had died, Luke had focused his attention on his Mum, so he hadn't immediately noticed the mole on his back changing. Its position made it difficult to see and he only '*noticed*' it by chance in the mirror one day. He saw his GP who had said that she was '*very concerned*', but did not elaborate any further. The subsequent feeling of not having enough information stayed with Luke throughout the study. I met him after his surgery and although he now knew his diagnosis he still had many unanswered questions. He had not been in touch with the CNS so, with permission, I asked the team to contact him. Despite this Luke did not develop a relationship with any HCP in particular as he had not seen the same person twice. He therefore did not nominate anyone.

When we met, Luke was still recovering from surgery and had not gone back to work yet due to the physical demands this placed on him. Luke had rarely missed a day's work so was keen to get back. He filled his time by going for long walks, taking photographs along the way. As he improved he managed to do some limited gardening and negotiated a return to work on light duties. Luke found this a little boring and preferred to be more active but realized that he wasn't yet able to do the heavy lifting required. When he did return to full duties he struggled as the promised support was not provided. However, following an occupational health review additional help was made available.

Luke didn't require any treatment beyond surgery but attended follow-up appointments for a year. He was then diagnosed with metastatic disease during a routine scan. Luke took part in one interview just after this but was then transferred to the hospice and died within weeks.

5.12 FRED

Fred was in his seventies but still worked at the local supermarket. He was a widower with four children and numerous grandchildren. He couldn't name an individual carer as he found it difficult to choose between his children who all shared his care. He would see one of his daughters for a meal each weekend and whilst his sons lived further away, they took their turn in taking him to his hospital appointments. His eldest teenage granddaughter would do his housework once a week for pocket money. Fred had a springer spaniel that he walked around the local park every day and he also spent time in his garden or with his friends in the pub.

Fred noticed a '*mark*' on his right cheek that did not look quite right so he went to see his GP who sent him to dermatology to have it removed. The histology result was indeterminate but thought to be low risk, so he was discharged. A year later another black spot appeared on his cheek, but as he had previously been discharged he needed another referral from his GP. After minor surgery Fred was given an appointment to get his results but received a worrying telephone call asking him to attend earlier. The result showed that, while the lesion had been completely removed it was a metastatic melanoma deposit rather than the primary lesion. He therefore had a skin examination, a CT scan and ophthalmological examination to identify the primary melanoma. However, one was not found; not uncommon in melanoma where the primary lesion can regress even after metastatic deposits have left the primary site.

Fred continued to have follow-up examinations every three months. At one appointment, a further black '*mark*' on his cheek caused concern, but it turned out to be a stitch that had not dissolved and had worked its way to the surface. During his investigations Fred spent time with the new CNS, who had taken an interest in his case. It transpired that her daughter and his granddaughter were friends at school and they had formed a close relationship. Fred had only needed to contact the CNS twice but he knew that she would always get back to him and trusted her to do whatever was needed. He therefore named the CNS for inclusion in this study.

Fred told his family and friends of the melanoma but did not make a '*big deal*' out of it. As he recovered from the melanoma, his hip became problematic and was a greater priority until he had a total hip replacement. Fred participated in all interviews and a focus group. At the end of the study he was attending for routine surveillance without any further problems.

5.13 MATT

Matt, at twenty-eight, was one of the youngest participants. He had a difficult childhood with an alcoholic mother and had some problems with addiction himself in the past. He had moved to a new area to '*start afresh*' and was trying to stay in work and mix with people who might be a '*better influence*' on him. His brother had been more successful at finding a career and he wanted to emulate him. He was still in contact with his mother, though they had a difficult relationship.

Matt's girlfriend at the time had '*noticed a mark*' on his back so he went to see his GP who referred him to dermatology to have it removed. I met Matt after he had found out that it was melanoma that needed a wide local excision. This meant that Matt had to take some time off

work and he was worried that too much free time might lead to old habits returning, so he wanted to start work again as soon as possible. Fortunately, as he worked in a call centre, he was able to return to work within a couple of weeks.

Matt turned to the internet for further information about melanoma. He discovered that the actor Hugh Jackman had been diagnosed with skin cancer in the past, and took comfort in knowing that someone he admired had been through something similar. Having moved to a new area, Matt had few friends and split up with his girlfriend before receiving the diagnosis. He noticed that he was becoming snappy at work and felt angry. This led to his boss calling him into her office to find out why. When he explained what had happened, she was sympathetic as she had had treatment for a different cancer in the past. Matt subsequently shared his experience with another colleague who was having treatment for cancer. Matt's mood and working relationships improved. The experience of having melanoma made him think about his spiritual beliefs. Matt thought that it was a sign from God to '*watch his back*' and look after himself. This reinforced his resolution to improve his life.

Matt continued to have regular follow-up but did not require any further treatment. As most of his contact had been with his plastic surgeon he nominated him as his HCP. However he did not respond to the invitation to take part and so could not be interviewed.

5.14 RUTH

Ruth worked as a care assistant in a nursing home. She was in her sixties, divorced with adult children and grandchildren. Her granddaughter would usually be at the house when I visited and her daughter or a friend would accompany her to hospital appointments. Ruth had enjoyed sunbathing on holidays in the Mediterranean for many years and '*noticed*' a change in a mole

on her lower right thigh so went to see her GP. After having the mole removed Ruth was told that it was melanoma. I met her following the surgery from which she had recovered quickly.

While wanting to take part in the study, Ruth tried to deny the melanoma. She was resolute that she would not think about it and stated that she didn't listen during clinic appointments. During the interviews she would answer questions as briefly as possible, and whilst stating that she didn't think about it she had evidently paid attention to some of the information given to her. Ruth didn't feel she had a carer but this may have also have been because she didn't want to admit that there was something wrong. Ruth confided in one particular friend she trusted not to say anything to anyone else. It was important to Ruth that she controlled who knew about her diagnosis.

Ruth attended routine surveillance for six months and nominated the plastic surgeon that she had seen to take part in the study. Unfortunately the surgeon did not respond to the invitation letter or the follow-up telephone call. During surveillance Ruth had planned another holiday abroad with her usual group of friends but didn't think that it was the same now that she couldn't sunbathe. Shortly after returning from holiday, Ruth was diagnosed with metastatic disease. She started a new targeted therapy and asked if we could do the next scheduled interview after the first cycle. Unfortunately during that time, Ruth was admitted to hospital and diagnosed with brain metastases so further interviews were inappropriate. She died a few weeks later. After her death, Ruth's family took the opportunity to meet the clinical team and ask questions about her treatment, possibly a reflection of the fact that Ruth had not shared much information with her family.

5.15 MARK & SANDRA

Mark was an outdoor worker in his forties. His wife Sandra was a care assistant at the local hospital, who had been treated for breast cancer ten years earlier. They lived in the country with their two German Shepherd dogs and were renovating their cottage. Mark had a 'spot' on his right ear that had started to bleed and was not healing. Sandra was having to regularly wash his pillow case so insisted that he went to the GP to get it checked, who referred him to the hospital for tests. When they went to receive the results Sandra realized that something was wrong when there were a lot of people in the room, including a nurse wearing a Macmillan name badge. Mark, not having worked in healthcare, did not pick up on these cues. After the initial melanoma diagnosis, Mark was left with a large piece of his ear missing so a prosthesis was made to disguise it. I met him at that point. Owing to the complex surgery to his ear, he felt as though the plastic surgeon had the most involvement with his care so nominated him for the study. However the surgeon did not respond to the invitation letter or follow-up telephone call.

The cancer diagnosis had shaken them both, despite Sandra's experience a decade before. Mark enjoyed his job but the constant sun exposure caused Sandra worry, particularly in the summer months. She wanted him to take a job where he was less exposed and 'nagged' him to use sun cream. At first Mark also felt strongly about this and spoke to the Health and Safety Officer at work to make sun cream available to all outdoor workers in the company. However, as time went on and he returned to his normal routine, he admitted to forgetting to use it sometimes. This caused a degree of tension between them. They both realized how serious melanoma could be and so Mark wanted to accelerate his plans for renovating the cottage so that everything was in place for Sandra should he become unwell. He also wanted to make sure that there was enough money put aside for her, so he would work any overtime offered. However, Sandra saw this as putting himself at risk owing to the additional sun exposure.

While they were a source of support for each other, Sandra felt that Mark did not open up enough to her. She had the support of her friends and he had support from his friends and colleagues but this was not always obvious. For Mark, having colleagues telephone to see how he was, was enough support. He would joke about the songs that he would have played at his funeral and if anyone made a comment when he wasn't wearing the prosthesis, he would tell them what had happened, adding a warning that there are consequences to not using sun protection. While Mark was attending for follow-up, another colleague had a lesion removed that was diagnosed with a less serious form of skin cancer, and Mark was happy to provide support.

During the study one of their dogs died from cancer, which Mark found particularly hard. Mark and Sandra took part in interviews to the end of data collection and wanted to take part in the focus group but Mark was unable to take the time off work.

5.16 JACKIE & NICK

Jackie and Nick were in their forties. Jackie worked as a secretary in a hospital and Nick was a transport manager. The long hours that Nick worked meant that arranging an interview was difficult so he only participated in one interview towards the end of the study, whereas Jackie was allowed time off work to attend the research centre. They had no children, having tried IVF in the past and as they both worked long hours, they made the most of their leisure time. They enjoyed regular holidays abroad and Jackie had used sunbeds in the past, believing that it would prevent her from getting burned. She had fair skin with freckles and red hair.

Jackie had a melanoma removed ten years earlier and had been discharged. Nick had recently '*noticed*' a freckle on the same arm as the earlier melanoma that seemed to be changing and urged Jackie to go to the doctor. When the diagnosis of melanoma was made Jackie was a little shaken but only took a couple of days off work for the surgery as it did not affect her ability to perform tasks. She shared the diagnosis with one close colleague and her family. This caused some tension as her mother blamed her love of the sun for the melanoma. Nick identified himself as her carer as he was meeting her emotional needs as well as ensuring she did not stay out in the sun too long.

After the first melanoma Jackie had used higher factor sun creams and sunbathed less. Her family would tell her not to lie in the sun and these reminders became more frequent after the second melanoma. Jackie now felt the need for more information, actively searching the Macmillan website. Jackie took part in the study until the end of data collection but was not able to attend one of the focus groups. She had no further episodes of melanoma during the study. She did not feel able to nominate one particular HCP to take part in the study.

5.17 JACK & CAROL

Jack and Carol were in their early sixties and were retired. They had been married for many years and had two adult children. Jack had been a miner and Carol was a home help. They had spent much of the previous year caring for their elderly parents who had now died. Their daughter, a nurse, had recently bought a house with her partner so Jack was helping with the renovations. In previous years Jack had been a keen runner, including marathons, but now preferred walking. They had both enjoyed holidays around the world including Thailand and China but would rather see the sights than lie on a beach. They became grandparents during the study and started to spend some of their time looking after their grandson.

A lump appeared on the right hand side of Jack's cheek which he didn't think anything of, until his son repeatedly suggested that he went to the doctor. When Jack saw his GP, he was reassured that it wasn't anything to worry about but Jack went back a second time to see another GP who referred him to dermatology. The dermatologist suspected a basal cell carcinoma, but the diagnosis revealed that it was melanoma so a wide local excision was undertaken. After surgery Jack was concerned about how it might look, as the dressing was larger than he expected but he was pleased with the result. I met Jack and Carol after his second surgery.

During the first interview Jack and Carol revealed that they had not spoken to each other during the journey home after being given the diagnosis, and had rarely discussed it since, not wanting to upset each other. When I met them, they were waiting for his CT scan to be reviewed as there was a suspicious area in his right lung. A further scan showed this to be benign.

Jack continued to attend for regular surveillance visits and had no further episodes of melanoma, but he was more cautious in the sun, wearing a hat and regularly using sun cream. He participated in the interviews and one of the focus groups, but Carol could not attend the focus group as she was recovering from foot surgery. Jack did not feel able to nominate a HCP to take part in the study as he did not think he had seen the same person twice during his care. Jack's diagnosis prompted his sister to have a suspicious mole removed which was subsequently diagnosed as melanoma.

5.18 JEAN & BOB

Jean, fifty, was partly home based as an area manager for a large company and Bob, forty-nine, her partner, was a long-distance lorry driver so travelled a lot. Jean had no children but Bob had children and grandchildren from a previous relationship. They had daily contact with members of their families but said very little about their social lives outside of the family. They both worked long hours but enjoyed regular holidays abroad. Jean was surprised when a mole that been assessed by a GP ten years earlier as benign began to change. She went to see her new GP as she had moved house since the last assessment and after referral to dermatology and surgery, found that it was melanoma. The size of the wide local excision meant that Jean needed to have a skin graft, which was taken from the back of her thigh. The response from her new GP that resulted in a quick referral for treatment and the support that he provided afterwards prompted Jean to nominate him to take part in this study but upon trying to contact him, I learnt that he was off work on sick leave.

Jean was keen to get back to work but the position of the skin graft made travelling difficult so she took extended time off. It was during this time that I met Jean and Bob. Jean was very independent and preferred to go to appointments alone as Bob didn't get paid if he took the day off work to go with her. When needed, Jean had asked her elderly parents to take her to the hospital but her father's driving made her nervous so she arranged for hospital transport after a couple of visits. Bob wanted to be more involved in Jean's care, but she resisted this as she admitted to trying to deny the melanoma to herself. This caused some tension between them as Bob wanted to support her more, but Jean wanted to get back to normal rather than dwell on the melanoma.

During the study Jean was admitted to hospital with costochondritis. This became more of a concern than the melanoma for a time. During surveillance visits for the melanoma Jean had

a further lesion removed from her right thigh as a precaution but this was benign. Jean's surveillance visits were eventually managed from her local hospital once she had been discharged from plastic surgery. She took part in the interviews until the end of data collection as well as one of the focus groups. Bob could not take part in the focus group owing to work commitments.

5.19 SUMMARY

Hopefully the descriptions above have enabled the reader to begin to '*get to know*' the participants in the study. In the following chapters I chart their '*melanoma journeys*' highlighting the main timeframes they identified and the major processes that captured key elements of their experiences. Together these aspects comprise the mid-range theory to emerge from the study, one that was agreed individually by participants and those who took part in the focus groups. This theory charts the '*ups and downs*' that the participants experienced and these are reflected in the metaphor '*Riding the Rollercoaster*' that was briefly introduced in the methods chapter. The next chapter begins with a brief overview of the theory before describing the early stages of the participants '*melanoma journey*'.

6 CHAPTER 6 LIVING WITH MELANOMA: RIDING THE ROLLERCOASTER

6.1 INTRODUCTION AND THEORY OVERVIEW

The primary aim of the study was to better understand the experience of living with melanoma from the perspectives of patients, their primary carer and the HCP that they identified as being the most influential. It was intended that the insights gained would result in the development of a mid-range substantive theory that had the potential for practical application in order that the melanoma *'journey'* could be improved for those who might embark on it in the future. In order to do so a constructivist Grounded Theory method was adopted that employed a longitudinal design involving multiple sequential interviews with participants. The intended result was a temporal account of living with melanoma that highlighted key points in the participants' *'journeys'* and when help and support might be provided most effectively.

The extensive volumes of data collected revealed a complex and multifaceted picture, with each *'journey'* having both shared and unique elements. To develop a theory that captured such complexity, but could also be easily understood by multiple audiences, some of this individual variation was necessarily lost. Such a compromise is inevitable in all such undertakings. Nevertheless I believe (as did the participants) that what follows provides a faithful yet simplified rendering of the major milestones experienced by those living with melanoma and the impact that it had on them. Furthermore, as was explained in the Methods chapter, I sought as fully as I was able to allow participants to play an active part in the co-construction of the theory. The extent to which this might be considered successful will be explored further in the discussion.

I begin with a brief overview of the theory as a whole, followed by an account of the early stages of participants' *'journeys'*. The later stages will be explored in subsequent chapters. This overview will provide readers with a *'route map'* to follow the relationships and interactions between the various stages and processes that marked the melanoma *'journey'* as it unfolded over time.

Consistent with a temporal approach the theory comprises a number of stages or *'moments'* in the melanoma journey, the overall effects of which, as suggested in the preceding chapter are captured by the metaphor *'Riding the Rollercoaster'*. This reflects the various *'ups and downs'* that participants experienced during their *'journeys'*, and whilst the nature of these understandably varied, as did the final outcome (for example between participants with fatal metastatic disease and those who remained melanoma free), all those who took part experienced both *'ups and downs'*. These are explored in the following chapters.

Based on an analysis of their accounts the melanoma experience can be considered to comprise of the following key *'moments'*. These are captured below using, where appropriate, both everyday language and their more medicalised equivalent:

- What's that mole?: Pre-diagnosis
- The Melanoma journey begins: Diagnosis and early treatment
- Ups and Downs: Surveillance
- The 'Bombshell': Advanced Melanoma, and for some, death

Clearly not all participants experienced all stages (for example metastatic disease and death) but all were experienced by some. In working through these various stages participants' lives underwent a number of changes brought about by the impact of the melanoma, and the nature of the interactions between patients and carers and their contact with the health care system.

These changes and the processes that accompanied them are captured in the theory by using an alliteration of **'R's**, which reflect the impact of the melanoma on the participants:

- **R**outines of daily life
- The **R**oles that they fulfilled, and
- Their **R**elationships with each other and the health care system

These impacts were mediated by the ways in which participants **R**ecognised and **R**esponded to the challenges that they faced and the **R**esources that they could draw upon in so doing. The participants' experiences are described below highlighting the ways in which these core elements of the theory interacted with each other at the differing stages of the melanoma journey, beginning with stage one, *'What's that mole?'*

6.2 WHAT'S THAT MOLE?: PRE-DIAGNOSIS

'Well it probably started last year when I noticed me mole on me back'. Luke

Many of the participants first became aware of what would later turn out to be a melanoma when they, or someone close to them, *'noticed'* something unusual, such as a mark or discolouration on their skin. Participants often referred to this as a *'mole'* but differing manifestations presented themselves. In order to provide a *'shorthand'* for such diversity the term *'lesion'*, although rather medicalised, will be used in the account that follows unless, when using verbatim quotes, participants used a differing term.

This process of *'noticing'* often occurred by chance, and might involve the patient seeing something unusual for the first time, or the lesion being brought to their attention by others, usually, but not always, family members who *'noticed'* it themselves. At this point many saw

no reason for concern and their 'response' was to ignore things. This tended to continue, either until there was a change which meant that the lesion could no longer be ignored or someone 'nagged' the patient to do something about it. This is described by Mark and Sandra:

"Well basically it was just a lump, a small lump on my ear, I did think it was a spot really. Typical bloke, you know, so it was left and left and left maybe up to a year afterwards, it just started losing a little spot of blood every now and again.... but Sandra (wife) was getting fed up of washing the pillowcases every other day, so she said 'You'd better go' (to the doctor)." Mark

"The only reason why he went to the doctor was because I were nagging him because there were blood on the pillowcases all the time, and I said 'This is not normal'." Sandra

For Luke the situation was somewhat different. His lesion was in a less visible place and his attention was drawn to it by chance. Although he 'kept his eye on it', other seemingly more important life events intervened and as with Mark, it was some time before he became aware of his 'mole' again:

*"Well it probably started last year when I **noticed** me mole on me back. It were only because I'd lowered the mirror in bathroom. So I kept me eye on it, nowt really changed, and then me Dad got ill again (with cancer) and I sort of forgot all about that (mole). And then come separation with me wife, ... I were just one day I were getting dressed (and) I caught it (mole) with me nail, and it started bleeding. I thought that's strange. After about two weeks it never healed, and that's when I went to the doctors." Luke*

In Matt's case it was his girlfriend who first 'noticed' a new 'mole', but, consistent with the others above, Matt ignored it until more radical changes occurred. As this point he started searching for more information, using the internet, until he became convinced that something 'dodgy' was happening, a realisation that prompted rapid action:

*"I didn't **notice** until my girlfriend at the time saying 'oh, what's that', I said oh, 'it's nothing, just a mole', ..I didn't really think anything of it, until it turned really, really funny. I thought 'that's just not right, this, just looks dodgy'. Just got bigger, colour went darker, started itching a bit. I started Googling it on the internet, and the Google images looked similar to what I had on my back. So I thought yeah, this could be dodgy, I thought I need a professional opinion. Well he (doctor) said 'oh, that looks dodgy, I'm going to refer you'. And I got referred to clinic, then the hospital, quite quick." Matt*

Others, upon '*noticing*' something unusual, looked for an explanation that meant it could be seen as '*normal*'. This continued until further changes occurred and/or '*nagging*' from family members resulted in a professional opinion being sought. For Tom and Edna below the news that Tom had a melanoma came as a shock, as it was something they had never heard of:

"I had what I thought was a birth mark, on the side of my foot. After a while, it started to show signs of roughening up and being painful..... and the upshot was that eventually with a bit of pressure from my wife, I went to the doctors with it." Tom

"Yeah, you didn't think it was melanoma when you went initially." Edna

"No, I didn't think it was melanoma when I went. Well to be honest, I didn't know what melanoma was." Tom

As Tom and Edna had seen the lesion as a '*normal*' birth mark, they initially '*discounted*' it. Similarly Anne also explained away the mark on her skin as being caused by gardening or feeding the chickens, resulting in a delay before seeking advice. This '*normalising*' meant that the lesion could be '*discounted*', resulting in delays before help was sought. As a result, by the time she joined the study Anne had more than one melanoma:

"The first Melanoma sat on the back of my hand just like a tea leaf. I did have it there for a while, longer than I should have had it there really but I felt that I had knocked my hand in the garden... or when I was feeding the poultry and I just really didn't take any notice of it." Anne

However, others, upon '*noticing*' a change to their skin did not ignore or normalise the situation but sought professional advice quickly, only for the professionals themselves to '*normalise*' things. This happened to Jean, and John and Esther, as they describe below.

"About 10 or more years ago, I went to the doctors because I had a very dark, very flat circular-ish thing on the back of my calf. The doctor said that he wasn't worried but that I should take photographs of it so that I would be able to identify if it ever changed. And so I did. But I totally trusted that first doctor, but just keep an eye on it in case it changes. And it never did, it sat there for, got to be at least 10 years. It weren't until something happened to it and because it was so dark and about the size of a 5p piece, (that) a few people had said to me that doesn't look good, you should get it checked out.." Jean

"Well I think it started probably (about) nine years ago, I got a small black patch on the side of my face. Esther (wife) said 'I think you should go to see the doctor about that', and the GP, they said 'is it flush with the skin?', I said 'well yes it is', he said 'well there's nothing to bother about then'. (Years later) We were over in Austria and the skiing instructor's wife said 'you should go and get that seen to, because Otto has just had one of those removed'. So I came back, went to the GP." John

"Yes, and that was the thing. When originally you had it checked, you went twice to him, twice he said it was okay, (we left it) ages, (but then) it just didn't look right ... and it was really this friend of ours who said you go and get it properly checked." Esther

In the above cases it was several years before further help was sought, often at the suggestion of others. In Jean's case the doctor had advised '*monitoring*' the lesion, which she did for a decade or more, until further changes happened and others urged her to seek advice. In John and Esther's case no active '*monitoring*' was suggested and it was only a chance encounter whilst on holiday that prompted them to seek another opinion. The seemingly innocuous nature of the lesion and the reassurance of their GP resulted in a lengthy delay. Sadly in this case the melanoma rapidly became metastatic and John died three months after joining the study. However, his wife Esther chose to continue and we will hear more from her later.

An exception to those 'noticing' a skin lesion, Irene 'noticed' bleeding that she attributed to haemorrhoids. She sought help from her GP immediately, who initially reassured her that the cause had been identified causing some delay in her diagnosis but when there was no improvement he referred her for investigations.

So far participants have described the events surrounding the discovery of a new 'mole' or similar change. These participants did not 'recognise' the need to act and so usually 'responded' by ignoring their 'mole', often for many years. For others however the onset of their melanoma was preceded by years of experiencing skin problems. Consequently because of this Helen and Phil were able to 'recognise' that something wasn't right quickly and their 'response' was to seek a professional opinion rapidly:

*"I **noticed** a mole which seemed a little bit abnormal. I've had moles forever, but this particular one seemed to be not behaving the same as the rest of them. So I went more or less straight away to see the doctor, and she agreed and things progressed from there."* Phil

"It didn't look right to me. I've had mouth ulcers before, it wasn't a mouth ulcer like that. I just got a funny feeling that something wasn't quite right, and I went to the doctors the beginning of January. And then she referred me." Helen

Tony was having regular skin checks as he had numerous Basal Cell Carcinomas removed over a twelve year period, when one was found to be a melanoma:

"Then I found one or they found one on my back which didn't seem untoward in its size, shape or anything else. That one came back as malignant." Tony

Things were rather different for Karen and her daughter, Laura. Karen had surgery for a benign skin lesion over a decade earlier, followed by further minor procedures. She had ‘monitored’ the situation for many years but was able to ‘discount’ and ‘normalise’ subsequent minor changes. Even when more pronounced changes occurred Karen did not suspect anything serious. When a melanoma was diagnosed it came as a genuine shock to both Karen and Laura, heightened because they were both experienced nurses:

I'd had a lump on my ear going back to 2003 that was removed. (It) came back in 2008, and they did sort of a shave, tidied it up, absolutely fine. After that I've always had a little bit of a lump so thought nothing of it. And then it started to grow quite large, in two areas... one that was a very big bluish vascular lump. So completely bizarre I'll go to the doctors, I thought 'well it's been nothing in the past, it'll be nothing this time'. And I suppose lucky for me in a way he (doctor) said 'I've got no idea what it is, but I'll put you on the fast track cancer referral'.”
Karen

“Well as long as I can remember basically my mum’s always had a lump on her ear and then when she told me obviously it was melanoma, I thought what if we’d have noticed this sooner, what if my mum would have stopped saying ‘oh it’ll be fine’ and gone (to the doctor), rather than just leaving it and leaving it, and what if we’d have pushed?” Laura

From the above accounts of the pre-diagnostic period two broad patterns have emerged. In the first the melanoma appeared as a ‘new’ lesion and in the second it was part of a much longer history of skin-related problems. The ways in which the melanoma was ‘recognised’ and ‘responded’ to in these scenarios tended to differ, but similar patterns can be seen.

The lesion needed to be ‘recognised’ as being something out of the ordinary, so that it could no longer be ignored, ‘normalised’ and ‘discounted’, before participants ‘responded’ to it. For Mark and Sandra, Luke, and Matt their story began with them ‘noticing’ a new skin lesion but their initial ‘response’ was to largely ‘ignore’ this (although Luke did ‘keep an eye on it’ (monitor) for a while until a more significant (and potentially worrying) change occurred and/or until they were prompted to act by others. It was only upon ‘recognising’ what they perceived

to be a worrying change or the pressure to act from others became strident enough that they '*responded*' by seeking professional advice.

Other participants with a new lesion (Tom and Edna/Anne) did not ignore it but rather '*responded*' by finding a '*normal*' explanation that meant any worries could be '*discounted*'. Once again it was not until there was '*recognition*' of a more significant change or because of '*nagging*' from others that they '*responded*' by seeking professional help. In both these scenarios lengthy delays ensued.

A third group of participants (Jean/John and Esther) '*recognised*' the need to act quickly and so '*responded*' by seeking professional help very soon after '*noticing*' their skin lesion. In their cases however the professional they contacted reassured them that their lesions were not a cause for concern and so any worries were '*discounted*'. Although Jean was advised to '*monitor*' the situation, because no major changes were noted, further action was not taken. As with all the participants so far it was only when more major changes were '*recognised*' and/or others advised action that further help was sought. This again resulted in lengthy delays.

Two participants with a long history of skin lesions (Phil/Helen) were able to '*recognise*' when a new lesion was a cause for concern and '*responded*' by seeking professional help rapidly. Tony's melanoma, however was recognised by a HCP during a routine examination. For Karen and Laura the situation was slightly different in that it was the same lesion that had been treated over many years (and was '*monitored*' by Karen during this period) that developed into a melanoma. Despite Karen and Laura being experienced nurses this came

as a shock to them both and caused considerable guilt for Laura who blamed herself for not '*monitoring*' the situation more closely.

6.2.1 SUMMARY

Even at this first stage of the melanoma '*journey*' many of the processes that would occur repeatedly had already emerged, although the relative emphasis was to change as the '*journey*' progressed and the impact of the melanoma became more pronounced.

During the pre-diagnostic stage the processes of '*Recognising*' and '*Responding*' and a variety of related processes, ('*Ignoring/Normalising*' and '*Discounting/Monitoring*') were apparent and these will, to a greater or lesser extent, re-surface throughout the '*rollercoaster*', with some, especially '*monitoring*' gaining greater prominence.

At this point the impact of the melanoma on the participants' '*routines, roles and relationships*' was relatively minor, nor had participants as yet had to draw on many '*resources*'. However what was quite clear at this early stage was that for the majority melanoma was not a solitary journey and it is already apparent that significant others played a major part both in '*recognising*' the initial lesion and in prompting a '*response*' by the patients. Moreover, all the participants, sooner or later, had contact with HCPs, and their '*responses*' either in rapidly referring on or suggesting no further treatment was needed, were crucial. As will become clear it is these sets of '*relationships*' (with significant others and HCPs), together with '*routines*' and '*roles*' that will achieve greater prominence as the melanoma '*rollercoaster*' continues. Furthermore whilst up until now the participants had not drawn on major '*resources*' (relationships aside), apart from the use of the internet by Matt, the importance of access to '*resources*' will emerge as being significant later.

Having described the pre-diagnostic stage of the melanoma *'rollercoaster'* and started to elaborate upon some of the main processes at play, attention is now turned to the next major juncture that marked the start of the melanoma *'rollercoaster'* proper: Diagnosis and initial treatment.

6.3 THE MELANOMA 'JOURNEY' BEGINS: DIAGNOSIS AND INITIAL TREATMENT

"It's really strange that one word can alter your life and, if you let it, destroy it." Tony

This section considers participants' experiences during diagnosis and initial treatment. It will highlight ways in which the melanoma *'rollercoaster'* unfolded upon diagnosis and how participants *'responded'* to the news. Following the temporal approach that characterises Grounded Theory we begin with the diagnostic process. However, this often merged into the initial treatment and efforts are made to capture this overlap so as to reflect the sometimes confusing sequence of events.

The first necessary step to obtaining a diagnosis was to *'recognise'* the need for action and to seek a professional opinion. Within the UK health care system entry to expert medical opinion is via a GP. When they decided to seek advice one crucial factor was the *'reaction'* they received from their GP. In the best cases GP's were seen as highly approachable and had genuine concern for their patients.

"My doctor's really nice and friendly, I would feel quite at ease going and saying 'I don't feel like there's something quite right'. She said I will send you to the hospital, fast track youAnd then she even phoned me up at half past nine at night... So yeah, she's a lovely doctor." Helen

"I'm just glad that she's (his wife Jean) changed to my doctor, he's an absolutely fantastic doctor. And she was only with him two weeks and he got her in (and) he's rung her up to see how she is. She'd been with her other doctor 10 years and he hasn't done anything." Bob

Fred was also pleased with the speed with which his case was dealt with but there is a hint that perhaps his doctor's 'bedside manner' was perceived as less than optimal:

"I mean don't get me wrong when I did get to see [my GP] about this, the spot, he did do it (refer to hospital) promptly. I got an appointment through very quickly, two or three days probably. I mean he didn't hang around. But they're a bit remote, you know." Fred

Following referral the quality of the participants' first contact with the specialist hospital teams and especially the way in which their diagnosis was relayed was a significant event. For some their first contact was very positive and this usually set the tone for what was to follow. Once again it was the 'human face' of the practitioners with whom participants came into contact that was often crucial:

"The way the hospital fast tracked everything gives you peace of mind to be honest, that the hospital and everybody else are doing everything they possibly can do to help you. 10 out of 10 to them for the way they told me, the doctor I saw, unbelievable, his knowledge, but you could still talk to him as a day to day person and ask him anything and he would come back with information, what is going to happen and they just relaxed you and reassured you about things that lay ahead for you." Tony

Therefore, from the outset the 'relationships' between participants and HCPs was of central importance and practitioners often became a major 'resource' which many participants would draw upon. Indeed, as diagnosis moved into initial treatment the importance of a good relationship with a HCP became even more apparent, as Karen makes clear below. However, her quote also reflects the feeling of being caught in a 'whirlwind', something that characterised the initial experience of many participants, as will be highlighted later:

"I have to say the registrar, I don't know what her name is. But she's been absolutely amazing, that continuity with her has been really good. But from a negative point of view you're just in a bit of a vortex and whirlwind and don't quite know whether you're coming or going." Karen

For Tony continuity of contact was central and he describes the positive effect this had on how he 'reacted' to his early treatment:

"In fact you get quite a good rapport going with the regular doctors you see each time and it used to be quite entertaining; one doctor, it was quite a highlight to go in there lie on the table and hear the conversations about what they had done all weekend, he would be totally relaxed with you while snipping and cutting... You just feel so relaxed. I know at the end of it people in the hospitals are doing a job but it seems a lot more to me. They just talk to you and ask how you are, what you're doing, how you are feeling, it just lifted you so much, it really did."
Tony

Sadly, not everyone's first contact with specialist services was as positive and Luke felt let down:

"I saw this doctor and she said we'll send you to dermatology, they might take a biopsy and have a look at it. So this other doctor come up, and she just turned round and said I'm very concerned, we need to get you in straight away. There were no explanation about what she thought it were, I just felt like I were being pushed away and I left with more questions (than answers)." Luke

Some people had to proactively 'chase up' their initial referral before further action occurred:

"(The oncologist) said he would send a letter out for him to come for a scan the next week. So we expected it... So then the fortnight came and went, nothing." Kate

"And they'd lost my paperwork." Phil

"So you actually phoned up, didn't you? And spoke to a receptionist at radiology... And she just said oh, we seem to have bypassed you or missed you." Kate

"And I only really did that because I was prompted by your other friend, wasn't I?" Phil

"Yeah, somebody, actually my uncle phoned up to see how you were, and he said no, he should have had his appointment before now." Kate

"Because his wife had just gone through breast cancer, so they knew the basic... You don't expect having to press people, you expect things to happen." Phil.

Skin cancer seemed an unlikely cause of the bleeding that Irene 'noticed' so she was referred to a colorectal surgeon and seemed to get 'lost in the system' which concerned both Irene and her GP:

"So it was a long while when nothing was happening, or I mean nothing's happening now, but I am getting feedback from my doctor and [the oncologist] and [the surgeon]. So I do feel a bit more as if I'm in the system. Whereas I felt that maybe they'd forget me, because I'd got lost somewhere en route." Irene

'Recognising' that there had been a delay in getting a diagnosis, Irene's GP made telephone calls to speed the process up and get her seen by an oncologist as he was unhappy about the delays and felt he "owed it to her":

"Because I think all of the MDT involvement was radiological and, you know, theoretical and academic. So they were making decisions about her care without needing to explain that to patients. And it keeps us very honest having to explain our mistakes or delays or whatever to patients sitting right in front of us." Henri, GP

Receiving the diagnosis, no matter how expertly given, was a major shock for many participants, even those with years of experience of skin-related lesions. Tony was 'amazed' that after having numerous moles removed over many years it was the 'last small one' that turned out to be malignant. He described his reaction to the diagnosis as follows: "It is hard when we both walked into that office and she said I had skin cancer. Doesn't matter how strong you are." Most participants, such as Anne, were 'surprised' by the diagnosis and it even came as a shock to Karen who, despite being a nurse, left the consultation confused:

"So even though you're from a clinical background, I'm not in oncology, and to me melanomas were a mole, oh that's a bit of a big lump, chop it off, and I knew very little else about the disease ...and went home knowing just I've got melanoma, it's on my ear and they're going to chop it off." Karen

The shock that participants felt was heightened for those, such as Jack and Carol, who had initially been led to believe that there was nothing to be concerned about:

“Yeah, it was the fact that we was led to believe it was nothing by our own doctor and also the dermatologist, and when we went back down we thought [he] was just going to have it checked to make sure everything was all right. And then when we sat down in there and they said that it was a melanoma and it was a stage two.” Carol

At this point many participants wanted some degree of certainty with respect to the diagnosis and what the future might hold but it was not always possible for practitioners to provide such reassurance. This uncertainty added to the fear that many initially felt:

“But they can't tell me (what will happen) because they really don't know, do they? But sometimes you expect them to know. The first doctor I saw, he said it were middle, then when I went to [oncology], they said it were high. Yeah. When they said middle, I thought oh well middle's not as good as low but better than high, but then [oncology] said high. More scary.” Ruth

HCPs ‘recognised’ this and wanted to provide patients with “a plan” but also ‘recognised’ the difficulty in imparting information at that time:

“So I think part of it is providing information in a way that they can digest... And then, rather than simply leave them with a diagnosis and without a plan for the future, but there being a clear plan for their future.” Ashley, Surgeon

The feeling of being ‘A bit shell shocked, to be honest’ voiced by Fred succinctly summarised the reaction of many, but for some, although the diagnosis could hardly be described as welcome news it nevertheless provided a sense of knowing what they were facing.

“And obviously it's the waiting that's the worst I think. I think once you know what you're faced with and there's something can be done, I think that you have a bit of a sigh of relief then” Helen

It was upon being given the diagnosis that the need for information became a central concern for many, even for those with clinical knowledge. However, the data revealed a paradox in that at the point of diagnosis, when information was seen as crucial, most patients were not able to process what they had been given:

“Because it is only after you walk away you think oh I should have asked about this. So if there was one thing, I think it would be information, you know. But I think the problem with it is on that, at that precise moment (being given the diagnosis), I don't think you're actually capable of processing the information, even though that's what you need.” Mark

Even when patients were given considerable amounts of information what they could meaningful assimilate was often limited:

“And I left with several pamphlets and cards and telephone numbers. (But)I needed somebody to spell something out to me. I mean I even remember coming out and reciting the words, it's a level 2 and there's four grades to it. And I even remember getting home and thinking well what's the worst grade? Is it one or is it four?” Jean

Others noted that immediately after being given the diagnosis, anything that followed ‘*went out of the window*’. For example, Jack ‘*did not take anything in*’, and for Mark the doctor might as well ‘*have been talking a different language*’. Even Karen, who in her professional capacity must have been used to relaying bad news, upon hearing the word ‘*melanoma*’ described how although she was aware that the doctor was speaking anything he said became ‘*all muffled*’. Clearly strategies to assist patients at this point are needed and one such was described by Esther who was advised to tape record the consultation. Whilst she valued this advice she felt that it would have helped if she had been provided with a list of questions to ask beforehand:

“They did say that you could record conversation. We really needed to have that tape recording and perhaps a list of questions, the right questions to ask. Because it was so dramatic, you've no time to sort of (take in), the enormity of it.” Esther

Some HCPs '*recognised*' that patients had a limited ability to take in information after being given their diagnosis but were sometimes still surprised by patients' lack of understanding after the event:

"The person that took him to clinic was a Greek Cypriot nurse and they had a chat about Cyprus and that's the only memory he's got of the consultation. We know that patients only retain a certain amount, but that was very interesting, I thought, because actually if we hadn't have investigated that a little bit further or pushed him a little bit further he might not have turned up for his radiotherapy, because he had no knowledge that it had been arranged for him." Jackie, CNS

CNSs tried to mitigate this for example by ringing patients some time later or '*tailoring*' how information was given so that it suited different patients' preferred means of contact:

"I'll try and ring every patient after they've had a melanoma diagnosis a week later, regardless... Because I think a week is a good length of time for them to assimilate information... And they often have questions that they won't have (asked) at the time." Lou, CNS

"We set up the email from quite early on, and that appealed to his way of preferred communication. And he's been very good at using it, and we've been able to respond back quickly. So I think that's helpful for him because it has given him less time to be concerned or anxious. So he's been able to articulate those particular problems, and then we can solve the problem and then get back to him pretty promptly really." Les, CNS

These examples of communication after diagnosis demonstrate '*best*' practice that had a positive impact on patients' and carers' experiences, but not everyone had access to such individualised services as some participants still had unmet information needs. For Mark his ability to take in information would have been much improved if the language used had been tailored more to his '*lay*' understanding:

"After that (being told the diagnosis) we went into the room with a Macmillan nurse and she said you're not saying a great deal Mark, and I just said I don't know what's happening. Maybe its big medical words if it were in layman's terms it might be easier... She said you've got cancer. Right, so that's a six letter word I can deal with. I know what that is, as opposed to a malignant melanoma." Mark

The technical nature of the information given to Irene by hospital consultants meant that her GP became a valuable 'resource' helping her to understand her situation.

"She had lots of me explaining hospital consultant's opinions and hospital letters, so I think - there was still not a lot of great communication." Henri, GP

Nick, as a carer, who accompanied his wife, Jackie, to the consultation felt that he was in a better position to ask the necessary questions and absorb any information that was given, highlighting the important 'role' played by carers:

"Jackie got quite upset understandably and didn't know where her head was, I was asking the consultant straightforward questions. Can it be dug out? Is it easily treated? I think Jackie can't see all the answers that's coming towards her, or can't pay full attention to what's coming in. So I just act as the information sponge." Nick

Some HCPs did not always 'recognise' the 'role' of carers and focussed their attention on the patient. Others however acknowledged that carers also had a crucial 'role' to play:

"Obviously the patient is always going to be my focus, but I'll try and bring in the carer as much as I can. But a lot of the initial questions and how they feel and checking their understanding to start with, more with the patient." Lou, CNS

"[Carers] need to know as much information as the patient does. Sometimes they want to know more... I think you need the same amount of support as the patient does. Maybe in a different way because the patient's going to go through treatment and it's affecting them and they're anxious about it. The relative is anxious about it but they're not going to have to go through surgery or treatment or investigations. But I think they probably need the same support." Alex, CNS

The importance of good information as a 'resource' was reaffirmed as initial treatment began.

For many this happened quickly:

"It happened so quickly (getting treatment). It were like a roundabout. Went through one room, waited in one room and had surgery, what I thought was just a minor operation, you know, in this big operation theatre." Mark

For others treatment was complex and could involve multiple sequential stages, which increased the uncertainty participants felt:

“I need to have a skin graft, I need to have skin cut out around the mole so I'm just taking one step at a time really. I mean that's going to take two weeks, to talk to a plastic surgeon, then another of couple of weeks to get that took out, then another couple of weeks to get my results, so looking at two months. So waiting for two months, basically, see if it's better or not, you know.” Matt

The degree of uncertainty was not helped when participants did not know what to expect of their treatment:

“People kept asking me do you have any questions, and I really was struggling to think of any, really didn't have any - because I didn't know the questions to ask!” Jean

HCPs recognised that some patients did not know what to ask but couldn't always anticipate the information that they needed:

“But I think there's a lot of patients that, they don't know what questions to ask, and they'll say that, I don't know well what should I be asking?” Jackie, CNS

“Because at the end of the day it's about the individual patient it's not about the group of patients because if you're an individual patient you want to know what affects you and you're the only person who'll know what to say what affects you.” Ashley, Surgeon

For some a lack of basic information resulted in avoidable delays to their treatment:

“In this system, there are things that you need to know, and if you don't know, you flounder. When I first went to the doctor, now you can choose where to see people, so I said well the closest one. They didn't tell me there was any pitfalls and the main pitfall was the surgeon's only there twice a month, so I ended up waiting and waiting weeks... Unnecessarily long gaps in between, when I could have, if only the doctor had have said well [go to another hospital] because he's there nearly every day.” Phil

Moreover, because of the multidisciplinary nature of melanoma treatment participants could get information from multiple sources, some of which seemed contradictory:

“But you see I have a dilemma, because in the literature from the dermatology, it says only wear very light things, cotton or silk preferred, but you see the things that she’s (lymphedema specialist) they’re tight, and it’s elastic, and the idea is it holds everything tight. So which do you do, who do you believe? And then there’s [the surgeon] in the middle with what he wants, so. And they all have slightly different views, they’re looking after what they’re covering, but whether they ought to be looking after the whole body itself, I don’t know.” Tom

Despite ‘*recognition*’ by some HCPs clearly improvements to the ways in which patients and carers are informed both about their diagnosis and their initial treatment could potentially make a big difference to their melanoma ‘*journey*’ and this is something that will resurface again. How such improvements could be made will be addressed in the discussion chapter.

As has already been noted for most participants melanoma was not a solitary ‘*journey*’ and family members/friends, were, for many, to become an increasingly important ‘*resource*’. However, upon being given the diagnosis it was HCPs who were the first point of contact and who played a key role in giving information and providing support.

6.3.1 HEALTH CARE PROFESSIONALS AS RESOURCES

“It’s quite nice to have that one person just to phone and ask anything really.” Helen

Most participants were shocked upon receiving the diagnosis and in the period immediately following this it was HCPs who, in the best cases, would prove to be a vital source of information and support. Once again how accessible and approachable the professional was, both in terms of being easy to contact and crucially their ‘*human face*’ were key factors in forging a ‘*relationship*’. For Edna it was the approachability and willingness of her surgeon to provide support that was important:

“Well, [the surgeon] has told us that if we have any problems to get in touch with his secretary, which we did a few weeks ago, because there was something Tom wasn’t very sure about. And they made an appointment for us straight away.” Edna

For the majority however, such as Tony, Helen and Fred, the Macmillan Nurse or the CNS was the key person, with accessibility, approachability and reliability being essential qualities:

“As we were walking through [the hospital] I saw the Macmillan nurses and I said ‘the wife’s coming down in a minute for a word’ and it was absolutely no problem at all. When Liz arrived we were ushered into a little room on our own, and it wasn’t as though you had to book an appointment it was there instantly.” Tony

“It’s nice to have your Macmillan nurse, just to ring up if you think of something, or sometimes when they’re telling you stuff as well, I think sometimes you only take half of it in... then it is nice having a Macmillan nurse just to ring up, and she always rings me straight back if I leave her a message.” Helen

“And the time or two I’ve rung [the nurse specialist] if they’ve not been there I’ve just left a message and they’ve rung me back, you know. So it’s, everybody’s been lovely.” Fred

The opportunity to talk to somebody outside the family who could ‘tell you how it is’ was valued and as Sarah, who had three young children described, for her it was the health visitor who fulfilled this important role:

“The doctor sent the health visitor out to me, and she came and spoke to me. She’s due to come back I think it’s this week to see me. So I’ve got, and I’ve got support there....at the end of a phone.... Because it’s alright having your family, but it’s like you need somebody out of the family who doesn’t know you, to basically tell you how it is.” Sarah

HCPs also ‘recognised’ that patients and carers needed them to be accessible and to provide information that was easily understood, they therefore tried to ‘tailor’ support to individual preferences:

“I went every day while she was in, just touched base with her, made sure she was all right. Because I think she felt that she’d dropped into a black hole, and I think having a specific

person who is going to be working on your behalf to make sure that you're not forgotten is quite important for patients when they're scared." Pat, CNS

"I mean ideally when you meet somebody at diagnosis, you do tend to get a feel for what somebody wants. Some people may be happy for you just to have the card and they'll ring you if there's any questions, whereas with others you might get a sense that oh 'will you be there at that next appointment?'" Max, CNS

Unfortunately not everyone's experience was so positive and Sarah also described how the promised support of a CNS did not materialise leaving her feeling disappointed and losing trust in the system:

"She's a lovely woman [the CNS], but when I had me operation she said she were going to come and see me that day or the day after to make sure I'm alright. Well I didn't hear nothing, there were no contact, and then I had to go for a check-up and I saw her again, (and she said) 'like if you need me, ring me'. But it's like you told me you were going to come." Sarah

It would become clear throughout the data that such trust was vital and had to be earned. Once lost however it was very difficult to regain, something that HCPs interviewed 'recognised':

"And then it's just kind of, if you say you're going to do something, to do it. I always find with my patients if I say I'm going to ring you, they trust that I will ring them. If you start breaking that then that trust breaks down a little bit." Chris, CNS

As highlighted earlier it was often the information, advice and support that HCPs provided that participants particularly valued, especially once the initial shock of the diagnosis had subsided. However, as noted above, simply providing information was not sufficient as it needed to be timed correctly and tailored to people's level of understanding. The situation was made more complex by the fact that people varied as to the amount of information they wanted, and for

some too much information was just as problematic as too little. For example, Jackie, clearly valued information and often actively searched for it using the internet as a 'resource':

"Well, he told me [the dermatologist] that it was Breslow's thickness of 0.8. So I thought I'd have a look to see what that entailed, on Cancer Research thing. It's quite good to look at that, I found it quite interesting. Because I'd got it into my head it was worse than it actually was." Jackie

Phil, on the other hand, kept away from the internet, and several others such as Tom and Jean really did not want to know too much about what the future might hold. The quote from Edna below captures the need to achieve the appropriate 'balance' when providing information. This is clearly a skill that HCPs need to master, and this is something that will be returned to in the discussion.

"You have to be careful sometimes. When I was at the hospice they gave me a card, a pamphlet for the lymphoedema association in London so I sent for this information, and I'm not kidding, there's enough in there to worry you to death. You'd never sleep for a year if you read it all." Tom

"I think you have to take a balanced view of all the information that you're given, rather than dwell either on just the good bits or the bad bits. I think that's the way I look at it." Edna

The value of building a 'relationship' with the patient and carer at diagnosis in order to be able to relate to their needs later was also 'recognised' by HCPs:

"The longer relationship you have, the better really... when you're planning things for the future, go back to the diagnosis" Les, CNS

The benefits of such 'relationships' were not one way, as HCPs got a sense of "satisfaction" from knowing that they had done "a good job":

"His daughter says he loves you, you know. So it does and it makes the job worthwhile I think, because sometimes it can be a thankless job and, you're in it for the patients, but it is quite nice to get a little bit of self-satisfaction back when you know that you've done a good job and you get told you've made a difference." Max, CNS

The important role of HCPs was clear in the data but family and friends were to play an increasingly important role as time went on.

6.3.2 FAMILY AND FRIENDS AS A RESOURCE

“Well I mean the support I’m getting really is from my family....” Fred

For some participants, such as Fred, family support, at least in the early stages, was a continuation of long-established patterns. Fred, although still working in his 70’s, had four children who had supported him for a number of years:

“The support I’m getting now is no different from before. I go to their houses for meals at the weekend. I go to one daughter on Friday, I go to the other daughter on Sunday. (My son) is probably once every three or four weeks. And so the support really that I’m getting now is absolutely no different from what it’s been for the last three years.” Fred

For others such as Irene, and her niece Sue, melanoma brought about, at least initially, a modest increase in the ‘role’ that Sue was to play. It is clear that such support was not only freely given by Sue but much appreciated by Irene:

“Well she ferries me about, takes me to the hospital, takes me, well wherever I need to go.” Irene

“It’s just what I do, be there really. They say things happen for a reason sometimes don’t they? I lost my job in October and I’ve not been able to find anything suitable since. And I’ve got all the time in the world to help Auntie Irene.” Sue

For many participants family support, if not taken for granted, was at least, in part, taken as a given:

“Yes, we can call on (the family) for support.” Edna

“We can call on them (family) any time, day or night, so yeah.” Tom

Others, in addition to their family, could rely on friends. This reinforced the importance of friendship:

"I've found as I've been very active with this club. The amount of support I've had from these people has been amazing, which has helped me through. It's made me realise how many true friends I've got actually and having their support has given me a lot of strength." Tony

Following treatment some participants experienced difficulties with routine tasks of daily life so family or friends lent a hand. Sarah, who had three young children to look after, was particularly fortunate in the amount of support her family provided. Indeed her sister made financial sacrifices in order to help Sarah:

"Like me sister's been, she's like me nurse (and) she's like me second mum. From me coming out of hospital, she did all me dressing, she's changed me, she bathed me, she took me kids to school, picked them up. She's knocked her hours down too so she can do the school runs, and the money just like went from up there to down there. She said it's not important, as long as you're alright. So I have had some good support around me. Me mum, me dad, me sister." Sarah

Others found tasks such as shopping difficult and again family and friends provided support:

"I had to get friends and family to go out and giving them shopping lists. And then paying the bills, the things that you had to deal with. Yeah, and they're still bringing me shopping, because I'm still not driving." Jean

However, not everyone was so well supported, a fact acknowledged by some participants. For example Anne, who felt well supported by her husband, recognised how difficult living with melanoma might be for those without close support, such as Luke who could turn to just one person, and only then in a limited capacity:

"I'm lucky in a way, Alan's lucky in a way that we've got each other to look after each other. We wouldn't get depressed about the situation because we've always had each other to talk to. But if I was on my own..." Anne

“I talked to me friend at work about it, but you don’t go into detail. He’s probably the only person I’ve really talked to about it, but you don’t go deep into it.” Luke

However if family, friends and others were to provide support they needed to be aware of the diagnosis and this was one of the first dilemmas that participants faced, how much information to disclose and to whom.

6.3.3 TO TELL, WHAT TO TELL AND WHO TO TELL: HIDING AND SHARING AS PROCESSES:

“I don’t go round advertising it, you know.” Phil

Participants’ were initially shocked on receiving their diagnosis but once this had begun to subside one of the first decisions to be made was who to tell about their melanoma and how much detail to divulge. For some this had been a concern even prior to the formal diagnosis when they had been undergoing ‘tests’. In this context the ‘*hiding*’ or ‘*sharing*’ of information became important processes, once again highlighting that information, of various types, was a key ‘*resource*’.

Many chose not to say anything until a diagnosis was certain so as not to cause any unnecessary concern:

“But I didn’t tell my mum and dad, because at 80 and 81 I didn’t want to worry them until I thought they had to worry. So when I actually got the confirmation from the doctor that’s when I told them.” Jean

Decisions came with their own challenges:

"It was a bit stressful last year because I didn't tell my mum either. I thought I'll wait until I get everything in, all my results and everything, because she's not very good at handling things. So I kept that from her, so that was a bit awful." Helen

For many it was only when a confirmed diagnosis had been given that this information was 'shared' with others. However, who it was shared with and how much was shared varied. Phil, for example, was selective with whom he shared information, focussing primarily on family and friends. Others, as will be described below, felt it was important to share their diagnosis with people at work as well.

"As soon as I got to know for definite myself then it's not something I kept secret. I don't go 'round advertising it, you know, I haven't told like work people and stuff like that, but certainly friends and family." Phil

'Sharing' the diagnosis reflected the degree of 'trust' within a family, as openness was essential if appropriate support was to be offered and accepted:

"They [sons] feel we'd hurt them if we didn't share it. It would be a sign of a lack of trust, so we do. So they are with us every step of the way and they are wonderful, very supportive, and feel devastated too." Esther

However, the amount of information given was often 'tailored' according to who was getting it:

"But I've always been a great believer in trying to be as straight as possible. So what I've always done with them is tell them as soon as I know, and then make sure I have one evening with each of them alone, because they all ask completely different questions." Karen

Fred made decisions about how appropriate it was for his grandchildren to know, based primarily on their age:

"I've got ten grandchildren. Some 18, 16, 14, 15 and 13, and the elder ones all know about it. Then I've got younger ones who we haven't even discussed it with them, I mean I've got one who's four, one who's two, one who's seven, and we haven't discussed it with them." Fred

Sarah possibly had the most difficult decision and chose to share the fact that she was ill with her three young children, but a degree of *'hiding'* was apparent. Sarah's children were a great comfort to her, reinforcing the vital *'resource'* that *'relationships'* provided at various levels:

"The boys can come home from school, they've made me a card, so they know I'm poorly, but I don't think they like to ask a lot of questions, in case it upsets me but they sometimes ask questions and it's like 'are you going to be alright mummy?', and 'you're never going to leave me?', and you think you're eight year old this shouldn't be happening. But I can honestly say it's down to them, me children. If I'd not have got them, then I think I'd be more at rock bottom."
Sarah

Concerns about how much and what to *'share'* were also recognised by HCPs:

"Often it's just getting down to, getting to know them as a person because they might not be worried about actually the surgery, they might be worried about other things. And if you can help them with them other things, they'll do a lot better and them other things might be money, they might be a holiday that's booked in two weeks... How am I going to tell my children?"
Chris, CNS

Moreover, where HCPs were aware of a patient's decision to *'tailor'* the information given to particular family members, such as children, these decisions were respected. Sarah's Practice Nurse *'recognised'* that she needed to offer support at the right time to be effective as Sarah wouldn't have had the conversation in front of her children:

"If she's on her own then I'll sort of ask her a bit more gently how things are really going, that kind of thing, but if her daughter's with her it's not appropriate." Charlie, Practice Nurse

'Sharing' with the close family was something most participants did but the amount of *'sharing'* that took place with wider networks varied. Some, such as Phil, did not raise the issue at work, whereas others did and found that this openness helped, as Mark and Matt describe below:

"Work's been very understanding, I can't fault work, they phone me on a regular basis, how are you, are you alright, have you got any more appointments that we need to book in? Lots of work colleagues just ring up out the blue, just nothing to do with work, just how are you?"
Mark

“When I talked to the manager about it. They could tell there was something on my mind, I was snapping at people and quiet, more quiet than usual really, yeah... Once I told her, then it just went better.” Matt

Inevitably the diagnosis had some impact on the family.

6.3.4 IMPACT OF THE DIAGNOSIS ON THE FAMILY:

“Cancer’s a bit like throwing a stone into a mill pond.....and the ripple hits everybody you know, friends, family and everything outside.” Mark

For most participants the ‘shared’ nature of living with melanoma emerged early in the data, but its impact varied. At almost an existential and abstract level were concerns voiced by those with children, such as Anne and Tony who were worried that melanoma might have a genetic element putting their children at increased risk:

“At the back of my mind I’m a little bit worried about the boys. We’ve got three boys and with both of us having cancer I’ve already said to them, you’ve got to be aware of this, if there’s a problem with me and there’s a problem with their father. I mean eventually in their life will they get cancer?” Anne

Patient’s concerns about family members were ‘recognised’ by HCPs, as Tony’s CNS describes below:

“We’ll have talked a little bit about implications for other family members, because I made a note of the fact he’d got two children, and there was, it obviously got a little bit complicated, the family, but I’ve got that he’s got a brother and, who was obviously the brother with the other melanoma, and mapped out his family tree a little bit here.” Lou, CNS

For Sarah such fears were far more immediate as she had actually been pregnant with her youngest child when the melanoma was diagnosed.

“What hit me most is they said I'd already had the cancer while I were carrying [my daughter]. They told me this afterwards. She hasn't got it she got all clear, luckily, but to think I had it while I were carrying her and she could have had it, then things probably could have been worse then.” Sarah

In addition to concerns about cancer in the family the emotional impact of the diagnosis itself was ‘recognised’. For example Laura (Karen’s daughter) felt guilty when she could not accompany her mother to her hospital appointments and Sarah’s Mum, Pam, was so upset that she needed counselling:

“I feel very guilty when I don't come with her here (to the hospital), like when I have to work or when I've got other commitments and things, and I don't like it when my sister comes because she doesn't understand, she doesn't get it at all.” Laura

“Well I am having counselling, and I have started the counselling when I found out that me daughter had got cancer. And obviously it threw me because you don't expect to like find something out like that.... I have to go every two weeks it's like a relief to me, you know, because I'm talking to someone who knows about this kind of thing.” Pam

Pam’s experience highlights the importance of emotional support being available to the family as well the patient and yet as the literature review highlighted very little attention has routinely been given to the support needs of carers of people with melanoma. This is something that will be returned to later.

The emotional impact of the diagnosis could also have an effect on the ‘relationships’ between family members:

“I dread him coming home every night, what kind of mood's he going to be in, because when work don't go right it's getting him down and I think he needs somebody else to talk to because I don't feel that he talks to me how he should, but I think it's because he knows I get upset.” Sandra

Bob also noted his wife’s mood changes and the fact that she was trying to ‘hide’ the emotional impact that the melanoma was having on her. Such ‘hiding’ was a sign of potentially more

damaging effects of the melanoma on their relationship for despite Bob desperately wanting to 'share' his wife's melanoma 'rollercoaster' she was, in his view at least, keeping him at a distance:

"I've had to coax her into telling me what's gone off. For some reason she didn't want me at hospital, I don't know why but she just didn't want me there. We couldn't have proper conversations about it, because she just didn't want to talk about it." Bob

HCPs also 'recognised' the psychological impact of a melanoma diagnosis and as we will see in the next chapter, aimed to reduce this impact over time:

"I suspect that for a lot of people there's been new diagnosis of cancer of a sort that may or not come back is a kind of sword of Damocles hanging over them, and that comes with some significant psychological sequelae in some patients and the question I suppose is how do they deal with that?" Ashley, Surgeon

Forging relationships with patients who had similar experiences was seen as a potential strategy to overcome some of the anxieties that patients experienced at diagnosis but not all HCPs felt confident to facilitate this.

"You see at [oncology] particularly people will be sitting on the corridor, and you know that they've got similar diagnosis and similar complexities, but obviously you can't say would you two like to meet and introduce them in terms of. And I'm sure that a lot of patients would benefit from knowing that there are other people around." Les, CNS

This section has further reinforced the importance of 'relationships' as a key 'resource' and started to highlight the impact of the melanoma on these 'relationships', some positive, others less so. It is paradoxical that at a time when family relationships and support were becoming ever more important that in some cases the melanoma began drive a wedge between people.

6.3.5 THE IMPACT OF THE MELANOMA ON ROLES:

"You know, I'm just trying to keep things as normal as possible." Mark

Following their initial treatment participants had to adjust to the effects of this both physically and psychologically. Physically, there could be side effects caused by the radiotherapy or the excision of the melanoma. These could impact on activities such as eating or sleeping:

"Obviously the radiotherapy doesn't make you feel very well. Because with it being on your throat and what have you, and the eating and stuff, that's not too grand. It's mainly my mouth, how your mouth feels, it's horrible. You like get yellow saliva that is also difficult to swallow because you've got a sore throat, and you can't brush your teeth properly." Helen

"But it's (the excision) healed, the thigh's just a little bit tender now but that's much improved. And as long as I've got something soft to sit on, I can wander around all day safely in the house and be happy that it's okay, I'm not going to bang into anything..... (but) I'm still nervous about getting into bed without any protection on it." Jean

Such effects meant that some participants had to cancel planned events, such as holidays which was an additional cause of stress:

"Well we did book for last May, Menorca, but this kicked off, so we had to cancel it." Jack

As already described family and friends often helped out with daily activities but despite this the melanoma began to have an impact on the 'roles' that participants had. For those of working age maintaining employment was important and could serve as a form of diversion, stopping them dwelling too much on the potential longer impact of melanoma:

"I work in the [supermarket] and I have to serve customers, so you've got to be smiley and happy when they come up to your till, you can't be all miserable and sad really. So that sort of helps. It's just nice, it's just nice to just talk about everyday things really, and not talk about...(the melanoma)... just to have a bit of a normalish day like you would have. So yeah, that helped really." Helen

HCPs also ‘recognised’ the importance of maintaining occupational roles for patients, both for financial reasons as well as a way of ‘keeping busy’ and where possible tried to facilitate this:

“Even though when I’d rung the week after (diagnosis), his wife said he was really anxious, his anxiety level was quite low, and it was just things like practical concerns about his work, because he was still working, worry, anxiety, and he’d got some tingling in his hands.” Lou, CNS

Indeed for many of the melanoma patients in particular ‘keeping busy’ seemed to be their main strategy to try and ensure that things remained, ‘as normal as possible’. For those still in employment, work provided a major diversion, even if patients chose not to share their diagnosis with work colleagues:

“Highest priority is staying in work. So keep, just keep myself busy.” Matt

“But while I’m at work occupied I don’t tend to think about it as much. It’s still there, but you see I’m not telling people at work as well about I don’t want people to know my business really, so I’m just putting on a front at work a bit as well.” Jackie

For family carers, such as Laura, work was also an important way of trying to keep her mind off the situation. However she had also started to think about what the future might hold with regard to her caring role:

“It’s weird, because I think I’ve just literally thrown myself into work, because I love my job and I’ve just focused on that, like I literally will just work and then when mum’s really, really poorly and I have to look after her and things and she needs help and she needs driving places, she needs her hair washing, things like that, like it just, I think I push it to the back of my mind that she’s my mum and I just go along with it.” Laura

Some had to give up work temporarily as they recovered from the immediate effects of their treatment, and this could be a novel experience:

"The last time I was sick from work and I had two days off in 2004 when I was 40. And then it's taken 10 years to have any more time off at all sick." Jean

Whilst initially this was something to enjoy, boredom could soon set in and for some this was the biggest impact of melanoma at this early stage:

"The first week you're happy as Larry, you've got a week off work. And then day after day it just gets more monotonous. There's only so many news websites you can read or films you can watch. It's not too bad now because I can go out in garden and help me mum a bit, no digging but she gets me potting all the plants up. It's not too bad, it's just boredom." Luke

Those not in work sought other ways to 'keep busy':

"Yeah, I mean he (Jack) has kept himself busy, because our daughter and son-in-law, they're moving, and the house needs modernising. So he's kept himself busy like that, and I think that's helped. Because if you're not busy, you ponder and think." Carol

Several others tried not to think too much about their melanoma and this seemed to be a major cognitive coping strategy. This was described by Mark as 'putting it in a box' and can be seen as another manifestation of 'hiding' behaviour, in this case the purpose of which was to allow participants to maintain a sense of 'normality' for as long as possible:

"I'm a very busy person as well, I'm not very often sat down. I'm always doing something. Yeah, sort of takes your mind off it, especially when you're waiting for results and stuff as well, just trying to be busy and just doing your normal things really rather than sitting there mulling things over in your head. I do try to be positive, but when you're laid in bed at night and stuff like that you're thinking oh God." Helen

"I don't really think about it to be that honest. I try not to, because like I say it's one of them things that you're powerless to do anything about, so it's just trying to get back and lead a normal life. No, I just take it as it comes." Luke

However, 'putting the melanoma in a box' did not mean completely 'burying your head in the sand' and even at this early stage some participants had started to plan for a possibly less

than rosy future. But, as Mark implicitly pointed out, this was being realistic rather than nihilistic, and for him at least actually served to reduce a source of stress:

"We have like made preparations for, you know, I mean a lot of the financial stuff was in my name, and I know how difficult it is dealing with banks and what have you. So I thought we'll do it now." Phil

"I'm just trying to do as much as I can, just in case the worst happens, that Sandra's looked after. We've gone through all the policies, we've gone through everything we can claim against. We've had the mortgage paid off, the insurance has paid out, so all that's done, that's one worry off my mind for Sandra." Mark

For others the melanoma meant having to give up work and take unexpected retirement. For Tony this raised fears that he might 'dwell' on things too much, something he tried to avoid for his family's sake:

"That was the hardest part because I had to retire and I had no intentions of retiring. Then I had this big fear of being sat at home sad and alone or not being with people all the time, that I would dwell on it but I haven't mainly for the family." Tony

Despite the challenges they faced most participants at this early stage wanted to try and keep things as 'normal' as possible, but this meant some changes to their routines of daily life were inevitable.

6.3.6 CHANGING ROUTINES:

"Still do the same routine, get up, get the kids to school, go and do me shopping, do whatever I need to do, so I just leave it like that still as though I'm just still doing the same routine." Sarah

Routines add structure to peoples' lives and help to shape and mark the passage of time. As noted by Sarah trying to keep to the same routines was an important indication that things

were still 'normal'. Despite this however some people were unable to maintain routines and/or activities that they valued. For Tom this meant giving up both gardening and his walking club, things he clearly missed. But despite this he tried to be philosophical:

"There's one thing I've had to do, and that's get a gardener, and it's not the same when somebody else has done it, you don't get that same pleasure (and) I used to belong to a walking club on a Tuesday... but I can't do that now, you see, I can't walk, so that has changed. But it would have probably changed anyway, because of my age. I mean some of these things are changing not from melanoma, but because I'm going on towards 90." Tom

But as noted earlier for many having to curb or even relinquish either valued roles, daily routines or both meant that boredom often ensued. Finding new routines or roles could help to alleviate this. For Jean even attending the hospital clinic took on significance that she couldn't have imagined earlier and became something to look forward to:

"I work full time normally, and I'm out and about, so I think that was just frustration. I'd get excited about the day out to the (clinic). I got to the stage where I was looking forward to it because it was the only time I was leaving the house in the initial stages." Jean

For many having melanoma meant that as well as needing to adjust their usual 'routines', new ones were added. The most obvious changes that participants made to their daily 'routines' (or long term behaviours) at this stage, were in their 'relationship' with the sun. While HCPs aimed to help patients and carers maintain their usual 'roles', they actively encouraged changes in their 'routines' related to sun exposure:

"Our plan is for them not to burn in the sunshine. To get that across, that some sunshine is necessary for vitamin D but be careful not to burn and do it safely to protect their skin. So in that respect if that's not something they've been doing before we actually need to change what they do." Pat, CNS

Some had been life-long 'sun worshipers' and had built holidays over many decades around following the sun. Jackie was one such person. Whilst she was not prepared to give up

sunbathing entirely, even after being diagnosed with melanoma, she did at least modify her habits and take greater precautions:

“Well I’ll probably not sunbathe as much, peak time between twelve and even four (and) I started using a higher factor I am now going to wear factor 50 at all times now, well, when I go away, and I am a bit wary of when I went for a walk even in the UK I’d put a bit of suntan lotion on if it was quite hot.” Jackie

Anne, who had never sunbathed seemed taken aback that she had developed melanoma, when her friend who had ‘roasted’ herself for years had not. However, as her husband Alan pointed out both their work as farmers and their hobby as keen gardeners meant that they had experienced considerable exposure to the sun over many years. As with Jackie, Anne now made sure that she was covered up whenever she went into the garden:

“I mean I’ve, I do wonder why it’s come. We don’t sunbathe, we don’t go on holidays where we lie roasting in the sun at all. My good friend who I’ve had all my life, she goes abroad on holiday and roasts literally roasts and gets away with it and she’s never had anything like this.” Anne

“We’ve always been very exposed to sunlight. Arms out gardening. We’ve always worked outside. So we’ve always had our sleeves rolled up, actually had an awful lot of exposure to sunlight without laying down in it.” Alan

The problem of occupational exposure to the sun was more immediate for Mark and Sandra. His outdoor occupation meant that Mark was often exposed to the sun. His diagnosis with melanoma had resulted in his employer looking at the firm’s policy with respect to protecting their employees from excessive sun exposure. However his wife Sandra was not particularly impressed with their efforts to date and one of her main worries was that Mark continued to spend long hours in the sun, despite the fact that he had recently started to take the need to apply sun protection far more seriously:

“I’ve always nagged him to put creams on his face with working outside, and he never has, the skin nurse has said even in winter he needs to wear an SPF... I’m a bit annoyed with his work. They have been good with him, but they did say that they were going to send an email out and try and bring some barrier cream in for the men that are working outside, and there’s nothing happening there.” Sandra

'*Recognising*' the need to be aware of the deleterious effects of the sun and taking precautions were an early manifestation of '*protecting*' behaviours. In addition some took to '*monitoring*' themselves, as Sarah describes:

"So it's like if I'm constantly looking at myself all the time, I do sit there in the bath and I'll look at them, what I can see, I do check all me, like me groins and things like that, If I worked that out in that doctors the very first time with me mole, I might not have been here now because it were already in the second stage, they told me." Sarah

Both '*protecting*' and '*monitoring*' were to become far more frequent as the melanoma '*journey*' progressed.

6.3.7 SUMMARY

For all of the participants the diagnosis of melanoma came as a '*shock*'. It was during the diagnostic period that many of the participants had their first sustained contact with the health care system and the quality of this contact and the nature of the '*relationships*' that they forged with HCPs at this time often proved crucial to their on-going '*journey*'. Some had a positive experience, others less so. As we have seen a number of HCPs were attuned to patients, but not always carers' needs. For those patients who had a positive first contact and forged good relationships, often with one HCP, their subsequent experiences were often more positive, even if the prognosis was not. In this sense, and at this point, HCPs became an important '*resource*' for many participants.

Furthermore, most participants knew little about melanoma and information was therefore another vital '*resource*', with HCPs often being the main source. However, the situation was complex and diverse. Some participants struggled to get enough information, others were given too much or what they were given was too complex. Even those participants who

received information often could not *'take it all in'*, following the *'shock'* of their diagnosis. Some participants wanted lots of information and actively sought it via the internet and other sources. Others wanted to know little and preferred to *'ignore'* their melanoma. But what participants most valued at this point was continuity of contact with an approachable and accessible *'expert'* in the form of a HCP who could guide them through the diagnostic period and beyond, into their initial treatment.

The nature of participants' initial treatment varied considerably depending upon the type of melanoma they had and the stage at which it had been diagnosed. For some treatment was relatively straightforward but for others it was far more involved. It was during treatment that the impact of the melanoma on their *'relationships'* with family and friends, and their *'roles'* and *'routines'* began to emerge.

One of the first decisions participants had to make was whether to *'share'* their diagnosis or to *'hide'* it from family, friends and colleagues. This was important as it was not until people were aware of the diagnosis that they could potentially offer support. It was usually at this point that family became an important *'resource'* offering both practical and emotional help. From a practical perspective early treatment often meant that daily, and previously taken for granted, *'routines'* such as shopping became potentially problematic. Most participants wanted to keep things as *'normal'* as possible but often had to turn to close family for help. For those with more complex and prolonged treatments *'routines'* could be considerably disrupted and melanoma began to impact on their *'roles'* such as employment or treasured leisure activities. Here the *'role'* of family members also began to alter as some took on a more overt *'caring'* role. However the needs of such carers went unrecognised by the health care system.

Paradoxically at this point some patients found it hard to *'share'* their emotional *'responses'* to melanoma with those closest to them and this *'hiding'* of emotions could cause *'relationship'* difficulties, just when such *'relationships'* were more important than ever.

Living with melanoma also meant introducing new *'routines'*, especially in participants' *'relationship'* with the sun and a number of protective behaviours were adopted. In addition more overt *'monitoring'* of their treatment and its effectiveness was practiced by many participants. Several of the *'responses'* described above were heightened as participants moved beyond early treatment and entered the *'surveillance'* phase.

7 CHAPTER 7: SURVEILLANCE – UPS AND DOWNS

In this chapter we explore the experiences of participants who, after having the melanoma removed, attended regular clinic visits for surveillance. The purpose of surveillance was to detect any new melanoma early so that it could be treated as soon as possible, something that patients and carers were aware of and that caused a significant amount of worry. Some participants experienced recurrent disease during this time and had further surgery. This part of their *'rollercoaster'* is captured in the phase termed *'ups and downs'*. In creating their rollercoasters some participants used *'downs'* to represent low mood caused by events related to melanoma with the *'ups'* representing their mood improving as the incident resolved. Others used *'ups'* to represent the anxiety that they felt related to the melanoma with the *'downs'* representing improvement of the situation. Despite these seemingly opposite descriptions they both capture the varying, often emotional, impact of the melanoma over time heightened by the fear, experienced by many, that the melanoma might recur.

7.1 IT MIGHT COME BACK

"I've always had that hope that perhaps this time it'll not come back, but it does come back, but I deal with it, so." Tom

Patients and carers were aware one of the main reasons for surveillance was to detect melanoma if it returned. This was something that everyone hoped would not occur, but it was nevertheless a latent anxiety, with Sarah noting that it was *'always on my mind'* and Anne *'recognising'* that *'nobody can give you 100% guarantee'* of cure. Many participants therefore held on to the *'hope'* that they would be one of the *'lucky ones'* and often kept their fears to the back of their minds, frequently using *'black'* humour to do so:

"A couple of the lads just ring me up on a regular basis, I keep telling them well you're not in my will... But again that's me just making a joke of it." Mark

Knowing that the melanoma might return and potentially mean a shortened life-span motivated participants to *'live life to the full'* and many re-considered their priorities such as reducing their working hours as Jackie noted *'life's too short'* or as Helen decided *'not putting off until tomorrow things you can do today'*.

Concerns about recurrence tended to lessen overtime, especially as patients began to be discharged, or *'fired'* as Jean put it. But despite this many still maintained their *'routines'* of *'monitoring'* and inevitably some found new changes themselves:

"I was just feeling round and I found this lump, and I didn't really think nowt of it because I thought it might be something to do with the stitches... But he said no, he says I'll have to cut it and get it out again." Ruth

Sometimes suspicious lesions or lumps were found during routine examinations by HCPs, and this was reassuring for many participants. New lesions were frequently excised and for both Fred and Tony this became part of their surveillance *'routines'*. Many of the lumps and lesions that were removed after the first melanoma were benign which Fred described as *'false alarms'*. Some were unfortunately another melanoma. This possibility was something that, as Kate noted, was *'always at the back of your mind'* but it understandably came as a major blow. Despite this participants' prior experience seemed in some way to help prepare them for this:

"In my language oh bloody hell, not again. But I think this time round we both suspected that's what it might be. So we were probably a lot more prepared for it. But when we went and she got the diagnosis, oh Jesus not again. I just felt awful for Jackie, and I thought oh here you go, just be as supportive as you can." Nick

This was one of the main *'downs'* of the rollercoaster, and was something that HCPs recognised as potentially having a *'devastating impact'* on people's lives:

“And recurrence when everything’s been stable, and then you hit a bump in the road, it brings it all back again, and that’s quite difficult. And then recurrence can mean different things can’t it, because it can just mean something as simple as a bit more surgery, but it can have other more devastating impacts on patients’ lives.” Pat, CNS

To mitigate their fear that the melanoma could come back meant that patients and carers adopted new ‘routines’ of ‘monitoring’ and ‘protecting’.

7.2 NEW ROUTINES: MONITORING AND PROTECTING

“Because I’m always looking. Every day I look. It’s just, from my perspective, I just want to make sure that there’s nothing there.” Fred

Patients and carers became more aware of new changes to their skin and ‘monitored’ these by, for example, checking the treatment site for signs of healing, or any changes that they might consider suspicious. Those patients who had extensive surgery or radiotherapy ‘monitored’ themselves for a longer period (beyond eighteen months) alongside signs of new melanomas. Carers also ‘monitored’ any psychological ‘responses’ to the melanoma as well as physical symptoms:

“I mean some days I come and she’s just full of life... And then you can come again and she’s like just sat there... she’s just feeling so down and low and tired, drained... and it’s hard.” Pam

‘Monitoring’ for signs of a new melanoma could be overt or covert. Patients and carers might conduct ‘monitoring’ together as a ‘shared routine’ for the reassurance it brought. In some cases though patients would not admit to carers how much they engaged in ‘monitoring’ or carers would take opportunities to look for changes without the patient being aware as they did not want to cause each other to worry. This is another way in which information or the melanoma experience was ‘hidden’ or ‘tailored’. Tony and his wife photographed his moles, openly monitoring them together with their children. For Kate and Phil monitoring together

became a *“ritual”*. For those who lived alone *‘monitoring’* was difficult without someone to assist:

“I wouldn’t say I have a set routine but this week I’ve probably done it twice.... just have a quick look in the mirror. It’s a pain in the backside seeing spots - I’ve got two, two wardrobe doors with mirrors on so I have to sort of put them at different angles and turn round.” Luke

John did not share his *‘monitoring’* with Esther who nevertheless did this covertly herself, so as not to worry her partner:

“I checked it without (him knowing)... because to go on about something is to make matters worse, and they make you more worried.” Esther

Sandra also adopted a similar approach:

“I try to do it without him knowing but when he’s in bath or he’s undressed I can see me visually scanning, x-raying his body to see if I can see anything new... I’m consciously doing it; I am looking to see if I can see any changes.” Sandra

If their monitoring efforts were to be effective patients and carers needed to know what to look for. This might be quite obvious in respect of a visible lesion but checking for things such as enlarged lymph nodes was not so easy:

“Press as deep as you can under your armpit and look for a grain of rice. That was entirely wrong, entirely wrong information.” Phil

Over time if there was no recurrence patients and carers began to worry less and relaxed their *‘monitoring’* but this could take many months. For instance, 12 months after diagnosis Fred and Matt still checked themselves every day, but six months later they had relaxed their *‘routines’* with Matt only checking every six months and Fred almost stopping, as for him it was a case of *‘out of sight out of mind’*.

Even if there was no recurrence the melanoma was never far from some peoples' minds as the surgical scars served as permanent reminders for some. For Jackie the worry never completely went away as she had '*a reminder of it always there*'.

There were however psychological benefits to '*monitoring*' and as participants became more skilled they were confident that they could detect any changes at an early stage. However this was not infallible and Sarah was dismayed to be told that she had a new lesion by her surgeon. This knocked her confidence:

"But it's like this time I didn't notice that on my leg what obviously the surgeon did and he was really concerned over it, but to me it didn't look like nowt... I didn't feel no different or notice owt if I'm being honest." Sarah

This sort of episode reinforced the value of '*expert*' opinion with patients and carers continuing to see HCPs as an important '*resource*' and their '*relationship*' with them continued to be a central factor in the melanoma experience. Participants who experienced ongoing effects from surgery or new skin changes often wanted to be reassured that their own interpretation of any changes was correct:

"I don't know whether it's one of them... Tags yeah, you've got one or two of them there. But I don't know... it does need checking out." Carol

Regular follow up appointments were an opportunity for face to face contact and gave patients and carers access to the expertise of HCPs:

"I mean it's a safety valve really isn't it, coming and having it checked." Anne

For many surveillance was an integral part of the melanoma journey which often involved frequent attendance for tests, scans and physical examinations. This added a further '*routine*' to participants' daily lives which brought its own anxieties and/or moments of '*good news*'

which added to the *'ups and downs of the rollercoaster'* and provided participants with a sense of their own potential futures, as Edna describes below:

"I think apprehension after the first operation... it brings it back just a little bit each time (you attend the clinic)... But when we've been to the hospital and... you get an all clear, in my diary it goes down as a red letter day, so that marks a point where, and you can move forward again." Edna

For some, such as Anne, having examinations that proved negative were a source of reassurance that allowed her to *'live her life'* relatively free of worry. For Luke however they were a reminder that the melanoma could recur at any point. HCPs recognised the combination of anxiety and relief that participants could experience:

"Even if there's nothing going on I've had patients say that they get worried and don't sleep a few nights before the appointment, because they're worried that something will have cropped up that they hadn't noticed... and then after the appointment there's that sense of relief that you've said everything's fine." Pat, CNS

Scans caused anxiety but also provided reassurance, creating some of the *'ups'* and *'downs'* of the rollercoaster:

"In between you having your test and getting your results, that's when you're in no man's land." Jack

"They do want the scans. But then we've got all the waiting... So I think that's quite significant... there's a level of relief once they've had those results." Les, CNS

Mark and Sandra found that surveillance seemed to lack structure compared to the treatment and follow-up that Sandra received for breast cancer. They understood that treatment was not available at the time but felt they should be doing something to prevent the melanoma coming back. Matt, however found the lack of intervention as a positive sign that his treatment had been successful.

"I thought is this it, is that it? They just checked my glands, the scar, that were it, see you in four months' time. Yeah, it felt a bit quick... Must be a good thing." Matt

Patients and carers also began to 'monitor' their sun exposure, 'recognising' it as a risk to their health. This led to them adopting new 'protecting' routines to limit UV exposure.

"I've kept my shirt on when I've been out in the sun, worn a hat and slip slap slop, as they say." Phil

Protecting themselves and others from the detrimental effects of sun exposure became a new 'routine' for patients and carers as their 'relationship' with the sun changed, especially for those who had not previously understood the risks involved or the importance of taking protective measures. Three months after his diagnosis and on finding more information about melanoma, Fred considered changing his habits:

"Until I started reading about it I didn't really associate walking in sun and being in garden in sun was a danger. I've never put sun cream on when I've been walking the dog or when I've been working in the garden. Perhaps I should start." Fred

Similarly Jackie, and Jean who had been using sun cream, decided to use one with a higher protection factor.

"So normally I would have taken 30 for the first week, and 15 for the second... Well now it's 50 the first week and 30 the second." Jean

For Tony, the effect of the melanoma extended to his family:

"She (daughter) has gone totally the other way now, whereas she would lay on the beach all day long, she won't anymore, so something is rubbing off, which can't be a bad thing." Tony

These new *'routines'* both affected and were influenced by the participants' *'relationships'* and *'roles'*. The dynamic between these three factors was in flux throughout the melanoma *'rollercoaster'*. Below we consider the impact at this stage on participants' roles.

7.3 THE IMPACT OF MELANOMA ON ROLES

"And I'm back at work, that's quite nice to be back at work, bit of normality." Helen

After their initial treatment patients and carers aimed to return to their usual roles as soon as possible. How quickly they achieved this depended upon the nature of their treatment. This varied considerably, for example, Jackie only needed to take a few days off before she could return to her usual activities following a small operation whereas Tony struggled with the physical demands of his job, making the decision to retire. Leisure, social and family roles were also affected although participants aimed to maintain their normal roles and activities as much as possible. These sometimes required modifying to accommodate the after effects of treatment, which for some only emerged over time. For instance, Sarah coped well throughout surgery and radiotherapy, only noticing the full effects after treatment finished when she struggled with the tiredness caused by her lymphoedema. This affected all aspects of her life as a mother and a partner. Consequently she continued to rely on family members to help her care for her children:

"But obviously I've got three kids to look after. I'm just constantly tired and drained and finding it really hard. If I didn't have my auntie here or my sister, they stay with me until teatime-ish, they'll help me bath them, ... make sure they've had their tea... then I can just go and lay in bed until I wake up the next morning." Sarah

In marked contrast Fred and Jackie returned to work with minimal disruption, while others needed to modify their work patterns. Luke received help from his firm's occupational health

department and worked between the office and warehouse, while Jean who could not do any physical activity could work from her computer at home until she was able to travel:

“Sitting was a problem... Getting in the car and driving, being on the road, having to think about getting on a train and maybe travelling a couple of hours and having to sit and things like that. But because I could go back and sit in (the bedroom) and not move all day while I caught up, I could do it.” Jean

For many such as Helen, returning to work was a sign of recovery and she was assisted to do so by her nominated HCP:

“Helen was quite adamant to keep things normal at home and was really keen to get back to work. And I know when I saw her recently in clinic she was like yeah I’m back at work and, you know, quite buzzing with life really and that was always her focus.” Chris, CNS

Some, such as Tony, could not modify their work and had to make the decision to retire from their job. However, Tony found alternative employment that gave him a meaningful role:

“September I started, delivering pharmacy three hours a day and it’s just nice, because most of my patients are seniors and it’s more than just dropping the stuff off. You have a little chat with them.” Tony

HCPs recognised the importance of maintaining valued roles for ‘*patients to be healthy mentally and physically*’. Of course not all participants worked and so maintaining leisure and social roles were equally important. However even with modifications this was not easy with Tom and Edna, for example, having great difficulty getting holiday insurance. Despite help from their CNS they still struggled and so modified their plans by getting mobility aids, such as a scooter and having a ramp fitted. They made the most of their limitations and still felt that they had a good life:

“Well, what we’ve tried to do is just to make it that we can live as normal life as possible because we’ve got the facilities and there’s not an awful lot we can’t do is there?” Edna

"I suppose some of the things that I'm not doing is just because... I wouldn't be doing them because of my age I don't think. I am nearly 90. I've been cutting the hedge this morning so I can't say there's anything I don't do." Tom

Others too made modifications. We have already noted that some people, such as Helen, who could not eat solid food in the early stages, still went out with her friends (although would not eat in public) or invited them to her house instead. This went on for eighteen months after her treatment finished. Others, such as Sarah, curtailed activities, such as taking her children swimming as she struggled to come to terms with her body image. This caused her considerable guilt:

"I feel like everybody's just like looking at me because they'll see my scar down my leg, and then that leg's a lot bigger than that one... But then it's like the kids are missing out because of me, so then that makes me feel bad." Sarah

The need to adopt new 'routines' to protect themselves and others from the sun also had a long-lasting effect on patients' and carers' leisure and social 'roles'. Some changes were minimal, for example Helen continued to go on holiday to the sun but her friends adopted protective behaviours to ensure that she did not have too much sun exposure. Others made similar changes, some were more extensive and might involve cancelling holiday plans:

"I was worried about the sun.... I didn't find it easy... It's just that we've always sunbathed, we've always had like a routine and this time, I mean I said to [my friends], you just do the sun business, I'll get under the umbrella or I'll just shop." Ruth

"I turned down a holiday in Spain because I know like when I get drunk all responsibility goes out the window and I'll just end up getting really badly burnt... I'm going to Holland in September and the climate's quite temperate there so should be all right there." Matt

HCPs also 'recognised' the effect of the melanoma on patients' leisure 'routines':

"Then you get the odd person that is so worried about it that they stop going away on holiday abroad... they're almost hiding from the sun." Lou, CNS

For some having the melanoma motivated them to get as much out of life as possible. For instance, Matt applied himself to his job, sought promotion and tried *'to do the best I can in life'*. Sarah and Tony spent some of their leisure time fundraising for cancer charities, so that *'something good's come out of it'*. In their efforts to keep things as normal as possible participants tended not to see themselves as *'patients'* and as the physical demands often diminished for many, partners and close family members were less likely to identify themselves as *'carers'*, seeing what they did more as *'helping out'*, *'being there'* or *'organising'*. This however was still an important role that patients valued.

Jean, for instance, arranged for her parents to take her to hospital appointments as her partner Bob would not have been paid if he took time off work. While Bob initially felt that the melanoma brought them closer as a couple, during surveillance he felt as though Jean was doing everything *"on her own"* and he was being *"kept out"* of her melanoma treatment. He did not *'buy into'* the cost argument:

"We're supposed to be a team partnership and it just doesn't seem to be that way. But if it were me that were going through it, it'd be a different ballgame... And if cost is the argument, it's not a very good argument as far as I'm concerned." Bob

The potential for close *'relationships'* to suffer in this way was not unique and we have already noted that Sarah's relationship with her mother gradually became more strained as her mother could not accept the diagnosis and failed to fulfil the caring role that Sarah was expecting.

This caused tensions in the rest of the family:

"It's my sister.. I've always said, if it was my daughter going through this then I'm sorry I'd have to be there 24 hours, well, do whatever I could. When she comes, yeah, she does her ironing and that, and this, that and the other, but she's always got an excuse." Lynn

The importance of *'relationships'* was often heightened during the surveillance period, with *'hiding'* and *'sharing'* playing a key role.

7.4 RELATIONSHIPS AS A RESOURCE: SHARING AND HIDING

“Sometimes it helps when somebody’s got a problem and you’ve got a problem and you just talk.” Jack

As patients and carers began to recover from the initial treatment and settle into their new ‘routine’ of surveillance the importance of their ‘relationships’ with others became increasingly apparent. The practical help received from their social network often continued for some time and was evident in changes to ‘roles’ and ‘routines’ as these elements of the experience continued to interact. However, as their physical recovery progressed, the provision of social support depended upon whether information or experiences were ‘shared,’ ‘tailored’ or ‘hidden’. The degree of ‘sharing’ or ‘hiding’ that took place was a key factor. Couples in particular valued each other as a source of support as they talked about the melanoma and ‘shared’ their feelings about it. In addition to the emotional support that their relationship brought, other benefits were seen. For example, having someone to accompany them to appointments which, for Tom and Edna, meant that they could both listen to any information given. Other couples felt that the experience brought them closer:

“I think it’s brought us a bit closer actually, because now she’s sharing things with me that she wouldn’t have done before.” Bob

“It does change you. It’s either going to fetch you closer together or it’s just going to push you apart. Sandra always says to me, she says I’ve had a breast off, most blokes would run a mile, and I say but I’m not most blokes. We were strong enough at that point, but I think now that we’re going through it again the other way around you understand more. I think it’s brought us closer together again.” Mark

Even though Tony had divorced his wife during the study, they remained in contact and he realised it still had an emotional effect on her, noting *“It’s as much a rollercoaster for the partner as it is for the patient.”*

During surveillance wider family and friends also provided practical and emotional support for patients and carers. Sarah's support came mainly from her sister who reduced her working hours to make herself available. Tony was fortunate that his brother was a counsellor and as he stated *'when I'm down, he's the one that can lift me back up'*. Tony's brother was himself diagnosed with melanoma eighteen months later so Tony was able to repay the support he had received.

Anne and Alan shared their diagnosis with their sons, but as they lived some distance away, they relied mainly on their friends for immediate help, describing them as a *'support network'*. Rather than a network Ruth turned to a particular friend, who knew her well enough to let Ruth talk about things in her own time.

Patients particularly valued support from others who had experienced a cancer diagnosis, recognising the shared experience:

"I was talking to him (friend), and he'd had exactly the same treatment as I'd had and he was two years down the line. It's like a little club. It's amazing how you find people and you suddenly have that bond because you've been in the same situation." Tony

Sarah struggled to come to terms with her altered body image and wanted to talk to someone who had been through a similar situation but did not know where to start:

"I've got really good support... it's just now I think I need to talk to somebody who's been through it... see their scars and see how they deal with it. If they like love their self, how did they get to that point? ...I need to learn to accept myself again." Sarah

HCPs recognised that some patients would need help to deal with the disfiguring effects of surgery:

"Will all the men down the pub pick on me because I look different? You know, those kind of things really. For the ladies... and they get used to looking the way they do, like the make up"

and the hair doing and things like that. And it's just helping them through that process.” Chris, CNS

When the physical effects of the melanoma and treatment reduced, the need to ‘share’ the experience to gain support lessened:

“When I were diagnosed with it initially. I did maybe, talked about it more then, but now I feel like I’m more or less back to normal.” Jackie

‘Sharing’ the experience of melanoma like this had a notable effect on participants’ relationships with friends and family. Whilst most of these were positive and brought people closer together some relationships unfortunately broke down. For example, Matt, Sarah and Mark were all disappointed at the lack of support offered by their mothers. Sandra, Mark’s wife, felt that his family did not understand how serious melanoma was, thinking of it ‘only as skin cancer’, conversely Sarah’s Mum realised the seriousness of the condition but couldn’t handle the implications. She tended to limit contact with Sarah so that her sister and aunt took on greater support roles. Matt’s relationship with his mother had been fragile before his diagnosis so when she was not able to offer him any support he did not make the effort to keep in touch with her.

An inability to ‘handle’ the diagnosis was not confined to close family and Sarah decided to reduce contact with those friends who she felt had ‘abandoned’ her at her time of need:

“They can’t be bothered to come and see me when I’m at my worst and I’m down. I get odd texts off her but it’s not like, you’re supposed to be my friend, you live on my road.. what’s ten minutes to come up for a cup of coffee and a little chat. To me that would mean the world to me, so I’ve pushed quite a few people out.” Sarah

Conversely, some relationships changed for the better after 'sharing' the melanoma diagnosis. Matt, for example reflected on the threat that the melanoma posed to his life, and this prompted him to re-build his relationship with his father.

"It does put things in perspective more, you know what I mean, you just feel like how fragile life is... finally got in touch with my dad after nearly 20 years. That went well." Matt

Whilst relying on family and friends, patients were also aware of the emotional impact that providing support had and so tried to mitigate this. For instance, Fred realised that 'sharing' the cancer diagnosis with his daughter caused her worry so he made a point of focussing on any good news with her after his clinic visits.

The need for patients and carers to 'share' their experiences tended to reduce with time. Although melanoma as something that was 'always there' many people were able to put it "at the back of my mind". Keeping busy was a key strategy but despite this at certain times, such as when results were due, concerns tended to resurface again. This was the nature of the 'rollercoaster'. However, with time even major psychological concerns, such as body image tended to subside as people began to accept their new reality:

"So I've accepted that it's (scar) there, I've been reasonably comfortable in the bikini and the shorter frocks. And I just ignore it, and to be honest other people seem to have ignored it." Jean

For others it was not so easy. Jack was aware of the scar on his cheek but took a stoical view, knowing that he would not be entering into any new relationships. However, Sarah had rejected the possibility of a new relationship as she had not been able to accept the way she now looked:

"He wanted to be with me and everything and be with my kids, you'd think I'd be the happiest woman alive. But I don't feel comfortable in myself, I don't like myself, and it's horrible because

I can't be happy with anyone because I'm not happy in myself because of my leg and my scars." Sarah

Sarah's case illustrates how people reacted differently to melanoma. In this section we have considered the potential benefits of 'sharing' but not everyone was comfortable with this idea. For instance, Jean had not told many people about her diagnosis before she had surgery and subsequently found it difficult to 'share' the news afterwards, feeling that it tended to end conversations:

"It's almost like a bereavement. Are you all right? No I've got cancer. Cut off, end of conversation. What do they say, they ain't got a clue. It's a bit like - are you all right? No, my mother's just died." Jean

Some participants continued to 'hide' certain aspects of their condition just as they did at the time of diagnosis. Consequently not all of the information available to participants was openly 'shared' but such decisions were reviewed as new information was available. For example, Jack and Carol waited to tell their adult children about the melanoma until a follow-up scan was available three months later to confirm all the melanoma had been removed. Helen had also delayed telling her mother about the melanoma but because of this her mother now made frequent contact with Helen to check on her progress:

"My mum likes to see me now. Whereas before she'd go a few days with not seeing me...But she phones me up and I'll say are you all right? She'll go no, are you all right?" Helen

Even if they 'shared' information patients and carers still often did not 'share' their true feelings with everyone as they did not want to cause undue worry. This could even happen with close couples such as Jack and Carol, which paradoxically caused more rather than less worry for the non-affected partner:

"Jack didn't want to talk about it. So you can imagine what's going round in your head... Didn't want anybody to be worried unnecessarily." Carol

"It's pointless isn't it." Jack

"Well sometimes it just helps to lighten the load. Just to tell somebody...I mean it were eating away at me." Carol

"Well it were me really." Jack

"Yeah but you didn't talk to me about it..." Carol

When young children were involved participants tended to *'tailor'* the level of information, again with the intention of avoiding unnecessary upset:

"My niece and nephew... They haven't been told it's the big C because [my niece] is probably a bit, she's starting to understand now... And it would upset her." Sandra

A similar approach was taken in Ruth's family, even though her granddaughter was an adult:

"I don't really tell her [granddaughter] much because she panics, I just say oh, it's all right." Ruth

Clearly living with melanoma during the surveillance phase had an ongoing impact on *'routines'* and *'relationships'*. In some cases, this caused tension in the *'relationship'* between patients and their family, and often their *'relationship'* with an HCP took on even greater significance.

7.5 HEALTHCARE PROFESSIONALS AS A RESOURCE

"When you don't know anything at all about it, you take their advice and listen to what they tell you." Edna

Edna's comment above captures the vulnerability that many patients and carers still felt at this stage, turning to HCPs for information, expertise and reassurance. As we found in the previous chapters participants often built a *'trusting relationship'* usually with one particular HCP at an

early stage, HCPs who *'spent time'* with participants or who *'went the extra mile'* were particularly appreciated. This *'relationship'* gave HCPs an opportunity to influence patients' and carers' routines and the best HCPs actively cultivated such interactions;

"From when you first meet them to say six or 12 months ahead, or three years, you expect the relationship to evolve and you know that you can get your patient from severely traumatised to reasonably comfortable living life as normal." Les, CNS

Just as in the initial diagnostic stage, not all participants felt that they had received the type of information that they needed. For example after her second surgery Jean did not feel that she had been prepared for the true extent of the resulting lesion nor how the surgery would affect her daily *'routines'*:

"So yeah there seems to have been a lack of information to help me understand just how big it actually ended up being and how much it was going to affect me." Jean

In the absence of information from their HCPs some continued to look on the internet but many, such as Mark preferred to have a HCP explain information to him rather than looking it up on the internet, as did Tony. They had discovered that not all information on the internet was to be *'trusted'* and preferred to talk to someone they did *'trust'*, as Mark said *"Sometimes it's easier and better to talk to somebody"*.

After completing their initial treatment, patients and carers remained anxious and looked for reassurance to mitigate this but understanding the rationale behind the surveillance visits and building ongoing relationships with HCPs took time. Seeing the same person at each visit helped but as participants often went to multiple departments this could be difficult. This could be offset if there was a special *'relationship'* with a particular HCP. For example, Anne found that seeing different doctors was not a problem as the relationship with the CNS felt *'personal'*.

“Well all I can say about that is I see [the CNS] every time I go... I don’t always see the same doctor but she’s always there really... and I suppose I feel that if I wanted any personal connection I think I would go and talk to her.” Anne

Others found the opportunity to be seen by different doctors as reassuring:

“If you were to see one person, that one person could be wrong. If you see two or three people, somebody’s going to pick up on, you know. So it’s like a second opinion isn’t it.” Jack

For those who had not built a relationship with an HCP, such as Luke, seeing a number of different people meant that *“There’s been no consistency at all”*. Participants’ experiences of surveillance varied considerably, but for many it was nevertheless a reassuring process:

“And I think it’s a form of support coming up here, being examined, and somebody saying it’s fine, we can’t find any problem... Someone who is professional, rather than us talking to each other... You feel you can go away for a period of time and literally forget it, and put it to the back of your mind.” Alan

As we have noted surveillance often required participants to alter their usual *‘routines’* so that these were disrupted as little as possible and help from HCPs to achieve this was valued. For instance Helen and Fred’s CNSs did their best to ensure that appointments fitted in with the patient’s work demands, as far as possible:

“And we tried to negotiate around work because she’d missed quite a bit of work already with having surgery. So I was trying to fit it round her shifts at work because she was worried about losing her job. So I had her mobile [number] and I kept ringing her when I found slots for her.” Chris, CNS

As participants fell into the *‘routine’* of surveillance and became confident that HCPs would detect any changes some patients and carers felt they could relax their own *‘monitoring’* efforts:

"I don't worry so much about having to check him or look for lumps because he's going every three months, they're going to see or find anything. So that's my support knowing he is being monitored." Sandra

Sarah was an exception to this as she was diagnosed with melanoma while she was pregnant.

This meant that her daughter was also being monitored so she had few breaks in the cycle of anxiety and relief:

"I haven't been sleeping for a bit, to be honest. If you like with [my daughter] as well, all the pressure from her, that kept me awake... because I'm waiting for her results, if not waiting for the results from me and it's been going on quite a few months now." Sarah

During surveillance the 'relationship' forged with HCPs often grew, so that Tony, for example, chose to keep his care at his original clinic, even after moving some distance away:

"I could so easily go to [a nearer hospital] and I thought no, because of the rapport that I'd got with [the oncologist], [the CNS], [the dermatologist] and [the surgeon]. Again, if you've got a slight niggle you know that any one of those will explain things in layman's terms to you and will assist and that is a big thing." Tony

For many such 'relationships' lasted for several years and HCPs 'recognised' the value of this relationship and the difficulty some patients experienced with discharge:

"Some of them get upset that you're discharging them because I think they feel reassured by coming to see you. And it's, you've given them as much information as you can over the five years about sun exposure and vitamin D, all that sort of thing, and then you can trust them I suppose to go off and look after themselves. They don't need you anymore." Alex, CNS

But not all relationships were so positive and once lost 'trust' could be impossible to regain.

For example, Jack and Carol changed their GP after their concerns about the initial lesion were not recognised and Luke never recovered from the disappointment of the CNS not attending his appointments, and therefore navigated his journey alone:

“I’ve dealt with it by myself from beginning and I’ve been happy to do it but it’s more the fact that [the CNS] let me down. It’s the fact that when you go and she’s not there... And then next time I saw her there were no inkling about why she didn’t come. And then when I’d mentioned my next appointment she went right I’ll see you there. And then I went to my next appointment, she weren’t there.” Luke

However, those with positive relationships with HCPs formed a partnership that was influential in shaping their *‘routines and responses’* to melanoma. Even for Ruth who had claimed that she did not want to know anything about her melanoma, undertook *‘monitoring’* to please her HCP, noting that; *‘I do it every week because they’ve told me to do it’*. In addition to encouraging *‘monitoring’* HCPs actively sought to change patients’ habits regarding sun exposure and protection, whilst also encouraging them to continue to enjoy the benefits of safe sun exposure:

“You work on that... When you first start with them you start from scratch and you’re going through sun safety, sun awareness, sun protection, vitamin D synthesis. Some of them avoid it altogether, the sun.” Alex, CNS

“Because I always find that patients need some reassurance that they can continue to get some sun exposure... encourage him that he still needs to go out and enjoy himself, and it’s not going to affect his motorbiking and his holidays and things like that.” Lou, CNS

To be maximally effective many HCPs recognised that they needed to *‘make themselves available’* and made every effort to do so.

“Just to ring up (she said), and you’re not frightened to ask her anything either.” Helen

For HCPs to be an effective *‘resource’* during surveillance it was important that there was someone that patients and carers could contact easily should they notice any changes. If they had concerns patients and carers would contact whomever they had built the best *‘relationship’* with, be that a consultant, CNS, GP or other HCP. Tom felt that he had been

given 'permission' to contact his doctors at any time, whereas Matt was reluctant to telephone as he had not built a relationship with the person he would be talking to:

"I have the OK from both doctors actually, both consultants, that if I see anything I've to let them know or their secretaries know and they'll see me." Tom

"They offered me a phone number like a helpline... I felt like if I did ring somebody, they'd be probably speaking off a script if you know what I mean." Matt

Some participants were reluctant to "trouble" or "bother" an HCP and "waste their time", particularly for anything that might be 'trivial':

"You see things, oh we'll just keep an eye on that, oh just leave it, if it gets no better. But we've not actually thought, I'd probably feel again like I was just wasting their time. I know that's not right because they just say anything at all you just ring, and I appreciate that. But then I think well if you're dealing with me you're probably missing out on somebody who's more important." Mark

"I'd maybe not have bothered with the nurse as much. Because I know they're busy as well, nearly as busy as consultants, it's probably why I wouldn't." Jackie

HCPs were aware of this and tried to make sure that participants felt able to contact them for information or reassurance, especially during surveillance:

"...from my point of view it's important they understand that if, that I'm happy to see them at any time in the future for whatever reason... the door's always open if they want to come back and ask further questions." Ashley, Surgeon

Some patients were reluctant to contact their doctor with what might be 'stupid' questions and so turned to their CNS instead:

"Because if it's only something like minor or something, not stupid but you don't really want to ring a consultant up to ask him... I didn't mind ringing her (CNS) up. And then she sorted it out from there." Helen

This was not a unique example, with the CNS below describing how she would often see Phil, mainly to reassure:

"We saw him a lot and examined him quite often. At his request he would come outside of clinic appointments for an examination, just to be reassured." Les, CNS

Nurses recognised that they were often seen as being more accessible than doctors and consequently would be contacted more readily by patients. However they were also under pressures of time and resources which meant that they might not always be free when they were needed:

"...because there's only two of us we, and we're spread over three sites, we have to prioritise and some patients miss out, don't they?" Les, CNS

"You want to give this patient extra time and, but you've got three or four patients sitting out there waiting, very difficult." Lou, CNS

Because of this psychological support beyond reassurance was something that the patients were more reluctant to ask for, and Jackie would have liked the opportunity for "a bit like a counselling session". This was echoed by others:

"They're looking after patients and that and they don't want to be listening to everybody's woes personally because they are busy aren't they. So if they had a specialist person, that's what they did, you know I think it would be a good thing." Jack

However, providing such support was something that HCPs viewed as part of their role:

"When you first meet patients at diagnosis, and the care that you have to give to get them from the diagnosis to a point of being, feeling psychologically and physically healthy again and getting on with normal life is, that's your responsibility." Les, CNS

The impact of such support was clear in the data. When Jean was in tears between operations, Bob was so worried that he contacted their GP, who spoke to Jean on the telephone. While

Jean felt that there was “*nothing he could do*”, she appreciated him contacting her. Similarly, when a CNS gave Sarah an opportunity to talk when she obviously needed it, this enabled her to put her concerns to one side:

“It’s like nurse said to me, she went are you all right, and I said yeah. And then she went are you all right, she could see that I weren’t all right. So it’s like I’m trying to put a brave face on but even she knew I weren’t all right. So then I like sat and I spoke to her for a bit, and she just said go away and try and forget about it - which I did.” Sarah

Patients and carers relied on HCPs for their specialist support, drawing on their expertise for reassurance but for some people the melanoma did come back. If there was any possibility that a melanoma could be removed then patients and carers remained under surveillance, but at some point, for some people this was not possible. At this time they were considered to have advanced disease and this is the subject of the next chapter.

7.6 SUMMARY

During surveillance the ‘*rollercoaster*’ continued to have ‘*ups*’ and ‘*downs*’ relating mainly to anxiety or concern arising from a variety of sources, such as:

- Concerns that the melanoma might coming back
- Monitoring and protective routines
- Recovery from initial treatment
- Sun exposure
- Surveillance visits and scans
- Removal of suspicious lesions

To counter these concerns patients and carers often took steps such as adopting new ‘*monitoring*’ and sun protection routines. Their anxieties were also mitigated by the expertise,

information and reassurance provided by HCPs who built *'relationships'* with patients and carers. Such *'relationships'* were valued by patients, carers and HCPs and provided a positive experience where they were formed. Where they were absent patients and carers negotiated their *'rollercoaster'* without guidance. Where a *'relationship'* was formed HCPs were able to influence patients' and carers' sun related behaviours in a positive way and reduce their anxiety. The ability to form and maintain these *'relationships'* depended largely on the HCP being accessible to patients and carers. Barriers to access from the perspective of patients and carers were the HCP being seen as *'too busy'*, not feeling able to ask their questions for fear of appearing *'stupid'* or physically not being able to make contact if calls were not returned or appointments not kept.

'Relationships' with family and friends also remained significant and these were often shaped by the extent to which both parties either *'shared'* or *'hid'* both information and their feelings about the melanoma and the *'ups'* and *'downs'* they experienced. This chapter has sought to capture the dynamics between these various factors.

For some participants surveillance marked the end of their *'melanoma journey'*, others however were not so fortunate.

8 CHAPTER 8: ADVANCED MELANOMA: THE 'BOMBSHELL'

As noted in the preceding chapter many patients' melanoma *'rollercoaster'* either ended or continued in the surveillance phase after the end of data collection. However, for those who were deemed to have *'advanced'* disease this was not the case. It is their stories that we consider here. For these individuals their melanoma had spread to distant lymph nodes or other organs such as the lungs, liver and brain or the melanoma was not amenable to surgery.

During the study a number of new treatments for advanced melanoma became available (see Figure 2.3 in Chapter 2) changing the experience of melanoma patients while data were being collected. Whereas, at one time, there were few treatment options available with limited effect, towards the end of the study patients could access multiple lines of treatment. The experience of patients with advanced disease therefore varied considerably.

I recruited Irene, Sue, John and Esther when their melanoma had already reached the advanced stage. Karen's melanoma progressed quickly during the recruitment process so she had advanced disease by the time Laura and herself were first interviewed. Luke, Sarah, Amy, Lynn, Phil and Kate experienced melanoma over a longer time from the removal of a mole, through surveillance and recurrent disease before experiencing advanced melanoma. This chapter seeks to capture their experiences.

8.1 THE BOMBSHELL

"You know it might come, (but) you don't want it to." Luke

As noted above some patients were initially diagnosed with metastatic disease whereas for others, distant spread developed after several surgeries and over some months. Despite this variation the discovery of metastatic disease came as a *'bombshell'* for all the participants, and was undoubtedly one of the major *'downs'* of the *'rollercoaster'*. Even those such as Karen who had a clinical background and had undergone treatment for many years had not seriously thought about the possibility of progressing to advanced disease:

"And then again I still had it in my mind 'it's fine', even when obviously I knew it just kept spreading and spreading, so they kept chopping bits of my ear away, to the point that they had to do the amputation and then the skin graft. And I kept thinking 'it's fine, they'll get it.' I think the bombshell hit me when it was this is bad news. And I suppose it's the realisation that it can't be chopped away and that there's other things that need to be done now." Karen

Like Karen, Phil also *'recognised'* that surgery was not now an option, and that the melanoma was not curable as *"the iron door has closed"*. Finding out that he had advanced disease despite numerous surgeries *'shocked'* Phil, and he also felt disappointed that he had endured surgery:

"I've had the operation and through the first scans and things like that they've found more metastasis. And they've said they're inoperable so the only option is a drug...shock, total shock, I mean every time I've had an operation it's gone somewhere else. So it all seems a bit pointless. You know, why didn't I just go on the drug straight away?" Phil

Some participants such as John, as his wife Esther explains below, had initially thought that the change in his condition was due to a chest infection, only to be diagnosed with metastatic disease immediately:

"Because you used to say you felt as if you had a weight on your chest, and that's why I said you must go for a chest x-ray, because infection's the first thing you think, isn't it? And that's all you went thinking, when you went for the results. We both sat there waiting, oh it's a really bad chest infection." Esther

The distress that Sarah felt when she learned that the cancer had returned was compounded as her daughter had a mole removed around the same time. This combination of events prevented her from sleeping:

“Devastated. Just not sleeping, I can’t sleep. Why is it coming back there, you know, it’s just that same place... I’ve been going through it with [my daughter] as well, my little girl, because she had a mole appeared on her bum, same place as mine and it had changed and it was going like mine, so she’s had to have surgery and have it removed. Luckily hers has come back all right, all clear.” Sarah

When being told that the melanoma was now at an advanced stage patients and carers again struggled to understand this information. Phil was in ‘*shock*’ and Karen just wanted to go home. She was not able to ask questions or process information until she returned to clinic the following week for a further discussion.

“But I think that day I was just devastated, I just wanted to go home, I sort of took all the clinical trials leaflet stuff and thought I’d just rather go home. So no, I didn’t ask any questions that day, it was the following week when I came back in. Then it all slots into place, all the things that have been happening.” Karen

Mirroring the situation with the initial diagnosis participants were then faced with the decision about who to share this information with.

8.2 TO TELL, WHAT TO TELL AND WHO TO TELL: SHARING AND HIDING AS PROCESSES IN ADVANCED DISEASE

“They (family) can support me in the way that I need support, but the whole world doesn’t need to know.” Esther

As was the case throughout who participants decided to ‘*share*’ their news with largely depended on their ‘*relationship*’ with people and whether they considered that they ‘*needed to know*’. The news was therefore most often ‘*shared*’ with close family or friends. Telling

family and friends that the disease was advanced was difficult for everyone, but especially for those, such as Irene, Sue, John and Esther who were diagnosed with metastatic disease from the outset. Here the 'shock' reverberated to everyone and patients had to try and manage the 'response' of family and friends as well as their own. Irene found it a difficult conversation to have so tried to 'lighten the mood':

"Well they sympathise and then they say 'oh but you look so well. They looked shocked... So you try and make a joke and say well nobody lives forever." Irene

Others, such as Luke, took a very stoical view and could not understand why people, even HCPs, felt the need to apologise to him when he talked about his advanced melanoma:

"I said to the nurse who were taking blood, I said well it comes to us eventually don't it? And she looked a bit shocked. She says I know, but it shouldn't be at your age." Luke

Consequently Luke did not really 'respond' in the way that people expected, possibly making an already difficult conversation more challenging for others. Conversely, Karen, when telling her daughters that she now had advanced disease 'recognised' the need to help them deal with their 'responses', and so 'tailored' information accordingly. This seemed to make subsequent conversations easier, with humour again playing a role:

"I mean I do cry with them...but we tend to have a talk about it. And they joke because they go 'God mum, you've been poorly for 10 minutes now, it's really boring, can we do something else?' And that is really nice then because we can go into other things." Karen

For Karen such a 'light hearted' 'response' was easier for her to deal with than the way that her partner reacted:

"I have a partner and he's very supportive, (but) he hates hospitals and medical stuff so it's been quite a challenge for him. He's been upset, which I understand completely but I do find it difficult to cope with...because I just don't know what to do." Karen

However, not everyone 'shared' their diagnosis, even with close family members. Esther encouraged John to be more open with their sons as she 'recognised' that 'sharing' information was essential if people were to provide future support, much of which came from family and friends.

"Well (we told) just a handful of close friends, yeah. They know what's happening." John

"Would you talk more to [our sons], do you think?" Esther

"Maybe, yeah... because they need to know. It's one of those things." John

The dynamic between 'sharing' and 'hiding' of both information and feelings was often more complex at this stage than it had been previously. For example while Esther and John shared information within the family Esther was aware that John was not fully 'sharing' his feelings with her as he wanted to protect her from his own anxiety. 'Recognising' this, she provided opportunities for him to share his feelings with the Macmillan nurse as a 'neutral' person:

"Esther spoke with me separately as I was leaving the house... she actually made a deliberate action to go and make a cup of tea to see if John would open up to me but he didn't really say anything an awful lot. But that was trying just to engage him in any conversation, but it was more about Esther." Sam, Macmillan Nurse

This also happened between Karen and Laura, although it was more openly acknowledged here, with Laura 'recognising' that her Mum 'sugar coated' her emotions, and that she had to get beyond this if a 'real conversation' was to be had:

"I think I just ask more questions, and I obviously understand it a bit more. I do think sometimes you sugar coat it a little bit though. I can tell when mum's sugar coating it, and I'll go come on, tell me. And then we have the real conversation, whereas other people obviously just go okay then, and that's that." Laura

As with the initial diagnosis the information that was 'shared' was sometimes 'tailored' according to the recipient rather than totally 'hiding' it. Sue, for example, tailored the information given to her children about their Great Aunty Irene:

“They’re (children) kept in the loop because you can’t cosset kids forever. You know, they’ve been talked to in a manner that is appropriate, but they’ve always been told if anybody’s poorly and they might die or whatever so they’re now at an age where they can accept it. I mean Auntie Irene was in agreement, you know, but they were told what was going on.” Sue

Phil, however, chose to ‘hide’ his diagnosis from his elderly mother for as long as possible as he was concerned that she may not be able to cope with it:

“I mean she’s... 93. To be quite honest if I told her now she’d forget in ten minutes anyway. I’m not afraid of telling her, I just think it’s pointless at this time. If she was upset too much I would always regret telling her.” Phil

It was only when information was ‘shared’ with family and friends that they could provide any support, again highlighting the importance of information as a ‘resource’. But as was the case throughout the melanoma ‘journey’ it was family and friends that proved to be the major ‘resource’.

8.3 FAMILY/FRIENDS AS A SUPPORTIVE RESOURCE:

Given the often rapid spread of the disease once metastatic, patients became frail quite quickly and needed both emotional and practical support. This usually came from close family/friends, who were a vital ‘resource’ for participants. Irene, despite having no children of her own saw herself as fortunate to have a caring niece and good neighbours, even if sometimes their support was not strictly needed:

“She’s (niece) good. And my neighbour, across the road there, she came in yesterday just at my lunchtime, she always comes just then, just wanted to put my dinner in the oven and stays for an hour. And the other one at the bottom of my garden she was going to come with me to [the hospital] if necessary. And I have a lady who walks my dog whether I want her to or not...” Irene

Others also got good support from their neighbours of many years, several of whom had experience of cancer themselves:

“They’ve (neighbours) all been good. Some of them have been through similar scenarios. We’ve lived in the same house for 30 years. We know everyone..... He’s got prostate cancer, his wife’s got NHL. Another chap had bone cancer because he’s on a trial here.” Phil

It was often carers who needed the most emotional support and this was ‘recognised’ by patients who encouraged them to seek whatever help they could:

“He’s (partner) got a really good supportive network. We both work (for the same organisation) so his work colleagues were my ex work colleagues, so he does have quite a wide group of people that know me that he can talk to. I think most of them (family) do, I think the only two that probably don’t talk to anyone other than family are my twin daughters.” Karen

Karen’s daughter, Laura, was a mental health nurse, and she considered herself particularly lucky to have support, both from colleagues and her friends:

“...support in my job is amazing, which I think is the perk of working in mental health, a clinical psychologist who comes and talks to me quite a lot and we talk a lot about how I feel and that’s really helpful. Then I’ve got a really good support network of friends that are amazing, again they’re all mental health nurses.” Laura

However despite such support, having a family member with melanoma could cause difficulties in family ‘relationships’. For example we heard earlier that Pam, Sarah’s mother, had sought counselling to cope with her daughter’s diagnosis and despite this found it difficult to accept things and so slowly withdrew from the family.

As already noted for many the internet became an important ‘resource’, providing valued information. But others turned to it for emotional support and in so doing formed new ‘relationships’ with others in a similar situation. The ‘sharing’ of their stories was in itself a way

of fostering hope, but also, as Sarah's story will show later, it was a way for participants to give hope to other melanoma patients.

Both Sarah and Karen felt the need for specific support from others experiencing melanoma and they turned to the internet. In doing so they found the Facebook group 'Melanoma Mates', comprising only of melanoma patients and their carers without any formal moderation useful. However, they were also aware that some aspects of discussion need to be taken with a '*pinch of salt*'.

"So yeah, I think information is incredibly important, but it's also knowing to filter it properly. Because you can go online can't you, and there's some hideous stories. But I suppose with doing research and assignments and stuff ourselves, we know which is rubbish and which to actually read." Karen

On the whole, though, Sarah and Karen found the group helpful, allowing them to access others going through similar experiences. This made them feel less isolated, better informed and more '*normal*': Karen had subsequently met one of her online contacts, who lived close by, face-to-face:

"You can read someone's post and someone will say 'oh yes I had that or I had that', so you don't feel abnormal. So it is really useful. I know of three others on the group that are here, and one I've actually met today and said hello to her. It just feels quite nice that there is somebody else that has got the same. So it normalises it a bit. The Melanoma Mates I do find quite comforting at times." Karen

Irrespective of how they met, other patients were an important '*resource*' for a number of participants. For example, Sarah met with a melanoma patient of a similar age via the CNS, who had recognized that Sarah needed additional support at that particular point in time.

"I talk to (to the other patient) a lot, obviously because she's been through, it's just getting comfort off each other. She's been there, we understand each other. And it's just comfort to be honest, it's someone to talk to who knows, who's on my level kind of. I mean I know you've got your family and everyone, but there's only so much they can understand. So yeah, it's just some support but on the outside of family." Sarah

As Sarah continued to interact with other melanoma patients she was able to share her experiences more openly than she had done with friends and family. As well as benefiting her she found herself helping others in a similar situation. This gave her a sense of satisfaction:

“It’s like that girl I’m following now. She’s wrote her story and stuff, and she’s scared. Now at one point I wouldn’t tell nobody my story. But I sat and I read through hers, and then I explained what I’ve been through in the last four years. And she’s like you’re so inspiring and how do you keep going and things like that. So I think me speaking to her because she’s so young, I’ve kind of helped her. And it’s just nice to know that I can actually help someone else.” Sarah

HCPs *‘realised’* the potential benefit of patients talking to one another at a time when they had complex needs but did not always feel able to facilitate this:

“We’ve had young people recently with metastatic disease that have needed, husband and wife and the children, and you think oh I’d just love to put you in a room and you could just say actually yes, I know how you feel because I’m going through the same thing.” Les, CNS

The data clearly demonstrated the importance participants accorded to their *‘relationships’* with a wide range of people including, family, friends and other people with melanoma. Amongst other benefits such *‘relationships’* helped many retain a sense of being *‘normal’*. HCPs remained an important *‘resource’* at this time and we now consider the role that they played, again highlighting the *‘relationships’* between HCPs and participants.

8.4 HEALTHCARE PROFESSIONALS AS RESOURCES

“Hopefully you gel with the person that’s caring for you, and you have a good relationship. We did.” Sue

We have already seen the importance of the *‘relationships’* participants had with HCPs from the outset. However as treatment progressed patients and carers experienced changes in their *‘relationships’* with HCPs as they were transferred to new services or departments.

During such transitions it was most important that HCPs were 'accessible' to patients and carers but as before participants had both positive and negative experiences at this point too.

Irene, Sue, John and Esther who experienced advanced melanoma from the outset, were rapidly seen by several doctors in different specialities and were frustrated by the often poor communication within the healthcare system. In particular Esther felt 'out of the loop' and would have liked a better understanding of John's condition, as well as help to deal with her own 'shock':

"Just what do I do now? Something you've never faced before, you're in confusion, a lot of people are approaching you, nobody's quite got all the information that you need. Three months, it was so short (especially) if you're waiting two weeks for each letter and each visit."
Esther

Having community based support was an advantage as their Macmillan nurse describes:

"Because of my role we do community visits... and we're able to spend that little bit extra time with the patient and the family and explaining things a little bit better." Sam, Macmillan Nurse

Conversely, those who had an established 'relationship' with a HCP clearly felt the benefit. Since getting to know his CNS Phil hadn't 'felt quite so alone'.

HCPs were 'recognised' as a different kind of 'resource' than friends and family, who complemented the efforts of the former by providing differing types of support, including information and helping people to use the 'system' more effectively, as Esther and Phil describe:

"It's nice to have the friends, but sometimes you need a professional just to be in there saying 'well what would happen if we did take that', or 'what would happen if we don't do that?'"
Esther

“They’ve (HCPs) been so helpful they may even have bent the rules to make the path more easy. I mean with appointments, like this week I came to see the surgeon, I’ve got to come again to see [the oncologist], got to come again next week for a CT scan... Pick up the telephone and hey presto they are all in one day.” Phil

Participants often struggled to understand the information they received (as noted previously) and in such circumstances other support was needed. Irene turned to her GP to explain things in ‘lay’ terms whereas Sue turned to her cousin, an occupational therapist, when her Aunt Irene became ill.

“They were all very, very busy so they would talk to you, but you had to stand about for ages waiting until they’d got 30 seconds to speak to you. But with [my cousin] I could just say what I felt and she’d get the gist of what I was saying and not look at me like I’m an idiot, if you know what I mean.” Sue

Patients and carers sometimes needed differing types/amounts of information and this was also ‘recognised’ by HCPs. Esther and John’s Macmillan nurse noted:

“I think from the point of view of what Esther wanted to know, the background information of the support that’s available and how the different services worked. Whereas John, he was engaging in conversation but didn’t particularly want to know in-depth information.” Sam, Macmillan Nurse

In addition to being a potentially important source of information in the best circumstances HCPs also provided much needed emotional support, especially when a good ‘relationship’ was established. For this to happen however participants needed to know who was available.

This was often not made clear, as Kate, Phil’s carer describes:

“When we first started there were no information sheets. Then they said get through to your cancer nurse. What cancer nurse? We didn’t know [the CNS] then... I mean you can’t fault them at all now but in the beginning we didn’t know who they were.” Kate

As John had treatment from multiple specialties Esther also did not know who to contact:

“Who is your point of contact? I’m not quite sure. Loads of names there, but who do we contact? I’m still not sure who we contact.” Esther

Fortunately her Macmillan nurse ‘recognised’ this and tried to make sure someone would always be available for them, including an out of hours service.

Similarly Irene’s GP had made a point of being available during the lengthy and complex diagnostic period that she experienced.

“And so I had a series of conversations with her in our branch surgery near her house. They were usually long appointments, sort of 20 minutes, half an hour. I wanted to make availability to me easy. Which it should be for palliative patients in general, that’s our sort of practice policy.” Henri, GP

Transfers through the system could disrupt established relationships and starting again with a new specialist often took time. Karen, for example, had developed a relationship with her surgeon and now knew him so well that she could gauge whether the ‘news’ was likely to be ‘good’ or ‘bad’ by his non-verbal cues. She felt that she needed to develop the same level of understanding with her oncologist if she was to get the most from their ‘relationship’:

“[The oncologist] has a very different style to [the surgeon], and I suppose because I didn’t know him very well it’s gauging what is bad news isn’t it? [The surgeon] I know completely when it’s bad news, but with [the oncologist] I was thinking is this bad news or is this just news that you deliver to lots of people who come in here?” Karen

Many HCPs ‘recognised’ situations such as Karen’s and appreciated the need to establish a relationship quickly:

“They may have started off in [other hospitals], so had very close contact with the CNSs there, and then we just meet them when things aren’t great really. And I think sometimes it’s hard to try and get a relationship going when you don’t know that patient’s history. I find it quite hard to sort of establish any kind of thoughts around a patient.” Sandy, CNS

Karen worked on her *'relationship'* with her oncologist and was so successful that she refused to be referred to a hospital closer to home. The need to establish new *'relationships'* was something most participants experienced if they were to move through the hospital *'system'* as smoothly as possible.

HCPs also felt a sense of satisfaction from their relationships with patients/carers and were disappointed when circumstances meant that this did not happen as often as it might:

"And I'm saddened in a way from my experience about palliative care I didn't have the conversation of where would be your preferred place of death. I didn't have those sort of more extended kind of planning palliative conversations with her. I didn't facilitate her being nursed at home or get involved in visiting patients at home, which from a GP looking after a palliative care patient can be the most rewarding times. Being completely honest I felt disappointed I couldn't try and provide that high level of palliative care right to the end." Henri, GP

In the face of often unpleasant and invasive treatment participants sought ways in which they could maintain some hope. In this sense hope and the desire to keep things as *'normal'* as possible became a *'resource'*. Despite this the melanoma and its ongoing treatment inevitably impacted on participants' daily routines.

8.5 CHANGING ROUTINES

"Yeah, it's (the melanoma) just become part of my life." Luke

Living with advanced melanoma had an impact on participants' daily *'routines'* on a number of levels. As noted above, new treatments became available during the study which some patients were able to access. This meant there was a need to go to hospital for further investigations, consultations and (where appropriate) treatment. For many this became the new *'normal'*:

“So I suppose that’s the whole scary bit of knowing that yes, you start to normalise coming to this hospital and knowing that you get a ticket for your bloods or you go up here. You start to know the process; does that make sense? And then it becomes just very normal to you.” Karen

However, probably the greatest impact on patients’ and carers’ ‘routines’ was the need to ‘monitor’ their melanoma, its associated symptoms and the efficacy and side-effects of treatment. Side-effects of treatment were constantly compared to the list of possible side-effects so having good information was essential. Patients were pleased when they did not experience all of the possible side-effects and felt that those that they did experience were manageable. This was taken a positive sign, especially if other activities, such as work, could be maintained:

“Just makes me feel lethargic and all my muscles in my back hurt, oh they’re really tight, but apart from that just normal. Not had any other side-effects. God I’ve got a sheet about that long full of side effects, the only ones I seem to have got is my aching muscles, and like I said just feeling a bit tired. But at the same time I’ve gone back to work full time.” Luke

To manage such side-effects new routines were often needed. Phil, for example, regularly applied cream to the blisters on his fingers and Luke, who developed a phobia of needles, found strategies to manage this such as concentrating on “*gulping coffee*” while the needle was inserted.

In addition to ‘monitoring’ side-effects participants, both patients and carers, also kept a close eye on their symptoms in order to judge how well they were doing. So even with advanced disease Karen still ‘monitored’ her moles, feeling that this gave her a ‘*sense of control*’ as she could see when things were changing. She also felt that if she was reporting side-effects to HCPs but not being admitted to hospital, she was ‘*alright*’.

“So I jot down on a daily basis not everything but just main things. So you do get an idea of I wasn’t writing those sorts of things a couple of months ago, but every day I’ve got the cough and breathlessness, whereas a couple of months ago it was fine, I could walk up the stairs like anybody else. So yeah, I know that I monitor. I feel sometimes I’m a hypochondriac because I’m monitoring it so much, but I know I’m not.” Karen

Others such as Phil, who had no initial symptoms, found it hard to accept how rapidly his melanoma had spread:

“It’s showing no symptoms whatsoever, I mean they’re telling me I’ve got lumps here, there and everywhere. I can’t feel any lumps. Or being affected by anything.” Phil

Family or friends who saw the patient regularly ‘noticed’ subtle changes week-to-week, that the patient themselves might not appreciate as Sue describes below:

“But I did notice that she was more sluggish, she wasn’t as sparkly as she usually was. When we were going places she didn’t walk as fast. She was just gradually slowing down.” Sue

Others actively sought the help of family. Sarah realized that she found it difficult to assess the melanoma on her leg as she looked at it every day, so she shared this task with her family, and they would make comparisons:

“And I showed my dad a few weeks ago and he took a photo of it then. Because he said he can see a change. But then I’ve not shown him again for weeks. So he’ll come with me Thursday, I’ll show them and I want to see if it’s changed from his photo.” Sarah

As the quote above suggests participants devised a variety of ways of ‘monitoring’ their condition but more substantial evidence came from their regular scans and these were a further cause of potential concern. Even though hospital visits had become ‘routine’, when the results of scans were going to be discussed, this still caused anxiety. Luke describes the sleep disturbance he experienced before receiving results and Sarah talks about feeling scared:

“I just found that the night before I’d come to hospital (for results) I always had restless nights.” Luke

“I’m not saying I haven’t had my down days and I haven’t been snappy, because I have, I think it’s to do with Thursday (results). I’m not saying I’m not scared, I’m really scared, but I’m at that stage I think, here we go again and whatever it is, it is. I’ll still keep fighting it.” Sarah

The psychological impact of living with melanoma is clear from the above but patients still often tried to 'hide' this from others and keep things to themselves. Carers often became aware of this and therefore, as well as 'monitoring' physical symptoms, they also assessed the mood of the patient to judge how well they seemed to be coping. This could be done covertly so as not to worry patients unduly. Lynn, Sarah's aunt, describes this:

"It's like when she's feeling down, she doesn't know that I know she's feeling down. And she doesn't know that I'm thinking about it. I've seen a change in her, especially this last month or so. She's been more like herself than what she has been, because there's been times when I've looked and I'm thinking she's not herself at all. But I've been really pleased this last month." Lynn

Esther noted John's mood changing as the metastases spread to his brain and she found this the most difficult aspect to deal with as she felt she was losing the person he had been:

"The brain thing was very disturbing, because that's the one that really affected him badly in the end. He changed, his whole behaviour changed. He stopped being the (person) that I knew. He withdrew completely from everybody, everything." Esther

As noted above both patients and carers did not always 'share' their observations/feelings with each other and this can be seen as another subtle manifestation of the 'hiding' behaviours that both could engage in.

In addition to 'monitoring' their side-effects, perceived progress and mood, living with melanoma also changed other aspects of participants' daily life, for both patients and carers. The latter in particular began to play an increasingly more active role as things developed. John experienced difficulty sleeping and so was frequently up during the night. Esther worried that he could hurt himself while walking round so she stayed up with him to make sure he was safe.

“The lack of sleep was quite hard, because he was on the move continually. I’d say let me just sit with you and settle you. No, leave me alone, leave me alone. So he’d settle for a bit, then he’d go into the other bed. So sometimes I’d sleep in the chair a bit.” Esther

As her aunt became frailer Sue visited her three times a day to help her get up, go to bed and cook her meals, varying the dishes to try and accommodate her aunt’s changed sensation of taste:

“Obviously her diet changed because she didn’t feel like eating. She felt sick with a lot of things so I did think about things that were more neutral in flavour because sweet things tasted wrong and salty things tasted wrong so I tried to find things that were neutral for her or that might just sort of taste a bit.” Sue

As is apparent from the above ‘*monitoring*’ of various sorts became part of the daily ‘*routines*’ of living with melanoma, as did ‘*protecting*’, which took a variety of forms. We have already seen how both patients and carers often tried to covertly ‘*protect*’ the other from the impact the melanoma was having on them. Another more overt form of ‘*protecting*’ was apparent with regard to sun exposure. For Sarah ‘*protecting*’ herself and her children from sun exposure was part of her regular routine. In addition to sun cream she had bought a canopy to provide an area of shade in her garden. She also took care to avoid the sun when out with her friends, something that was treated with gentle humour:

“Been doing more stuff with girls from up at school with their children, just go on park for a couple of hours after school and things. But I have to go and sit over in shade while they’re in sun. I’m like hiya, I am still here. And the sun, as it’s moving round I move round too, so we all laugh and joke about it.” Sarah

Phil was ‘*sun aware*’ but became more vigilant while on treatment when he developed a rash that he attributed to sun exposure:

“I mean I’ve got a wide brimmed hat, I’ve got long sleeved shirts, trousers, that’s all I need. If I keep the sun off me then I won’t get the (rash) - see I’m blaming the rash last time on the sun, I might be wrong. But it could well be at that time of year that excess sunlight just tipped me over onto a, you know, that rash situation.” Phil

In addition to the impact of the melanoma on daily routines it also impacted more widely on participants' roles.

8.6 THE IMPACT OF ADVANCED MELANOMA ON ROLES

"But I've got to think that my time is limited and start planning ahead... before anything happens when I can't... it might be years, it might be months, we don't know." Irene

Patients' and carers' roles changed again as the melanoma advanced. As already noted some didn't consider themselves as patients, even when they had advanced disease. The exception was Karen who saw herself move into the 'classic' patient role, a change in 'status' that was difficult for her to accept:

"I suppose it's the times that I'm spending here (in hospital). I'm here all day today, which I suppose in a way gives you a whole new career path doesn't it. And sometimes you sit there waiting and you think 'Crikey, is this what I've become?' You go from being a senior clinical manager with lots and lots of responsibilities and running round to like thinking 'right what's my job now?'" Karen

Other 'patients' cited few perceived changes in their role however relatives were far more likely to see themselves as moving into a caring role, which often had unexpected impacts. For example, Laura recognised the importance of her role as a carer but this caused tension between her and others in her life who did not share her view:

"Like I have got a really good friend support network, they are really understanding, but like my partner, me and my partner have split up due to the pressure of me being with my mum and working and things like that, and not having enough time for him in his head. And also the breakdown in my relationship actually with my sister, with one of them, you know I've got twin sisters. One is amazing, but [the other], I just can't even begin to describe that girl. She's just, she hasn't dealt with it, and instead of dealing with it she has pushed everybody away and been very nasty and very volatile, and she's been quite horrible to mum, and that's not acceptable." Laura

Both Karen and Laura 'recognised' the reversal in their roles with Laura now having to look after her Mum and at times herself 'becoming Mum'. Karen also knew that Laura was giving up a lot to support her, albeit willingly:

"So yeah, there's times when it is quite a role reversal, in a nice way not in a horrible way. But it does make me smile because I think, you know, my gosh. And I think, that you feel guilty if you're not with me or not doing something for me. And that's hard for me, because I've always tried to be very clear that you've still got your own life to live." Karen

"Yeah, I don't go out with my friends as much anymore, because I'd rather be with mum. I worry when I go to work that I'm going to get a phone call or something's going to happen, like mum will need me and I won't be there. If I had my way I'd quit my job and I'd just live with you all the time. But I can't do that because it's not very realistic, and I'd go a bit stir crazy." Laura

"Yeah, we'd drive each other mad." Karen

Sue was also disappointed with the 'response' of a family member who did not understand the importance that she attached to caring for her Aunt:

"One of my cousins... Yeah, well, well I can't do anything I'm working. OK, well I've given my job up for her so you live with your conscience. And that was it." Sue

However, as was the case with Karen and Laura the care that Sue, and others, unconditionally gave Irene, even though they had other demands, did not go unnoticed:

"They are there for me when I need them and they do it willingly, not half-heartedly. I mean Sue is always there when I need her. My friend's always there, although she's had a lot of trouble because she's had another friend that's been poorly, and she's got another one now that's been taken ill with something like, ovarian cancer." Irene

As the melanoma progressed sooner or later participants began to think about what the future might hold and 'recognised' the need to both change certain roles and to begin 'putting their affairs in order'.

In addition to the *'protecting'* roles described above patients and carers experienced changes to their occupational, leisure and family roles at this stage of the melanoma *'rollercoaster'*. Despite this they tried to continue to keep things as *'normal'* as possible by making modifications that were necessary. Therefore goals were subtly changed so that they were achievable and future planning became more day to day rather than long term.

Most participants in employment experienced changes to their occupational roles. Irene and Phil were already retired and Sarah had stopped working when she was diagnosed with early stage melanoma. John's rapidly deteriorating health meant that he could not continue to work as a farmer and Karen also had to reluctantly stop working as a senior clinical manager which led to fundamental changes to her identity:

"And then I'm in that scared bit thinking well I don't want that to be normal to me, because I've still got my bag with my laptop and my notebook and my work clothes in the wardrobe, and that's normal for me. And I'm having to leave that for a bit for this to be normal for me, which is probably where I don't do patient very well." Karen

As with Karen, Luke liked to be busy and work was also a big part of his *'normal'* identity so he negotiated with his employer to keep working for as long as possible:

"I were off for about two months... Boring. It were, just pottering round house. But they didn't want to let me back to work, they were scared to death in case owt happened to me. I says I'm all right. So I ended up building back up to half days, which finished two weeks ago. I didn't bother getting a doctor's note and I just went back full time. I got a slap on wrist. So they've took two hours off me again, so I finish at three now - can't win." Luke

Taking on a caring role also impacted on the employment of participants. We have already heard how Sue postponed finding a new job after being made redundant so that she could care for Irene. Similarly, when Phil was diagnosed with advanced melanoma, Kate decided that it was time for her to retire in order to enjoy more time together:

“Deep down I’ve been wanting to [retire] for a while but obviously it’s that push. That were that when we knew that [Phil had advanced disease]. I said that’s it I’m packing in and I only worked a week. That’s out of the way now. Emptying cupboards. We went away with friends and we just potter.” Kate

Laura continued to work as she got support from colleagues, but as was noted above always felt guilty when she was away from Karen. Sarah’s sister Amy had reduced her hours at work to care for her when she had her initial treatment and now the whole family were involved with the exception of her mother who was unable to cope with her daughter’s illness.

For many participants the reduction in working hours meant that they could spend more time together and even those reluctant to cut ties with work, such as Karen, recognised the benefits of this:

“And we talk a lot more, that’s changed. Because obviously we spend a lot more time together, I suppose it comes hand in hand doesn’t it? We’ve had a lot more time together than perhaps we would have done if I was working full time and you were doing other things.” Karen

Changes to occupational roles brought with it the need to begin to ‘*put affairs in order*’ and reorganize many aspects of their lives, such as insurance and pensions. This brought further, albeit reluctant, ‘*recognition*’ of the permanent nature of changes:

“There’s lots of things like pension forms, at work I’m coming up to six months so I’m changing from salary to insurance schemes. I think it’s the amount of letters coming through and contact I’m having with people to sort out finances and work that it all, even though really it becomes more real that I’m not going back, and that I’m just putting things in place. It’s like getting your affairs in order isn’t it, but not trying to think of it that way.” Karen

When Karen began to ‘*put her affairs in order*’, the situation also became more ‘*real*’ for Laura who ‘*recognised*’ that she would be taking on some of her Mum’s roles after her death:

“It’s the realisation - I’m going to get upset now and I don’t want to. Like it’s the realism that mum’s not going to be here forever, sorry. Because of like all the affairs and stuff... Yeah, but

I think that just comes from like the sorting out of affairs and stuff like that, that's quite real, that's scary." Laura

Others began to plan for an increasingly inevitable future:

"I've been talking to Sue while I was waiting for you about these funeral plans that you can go into beforehand." Irene

Despite the above participants still wanted to maintain an element of normality and to continue to enjoy their remaining time so that things like holidays became increasingly important. But owing to increased frailty or difficulties in getting holiday insurance changes were necessary here too. Differing kinds of holiday, such as visiting family, began to replace more traditional breaks, but this type of holiday was still enjoyable and also another manifestation of *'putting things in order'*:

"Yes, my other niece. I've just been for a week's holiday, well Wednesday to Sunday. Yeah, I went for a holiday to stay with her and her two cats and a dog, yeah. Yes, we went about quite a bit. A lot more than I thought we would be doing because I thought I wouldn't be able to walk very far, but we did quite well really." Irene

Conversely, others were frustrated by their newly imposed limitations. For example, Karen's desires to go abroad were thwarted because of the difficulty she had getting insurance, much to the disappointment of Laura, who had saved hard for such a treat:

"My mum really wanted to go to Florida, to go to Disney again, because we went when we were younger, and obviously we can't go because insurance either doesn't cover it or is just ridiculous amount of money, and that really upset me, because I've saved up like three grand to take her, and I was like continually saving because I really wanted her to go, because it's something she wanted to do." Laura

Others, such as Phil, planned their holidays around their treatment regime and decided to take the risk and go without full insurance cover:

“But I mean I’m perfectly willing to stand the insurance. I’ve been open and honest with them, all they’ve said is we’re not covering you for any aspect of your illness. I mean we did Jamaica last January, we’d just done Norway on that basis. And I felt perfectly all right. But I mean everything is in four week blocks. Because like one four week block we’ve got the scans in between, so we can’t do it on that block. So this block is a clear.” Phil

As well as the effect of melanoma on ‘treats’ such as holidays participants also had to restrict their usual leisure activities, and sometimes families colluded to ensure this. For example Karen’s daughters had hidden her locker keys for the gym so that she did not do too much. For Phil the advanced disease meant he was not able to use his new bicycle as much as he wanted to and Luke’s gardening was restricted. Irene was able to maintain some of her usual activities with the help of Sue. As Sue describes below she was aware of her aunt’s need for a degree of closure with friends and was happy to help her achieve this, although it was painful for Sue as well:

“I think she wanted to fill as many blanks in her calendar as she could, you know, get as many people visited and just set her world to rights, you know. And I was quite happy to tag along with her, you know. I don’t think there was any of her friends that I didn’t get along with so it was quite nice in a way, although there was always that little note of I wonder when it’s going to be in the back of your mind.” Sue

In contrast to the others Sarah began to feel better while she was being treated for advanced melanoma and planned to start going back to her usual activities and looked forward to a more positive future:

“I feel well in myself, I feel fine. Like after Christmas I’ve looked into going to the gym and getting a personal trainer, and I’ve told them all about my situation and they can help me do that. And they’ll give me support with my leg and stuff. So I’ve said [this] is going to be my year. I’m going to get my results, I’m going to go to the gym, get healthier and just go from there. It’s like I’ve already made plans, because I feel all right in myself, I don’t feel poorly.” Sarah

Despite Sarah's optimism others began to increasingly 'recognise' that time was perhaps limited and some, such as Irene, began to pass on what might be called their 'biographical legacy' to the next generation, as Sue recounts below:

"We were doing a bit of family history storytelling. She was telling me about who was who, people that I've not met, obviously they'd passed before I'd been born, but she was telling me who they were, who they were related to, little stories about them. We've had some good days." Sue

Karen, whilst wanting to spend time with her family, also began to do things that she had wanted to, rather than putting them off for another day, knowing that time was of the essence:

"But latterly however, I have a new folder of things that I've planned to do. Not a bucket list but things that, I'm probably a little bit more impulsive as just booking something. Like we chat about doing something, and before we'd talk each other out of it or I'd talk myself out of it and think oh we'll do another day. But I don't do that." Karen

Despite Sarah's new found optimism she also started to make preparations for her children, to enable them to be cared for together should she die:

"We went to the cancer support centre and I met someone, like a lawyer wise. Because my Dad said he'd always take over all three of them, he'd carry on as normal... That's the only thing what's not got sorted, something in writing to make sure they're together." Sarah

The perceived need to "put their affairs in order" occurred throughout the melanoma experience with a varying sense of urgency, but this became more pressing when faced with the news that treatment was no longer working. The 'hope' that patients and carers had sought to maintain was reduced and they had to decide how to spend the limited time that they had left. Many of the patients were not well enough to take part in interviews by this time, but Karen and Laura were interviewed shortly after finding out that Karen's treatment was not working. They both partly expected the news but it was nevertheless a difficult time, described as the

'strangest' moment in their melanoma experience, which left them both unsure what to do and say:

"When we got the results, we went to [a café]. And it was, it was really quite a surreal moment, because everything feels in fast forward around you, and we were just sort of sat there staring at each other. And we didn't quite know what to say to each other..." Karen

"Which doesn't happen with me and you, because we just talk about anything and everything, it was hard. It was weird wasn't it?" Laura

"It's been the strangest moment I think in all of this, was just sat eating and trying to talk about normal things but thinking oh what's the point, we'll just sit here and then that's it." Karen

"Yeah, first time in a long time I've not known what to say." Laura

As patients and carers began to "put their affairs in order" there was an increasing 'recognition' that this was in preparation for saying goodbye to one another. This understandably raised a variety of emotions including anger and sadness as Laura and Esther describe below:

"But I am really angry that she's had to have this, because she doesn't deserve it. And the stuff my mum's been through in her life, like this is just not fair, like she didn't deserve it. And I don't think the family deserves it either, like I don't think I deserve to lose my mum at 22 years old, that's not fair. But that's quite a selfish way to look at it I guess, but no, I do get angry." Laura

"And I spent so much time telling him how much I loved him. And when I did he'd look at me and then he'd just sort of stroke my arm. But it was hard losing him before he'd gone really, that was hard, because he was a big softie." Esther

A number of those left behind decided to continue to contribute to the study and to share their experiences with me.

8.7 BEREAVEMENT

"So again I've had to think ahead as to how do I plan my life now because it's empty." Esther

John's wife Esther and Irene's niece Sue wanted to continue to take part in the study after the deaths of their loved ones. Two interviews were conducted with Esther and one with Sue. They both also took part in a focus group at the end of the study. It is their experiences of bereavement that are explored here, showing how their 'roles', 'routines' and 'relationships' continued to change.

Below both Esther and Sue movingly recall their last moments with their loved ones and it seems that these were a time of understandable sadness but were also peaceful and reflective:

"Well only a year ago I was with his father when he died. I'm not frightened of people dying; I think it's a privilege to be with somebody when they die. And to be with him was the most natural thing in the whole world, and to be able to talk to him. And I didn't even ring the bell, I could see the breathing, it comes from the diaphragm, I knew what was happening. And I thought I'm not going to call anybody, I don't want anybody here, I know what's happening. And so I waited until he'd finally breathed his last, and then I rang the bell. So we had that time, but he wasn't with me, he was on the morphine by that time. At least he was quiet."
Esther

"But she was content, she wasn't upset or frightened or anything like that, she was quite content when I left her. And I knew that she was going to pass, I just, I don't know, it's just a sense, you know, I said goodbye, because she was laboured with her breathing a little bit and I'd said to her, because she was a tiny bit worried about it and I said if you relax, I said and just drift off to sleep you'll feel better because your body will all relax. And she closed her eyes and I'd kissed her and that and so it did calm down. But then when I was going I kissed her on the forehead and she felt different so I knew that she was going." Sue

Afterwards the inevitable grief began to have an impact. For Sue this seemed to happen almost immediately, whereas Esther, who had lost her life partner, describes how she struggled to 'hide' her emotions so that they did not overwhelm her:

"And I went and by the time I got downstairs I think she had probably passed by then because I was just overcome and I cried all the way to my car." Sue

"I mean I'm weeping now, now and again, but I don't know, it's also a fear... Of letting go too much and not being able to scramble back again. It's so deep the grief, I might just lose control and not be able to fight my way back. So my grief has to be measured, and crying at

night and sobbing, and then say right come on, pull yourself together, it's another day, get over it. So it's all, I mean you can see, I go like I've got to scramble back." Esther

Both Esther and Sue had invested a great deal of themselves in their caring role and they had not only lost their loved one but also a role that had played such a prominent part of their lives over recent times. However despite all she had done Esther questioned whether she could have done more and this added another layer to her grief:

"I'm not resentful at all of any of the time; I wish I could have given more. It's difficult isn't it, it just felt totally normal. Whatever you had to do you would do for somebody you loved. You do it for your children; you do it for anyone you love.... still the same things going on and on in your mind of I should have done this, I should have done that, I should have said this, I should have been there for that, all that running through my mind for 10 days just made me desperately unhappy." Esther

Sue, however, had spent a great deal of time with her aunt in the period immediately prior to her death and had been able to help her achieve a sense of inner peace.

"So, in a way I feel privileged that I've been able to spend those last few weeks with her, because we did talk about so many things and I know she was quite content, she'd put everything to rights that she needed to, there was nothing that she wanted to do or no regrets. The only thing that she'd said that she wished she'd been a bit less shy, because she was when she was younger apparently quite shy and she felt that she could have done more with herself, but other than that no regrets. I think that's quite nice to be able to look back like that, isn't it? Not many people get the opportunity. And it was a lovely funeral as well, as funerals go." Sue

For Esther the loss of John was felt acutely as she began to 'recognize' that they were no longer an 'us' and this is captured below as she describes her on-going 'relationships' with their children and grandchildren:

"Suddenly something that I had shared with John that was an 'us' thing with our eldest son and family out there, suddenly it was just me and there wasn't some, wasn't this body next to me to share it with, to discuss things. Even the babysitting type of thing, it's harder with two kids just on your own." Esther

In the midst of this sadness there was however still *'business'* to complete and Sue, for the first time, saw her role as a form of *'work'* rather than as a labour of love. The ongoing emotional impact of this is captured eloquently below:

"Instead of it (Irene's house) being a place where I'd go to either socialise, do little jobs, familiar type jobs, it became almost a place of work because we've been going and emptying cupboards, packing stuff up and then we've been having to have, because the family is far flung, we've been photographing and sending pictures of stuff to say, look, these are things that are available if anybody wants them, rather than just getting rid of anything and then people being, oh where was so-and-so, I wanted that? So they've all had their fair chance, so we've almost worked there shall we say, off and on, but we've not been able to do more than a couple of days a week because it's just so emotional. You come home and you're absolutely drained." Sue

For Esther, there was a more urgent need to attend to practical and financial affairs as John had deteriorated quickly and there hadn't been time to do anything beforehand. John's death also had a more immediate impact on Esther as she now had to move out of their home, adding another layer of loss:

"I don't think I'm anywhere near really being able to get used to the life without him, it's a totally different life it's going to be. So it's something I have to find my way, I have a lot of very big practical issues I have to contend with, and that's what I have to be strong to do. Moving from here. I have to move, it's too big here, it's too remote, it's a huge garden, going out the back as well. Finances, everything, big challenges ahead. So it's not just the emotional side of getting used to being without him, it's having to be practical. Not just with this but there are other things as well I have to deal with." Esther

Losing her husband also meant that Esther felt that other people saw her in a new role as a widow. She noticed this more when completing documents and being asked for her marital status. Esther did not want the title and the assumptions that she felt other people made about her. After years of being seen as part of a couple, Esther felt the loss of the *'relationship'* with her husband and began to *'recognise'* how this had in large part defined who she was:

"But you do, you're no longer parents, you're a parent, I'm a mother, the mother-in-law, little old lady on her own, little old widow. It's a funny place to be, strange place." Esther

Although grieving, Esther felt that she had to “*be strong*” for her immediate family. This meant ‘*hiding*’ some of her emotions from her children as she did not want them to feel upset. However this meant that she had to shoulder much of her grief alone:

“I feel I have to be strong because I have to survive, and because my children want me to be strong. And they want me there for the grandchildren, and I’m the strong one. Oh mum, you’re so strong. I think if only they knew I was sobbing in my room.” Esther

This grief also impacted on her ‘*relationship*’ with her friends as Esther felt that if she cried too much in front of people, it would make them feel awkward and so whilst acknowledging her sadness she did not want to burden them with her grief in case this in some way drove them away. Esther showed a remarkable degree of insight and sensitivity in the way that she ‘*recognises*’ and ‘*responds*’ to the changing ‘*dynamics*’ of her ongoing ‘*relationships*’:

“And so the dynamics of your life change. The way people, I wouldn’t say see you, that’s slightly different, but you’re very aware of how the dynamics change. You’re no longer a couple, that’s the first thing. Luckily still friends invite me and that’s all fine. I have invited people too. I had six for dinner on Sunday to try and get them to not be frightened of me in a way, and whatever my grief is. Because I think people are quite nervy about how you are and how you’re going to be. There’s a caution. I have one friend who as soon as I say John she bursts into tears. Which I then go and say it’s all right, it’s fine, don’t worry about it - because she is so soft, so gentle. But you see people are afraid of their own reactions somehow. I’ve heard stories of people crossing over roads and things, nobody’s done that to me but some people have told me that people avoid rather than having to confront.” Esther

It was quite humbling for me to realise that it was only in the context of her participation in the study that Esther felt able to share the full extent of her feelings with someone else. This is something that will be considered further in the discussion. Neither, Sue or Esther had accessed any bereavement support and did not say that any had been offered. However during the focus group CNSs recognised that carers may need support during the grieving period; that they may have questions that needed answering as they tried to make sense of what had happened.

“And sometimes supporting families after patients have died as well, I think we do that as well. So that they, although the patient may no longer be there the carer or partner that’s been

coming with them we still, because you've had that relationship with them for a few years and they still want to talk to you about things. And I think that that's nice from our point of view to be able to be there to support them through that difficult time as well. Fortunately for me it doesn't happen very often." Pat, CNS

For Sue the process of sorting her Aunt's possessions meant that she needed to contact wider family members, which she found, brought them together:

"But it was interesting that people that normally wouldn't have talked a lot to each other, because we've got quite extreme differences in personality in our family and some of the people that wouldn't normally talk were actually sitting talking, because we'd taken photos, she'd sorted photographs out had Auntie Irene and there was a little bundle for each member of the family, each of the cousins. So we'd taken those and given them to people at Christmas and so everybody was looking at the photographs and saying, oh, look at this and so on, and I think that's probably why people were talking more. It was quite good in that respect, but a bit sad in another respect, because then all our parents that are now passed they were all in these pictures, so everybody was a bit choked and it was very emotional, but we enjoyed it." Sue

The prolific impact of bereavement meant that daily 'routines' were altered for both Sue and Esther but more so for Esther owing to the nature of her 'relationship' with John and the huge part it had played in shaping her identity. This was 'recognised' by her family who tried to help her reshape her life, by making apparently superficial but nevertheless important changes:

"[My eldest son] was fantastic. He came and he did very clever things I have to say while he was here. He changed the bedroom completely. We have two single beds pushed together, and he took the one bed away. He took that single bed and put it into the smaller room. Took a double bed from another room, put it in there, moved the furniture around, and he said you'll use the room now. And he was right. I haven't for a while really because John was so sick. But the fact is it's made it different, so he did that. He did the garden. He did all the things that I couldn't do. And [my youngest son] was helping with the same thing, and he was with me one week, and then [my eldest son] was with me another week, so between them they really did a lot. But he had to go back to Australia, and [my youngest son] has to go back to work and he's got a new baby who's only three months old. So all this happened with a new baby. Poignant isn't it?" Esther

8.8 SUMMARY

As the accounts above have shown the *'rollercoaster'* continued to have *'ups'* and *'downs'* after the diagnosis of advanced disease, with such a diagnosis being one of the major *'downs'* that participants experienced. However, new treatments became available during the study and this provided a sense of renewed *'hope'* for some. Responding to these new treatments, living with advanced disease and the growing realisation that death was a possibility had further significant impacts on participants' *'routines'*, *'roles'* and *'relationships'* both with family members and HCPs. *'Sharing'* and *'hiding'* continued to play an important role in mediating such *'relationships'* during a time of increasing uncertainty which involved participants trying to maintain *'normal'* activities as far as possible while also preparing to say goodbye to one another.

For some the death of the patient meant further changes to the *'roles'*, *'relationships'* and *'routines'* of surviving family members, who could struggle to deal with their grief with minimal *'resources'* to do so. This is something that will be considered further in the Discussion chapter that follows.

As has been noted at various points the primary aim of the study on which this thesis is based was to better understand the experience of living with melanoma from the perspectives of patients, their primary carer and the HCP that they identified as being the most influential. It was hoped that the insights gained would result in the development of a mid-range substantive theory with the potential for practical application in order that the melanoma *'journey'* could be improved for those who might embark on it in the future.

Analysis of the extensive volumes of data collected, revealed a complex and multifaceted picture, with each *'journey'* having both shared and unique elements. In developing a theory that captured such complexity, but could also be easily understood by multiple audiences, some of this individual variation was necessarily lost. At the start of Chapter 6 I provided a brief overview of the substantive theory that I, and the participants, believed provided a faithful rendering of the major milestones experienced by those living with melanoma and the impact that it had on them. It is this that has been elaborated upon in the preceding pages.

Consistent with the temporal approach underlying Grounded Theory this account of the *'melanoma journey'* comprised a number of stages captured by the metaphor *'Riding the Rollercoaster'*. This reflects the various *'ups'* and *'downs'* that participants experienced during their *'journeys'*, and whilst the nature of these understandably varied, as did the final outcome (for example between participants with fatal metastatic disease and those who achieved cure), all those who took part experienced both *'ups and downs'*.

Based on an analysis of their accounts the melanoma experience was described as comprising of the following key phases or *'moments'* :

- What's that mole?: Pre-diagnosis
- The Melanoma journey begins: Diagnosis and early treatment
- Ups and Downs: Surveillance
- The 'Bombshell': Advanced Melanoma, and for some, death

As has been described not all participants experienced all phases (for example metastatic disease and death) but all were experienced by some. In working through these various stages participants' lives underwent a number of changes brought about by the impact of the

melanoma, and the nature of the interactions between patients and carers and their contact with the health care system. These changes and the processes that accompanied were captured in the theory by using an alliteration of '**R**'s, which reflect the impact of the melanoma on the participants':

- **R**outines of daily life
- The **R**oles that they fulfilled, and
- Their **R**elationships with each other and the health care system

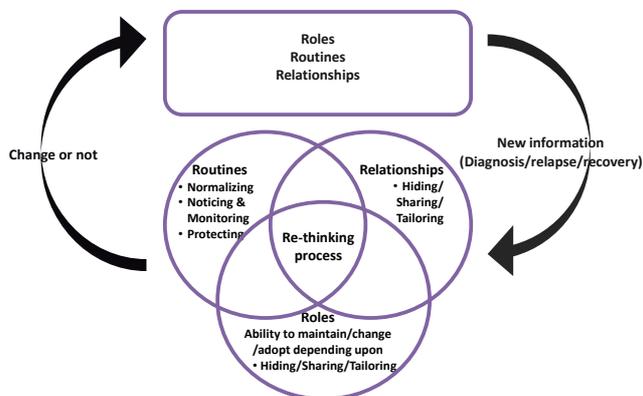
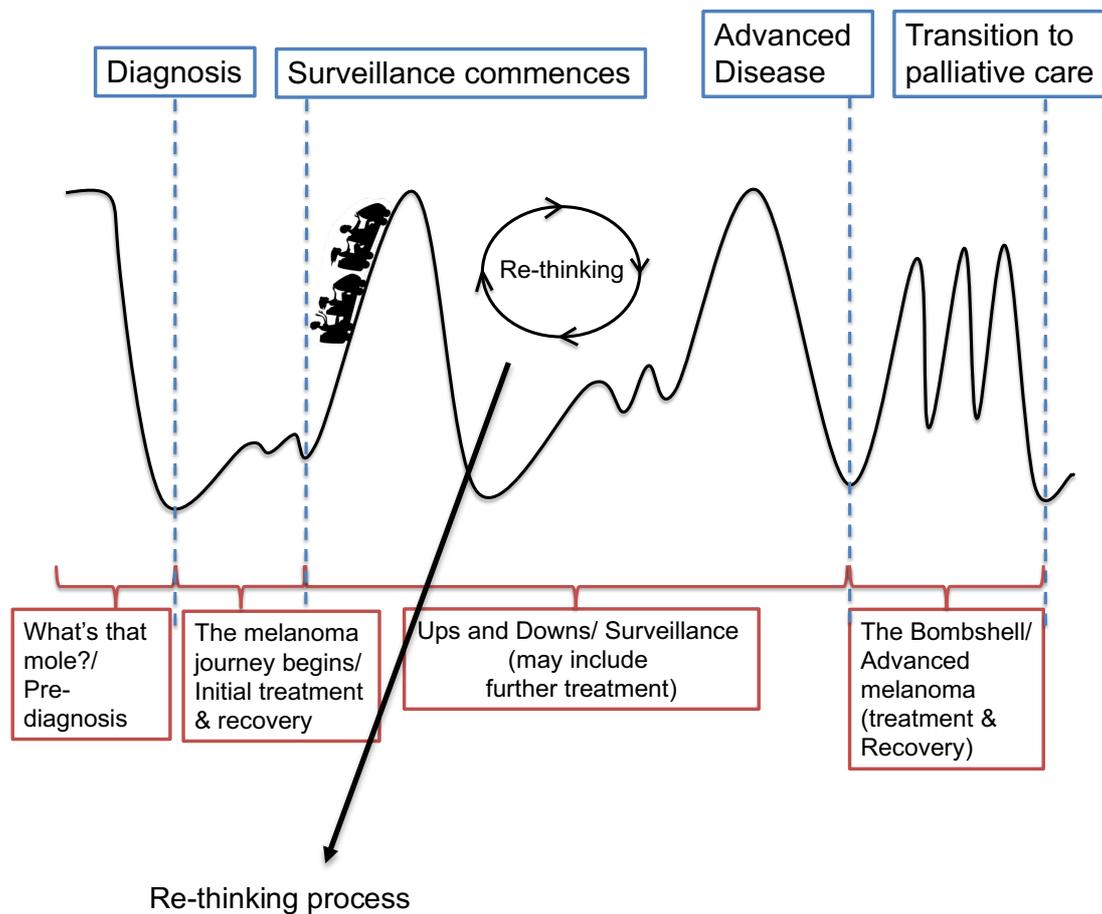
These impacts were mediated by the ways in which participants **R**ecognised and **R**esponded to the challenges that they faced and the **R**esources that they could draw upon in so doing.

The phases of the melanoma rollercoaster are shown in Figure 8.1 along with the transition points between these phases where the greatest effect on patients' and carers' '*roles*', '*relationships*' and '*routines*' are seen. While not illustrated on the diagram, there is a further transition point for carers upon the death of the patient into bereavement. Throughout the rollercoaster patients and carers experience a constant process of re-thinking their '*roles*', '*routines*' and '*relationships*' as they are presented with new information. New information may take many forms such as a new mole or lump, treatment, recovery, the presence or absence of side-effects or symptoms, scan results or physical examination findings. Re-thinking '*roles*', '*routines*' and '*relationships*' involves the key social processes of '*normalizing*', '*noticing*', '*monitoring*' and '*protecting*' which underpin '*routines*' and '*sharing*', together with '*hiding*' and '*tailoring*' which underpin '*relationships*' and '*roles*'. There is however, overlap between these processes as they do not occur independently of one another.

Of the transition points between phases of the rollercoaster, diagnosis (being told that it is melanoma/cancer), advanced disease (that the aim is control rather than cure) and the

transition to palliative care (where there is no more treatment available) are key points where new information has a profound impact on 'roles', 'routines' and 'relationships' for patients and carers.

Figure 8.1: Riding the melanoma rollercoaster: a Mid-range Grounded Theory



The transition between initial treatment and surveillance is not always obvious as patients with small lesions may have their treatment completed before their diagnosis is available as the whole lesion is removed to gain the diagnostic information. Other patients, however, may require multiple surgeries possibly with other treatments before a more definite progression to surveillance at the end of treatment. This transition may therefore be experienced differently depending upon physical disease indications.

Prior to diagnosis '*noticing*', '*monitoring*', '*normalising*' and '*protecting*' were the main processes. Where the lesion was obvious, sharing rather than hiding took place as carers or family members encouraged patients to seek medical advice.

After diagnosis the process of '*hiding*', '*sharing*' or '*tailoring*' the new information had an effect on the resources available. An example of the impact of the '*hiding/sharing/tailoring*' process is the choice made by participants to share or hide their diagnosis from work colleagues. Participants were supported in the workplace emotionally or physically but only after '*sharing*' the information. The process of '*sharing*' was a pre-requisite to gaining supportive relationships as a resource to maintain occupational roles. This also applied to family and leisure roles where '*sharing*' information within family and social circles meant that supportive relationships were available as a resource to help maintain roles, even if these were modified. '*Protecting*' primarily related to sun-protection behaviours which may also impact upon '*roles*'. '*Noticing*' and '*monitoring*' and to an extent, '*normalizing*' continued but these processes were directed towards healing and recovery and the absence or presence of any new symptoms. Where suspicious lesions or new melanomas were removed during surveillance, this new information was fed into the process of re-thinking '*roles*', '*routines*' and '*relationships*' and having surgery may even have become a new routine along with attendance for surveillance visits and scans. Diagnosis was a critical point for '*relationships*' with HCPs to be built and

where these occurred, they became a major resource for patients and carers. Diagnosis formed the first major 'down' of the *'rollercoaster ride'* as it was perceived as a rapidly occurring, negative event. Recovery from this 'down' was a 'slower ride' as patients and carers made changes to *'roles'*, *'routines'* and *'relationships'* in light of the melanoma and treatment. Surveillance then comprised a number of 'downs' and 'ups' as patients experienced anxiety and relief during scans, examinations and where indicated lesion removal.

Progression to advanced disease was the next major 'down' of the riding process as this was a further negative event that again meant re-thinking *'roles'*, *'routines'* and *'relationships'*. Sharing facilitated the availability of Resources, but hiding or tailoring were often motivated by the desire to protect others. The focus of noticing and monitoring shifted towards the effects of treatment and symptoms related to melanoma. Carers' roles began to take on a noticeable change as they undertook more elements of physical caring. Once again the resources needed to maintain roles depended largely on information being shared. *'Relationships'* with HCPs again were an important resource as new information was needed. The 'ups' of the rollercoaster during advanced disease were experienced when the melanoma was controlled and roles could be maintained, albeit with modifications. The 'downs' came when the melanoma was no longer controlled by treatment and impacted on *'roles'*, *'routines'* and *'relationships'*. In some instances further recovery and the next 'up' of the rollercoaster came with new treatment.

When treatment was no longer an option and palliative care became the focus patients and carers experienced the next steep 'down' in the *'melanoma rollercoaster'* as this further negatively impacted their *'roles'*, *'routines'* and *'relationships'* which then required further modifications. HCPs were a continued source of emotional support and information. However, where good Relationships had been developed, these were difficult to end where a transition

to a different service (for example community care) was required. Carers' Roles continued to change as the physical aspects of caring were needed more and they often relied upon other Relationships as a Resource to allow them to do this.

The Theory of riding the melanoma rollercoaster is therefore made up of phases with transition points, but throughout the rollercoaster patients' and carers' Roles, Routines and Relationships are mediated by the processes of sharing, hiding and tailoring and noticing, monitoring, normalizing and protecting.

The next, and concluding chapter, will consider the extent to which the study's aims have been met and address issues of rigour and reflexivity. The potential contribution of the findings to a better understanding of the melanoma journey will be explored and the thesis will conclude with recommendations for policy, practice, education and further research.

9 CHAPTER 9: DISCUSSION & CONCLUSIONS

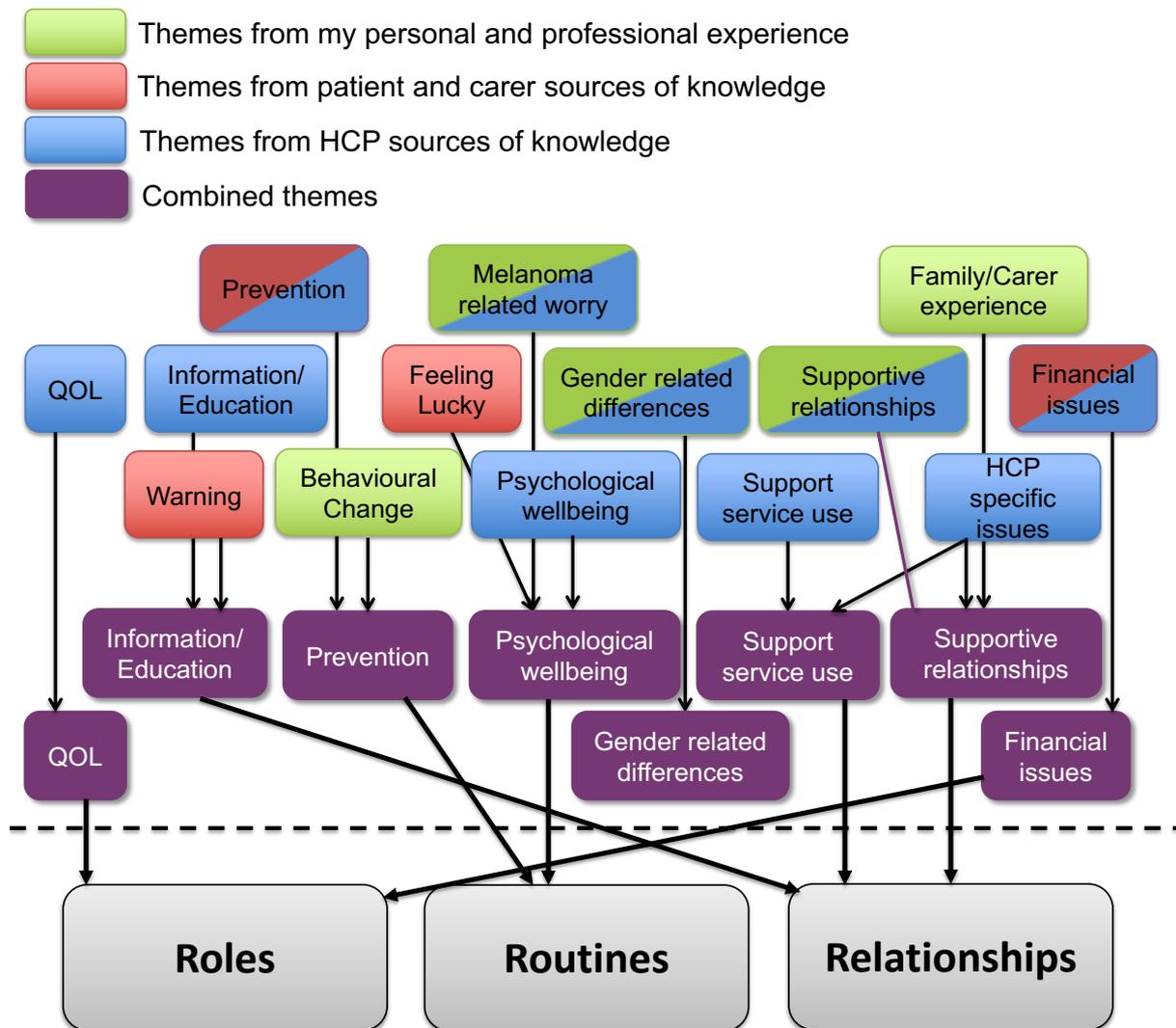
Having explored the study results in depth in the preceding chapters, the final chapter seeks to; consider whether the theory addressed the initial foreshadowed questions that informed the study at the outset, address issues of rigour, reflexivity and the limitations of the research, discuss how the study contributes to a better understanding of the melanoma experience, and suggest a number of implications for policy, practice, education and further research.

9.1 HOW WELL DID THE STUDY ADDRESS THE FORESHADOWED QUESTIONS?

The primary aim of this study was to explore the changing experiences and support needs of patients with melanoma and their carers throughout the disease pathway. I will discuss the ways in which the research contributes to a better understanding of melanoma later in this chapter with reference to how melanoma is experienced over time. Here I consider how well the study addressed the initial foreshadowed questions and the ways in which the findings reflected (or not) the themes identified as part of the review of existing knowledge as presented in Chapter Three.

The initial foreshadowed questions were derived from a distillation of the current understanding of the melanoma experience derived from three main sources: patient/carers research and personal accounts, the professional and research literature and my own prior knowledge. Figure 9.1 below shows which themes generated from this synthesis were reflected in the interview data. From this it is clear that only one theme, gender-related differences, did not emerge as an influencing factor in the participant data so this was not carried forward beyond the review stage. All other themes were represented in the data to some extent and influenced to a greater or lesser extent the complex interactions between Roles, Routines and Relationships and their underlying processes.

Figure 9.1: Themes from the literature review seen in interview data



The ways in which the aspects of 'roles', 'routines' and 'relationships' play a key role in the resultant Grounded Theory were illustrated in Figure 8.1.

I now consider how the study addressed each of the foreshadowed questions individually.

- How do patients and carers experience melanoma, and what impact does it have on various aspects of their lives such as QOL, psychological well-being, their

worries and concerns and their financial situation?

The study suggested that patients and carers experience melanoma as a *'rollercoaster'* comprising a number of physical and emotional *'ups'* and *'downs'* that vary over time. Although the impact of living with the disease on patients'/carers' QOL was not specifically discussed there is no doubt that it affected their psychological well-being in a number of ways. Many of these were negative, with there being numerous worries and concerns about, for example, the effect of the melanoma on: their body image, their ability to maintain valued *'roles'* and activities (including work and consequent financial worries for younger patients) and in some cases, worsening *'relationships'* with family and friends. One of the major concerns related to fears that the melanoma would return. These feelings capture some of the *'downs'* of the melanoma *'rollercoaster'*. However, impacts were by no means all negative and some participants described improved *'relationships'* and an enhanced realisation of what matters in life.

For the first time this study made a detailed exploration of the melanoma experience from the perspectives of both patients and carers and charted how it impacted on both groups. The roles of carers as an essential *'resource'* supporting patients with melanoma emerged, as did the various struggles that they faced throughout the journey. Whilst there was some recognition of the challenges carers faced there was often very little tangible support for them from the healthcare system. Some of the implications of this will be considered later.

- How do these experiences and impacts vary over time?

The theory suggested that the melanoma experience can best be understood as comprising a number of stages or *'moments'* beginning with the pre-diagnostic phase, through diagnosis and early treatment, surveillance and for some, advanced disease and

death. Whilst these stages were not discrete or clear cut they did mark major transition points for patients and carers. The ways in which the impact of living with melanoma varied over time was described in detail in the preceding chapters which identified impacts on *'routines'*, *'roles'* and *'relationships'* and highlighted how these varied depending upon how patients and carers *'recognised'* the need to act, the *'responses'* that they evoked and the *'resources'* that they could draw upon. Key processes such as the *'hiding'*, *'sharing'* and *'tailoring'* of information; *'noticing/discounting/normalizing'* and *'monitoring/protecting'* occurred to a greater or lesser extent throughout the melanoma *'journey'* and helped to explain the varying impact that the disease had over time. However, probably the most important factor in shaping individual experiences of melanoma was the nature and quality of the *'relationships'* between patients, carers and HCPs.

- Do patients and carers make changes to their lives as a result of melanoma?

As described briefly above, and elaborated upon in the findings chapters, patients and carers made numerous changes to varying aspects of their lives especially in terms of their day to day *'routines'* and more widely to the *'roles'* that they saw themselves as fulfilling. Such changes could be temporary while the patient recovered from treatment but in many cases were more permanent.

The complexity of the treatment regime often meant frequent visits to hospital and this inevitably impacted on the daily routines of both patients and carers. Work could be disrupted for both patients and carers and in many cases the patients' ability to undertake previously taken-for-granted activities was compromised. Family members in particular often had to move into a more noticeable caring role, especially for patients with advanced disease. *'Monitoring'*, both overtly and covertly, became an important new *'routine'* for most participants, as did changes in their *'relationship'* with the sun. This could have a

wider impact on previously treasured activities such as taking holidays abroad. For others a deterioration in their physical abilities meant restrictions to hobbies and leisure activities.

Melanoma also resulted in more fundamental changes to important roles, including occupation, with some having to give up or change their jobs. The taking on of a more noticeable caring '*role*' was identified above. However, probably the most significant change for many participants occurred in their '*relationships*' with those they were closest to. These changes were most often a result of the '*sharing*' and '*hiding*' processes identified in the theory and these could result in relationships becoming closer or more distant.

- Are patient and carer experiences and impacts influenced by factors such as gender, information and education, the nature of supportive relationships and the support services accessed? What are their experiences of the latter?

Neither gender nor education, in terms of prior educational achievement, appeared to have a major influence on the experience of melanoma. It should be stressed that these aspects were not explicitly explored as they were not raised as issues by the participants. Even if they had been, it is unlikely that the sample size would have been sufficient to allow a detailed consideration of the impact of such factors.

However, the impact of information and education about melanoma was significant for both patients and carers. The type of information that was given, the form in which it was provided and when it was made available were all important. Some participants felt that they had either been given too little information, or that what they had been given was too complex. Most struggled to '*take in*' the information that they were given, especially around

the time of diagnosis. Some carers felt that they were better placed to *'make sense'* of the information provided but no information, either about the disease or their own role, was specifically given to carers. Paradoxically some patients chose to limit the involvement of carers and might *'hide'* information from them. Consequently the extent to which carers were fully involved depended largely on the *'sharing'* and *'hiding'* activities that both parties could engage in.

Such activities were pivotal as supportive *'relationships'* were central to the experience of patients and carers with most people turning to their existing social networks (including family and friends) for support. For those with a limited social support network, interactions with HCPs were particularly important, but the supportive role of HCPs was of great significance for the vast majority of participants. HCPs were a key *'resource'* providing not only information and clinical expertise but also emotional support. However, participants' experiences varied. Many established a close *'relationship'* with a particular HCP, most often a CNS, and in the best circumstances this relationship started early and could last throughout the melanoma *'journey'*. Participants valued an HCP who was approachable and made themselves available, thereby establishing a *'relationship'* built on trust. Unfortunately, some participants had poor initial contact with HCPs, for example if an HCP did not deliver on an arranged meeting or telephone call. In such circumstances trust was rapidly lost, sometimes never to be regained.

- Do the experiences and perceptions of patients, carers and health care professionals vary?

The theory clearly indicated that many of the experiences of patients and carers were *'shared'* and therefore in most instances melanoma could not be understood as a solitary *'journey'*. Differences in the perceptions of patients and carers did of course emerge and

the theory hopefully highlights such differences, often owing to the subtle interactions between '*sharing*' and '*hiding*' behaviours.

The situation with respect to HCPs was a little different. They primarily viewed the melanoma '*journey*' and their role in it in terms of the care pathways prevalent when the study was undertaken. These mainly related to the major treatment milestones. These were of course important aspects for patients and carers as well, but their concerns were often wider and their need for support was not confined to those periods prescribed by the care pathway.

That said the best HCPs were attuned to patients' needs and sought to address them as best they could but their efforts could be constrained by resource and time restrictions. Moreover, it must be remembered that the HCPs who took part in the study were, almost by definition, providing good support as they had been nominated by patients primarily on that basis. Even then a number of HCPs that were nominated did not respond to my invitation to take part. The fact that several participants failed to nominate an HCP also highlights that good support was by no means universal. In particular the support needs of carers was not always explicitly recognised by HCPs who focused primarily on the patient.

- How can the experiences of patients and carers and the impact of melanoma be improved?

This will be considered in detail when the implications of the study are discussed later in this chapter. Before attempting this it is essential to establish if the theory arising from the study, and the manner in which the study was undertaken, were sufficiently robust.

9.2 RIGOUR

In Chapter Four I considered the possible approaches to judging both the *'quality'* of a Grounded Theory and the extent to which the Constructivist Grounded Theory methods I applied in the study ensured meaningful engagement with the participants. Below I explore the quality of the Grounded Theory that emerged from the study using the criteria set out by Charmaz (2006, 2014), before establishing the extent to which the study engaged with participants using the Modified Authenticity Criteria proposed by Nolan et al. (2003).

For Charmaz (2006) the quality of a Grounded Theory is best considered with reference to its credibility, originality, resonance and usefulness. I will now consider the extent to which the Grounded Theory described in this thesis can be considered to have met these criteria.

9.2.1 CREDIBILITY

Credibility is established by a combination of the researcher's familiarity with the subject, whether the data support the theory and whether the reader is able to form an independent assessment of this.

My familiarity with the setting and subject of melanoma has been transparent throughout the research process. Indeed, it was my clinical involvement as a Research Nurse that led me to initially explore the experience and support needs of melanoma patients. My prior clinical experience meant that I was very familiar with the subject but this could have resulted in me making *'taken for granted assumptions'* about the experience of living with the condition. I therefore tried to make the potential influence of my clinical role and other prior experience as

transparent as possible in Chapter Three. Further attention will be given to this later in the section addressing reflexivity.

In Chapter Four I also tried to demonstrate how the data were co-constructed with participants through repeated interviews and diagramming. This enabled a range of data to be collected over the course of the study, and the use of longitudinal interviews allowed for an explicit exploration of the temporal dimensions of the melanoma experience. I made numerous efforts to involve the participants as fully as they wished both in making sense of the data and ensuring that they felt that their story had been told. Engaging with participants over time enabled me to clarify meanings at subsequent interviews, and allowed categories to be co-constructed facilitating consensus on the final theory.

The large volume of data supporting the theory cannot be presented in its entirety but the excerpts selected for inclusion in the results were chosen to represent a variety of observations and ensure the voices of all participants were heard, even though there were significantly larger amounts of data from some participants compared to others owing to the varying number of interviews conducted with each person.

On this basis I believe that the important tenets of credibility have been met and trust that the way in which the results and the theory have been presented will enable the reader to reach a similar conclusion.

9.2.2 ORIGINALITY

To the best of my knowledge at the time of writing this thesis, this work comprises the first longitudinal qualitative exploration of the experience and support needs of both patients with melanoma and their carers. As highlighted earlier the experiences of carers of people with melanoma had hitherto not been systematically explored. Part of my motivation for undertaking this study was the lack of ‘*evidence*’ concerning the support needs of melanoma patients and their carers and the overreliance on quantitative methods and standardised measures of outcome, as reaffirmed in recent considerations of research relating to melanoma (NICE 2015). The very limited attention given to carers’ needs remains a major omission. On the basis of the above I feel that the study within this thesis can be said to be original.

Furthermore, if we consider the additional criteria suggested by Charmaz (2014):

- Are the categories fresh and do they offer new insights?
- Does the analysis provide a new conceptual rendering of the data?
- What is the social and theoretical significance of this work?
- How does the Grounded Theory challenge and extend current ideas and practices?

I believe that the categories I generated are fresh and provide new conceptual renderings of the data. The social and theoretical significance of the work and the extent to which it potentially extends current ideas and practices will be considered later.

9.2.3 RESONANCE

Resonance is concerned with whether the theory makes sense to participants, captures the fullness of their experience, reveals taken-for-granted meanings and draws links between institutions and individual lives. As has been described in some detail the theory was ‘*checked*’ with the participants on both an individual and a group level and all agreed that it made sense to them. Moreover, whilst it has already been acknowledged that no collective theory can

capture every individual nuance, there was also widespread agreement that the theory reflected all of the most significant events/experiences of the participants.

It is often not the *'convention'* to include new data in the discussion section of a thesis but being true to the constructivist principles underpinning this thesis I will let some of the participants *'speak for themselves'* in support of the resonance of the theory. I feel that Fred does this concisely:

"Well I mean a lot of this does apply to me, sort of new relationships, which I do share and we do trust one another, routines, the noticing and monitoring and protecting that applies to me..."
Fred

For Carol, certain processes such as *'hiding'* really resonated:

... I mean the hiding and everything, that you hide it, you hide it from your relatives, your close family to start with don't you." Carol

Resonance not only applied to patients but also HCPs. In addition to those who had participated in the study, feedback from other HCPs was obtained during the presentation of initial results at conferences and meetings. These HCPs identified with many aspects of the theory, particularly the importance of building *'relationships'* with their patients. However the need to also build such *'relationships'* with carers challenged some of the *'taken-for-granted'* assumptions that they had about their role.

During presentation of initial finding to the Yorkshire and Humberside Consumer Research Panel, which included members with melanoma but also those who had experienced breast cancer and prostate cancer, numerous people identified with several aspects of the theory, especially ideas such as the *'tailoring'* of information. In addition I have presented a number of the *'diagrams'* arising from the study at various conference and meetings (Sheffield

Innovation and Research in Oncology Nursing Meeting 2016, Sheffield University Academic Unit of Clinical Oncology Study Day 2016, British Association of Skin Cancer Nurse Specialists Conference 2018) as well as them being available on the website of the Yorkshire and Humberside Consumer Research Panel. These have proved to be a real stimulus for discussion amongst both HCPs and consumer representatives, with the idea of a 'rollercoaster' comprising the emotional 'ups' and 'downs' of the melanoma experience being particularly resonant.

9.2.4 USEFULNESS

Usefulness concerns how the theory may be used by others in their everyday worlds and how it has contributed to knowledge and further research. I consider this in greater detail shortly.

Having gauged the 'quality' of the theory according to Charmaz's (2014) criteria, I now consider the extent to which participants contributed to the research process in keeping with a constructivist approach. The Modified Authenticity Criteria suggested by Nolan et al. (2003) which include: Equal Access, Enhanced Awareness, Encouraging Action and Enabling Action were applied during the planning of the study, the process of undertaking the work and the final product. As was described in the methods chapter, this framework remains true to the principles underpinning the authenticity criteria as originally proposed by Guba and Lincoln (1989) but hopefully uses a more accessible language.

9.2.5 EQUAL ACCESS

Equal access is concerned primarily with the extent to which all participants have the opportunity to contribute to the study as fully as they would wish and feel that their views

are listened to and valued. It was originally termed 'fairness' by Guba & Lincoln (1989). In modifying this criteria Nolan et al. (2003) also considered it important that the results of the study are made as widely accessible as possible. This requires that they are made available in a wide variety of forms, using a language that is readily understood by a non-academic/professional audience. This is something that I tried to ensure throughout.

In the **planning** of this study, I consulted members of the Yorkshire and Humberside Consumer Research Panel (YHCRP) who had input into the funding application, project design, patient materials and ethics application. In Chapter Four, I noted the advantage of incorporating their views into the project so that a 'user' voice was integral from the outset. In addition when considering the foreshadowed questions I explicitly drew on as wide a range of prior knowledge as possible to counter the professional hegemony apparent in the usual notions of 'evidence'.

I have already described in detail the many ways I sought to fully engage participants during the research **process**, so attention is turned here to the **product(s)** of the study. To try and make the primary product of the study (the theory) as accessible as possible, I sought to ensure that it was written in a language and used ideas (concepts) that could be readily understood by the participants. I hope I have succeeded in this, and I feel that the endorsement provided by my participants gives confidence that I have.

The thesis is itself a further product of the study and it is here that the PhD student faces something of a dilemma: the thesis needs to be 'examined' by outside 'experts' and deemed to be worthy of the award of a PhD, whilst at the same being intellectually accessible to any participants, and others, who might want to read it. This is a delicate balance and one that I have worked hard to achieve. However to paraphrase a well-known saying 'The proof of the pudding will be in the reading'.

Lastly it is important that future dissemination of the work will ensure that it is widely accessible. I have already alluded to several public presentations of various aspects of the thesis and I intend to ensure that any further outputs are published as widely as possible in a variety of media including professional outputs as well as via my Patient and Public Involvement links.

9.2.6 ENHANCED AWARENESS (OF SELF AND OTHERS)

Enhanced Awareness of *'others'* and *'self'*, replaces ontological and educational authenticity in the formulation of Guba and Lincoln (1989). It is concerned with the extent to which taking part in a study (or vicariously by reading the results) enhances an individual's understanding of their own situation and/or the situation of others (Nolan et al. 2003). In respect of this study it primarily refers to patients, carers and HCPs, although as will be considered under reflexivity, it may also enhance the researcher's awareness. In terms of the chronology of a study, these criteria most likely apply to the **process** of being involved in a study. The data and participants' reactions to their participation suggested that taking part in the study enhanced peoples' awareness of their own situation and that of others.

During the **process** of data collection and analysis participants became more aware of their own situation and that of others. Jackie, for example, became more aware of her *'hiding'* behaviour, as the following suggests:

"I wouldn't say with things like hiding, I don't hide things. But then I wouldn't say I talk enough about it probably, so maybe that's classed as hiding." Jackie

Indeed for some participants the interview was the first time that they were enabled to, or had let themselves, talk about their feelings and so naturally new insights emerged. In addition where joint interviews took place with the patient and carer, each often became more aware of each other's point of view, especially if a degree of 'hiding' had been taking place. Although I was concerned that this might raise problems in relationships this didn't seem to be the case in most instances.

The interviews also gave HCPs an opportunity to reflect on their interactions with patients and carers and to consider how they might do things differently:

"One of the advantages of you doing something like this is that having it clearer makes us I guess look at what we're doing and how we're interacting and relating, and how we're listening and what we're hearing." Les, CNS

In the context of this study an enhanced awareness was largely a by-product of taking part rather than a specific aim. On the other hand as one of my main motivations for completing the study was to generate insights that would raise peoples' awareness of living with melanoma then it is to be hoped that the product of the study (theory/thesis/output) will result in enhanced awareness of those exposed to these outputs. To begin to achieve this, a summary of the results (accessible to all participants) has been sent to patients, carers and healthcare professionals who participated in this research (see Appendix 9) and plans for future dissemination have already been outlined.

9.2.7 ENCOURAGE ACTION

Encouraging action (which replaced 'catalytic authenticity') is concerned with whether the results of the study identify areas for change (Guba & Lincoln 1989, Nolan et al. 2003). When **planning** this study this was at the forefront of my thinking with the aim being to identify areas

in which the melanoma *'journey'* might be improved as informed by the participants' experiences.

During the research **process** patients, carers and HCPs reflected on their experiences and began to consider improvements. For example Tom's surgeon considered how improvements could be made to the patient and carer's experience by everyone working together:

"I suppose the question is what might help to change? maybe health checking and maybe talk and sharing. You know, I suppose there's, what can the patient do, what can healthcare do, what can the people around the patient do?" Ashley, Surgeon

Of course the ultimate aim is not only to encourage action but to enable it to happen.

9.2.8 ENABLE ACTION

Enabling Action (which replaces *'tactical authenticity'*) considers the extent to which taking part in a study or being exposed to its results actually facilitates or enables change (Guba & Lincoln 1989, Nolan et al. 2003). This study, unlike an action research project, was not intend to effect immediate change but it is hoped the results will lead to improvements in the care of patients with melanoma and their carers. This will hopefully be a major **product** of the study and in this respect it is closely related to whether there is *'equal access'* to the results as highlighted earlier. Action can only take place if key groups have the information and are aware of potential changes that could be made. I consider the potential for the results to encourage and enable action in the implications section which follows shortly and have already outlined plans to disseminate the results as widely as possible.

Having considered both the *'quality'* of the theory that emerged from this study and the extent to which participants were engaged in a way consistent with a Constructivist approach, attention is now turned to reflexivity.

9.3 REFLEXIVITY

As was discussed in Chapter Four reflexivity has, until recently, rarely been fully addressed in Grounded Theory. To begin to redress this deficit I decided to use the suggestions of Gentles at al. (2014) to frame my consideration of reflexivity. They identified four sets of issues that need to be addressed, these being:

- Types of researcher interactions that may influence the research
- Researcher influence during all stages of the research process
- How researcher influence is handled
- How researcher influence is viewed

Many of these were given consideration in Chapter Four but some insights are only possible when the study has been completed and I turn attention to these now.

Given my clinical background and that fact that participants knew I was a nurse the impact of this on the study is an important area of reflexivity. In order not to make '*automatic*' assumptions as to a participant's meaning I always '*checked*' these with participants, returning to seek extra clarification if meaning remained unclear. The use of a longitudinal design and repeated interviews greatly facilitated this.

In many respects the fact that I was a nurse enabled some participants to talk more openly about their situation and feelings, for as Sue said, '*You could talk about it because she would understand*'.

This openness came with responsibilities however as a number of participants were surprised at how much they had '*opened up*', especially some of the men:

“Yeah, I don’t know if I should be telling you all of this actually.” Tony

“I never talk about this, you know, I don’t know why I’m talking to you about it.” Tom

I always reassured people as to the anonymity of their stories and gave them the chance to have any sensitive issues removed. This option was rarely chosen.

Taking part in the research also encouraged some participants to talk more openly to each other about the melanoma. This had the effect for some of bringing melanoma to the front of their minds when they had previously chosen to ignore it, as Sandra explains below:

“I think we think about it more and talk about it more because you’re here and you’re asking questions. We don’t talk about it, and I carry on my normal life and I don’t worry. But when you’re talking about it, it makes you realise that yeah you do worry, it’s still there.” Sandra

This again required great sensitivity on my part but as they reflected on it participants often valued the renewed focus that the interview gave them and the opportunity to talk to a neutral but sympathetic person could be seen as therapeutic:

“I feel like I’ve got everything off my chest to be honest. It’s like it bottles up and then finally I talk and it’s like everything’s off my chest now.” Sarah

Most patients and carers found being interviewed together beneficial. Esther was pleased that John had spoken to ‘*someone else*’ about his experience and Carol and Jack felt that communication between them had improved as a result of the interview. However, during the focus group Jean admitted that divulging information during the interviews that she had not discussed previously with her partner had caused some tension between them. Clearly great care is needed as not all ‘*enhanced awareness*’ is necessarily beneficial.

Taking part in the research was also an opportunity for HCPs to reflect on their practice in a way that they may not otherwise have done. Many of them found this was a positive experience for them, as Lou notes: *'It's been quite good looking back on it really'*.

Interestingly, whilst I was very experienced in the field of melanoma, participating in the study as a researcher also had an impact on me, especially with regard to future research. Through using a Constructivist Grounded Theory method I have become aware of the contribution that patients and carers can make to the research process at all stages and now value this contribution more than prior to commencing the study. This has led me to consider how I might involve patients and carers in future research in a meaningful way. As a result of the study and the PhD Fellowship overall I have cemented my belief in the benefit of clinical academic roles in nursing and the need to actively involve patients, carers and fellow clinicians in the research process.

In addition to reflecting on my influence on the data collection process and its impact on participants, I need to make transparent my influence on the analysis of the data and the presentation of the findings.

The process of data analysis and the rendering of the *'results'* in constructivist research relies on creating a partnership between the researcher and participants at all stages (Charmaz 2014). This is something that I aspired to from the outset and I have tried to make this transparent throughout. Inevitably however there are some power differentials in evidence. For example, together with my supervisors I made the initial decisions regarding the direction of the study and the sort of questions I wanted to address. However, in doing so I tried to ensure that the patient/carer voice was explicitly included as described in Chapter Two. The

efforts I made to ensure patient/carer participation during all phases of the study have already been described and I can but hope that these were successful.

I feel in particular that the use of diagramming during data collection was particularly helpful in engaging participants. I drew on the work by Keady and colleagues (Keady et al. 2007a, b, Williams and Keady 2012) to inform my decision to use diagrams and whilst I did not use them within a life story approach they nevertheless proved very useful in helping many participants to tell their '*melanoma story*'. Even those participants who could not generate '*diagrams*' of their own responded very positively to the more professional '*artistic*' representation of the '*rollercoaster*', which has also proved very useful in stimulating debate in other arenas such as consumer engagement events. This is definitely an approach that merits further exploration.

Diagramming was particularly useful in capturing the definition of time and change for participants. Saldana (2003) notes that both time and change are contextual and key elements of longitudinal research. In this study the element of time is perhaps best captured by the metaphor of the '*rollercoaster*', which seeks to capture change '*over time*' as it was experienced by the participants. The '*rollercoaster*' seeks to identify the shared '*moments*' of the melanoma journey but at the same time to highlight variation over time depending of each participant's unique set of circumstances. The concepts of time and change were constructed by participants and the researcher together through diagramming and analytic processes. The '*ups*' and '*downs*' of the rollercoaster captured the events that marked the phases and transitions of participants' experiences. Where patients and carers drew their own rollercoaster and what they thought the other person's rollercoaster would look like differences in perceptions of time and the impact of events were seen. The rollercoaster, represented a '*journey*' made up of events that occurred in a linear fashion, but not all participants

experienced all events, phases or transitions. Longitudinal interviewing and repeated contact made the rollercoaster metaphor possible as it took two or three interviews for it to emerge and its significance in the data collection process to become apparent. Using the rollercoaster as part of data collection may in itself have influenced the data as it allowed participants to reflect on their experience in a particular way. It was during the focus groups that the collective experience of time and change emerged more clearly, giving participants access to a wider context and timeframe in addition to their own. Longitudinal interviewing also enabled changes to be seen, defined and placed within a temporal context. Without repeated contact, the development of the relationships between the various aspects of the final theory would not have been seen as they were, nor would the temporary or permanent nature of changes to participants' roles and routines. Diagramming therefore enhanced the individual, and collective constructions of time and change within the study.

With regard to the presentation of the thesis, I have already considered my efforts to meet the requirements of a PhD whilst also presenting the work in an accessible form as possible. It is for readers to judge the extent to which this has been achieved.

9.4 LIMITATIONS

Whilst every effort was made to ensure that the study was conducted in a manner consistent with the best principles of constructivist work some limitations are inevitable within the time and resource constraints of a PhD. The study was limited to the setting of a single teaching hospital and surrounding district general hospitals in the north of England. Furthermore limitations were apparent with regard to the sample of patients, carers and HCPs that participated. Patients were the primary access route to both carers and HCPs and these were largely self-selected in that they were willing to talk about their experiences. Many of the patients approached about the study declined to participate due to the time commitment

involved but others wanted to forget about the melanoma. This may well mean that the views of patients who employed certain types of responses to melanoma were not captured in the study. Carers were only able to take part if patients nominated them. This may well have resulted in only dyads who enjoyed a good relationship taking part, thereby excluding those whose relationship was fragile. HCPs taking part in the study were similarly limited to those nominated by the patients at their six-month interview or as soon thereafter as was possible. Interestingly nominations were confined largely to plastic surgeons or CNSs with no dermatologists or oncologists being identified. This may be because at the time of nomination the majority of contact had been with the two former groups whereas contact with oncologists and dermatologists happened at a later point in time. Patients with lower grade melanomas did not have contact with oncologists at all. Some patients also felt that they '*never saw the same person twice*' or did not establish a relationship with an HCP so no data were collected from HCPs at all. Moreover HCPs were nominated because they had a positive influence on the patient's experience and this may well have resulted in any overly positive picture emerging that may not capture the overall contribution of HCPs to the melanoma experience. Such issues to do with '*sampling*' are to an extent inherent within studies of this nature and may in part have been overcome if there was time to involve more than one carer or HCP. But as '*representation*' and '*generalisation*' are not the goals of this type of study such limitations should not compromise the integrity of the findings significantly. However, the study is best viewed as an initial attempt to provide an in-depth understanding of the melanoma experience from the perspectives of the main groups involved. Hopefully it provides a solid platform on which to build. Areas for further research will be considered later.

Having now considered issues to do with the rigour of the study consideration is now given to its potential contribution to knowledge.

9.5 CONTRIBUTION TO KNOWLEDGE

Given the paucity of prior in-depth qualitative explorations of the melanoma experience it is hoped that the present study has provided new insights that prove to be of value, both theoretically and practically. This study is the first to consider the experience of melanoma patients and their carers longitudinally from pre-diagnosis to death highlighting the temporal nature of the experience and the fact that patients' and carers' support needs change over time. Of particular importance is the period around diagnosis when early patterns of interaction between both patients and carers and HCPs are established. I now consider contribution to knowledge framed using the temporal stages identified in the study.

9.5.1 PRE-DIAGNOSIS

This study captured the ways in which melanoma may be '*noticed*' but is subsequently often '*normalised*' and '*discounted*'. This process could go on for some time and was noted amongst HCPs as well as patients and carers. This could result in significant delay in receiving the necessary investigations and treatment. Similar findings have been seen in other studies published since my study commenced. For example, Walter et al. (2014) when examining reasons for delayed melanoma diagnosis found that initial skin changes and new lesions often did not cause concern for patients who would attribute them to other causes or normal skin changes rather than seeking help immediately. Also consistent with my findings, Walter et al. (2014) found that some patients experienced delays in accessing the healthcare system because they had been given '*false reassurance*' by GPs that skin changes were nothing to worry about. To compound matters, they had not been given enough information on monitoring the lesion and when further changes warranted a return visit.

Walter et al. (2014) suggest that the diagnostic process involves four stages (appraisal, help-seeking, diagnostic and pre-treatment) with each being affected by factors relating to patient and healthcare provider/system interactions. The findings from this study support such conclusions but also highlight the longer term impact of the early diagnostic experience on future contact with the healthcare system.

The results have shown that throughout all stages of the patient journey, HCPs are a valuable 'resource' to patients and carers. Their expertise is valued as patients and carers seek information to navigate their way through the healthcare system. Having personal contact with someone who acted as the 'face' of the healthcare system improved the experience. If that person was then able to deliver the information that the patient and carer needed in a way that was understandable this further improved the experience.

Prior to diagnosis, GPs were an important 'resource', acting as the gatekeeper to specialist care. The 2017 Cancer Patient Experience Survey (Quality Health 2017) suggested that patients' concerns are generally actioned at this point with 69% of patients only seeing their GP once before being referred for treatment.

9.5.2 DIAGNOSIS & INITIAL TREATMENT

During diagnosis and initial treatment, patient and carer experiences varied depending on the nature of the further treatment required. This study highlighted the impact of treatment on patients' and carers' 'roles', 'routines' and 'relationships'. Similarly Tan et al. (2014) found that patients with stage III melanoma described the impact of treatment on 'roles' and 'routines' including work, socialising, hobbies and activities of daily living related to lymphoedema or pain from the site of surgery. They also considered the role of carers, one of the few studies

to do so. They found that carers can feel inadequate in their role, believing that they were not doing enough to help patients. A particularly interesting finding by Tan et al. (2014) was that some patients and carers described '*putting on a brave face*' to prevent loved ones from worrying. This is entirely consistent with the notions of '*hiding*' and '*tailoring*' described in detail in this study. This is something that I will build upon later. As has already been highlighted few prior studies have considered carers' needs and this remains largely the case.

Patients first turn to the person who may be considered their carer for support and NICE (2012b) recommend that family members and carers are involved in patients' care. It is therefore surprising that some carers in our study were not able to form relationships with HCPs. Patients and carers then used their existing social networks for support but often '*tailored*' information to protect elderly or young family members. This finding has been echoed in recent publications involving melanoma. The importance of relationships and social support has been found in long-term melanoma survivors (Stamataki et al. 2015) and patients with advanced melanoma and their spouses (Engeli et al. 2016). These studies also found that the process of telling people about the melanoma to gain their support was difficult and not all information was disclosed so as to not overburden family members (Engeli 2016, Stamataki et al. 2015). This study however, found that while carers (who were often close family members) provided the majority of support for the patient, they themselves also needed support and may be drawing on the same wider social network as the patient.

Support from social networks however, can only be gained if information about the melanoma diagnosis is shared, something that not all patients in this study were willing to do. The study also uncovers the strain that a melanoma diagnosis can put on relationships. Participants in this study found that melanoma and its treatment negatively affected some relationships which became more distant as a result. Patients and carers may turn to their existing social networks

for support, but not all members of these networks are able to fulfil the role. Furthermore some people whom the patient would turn to as their main carer are not able to fulfil that role so the patient then needs to seek support from their wider network. Support needs to be tailored to the individual and a full assessment of a patient's social network may help HCPs to identify their place within that as a source of support.

At diagnosis patients, and to some extent carers, described feelings of '*shock*'. This was also echoed in an exploration of the psychosocial impacts of stage III melanoma on patients (Tan et al. 2014). These feelings of '*shock*' can then prevent carers and patients from understanding all of the information given to them at that time (Tan et al. 2014, Girgis et al. 2018), something that clearly emerged from the present study.

While an unmet need for information has been reported (Palesh et al. 2014, Tan et al. 2014) it is also recognised that information provision alone is not enough (Ribi et al. 2018). Patients require clarity, quality and availability of information (Stamataki et al. 2015). In this study this amounted to personalised information delivered at a pace and using phrases readily understood by patients and carers.

Patients have reported difficulties in communicating with their clinical team (Tan et al. 2014) which may relate to a lack of clarity, or opportunity. Stamataki et al. (2015) found that patients who had the opportunity to discuss their emotional and informational needs with CNSs felt that their needs had been met but this was done at a later timepoint whereas patients in our study felt they needed that support at diagnosis. Feelings of '*shock*' combined with the need for information makes diagnosis a pivotal time for patients and one where HCPs can contribute to their positive experience by providing information in a way that is understandable to them.

Given the impact that the '*shock*' of a diagnosis has on patients' and carers' ability to understand information, it would seem that more than one information-giving encounter is needed. The National Cancer Patient Experience Survey 2017 (Quality Health) found that around 70% of patients found it easy to contact their CNS and understood the answers to their questions. However, the survey included patients seen as a day case for cancer related treatment and discharged, so the results may be biased towards patients receiving day surgery for melanoma rather than more complex treatments. HCPs are a valuable source of expertise for patients and their families. This study demonstrated that despite attempts by HCPs to help patients maintain their usual activities while remaining safe in the sun, some patients and carers reduced their outdoor activities. Robinson (2018) also found that melanoma survivors reported lower levels of physical activity after being diagnosed with melanoma which was possibly related to the need to avoid sun exposure. Information provision even after the diagnostic period is therefore important. This study showed that some nurses had developed ways to meet these needs by arranging further meetings or telephone calls but some patients felt abandoned.

The experience of diagnosis and initial treatment will change further in the coming months as adjuvant treatments have been approved for melanoma (NICE 2018a, 2018b, 2018c). The lack of structure that Mark and Sandra felt in comparison to Sandra's experience of breast cancer will change in light of this, along with the support needs of patients. Patients and carers are likely to be given information about relatively new treatments with unfamiliar side-effects during the time that they are coming to terms with the diagnosis and experiencing feelings of '*shock*'.

9.5.3 SURVEILLANCE

One of the major concerns of both patients and carers during the surveillance period was the fear of recurrence. This was a significant *'down'* on the *'rollercoaster'*. Consistent with this finding other studies of melanoma patients with local disease have found clinically significant levels of fear of recurrence (Bell et al. 2016, Wagner et al. 2018). The present study also shows that these concerns are understandably experienced by carers.

The literature review revealed the anxiety felt by melanoma patients from the diagnostic period may reduce in intensity but can nevertheless be experienced for years. Research published since the original literature review also demonstrated patients' ongoing worry about melanoma recurrence (Beesley et al. 2015, 2017, Kasparian 2013b, Molassiotis et al. 2014, Palesh et al. 2014). This study reflected this but also demonstrated that these feelings of anxiety and worry related to the melanoma were also experienced by carers. The anxiety experienced by carers of melanoma patients has not been previously reported.

After an intensive period of treatment and recovery, survivors can experience a special trust-based relationship with caregivers such as their oncologist and CNS (Kroon 2017). In this study, the biggest barrier to HCPs providing support was time as they had to *"prioritise"* patients. Where trust was built at diagnosis, this study demonstrated that it lasted as the patient's and carer's experience progressed. In such circumstances patients/carers felt that the clinical team would answer any of their questions with genuine concern and insight. As other studies have found, some melanoma patients and carers felt that they were *'abandoned'* by the clinical team, this was especially prevalent amongst carers who felt that the patient was the priority (Tan et al. 2014, Kroon 2017). This study demonstrated that patients used HCPs responses to their needs as a measure of the quality of their relationship. Where expectations were met, such as telephone calls or appointments being kept as promised, trust was

reaffirmed but if planned contact was not forthcoming, the trust within the relationship was usually lost and proved very difficult to regain.

Interviews and the focus group with HCPs demonstrated that the patient was the priority, with varying recognition of the need to support carers or the wider social support network. It may therefore be harder for carers of melanoma patients to be recognised. Melanoma patients, until recently, have not received anti-cancer treatments until the advanced stages of disease. Carers provide valuable support to patients and, as this study shows, the melanoma diagnosis affects them as well. It is therefore short-sighted not to include them in the patient's care. This is particularly relevant as carers are the main support for patients at home and often prompt further contact with HCPs by contributing to patients' *'monitoring'* routines. Consequently carers, as well as patients, need to feel that their concerns are recognised and that HCPs are available to them, particularly when the patient does not feel able to ask for help themselves.

There is a lack of evidence based interventions to support HCPs caring for melanoma patients. One recent study reporting on a psychoeducational intervention to reduce fear of recurrence in patients at high risk of another melanoma found that while HCPs (CNSs in particular) aimed to reduce melanoma worry in patients, they did not use any specific interventions (Dieng et al. 2016). The authors therefore developed a psychoeducational intervention that was found to reduce fear of recurrence. This is an area that merits further study.

9.5.4 ADVANCED MELANOMA

The experience of patients and carers changed further as patients developed advanced disease. Carers took on more physical aspects of caring as patients experienced side-effects of their treatment and further symptoms developed. Patients in our study receiving treatment

spoke of positive experiences with HCPs but they and carers voiced concerns about who to contact when they needed help as they transitioned from one setting to another. Once new relationships were established patients felt supported and family members were better able to continue in their more demanding caring role.

Patient and carer experiences also changed during the study as new treatments for melanoma were approved. Further work is needed to explore the experience of melanoma patients receiving these new therapies, which can enable patients to have long periods of stable disease during the advanced stage. When reviewing the literature regarding nursing interventions to support melanoma patients receiving targeted therapies, Koldenhof et al. (2018) found that the majority of these were focussed on adherence to treatment. The authors suggest that future nursing interventions should also focus on QOL and quality of dying, with respect to the patient's needs and wishes. Kroon (2017) explored the experience of melanoma patients surviving two years after ipilimumab immunotherapy for advanced melanoma, finding that patients experienced anxiety about the future and physical problems that limited their usual activities. Their experience was improved by the presence of a social network and engaging in normal activities. They trusted HCPs to care for them but medical follow up decreased when the melanoma was stable leaving patients with support issues that weren't addressed. During this study patients experienced relatively short periods of stable disease but their expectations of treatment and support needs changed. Whereas patients would at one time progress fairly predictably to palliative care and terminal illness, after multiple lines of treatment for advanced melanoma they deteriorated quickly. This made the transition to palliative care more difficult as patients with advanced disease towards the end of the study quickly progressed from having active treatment to terminal illness often without much time to establish relationships with palliative care teams.

The benefit of *'relationships'* and social networks as a *'resource'* was evident at all stages but some patients also valued the opportunity to make contact with other melanoma patients. Melanoma patients in this study did not have treatment visits until they had advanced disease so opportunities to meet other patients were restricted to people within their existing social networks who had experienced a cancer diagnosis. To meet this need, some patients in this study sought peer support from the internet, reporting use of a closed Facebook group, which is only available to melanoma patients and their carers and not moderated by HCPs. The use of social media and online forums has shown benefit for patients. However there are no moderated forums for melanoma. Participants in this study reported caution when interacting with the Facebook group and the only other support groups available online provided by OcuMelUK (a charity providing support for patients with ocular melanoma) are also closed groups run via Facebook (OcuMelUK 2018). Spaces that are not moderated are less trustworthy as there is no one checking the accuracy of posts (Hargreaves et al. 2018a), so the opportunities for melanoma patients to interact online are currently limited. Social media is not easily available to all cancer patients but melanoma is prevalent in younger, working age adults so online support may be more readily used by this group and is an area for further investigation.

For some, taking part in the research also helped patients and carers to reflect on their experiences. This seemed especially important during disease and reinforces the potential benefits of being enabled to reflect on their melanoma experience with an interested but *'neutral'* listener.

Having considered potential additions to knowledge regarding melanoma, attention is now turned to how the theory might be developed further.

9.5.5 FURTHER THEORETICAL DEVELOPMENTS: MOVING FROM SUBSTANTIVE TO FORMAL THEORY

As with all initial Grounded Theory studies the primary aim of my work was to develop a substantive theory of the experience and support needs of melanoma patients and their carers. A substantive theory is one that addresses a given phenomenon in a certain context, in my case melanoma. However, one of the key characteristics of a Grounded Theory is that of '*modifiability*': the ability to accommodate new data in a related but somewhat different context and to expand and develop as a consequence (Glaser & Strauss 1967). In so doing the theory accounts for a growing number of phenomena in differing contexts and moves from a substantive to a formal theory (Glaser and Strauss 1967).

Elements of the substantive theory relate to the wider cancer literature, suggesting application beyond melanoma. Carers of patients receiving treatment for other types of cancer have reported '*monitoring*' symptoms (Ream et al. 2013, Ullgren et al. 2018) but it is not explored whether this is done in an overt or covert way as part of '*hiding*', '*sharing*' and '*tailoring*' processes as in this study. Investigations regarding wider cancer groups have found that patients and carers rely on their existing social networks for support. A large social network may prove beneficial (Kroon 2017, Ream et al. 2013, Drury 2018, Lynalla 2017, Howard-Jones 2018) but a limited social network can result in unmet support needs (Ream et al. 2013). The involvement of a social network for support suggests that patients and carers engage in '*sharing*' processes but this has not been explicitly explored and warrants further investigation. The use of peer support is growing in the general cancer literature, again with some benefits noted (Lynalla 2017, Drury 2018, Walshe et al. 2017). As the use of technology has increased there is interest in the use of online peer support forums (Benetoli et al. 2018, Chiu & Hsieh 2013, Hargreaves et al. 2018b). Peer support begins with a degree of '*sharing*' but Hargreaves et al. (2018b) describe instances of '*sharing*', '*hiding*' and '*tailoring*'. Their work suggests that

these elements are applicable to other cancer sites but as they also included patients with Motor Neurone Disease there is evidence within the wider context of chronic disease.

When exploring death and dying in acute hospitals in the first ever Grounded Theory study Glaser and Strauss (1967) identified a core category that they termed '*awareness contexts*'. This explained the varying levels of awareness amongst patients, family and staff of the likelihood of death. At the time the study was completed patients were not usually informed that they were dying and so they had a '*closed awareness context*'. On the other hand staff and families often knew of the impending death (open awareness) but tried to '*hide*' this from the patient. To do so they engaged in subterfuge and this could cause difficulties in family relationships. Since the 1960s the idea of awareness contexts has been developed and applied to other conditions that have been, or still are, kept '*hidden*' from patients, such as dementia (Hellstrom et al. 2005). There has therefore been a move from substantive to formal theory.

A number of the processes identified in my work have previously been described in other studies, these are: '*noticing, normalising and discounting*' (Keady et al. 2003) in relation to dementia; and '*hiding, sharing and tailoring*' (Wang and Nolan 2016) in acute stroke. None of these processes were imposed on my theory but rather '*earned*' their way in because of their potential to illuminate important parts of the melanoma '*journey*'.

In exploring the interactions between people with early dementia and their close family Keady and Nolan (2003) described how the early symptoms (such as forgetfulness) were often '*noticed*' but then '*normalised*' (I'm getting old or I have the flu) and then '*discounted*'. Both people with early dementia and their family could do this (often '*hiding*' this activity from each other) for many months or even years before seeking help. Unfortunately GPs would then often do the same thing resulting in extensive delays before formal assessment was made.

During this period the relationships between people with dementia and their family could subtly deteriorate resulting in them *'working apart'*, a pattern of behaviour that could become embedded.

Wang and Nolan (2016) studied the experience of acute stroke in mainland China and described many examples of *'hiding'* behaviours. For example family and professionals would collude to *'hide'* any serious news from the patient believing that if they knew this would create a negative mental state and make any recovery unlikely. Some information was *'shared'* but any that was given was usually *'tailored'* to present a more positive picture. This effectively excluded the person with stroke from taking an active role in decisions about treatment and further care and could have a detrimental effect on relationships.

The addition of my own accounts of *'noticing/normalising/discounting'* and of *'hiding/sharing/tailoring'* suggest the potential for the incorporation of these processes into a more *'formal'* theory and other researchers might want to consider exploring these ideas further in other contexts.

Having considered contribution to the knowledge of melanoma and possibility for further theoretical developments, I now consider how the experience of melanoma patients and their carers may be improved.

9.5.6 WHAT IMPROVES OR HINDERS THE EXPERIENCE OF PATIENTS AND CARERS AND HOW CAN IT BE IMPROVED FURTHER?

Our study has shown that patients and carers experience a *'rollercoaster'* of emotions and events during the melanoma experience. Factors that seemed to improve their experience include:

- Access to social networks: Patients and carers obtained much of their support from their existing social networks including family and friends. Limited social networks seemed to make the experience harder. Where participants sought out peer relationships with other cancer patients, this also improved their experience. If HCPs recognise the resources available to patients including existing relationships, they may then be able to identify where further support is needed. It would also be beneficial for HCPs to recognise where appropriate peer relationships may be helpful and facilitate these where possible.
- The formation of trusting relationships with HCPs: Where HCPs actively forged relationships with patients and carers and represented the *'human face'* of the healthcare system they became a powerful and valued resource for patients (and occasionally carers). Many HCPs already recognise the important time points in the *'rollercoaster'* experienced by patients and carers and seek to provide support when it is most needed. Their efforts can be thwarted by time and other constraints. Lack of access to HCPs can leave patients feeling isolated and limit the availability of reliable, personalised information. It is important that HCPs recognise the importance of being the *'human face'* of the healthcare system and make efforts to establish a relationship of trust at the earliest possible moment.

- Active and explicit support for carers: It is essential that the role of the carer is recognised at all stages of the melanoma '*rollercoaster*'. They are the main support for the patient and play a key part in their physical and psychological care. Carers also have their own support needs, particularly as melanoma may affect the wider family in numerous ways. It is therefore important that HCPs involve carers in consultations wherever possible, but also explicitly recognise their own need for support.
- Access to easy to understand information: Currently much of the information given to patients/carers is provided whilst they are still coming to terms with their diagnosis and are experiencing considerable '*shock*'. This makes it difficult for them to understand any information they are given, particularly if complex treatments are being explained to them. Without further opportunities for discussion and questions it may be difficult for patients and carers to fully understand what they are being told. This has implications for the informed consent process. Where information about melanoma and treatment is provided in a personalised way, that is, at a pace that patients and carers can understand and with opportunities made available for them to ask questions then the experience can be improved. Without opportunities to clarify issues patients may have regrets after treatment and feel that they were not fully informed. This may be difficult where treatment needs to be delivered in a timely manner, particularly within national target times, so the MDT need to work together to provide opportunities for patients and carers to explore issues fully. The use of patient generated questions may also improve the experience as some participants stated that they didn't know which questions to ask.

All of the above have a number of implications across a range of fronts. These are considered below.

9.6 IMPLICATIONS

9.6.1 PRACTICE & POLICY

Improvements to the experience of melanoma patients and carers can be made by assessing the extent of their support network and recognising the role of the carer as it may be the carer that needs the most support. Even where the patient is not receiving complex treatment, the carer may be providing significant psychological support. Assessment of the patient and carers' support network can identify those in need of additional support. This may not require formal evaluation if included in existing holistic needs assessments.

Information provision has received much attention in the cancer population in general but there are still improvements to be made. Providing information over multiple occasions rather than a single visit is beneficial with opportunities to ask questions after information has been assimilated. Where patients do not know which questions to ask, it may be beneficial to have a resource where questions generated by previous patients can help to guide the conversation.

One of the main barriers to HCPs providing support to patients and carers was them being perceived to be inaccessible because they were too busy. HCPs, CNSs in particular, recognised that they prioritised certain patients owing to workload pressures suggesting that access to support via CNSs is not equitable for all patients. The HCPs taking part in this study were nominated because of their positive influence on the patient's experience. However, there were still a number of patients who did not feel able to nominate a HCP. To provide adequate support to all patients rather than only those who ask for it or that HCPs judge in greatest need, staffing levels need to be adequate to facilitate this. An increase in staffing levels, particularly of CNSs, may therefore be required. A recent report by MCS (2017) citing the average caseload of CNSs in England found that Skin Cancer CNSs had a comparable caseload compared to CNSs in other disease sites. However, the figures only included

melanoma and not any other skin cancers, even though a large part of the workload includes non-melanoma skin cancers. The availability of Skin Cancer CNSs as a resource is therefore less than that of other cancer sites demonstrating a need for greater investment.

HCPs need to be aware of the extent to which carers provide support to patients with melanoma at all disease stages and that the pathological stage of the melanoma does not necessarily reflect the patient's or carer's assessment of the situation or their reaction. Identification of the involvement of carers in the care of melanoma patients is therefore required, but this goes beyond the NICE (2015) recommendation of encouraging patients to bring a companion to consultations. The needs of carers are not currently accounted for in national policy for melanoma (NICE 2015). There may therefore be a need to evaluate roles within the MDT to ascertain who should take responsibility of assessing and meeting the needs of carers.

The fact that many of the patients and carers who took part in the study did not know what melanoma was prior to their diagnosis suggests that there is a lack of public awareness regarding melanoma. In Australia the success of mass media campaigns such as the '*slip slap slop*' campaign have achieved success through the backing of policies, supportive environments (such as the availability of shade) and the availability of quality sun-protection products governed by national standards (Innacone & Green 2014). In the UK there has been limited success of such campaigns (Diffey & Norridge 2009, Butler et al 2013) but many of these are run by charities rather than the government so do not have equivalent backing. Given the rising incidence of melanoma and the costs of treatment government investment in public awareness campaigns for skin cancer may be cost-effective.

9.6.2 EDUCATION

Patients and carers experienced difficulty understanding information provided to them at diagnosis. Further education for HCPs is therefore required regarding the delivery of information, particularly when the patient has received bad news and this is in keeping with recommendations by NICE (2015) for the care of melanoma patients. The lack of information to date on the experience of patients with melanoma and their carers brings with it a lack of education regarding how to meet their support needs and the ways in which they meet these needs themselves. The difficulty that patients talked about in understanding information while coping with the 'shock' of diagnosis is likely to be compounded by the addition of adjuvant treatment. Patients will now be given information about treatment with life-threatening side-effects at a time when they are coming to terms with their diagnosis. It is therefore important that employing organisations provide HCPs with educational opportunities regarding ways to deliver information at such an emotional time so as to provide important information about treatments in a way that patients and carers can understand it. Not providing these educational opportunities may have consequences for the informed consent process and therefore legal ramifications for healthcare trusts. HCPs will also need educational opportunities regarding the side-effects of new adjuvant therapies so that they may in turn educate patients and carers.

We have seen that patients use their social support network as a resource throughout the melanoma 'rollercoaster' but HCPs need to be aware of how patients and carers hide and share information to identify the amount of support available to the patient and recognise the role that they need to play in that network. In the digital age more patients are seeking the internet as a source of support as well as information. HCPs therefore need to be aware of available resources so that they can direct patients to credible sites and educate patients in the risks and benefits of online peer support.

The difficulty experienced by some patients and carers in the pre-diagnostic period suggests that awareness of melanoma needs to be raised within healthcare professions at an undergraduate level as well as for those specialising in primary care. The majority of patients presented to their GP but as nurses take on more advanced roles within the wider healthcare system they may also be involved in the diagnostic pathway. It is therefore essential that the possible presentations of melanoma are covered within the educational curriculum of HCPs within primary care.

9.6.3 RESEARCH

Relationships are key to the experience of melanoma patients and carers, but the use of support networks by melanoma patients has not been explored and warrants further work. The use of peer support, particularly the use of internet forums that cross geographical boundaries requires exploration as patients are seeking these out but the evidence base is not yet thoroughly developed. Whether the advantages of peer support extends to carers should also be considered.

The changing nature of melanoma treatment means that there is a need to explore the experience as it unfolds over time, particularly the experience of patients receiving targeted or immunotherapies for advanced melanoma and the experience of patients receiving adjuvant treatment for surgically resected melanoma to reduce the risk of recurrence. A recent study I have been involved in had explored the experience of patients receiving targeted and immunotherapies for advanced melanoma (Smedley et al. 2018) indicating that patients commence cancer treatment with preconceptions about chemotherapy that may prevent them from reporting side-effects from newer treatments appropriately. As adjuvant therapy is aimed

at curing melanoma patients, they may live for years or the rest of their lives with ongoing effects of their treatment. There is therefore a need to investigate the incidence of long-term side-effects, the experience of living with these and how they might impact the daily lives of patients and carers and if indicated, design supportive interventions. To understand how patients and carers will be affected by these changes in treatment, research must be conducted in partnership with them. The advantage of constructivist research is that the process of clarifying meanings with participants can reveal new insights that a healthcare professional could not conceive from their perspective. The addition of diagramming or using visual representations means that for those patients that are able, they can convey very powerful emotions that may be difficult to otherwise describe. This is particularly helpful in cancer research where the patient and carer may begin to prepare for death and saying goodbye. It can also be a way for patients and carers to see the experience from the point of view of the other.

The study provided the opportunity for initial exploration of the experience of carers after the death of the patient and the profound effects on their lives. However, this was only a small part of the study and not all carers felt able to continue participation at that time. It may be that those who did not participate had unmet needs that were not captured. Therefore, there is a need to further explore the transition that carers experience after the death of the patient and how the relationships built with HCPs are brought to a close.

9.7 CONCLUSIONS

The theory described in this thesis has captured the *'rollercoaster'* of changing *'roles, routines and relationships'* experienced by patients and carers as a result of a melanoma diagnosis. Even when melanoma is easily treated it can have significant effects and for those with more serious disease the consequences can be life-changing, profound and prolonged. The role of

HCPs in providing information, expertise and emotional support in an accessible way has been shown to be a vital resource. HCPs are aware of the key timepoints in the patient pathway where support is required but an increasing workload can prevent this support from being provided.

Patients and carers turn to their existing networks for support so assessment of the extent of this network as part of a holistic needs assessment may provide an indication of how much additional support is required from HCPs and peers.

The rapidly changing treatment pathway for melanoma means that the experience of patients, carers and HCPs is changing at the same rate. Incidence of melanoma continues to rise but with treatments now available there are more patients and carers requiring support for a greater length of time. It is essential that future research regarding the experience and support needs of melanoma patients keep pace with the ever-changing treatment landscape to ensure that evidence-based care is provided.

As noted at numerous points my primary aim in undertaking this study was to provide new insights that might have the potential to improve the melanoma experience. This study has led to ways that improvements might be made but this can only be achieved if they are put into practice. Work is being carried out locally to ensure that this is carried out. On a national level this depends on the published results being considered when the NICE guideline is next revised.

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11 APPENDICES

11.1 APPENDIX 1: EXAMPLES OF MELANOMA PATIENT INFORMATION LEAFLETS

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Treating Melanoma Skin Cancer

A Quick Guide

Contents

This is a brief summary of the information on Treating melanoma skin cancer from our website. You will find more detailed information on the website.

In this information there are sections on:

- The stages of melanoma
- Statistics and outlook
- Treating early melanoma
- Treating medium stage melanoma
- Treating advanced melanoma
- Surgery
- Chemotherapy
- Regional limb perfusion
- Radiotherapy
- Biological therapy
- Melanoma vaccines
- Follow up for melanoma
- Melanoma research
- Questions for your doctor

You can view this information in a larger print on our website.

The stages of melanoma

The stage of a melanoma describes how deeply it has grown into the skin, and whether it has spread. In the UK 9 out of 10 melanomas (90%) are found at an early stage when the chance of cure is very high. It is

important to know the stage because doctors will often use it to decide on the type of tests and treatment you need, and the likely risk of the melanoma coming back after treatment.

The different systems doctors use

Doctors use a number of different systems and scales to describe the stages of melanoma. Further down this page, there is information about two scales that are used, called the Clark scale and the Breslow scale. These measure how deeply the melanoma has spread into the skin.

TNM staging system

TNM stands for Tumour, Node, Metastasis. T describes the size and depth of the melanoma. N tells you whether or not melanoma cells have spread to the lymph nodes. And M tells you whether or not it has spread to the rest of the body.

Number stages of melanoma

Using the TNM classification, melanomas are grouped into number stages from 0 to 4. Stage 0 means the melanoma cells are only in the top surface layer of skin cells. It is also called in situ melanoma. Stages 1 and 2 are the earlier stages, where the cancer has not spread. In stage 3 it has spread to the lymph nodes or the lymphatic vessels. Stage 4 melanomas have spread elsewhere in the body, away from where they started.

Melanoma statistics and outlook

Outlook means your chances of getting better. Your doctor may call this your prognosis. With melanoma, the likely outcome depends on how advanced the cancer is when it is diagnosed (the stage). If melanoma is diagnosed early, the survival statistics are very good.

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We have quite detailed information about the likely outcome of different stages of melanoma on our website. The studies we use are taken from a variety of sources, including the opinions and experience of the experts who check every stage of Cancer Research UK's patient information. The studies are intended as a general guide only. For the more complete picture in your case, you need to speak to your own specialist.

We include statistics because people ask for them, but not everyone wants to read this type of information. Remember you can skip this page if you don't want to read it, you can always come back to it.

How reliable are cancer statistics?

No statistics can tell you what will happen to you. Your cancer is unique. The same type of cancer can grow at a faster rate in different people. The statistics cannot tell you about the different treatments people may have had, or how that treatment may have affected their prognosis. There are many individual factors that will affect your treatment and your outlook.

Treating early melanoma

The treatment team

NHS guidelines emphasise that people with melanoma should be looked after by a team of health professionals who work together. The team includes surgeons and cancer doctors, a specialist nurse, an occupational therapist, and a counsellor or psychologist.

Treating early melanoma (stage 1)

Very early melanomas are stage 1 on the number staging system. This means they are thinner than 2mm, or less than 1mm thick but have broken the surface of the skin (an ulcerated area). They have not spread anywhere else in the body. The chances of a very early stage 1 melanoma spreading are low.

Your doctor will remove the affected mole. They will also do a further operation to remove some of the surrounding skin and tissue. This operation is called a

wide local excision. As long as your doctor is sure that there was a border of healthy tissue removed from all around the area of the melanoma, this is all the treatment you need.

What happens after treatment?

You will need to have follow-up appointments. Between appointments, you need to contact your specialist to arrange an extra check up if you notice:

- Any changes in other moles
- Dark, mole like spots appearing near where your mole was removed
- Any enlarged glands (lymph nodes) close to where you had the mole removed

Once you have been diagnosed with a melanoma, you need to take care to protect your skin from the sun. This is very important, because your risk of developing another melanoma is higher than average.

Treating medium stage melanoma

The treatment team

A team of health professionals working together plan your treatment. They are specialists in the treatment of stage 2 and 3 melanoma. The team is called a Specialist Skin Cancer Multidisciplinary Team (SSMDT).

Treating medium stage melanoma (stage 2 and 3)

Your first treatment is surgery to remove the melanoma. You then have another operation to remove more tissue to lower the risk that any melanoma cells were left behind in the area. Doctors measure how deeply the melanoma cells have gone into the skin.

Stage 2 melanomas are more than 1mm thick. They may have broken the surface of the skin (ulcerated). The melanoma cells are only in the skin and there is no sign that they have spread to lymph nodes or other parts of the body. Stage 3 melanomas have spread into nearby lymph nodes, skin, or lymph vessels.

Your doctor may do a test called a sentinel node biopsy to see how likely the melanoma is to come

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back and whether you need further treatment. This technique finds the first lymph node to drain tissue fluid from this area of the primary melanoma. A pathologist then checks the node for melanoma cells. If the sentinel node doesn't contain any melanoma cells, you won't need any further surgery. If the node does contain melanoma cells, you will have another operation to remove all the other nodes in the area in case they contain melanoma cells too.

Removing your lymph nodes

Removing the all the lymph nodes in the area can be quite a big operation. The type of surgery you have will depend on where your melanoma was.

If the melanoma comes back

If the melanoma comes back after initial treatment, you may have surgery to remove the melanoma. Or you may have laser treatment to destroy the melanoma areas. If the melanoma is on an arm or leg, you may have chemotherapy into the affected limb (regional chemotherapy).

Treating advanced melanoma

The treatment team

A team of health professionals working together will plan your treatment. They are specialists in the treatment of advanced stage melanoma. The team is called a Specialist Skin Cancer Multidisciplinary Team (SSMDT).

What advanced melanoma is

Advanced melanoma means the cancer has spread to another part of the body. Your melanoma may have already spread when it is diagnosed. Or it may come back in another part of the body some time after you were first treated. This is called recurrent melanoma. Cancer that has spread to another part of the body is called secondary cancer or metastatic cancer.

Treatments for advanced melanoma

Treatments that may be used for advanced melanoma include chemotherapy, radiotherapy, biological therapies and surgery. Chemotherapy and radiotherapy may help to shrink melanoma and

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relieve symptoms. The biological therapies (ipilimumab (Yervoy), vemurafenib (Zelboraf), interferon and interleukin 2) can help to shrink and control melanoma for a time. Vemurafenib only works for people who have a change in a gene called BRAF V600. Sometimes surgery can remove tumours that have spread to other parts of the body.

Which treatment should I have?

Which treatment is right for you will depend on where your cancer has spread, the symptoms it is causing, and the treatment you have already had. Your doctor or specialist nurse will discuss the options for treatment with you.

Clinical trials

Experimental techniques using new drugs or combining chemotherapy with biological therapy are also being tried. If you would like to be part of a clinical trial into a new treatment, talk to your doctor.

Surgery for early and medium stage melanoma

Surgery is the main treatment for early and medium stage melanoma. Once a melanoma has been diagnosed, you have an operation called a wide local excision. The surgeon removes the area of skin and tissue around the melanoma. You may have this operation under local anaesthetic. Sometimes the surgeon will do a test called a sentinel node biopsy at the same time. This test checks whether melanoma cells have spread into the nearby lymph nodes. If you have a sentinel node biopsy you have a general anaesthetic.

Surgery to nearby lymph nodes

If melanoma has spread into the lymph nodes close to the melanoma your doctor will recommend removing all the lymph nodes in that area. This can be a big operation. It is called lymph node resection. The surgery will depend on which part of the body the lymph nodes are in.

Surgery for melanoma that has spread

Surgeons can sometimes remove melanomas that have spread to other areas of the body. This is called metastasectomy. If all the metastases can be

removed, it is called a complete metastasectomy. After this type of surgery people can sometimes stay well for months or perhaps years afterwards.

Chemotherapy for melanoma

Chemotherapy uses anti cancer drugs to destroy cancer cells. You may have chemotherapy as a treatment for an advanced melanoma that has spread to another part of the body. You may have one chemotherapy drug or a combination of several drugs. You usually have injections or tablets for a few days. Then you will have 5 or 6 weeks without any drugs. Then you have another few days of drugs. This cycle is usually repeated six or more times to make up a complete course of chemotherapy.

Side effects

Different drugs have different side effects. And some people react more than others. Some common side effects of chemotherapy include a drop in the number of blood cells, feeling sick, diarrhoea, hair loss or thinning, a sore mouth, feeling tired, and loss of fertility.

Chemotherapy into an arm or leg

If the melanoma comes back in the original area (local recurrence) some people have chemotherapy given just into one arm or leg. The drugs do not then circulate through the rest of the body. It is called regional chemotherapy.

Radiotherapy for melanoma

Radiotherapy uses high energy rays to kill cancer cells. You may have radiotherapy for advanced melanoma, to shrink melanoma tumours and help control symptoms. Some people have it as a treatment after surgery, to try to lower the chance of the melanoma coming back but this is not common.

Having radiotherapy

You usually have treatment once a day from Monday to Friday, with a rest over the weekend. This may go on for several weeks. Radiotherapy for advanced cancer may be between 1 and 4 treatments.

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Radiotherapy is carefully planned. On your first visit, you lie under a scanner or a large machine called a simulator, which takes X-rays. The doctor uses the X-rays or scans to work out exactly where to give the treatment. They will make ink marks on your skin. These marks will be used to line up the radiotherapy machine every day when you have treatment. The actual treatment only takes a few minutes. You will not be able to feel it. This type of radiotherapy does not make you radioactive.

Side effects

The side effects will vary depending on where in the body you are having treatment. Radiotherapy just to the skin does not have very many side effects. The skin may become slightly red and sore.

Biological therapy for melanoma

Biological therapies are treatments that use natural substances from the body, or that change chemical processes in cancer cells. Some types stimulate the immune system to attack cancer cells. Biological therapies can help some people with advanced melanoma. They don't cure the melanoma but can control it for a time. The drugs include vemurafenib, ipilimumab, interferon, and interleukin 2.

Vemurafenib (Zelboraf)

Vemurafenib (Zelboraf) can shrink melanoma in people who have a change in a gene called BRAF V600. About half the people with melanoma have this gene change. You take vemurafenib as tablets. The side effects include joint pain, tiredness, a rash, skin sensitivity to light, feeling sick, hair loss and itching. Some people develop squamous cell skin cancers.

Ipilimumab (Yervoy)

A monoclonal antibody called ipilimumab (Yervoy) can help some people with advanced melanoma to live longer. It is for advanced melanoma in people who have already had other treatments. You have it into a vein by drip. The side effects include a mild effect on the liver, inflammation of the bowel, diarrhoea and a skin rash.

Interferon

You have interferon as an injection under the skin 3 times a week. Some treatment plans include interferon given daily for the first few weeks. The treatment may continue for several years. In the first weeks of treatment, you are likely to have flu-like symptoms such as headaches, low temperature or chills, tiredness and aches and pains in your muscles and joints.

Interleukin 2

Interleukin 2 is also called a desferulin (or IL2 or Proleukin). You are most likely to have it as an injection just under the skin (subcutaneous). But you may have it into a vein, either as an injection or through a drip. The side effects can include low immunity to infection, tiredness, flu-like symptoms, low blood pressure, a skin rash, feeling sick, diarrhoea, and poor appetite.

Melanoma vaccines

Cancer vaccines are a type of biological therapy. These are treatments that use natural body substances, or drugs that block them, to treat cancer. Vaccine treatment is not yet widely available because it is still experimental. You can usually only have it as part of a clinical trial. Vaccines are being used:

- As treatment for people with advanced melanoma that has spread to another part of the body
- As treatment after surgery for people with high risk melanoma particularly where it has spread to the lymph nodes

The vaccines are designed to try to stimulate the body's own immune system to fight the melanoma. Several different types of vaccine are being tested.

How is the treatment given?

Cancer vaccines are usually given as a small injection just under the skin. The vaccine has to be repeated often. You may have a vaccination every week for a few weeks. And then two weekly or monthly injections. The treatment may be given over a long period of time.

What are the side effects?

Apart from soreness at the place where the injection is given in some people, there do not appear to be many side effects. Some people have flu like symptoms.

Follow up for melanoma

After your treatment you may need to have regular check ups. How much follow up you have will depend on the stage of your primary melanoma.

Early melanoma

If you had a very early melanoma that was just in the surface layer of skin (in situ melanoma) you will be asked to go back to the hospital to check the results of your surgery and make sure the operation site is holding up well. Your doctor or specialist nurse will show you how to check your skin. Then you don't need any further follow up.

If you had a melanoma that was just in the upper layer of skin (stage 1A melanoma) you will have check ups 2 to 4 times over a year. Then your doctor will discharge you.

Stage 2 and 3 melanoma

If your melanoma was in the deeper layers of skin or had spread into the lymph nodes you will usually need to have check ups every 3 months for 3 years. After 3 years the check ups may only be every 6 months. If you are worried about anything between follow up appointments, contact your hospital doctor or specialist nurse. At each appointment your doctor will examine you, and ask you about your health and whether anything is worrying you. If you have any symptoms or concerns you may be offered a scan or X ray. This is to look for any signs that the melanoma has come back anywhere in the body.

Advanced melanoma

You will have regular check ups with your specialist, probably three to six monthly for 5 years and then yearly for up to 10 years.

Coping with check ups

Many people find their check ups quite worrying. They may bring back all the worry about your melanoma. It may help to tell someone close to you how you feel. Many people find counselling helpful. Look in the coping with cancer section for information about counselling.

Melanoma research

All treatments must be fully researched before they can be adopted as standard treatment for everyone. This is so that we can be sure they work better than the treatments we already use. And so we know that they are safe.

First of all, treatments are developed and tested in laboratories. Only after we know that they are likely to be safe to use, are they tested in people, in clinical trials.

Researchers are looking into preventing and diagnosing melanomas, and treatment with biological therapies and chemotherapy. Trials are also looking at ways of treating swelling (lymphoedema) caused by melanoma treatment.

Questions for your doctor on treating melanoma

- What stage is my melanoma?
- How does the stage affect my treatment?
- How thick was the melanoma?
- Can you explain what this means for me?
- What is the chance that the melanoma will come back?
- Is there any other treatment you recommend for me after surgery?
- Why do I need this treatment?
- Do I have a choice in the treatment I have?
- Will this treatment reduce the risk of the melanoma coming back?
- How long does the treatment take?
- What are the side effects of this treatment?
- Are there any long term side effects of this treatment?
- Are there any experimental treatments I could try?

- Are there any trials running at this hospital (or another hospital) that you would recommend for me?
- How can I get a second opinion?
- How often will you want to see me after my treatment has finished?
- What will happen at these follow up appointments?
- What should I do if I am worried between appointments?
- Should I have my other moles checked regularly and if so, how and where?

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Notes

For more information, visit our website <http://www.cruk.org/cancerhelp>

You will find a wide range of detailed, up-to-date information for people affected by cancer, including a clinical trials database that you can search for trials in the UK. Our information is based on the best current scientific evidence and reviewed regularly by leading clinicians and experts in health and social care.

For answers to your questions about cancer call our Cancer Information Nurses on 0800 800 4040 9am till 5pm Monday to Friday.

Adapted from Cancer Research UK's Patient Information Website, Cancerhelp, UK, 14 May 2012. Cancerhelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through Cancerhelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have or suspect you may have a health problem you should consult your health care provider. Copyright Cancer Research UK 2008. Cancer Research UK is a registered charity in England and Wales (1289464), Scotland (SC041566) and in the Isle of Man (1102).



Treating Melanoma Skin Cancer – A Quick Guide



STAGE 1 MELANOMA

What are the aims of this leaflet?

This leaflet provides you with information about stage 1 melanoma. In particular, it tells you what a stage 1 melanoma is, what will be the investigations/treatments and where to find out more information. It has been prepared in response to some of the questions people with melanoma often ask.

What is melanoma?

Melanoma is a type of skin cancer, which arises from the pigment cells (melanocytes) in the skin. In a melanoma skin cancer the melanocytes become malignant and multiply excessively. One of the most important causes of melanoma is exposure to too much ultraviolet light in sunlight. The use of artificial sources of ultraviolet light, such as sunbeds, also increases the risk of getting a melanoma.

Melanocytes make a brown/black pigment (known as melanin), and often the first sign of a melanoma developing is a previous mole changing in colour or a new brown/black lesion developing. Most frequently there is darkening in colour but occasionally there is loss of pigmentation with pale areas or red areas developing. This melanoma on the skin is known as the primary melanoma.

Melanoma is considered to be the most serious type of skin cancer because it is more likely to spread (metastasise) from the skin to other parts of the body than other types of skin cancer. If melanoma has spread to other parts of the body, those deposits are known as secondary melanoma (secondaries/metastases).

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Diagnosis and initial treatment

Although a diagnosis of melanoma can be serious, most melanomas are caught at an early stage and so do not cause any further problem. If lesions are not caught at the early stages then there is a higher risk of the melanoma spreading, which can reduce life expectancy.

The initial treatment for a suspected melanoma is to cut out (excise) all of the melanoma cells. When the lesion is first removed, we do not know for sure if it is a melanoma or not, and if it is a melanoma how thick it is, so the excision is usually done with narrow margins (the area of normal skin around the suspected melanoma). The specimen that is cut out from the skin is sent to a laboratory, so that a pathologist can examine it under the microscope. Pathologists look to see if what has been removed is a melanoma and how thick it is. This is the only way a diagnosis of melanoma can be confirmed.

What is stage 1 melanoma?

Doctors use a staging system for melanoma to indicate both the outcome and the best treatment. The system used in the UK stages melanoma from 1 to 4. Stage 1 is the earliest melanoma and stage 4 is the most advanced. The staging system takes into account if there has been any spread of melanoma from the skin to other parts of the body. Stage 1 and 2 melanomas are present in the skin only and have not spread elsewhere in the body. Stage 3 and 4 melanomas are those that have spread to other parts of the body.

The pathologist will look under the microscope to measure certain features of the melanoma. These include the thickness of the melanoma (called Breslow thickness, after Dr Breslow who described it), which measures how far the melanoma cells have grown (or invaded) down into the layers of skin. The pathologist will also note other special features under the microscope. These findings are then summarised in a pathology (histology) report. This is used as part of the staging process and according to this system you have been diagnosed with stage 1 melanoma. Stage 1 is considered a thin melanoma. You can discuss this in more detail with the medical team looking after you if you would like to know more.

What happens next?

A team of experts (including dermatologists, surgeons, pathologists, a doctor specialising in cancer treatment and specialist nurses) will meet to discuss the best treatment option(s) for you. A member of the team will explain those options and you may also meet a melanoma/skin cancer clinical nurse

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specialist (CNS) who may be the point of contact for you and advise you accordingly.

How is stage 1 melanoma treated?

Removing the melanoma from the skin by surgery offers the best chance of a complete cure, and this treatment alone is usually successful in stage 1 melanoma. Most patients do NOT need either radiotherapy or chemotherapy.

After the melanoma was initially removed for histological diagnosis you will usually be offered a second surgical procedure to remove more skin from around and beneath the melanoma scar. This second procedure typically removes a further 1cm margin of skin around the first scar site. It is called a Wide Local Excision (WLE) and is usually carried out under local anaesthetic (via an injection to numb the skin). Your doctor will discuss with you how much skin will need to be removed as the recommended margin depends on the thickness of the melanoma. The purpose of this further surgery is to try and make sure that no cancer cells are left behind in the nearby skin.

What scar(s) can I expect following a wide local excision?

The type of scar(s) will depend on location and the type of surgical technique required. The WLE might result in a scar similar in shape but bigger in size than the one that was left by cutting out the original melanoma. Some scars can be more complex in shape because a "flap" or skin graft was required. Further information on flaps and grafts can be found via the website links given at the end of the leaflet.

What is the risk of stage 1 melanoma recurring?

A diagnosis of stage 1 melanoma means it has been caught early and most patients don't have further recurrence of their melanoma once treated. If you want to know more precisely the chances of your melanoma recurring, talk to your dermatologist and/or your CNS.

After treatment, why am I followed up?

Patients are routinely followed up in the out-patient clinics after the completion of the WLE for three reasons:

- 1) To check that the melanoma has not come back or spread.
- 2) To detect new melanomas or other skin cancers.
- 3) To provide support, information and education.

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How often and for how long will I be followed up?

The follow-up plan should be agreed between you and your dermatologist and/or the surgeon who did the WLE. You will most likely see your doctor every 3 months, for between 1 and 3 years. It is not unusual for your follow up to be shared between the different doctors, and/or a CNS, involved in your care.

How will a recurrence of the melanoma or a new melanoma be detected?

Your doctor will want to examine the area of your melanoma scar and also check your lymph nodes (glands). They will also ask to examine your entire skin to make sure there are no signs of any new melanomas. Photographs might be taken to help compare the way your moles look now with how they looked before and will be kept in your notes if you agree. If a new or recurrent melanoma is suspected then, as before, it will most likely be removed surgically.

What makes somebody more at risk of developing a new melanoma?

One of the biggest risk factors is a strong family history of melanoma (3 or more family members affected). The following are also risk factors:

- Having fair skin that burns easily in the sun, freckles and/or red hair.
- A history of severe sunburn, especially sunburn that caused blisters, occurring in childhood.
- A "weaker" family history of melanoma, i.e. only 1 or 2 other family members affected.
- A large number of moles, and moles which are large and irregular in colour and shape ("atypical" moles).
- Having a very large dark birthmark (a giant congenital mole)
- Having already had a melanoma.
- A weakened immune system (for example, because of treatment with immunosuppressive drugs).

Self care (What can I do?)

Normally, your CNS will discuss the following with you after treatment:

You can examine your skin

Most patients do not develop further melanomas; however, some do and they may also develop other forms of skin cancer. The best way to detect skin cancer is to check all your skin every month (please see Patient Information

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Leaflet on early detection). Essentially, you are looking for changes in the size, shape or colour of any moles, a new mole, or a mole that looks different to the others. There are patient information web-packages, which outline how to look after your moles (please see the web links at the end of this leaflet).

Reduce the risk of further melanomas.

The best way you can reduce risk is to not let your skin burn in the sun. You do not have to hide from sunny days, but you do need to be careful to avoid turning pink and this applies also to any children you have as they are likely to have a similar skin type to you. Information on the best methods of sun protection can be found on the website links provided at the end of this leaflet (see Patient Information Leaflet on prevention).

Top sun safety tips:

- Protect your skin with clothing, and don't forget to wear a hat that protects your face, neck and ears, and a pair of UV protective sunglasses.
- Spend time in the shade between 11am and 3pm when it's sunny. Step out of the sun before your skin has a chance to redden or burn.
- When choosing a sunscreen look for a high protection SPF (SPF 30 or more) to protect against UVB, and the UVA circle logo and/or 4 or 5 UVA stars to protect against UVA. Apply plenty of sunscreen 15 to 30 minutes before going out in the sun, and reapply every two hours and straight after swimming and towel-drying.
- Keep babies and young children out of direct sunlight.
- The British Association of Dermatologists recommends that you tell your doctor about any changes to a mole or patch of skin. If your GP is concerned about your skin, make sure you see a Consultant Dermatologist – an expert in diagnosing skin cancer. Your doctor can refer you for free through the NHS.
- Sunscreens should not be used as an alternative to clothing and shade, rather they offer additional protection. No sunscreen will provide 100% protection.
- It may be worth taking Vitamin D supplement tablets (available from health food stores) as strictly avoiding sunlight can reduce Vitamin D levels.

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Vitamin D advice

The evidence relating to the health effects of serum Vitamin D levels, sunlight exposure and Vitamin D intake remains inconclusive. Avoiding all sunlight exposure if you suffer from light sensitivity, or to reduce the risk of melanoma and other skin cancers, may be associated with Vitamin D deficiency.

Individuals avoiding all sun exposure should consider having their serum Vitamin D measured. If levels are reduced or deficient they may wish to consider taking supplementary vitamin D3, 10-25 micrograms per day, and increasing their intake of foods high in Vitamin D such as oily fish, eggs, meat, fortified margarines and cereals. Vitamin D3 supplements are widely available from health food shops.

Having had a melanoma may impact on future applications for life or health insurance, particularly for the first five years after diagnosis. If you have particular concerns about this, you should seek financial advice.

Where can I get more advice, support & information about melanoma?

When you have been diagnosed with melanoma you might experience a range of emotions including worry, confusion or even feeling unable to cope. It will probably help if you discuss and share your thoughts and feelings with someone close. This might be a family member or friend. It could also be your doctor, CNS or another member of the team looking after you.

When you are diagnosed with melanoma, you will be given a lot of information. All this information at once can be hard to take in. If you are not clear about anything during your treatment, please don't be afraid to ask.

Web links to detailed leaflets:

British Association of Dermatologists

- Information on early detection and prevention of melanoma
www.bad.org.uk/site/1260/default.aspx
- Information on sun-safety
<http://www.bad.org.uk/sunawareness>
<http://www.bad.org.uk/sunawareness/factsheet>
- Information on Vitamin D
<http://www.bad.org.uk/vitaminD>

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Cancer Research UK (CRUK)

- cancerhelp.cancerresearchuk.org/type/melanoma/
- Information on sun-safety
www.sunsmart.org.uk/

GenoMEL: The Melanoma Genetics Consortium

- Information on looking after your moles and vitamin D
www.genomel.org/patient_information.php

Macmillan Cancer Support

- www.macmillan.org.uk/Cancerinformation/Cancertypes/Melanoma/Melanoma.aspx
- Information on flaps/grafts
www.macmillan.org.uk/Cancerinformation/Cancertypes/Melanoma/Treating%20melanoma/Surgery/Surgery.aspx

National Cancer Action Team (NCAT)/ NHS Choices

- Create your own personalised information
www.nhs.uk/ips
- Information on Vitamin D
www.nhs.uk/Conditions/vitamins-minerals/Pages/Vitamin-D.aspx

For details of source materials used please contact the Clinical Standards Unit (clinicalstandards@bad.org.uk).

This leaflet aims to provide accurate information about the subject and is a consensus of the views held by representatives of the British Association of Dermatologists: its contents, however, may occasionally differ from the advice given to you by your doctor.

This leaflet has been assessed for readability by the British Association of Dermatologists' Patient Information Lay Review Panel

**BRITISH ASSOCIATION OF DERMATOLOGISTS
PATIENT INFORMATION LEAFLET
PRODUCED APRIL 2013
REVIEW DATE APRIL 2016**



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Melanoma that has come back in the same area – other treatments

This information is an extract from the booklet *Understanding melanoma that has come back in the same area*, which is part of a series of booklets on melanoma. You may find the full booklet or others in the series helpful. We can send you a copy of any of these booklets for free, see page 8.

Contents

- Treatment overview
- Laser therapy
- Isolated limb perfusion and infusion with chemotherapy
- Radiotherapy
- Follow-up

Treatment overview

When a melanoma comes back in the same area, surgery is the main treatment. Surgery can be used to remove a single recurrence or more than one recurrence. But if there are a lot of recurrences it may be difficult to remove them all with surgery. In this situation your specialist may advise other treatments such as laser treatment, or isolated limb perfusion or infusion with chemotherapy. These treatments are carried out in specialist centres.

Occasionally, radiotherapy may be used to treat a recurrent melanoma that's too big to remove with surgery or not suitable for other treatments.

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Planning your treatment

The **multidisciplinary team (MDT)** who planned your original surgery will be involved in planning the treatment.

The MDT will take a number of factors into account when advising you on the best course of action, including your age, general health, the size of the recurrence, and whether it has begun to spread.

If two treatments are equally effective, your doctors may offer you a choice of treatments. Sometimes people find it hard to make a decision. If you're asked to make a choice, make sure you have enough information about the different options, what's involved and the possible side effects. This will help you decide on the right treatment for you.

Remember to ask your cancer specialist or nurse specialist any questions you have about your treatment, including its benefits and disadvantages. Don't be afraid to ask for more information if there's anything you don't understand or feel worried about.

You may find it useful to write down a list of questions and to take a close friend or relative with you when you discuss your treatment. You can also contact our cancer support specialists on **0808 808 00 00** for more information about your treatment.

Our booklet *Making treatment decisions* has more information that you may find useful.

Giving your consent

Before you have treatment for a recurrent melanoma, your doctor will explain its aims. They'll ask you to sign a form saying that you give permission (consent) for the hospital staff to give you the treatment. Before you're asked to sign the form, you should be given full information about:

- the type and extent of the treatment
- its benefits and disadvantages
- any significant risks or side effects
- any other treatments that may be available.

If you don't understand what you've been told, let the staff know straight away so they can explain again. It can help to have a relative or friend with you when the treatment is explained, to help you remember the discussion. You may also find it useful to write a list of questions before your appointment.

You can choose not to have the treatment. The staff should explain what may happen if you don't have it. It's essential to tell a doctor or the nurse in charge, so they can record your decision in your medical notes. You don't have to give a reason for not wanting treatment, but it can help to let the staff know your concerns so they can give you the best advice.

Second opinion

Usually the specialists who are treating you use national treatment guidelines to decide the most suitable treatment for you. Even so, you may want another medical opinion. If you feel it will be helpful, you can ask either your specialist or GP to refer you to another specialist for a second opinion. Getting a second opinion may delay your treatment, so you and your doctor need to be confident that it will give you useful information.

If you do go for a second opinion, it may be a good idea to take a relative or friend with you. You may also want to have a list of questions ready so that you can make sure your concerns are covered during the discussion.

Laser therapy

A treatment called carbon dioxide laser therapy can be used to treat small melanomas that come back in the same area in the skin. It involves directing a high-intensity beam of light at the affected areas of skin to destroy the melanoma.

You can have this treatment as an outpatient and you can receive it more than once. You may be given a local anaesthetic to numb the area beforehand. During and after treatment you may feel some discomfort in the skin, but this can be relieved with mild painkillers. The area may be covered with a dressing to protect it after treatment.

Isolated limb perfusion and infusion with chemotherapy

Isolated limb perfusion

Isolated limb perfusion is a way of giving chemotherapy directly into a limb (arm or leg). It's sometimes used to treat 'clusters' of melanomas that come back in the same limb. These are known as **satellite lesions** or **in transit metastases**. The treatment is only carried out if the melanoma is confined to the limb and hasn't spread anywhere else in the body.

Doctors are still trying to find out more about how helpful limb perfusion is, so this treatment is usually carried out within a research trial. Also it's not widely available and is only carried out in some specialist centres in the UK.

With this treatment, high doses of chemotherapy drugs are given directly into the affected limb. The limb is isolated using a tight band (tourniquet). This means the drugs don't go to other areas of your body, so you're unlikely to get the side effects chemotherapy usually causes when it circulates around the body.

The procedure is carried out under a general anaesthetic and usually involves staying in hospital for 7–10 days. It's carried out in the following way:

- The surgeon makes a small cut in your thigh or groin (if the melanoma is in your leg), or in your armpit (if the melanoma is in your arm).
- The surgeon temporarily disconnects the blood flow (circulation) between your affected limb and the rest of your body.
- Fine tubes are placed into your blood vessels. These are used to transfer the blood flow from your limb to a pump. Your blood is circulated through the pump and back into your limb. During the procedure, oxygen is also added to your blood, and your blood may be heated as some research shows that this improves the results of treatment.
- A tourniquet is applied to the top of your limb to make sure the blood and circulating drugs stay in your limb.
- High doses of anti-cancer drugs are given into the blood circulating through the pump and then into your limb.
- The drugs circulate in the blood that's flowing through your limb for about an hour.

- After the procedure is finished, the blood flow from your limb is reconnected to the rest of your circulation and the tourniquet is removed. The blood supply to your limb will then go back to normal.

The main side effects of this treatment are swelling, redness and occasionally blistering of the skin on the affected limb.

We have a fact sheet with more information on isolated limb perfusion that we can send you.

Isolated limb infusion

This is similar to isolated limb perfusion. It's sometimes used if isolated limb perfusion isn't suitable for health-related reasons. With this treatment, the blood flow from the limb doesn't need to go through a pump. Instead, two tubes (catheters) are placed through the skin into the main artery and vein of the affected limb. A tourniquet is then applied to the top of the limb to prevent blood flow from and to the limb. After this, the chemotherapy drugs are infused into the limb through the arterial catheter. Once the chemotherapy drugs have been infused for about 15–30 minutes, they are flushed out of the limb. The tourniquet is then removed and normal blood flow returns to the limb again.

Your doctors can give you more information about isolated limb infusion if this treatment is suitable for you.

Radiotherapy

Radiotherapy treats cancer by using high-energy x-rays to destroy the cancer cells, while doing as little harm as possible to normal cells.

Radiotherapy is occasionally used to treat recurrent melanomas that can't be removed with surgery or aren't suitable for other treatments. Your specialist will let you know if radiotherapy is suitable for you.

External radiotherapy

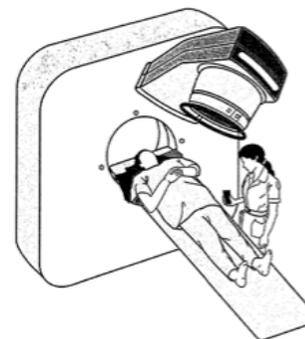
The treatment is normally given in the hospital radiotherapy department as a series of short sessions on weekdays, with a rest at the weekend. Each treatment takes about 10–15 minutes. Your doctor will discuss the length of the treatment and possible side effects with you.

External radiotherapy doesn't make you radioactive and it's perfectly safe for you to be with other people, including children, after your treatment.

Planning radiotherapy

Radiotherapy has to be carefully planned to make sure that it's as effective as possible, which may take a few visits. On your first visit to the radiotherapy department, you'll be asked to have a CT scan or lie under a machine called a simulator, which takes x-rays of the area to be treated.

The treatment is planned by a cancer specialist (clinical oncologist). Marks are likely to be drawn on your skin to help the radiographer (who gives you your treatment) position you accurately and show where the rays will be directed. These marks must stay visible throughout your treatment. Permanent marks, like tiny tattoos, may be used. These will only be done with your permission, and may be a little uncomfortable while being done.



Positioning the radiotherapy machine

Treatment sessions

At the beginning of each session of radiotherapy, the radiographer will position you carefully on the couch, and make sure you're comfortable. During your treatment you'll be left alone in the room. You'll be able to talk to the

radiographer, who will be watching you from the next room. Radiotherapy is not painful but you do have to lie still for a few minutes while the treatment is being given.

Side effects

Radiotherapy will make you feel tired and this can sometimes last for some weeks or even months after your treatment finishes. Other side effects will depend on the area being treated.

Radiotherapy can cause a skin reaction (like sunburn) in the area being treated. You'll be advised by the radiographers on how to look after your skin. If you're having radiotherapy to your groin, you may get some diarrhoea or feel that you want to pass urine more frequently. Radiotherapy to the neck can make your mouth or throat sore. Your doctor can prescribe drugs to help relieve these side effects.

Most of the side effects of radiotherapy are temporary and will gradually go away when your treatment is over.

You can read more about the side effects in our booklet *Understanding radiotherapy*.

Follow-up

After your treatment, you'll have regular follow-up appointments. During your clinic appointments, your specialists will examine any areas that have been treated for melanoma. They will also examine any existing or new moles and your lymph nodes.

Sometimes a melanoma that has previously come back in the same area can spread to other parts of the body. This is known as a **secondary cancer (metastasis)**. If a melanoma does spread to other parts of the body, further treatment can be given. These treatments are discussed in our booklet *Understanding advanced melanoma*. We can send you a copy.

What to look for

You'll need to continue checking your skin after your treatment. Follow your specialist's advice about what to look and feel for, and make sure you examine yourself at least once a month. If you notice anything that concerns you, let your specialist team at the hospital know.

Our information booklets on melanoma are:

- *Understanding melanoma*
- *Understanding melanoma – treatment with local surgery*
- *Understanding melanoma – lymph node assessment and treatment*
- *Understanding melanoma – adjuvant treatments after surgery*
- *Understanding melanoma that has come back in the same area*
- *Understanding advanced melanoma*

More information and support

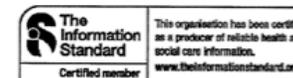
If you have any questions about cancer, ask Macmillan. If you need support, ask Macmillan. Or if you just want someone to talk to, ask Macmillan. Our cancer support specialists are here for everyone living with cancer, whatever you need.

Call free on 0808 808 00 00, Monday–Friday, 9am–8pm
www.macmillan.org.uk

To order a copy of *Understanding melanoma that has come back in the same area*, the other booklets in the melanoma series or one of the other booklets mentioned in this information, visit be.macmillan.org.uk

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REVISED IN NOVEMBER 2011



11.2 APPENDIX 2: DESCRIPTION OF WEBSITES INCLUDED IN THE SEARCH

Website	Address	Country	Funding	Description	Information
Aim at melanoma foundation	https://www.aimatmelanoma.org/stages-of-melanoma/stage-i-melanoma/	USA	Not for profit/ Charitable	International melanoma organisation focused on research, education, legislation, and awareness. Formed by merging two foundations created by the families of melanoma patients.	Information about melanoma risk, diagnosis, research and living with melanoma. Provides information on US based support groups and the option to contact a nurse for support.
American Cancer Society	http://www.cancer.org/cancer/skincancermelanoma/	USA	Not for profit/ Charitable	A nationwide, community-based voluntary health organisation dedicated to eliminating cancer as a major health problem.	Provides information about what melanoma is, prevention. Treatment, support, research, related news articles, online support community, stories of hope.
Boots Web MD	http://www.webmd.boots.com/melanoma-skin-cancer/skin-cancer-guide/sun-exposure	UK	Commercially sponsored	UK specific, GP reviewed health information.	Provides information about sun exposure, causes, risks, symptoms & types, diagnosis & tests, treatment & care, living & managing which includes a list of questions that patients may want to ask their doctor.
British Association of Dermatologists	http://www.bad.org.uk/for-the-public/skin-cancer/melanoma-leaflets	UK	Professional Medical Body	Information leaflets produced for each stage of melanoma.	Information on staging, diagnosis, treatment and sun avoidance advice.
British Skin Foundation	http://www.britishskinfoundation.org.uk/SkinInformation/AtoZofSkindisease/Melanoma.aspx	UK	Not for profit/ Charitable	Charitable organisation who aim to raise money and fund research to find cures for skin disease and cancer	Information about melanoma, symptoms and diagnosis.
David Cornfield Melanoma Fund	http://dcmf.ca/melanoma	Canada	Not for profit/ Charitable	The DCMF is devoted to saving lives from melanoma through prevention and research.	Information about melanoma and patient stories.

Website	Address	Country	Funding	Description	Information
Irish Cancer Society	https://www.cancer.ie/cancerinformation/melanoma#sthash.xipEgsgn.dpbs	Ireland	Not for profit/ Charitable	Cancer support and information	Provides information about melanoma, symptoms and diagnosis, causes and prevention, treatment, living with melanoma (support group contacts), access to online cancer community and telephone helpline.
Mayo Clinic	http://www.mayoclinic.org/diseasesconditions/skincancer/multimedia/melanoma/sls-20076095	USA	Healthcare Provider	Non-profit healthcare organisation.	Information about melanoma, identification, prevention, sun exposure, expert advice, treatments and care at the clinic.
Melanoma Education Foundation	http://www.skincheck.org/Page4.php	USA	Not for profit/ Charitable	Aims to promote awareness of melanoma and early detection. Developed from Dan's father's website tribute to his son.	Information about detection, what melanoma is, how it develops, prevention, information for schools and Dan's story.
Melanoma International Foundation	http://melanomainternational.org/melanomafacts/pathology/#.WCiZrXSLT1o	USA	Not for profit/ Charitable	Aims to develop personalised strategies with patients so they may live longer, better lives. Website for educational purposes.	Information about melanoma, pathology, sunscreen, prevention, staging, skin examination, details of helplines and centres based in USA. Online forum.
NHS Choices	http://www.nhs.uk/conditions/malignantmelanoma/Pages/Introduction.aspx	UK	Healthcare Provider	Healthcare provider information related to melanoma and available NHS services.	Overview of melanoma, symptoms, diagnosis, causes, treatment and clinical trials.
Patient	http://patient.info/health/skin-cancer-melanoma	UK	Commercially sponsored	Commercially sponsored health information site.	Information about melanoma, prevention and treatments, links to clinical trials, links to support groups.
Pub Med Health	https://www.ncbi.nlm.nih.gov/pubmedhealth/PMHT0024659/	USA	Government Info	Reviews of clinical effectiveness research, with easy-to-read summaries for consumers	Information about melanoma, symptoms, tests, treatments and prevention.

Website	Address	Country	Funding	Description	Information
Skin Cancer Foundation	http://www.skincancer.org/skin-cancer-information/melanoma	USA	Not for profit/ Charitable	Aims to set the standard for educating the public and the medical profession about skin cancer.	Provides information about causes, risk factors, prevention, treatments, staging and sub-types of melanoma. Links to true stories including Eric Sizemore's video diary & Vivian Bucay's story.
Teens Health	http://kidshealth.org/en/teens/melanoma.html	USA	Not for profit/ Charitable	Teen health information site.	Information on melanoma, detection and tanning.
Wikipedia	https://en.wikipedia.org/wiki/Lentigo_maligna_melanoma	International	Encyclopedia	Information - sources unknown	Definition of lentigo maligna melanoma (a specific type of melanoma)
You Tube - Derm TV	https://www.youtube.com/watch?v=ZHHdAaV-P10	USA	Individual medical professional	Dermatology information videos	Shows surgery to remove a melanoma including the size of the surgery needed for a wide local excision.

11.3 APPENDIX 3: DATABASES AND SEARCH TERMS USED FOR THE PROFESSIONAL LITERATURE SEARCH

Searches were conducted to identify published and unpublished literature conforming to the selection criteria.

11.3.1 ELECTRONIC SEARCHES

In order to find papers regarding the needs and experiences of patients with melanoma the following databases were searched between January 2005 (published following papers included in the NICE review) and June 2013 (commencement of the study):

- AMED
- British Nursing Index
- MEDLINE
- PsychINFO
- PsychArticles
- Cinahl
- Cochrane Library
- ASSIA for Health
- National Research Register

The databases were selected to encompass literature from the fields of nursing, medicine, psychology and social sciences that may relate to melanoma.

For patient related literature the term 'melanoma' was used in each database. This was not limited by combining with any other terms so as not to miss any important papers. The term skin cancer was not used as this covers multiple diseases and only papers relating to melanoma were required. The search was limited to papers published between 2005 (those published following the NICE review, 2006b) and the start of the study in June 2013.

The following search terms and combinations were used to find literature related to the needs of carers of melanoma patients:

1. caregivers.mp. or Caregivers/ or Social Support/
2. cancer.mp. or Neoplasms/
3. Melanoma/ or melanoma.mp.
4. 1 and 3
5. 1 and 2

The search for melanoma-specific papers produced limited results therefore the search was widened to include all cancers and papers then scanned for those that included melanoma patients. The searches were limited to papers published after 2005.

11.3.2 GREY LITERATURE

Conference proceedings and other unpublished works were sought through correspondence with CNSs and research nurses currently treating melanoma in the United Kingdom. Current research and trials registers were also searched. The contents lists of relevant textbooks were also searched for chapters relating to psycho-social needs. Guidance regarding the care of

melanoma patients was also included where the patient experience or support needs were considered.

11.3.3 HAND SEARCHING

Hand searches of key journals likely to publish papers about melanoma or the needs of cancer patients were performed to identify articles not found through electronic searches. The following subject specific journals were hand searched:

- British Journal of Dermatology
- European Journal of Cancer Care
- Supportive Care in Cancer
- Psycho-Oncology

11.3.4 REFERENCE LISTS

Reference lists from texts relating to the treatment of melanoma were examined for any additional material. The personal manuscript collections of colleagues involved in melanoma care were also accessed to retrieve relevant information.

11.3.5 WORLD WIDE WEB

Sources of information published via the World Wide Web were identified via the Google search engine (www.google.co.uk – set to retrieve international results). The Google search engine was chosen as its database catalogues the greatest number of web pages of any of the freely available search engines. It also enables the retrieval of information generally or

specifically as academic papers or books with limitations placed on the date of publication. The same search terms were used to retrieve papers via electronic databases.

11.3.6 CORRESPONDENCE

Experts and organisations contacted in order to retrieve other information sources for review included the British Association of Skin Cancer Specialist Nurses.

11.3.7 SEARCH TERMS

Owing to the relatively small number of published papers on the subject melanoma could be used as a keyword search and mapped to subject headings where possible. The remaining papers could be quickly searched by title. All papers were considered in terms of patient, carer and healthcare professionals' experience of melanoma.

11.3.8 SEARCH COMPLETION

The search was considered complete when no new papers were found.

11.4 APPENDIX 4: SELECTION CRITERIA FOR PROFESSIONAL LITERATURE INCLUDED IN THE REVIEW

Professional literature was selected according to the criteria below:

11.4.1 TYPES OF STUDIES

Owing to the lack of evidence found during the review conducted by NICE (2006a) it was anticipated that the amount of available literature would be limited. Studies may have used quantitative or qualitative methods to address related aims but in either case would be likely to be relatively small scale. Broad criteria were set for the types of studies and included:

- Randomised Controlled Trials
- Systematic Reviews
- Meta-analyses
- Non-randomised experimental designs
- Cohort studies
- Interview and questionnaire studies
- Observational studies
- Case Studies
- Anecdotal/opinion papers
- Letters
- Papers not peer reviewed
- Guidance and policy documents

11.4.2 TYPES OF PARTICIPANTS

Patients with melanoma of any histological sub-type, age, sex or setting were included. Carers or family of melanoma patients were included without restriction. Healthcare professionals of any discipline were included.

11.4.3 TYPES OF INTERVENTIONS

Interventions affecting the patient experience were not restricted and included surgery, chemotherapy, immunotherapy, radiotherapy, physical examination, skin surveillance, palliative care, counselling and complex interventions relevant to the study population.

11.4.4 TYPES OF OUTCOME MEASURES

Outcomes were included if they related to patient or carer experience, Quality of Life, anxiety, satisfaction with treatment and care or side-effects of treatment. Other outcomes deemed relevant to the study population were considered including qualitative findings.

11.4.5 OUT OF SCOPE OF THE REVIEW

Studies were not considered to fall within the scope of the review where melanoma patients and their carers were included but outcomes were not separated from those of other patients or carers. Papers were excluded if they did not focus on melanoma or had a focus on outcomes that did not include the experience of having melanoma such as:

- Perceived risk of melanoma in the general population or perceptions of sun exposure prior to diagnosis
- The role of sentinel lymph node biopsy
- The evaluation of Patient Reported Outcome or Quality of Life tools
- The evaluation of Quality of Life reported as part of a clinical trial of a new intervention rather than the focus of the paper

11.5 APPENDIX 5: CHARACTERISTICS OF STUDIES INCLUDED IN THE LITERATURE REVIEW

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Mancini J, Baumstarck-Barrau K, Simeoni MC <i>et al.</i> (2011) Quality of life in a heterogeneous sample of caregivers of cancer patients: an in-depth interview study.	Cross-sectional study. Qualitative interviews with thematic analysis (quantitative & narrative).	To identify the main domains of QoL in terms of their impact on caregivers.	Carers of patients with melanoma accounted for 17 patients in the total group of 77.	Caregivers of melanoma patients in particular reported a decrease in sun-related activities. The caregiver–patient relationship influenced the domains of the caregivers' lives that were impacted by cancer.	Only 17 of 77 participants cared for melanoma patients.
Al-Shakhli H, Harcourt D & Kenealy J (2006) Psychological distress surrounding diagnosis of malignant and non-malignant skin lesions at a pigmented lesion clinic.	Prospective observational cohort study.	To prospectively investigate psychological distress throughout the diagnostic process in an outpatient pigmented lesion clinic .	Patients with suspected malignant skin lesions who had been booked for a new appointment, with the exclusion of those under 18 years old, elderly, infirm and non-English speaking. 324 of 463 eligible patients took part.	Women reported more anxiety than men. Patient's quality of life prior to diagnosis was excellent, but emotional functioning, insomnia and global health status deteriorated throughout the diagnostic process for those patients who were finally diagnosed as having malignant melanoma. Patients reported high levels of satisfaction with clinic attendance and treatment but a need for further information was identified.	129 did not complete all time points required for analysis. The conclusions presume that the CNS is involved pre-diagnosis which does not reflect my clinical experience where the CNS is involved at diagnosis.
Burdon-Jones D, Thomas P & Baker R (2010) Quality of life issues in non-metastatic skin cancer.	Cross-sectional qualitative questionnaire with thematic analysis and comparison between groups using frequency count and Fischer's exact test.	To determine the impact of non-metastatic skin cancer on patients' QOL by asking such patients for their opinions.	50 patients with melanoma and 50 patients with Non-melanoma skin cancer at diagnosis of primary lesion.	10 main themes were identified: Avoiding excess sun exposure, concern that skin cancer could spread, concern about the public's lack of understanding of skin cancer, a sense of relief/gratitude following treatment, feelings of anxiety/depression/guilt/stress, concern regarding possible scarring/disfigurement, initial shock at diagnosis of skin cancer, inconvenience/discomfort of surgery; fear of hospitals, realization of one's mortality,sStrengthening of emotional relationships.	Recruitment of a convenience sample. The study was performed to develop a Skin Cancer QOL measure for use in both non-metastatic MM and non-metastatic NMSC which the authors report as being under way.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Clarke SA, Booth L, Velikova G <i>et al.</i> (2006) Social Support: Gender Differences in Cancer Patients in the United Kingdom.	Cross-sectional qualitative study using semi-structured interviews and thematic analysis.	It aims first to explore perceptions of available support services, second: preferences for source and type of support, and last: satisfaction with information and emotional support.	11 melanoma patients receiving observation or adjuvant trial treatment and 5 breast cancer patients receiving adjuvant chemotherapy after surgery for first relapse.	Men tended to access support for information and perceived the staff's provision of information as emotional support. Men perceived every day pleasantries to represent emotional support. Women had less flexible perceptions of emotional support and perceived intimate and lengthy chats, inquiries about their emotions, and reassurance to constitute support.	All authors were female. Given the gender specific investigation, this may have influenced the results. Findings were validated via oncology medical professionals rather than participants.
Constantinidou A, Afuwape SA, Linsell L <i>et al.</i> (2009) Informational needs of patients with melanoma and their views on the utility of investigative tests.	Cross-sectional survey using a face-to-face semi-structured questionnaire.	To identify the informational needs of patients with melanoma on disease status and prognosis, and to ascertain their views on the utility of positron emission tomography (PET) and sentinel node biopsy (SNB).	106 English speaking patients with melanoma diagnosed within the previous 4 months. Metastatic: 17%, Disease free: 83%, Time since diagnosis (years): Median (range) 3 (0.3–17).	The vast majority (88%) reported that they wanted to know everything about their disease and over 90% would like to be informed about the spread of their disease and their chances of cure. Around 85% wished to know the length of time to live (with and without symptoms), and 97% wanted to know about the palliative care input available. Most patients wanted to discuss prognosis and palliative care support as soon as their disease became metastatic, and over 50% expected the doctor to impart the information without negotiation.	High response rate. The authors note that the sample was derived from one area in London that may not be representative of the UK as a whole.
Cornish D, Holterhues C, van de Poll-Franse LV <i>et al.</i> (2009) A systematic review of health-related quality of life in cutaneous melanoma.	Systematic literature review.	To evaluate, summarise and discuss the available literature concerning HRQOL in patients with cutaneous melanoma.	44 full articles on melanoma were considered, but only 13 were eligible for this review. The tumour stages varied, but most studies focused on localised disease, and only a few focused on metastatic melanoma.	20 different instruments were used in 13 studies. The results indicated that there are three distinct periods of HRQOL impact: diagnosis, treatment and follow-up. The immediate period following diagnosis was often associated with high levels of HRQOL impairment. Extended survival is dominated more by fears of recurrence and less by physical limitations. In the follow-up phase, psychological distress can interfere with screening recommendations and preventive behaviours. The proportion of patients with melanoma who report high levels of HRQOL impairment is comparable to that observed in other cancers.	The authors note that patients participating in the clinical trials for interferon may be more motivated and optimistic so may rate their HRQOL higher.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Hamama-Raz Y, Soloman Z, Schachter <i>et al.</i> (2007) Objective and subjective stressors and the psychological adjustment of melanoma survivors.	Cross-sectional questionnaire.	Examines the associations between the adjustment of melanoma survivors and their objective and subjective stress.	300 survivors of malignant melanoma (182 women and 118 men). Stage IA, IB, IIA, or IIB, and having been in oncological follow-up for at least a year with no signs of recurrent cancer or of other chronic illness.	Mean distress and wellbeing scores were similar to scores among a normative Israeli sample. All the correlations were weak, however, none of them accounting for more than 5% of the shared variance. A small correlation suggested that the more children the survivors had, the better their psychological well-being and the lower their distress. Married survivors had greater wellbeing and less distress. Neither stage or time since diagnoses proved significant predictors of well-being or distress.	Same study as Hamama-Raz (2012) & Hamama-Raz & Solomon (2006). Kessler's scale was translated and modified for use in the study but details of the pilot are brief and not reported in full elsewhere. The cross-sectional nature of the study makes it impossible to know with any certainty how much the survivors' appraisal contributed to their adjustment and how much was the product of their adjustment.
Mols F, Holterhues C, Nijsten T <i>et al.</i> (2010) Personality is associated with health status and impact of cancer among melanoma survivors.	Cross-sectional questionnaire.	To investigate the prevalence of Type D personality (the conjoint effects of negative affectivity and social inhibition) among melanoma survivors and to obtain insight into its effects on health status, impact of cancer and health care utilisation.	562 patients diagnosed with melanoma between 1 January 1998 and 1 August 2007. Mean years since diagnosis 4.6. Stage I to III.	22% of melanoma patients were classified as having a Type D personality. Type D patients reported statistically significant lower scores on clinically relevant subscales for general health, vitality, social functioning, role limitations, emotional and mental health. Type D patients reported statistically significant and clinically relevant differences for the subscales body changes, negative self-evaluation, negative life outlooks, life interferences, health worry and higher order negative scale. Type D patients more often reported more sun avoidance.	Same study as Husson et al (2010). The authors note that the reasons for declining to participate remain unknown and although Type D personality is a stable construct, the cross-sectional design of the study limits the determination of causal association between Type D personality, health status and impact of cancer.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Murchie P, Delaney EK, Campbell NC <i>et al.</i> (2010) GP-led melanoma follow-up: views and feelings of patient recipients.	Semi-structured audio-taped telephone interviews thematically analysed.	To explore the practical experiences and feelings of people with cutaneous malignant melanoma about receiving structured melanoma follow-up from their general practitioner (GP) as an alternative to traditional hospital-based follow-up.	18 patients randomised to receive GP led follow up for malignant melanoma as part of a clinical trial. All patients had been treated solely by potentially curative surgical excision for primary cutaneous melanoma and were recurrence free.	Almost all patients were happy that they knew what to do and who to contact if they became worried between GP-led melanoma follow-up appointments. When comparing GP with hospital follow-up, the most frequent advantage stated was convenience. Seeing a GP who knew them well was seen as an advantage. The main benefit of attending the hospital for melanoma follow-up was being seen by a specialist and having an immediate diagnosis about any concerns. A disadvantage of the hospital system was a lack of continuity. Patients went through a process of adjustment following their diagnosis, becoming less anxious as time went by.	Same study as Murchie <i>et al.</i> (2009). The authors note that the data were collected and analysed by PM (a GP) meant that there is a possibility that patients may have felt restricted in voicing negative views of the study. The study does not take funding arrangements into account which differ in Scotland to the rest of the UK and may affect the feasibility to run this study elsewhere.
Banks E, Byles J E, Gibson R E <i>et al.</i> (2010) Is psychological distress in people living with cancer related to the fact of diagnosis, current treatment or level of disability? Findings from a large Australian study.	Self-reported questionnaire data on demographic, health and lifestyle factors and mental health.	To investigate whether the observed elevated levels of psychological distress in cancer survivors relate specifically to aspects of cancer diagnosis, to treatment or to disability.	89,574 patients with cancer in total of which 2337 had melanoma. Over 45 years of age. Self-reported cancer diagnosis.	A similar pattern of increasing psychological distress with increasing degree of functional limitation was seen, independent of the diagnosis of cancer. Psychological distress related much more strongly to disability than to site-specific cancer diagnosis.	The authors note that the measure of disability does not specify the cause of the disability and therefore includes disability resulting from mental health problems. Activity changes such as sun avoidance were not measured here and may have changed the results if the study was specifically focussed on melanoma.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
<p>Husson O, Holterhues C, Mols F, <i>et al.</i> (2010) Melanoma survivors are dissatisfied with perceived information about their diagnosis, treatment and follow-up care.</p>	<p>Cross-sectional questionnaire.</p>	<p>To measure the perceived level of, and satisfaction with, information received by melanoma patients.</p>	<p>562 patients diagnosed with melanoma between 1 January 1998 and 1 August 2007. Mean years since diagnosis 4.6. Stage I to III.</p>	<p>A large percentage of patients indicated the absence of information about different aspects of melanoma, treatment and aftercare. None of the patient characteristics were significantly associated with perceived information provision about the disease. More information about medical tests was associated with shorter time since diagnosis and a higher stage melanoma. More perceived information provision about treatment was significantly independently associated with younger age, higher stage of disease and higher educational level. Satisfaction with information was independently associated with high educational level and less frequent use of the internet for additional information.</p>	<p>Same study as Mols <i>et al.</i> (2010) The questionnaire does not detail the format of the information or whether it was discussed.</p>
<p>Noorda E M, van Kreijl R H J, Vrouenraets B C <i>et al.</i> (2007) The health-related quality of life of long-term survivors of melanoma treated with isolated limb perfusion.</p>	<p>Cross-sectional questionnaire.</p>	<p>To assess the long-term Health Related Quality of Life (HRQOL) of melanoma survivors who had undergone Isolated Limb Perfusion (ILP) of the extremities and to identify the patient, tumour and ILP-related factors associated most strongly with the patients' self-reported HRQOL.</p>	<p>51 Patients who had undergone ILP between 1978 and 2001 who were alive and disease free for a minimum of 6 months prior to recruitment. Stage I-IV. Median follow-up after ILP = 14 years (range 3-25 years).</p>	<p>Overall, the self-reported HRQOL was better than that of the age and gender matched comparison group. 49-55% of the patients reported physical symptoms including oedema, stinging sensations or limb stiffness. 72-82% of those who experienced any degree of physical symptoms indicated that those symptoms resulted in some impairment in their daily activities. 61-69% of the patients with a cosmetic problem (including oedema) were bothered by it. 63-77% reported fear of local or distant disease recurrence. 55% frequently checked their limb for new recurrences. Some patients also reported financial consequences of their diagnosis and treatment.</p>	<p>The authors note the limitations of having a small sample size, a single centre, lack of an adequate control group and variation in the time since ILP. Validity and reliability of the ILP-specific tool are not reported or referred to.</p>

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Trapp M, Trapp EM, Richtig E <i>et al.</i> (2012) Coping strategies in melanoma patients.	Observational, questionnaire-based, cross-sectional study.	To assess possible differences in coping patterns of patients with MM compared with those of a control group of patients with benign dermatological diseases, such as varicosis, leg ulcers, and keloids.	46 patients having planned excision biopsy or wide local excision the following day. Stage not defined but no evidence of metastasis prior to surgery. Patients with a history of melanoma or non-melanoma skin cancer were excluded.	This study shows that chosen coping strategies allow prediction with statistical significance of the diagnosis of MM vs. benign dermatological disease, thus suggesting the existence of some differences in coping strategies in patients with MM compared with a control group. Low scores for situation control indicate that stressful situations are not adequately analysed and, consequently, few attempts are made to control the stressor and the stress-reaction. High scores in the subtest resignation indicate the tendency to give up quickly in a stressful situation (type C behaviour), which may produce feelings of helplessness and hopelessness.	The analysis is based on clinical rather than histological information as data was collected prior to surgery. The authors note that the assessment provided information on "original" traits and not on states that might have "become chronic" as a consequence of a long-standing unfavourable diagnosis.
Holterhues C, Cornish D, van de Poll-Franse LV <i>et al.</i> (2011) Impact of melanoma on patients' lives among 562 survivors: a Dutch population-based study.	A cross-sectional Dutch population-based postal survey.	To assess the impact of melanoma on the health-related quality of life of patients from the general population up to 10 years after diagnosis and its determinants.	562 patients diagnosed as having melanoma from January 1, 1998, to August 1, 2007 returned the questionnaire. Any stage at diagnosis. Time since diagnosis was 6 months to 10 years. Patients older than 85 were excluded.	Melanoma survivors did not report impaired HRQoL compared with an age- and sex-matched sample. IOC scores implied that for every year further from diagnosis the patient may be less negatively influenced by their cancer. This observation suggests that generic and even cancer-specific HRQoL questionnaires might not be sensitive enough for patients with predominantly low stages of melanoma. UV related aspects of patients' lives were affected and a diagnosis of melanoma had practical implications for their daily life (eg, getting a mortgage, health insurance or life insurance).	The SF36 and IOC are validated measurement scales but the authors note that they had not been formally tested in melanoma patients. Additional questions were based on expert opinion so may not have been interpreted as intended by participants. Validity of the additional questions is not addressed.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Korner A & Fritzsche K (2012) Psychosomatic services for melanoma patients in tertiary care.	Retrospective cross-sectional data collection of referral data. Descriptive and inferential statistics were employed to compare patients with melanomas and patients with other dermatological diseases.	To enhance the knowledge about patients with melanoma identified by their dermatologist as needing psychosomatic–psychotherapeutic CLS provided within a comprehensive clinical care approach at the general hospital.	All patients (3658) referred to the psychosomatic–psychotherapeutic consultation–liaison service (CLS) between 2005 and 2008. 49 had melanoma and 262 had non-melanoma skin cancer. Details of the melanoma diagnosis are not reported.	Melanoma patients were referred to the service more often and required more interventions than patients with dermatological conditions but less frequently than patients with other cancers. The most common reasons for referring melanoma patients were: “coping issues” (57%) and acute psychological symptoms (39%) (anxieties or depressive symptoms). Both groups had some mild symptoms difficulty in social, occupational or school functioning but were generally functioning quite well and had some meaningful interpersonal relationships.	Descriptive study confirming that some melanoma patients require psychosomatic therapy but only includes those referred to the service.
Rychetnik L, McCaffery K, Morton R <i>et al.</i> (2013) Psychosocial aspects of post-treatment follow-up for stage I/II melanoma: a systematic review of the literature.	Systematic literature review.	To investigate patient and clinician preferences and experiences of follow-up after surgical treatment of stage I or II melanoma (including adherence to guidelines).	The review included all (15) empirical studies that considered psychosocial factors as anticipated or experienced outcomes of routine follow-up after treatment of stage I/II primary cutaneous melanoma and as reported by patients or clinicians. Articles published in languages other than English but catalogued with an English abstract were included.	Over half of the patients were interested in professional emotional support, and the majority preferred to get this from their doctor than from a psychiatrist or psychologist. Overall satisfaction with hospital-based follow-up was high with patients finding it worthwhile and useful because they felt reassured and were able to ask questions. Disadvantages related to transport, parking and associated costs, anxiety associated with attending follow-up appointments (which could begin over 24 h prior to their appointment and may include physical symptoms such as diarrhoea, nausea and sleeplessness). Follow-up was also an important source of reassurance and information. Around three quarters of patients also conducted skin self-examination. Around half of surveyed patients participated in melanoma follow-up in accordance with recommended schedules.	Covers papers also reviewed separately: Murchie <i>et al.</i> (2009) & Murchie <i>et al.</i> (2010). The findings related to these studies were easily identified and have not been included here to prevent over-reporting.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Winzer A, Hoppe A, Altenhoff J <i>et al.</i> (2009) Interest in a psycho-educational group intervention among out-patients with malignant melanoma in relation to their need: which patients are likely to participate?	Cross-sectional mixed method study; semi-structured interviews with standardised questionnaires.	To determine the perceived and the normative need of psychosocial support and the interest for a psycho-educational group intervention among patients with malignant melanoma.	144 patients with stage I-IV melanoma, had an appointment for their next control visit in the outpatient clinic, and were able to communicate in German. Exclusion criteria were melanomas in the eye or the mucous membranes, diagnosis of cancer at another site, and a history of psychiatric illness.	The two main reasons melanoma patients stated for participating in the intervention were to gain information about the disease (n=42) and to meet other people with whom they could share experiences (n=24). There were slightly more patients in the non-interested group than in the potentially interested group who stated 'they don't want to be reminded of their illness'. Older people, those not in employment, those with higher cognitive avoidance scores and those with less health behaviour knowledge were less interested in a support programme. Patients who were younger, male, had no partner and had lower scores on the cognitive avoidance scale were more likely to be interested in the intervention. Medical variables were not predictive of an interest in the support programme.	The authors discuss the self-perceived need for support compared to professionally determined need for support or intervention, but this is limited to the expert-defined cut off on the HQ and testing the benefit of an intervention may require differing cut off points.
Schubert-Fritschle G, Schlesinger-Raab A, Hein R <i>et al.</i> (2013) Quality of life and comorbidity in localized malignant melanoma: results of a German population-based cohort study.	Cross-sectional questionnaire.	To examine the influence of additional chronic diseases on QoL in a population-based cohort of disease-free malignant melanoma patients after presumably curative treatment.	644 patients with malignant melanoma but without distant metastasis 21–24 months prior to the start of the study, the absence of disease progression at the time of questionnaire administration, and the ability to read German. Stage 0-IIIc.	Two years after initial diagnosis, disease-free patients with localised malignant melanoma are able to experience a QoL similar to that enjoyed by the general population. In this survey of melanoma patients, the results indicate that other chronic diseases have strong influences on QoL, irrespective of a patient's malignant disease. Therefore, localised malignant melanoma per se is not associated with reduced QoL.	Same study as Schlasinger-Raab <i>et al.</i> (2010). QLQ-C30 Questionnaire is a recognized and validated QoL evaluation tool. Other items are not clearly validated or drawn from other tools. Parts of questionnaires may not be valid on their own. It is not evident that the original tools were developed in German or any processes used for translation.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Ludgate MW, Sabel MS, Fullen DR <i>et al.</i> (2011) Internet use and anxiety in people with melanoma and non-melanoma skin cancer.	Prospective survey.	To compare the patterns of Internet use of people with skin cancer with previous findings by including people with nonmelanoma skin cancer (NMSC) using a comprehensive survey. To evaluate perceived anxiety levels and overall satisfaction after searching the Internet of people with skin cancer.	Patients diagnosed with Melanoma (395), BCC (290) or SCC (108) attending an initial consultation. Individuals younger than 18 or who had previously been seen in the Multidisciplinary Melanoma Clinic were excluded.	Participants without Internet access were significantly older than those with access. Regardless of their type of skin cancer, the majority of participants were satisfied with the amount of information provided by their referring physician. Despite this, a large number of participants sought additional information regarding their diagnosis on the Internet. Participants with skin cancer who searched the Internet themselves for information related to their diagnosis were more likely to be younger, female, diagnosed with melanoma, and more-highly educated. More than half of all study participants reported that they trusted only some of the information they found on the Internet. One-third reported that their search had made them more anxious, one-third felt less anxious, and one-third felt neutral.	Descriptive data, no causal relationships. The majority of websites visited were american cancer societies as the study was conducted in the U.S. This may differ for a UK population.
Bowen D, Jabson J, Haddock N <i>et al.</i> (2012) Skin care behaviours among melanoma survivors.	Cross-sectional telephone survey.	To investigate the melanoma risk-reduction behaviors of survivors recruited through a population-based registry to better understand the needs and behaviors of survivors living in the general population.	313 melanoma survivors aged 18 years or older with internet access and a relative who was a parent of a child 18 years and younger. Stage 0-IV. Average survival since diagnosis was 5 years.	59% were compliant with wearing a long-sleeved shirt, 80% wore long pants or skirts, 45% used sunscreen with SPF 15+, 35% wore something to cover their head, 16% wore a hat with a brim of 2.5 inches around, 46% wore sunglasses, 36% stayed in available shade, and 20% avoided the outdoors when the sun is strongest. 74% believed their chances of getting melanoma again are 'a little higher than average' or 'much higher than average'. Men reported nearly seven times more usage of hats, caps, or scarves than women. 12% were considered to have a 'high cancer worry'. 22% believed they 'conducted a thorough skin examination'.	The authors caution that the results are specific to the population of the Pacific Northwest region of the USA. More of the population hold college degrees that other regions and skin protection and screening behaviours could vary because of the sun exposure specific to the area.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Oliveria S A, Shuk E, Hay JL <i>et al.</i> (2013) Melanoma survivors: health behaviours, surveillance, psychosocial factors, and family concerns.	Focus groups with thematic analysis.	To examine experiences of melanoma survivors regarding sun protection, surveillance practices, psychosocial and family concerns using focus groups.	48 participants in 8 focus groups, ≥18 years of age, diagnosed with invasive primary cutaneous melanoma, stages I–III, and 1–10 years since diagnosis treated during 1996–2005. Patients who had prior malignancies, did not speak English or lived more than 2 hours from the centre were excluded.	Receiving good news from physician screenings was psychologically reassuring for survivors. Melanoma diagnosis prompted many survivors to assess and reprioritise life values and develop a more positive life outlook. Receiving a melanoma diagnosis served to either strengthen or place stress on survivors' relationships with romantic partners. Survivors became more conscious of sun exposure and expanded use of sun protection measures following diagnosis. Seeing a dermatologist was seen as an effective strategy to ensure new melanomas would be identified early. Skin self-examination varied significantly across the sample but most did not conduct skin self-examinations on a regular basis. Lack of confidence in ability to identify a suspicious mole was cited as a barrier to conducting skin self-examination, and some survivors preferred to off-load the responsibility to the doctor.	The authors state that the focus groups served as a pilot study to inform a larger scale survey study currently underway so the cohort reflects a convenience sample.
McLoone J, Watts K, Menzies S <i>et al.</i> (2012) When the Risks Are High : Psychological Adjustment Among Melanoma Survivors at High Risk of Developing New Primary Disease.	Qualitative interviews with framework analysis.	To explore the subjective experiences, risk perceptions, and coping responses of melanoma survivors known to be at high risk of developing new disease.	20 participants attending a High-Risk Clinic (HRC) and had attended a minimum of at least three clinical skin examinations (CSEs), spoke English and over 18 years of age were included. Individuals receiving active treatment for locally advanced or metastatic melanoma were not included.	Participants perceived melanoma as potentially terminal and reported persistent worries about the possibility of developing new or metastatic disease. Fear of developing a new melanoma endured for years after treatment. A substantial proportion reported concurrent and persistent uncertainty, anxiety, and fears regarding recurrence. Not a single participant in the current study reported seeking or receiving professional emotional support, despite a desire for such support on the part of some individuals. Belief in the benefits of early intervention, including self- and clinical skin examination, provided a sense of control. The expertise of physicians was perceived as instrumental in creating a sense of reassurance.	Same study as McLoone <i>et al.</i> (2013). Codes were inductively derived from the data. Discrepancies in coding were discussed with the team until a consensus was reached.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Kasparian N A, Branstrom R, Chang Y M <i>et al.</i> (2012a) Skin examination behaviour: the role of melanoma history, skin type, psychosocial factors, and region of residence in determining clinical and self-conducted skin examination.	Cross-sectional web-based survey.	To examine the frequency and correlates of skin examination behaviours in an international sample of individuals at varying risk of developing melanoma.	Participants may have no history of melanoma, a family history of melanoma or a personal history of melanoma.	Frequency of skin examination was strongly associated with melanoma history. Participants with a personal history of melanoma reported the highest frequency of examination. Skin examination frequency was lower in Northern Europe than Central Europe, Southern Europe, Australia or the US. For participants with a personal history of melanoma, frequency of examination increased only with perceived benefit, not perceived risk or skin cancer-worry.	Much of the raw data is reported elsewhere. The online method of administration limited the sample to those with internet access and the skill to access and complete the survey.
Campolmi E, Mugnai F, Riccio M <i>et al.</i> (2011) Simultaneous care and melanoma: preliminary report about the psycho-oncological approach.	Pilot study. Cross-sectional quantitative survey.	To investigate the efficacy of a 'take in charge' model of advanced stage melanoma patients by a multidisciplinary team and highlight the psychological patterns of the disease compared to a traditional pre-terminal end of life care model.	44 patients with unresectable advanced melanoma (stage IIIb -IV).	Both men and women demonstrated low mental and physical scores. Patients have a low mental score and do need a structured and professional psychological support. This appeared to be worse for patients with skin rather than visceral disease.	The clinical relevance of the data is not clear. The methods talk about an intervention and semi-structured interviews but only baseline data for the SF12 in patients with advanced melanoma is presented.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Hetz S P & Tomasone J R (2012) Supportive care needs of Canadian melanoma patients and survivors.	Cross-sectional quantitative survey.	To determine the support needs for melanoma patients in Canada in order to help direct future support services and research. In addition the study attempted to examine how level of education may affect these support needs.	31 patients with a current or past diagnosis of melanoma. Stage I-IV. Mean years since diagnosis was 5.	The highest reported supportive needs were: access to a second opinion, information about non-surgical treatment, information about how and when to check for skin changes, information about side-effects of surgical treatment, skin soreness and lymphoedema. Individuals without post-secondary education had a higher information need. Additional information needs included: information at diagnosis, treatment options, diagnosis and prognosis. The majority of patients felt comfortable asking questions to their medical team but those with less than secondary education felt less comfortable and reported conducting less regular SSE.	The prescriptive responses did not allow for patients to express additional concerns. Not all participants completed all items. The authors cautioned that the questionnaire asked about current needs/within the last month and it is likely that needs change over time.
Hamama-Raz, Y (2012) Does psychological adjustment of melanoma survivors differ between genders?	Cross-sectional quantitative survey.	Are there gender differences in the psychological adjustment, cognitive appraisal and personal resources of survivors of malignant melanoma?	300 melanoma patients (182 women and 118 men). Age (25–60), no other chronic illness, Hebrew speaking, stage of illness IA, IB, IIA or IIB, and having been in oncological follow-up for at least a year with no signs of recurrent cancer.	Distress was found to be significantly higher among women than men. Mental distress and wellbeing of melanoma survivors is by far better predicted by their attachment style than by other variables. Avoidant or anxious attachment reduced well-being and increased distress. This highlights the importance of social relations in the adjustment of cancer survivors.	Same study as Hamama-Raz <i>et al.</i> (2007) & Hamama-Raz & Solomon (2006). In modern society gender roles are changing so the interpretation of gender specific differences must be considered with caution. It may be preferable to consider personality traits that apply to all genders to facilitate person centred care.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
<p>Passalacqua S, di Rocco Z C, Di Pietro C <i>et al.</i> (2012) Information Needs of Patients with Melanoma: a nursing challenge.</p>	<p>Cross-sectional quantitative survey.</p>	<p>To evaluate the information, psychological, social and practical needs of patients with melanoma and to compare such needs with those of patients with other malignancies.</p>	<p>35 melanoma patients and 186 with other cancers. Aged 18 years or older, Italian speaking, without psychiatric disorder or cognitive impairments, cancer stage 0-IV, time since diagnosis between 0 and 18+ months.</p>	<p>Patients with melanoma had a higher frequency of information needs compared to patients with other cancers. They showed significantly higher frequencies for "better dialogue with clinicians" and "more sincerity". They had consistently lower median symptom scores than all other cancers combined and as such were statistically significant for pain, depression, anxiety, wellbeing and breathing. Among patients with a non-metastatic stage, those with melanoma needed to be more involved in therapeutic choices, wanted nurses and physicians to give more comprehensible information, wanted clinicians to be more sincere, and expressed more information needs compared to those with other cancers.</p>	<p>To compare melanoma to other cancers a generic, rather than specific measure was required. Tumour specific issues may not be easily compared. The authors caution that the NEQ has been validated previously and used in studies on patients with liver, breast, colorectal, head & neck and other cancers but never for melanoma.</p>
<p>Cashin R P, Lui P, Machado M <i>et al.</i> (2008) Advanced Cutaneous Malignant Melanoma: A Systematic Review of Economic and Quality-of-Life Studies.</p>	<p>Systematic literature review.</p>	<p>To examine all of the information published so far on the impact of interventions on QoL, including all available treatment strategies or screening programs for MM.</p>	<p>The patients of interest were adults with metastatic disease. Studies were excluded from this analysis if the intervention studied involved surgery, resectable disease, or radiation therapy. Studies that grouped different types of cancers together where subjects with MM could not be separated from others were also excluded.</p>	<p>13 articles were reviewed. There were six studies that used survey methods to obtain longitudinal data from patients and seven that were based on clinical trials. Four of the six survey-based articles concerned the same study. Physician-rated outcome variables did not correspond to the patients' measured QoL. There were no statistical differences between the responses of the patients and those of the relatives. Nurses more often underestimated patients' fatigue and difficulty in concentrating and overestimated the degree of nausea and vomiting as well as the patients' global QoL.</p>	<p>Only QOL results are considered here as economic analysis is outside of the remit of this review.</p>

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Zucca A C, Boyes A W, Linden W <i>et al.</i> (2012) All's Well That Ends Well? Quality of Life and Physical Symptom Clusters in Long-Term Cancer Survivors Across Cancer Types.	Cross-sectional quantitative survey.	To assess QoL and the clustering of patient-reported symptoms by cancer type in a large-scale population-based sample of long-term cancer survivors five to six years post-diagnosis.	864 patients with a new histologically confirmed cancer (local or metastatic) five to six years ago, aged between 18 and 75 years at the time of diagnosis, able to read and understand English. 131 patients with melanoma were included.	One-fifth of breast (21.1%), prostate (20.2%), and colorectal (19.0%) cancer survivors reported two or more symptoms, compared with only 4% of melanoma survivors. No unique physical symptom clusters by cancer type were found in long-term survivors diagnosed with either breast, prostate, or colorectal cancer or melanoma. This suggests that by five to six years post-diagnosis, long-term cancer survivors' experience of clusters of generic physical symptoms are similar to one another, regardless of their primary diagnosis. Melanoma patients were found to have moderately better global QoL compared to a normative data set for cancer patients pre-treatment.	Differences may not have been detected because generic, rather than cancer specific measures were used. The authors caution that the comparison data were not directly matched to the sample and were primarily from European countries, which are culturally different to Australia.
Reimer J, Voigtlaender-Fleiss A, Karow A <i>et al.</i> (2006) The Impact of Diagnosis and Plaque Radiotherapy Treatment of Malignant Choroidal Melanoma on Patients' Quality of Life.	Longitudinal quantitative survey.	To test the hypothesis that (a) diagnosis and treatment of MCM lead to QOL impairment compared with healthy controls, and patients with a different oncological or ophthalmologic diagnosis, and (b) plaque radiotherapy treatment leads to a decline in QOL.	All 35 patients with Malignant Choroidal Melanoma (MCM) admitted to the centre for ophthalmology for plaque radiotherapy treatment during the recruitment period. The average time-period between diagnosis and participation in the study was 12 days (+/- 7.1).	Out of the 51 patients participating at t0, 35 (68.6%) took part in the survey at t1. 16 patients (45.7%) suffered from one or more complication postoperatively. The MCM diagnosis compromises QOL, which is additionally impaired by radiotherapy. Regular QOL assessment can help to identify patients at risk.	Psychometric properties of all tools are addressed but the internal consistency of one was limited to medical students; student nurses; and patients with an immunodeficiency syndrome. Administration of the questionnaires is not reported. Visual impairment may have affected participants ability to complete them and carers may have helped.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Mujumdar U J, Hay J L, Monroe-Hinds Y C <i>et al.</i> (2009) Sun protection and skin self-examination in melanoma survivors.	Cross-sectional quantitative telephone survey.	This study examined performance of Skin Self-Examination (SSE) and sun protection behaviours in individuals with melanoma drawn from the general population.	115 individuals with a first primary melanoma.	115 (response rate 78%) patients participated. 20 individuals (17%) conducted deliberate and systematic SSE as defined as 'always or nearly always' examining all but one body parts. 23% met the criterion for regularly conducting all but one sun protection practice and this includes the 12 participants (10%), who 'never went out in the sun,' thus were classified as practicing full sun protection. Individuals who reported having moles, as compared with those reporting no moles, were more likely to report conducting comprehensive SSE. Significant predictors of regular sun protection strategies included older age, being female and higher sun protection self-efficacy.	Participants were also asked about family discussions about melanoma risk, and these results are reported elsewhere. The sample are recruited from a research active population so they may be more motivated to take part in melanoma prevention strategies.
Kasparian N A, McLoone J K & Butow P N (2009) Psychological Responses and Coping Strategies among patients with malignant melanoma: a systematic review of the literature.	Systematic literature review.	To systematically review the body of literature on the prevalence of psychological distress among individuals affected by melanoma.	The review was concerned with the psychological responses of patients with melanoma. All stages were included. Time since diagnosis ranged from diagnosis to 108 months afterwards. The number of participants in each study ranged from 44 - 427.	43 studies remained after applying exclusion criteria. Approximately 30% of all patients with melanoma report clinically relevant psychological distress but their psychosocial needs frequently go undetected and unmet. Demographic factors associated with adverse psychological outcomes in patients with melanoma include: female gender, younger age, absence of a spouse or partner, lower education, and economic adversity. The association between clinical factors and psychological distress is unclear. Patients with melanoma who form positive or meaningful appraisals of their cancer experience, have an active-cognitive coping style, and/or greater social support are more likely to demonstrate healthy psychological adjustment.	The authors suggest the use of validated tools such as the IES but do not discuss the merits and validity of the many tools found in their review. The review covers some of the papers also included here.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Schlesinger-Raab A, Schubert-Fritschle G, Hein R <i>et al.</i> (2010) Quality of life in localised malignant melanoma.	Cross-sectional questionnaire survey.	To present QoL data from a population-based cohort of melanoma patients after treatment with curative intent and the cessation of treatment-related acute side-effects.	664 patients with an initial diagnosis of melanoma without distant metastasis 21–24 months before the study, the absence of disease progression at time of questionnaire administration and the ability to read German. Stage 0-III disease.	QLQ-C30: women had lower emotional and sexual functioning scores and higher symptom scores of insomnia and constipation and men had higher diarrhoea scores. Younger age correlated overall with better functioning and symptom scores. More than 50% of the participants felt incompletely informed about their illness. Almost half of all study participants (47%) indicated that their doctors did not ask about their ability to cope with their disease. Women felt significantly more supported by their friends, while men felt supported by their family. 42% worried about a relapse. A greater number of comorbidities was related to worse physical and mental functioning scores.	Same study as Schubert-Fritschle (2013). QLQ-C30 Questionnaire is a recognised and validated QoL evaluation tool. Other items are not clearly validated or drawn from other tools. Parts of questionnaires may not be valid on their own. It is not evident that the original tools were developed in German or any processes used for translation.
McLoone J K, Watts K J, Menzies S W, <i>et al.</i> (2013) Melanoma survivors at high risk of developing new primary disease: a qualitative examination of the factors that contribute to patient satisfaction with clinical care.	Semi-structured interviews with framework analysis.	To investigate satisfaction with clinical care among individuals at high risk of developing melanoma, while receiving best practice follow-up care at a highly specialised melanoma clinic.	20 patients who had attended a minimum of three consultations at the High-Risk Clinic. Participants were at least 18 years of age and English speaking. Patients on current active treatment for locally advanced or metastatic melanoma, those with a strong family history or carrying a p16 mutation were excluded from the study.	Counselling to aid the adoption of positive coping skills relating to fears about the possibility of recurrence was not addressed. This left many participants expressing ongoing emotional challenges. The majority of participants reported receiving sufficient information about melanoma. The most frequently reported source of melanoma-related information was the internet (8/20). Several participants (6/20) felt insufficiently trained in how to perform skin self-examinations.	Same study as McLoone <i>et al.</i> (2012) All participants had thin melanomas. The model of care may be specific to a large centre that can identify a sub-population of high risk individuals.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Hamama-Raz Y & Solomon Z (2006) Psychological Adjustment of Melanoma Survivors: The Contribution of Hardiness, Attachment, and Cognitive Appraisal.	Cross-sectional questionnaire.	To test the hypotheses that high hardiness, secure attachment style, appraisal of one's situation as a challenge, and a high subjective sense of one's ability to cope will all contribute to cancer survivors' psychological adjustment.	300 patients with melanoma from 400 potential subjects aged 25–60, Hebrew speaking, stage of illness IA, IB, IIA, or IIB and having been in oncological follow-up for at least a year with no signs of recurrent cancer or of other chronic illness.	Findings support the view that inner resources contribute to the psychological adjustment of melanoma survivors. They also suggest that, for the most part, melanoma survivors do not differ substantially from other cancer patients or healthy populations in the role that inner resources play in their psychological adjustment.	Same study as Hamama-Raz <i>et al.</i> (2007) & Hamama-Raz (2012). The translation of tools & modification may affect their validity. The authors note that the study does not examine the day to day functioning of patients or include any of the residuals of melanoma and associated treatment.
Boesen E H, Ross L, Frederiksen K, <i>et al.</i> (2005) Psychoeducational Intervention for Patients with Cutaneous Malignant Melanoma: A Replication Study.	Randomised controlled trial of a psychoeducational intervention.	To test the hypothesis that psychoeducation among a group of Danish patients with malignant melanoma would decrease psychological distress and improve active coping methods and health behaviour.	259 patients, 18 to 70 years of age with cutaneous malignant melanoma stage IIA-IIB, 3-12 weeks after surgery.	The beneficial effect of the intervention was larger for patients with higher baseline values for total mood disturbance (TMD). The intervention group used significantly more active-behavioural coping and active cognitive coping than the control group at 6-months. No differences were seen at 12-month follow-up. No significant differences between the two groups were observed for avoidance coping.	Levels for clinical relevance were not discussed in the study. The revision of the intervention and lack of validation of the DWI-R mean that no judgement can be made as to the clinical relevance of the intervention in this population.
Vurnek M, Buljan M & Situm M (2008) Psychological Status and Coping with Illness in Patients with Malignant Melanoma.	Cross-sectional survey.	The aim of this paper was to investigate the quality of life (QoL), emotional status and coping styles in patients with melanoma.	31 patients with malignant melanoma attending the department of dermatology during the study period. Diagnosed 1 to 14 years previously.	Melanoma had a minimal impact on QOL. Beck Depression Inventory scores indicated that 4 patients had mild or moderate depression and two had severe depressive symptoms. Women were significantly more depressed than men. The higher the number of depressive symptoms, the more influence melanoma has on QoL. The more patients use avoidance the less impact melanoma has on the quality of their life.	The use of a small, convenience sample limits the results. Validation of Croatian versions of the measurement tools used is not reported so the results need to be interpreted cautiously.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Lehto U-S, Ojanen M & Kellokumpu-Lehtinen P (2005) Predictors of quality of life in newly diagnosed melanoma and breast cancer patients.	Cross-sectional survey.	To evaluate psychosocial factors and QoL in melanoma and breast cancer patients with localised disease 3–4 months after diagnosis and whether psychosocial factors, sociodemographic factors, cancer type or treatment modality predict QoL.	72 melanoma and 103 breast cancer patients, 28–71 years of age with localised disease who were newly diagnosed and admitted for treatment and/or follow-up to the Oncology Clinic during the study period. Patients with a previous cancer diagnosis were excluded.	Social support was the major distinguishing factor in the sample, the division occurring between melanoma and breast cancer. Comparison between treatment modality groups within the total sample indicated a possible support-increasing effect of adjuvant cancer treatment. If adjuvant medical cancer treatment has the additional effect of resulting in more social support, which in turn affects the psychological stress processes and QoL, those patients not undergoing these treatments also receive something less in the psychosocial sense. The highest amount of support was received from the spouse or partner and, rather unexpectedly, from physicians and nurses. Breast cancer patients received more support than melanoma patients. The younger the melanoma patients, the more likely they had psychological symptoms and depression.	The authors note that a disadvantage of this study was that the subgroups were relatively small. A disease-specific measure was used for breast cancer patients but not melanoma patients. Melanoma-specific findings are therefore limited.
Lichtenthal W G, Cruess D G, Clark V L <i>et al.</i> (2005) Investment in body image among patients diagnosed with or at risk for malignant melanoma.	Cross-sectional survey.	To assess whether or not there are gender differences in investment in body image in patients with malignant melanoma (MM) and benign lesions.	New patients diagnosed with either Malignant Melanoma (MM) or Dysplastic Naevus (DN), at first or second visit to the clinic, aged 21 to 60 years inclusive. Melanoma stage 0-III. Median time since diagnosis was 277 days.	No significant interactions were found with regard to gender although women reported significantly greater investment in their appearances than men. With regard to fatigue, perceived stress, and depressive symptoms, in the total sample, concerns about physical appearance were significantly associated with mean level of fatigue.	Many of the tools were validated in general populations or student populations. The authors state that the study also lacks a healthy comparison group to determine how the investment in body image of this patient group compares to the general population and that statistical power was reduced because of the relatively small sample size.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Lehto U-S, Ojanenb M, Dybac T, <i>et al.</i> (2007) Baseline psychosocial predictors of survival in localized melanoma.	Cross-sectional survey	To investigate the impacts of the baseline psychological and psychosocial factors in the psychobiological process: coping, social support, NE (anger), non-cancer life stresses, and domains of QOL on survival time in primary localised melanoma.	59 newly diagnosed 28 - 70-year-old melanoma patients with localised disease who attended the oncology clinic for treatment and/or follow-up during the study period. One patient was excluded owing to a prior cancer diagnosis.	A shorter survival time was predicted by male gender, anger-in trait (repression of angry feelings), the existence of feelings of hopelessness, and better single-item reported QOL at baseline. When the variables of the final model were tested one by one with the adjustment variables, only the Cognitive Avoidance coping was significant. Responding to the cancer diagnosis by denying the disease or its seriousness improved survival.	Same study as Lehto et al. (2005).
McLoone J, Menzies S, Meiser B, <i>et al.</i> (2013) Psycho-educational interventions for melanoma survivors: a systematic review.	Systematic literature review.	To critically evaluate both the effectiveness and quality of all psychological and educational interventions developed specifically for people affected by melanoma.	Abstracts of identified articles were screened and included studies involving: development and evaluation of an intervention that was educational or psychological in nature, administered to melanoma patients, case studies, published in English between January 1980 and December 2010.	Educational interventions aimed to increase melanoma knowledge had mixed results with some, but not all studies reporting increases in melanoma related knowledge, SSE, adherence and self-confidence in SSE. No significant changes were reported in anxiety, depression or psychosomatic symptoms after education or 6 months later. Of 4 psychological interventions studies, 4 were CBT based. One reported a reduction in anxiety in the intervention group at 2 and 6 months follow up, one reported a reduction in distress and another reported no reduction in distress.	The authors state that there was an absence of educational interventions that addressed sun protection attitudes and behaviours in the studies reviewed and variations in what constitutes a 'session' in terms of content, duration, and facilitator rapport as well as inconsistent reporting limited comparison between studies.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Kasprian N A, McLoone J K, Meiser B, <i>et al.</i> (2012b) 'Living beneath the sword of Damocles': perceptions of risk and fears of cancer recurrence amongst Australian melanoma survivors at high or moderate risk of developing new primary disease.	Cross-sectional questionnaire.	To examine risk perceptions, fears of cancer recurrence, melanoma-related behaviours, and satisfaction with clinical care amongst melanoma survivors at high or moderate risk of new primary disease.	310 individuals at high or moderate risk of recurrent melanoma.	Clinically-relevant levels of anxiety and depression, as measured by the HADS, were reported by 25% and 9% of participants, respectively. 73% of participants reported clinically-relevant levels of fear of cancer recurrence, with mean scores similar between groups. Participants reported high levels of satisfaction with melanoma care.	Poster abstract only.
Lehto U-S, Ojanen M, Dyba T, <i>et al.</i> (2012) Impact of life events on survival of patients with localized melanoma.	Longitudinal questionnaire.	To investigate the effect of life events evaluated cumulatively over 4 years on survival of patients with localised melanoma.	59 patients diagnosed with Clark level II-IV (Breslow I-II) melanoma.	Life events demonstrated an impact on survival when evaluated with stress mediators such as coping mechanisms and evaluated cumulatively over time. This supports the idea that psychological stress has a slow but cumulative effect on cancer survival.	Same study as Lehto <i>et al.</i> (2005) & Lehto <i>et al.</i> (2007), but with longitudinal data.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Grichnik J M (2011) Unrecognized sex-specific stress and behaviour differences in patients with melanoma.	Letter to the editor.	Comment on Holterhues et al. (2011)	N/A	The study by Holterhues reveals differences in the way that men and women respond to their melanoma diagnosis. This may represent a practice gap for dermatologists who do not modify their counselling to account for sex-specific patient needs. The effect was more extreme for women both positively and negatively. Improved sun-protection is beneficial but increased anxiety can impair QOL. The reason for this gap is not clear and further examination of possible causes, such as information seeking behaviour and social networks should be conducted.	N/A
McArdle C (2012) Patients with melanoma are avoiding follow-up to get insurance.	Personal View.	N/A	N/A	The author notes that in their plastic surgery unit they have seen an alarming rise in the number of patients electing to withdraw from regular review because of difficulties in trying to secure insurance, particularly referring to patients with stage I and II disease. Upon investigation the author found that 7 of 10 leading insurance companies would decline an application for insurance within 5 years of diagnosis and two others would decline insurance within 5 years of diagnosis, treatment or follow-up (which they class as ongoing care or treatment). After 5 years patients faced an increased premium. The stage of melanoma was considered irrelevant but the author argues that this penalises otherwise healthy individuals.	Personal view. Not peer reviewed. The purpose of the insurance is unclear. Life insurance may be taken up by fewer patients than travel insurance and the cost of insurance excluding melanoma is not discussed.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Griffin K (2011) "Everyday I'm alive, it's a miracle".	Magazine article.	N/A	N/A	The author tells the story of Maggie Barbieri who was diagnosed with stage III melanoma and then metastatic disease. Maggie describes how important it was to be there for her family, to continue to look after her children and how her job as a writer helped her to cope with treatment. She didn't want to "just be a cancer patient". Having a complete response to an experimental treatment Maggie sees being alive as a "miracle". Her husband is mentioned once as he didn't cry when they were told that the melanoma had come back but telling his mother made it real and he couldn't stop crying. Maggie also talked about comforting her 11-year-old daughter.	The magazine article has selected quotes from Maggie which present an edited version of the interview. The quotes were used as the information source rather than the journalist's interpretations.
Kasparian N A (2013a) Psychological stress and melanoma: are we meeting our patients' psychological needs? [Review].	Discussion paper.	N/A	Covers all stages.	The psychological and emotional needs of patients are often overlooked. The reasons for this vary and may include under-recognition of the need for psychological care by the treatment team, difficulties in doctor-patient communication about psychosocial issues, an absence of clear referral pathways, inadequate funding and resources, difficulties experienced by patients attempting to access support, and the perceived stigma associated with uptake of psychological services.	The evidence rating system of the National Health and Medical Research Council of Australia was used to select the intervention studies discussed.
Korner A, Coroiu A, Martins C <i>et al.</i> (2013) Predictors of skin self-examination before and after a melanoma diagnosis: the role of medical advice and patient's level of education.	Questionnaire.	To examine the predictors of Skin Self-Examination (SSE).	47 Patients with stage I-III cutaneous melanoma.	Most melanomas were first detected by patients themselves, partners/spouses and other laypersons. Higher education was associated with an increased likelihood of a) having ever self-examined the skin for suspicious lesions at pre-diagnosis, b) having used a melanoma picture to assist with SSE post-diagnosis and c) having been advised to perform SSE by a health care professional at post-diagnosis. Age and gender were not significantly related to any of the four SSE-related behaviours.	Convenience sample but only a pilot study.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
Manne S & Lessin S (2006) Prevalence and Correlates of Sun Protection and Skin Self Examination Practices Among Cutaneous Malignant Melanoma Survivors.	Cross-sectional questionnaire.	To examine engagement in and stage of adoption of sun protection behaviours and SSE practices among individuals diagnosed with melanoma.	229 patients diagnosed with cutaneous malignant melanoma, greater than 18 years of age and English speaking. Stage 0-IV disease. 1.5 - 2.2 years since diagnosis. 16 (7%) had recurrent disease.	Male melanoma survivors were less likely to engage in SSE and sun protection. Reducing reliance on the beliefs of friends and the general population regarding sun protection, reducing perceived barriers to sun protection, and bolstering confidence in sunscreen use may improve sun protection. It is important that dermatologists and other HCPs educate survivors about correct SSE performance and the importance of sun protection.	The IES was the only measurement tool used in its original form. All other measures were adapted for use with the population.
Smith R (2012) Living with familial melanoma syndrome: coping with the anxiety of three melanomas.	Personal account of having melanoma.	N/A	N/A	Rebecca was diagnosed with three stage I melanomas within a six-month period. Having lots of irregular moles, they didn't look out of the ordinary and Rebecca was afraid that she would not be able to identify another melanoma until it was too late and reached stage IV. She was 'consumed by anxiety' that she would not see her daughter's wedding the following year. Over the next 4 years Rebecca had 120 moles removed which were atypical or benign. This aggressive treatment plan gave her hope and reduced her fear. Rebecca talks about hope and anxiety, almost as counterbalances. Continuity of care and collaboration were also important.	Rebecca was working as an oncology nurse when her first mole was removed and had an oncology position at the time of publication. Her awareness of melanoma from a professional perspective means that she may not represent a typical melanoma patient.
White K, D'Abrew N, Katris P <i>et al.</i> (2012) Mapping the psychosocial and practical support needs of cancer patients in Western Australia.	Cross-sectional questionnaire.	To describe the prevalence of cancer patients' unmet needs and explore how these needs vary across the five most common cancers in Australia (prostate cancer, colorectal cancer, breast cancer, melanoma of the skin and lung cancer).	90 patients with melanoma out of 786 patients diagnosed with cancer between 6 months and 2 years ago.	The two most common needs expressed by all patients were: Fears about the cancer returning and fears about the cancer spreading. When tumour groups were considered separately this was also true for melanoma patients. Unlike other cancer subgroups, participants with melanoma did not rate any items from the physical & daily living domain highly but a significant minority (41%) reported unmet needs from the health system & information domain. Unmet information needs were higher in melanoma patients.	The authors note that during the study, the research assistant received calls from potential participants who wondered why they had been sent the survey as they had not had cancer despite diagnosis and treatment for melanoma. This perception may influence the respondents' perceived unmet needs.

Author(s), Year & Title	Study Design	Aim/Objectives of the study	Sample	Key findings	Limitations/comments
McLoone J K, Kasparian N, Meiser B, <i>et al.</i> (2011) Melanoma risk, clinical care and patients' fears of melanoma recurrence: what is the interplay between these factors?	Cross-sectional survey.	To investigate the prevalence of Fear Of Recurrence (FoR) among moderate and high risk melanoma survivors and explores the psychological mechanisms which may moderate the relationship between risk and fear.	306 melanoma patients with high (54%) or moderate (46%) risk of recurrence.	Participants reported clinically-relevant levels of Fear Of Recurrence (74%), which did not differ significantly between risk groups. However, high-risk (HR) participants did report significantly greater perceived risk of developing a melanoma in the future, compared to moderate-risk participants. They also reported significantly greater satisfaction with clinical care and a greater percentage reported that their doctor had provided education regarding sun protection.	Same study as Kasparian et al. (2012).
Boesen E H, Boesen S H, Frederiksen K, <i>et al.</i> (2007) Survival After a Psychoeducational Intervention for Patients With Cutaneous Malignant Melanoma: A Replication Study.	Randomised controlled trial of a psychoeducational intervention.	To report the effect of the intervention on disease recurrence and mortality up to 5 years after primary surgery. Results for patients who refused to participate in the randomised study are also reported.	262 (128 intervention, 130 control) patients with cutaneous malignant melanoma, 18-70 years old, stage IIA-IIB, 3-12 weeks after surgery.	The cumulative disease-free and survival rates of the groups indicate that non-participants survived for a shorter time than the intervention and control groups, for which there was no difference in survival. No difference in time to recurrence was observed among the three patient groups. Breslow depth and lymph node status were significant prognostic factors for time to recurrence and length of survival. None of the scores for profile of mood and dealing with illness predicted time to recurrence or death.	The authors state that the participants overall had low levels of distress. To identify a survival benefit among patients with low rates of distress, a substantially larger sample size would be needed.
Murchie P, Delaney E K, Campbell N C <i>et al.</i> (2009) GP-led melanoma follow-up: the practical experience of GPs.	Semi-structured audio-taped telephone interviews with GPs delivering the intervention.	To explore how GP-led melanoma follow-up had worked from the perspective of GPs by exploring in detail the practical experience of GPs running the programme.	17 GPs from rural, suburban or urban areas taking part in a GP-led follow-up programme as an alternative to traditional hospital-based follow-up. All 17 GPs who received training and delivered melanoma follow-up during the study year took part in interviews.	GP-led melanoma follow-up worked well from the perspectives of GPs. They felt that they were well equipped and supported in undertaking the follow-up consultations and that patients appreciated the convenience. The GPs felt that a robust recall system, initial training with regular refreshers and effective consultant backup were vital components of a successful long-term programme.	Same study as Murchie et al. (2010).

11.6 APPENDIX 6: EXAMPLE OF CODING, CATEGORY AND THEORY DEVELOPMENT FROM AN INITIAL TO LATER INTERVIEW

Transcript	Open Coding	Focussed Coding
<p>Sarah: Yeah, it started when, well I've always had a mole on me bum, and when I were pregnant with Eva, there were some changes going off in it, mainly towards the end, where it started itching, it had grown outwards. And then when I'd had, I went for me six weeks' check, and I were just going to walk out of the doctors to be honest. I'd had me check in, something just like told me just to get it checked. So I asked if they'd check it, mean I just told them the symptoms, what had changed in it and stuff, and they sent it off. They told me it were probably nowt, it looks fine, probably nowt, and I went to see somebody. They said it'd be nowt, and then it come back, they took something from it, and it come back it were melanoma, in the second stage of it. So then I started to have, I had to have an operation on it, have it all removed and things. And then obviously I had to have follow ups at hospital, where having all me moles constantly checked.</p> <p>I had to have a couple more removed on me belly, one had changed, one were changing, so they took them off, a precaution. And then obviously I've seen them like check me groins and stuff like that, and I missed an appointment in, I think it</p>	<p>Seeing mole change</p> <p>Feeling mole itch</p> <p>Seeing mole growing outwards - Noticing changes</p> <p>Delayed seeking help.</p> <p>Deciding to get it checked while at the doctors/seeking help.</p> <p>Telling the doctor what had changed</p> <p>Being told by the doctor it was probably nothing. Reassured. Trusted the doctor.</p> <p>Being told it was melanoma. ?Loss of trust in doctor.</p> <p>Needing an operation</p> <p>Constantly checking moles.</p> <p>Needing another operation</p>	<p>Noticing</p> <p>Delaying</p> <p>Normalising</p> <p>Trusting</p> <p>Being told (it's melanoma)</p> <p>Needing treatment</p> <p>Monitoring (hospital)</p> <p>Treatment as part of monitoring</p>

<p>were July last year, completely forgot all about it, so I chased it up and they got me in in November. Well the week before I were due to go, I'd like been checking me groins and I'd found a lump. There were three. There were one on me leg, there were two other ones, but one hurt, that's why I realised it. So I booked straight back into the doctors. It had been there for two weeks, so they said they'll transfer me back up to hospital. But I'd already had appointment coming up so they left it at that, and then they got, they checked it all and stuff and did some tests, I had to have a biopsy and everything, and it came back as lymph nodes.</p>	<p>Checking groins Recognising appointments as important Checking my groins Finding a lump that hurt Finding two other lumps that didn't hurt Delaying seeking help from GP Waiting until routine appointment</p>	<p>Monitoring (self) Monitoring (hospital) Monitoring (self) Delaying</p>
<p>It were lymph nodes, and when I were sat in the room with me friend, I could tell on their faces, from the last time I got diagnosed with it. It's like for a second time you're like [sighs]. And me friend said to me why are we sat in this room? I said because they're going to tell me it's bad news. She said no, no, it's not. I said they are, I've got a feeling. The one lump what hurt had gone, but the other two had like joined together and got bigger. So I knew myself, and then they come in and I looked at me friend and she looked at me, and I nodded to her because I</p>	<p>Getting bad news Being able to tell [that it was bad news] from their faces Knowing from last time Expecting bad news from the room that we were in. Having a feeling that it would be bad news. Checking lumps. Seeing the lumps change/grow so knowing that it was bad news</p>	<p>Being told (it's come back) Monitoring (self)</p>

<p>just, I saw their faces. And then the doctor sat down and told me, and just like, you think not again, really. I'm 28 year old, I've got three young children, why me, what have I, you know, it's not fair on nobody but you think.</p> <p>And then it had been, the doctor had told me from when I had me first operation with the mole on me bum, some had broke off, so that's been travelling around me body for over a year and a half. So, because it's gone to me lymph nodes there, they're thinking has it gone anywhere else, has it gone to me brain, because it's been over a year and a half? So I had to have all the scans done, and you're just like, you know, just scared really. There were some results coming back to see if, because I'd already had a brain scan to see if it had gone up to me brain and everything, so we had to wait about in hospital. We went back up, and me dad had asked before I'd even like looked, and he said it's alright, so it were like a relief. When he took me back into the room and told me, it were like, you know, it had not gone up to me brain but they found some more, like in me belly a bit up. They said they don't, they're not cancerous but they're still there, so</p>	<p>Knowing that it was bad news from their expressions</p> <p>Thinking why me. Thinking that it's not fair</p> <p>Being told that it has travelled around my body</p> <p>Wondering if it has gone anywhere else</p> <p>Being scared while waiting for results (of cancer/consequences of cancer)</p> <p>Feeling relieved that the scan was alright</p> <p>Finding things that weren't cancer</p>	<p>Trusting (non-verbal)</p> <p>Reaction – why me?</p> <p>Being told (it could have spread)</p> <p>Reaction (waiting)</p> <p>Reaction (relief)</p>
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<p>they were going to take them away, so it were like basically what, he talked through one operation had now turned into two in one.</p> <p>I just, I were relieved it had not gone nowhere else, but in another way like it's still something else what's happened and stuff. It were all near Christmas time, new year time. They'd given me me operation date for 6th January, so I just had to, for them few weeks, just put a brave face on for me three children, they didn't want to know, and then after that I actually sat down and told them. I'd brought me two boys into the hospital to see the CNS. She spoke to the boys with me and took them up to the ward actually where I'd be staying, to tell them that I'd be alright and be in for a few days. They were alright about it. They've been good, haven't they, they've been supportive.</p> <p>Mum: Yeah, they have, they've done really well to say, you know.</p>	<p>Needing another operation</p> <p>Feeling relieved that it hadn't gone anywhere else</p> <p>Feeling as though it's another thing to worry about</p> <p>Putting a brave face on for the children</p> <p>Telling the children</p> <p>Taking the boys to the hospital to see the CNS and where I would be staying.</p> <p>Telling the boy that I'll be alright.</p> <p>Feeling that the boys are being supportive.</p>	<p>Needing treatment</p> <p>Reaction (relief)</p> <p>Reaction (worry about melanoma)</p> <p>Being strong</p> <p>Talking (tailoring)</p> <p>Talking (support)</p> <p>Monitoring (reactions)</p>
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<p>Sarah: You see, they think I'm, I tell them I'm poorly, I'm not well, but they look at me and think, you know, mum, I've played that act, I'm poorly but I'm not.</p>	<p>Not looking poorly.</p> <p>Children not believing that I'm poorly</p>	<p>Talking (being believed)</p>
<p>Mum: It's not so much the older one, it's the younger one, isn't it, and he gets really emotional. He looks at his mum and thinks, you know, and then he like goes to her and hugs her and, so he knows, he's a very emotional little boy.</p>	<p>Dealing with the reactions of the children</p> <p>Recognising that the youngest son is upset when he hugs Sarah more</p>	<p>Reactions/ Monitoring</p>
<p>Sarah: Yeah, they realised I were poorly when I come out of hospital and when I had to have the bag, the tube thing what I had to come out with. Then they realised like yeah, mummy's poorly. And then once that had gone, they think I'm alright again. I've just like told them now I have to go to hospital every day while you're at school. And I've shown them and stuff, because I've had changes in me body, so I've told them this is, I've got three big scars, this is what's happened, this is, mummy's poorly, she just had to have some lumps took away. And then like such as yesterday, I got out the bath and Josh went mum, what's that on your leg, and seen me scar, because it's all been getting a bit more red and stuff now.</p>	<p>Looking poorly when I came out of hospital</p> <p>Tubes and bags make me look poorly</p> <p>Looking better because the tubes have gone</p> <p>The boys think I'm better because they can't see anything.</p> <p>Showing the scars to the boys to help them understand what has happened.</p> <p>Having three big scars.</p> <p>Children noticing the scars</p>	<p>Sharing</p>

<p>And I just say that's where mummy's poorly, and it's what mummy has to go to hospital for, to make it better.</p> <p>So they understand, but it's just hard me being - I get support through the day, me mum's there, me sister's there, but it's just at night, do you know, like they sometimes ask questions and it's like are you going to be alright mummy, and you're never going to leave me, or you haven't, you know, and you think you're eight year old, you know, you're eight, you're six, this shouldn't be happening. But getting there, I've got me head round it and stuff. I just have all me check-ups and hopefully once this is done with, hopefully I'll be alright in the end. This will sort me out and fingers crossed, they'll be no more. I don't know really.</p>	<p>Explaining what the scars are for</p> <p>Having support during the day from sister or Mum</p> <p>[providing distraction]</p> <p>Being asked if I am going to be alright</p> <p>Dealing with the children's reactions</p> <p>Finding it difficult to have the boys ask if I'm going to leave them, that they are thinking about death. Getting my head around it</p> <p>Having check-ups (to reassure?)</p> <p>Hoping that I'll be alright. Hoping that there won't be any more melanoma</p> <p>Not knowing the future</p>	<p>Sharing</p> <p>Support (practical)</p> <p>Talking (tailoring)</p> <p>Reactions\ monitoring</p> <p>Monitoring</p> <p>Reactions (hope)</p> <p>Reactions (worry)</p>
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Beginning the rollercoaster: Categories and time points shared with Sarah and Lynn during one of the interviews to begin to develop their rollercoaster including a short summary of how the categories fit their experience. This was used to generate discussion during the interview.

P05 & C05 Rollercoaster intro

Important time points	Roles	Relationships	Routines	Resources	Reasoning & Reactions
Before noticing anything	Being a Mum	Kids	Noticing	Family	Why
Noticing	Being normal	Aunt	Monitoring	Healthcare professionals	Worry about it coming back
Diagnosis		Sister	Protecting		Worry about treatment
Finding something new		Mum			Hoping it will be ok
Surgery		Healthcare professionals			
Radiotherapy		Self			
New moles					
? Treatment					



July 2015

P05 & C05 Rollercoaster intro

ROLES

BEING A MUM

This is the most important thing to you. You have maintained the role as much as possible but accepted help from family members when they have offered it. Help has been needed more so during surgery or treatment. Your role as a Mum is limited by tiredness, awareness of the sun on nice days and the need to attend hospital appointments. Your daughter needed to have a mole removed, which caused worry. You have also been thinking about what might happen if you can't be a Mum anymore – will the kids stay together?

BEING A CARER

Your Mum and Auntie have taken on the role of carer at different times, but in different ways. Your expectations of the kind of support you need are similar to your Aunt's expectations and different to your Mums. Your Auntie has been more successful in meeting your needs and expectations, with the help of other family members.

ROUTINES

PROTECTING

Since the first surgery you are more cautious in the Sun and have always been careful to protect your kids. Your awareness of sun protections may have started before you got the first mole. You are aware that protecting yourself from the sun can interfere with playing with the kids in good weather.

NOTICING AND MONITORING

This started when you noticed the first mole – or were you monitoring your skin before? Since then you monitored your body and found the second lump. While looking for changes, the surgeon noticed when the melanoma came back a third time. You have also started to notice and monitor symptoms such as levels of tiredness since the radiotherapy.

RESOURCES

Your main resource has been your family, although your Mum has taken a back seat and your Auntie has provided more support recently. One the melanoma came back a third time, you felt that you needed more help from professionals, such as the Nurse Specialist and allowed yourself to use the help that was offered. You didn't seek help for yourself at any point, from family or nurses until it was offered.

Your belief in spiritualism is a great source of strength and makes you feel better. You haven't been recently but still believe that your Nana is looking out for you and this helps.

July 2015

P05 & C05 Rollercoaster intro

RELATIONSHIPS

FAMILY

You hide a lot of information about your melanoma from people and select who it is shared with. You have sometimes tried to hide from it yourself, but are more accepting of it now that it has come back a third time. You open up more when relaxing with a drink at the weekend with friends or family. Your relationship with your Mum has become more distant as she is unable to provide the support you need, but your Auntie and Sister have been there. Your Dad has been there although he has also been ill.

Your relationship with yourself has been difficult as you struggle to accept the limits of what you can do and how your leg looks after the radiotherapy. Your body image has changed and you have been trying to accept that.

You have tried to hide how ill you are from the kids but have noticed that they are more clingy and may know more than they let on.

REASONING AND REACTIONS

This is mostly concerned with thinking about why you got the melanoma in the first place and then why it came back. You worried about it coming back until it did and then when faced with treatment your worry changed to being about the effects of treatment. You take things a step at a time and create milestones for yourself to get to.

July 2015

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11.7 APPENDIX 7: EXAMPLE OF A THEORETICAL MEMO USED IN THE STUDY

The Memo below shows in part how the process of 'hiding' was developed from interview data and elaborated upon during the analysis process. It illustrates a number of reflective 'questions' that I posed to myself and subsequently explored in the data. Through posing these reflective questions, links between the processes of 'hiding' and 'sharing' became apparent along with a further link to 'relationships'.

Hiding (not sharing)

A number of patients describe '*putting on a brave face*'. They feel that they don't want to burden others with their worries or concerns. Others describe '*choosing*' to tell certain amounts of information to others. Sharing may be delayed to a point where the information feels complete enough to be shared as there would be fewer questions surrounding the information and therefore less to worry others about. This raises a number of questions that I reflected upon such as:

- How do patients and carers decide whom to share information with, when they share it and how much of it is shared?
- Does this relate to age/stage in the lifecycle? Older patients and carers talk more freely about melanoma and what is happening to them but do not always share how they are feeling with others.

It seems that '*hiding*' is usually purposeful, often serving a protective purpose. Does '*sharing*' also have a separate purpose of warning others about the dangers of melanoma specifically or cancer more generally? Or where the effect of not sharing would be seen to be more detrimental (family members who would be more upset to be excluded than by the information or HCPs where not sharing could be detrimental to treatment/recovery)?

Hiding seems to occur throughout the melanoma experience and I wonder if it is a constant process depending upon new information being available to hide or share? This raises the possibility of further questions, such as:

How do patients and carers choose who information is hidden from/shared with?

There also seems to be a variation in who participants want to protect – For example is protective behaviour towards young children or older adults based on an assessment of comprehension or understanding?

Also it is important to consider when information is hidden or shared. From the data it seems that this may be:

- Immediate – to gain support. Family/friends are a resource. Information must be shared with HCPs to gain support (but only if HCP is available and forming a relationship is required for ongoing sharing).
- Delayed – trying not to worry people until it is known that there is something to worry about. This may also depend on how obvious any treatment is (surgery to the head or neck is usually obvious). Not wanting to *'bother'* HCPs if perceived as busy.
- Never – Distant relationship e.g. work colleagues, or more distant family or friends.

Questions also arose in my mind about the amount of information that may be hidden

What information is hidden?

- All – distant relationship with the other person, it won't affect them.
- Some – assessment of the relationship or person means that they need to know some information but not all. Hiding everything may be more detrimental.
- None – usually an existing close relationship where sharing is needed to gain emotional support.

So far the data seem to be indicating that *'hiding'* or *'putting on a brave face'* depends on assessment of the relationship and person with whom the information is to be hidden from. Most effort is put into the situation where some, but not all information is shared, or where information is shared. The data would suggest that this assessment includes a consideration of the:

- Nature of any existing relationship
- How much the information would affect the other person
- Ability of the other person to understand the information
- Ability of the other person to deal with the information
- Perceived benefit of hiding the information/perceived disadvantage of sharing
- Perceived advantage to hiding immediately but sharing at a later time.

This suggested the following type of interactions:

'Putting on a brave face' is part of *'hiding'*. → *'Hiding'* cannot be considered without sharing as they are two points on a continuum. → *'Hiding'* depends on an assessment of a relationship but the action decided upon can then affect that relationship.

If patients are *'putting on a brave face'* or *'hiding'* some information from some people, but talking about this in the interview then that suggests that they do not feel the need to hide

any information from me. Reasons for this disclosure could include: the situation of the research interview, my role as a researcher, early development of the research relationship, knowledge of my role as a nurse, that I am seen as being removed from the situation so not affected by the information in the way that friends or family would be. If the research situation allows participants to talk more freely it begs the question – do participants ever hide any information or feel that they have to *'put on a brave face'* for HCPS? If so, why and what, if any are the barriers to sharing information with HCPS?

11.8 APPENDIX 8: DOCUMENTATION OF ETHICAL APPROVAL



NRES Committee Yorkshire & The Humber - South Yorkshire
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01 July 2013

Miss Joanne Bird
NIHR Research Fellow
University of Sheffield
Academic Unit of Clinical Oncology
Weston Park Hospital
Sheffield
S10 2SJ

Dear Miss Bird

Study title: Understanding the experiences and support needs of patients with melanoma and their carers: Charting changes over time

REC reference: 13YH/0212
Protocol number: STH17039
IRAS project ID: 126810

The Research Ethics Committee reviewed the above application at the meeting held on 27 June 2013. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Miss Sarah Grimshaw, nrescommittee.yorkandhumber-southyorks@nhs.net.

Ethical opinion

The Chair, Ms Jo Abbott, welcomed you to the meeting and thanked you for attending.

The Committee commented that this was an interesting study.

It was noted that in the application form patients and carers would be interviewed separately, yet in the Participant Information Sheet they would be interviewed together and it was queried which was the case.

You clarified that this was primarily a patient decision, though they could discuss it with their carer. You commented that there could be a benefit from interviewing them together but the patients may feel more comfortable discussing it separately to their carer; it would depend on the relationship the patient had with their carer.

Members questioned whether this could cause difficulties with the analysis of the data.

A Research Ethics Committee established by the Health Research Authority

You replied that as you were undertaking an inductive approach you did not think it would affect the study as you will only be told what patients and carers want to tell you.

The Committee noted that in the Health Care Professional Information Sheet it was stated that they were being invited to take part in the research because their patient had found them "helpful", but Members questioned whether this could cause them to respond more positively.

You commented that you would be happy to change this if the Committee felt it necessary, however you wanted to draw out good practice and share this with GPs. You felt that most of the feedback would be down to what was said in the interview.

The REC queried whether carers would continue to be included in the study if patients died.

You replied that you did expect some patients to die and had accounted for that. You commented that if carers wanted to continue they could do but it would be up to them. Similarly if patients were moved onto an end of life pathway and were well enough and willing to participate you would let them.

Members requested clarification as to whether travel expenses would be paid for participants choosing to attend the hospital.

You confirmed that that was the case.

You left the room.

The Committee discussed the responses.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

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

Conditions of the favourable opinion

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

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the

A Research Ethics Committee established by the Health Research Authority

procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Covering Letter		06 June 2013
GP/Consultant Information Sheets	Version 2.1	28 May 2013
Investigator CV		01 June 2013
Letter of invitation to participant	Version 2.1	28 May 2013
Other: Summary CV for Clinical Supervisor - S.Danson	Version 2	03 December 2012
Other: Summary CV for Supervisor - M.Nolan	Version 2	06 June 2013
Participant Consent Form	CF Patients - V2.1	28 May 2013
Participant Consent Form	CF Carers - V2.1	28 May 2013
Participant Consent Form	CF Healthcare Professionals - V2.1	28 May 2013
Participant Information Sheet: Information Sheet for Patients	Version 2.1	28 May 2013
Participant Information Sheet: Information Sheet for Carers	Version 2.1	28 May 2013
Participant Information Sheet: Information Sheet for Healthcare Professionals	Version 2.1	28 May 2013
Protocol	Version 2.1	28 May 2013
REC application	IRAS V3.5	12 June 2013
Referees or other scientific critique report		

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

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

After ethical review

Reporting requirements

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

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

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

Feedback

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

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

13/YH/0212 Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

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

Yours sincerely



pp
Ms Jo Abbott
Chair

Email: nrescommittee.yorkandhumber-southyorks@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers" SL-AR2

Copy to: Miss Clare Hockley, Sheffield Teaching Hospitals NHS Foundation Trust

NRES Committee Yorkshire & The Humber - South Yorkshire

Attendance at Committee meeting on 27 June 2013

Committee Members:

Name	Profession	Present	Notes
Ms Jo Abbott	Consultant in Public Health	Yes	
Dr A H Abdelhafiz	Consultant Physician, Elderly Medicine	Yes	
Reverend Joan Ashton	Co-ordinator of Chaplaincy Services	Yes	
Ms Helen Barlow	Knowledge Service Manager	Yes	
Professor Nigel Beail	Consultant Clinical Psychologist & Professor of Psychology	No	
Dr Rhona Bratt	Retired Multimedia Project Manager	No	
Mr Ian Cawthorne	Chief Pharmacist	No	
Ms Susan Hampshaw	Head of Research, Evaluation and Innovation	Yes	
Mr Neil Marsden	Police Staff	No	
Mrs Andrea Porritt	Community Specialist Practitioner	No	
Ms Stephanie Rhodes	Neonatal Sister	Yes	
Dr Paul Spencer	Consultant Radiologist	No	
Mrs Carole Taylor	Deputy Chief Pharmacist	Yes	

Also in attendance:

Name	Position (or reason for attending)
Miss Sarah Grimshaw	Committee Coordinator
Miss Laura Kirkbride	Senior Coordinator

RISK ASSESSMENT FORM

Sheffield Teaching Hospitals 
NHS Foundation Trust

To be completed for all newly identified risks
For further guidance on completing this form please refer to [Guidelines for Completing a Risk Assessment Form](#) (available on the Trust's intranet) or contact your directorate Risk Lead

Department / Directorate	Cancer Clinical Trials Centre		
Description of risk	Loss or breakdown of laptop containing patient, carer and healthcare professional interviews for STH 17039 research study.		
Existing controls in place when risk was identified	Laptop is encrypted so data would not be accessible to others if found. Data is backed up weekly to University server to reduce the likelihood of loss of all data. University server is covered by university backup policies. If loss were to occur a maximum of 2 interviews would be lost. This would not be detrimental to the study as interviews are repeated throughout the study and data revisited. It is therefore unlikely that important data were not re-visited at a later interview.		
Initial Risk Score i.e. with existing controls in place	Consequence (1-5)	1	
	Likelihood (1-5)	2	
	Risk Score (1 - 25)	2	
Action Plan to reduce the risk to an acceptable level			
Description of actions	Cost	Responsibility (Job title)	Completion Date
Register risk on DATIX (for all risks > 3)	nil		
Target Risk Score i.e. after full implementation of action plan	Consequence (1-5)		
	Likelihood (1-5)		
	Risk Score (1 - 25)		
	Date for completion		
Assessment undertaken by:	Name		
	Job title		
Lead: Joanne Bird	Senior Research Sister & NIHR Research Fellow		
Date of assessment	21/06/2013	Date of next review	21/06/2014

NHS
Health Research Authority

NRES Committee Yorkshire & The Humber - South Yorkshire

North East REC Centre
Unit 002, TEDCO Business Centre
Rolling Mill Road
Jarrow
Tyne and Wear
NE32 3DT

Tel: 0191 428 3561

03 March 2014

Miss Joanne Bird
NIHR Research Fellow
University of Sheffield
Academic Unit of Clinical Oncology
Weston Park Hospital
Sheffield
S10 2SJ

Dear Miss Bird

Study title: Understanding the experiences and support needs of patients with melanoma and their carers: Charting changes over time
REC reference: 13/YH/0212
Protocol number: STH17039
Amendment number: Substantial Amendment 1
Amendment date: 05 February 2014
IRAS project ID: 126810

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 1	05 February 2014
Covering Letter	Letter from Joanne Bird	05 February 2014
Summary of Changes		14 January 2014
Protocol	Version 2.2	14 January 2014

A Research Ethics Committee established by the Health Research Authority

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

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

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

13/YH/0212: Please quote this number on all correspondence

Yours sincerely

pp



Mr Neil Marsden
Chair

E-mail: nrescommittee.yorkandhumber-southyorks@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Miss Clare Hockley, Sheffield Teaching Hospitals NHS Foundation Trust

A Research Ethics Committee established by the Health Research Authority

NRES Committee Yorkshire & The Humber - South Yorkshire

Attendance at Sub-Committee of the REC meeting via correspondence.

Name	Profession	Capacity
Ms Helen Barlow	Knowledge Service Manager	Lay Plus
Miss Kerry Dunbar	Assistant Coordinator	None
Mr Neil Marsden	Police Staff	Lay Plus



Sheffield Teaching Hospitals NHS Foundation Trust

Department
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Academic Unit of Clinical Oncology
Head, Prof P. J. Wool
Cancer Clinical Trials Centre
Weston Park Hospital
Whitham Road, Sheffield S10 2SJ

Tel: 0114 226 5000/5208 Fax: 0114 226 5678

Understanding the experiences and support Needs of patients with melanoma and their carers: charting changes over Time (UNITI)

Information Sheet for Patients

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information - contact details can be found at the end of this sheet. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

The purpose of this study is to consider the experiences of both patients with melanoma and their carers and the kind of support that they need. The type of support has been shown to be an important part of care for cancer patients in general. This study is looking at what patients and carers feel they need.

Why have I been invited?

You have been invited because you have been diagnosed with melanoma and we are interested in your experience and your views about the care you received. We will be asking people to help us who, like yourself, have had treatment, or are currently having treatment, for melanoma.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet and asked to sign a consent form. If you change your mind and want to withdraw you can do so at any time without giving a reason. If you do not want to take part or withdraw from the study, it will not affect you or the care you receive in any way. If you withdraw from the study, any information that can still be identified as yours will be destroyed if you wish.

What will be involved if I agree to take part?

If you would like to take part we would like you to be involved in a series of interviews over three years. These can take place somewhere that is convenient for you, which could be your home or at the Cancer Clinical Trials Centre, Weston Park Hospital. We would like to ask you about your experience of being treated for melanoma and how it has affected you. If you agree, we would like to audio-record the interviews to help us to remember the things you have said. The interviews should take about an hour. Interviews will take place at different time points over the three years to look at how things have changed for you. This would be an initial interview followed by further interviews at 3, 6 and 12 months then 6 monthly interviews. If you have any further treatment for melanoma we would ask to do another interview at that time.

If you agree, we may contact you after the interviews to ask if you would like to help us to create recommendations for the care of future melanoma patients. This is optional and you may choose not to take part at that point.

We are also inviting carers to take part and with your permission would invite whoever is most involved in your care at home to take part. This could be a relative, friend or someone else. We will provide them with a separate information sheet and ask them to complete a consent form if they would like to participate. If your carer decides to take part, you may choose to be interviewed together or separately.

Healthcare professionals are being included in this study and if you would like to take part, at the 6 month interview we would like to ask you to nominate a healthcare professional who you think has been helpful during your care. This could be nurses, doctors, complementary therapists or other professionals from the community, hospital or charitable teams.

We will also ask for your permission to look at your medical notes to obtain information about your diagnosis and treatment.

At the end of the study we will create guidelines for the care of patients with melanoma based upon the findings of the study. You will have the opportunity to take part in this if you wish to and this may be done individually or as a group.

What are the possible disadvantages and risks of taking part?

We will be asking you to spend an hour of your time with us to talk about your experience of being treated for melanoma on 8 to 10 occasions. Your healthcare will not be affected in any way by taking part in this study but talking about some experiences may be upsetting.

What are the possible benefits of taking part?

There is no intended clinical benefit to you from taking part in this study although some people find it helpful to talk about what has happened to them.

The information we gain may help improve the experience of people who are treated for melanoma and their carers in the future.

What if I experience distress as a result of taking part in this study?

The researcher, Joanne Bird, will be happy to answer any questions you may have as a result of taking part in this study and can be contacted on 0114 2265208.

The Skin Cancer Clinical Nurse Specialist team can also be contacted if you wish to discuss your participation in this study or have any questions about your care. They are independent of the research team and will not have access to any information you provide as part of this study.

Claire Powell: 0114 2713014
Marion Page: 01226 435311

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

Anything you tell us in the interview will be kept strictly confidential. We will not tell anyone else of your involvement in the study or of anything that you may say to us without your permission. Only members of the research team will have access to the audio recordings and the written transcripts obtained from the audio recording. The transcripts will not identify you personally or anyone who you may have talked about. The audio recordings of the interviews will be kept in a locked cupboard for the duration of the study, and destroyed afterwards. The reports and publications arising from the study will not identify anyone who has participated.

If your carer or nominated healthcare professional takes part in the study and the interview takes place separately, then we will not discuss what you have said in these associated interviews.

With your permission, we will write to your GP to let them know of your participation in this study and what it involves, but they will not have access to any of the information that you provide in the interview.

What will happen to the results of the research study?

The findings from the study will be published in medical journals. No-one will be identifiable.

Who is organising and funding the research?

The study is being undertaken by researchers from the Department of Clinical Oncology and School of Nursing & Midwifery at the University of Sheffield. The research is funded by a grant from the National Institute of Health Research.



Sheffield Teaching Hospitals 
NHS Foundation Trust

Department Of Oncology

Academic Unit of Clinical Oncology
Head, Prof P.J Woll
Cancer Clinical Trials Centre
Weston Park Hospital
Whitham Road, Sheffield S10 2SJ

Tel: 0114 226 5000/5208 Fax: 0114 226 5678

Understanding the experiences and support Needs of patients with melanoma and their carers: charting changes over Time (UNITI)

Information Sheet for Carers

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information - contact details can be found at the end of this sheet. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

The purpose of this study is to consider the experiences of both patients with melanoma and their carers and the kind of support that they need. The type of support has been shown to be an important part of care for cancer patients in general. This study is looking at what patients and carers feel they need.

Why have I been invited?

You have been invited because you care for someone who has been diagnosed with melanoma and we are interested in your experience and your views about how this has affected you. We are asking people who care for someone who has had treatment, or is having treatment, for melanoma to help us.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet and asked to sign a consent form. If you change your mind and want to withdraw you can do so at any time without giving a reason. If you do not want to take part or withdraw from the study it will not affect you, the person you care for or the care they receive in

any way. If you withdraw from the study any information that can still be identified as yours will be destroyed if you wish.

What will be involved if I agree to take part?

You will only be able to take part if the person you care for also wishes to take part as we would like to look at how patient and carers are affected by the same experience. If you would both like to take part we would like you to be involved in a series of interviews over three years. These can take place somewhere that is convenient for you, which could be your home or at the Cancer Clinical Trials Centre, Weston Park Hospital. We would like to ask you about your experience of caring for someone being treated for melanoma and how it has affected you both. If you agree, we would like to audio-record the interviews to help us to remember the things you have said. The interviews should take about an hour. Interviews will take place at different time points over the three years to look at how things have changed for you. This would be an initial interview followed by further interviews at 3, 6 and 12 months then 6 monthly interviews. If the person you care for has any further treatment for melanoma we would ask to do another interview at that time. You may be interviewed with the person you care for or separately if you wish.

If you agree, we may contact you after the interviews to ask if you would like to help us to create recommendations for the care of future melanoma patients. This is optional and you may choose not to take part at that point.

Healthcare professionals are being included in this study and if the person you care for chooses to take part, at the 6 month interview we ask them to nominate a healthcare professional who they think has been helpful during their care to be interviewed. This could be nurses, doctors, complementary therapists or other professionals from the community, hospital or charitable teams.

At the end of the study we will create guidelines for the care of patients with melanoma based upon the findings of the study. You will have the opportunity to take part in this if you wish to and this may be done individually or as a group.

What are the possible disadvantages and risks of taking part?

We will be asking you to spend an hour of your time with us to talk about your experience of caring for someone being treated for melanoma on 8 to 10 occasions. The healthcare of the person you care for will not be affected in anyway by taking part in this study but you may find that talking about some experiences is upsetting.

What are the possible benefits of taking part?

There is no intended clinical benefit to you or the person you care for from taking part in this study although some people find it helpful to talk about what has happened to them. The information we gain may help improve the

experience of people who are treated for melanoma and their carers in the future.

What if I experience distress as a result of taking part in this study?

The researcher, Joanne Bird, will be happy to answer any questions you may have as a result of taking part in this study and can be contacted on 0114 2265208.

The Skin Cancer Clinical Nurse Specialist team can also be contacted if you wish to discuss your participation in this study or have any questions about melanoma care. They are independent of the research team and will not have access to any information you provide as part of this study.

Claire Powell: 0114 2713014
Marion Page: 01226 435311

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence.

Anything you tell us in the interview will be kept strictly confidential. We will not tell anyone else of your involvement in the study or of anything that you may say to us. Only members of the research team will have access to the audio recordings and the written transcripts obtained from the audio recording. The transcripts will not identify you personally or anyone who you may have talked about. The audio recordings of the interviews will be kept in a locked cupboard for the duration of the study, and destroyed afterwards. The reports and publications arising from the study will not identify anyone who has participated.

If your interview takes place separately from the person you care for, then we will not discuss what you have said with them.

What will happen to the results of the research study?

The findings from the study will be published in medical journals. No names or details of individual patients will be included.

Who is organising and funding the research?

The study is being undertaken by researchers from the Department of Clinical Oncology and School of Nursing & Midwifery at the University of Sheffield. The research is funded by a grant from the National Institute of Health Research.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has

been reviewed and given a favourable opinion by South Yorkshire Research Ethics Committee.

Who can I contact for independent advice about participating in this study?

If you would like independent advice about taking part in the study, you may wish to contact:

Patients Services Team
Tel: 0114 271 2400
Email: PST@sth.nhs.uk

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers listed below who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure by contacting the following person:

Simon Heller, Research Department, Sheffield Teaching Hospitals NHS Foundation Trust.
Telephone: 0114 2265934

There are no special compensation arrangements for patients harmed by taking part in this research project. In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for legal action for compensation against Sheffield Teaching Hospitals NHS Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Further information and contact details

If you would like more information about the study, would like to talk about taking part or are have any concerns about the study please contact:

Joanne Bird
NIHR Research Fellow
Tel: 0114 2265208
Email: joanne.bird@sheffield.ac.uk

Dr Sarah Danson
Consultant in Medical Oncology
Tel: 0114 2265000

Cancer Clinical Trials Centre
Weston Park Hospital
Whitham Road
Sheffield
S10 2SJ

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



Sheffield Teaching Hospitals **NHS**
NHS Foundation Trust

Department
Of
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Academic Unit of Clinical Oncology
Head, Prof P J Woll
Cancer Clinical Trials Centre
Weston Park Hospital
Whitham Road, Sheffield S10 2SJ
Tel: 0114 226 5000/5208 Fax: 0114 226 5678

Understanding the experiences and support Needs of patients with melanoma and their carers: charting changes over Time (UNITI)

CONSENT FORM - CARERS

Participant Identification Number for this study: Please
initial box

1. I confirm that I have read and understand the information sheet dated (version) for the above study.
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.
4. I agree to the use of audio-recording, with possible use of anonymised verbatim quotation.
5. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person Taking consent Date Signature
When completed: 1 for participant; 1 for researcher site file;



Sheffield Teaching Hospitals **NHS**
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Understanding the experiences and support Needs of patients with melanoma and their carers: charting changes over Time (UNITI)

Information Sheet for Healthcare Professionals

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information - contact details can be found at the end of this sheet. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

The purpose of this study is to consider the experiences of both patients with melanoma and their carers and the kind of support that they need. The type of support has been shown to be an important part of care for cancer patients in general. This study is looking at what patients and carers feel they need.

Why have I been invited?

You have been invited because one of your patients is taking part in our study and they have nominated you as a Healthcare Professional who has particularly helped them during their treatment and/or diagnosis for melanoma.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet and asked to sign a consent form. If you change your mind and want to withdraw you can do so at any time without giving a reason. If you do not want to take part or withdraw from the study, it will not affect you, the person you care for or the care they receive in any way. If you withdraw from the study, any information that can still be identified as yours will be destroyed if you wish.

What will be involved if I agree to take part?

If you would like to take part we would like you to be interviewed twice during the study, once now and again at the end of your patient's participation. The second interview could take place at any time in the next two years if you wish to participate in a further interview. Interviews can take place somewhere that is convenient for you, which could be your home, place of work or at the Cancer Clinical Trials Centre, Weston Park Hospital. We would like to ask you about your experience of providing healthcare for someone with melanoma and how you think it has affected them. If you agree, we would like to audio-record the interviews to help us to remember the things you have said. The interviews should take about an hour.

At the end of the study we will create guidelines for the care of patients with melanoma based upon the findings of the study. You will have the opportunity to take part in this if you wish to and this may be done individually or as a group.

What are the possible disadvantages and risks of taking part?

We will be asking you to spend an hour of your time to talk about your experience of providing healthcare for someone being treated for melanoma on 1 to 2 occasions. The healthcare of the person you care for will not be affected in any way by taking part in this study.

What are the possible benefits of taking part?

There is no intended benefit to you or your patient from taking part in this study although some patients find it helpful to talk about what has happened to them. The information we gain may help improve the experience of melanoma patients and their carers in the future.

What if I have concerns as a result of taking part in this study?

The researcher, Joanne Bird, will be happy to answer any questions you may have as a result of taking part in this study and can be contacted on 0114 2265208.

The Skin Cancer Clinical Nurse Specialist team can also be contacted if you wish to discuss your participation in this study or have any questions about melanoma care. They are independent of the research team and will not have access to any information you provide as part of this study.

Claire Powell: 0114 2713014
Marion Page: 01226 435311

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will

be handled in confidence.

Anything you tell us in the interview will be kept strictly confidential. We will not tell anyone else of your involvement in the study or of anything that you may say to us. Only members of the research team will have access to the audio recordings and the written transcripts obtained from the tape recording. The transcripts will not identify you personally or anyone who you may have talked about. The tape recordings of the interviews will be kept in a locked cupboard for the duration of the study, and destroyed afterwards. The reports and publications arising from the study will not identify anyone who has participated.

What will happen to the results of the research study?

The findings from the study will be published in medical journals. No-one will be identifiable.

Who is organising and funding the research?

The study is being undertaken by researchers from the Department of Clinical Oncology and School of Nursing & Midwifery at the University of Sheffield. The research is funded by a grant from the National Institute of Health Research.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given a favourable opinion by South Yorkshire Research Ethics Committee.

Who can I contact for independent advice about participating in this study?

If you would like independent advice about taking part in the study, you may wish to contact:

Patients Services Team
Tel: 0114 271 2400
Email: PST@sth.nhs.uk

What if something goes wrong?

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Telephone: 0114 2265934

Further information and contact details

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Joanne Bird
NIHR Research Fellow

Tel: 0114 2265208
Email: joanne.bird@sheffield.ac.uk

Dr Sarah Danson
Consultant in Medical Oncology

Tel: 0114 2265000

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



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Understanding the experiences and support Needs of patients with melanoma and their carers: charting changes over Time (UNITI)

CONSENT FORM - HEALTHCARE PROFESSIONALS

Participant Identification Number for this study: Please
initial box

1. I confirm that I have read and understand the information sheet dated (version) for the above study.
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected.
4. I agree to the use of audio-taping, with possible use of anonymised verbatim quotation.
5. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person Taking consent Date Signature
When completed: 1 for participant; 1 for researcher site file;

11.9 APPENDIX 9: LAY SUMMARY SENT TO PARTICIPANTS



Sheffield Teaching Hospitals 
NHS Foundation Trust

Cancer Clinical Trials Centre

Co-Directors:
Dr Jon Wadsley, Prof Janet Brown

Cancer Clinical Trials Centre
Weston Park Hospital
Whitham Road, Sheffield S10 2SJ
Telephone: +44 (0) 114 226 5208
Fax: +44 (0) 114 226 5678

Understanding the experiences and support Needs of patients with melanoma and their carers: charting changes over Time (UNITI)

Summary of Results for Patients, Carers and Healthcare Professionals

Thank you for taking the time to participate in this study. We hope you will find the final results of the study interesting and that they reflect your experience.

What was the purpose of the study?

This research aimed to explore the changing experiences and support needs of patients with melanoma and their carers throughout the disease process.

What happened during the study?

Patients, carers and healthcare professionals were interviewed up to six times over a two-year period. Interviews were transcribed and key events identified. Diagrams were also drawn to visually represent the experience of having melanoma.

What were the main findings of the study?

Interviews with patients, carers and healthcare professionals identified four important stages of the melanoma experience, these were:

- Before diagnosis
- At diagnosis
- During observation
- Living with advanced disease

The overall experience was described as being like '*Riding a Rollercoaster*' with melanoma causing both '*ups*' and '*downs*' for patients and carers as changes had to be made to their roles, routines and relationships.

Before diagnosis patients and carers usually '*noticed*' some unusual change to their skin, but this was often seen as nothing to worry about and could be forgotten until it further changes caused greater concern. It was only then that professional help was sought. This would usually be from the patient's GP who would either give reassurance and advise the patient to monitor any further changes or refer them to a specialist.

Patients then underwent investigations and when they were given a diagnosis of melanoma they talked about being in a state of '*shock*'. This often made it difficult for information about melanoma and any related treatments to be fully understood. In the best circumstances patients (but rarely their carers) were well supported by a healthcare professional and developed a trusting relationship, often with the same person. This relationship frequently lasted throughout their whole experience. However, not everyone was well supported and carers needs in particular were often not recognised.

UNITI Final Summary Draft Version 4.0 (14 Dec 2018)

1

During initial treatment, patients tried to continue with their normal work, family and leisure routines but these were often affected due to their treatment. These changes could be temporary but some were long lasting. Patients and carers usually turned to their family and friends for support at this time, but to provide the support needed family/friends had to have information about the melanoma. Not all patients shared their diagnosis with everyone, and sometimes they '*hid*' it so as to prevent people from worrying. This could have a negative impact on patients' relationships with family and friends.

At all stages healthcare professionals were an important resource providing information, clinical expertise and emotional support. It was therefore essential that healthcare professionals were accessible to patients and carers and could be easily contacted if help was needed. However, if healthcare professionals made promises that they did not keep, such as failing to return telephone calls, patients and carers lost trust in them and felt abandoned.

While recovering from treatment patients and carers remained under close observation requiring frequent visits to clinics. During this time, scans, examinations and if needed the removal of any suspicious lesions could be reassuring or a cause of major worry. Feelings of uncertainty were some of the major ups and downs of '*riding the rollercoaster*'. In between clinical visits patients and carers would keep a close eye on any changes to their condition ('*monitoring*'). Sometimes patients and carers would do this together but at other times carers would '*keep an eye*' on their relative but not tell them so that the patient wouldn't worry. In addition patients and carers often developed new sun protection routines such as applying sun cream or wearing more clothing in sunny weather.

Some patients developed advanced melanoma and at this stage monitoring for any side effects of treatment and the symptoms of melanoma became even more important. Family members also often had to take on more caring responsibilities, especially if the patients' condition worsened. Therefore relationships with family and friends became increasingly important as people prepared to say goodbye.

At this stage it was very important to have a healthcare professional to contact for advice. However, as patients often received treatment from a number of differing departments maintaining a close relationship with a trusted healthcare professional could be difficult. The quality of the overall experience of patients with melanoma and their carers is largely determined by their interactions with healthcare professionals which can have a positive effect, especially where a trusting relationship has been built. Unfortunately, at times too many healthcare professionals were involved and patients and carers did not know who to contact.

What will happen to the results of the research study?

The findings from the study have been presented at conferences and will be published in medical journals. They will also be made available via the websites of the Yorkshire and Humberside Consumer Research Panel and Cancer Research UK. It is hoped that the findings will be used to improve the experience of patients and carers living with melanoma in the future. No participants will be identifiable. Pictures created during the study can be seen on the website of the Yorkshire and Humberside Consumer Research Panel:

http://www.yhcrp.org.uk/?page_id=890

Further information and contact details

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