

NCSI Research Work Stream Survivorship Journey Mapping Project

Summary and reports for Bowel Cancer Breast Cancer Lung Cancer Prostate cancer

May 2009

This document brings together a selective summary of the four cancer site reports. For each report the groups reviewed the information provided and developed a suggested list of recommendations. These are indicative and not exhaustive. The summary which follows is a further summary of the four reports attached, and this document should be regarded as 'work in progress', which will contribute to the body of research and evidence being gathered to support the Survivorship Initiative.

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Please kindly note that pages 34 and 90 are on A3 and may need to be printed separately

A summary of the NCSI Research Work Stream Mapping Project

1. Purpose

This paper summarises the immediate outcomes of a key mapping project, that the National Cancer Survivorship Initiative Research work stream is undertaking to identify what is and what is not known about the health and well-being, care, support needs and experiences of people living with and beyond cancer.

This paper summarises the final reports submitted by four charities which represent the four most common cancers; Bowel Cancer UK, Breakthrough Breast Cancer, The Royal Castle Lung Foundation, and The Prostate Cancer Charity and considers key research questions that have arisen as a result of this work. Work is currently underway with the rarer cancer organisation, Cancer52, to identify issues and research gaps for the rarer cancers.

Due to the richness of the data provided in the four submitted and accompanying report, this paper should be read in conjunction with, rather than used as a replacement for, the original submitted reports.

2. Background

The aim of the mapping project is to:

- Map the 'survivorship journey' of people affected by cancer, ie what happens to survivors of cancer and what issues and challenges do they face?
- Identify where research is needed to better understand the needs of people living with and beyond cancer and to develop and test interventions to best meet those needs.

The final reports submitted to the NCSI Research work stream, highlight the key issues and research questions identified by the charities and cross cutting issues that may be relevant to all cancers.

The final reports are a result of internal and external stakeholder consultation. Stakeholder's views (patients, health care professionals, carers) were gathered, collated and analysed through the extraction of organisational knowledge, submission of grey literature from the charities' key organisational contacts, and validated through stakeholder meetings and focus groups. Each charity was asked to consider two survivorships frameworks/models, the Feuerstein Model and most recently the NCSI Vision document model to use as a guide during the process (see Appendix 1 and 2)

3. Cross Cutting Issues

During the process of identifying the issues for each site specific cancer, several themes were identified which could be considered issues for all cancers. These issues were either identified by the charities themselves and/or on preliminary analysis by the Research work stream supports and are summarised below. Research questions pertaining to some of these issues may be found in section 4 below. However, some require further investigation before relevant research questions can be formulated.

1. **Information:** what is the current availability, accessibility, appropriate timing of delivery, tailoring (for age, gender, ethnic minorities) of information on treatment decision making, availability and accessibility of support services (psychosocial service, complementary therapies, financial), side effects and late effects? What are the information needs of people moving towards the end of life stage? How can this be improved? What are the information needs of employers of people with cancer and their families and carers? and of cancer survivors returning to work or those requiring financial support?
2. **Access to services:** What is the scope of the current provision of support services for people with cancer? What is the current situation with access to clinical nurse specialists and how can this be improved? Are new treatments available to all cancer patients? What are the support needs of people moving towards the end of life stage and how can current provision be improved?
3. **Primary care:** How can the awareness of primary health care professionals be improved to address survivorship needs, eg knowledge of treatment side effects and detection of secondary cancers?
4. **Age:** Does age affect access to cancer care and support services?
5. **Psychosocial issues:** anxiety, depression, fatigue, pain, long and short term side effects. What interventions can be used to address these issues?
6. **Marital status:** What are the needs of single people living with cancer?
7. **Implementation of good practice:** A lot of research already exists but does not always get implemented into best practice. What are the barriers to good practice being integrated into daily service delivery?
8. **Recording data:** A national system is required to record outcomes/long-term effects following cancer treatment – what is the best way to measure and record such effects?

4. Summary of main reports: Key issue and themes for consideration

The section below summarises some of the key issues/themes and research questions identified by each site specific charity to be priorities for people living with and beyond cancer. The main reports contain more detail and a further record of additional priority research questions.

4.1 Bowel cancer

The report, entitled '*Bowel Cancer Survivorship Report*' was provided by Bowel Cancer UK. The Charity identified 5 conclusions which they felt were issues for bowel cancer patients:

1. Misdiagnosis and delayed diagnosis are a common issue
2. The need for more emotional support such as counselling, or access for local bowel cancer support groups
3. A lack of verbal and written information on diet, financial assistance, and contact information for support and other issues

4. High variability in availability and quality of follow-up services and support
5. Variability in the availability of the bowel cancer screening programme

Example of research questions identified, relevant to each stage of the survivorship models are listed below:

1. *Diagnosis*

Many of the questions posed centre around themes and areas that will be dealt with through the National Awareness and Early Diagnosis Initiative (NAEDI) eg questions around misdiagnosis and delay, interventions to encourage people to act on their symptom and uptake to the national screening programme. Additional questions include:

- How can bowel cancer patients be provided with enough emotional support, verbal and written information during or immediately following diagnosis?

2. *Treatment (primary and secondary)*

- Are there enough colorectal nurse specialists to provide care and support to bowel cancer patients and what impact does the perceived change in numbers of CNS's have on patient care?
- How can the communication of treatment options be improved in order for bowel cancer patients to make informed decisions and who is the best health care professional to do this?
- What is the level of implementation and availability of new treatments eg laparoscopic surgery?
- How can written and verbal information about bowel cancer treatment and its side effects be improved?
- What support services could be introduced to help patients cope through their treatment phase eg chemotherapy central helpline, counselling services?

3. *Period immediately following treatment, remission and follow up*

- Are the national guidelines on follow up care for bowel cancer patients, all encompassing, adequate and up to date and widely implemented? If not how can these be improved?
- Is there sufficient practical advice on diet, nutrition, local support groups, counselling, realistic exercise, financial assistance and remaining well and how can patients access this easily?
- How can the support for bowel cancer patients and their families be improved after discharge from hospital eg access to CNS's and emotional support?
- Is the information about statutory benefits and employee rights for long term sick leave, advice and support effectively communicated to bowel cancer patients and well implemented? How can this be improved?

4. Long term effect of bowel cancer (including recurrence)

- What are the long term effects of radiotherapy and chemotherapy for bowel cancer patients, and how can these be addressed?
- How can bowel cancer patients be supported during times of anxiety in terms of recurrence?
- What is the impact of psychosexual issues of patients with permanent stoma and how can these be addressed?

5. End of life care

- How can palliative care for patients with bowel cancer and their families be effectively delivered and what are the issues around the implementation of NICE treatment guidelines for colorectal cancer and Improving Supportive and Palliative Care for Adults with Cancer?

The charity also identified issues and research questions which arise across most or all of the survivorships stages.

6. Ethnicity and bowel cancer

- How do different ethnic groups' incidence, mortality, five and 10 year survival rates compare? and why are some ethnic groups more or less likely to develop bowel cancer than others?

7. Socio-economic deprivation and bowel cancer

- Is there an association between deprivation and incidence for either men or women for either colon or rectal cancers?
- Is there unequal access to medical services in different social groups and how can this be improved?

4.2 Breast cancer

The report entitled '*Mapping the needs for breast cancer survivors: information from qualitative stakeholder research and grey literature*' was submitted by Breakthrough Breast Cancer.

A large amount of research into breast cancer survivorship has already been carried out, so the charity undertook a significant period of information gathering and analysis to identify and prioritise the relevant research gaps and subsequent questions. There are an abundance of research questions. These have been summarised and grouped into thematic areas as below:

1. Health Services Research

- How can we develop, and pilot, best practice models of follow up care that can be adapted to the individual, including how follow up should be conducted and who should provide follow up care and where?
- What is the most effective method for detecting recurrence and new primary disease?

- What are the best practice models for improving and joining up primary and secondary care pathways?
- Developing and piloting models of joined-up health and social care for patients needing end of life care.
- Which type of healthcare professional is best placed to act as a key worker for secondary breast cancer patients, by co-ordinating their health and social care at all levels?

2. Prevalence

- A national system is required to record outcomes/long-term effects following cancer treatment – what is the best way to measure and record such effects?
- What is the prevalence of metastatic breast cancer?
- What are the adverse effects and impacts of different modalities of treatment on quality of life? Are any groups more likely to have their quality of life significantly impacted (eg due to age, gender, ethnicity, socio-economic status, other diseases etc)? When are the effects likely to occur and how long are they likely to last?
- How does survivors' quality of life change over time?

3. Work and finance

- What are the information needs of the employers of breast cancer survivors?
- What are the information needs of breast cancer survivors returning to work or those requiring financial support?

4. Information

- There is a need for the development and testing of an 'information needs' assessment tool that would support healthcare professionals to provide relevant information to breast cancer survivors and people with secondary breast cancer.
- What specific information is needed in a breast cancer survivorship care plan and how is it best communicated to the patient and all relevant healthcare professionals?
- How can appropriate and timely information about what to expect at the end of life, and where to get advice and care, be best provided to patients and their families/carers?
- How should the information on the side-effects of drug treatments be delivered?
- What information and support is needed to assist breast cancer survivors to self-manage their care, post-diagnosis?

5. Physical and psychological effects of cancer, its treatment and effects of treatment

- What are the most effective methods for treating menopausal symptoms, problems with sexual function or sexuality and lymphoedema in breast cancer survivors?
- Development and testing of a tool to assess the emotional state of breast cancer survivors and people with secondary breast cancer.

- What are the most effective methods for treating the psychosocial effects, and improving quality of life, of breast cancer treatments?
- How do individuals' health behaviours, self-esteem and coping responses specifically affect quality of life and wellbeing after breast cancer?
- Interventions to address psychosocial problems in the long-term need to be developed and tested.
- How can the adverse effects of breast cancer treatment best be prevented or reduced?
- Greater research evidence on the safety and effectiveness of complementary therapies to inform patients, healthcare professionals and NHS commissioners.
- Development of an appropriate needs analysis to determine the services and support required by people with secondary breast cancer.
- How can people with secondary breast cancer be supported to "live well" (maintain a good quality of life)?
- How do location (eg urban v rural), employment, family structures and social support impact on the breast cancer survivorship experience, including psychosocial needs, access to and uptake of relevant support services and quality of life?
- What is the impact of breast cancer on carers and families? What are their support and information needs?

4.3 Lung cancer

The report, entitled '*Lung Cancer Research Work stream Final Report*' was submitted by The Royal Castle Lung Foundation.

The report initially recognises the lack of research into the impact of lung cancer on patient carers, the NHS and society as a whole. With relatively small numbers of lung cancer patients alive 1 year after diagnosis and only 7% of people diagnosed with lung cancer still alive after 5 years, the Charity welcomed the opportunity to take part in this initiative.

The report focuses on the identification of issues for those affected by lung cancer, rather than suggesting specific research questions. It considers the relevant cross cutting clinical, socio-cultural, individual and environmental factors throughout each stage of the lung cancer survivorship pathway and references relevant pieces of literature at each stage. The lung cancer survivorship model has been populated and is attached to the final report.

Initial analysis of the survivorship model shows that there are several prevalent issues which arise across all stages of the survivorship pathway from diagnosis through to end of life care. These are:

1. Anxiety, depression, fatigue, breathlessness
2. Common side effects of radiotherapy and chemotherapy
3. Psychosocial issues, eg anger guilt and the stigma attached to having lung cancer

Key issues which arise on preliminary analysis of the issues stated under the medical, socio-demographic, individual and environmental variable factors of the survivorship model are:

1. Access to services eg CNS/Specialist lung oncologists, breathlessness clinics, new treatments, clinical trials, post treatment rehabilitation and fitness planning, diet, and smoking cessation support
2. Lack of awareness of signs and symptoms of initial and recurrent cancer both in public and GPs – this can lead to a delay in diagnosis
3. Information and support services, e.g. need for tailoring of information and support services to socially deprived sector and to explore patient barriers to accessing appropriate care and support
4. Stigma, eg impact of stigma on patients and their families, impact of social deprivation, and social inequalities

The report lists grey literature which explores survivorship issues for lung cancer patients, but recognised that there is little research available on the impact of lung cancer. As such there is a large general research gap which exists and is relevant to lung cancer survivorship.

4.4 Prostate Cancer

This report, entitled '*Identification of research needed into the experience of men living with and beyond prostate cancer*' was submitted by The Prostate Cancer Charity. The top five research priorities identified by the Charity were:

1. *Psychosexual needs of men with prostate cancer*

- What is the impact of loss of sexual function and sexual desire on men?
- What are the appropriate interventions and forms of support for men experiencing loss of sexual function and sexual desire?

2. *The support needs of men from black and minority ethnic groups (and their partners)*

- What is the experience, including cultural perceptions, of having prostate cancer among different black and minority ethnic (BME) groups and accessing prostate cancer health and support services?
- What are the most appropriate interventions to support BME men (and their partners) affected by prostate cancer?

3. *'Empowering' interventions*

- What are the self management techniques which men are currently using to manage their disease and side effects and what is their effectiveness eg diet, exercise, and complementary therapy?
- What are the best self management interventions to help men manage their condition and treatment side effects?

4. Understanding the long term impact of treatment side effects to aid informed treatment decision making

- What is the existing evidence on incidence and long term impact of treatment side effects?
- What is the scale and long term impact of side effects of gaps that have been identified through the question above?
- How is information on potential long term side effects of treatment communicated by healthcare professionals to men making treatment decisions and how can this process be improved?

5. Follow up systems and support for men on hormone therapy

- What is the follow up experience of men on hormone therapy? In particular how do they feel about the follow up processes in place, and how well they are communicated with? Are they provided with information and support to help them cope with side effects?
- What are the best practice models of co-ordinated follow up for men on hormone therapy?
- What interventions can support men to cope with hormone therapy side effects? What is the impact on sexual function/sexuality and mental wellbeing?

Other areas identified as relevant research priorities:

6. Development, evaluation and implementation, of an assessment tool to identify the survivorship needs of men affected by prostate cancer.
7. Understanding the scale and causes of anxiety and depression among men living with and beyond prostate cancer and understanding what interventions or self management techniques may help men manage anxiety and depression and help them cope with anxiety around the time of their regular PSA tests?
8. Understanding the experience of men undergoing active surveillance and the development of interventions to support them.
9. Understanding the impact of loss of sexual function or sexual desire through prostate cancer treatment, and identifying interventions support needs of partners of men with prostate cancer.
10. Work, finance and social care needs of men with prostate cancer

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April 2009

Appendix 1

Feuerstein Model

SURVIVORSHIP FRAMEWORK TO INFORM THE RESEARCH AGENDA

1. Background to the modified Feuerstein conceptual framework

- 1.1 The Feuerstein model (see figure 1, tables 1-3) identifies six stages or phases involved: diagnosis, treatment, acute, sub-acute, chronic (now referred to as 'long term') and end stage. These phases can be influenced by medical, sociocultural, individual and environmental factors, each of which contains a number of variables that can lead to various challenges or benefits across each of the phases. The stages and interrelationships between them are not fixed and the framework recognises that transitions can occur, so that an individual can move back and forth between them. The framework was presented to help organise research and thinking in the area and with the recognition that its validity needs testing with well designed research studies. It will also be tested by practical application through the work of the Research Work Stream.
- 1.2 The model tries to conceptualise survivorship across time. Rather than just a non specific statement that many use which is 'from the time of diagnosis to end of life', the model tries to break down this time into discrete phases. However, the exact beginning and end of survivorship needs to be studied longitudinally in order to empirically define the phases, both in terms of time frames and specific challenges.
- 1.3 Please note that it is acknowledged that the model is not perfect. The NCSI vision document model was used in conjunction with the descriptions of the phases, factors and variable of the Feuerstein model in the final stages of the mapping project, to ensure that all each stage of the survivorship journey was considered.

Figure 1

BIOPSYCHOSOCIAL MODEL OF CANCER SURVIVORSHIP

Factors that Impact Optimal Survivorship

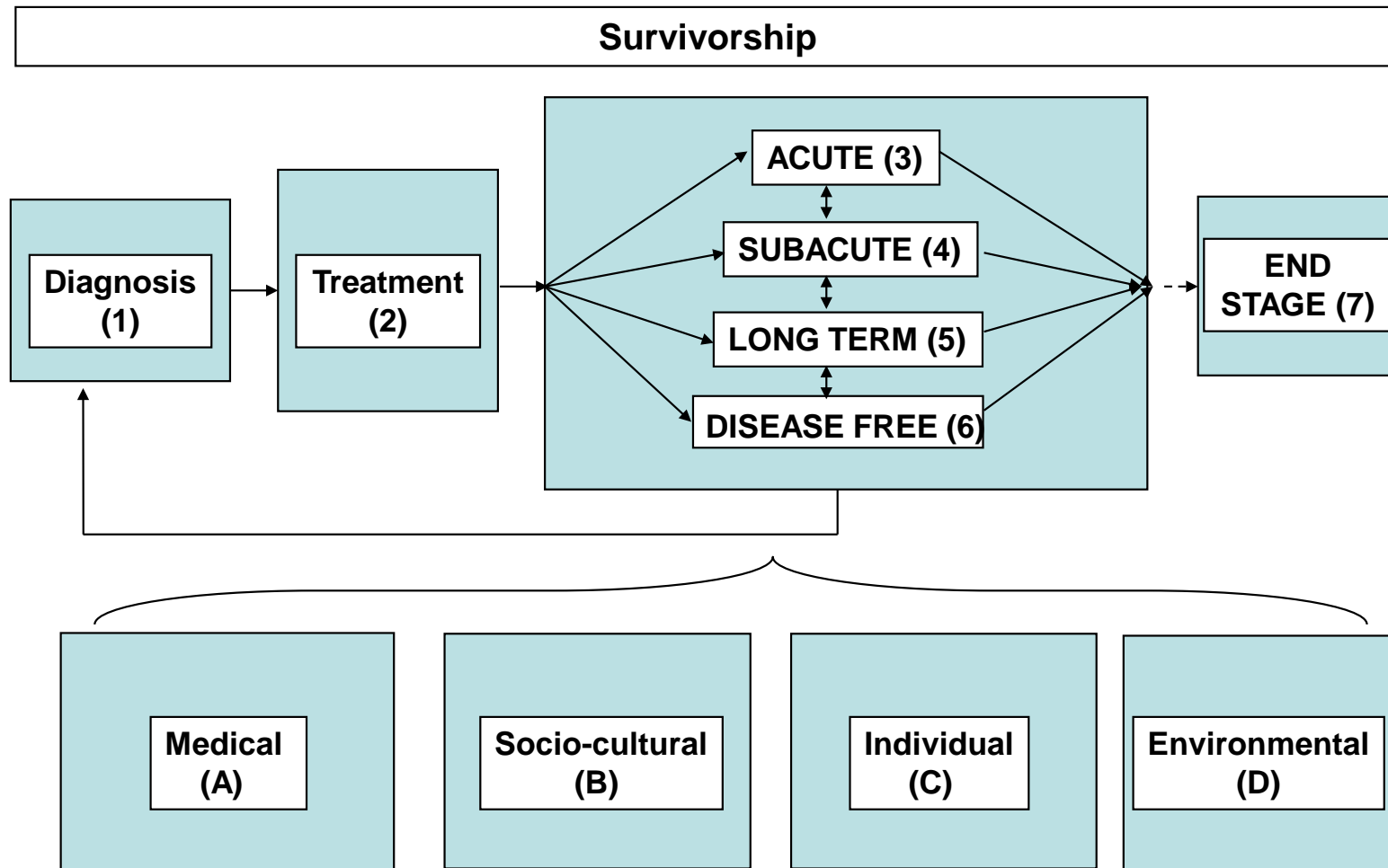


Table 1

Description of the phases for the survivorship model

Phase	Description (with reference to the Macmillan Principles of People Centred Care in italics)
1. Diagnosis	Covering all aspects from ' <i>something's wrong</i> ', the initial onset of symptoms and contacting primary care, ' <i>going for tests</i> ', referral from primary care, to ' <i>finding out what is wrong</i> ', the results of tests and diagnosis. Also covers screening and recurrence
2. Treatment	Covers ' <i>going through treatment</i> '. Primary treatment, ie surgery, radiotherapy, chemotherapy, hormones, no treatment/watchful waiting
3. Acute	Covering the immediate period following primary treatment and then ' <i>going home / follow up treatment</i> '. This stage overlaps with ' <i>treatment</i> ' but specifically covers long term treatment out of hospital, eg tamoxifen for breast cancer. This stage may be short or non-existent if the treatment is uncomplicated.
4. Sub acute	Covering ' <i>living with the consequences of cancer</i> ', this is a term used in many diseases / illnesses to refer to that time directly after initial treatment when there is an expectation that health and function will begin to stabilise
5. Long term	Also covering ' <i>living with the consequences of cancer</i> ' and encompassing the initial aspects of ' <i>if cancer comes back</i> ' prior to diagnosis again. Not every cancer survivor experiences problems but they go into this stage some time after acute and sub-acute stages with around a third to a half of all survivors experiencing problems. Some cancer survivors continue to experience problems for years covering a varying burden of symptoms and functional changes (eg fatigue, cognitive limitations, work, relationships, sexual function or sexual desire, physical activity, mood state /depression). Patterns of problems vary across survivors and across time.
6. Disease free	Added to the original model to specifically recognise that for those for whom treatment is successful and uncomplicated in terms of side effects and long term and late effects that the 'end stage' can be long term disease free survival. Also reflects that some people no longer consider themselves to be cancer patients any longer. It is important that there are records of the disease and treatment in case of recurrence or late effects, and as such will encompass ' <i>if cancer comes back</i> '.
7. End stage	To signify that survivorship reaches a conclusion that may be long term disease free survival as above or death from cancer either rapidly for some cancers or many years later for others

Table 2

Description of the factors and variables for the survivorship model

Factor	Variables	Description / comments
A. Medical (covering physical and some psychological and social dimensions of health and well-being)	Tumour biology: 1. Pathology 2. Response	Basic science and clinical research. Will cover mechanisms of recurrence of relevance to survival
	Health status: 3. current health 4. other diseases 5. past health	Physical and psychological measures of health and well being, co morbidities and health records
	Residual symptoms: 6. fatigue 7. depression 8. pain 9. cognitive limitations 10. relationships	Physical, psychological and some social measures of health and well being related to initial response to disease and treatment, side effects and the onset of persistent long term effects
	Medical Care: 11. access 12. quality 13. cost	Measures of patient satisfaction and economic evaluation
B. Socio-cultural (covering some of the social dimension of health and well-being)	14. Age 15. Gender 16. Ethnicity 17. Education 18. Socioeconomic status	Aspects of social well-being and status that impact on treatment decisions, survival rates and risks of recurrence and side and late effects
C. Individual (covering aspects of physical, psychological and spiritual dimensions of health and well-being)	Coping response: 19. behavioural 20. response 21. cognitive 22. biological	Coping identified as a major area of importance for patients, carers and families. Psychological and physical measures of health and well being and primary and secondary prevention
	Health behaviours: 23. smoking 24. alcohol 25. exposure to sun 26. diet 27. exercise 28. weight 29. stress	Primary and secondary prevention measures and general measures of physical health and well being
	Disposition: 30. problem solving 31. optimism	Psychological measures of health and well-being
	Transformative coping: 32. spiritual 33. non-spiritual	Spiritual measures of health and well being covering general sense of purpose and meaning in life and personal values
D. Environmental (covering some of the social dimension of health and well-being)	34. geographic 35. work 36. family 37. social support	Aspects of social well being and status that impact on disease and treatment as well as covering reintegration into society and wider societal impacts of diagnosis and treatment

Table 3

Matrix for use of the survivorship model to map research needs and issues:

Factor and variable	1. Diagnosis	2. Treatment	3. Acute	4. Sub-acute	5. Long term	6. Disease free	7. End stage
A. Medical - Tumour biology: 1. Pathology 2. Response							
A. Medical – Health status: 3. current health 4. other diseases 5. past health							
A. Medical – Residual symptoms: 6. fatigue 7. depression 8. pain 9. cognitive limitations 10. relationships							
A. Medical – Medical care: 11. access 12. quality 13. cost							

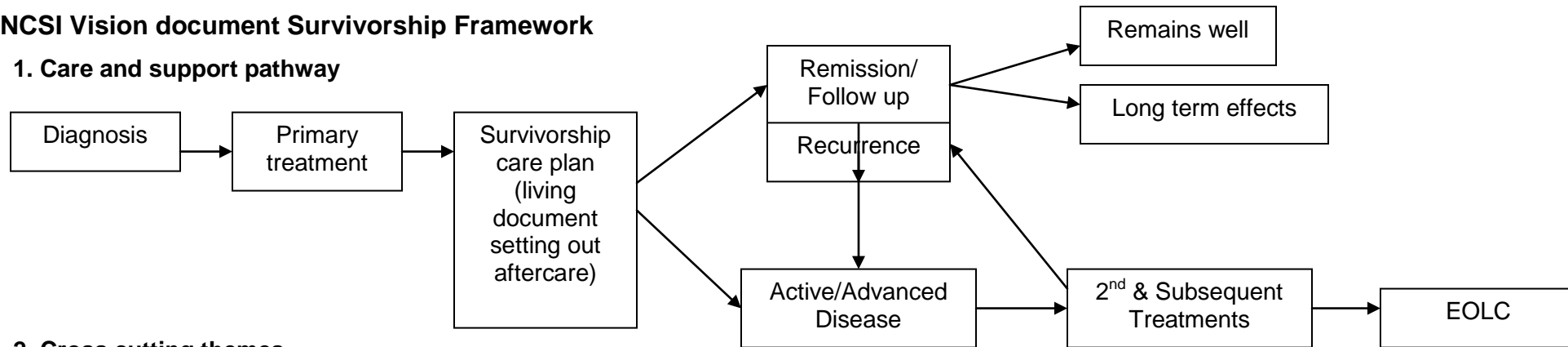
Factor and variable	1. Diagnosis	2. Treatment	3. Acute	4. Sub-acute	5. Long term	6. Disease free	7. End stage
B. Socio-cultural: 14. Age 15. Gender 16. Ethnicity 17. Education 18. Socioeconomic status							
C. Individual – Coping response: 19. behavioural 20. response 21. cognitive 22. biological							
C. Individual – Health behaviours: 23. smoking 24. alcohol 25. exposure to sun 26. diet 27. exercise 28. weight 29. stress							
C. Individual – Disposition: 30. problem solving 31. optimism							
C. Individual – transformative coping: 32. spiritual 33. non-spiritual							

Factor and variable	1. Diagnosis	2. Treatment	3. Acute	4. Sub-acute	5. Long term	6. Disease free	7. End stage
D. Environmental: 34. geographic 35. work 36. family 37. social support							

Appendix 2

NCSI Vision document Survivorship Framework

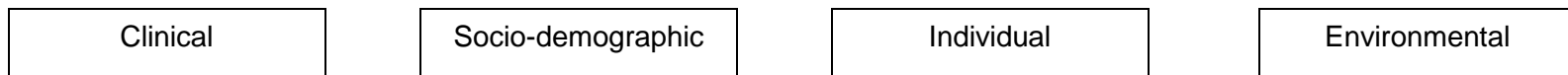
1. Care and support pathway



2. Cross cutting themes



3. Factors which impact on survivorship



Links to individual reports:

[Bowel Cancer](#)

[Breast Cancer](#)

[Lung Cancer](#)

[Prostate cancer](#)

National Cancer Survivorship Initiative

Bowel Cancer Survivorship Report

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April 2009

Abstract

Bowel Cancer UK has been invited to participate in the research strand of the National Cancer Survivorship Initiative in order to conduct a review of bowel cancer survivorship research gaps. To achieve this, we conducted a patient focus group; undertook a small scale patient questionnaire; held interviews with a range of clinicians; and also invited partner organisations and academics to comment on our findings. This process allowed us to identify a wide range of issues affecting bowel cancer patients, from the point of diagnosis on through treatment, remission, and finally the disease free or end of life care stages.

It is useful but problematic to attempt to create a hierarchical order of the most important issues, as not all of these affected each patient. In fact, the hegemony of patient survivorship experiences was noticeable; particularly in post treatment sub acute and long term stages. However, during the diagnosis and treatment phase, more homogenous patient experiences were observed. This implies that there are no national guidelines, or standard practices for the following up of bowel cancer patients once initial treatment has been concluded, or that these are not yet applied ubiquitously.

This research has allowed us to conclude that:

- Misdiagnosis and delayed diagnosis are common. Approximately one third of patients surveyed claim to have been misdiagnosed. Furthermore, more than half experienced delays to their initial diagnosis. This is critical for bowel cancer patients, as 83% of Dukes stage A patients survive for five years or more compared to just 3% of those presenting with Dukes stage D. GPs admitted they had difficulty in identifying bowel cancer symptoms due to two factors: Firstly, some bowel cancer symptoms are also indicative of more benign conditions, such as Irritable Bowel Syndrome, constipation or bleeding piles. Secondly, GPs feel unable to refer all such patients to hospitals as the hospitals would be unable to cope with the demand. Worryingly, this implies that a certain number of patients will inevitably be missed and present with a more advanced cancer.
- Many patients requested more emotional support such as counselling, or access to local bowel cancer support groups. Currently, there are very few bowel cancer support groups and the lack of NHS counselling options lead to some patients feeling a sense of anomie or abandonment at every stage of their pathway. Although this was less pertinent during the treatment stage (which was largely praised by nearly all patients), this was more of an issue during diagnosis and post-treatment from hospital. Patients also feel there is not enough emotional support for family or friends, who are also in need of assistance throughout the patient pathway.
- Many patients complained of a lack of verbal, but especially written information on a number of topics such as diet, financial assistance, who to contact for support and other issues. These problems persisted from the diagnosis stage right through to the end of life stage for a number of patients, but particularly in sub acute and long term stages.
- Patients had a generally positive experience of their treatment, and especially of colorectal nurse specialists, who were available to support them. However, individual patients' experiences of follow up are highly variable. Indeed, a common complaint amongst patients was that they did not receive sufficient (or in half the cases any) support following discharge from hospital.

- The introduction of the bowel cancer screening programmes in England, Scotland and Wales have allowed some patients to be diagnosed earlier. However, screening is not available to all, and according to the latest estimates, only 50% of those eligible are taking part in the programme. There is some qualitative evidence which suggests that Asian communities are less likely to participate in screening opportunities.

Methodology

Bowel Cancer UK initially held a number of internal meetings, with a GP, our colorectal nurse specialists, and our services and communications staff members, to brainstorm what we believed to be the key survivorship issues for bowel cancer.

On 11th February 2009, we held a patient focus group at the Salvation Army building near St Paul's Cathedral. This meeting involved 18 patient participants in various survivorship stages, whose ages ranged from 35 to 70. This group was divided into two smaller focus groups of equal size and the meeting divided into two approximately equal halves. Diagnosis and treatment were discussed in the first half and post-treatment issues in the second.

Our patients' contributions provided us with some invaluable information, which we were able to incorporate into the Feuerstein model provided for us. Since the focus group, we have been able to design, distribute, retrieve and analyse a questionnaire sent to all the patients who attended the focus group. We felt this was necessary to allow individuals to contribute anything they felt they were unable to say on the day, or simply did not have time to do so.

This questionnaire was also sent to 60 additional patients who we are in regular contact with. In total we received 44 completed questionnaires. Whilst this sample is too small for any significant quantitative analysis to be carried out, we have been able to use the information to help confirm (or otherwise) the information provided from the focus group, as well as provide additional qualitative input.

Analogous to the patient survey, we have designed interview schedules for a number of clinicians including: colorectal surgeons, colorectal nurse specialists, nurse consultants, GPs and NHS Bowel Cancer Screening Practitioners. We have analysed the information coded from the clinician interviews, which we have then been able to adapt in the Feuerstein model to incorporate their views.

We have conducted some desk research, and also within our own medical encyclopaedias, the journals we subscribe to and the internet. This suggests that there is a very large gap in the existing literature tackling these specific bowel cancer issues. When we extended this search to include assistance from partner organisations and academics, we received some modest information of existing research. However, this is still slight compared with the sheer quantity and variety of survivorship issues identified for bowel cancer patients.

There are a number of methodological weaknesses with the survivorship design, which diminish the strength with which we can generalise from data to results:

1: No ethnic minority patients participated, meaning it is possible that some important survivorship issues may arise in the future.

2: While we have naturally investigated patients who are still alive, it is possible that patients who do not survive will have had different experiences or concerns over any of the phases. I am

particularly thinking of the treatment phase. Almost all of the patients involved in this study had positive experiences of treatment. However, this may not necessarily be true for others.

3: The survey sample is very small (respondents). This means we are very limited in the analysis we can reasonably undertake, and to extrapolate anything other than the mildest of generalisations will potentially be unrepresentative, invalid or misleading. However, they are included as a part of this report mainly to triangulate the focus group findings and also offer further qualitative experiences using the open ended questions.

Diagnosis

The diagnosis phase of the bowel cancer survivorship experience is a critical phase for the emotional and physical outcomes for patients. Due to the nature of bowel cancer, 83% of patients who present Dukes stage A tumours survive for five years or longer. This compares quite dramatically with only 3% of Duke stage D patients, surviving for 5 years or more. Therefore, any delays or misdiagnoses to the diagnostic stage have serious implications for patients.

Unfortunately, the focus group and the associated questionnaire implied that both misdiagnosis and delayed diagnoses were common in bowel cancer.

The questionnaire substantively (although not significantly) suggested that approximately a third of the respondents were misdiagnosed and that there were delays to over half the patients' diagnosis. The most common reasons given for delayed diagnosis were initial misdiagnosis; patients ignoring or being unaware of any symptoms; patients not being offered a colonoscopy; the GP ignoring the concerns of patients; long waiting lists for scans and tests; and, in one case, the GP ignoring a combination of symptoms and first degree relative family history.

Within the focus group, it was implied that misdiagnosis is more common in younger people, although this claim is not supported by any relevant research, and needs examining further.

The interviews with the GPs were illuminating in explaining a possible factor in delayed and misdiagnosed patients. The GPs we spoke to confessed they had difficulty in diagnosing bowel cancer. This problem arises as:

“symptoms can often be vague and mimic common conditions”.

They feel they cannot refer every possible patient as:

“the hospitals will be swamped!”

When we suggested a scheme such as a specialised bowel cancer screening centre they were largely in agreement that this may assist them.

The introduction of the bowel cancer screening programme in England, Wales and Scotland should yield an increase in the number of people being diagnosed at earlier stage cancers. This should have a very positive impact in a number of bowel cancer survivorship experiences. However, this screening programme is still relatively young, with information regarding its efficacy largely undisclosed.

Patients often requested more emotional support during and immediately after diagnosis, such as counselling, a consultation with a specialist nurse or access to a 24-hour cancer helpline. One patient commented that:

“It was all a bit mind-blowing and it would have been nice to have somebody to sit and talk to. It was not offered, so I just went to work and tried to pretend it was not happening.”

This reflects the need for more emotional support, but also highlights a related issue, that patients are often shocked by the diagnosis and find it difficult to digest verbal information during the initial consultation. Therefore, unless patients are provided with access to the NHS and are provided with enough written materials, the anxiety and fear of an already frightening experience increases. This is particularly pertinent for people with memory issues. As the vast majority of bowel cancer cases present in patients over the age of 60, this is a genuine cause for concern.

A number of patients (albeit a minority of patients) stated that the manner of the way the diagnosis was delivered to them was in some way insensitive, or cold. For example, one patient recalled:

“After my colonoscopy, I received a letter from the hospital with a follow up appointment to ‘discuss the results.’ At that stage I thought it might be IBS or Crohns, as no one seriously thought I had bowel cancer...When the news was broken to me that I had cancer, I went into shock and was unable to take in any info. I was completely unprepared to be told such devastating news and did not have anyone with me at the appointment, apart from my two children aged 12 months and three years.”

Diagnosis Research Questions

A number of research questions on the diagnostic stage were identified:

- Why are some patients misdiagnosed?
- What proportion of patients are misdiagnosed?
- Are some demographic groups more likely to be misdiagnosed, and why?
- How do we access/encourage people to act on their symptoms?
- How beneficial is the introduction of the screening programme in reducing delayed diagnoses and misdiagnoses?
- Which groups are taking up the screening programme and how can we improve penetration in groups that are not engaging with it?
- How can bowel cancer patients be provided with enough emotional support during or immediately following diagnosis?
- How can bowel cancer patients be provided with enough verbal and written information at diagnosis?

Research Articles on Survivorship Diagnosis Issues

1: The UK CRC Screening Pilot Evaluation (Ethnicity) Team. (2003).
Ethnicity: UK Colorectal Cancer Screening Pilot. National Health Service.

The screening pilot report offered some explanations as to why some groups from Asian communities were less likely to participate in screening and other health promotion activities. However, the research methodology largely used a name recognition software model, which we do not consider to be a valid model. The follow up focus groups offered a more robust attempt to analyse screening uptake in ethnic minorities.

2: Julietta Patnick. (2004). *Issues in Cancer Screening*. Inequality in Cancer Prevention Conference Report. 2004.

3: Luck, M (2004). *Working with Non-responders*. Inequality in Cancer Prevention Conference Report. Cancer Research UK. 2004.

The above two reports offer a number of innovative ways in which to engage with non-respondents. However, these discuss the generic issue of cancer rather than bowel cancer specifically.

We have identified that there are a great number of research questions in the diagnostic phase of survivorship, with relatively few articles addressing these points. There are, therefore, a large number of research gaps, and many opportunities to improve on our current knowledge of bowel cancer diagnosis.

Treatment

The treatment phase of the bowel cancer survivorship model was generally positively received by almost all patients in both the questionnaire and focus group. Once diagnosis moved to treatment, most patients were operated on in within a few weeks.

The majority of bowel cancer patients have little or no choices with their treatment, as the treatment for most cases is similar (surgery with often chemotherapy and/or radiotherapy). However, of the patients who were offered any treatment choices, the majority appreciated this. However, around a third of these patients felt they did not have enough time to make treatment related decisions.

Patients had varying experiences with the multi-disciplinary team (MDT) treating them. Patients had universal praise for the colorectal nurse specialists treating them. One typically positive response stated that:

“Colorectal nurses are brilliant! You get to know them and you can ask them anything.”

However, many patients felt that colorectal nurse specialists have too much work to do, and as a result sometimes felt guilty in making demands on their time. When we interviewed the nurses they thought they did have enough time and capacity to provide patients with an appropriate amount of care. However, they did agree that with more time, they could offer a greater standard of care to each patient.

The communication from the MDT to the patient was delivered by a range of staff members. The most common communicator was the surgeon, colorectal nurse specialist and the oncologist. A third of our patients rated the communication to them from the MDT to be either poor or average. One of the concerns from patients at this stage is that the MDT is often large and so different messages arrive from different members of staff:

“You see so many people, so it’s hard to get any continuity. You might see one person initially, and then not see them again.”

The oncologists we interviewed openly admitted that different MDTs have different policies on who speaks to the patient during treatment and that this is not always the same person. However, this isn’t necessarily true of all cancers. One patient compared the experiences of her bowel cancer and gynaecological cancer MDTs:

“With my gynaecologist, the treatment is more joined up and better than bowel [treatment] which is all over the place.”

Whether this is a perceptual problem or a medical care one is something that is worth extra investigation to determine.

Some patients felt they weren’t necessarily informed of possible side effects from treatment such as chemotherapy. Some patients conceded, however, that they may indeed have been given this information, but received so much verbal information in one sitting that they may have forgotten being informed of it.

This implies that more written information could help patients remember their verbal conversations. Oncologists and colorectal surgeons agreed that there is not adequate written information given to patients during the treatment phase. Colorectal surgeons believe the responsibility to provide this should be assigned to colorectal nurse specialists.

Interestingly, the oncologists we interviewed were divided on the need for a chemotherapy central helpline. Some oncologists agreed that this would be comforting and useful for patients going through frightening side effects, although others warned that chemotherapy cases are unique to the individual, and a generic helpline might not be able to offer adequate assistance to them.

Positively, the vast majority of the patients were well informed of their pathway during the treatment stage. Most patients largely felt they were offered enough verbal information during this stage, but half suggested they did not receive enough written information. Interestingly, the colorectal nurse specialists do not agree with this, suggesting patients do in fact already receive adequate written information.

Few clinicians offered counselling for their patients, or families of patients, at this stage, although counselling would be welcomed by patients, both for themselves and their families.

Patients seem confused about whom to call in an emergency. They have informed us they would appreciate a 24 hour emergency support number. This was especially true at weekend. Some oncology teams provide clear information and support on this, but others do not.

Laparoscopic surgery often has advantages over traditional open surgery in recovery time and the length of stay in hospital. This is not yet available in all hospitals, however.

Treatment Research Questions

- How does the MDT assist patients in making informed decisions about their treatment?
- Are there enough colorectal nurse specialists to provide an adequate level of care?
- Are the numbers of colorectal nurse specialists increasing or decreasing?
- If the number of colorectal nurse specialists is decreasing, what is the magnitude of the detriment to patient care?
- Which members of the MDT should be responsible for communicating messages to patients?
- Would national guidelines on communicating to bowel cancer patients be useful for MDTs or colorectal staff?
- Is there a need for a chemotherapy central helpline for patients?
- What written and verbal information needs to be expanded to provide a patient with sufficient knowledge of their treatment and potential side effects?
- How cost effective and beneficial would counselling services for patients, family and friends be?
- How does the NHS ensure that each patient knows whom to contact for medical and emotional support during all times of any given day?
- Are the numbers of colorectal nurse specialists increasing or decreasing?
- If the number of colorectal nurse specialists are decreasing, what is the magnitude of the detriment to patient care?
- What proportion of bowel cancer patients are offered laparoscopic surgery, and how fast is this rate being increased?

Research Articles on Survivorship Treatment Issues

1: (National Institute for Health and Clinical Excellence (2006). *Laparoscopic Surgery for Colorectal Cancer. Review of NICE Technology Appraisal 17.*

This paper examines the benefits of offering laparoscopic surgery. However, the paper is now three years old and does not, therefore, contain up to date information regarding how this technique is being rolled out. Consequently, there is an almost entire research gap in bowel cancer treatment issues and survivorship.

Acute Stage or Immediately Following Treatment

The acute stage of the patient pathway covers the immediate period following primary treatment and the patient going home. This stage also involves follow up treatment. The patients in our focus group and survey almost unanimously agreed that they received relatively poor aftercare. This was especially so in contrast to their positive experiences at the treatment phase.

Not all patients experienced negative acute phase care. Indeed, the experiences of patients following hospital discharge were markedly varied. For example, half of the patients received no support whatsoever; some were provided with home visits by stoma nurses or colorectal nurse specialists; a minority were given dieticians to consult with; whilst some of the nurses we consulted said that patients were provided with a mobile phone number which they could call any time or day of the week to speak with someone from their oncology team. However, these initiatives are not applied to all hospitals. Therefore, there are large discrepancies in the provision of aftercare following treatment.

One common issue raised by patients is the lack of consistent follow up procedures by medical staff. As already outlined, a wide range of initiatives are offered to some patients, but many receive nothing at all. This has potential to increase feelings of abandonment by the NHS. As one patient puts it:

“Even a phone call would have helped.”

Another patient found it upsetting that he or she:

“had to chase blood tests and scans results.”

Some patients were provided with telephone numbers for medical advice. However, some hospitals do not offer this service. Furthermore, the majority of patients were not given information on who to contact for emotional support (such as counselling or local support groups), something many would have wished to receive. Furthermore, the majority of patients highlighted that there was not enough support for carers or relatives at this (or any other) stage.

There appears to exist an interesting dichotomy where patients feel an implicit pressure not to contact colorectal nurse specialists with problems or concern by telephone, as they don't want to burden busy staff. However, the colorectal nurse specialists we interviewed suggested they'd be happy to field phone calls from worried patients.

Patients, GPs, colorectal nurse specialists and oncologists concur that there is inadequate written information given to patients during this phase. This was especially true for dietary advice, which is critical for bowel cancer patients who may have had some of their bowel removed during surgery, as one patient put it:

“This is my biggest criticism of all. There was no diet advice. In hospital, plates of sausages and mash, or curries, were plonked down in front of me.”

Another patient exclaimed:

“Someone tell me what to eat!”

Some hospitals provided specialised dieticians who were able to provide helpful information, which was welcomed by patients. However, as stated, this is not universally provided.

Information on recommencing realistic exercise, how to access state benefits, the side effects of stoma and reversals and chemotherapy were also requested by patients.

Many bowel cancer patients (although not exclusive to bowel cancer) are fitted with stomas following surgery. These may be either permanent or temporary. Some patients receive training on how to use these and also receive home care visits for stoma health checks. However, this service is not universally provided.

Some patients expressed problems of access when urgently needing to visit a bathroom.

Research Questions on the Acute Stage of Survivorship

- Who should be responsible for organising follow up care to patients, and how should this be implemented?
- What are the national guidelines for follow up care of bowel cancer patients and how are these implemented?
- How can the written and verbal support for bowel cancer patients be improved, and who should be responsible for providing this?
- Where can patients find access to practical advice on diet, nutrition, local support groups, counselling, realistic exercise, financial assistance and remaining well?
- How do colorectal nurse specialists reassure patients that they are welcome to contact them for advice after discharge from hospital, and how can this be improved?
- How can emotional support for patients' family members and friends be improved?

Research Articles on the Acute Survivorship Stage

Professor Bob Steele from the University of Dundee is keen to point out that the long term experiences of bowel cancer survivors is associated with diet, avoidance of weight gain and appropriate exercise. Indeed, the Live Well Study that Professor Steele and his colleagues are currently working on demonstrates that:

“Patients who have recovered from colorectal cancer surgery welcome and respond to advice on diet, exercise and weight management.” Furthermore the study has ***“qualitative data that makes it clear that there is considerable demand for this type of information.”*** (Steele, 2009)

However, this report has not yet been published, and as such cannot mitigate the research issues outlined above.

Sub-acute, Remission and Follow up

The sub acute phase of bowel cancer survivorship covers those living with the consequences of cancer. This phase considers the time when there is an expectation that health and function will begin to stabilise.

For the sub-acute phase, all of the factors such as adequate written and verbal information; who to turn to for emotion and medical support; how to access local support groups; and who to turn to for counselling for patients, family and friends, are relevant, and need to be highlighted.

There are a number of government benefits, which patients can access at this stage of their survivorship, such as reduced gym membership schemes, disabled toilet access, financial assistance and disabled parking schemes.

Additionally, employment issues become more pertinent in the sub acute stage. In our patient focus group and questionnaire, the majority of patients had positive experiences with employers. This was particularly true with companies who employed occupational health workers.

However, this was certainly not ubiquitous, and there were some companies who did not accommodate their patient employers adequately. Suzie Scaddon from Beating Bowel Cancer was keen to point out that our focus group failed to acknowledge the number of people who have had to go off on long term sick; are made redundant; and have to seek work after their cancer diagnosis. These scenarios create additional stress not only for patients but also for partners, families or friends who may need to financially aid patients.

Research Questions on the Sub-Acute Stage

All of the research questions from the acute phase are still relevant in the sub acute section, and would therefore be included in this section, but are omitted to avoid undue repetition. This demonstrates how the borders of the survivorship model are not mutually exclusive rigid spheres, but interdependent and overlapping.

- Additional research questions include:
- How are statutory benefits for bowel cancer patients advertised?
- What are the laws regarding employee rights for longer term sick leave, and how can this information be provided to patients?
- How can employers' provision of information, advice and support be improved for patients returning to work after cancer?

Long Term Effects of Bowel Cancer

The long term effects of the bowel cancer survivorship stage covers living with the consequences of bowel cancer, as well as the issue of whether the cancer returns.

For bowel cancer, all the points offered in the acute and sub acute sections are still relevant here (e.g. need for support groups, counselling, access to medical services, written and verbal advice on a range of practical issues). However, this stage also includes a number of additional issues, including stoma reversal and the long term physical and psychological issues of medical treatment.

Most bowel cancer patients' stomas are temporary. However, approximately 10% of stomas are permanent. The permanent stomas provide body image and psychosexual issues, although (perhaps understandably) the patients at the focus group chose not to discuss these. Temporary stomas involve a process of reversal, which can have a number of possible side effects. Some patients mentioned they did not receive enough information about these possible side effects.

There is little information available on the possible long term physical and psychological side effects of radio or chemotherapy. We know, for example, that complaints such as Peripheral Neuropathy (numbness in hands and feet) are usually temporary, but some patients are reporting this problem several years after treatment. Another issue is the psychological worry of recurrence and of the experience as a whole on both patients and their families:

“An unanticipated consequence is that I never stop thinking about it. I fear another cancer diagnosis on some part of my anatomy, because I think I must be vulnerable, and worry every time I have a pain anywhere.”

“My daughter, who was nine at the time of my diagnosis, has become a bit of a hypochondriac but also continually worries about me too.”

Research Questions on Long Term Survivorship Stage

- How can issues surrounding anxiety of recurrence be addressed by National Health Services?
- What are the long term effects of radiotherapy on bowel cancer patients?
- What are the long term effects of chemotherapy on bowel cancer patients?
- How are the side effects of stoma reversals explained to patients?
- What psychosexual counselling would aid patients with permanent stomas?

None of the research we have uncovered has allowed us to answer any of the above topics and they are, therefore, research gaps on survivorship.

All of the above concerns affect those in the disease free stage. For the sake of avoiding repetition, the disease free stage is not included in this report.

End of Life Care

The two main issues of the end of life care stage are palliative care choices and access to life-prolonging drug treatments. During this stage of survivorship, patients may not be able to internalise information on options. However, it is important for choices, such as access to hospices, to be delivered to family members. There is an issue as to who should provide this information, and how.

There is much reported debate on the access of certain life-extending drugs for certain cancers, and bowel cancer is not immune from this. Currently, NICE guidelines on specific drug treatments are interpreted differently by PCTs. As a result, patients' experiences of access to these treatments vary widely, dependent upon which catchment area they are in.

End of Live Care Survivorship Research Questions

- How should palliative care options be delivered to the patient or family?
- How should NICE drug treatment guidelines be interpreted?
- Would a single body interpreting NICE guidelines and providing a national standard be beneficial?

As with most of the previous survivorship stages, we have found very little in terms of appropriate research on these matters.

Cross Cutting Themes

There are a number of issues which cut across many or all of the survivorship stages. We have seen how the provision of verbal and written information, counselling, support groups and access to medical staff are paramount in all stages. However, there are a few other points on bowel cancer which do not necessarily fit into the above sections, which are outlined here.

Ethnicity and Bowel Cancer

One of the most frustrating aspects of conducting research into cancer is that, at present, ethnicity is not monitored at the cancer registration stage. This means that making any reliable comparison between ethnic groups is virtually impossible. As far back as 2004, Screening Director Julietta Patnick highlighted (in Issues in Cancer Screening, within First Equality in Cancer Prevention Conference Report) the need for these statistics to become available. She said:

“I want to emphasise that if we are going to achieve change, we must increase our understanding and our data on ethnicity in the NHS.”

However, five years later there appears to be no progress on this issue.

Ethnicity Survivorship Research Questions

- How do different ethnic groups' incidence, mortality, five and 10 year survival rates compare?
- Why are some ethnic groups more or less likely to develop bowel cancer than others?
- How do agencies delivery effective health prevention messages to different ethnic groups?

Julietta Patnick's report mentioned above begins to tackle the last question, but we have been unable to uncover any satisfactory evidence examining the other two questions.

Socio-economic Deprivation and Bowel Cancer

As with many cancers, there is an association between socioeconomic deprivation and the incidence and mortality of bowel cancer. However, for bowel cancer, much of the evidence is contradictory. There are a number of research papers which suggest that incidence and mortality of colon cancer in men and women is not associated with increased incidence or mortality, or rectal cancer for women, but there is so for men. However, there are other reports that suggest the incidence and mortality rates for both colon and rectal cancer in both sexes correlate positively to increasing deprivation. The discrepancy prevents charities such as ourselves from effectively target those most at risk on developing bowel cancer, and thus hinders our capability to achieve our organisations aims.

Socioeconomic Research Questions

- How do you measure 'deprivation' nationally?
- Is there an association between deprivation and incidence for either men or women for either colon or rectal cancers?
- Is there an association between deprivation and incidence for either men or women for either colon or rectal cancers?
- Is there an increase in inequality from incidence to mortality for bowel cancer?
- If yes, what are the causes of this widening inequality?
- How can unequal access to medical services be mitigated?

There are a number of research papers which purport to answer these specific questions. However, as mentioned previously, these are somewhat contradictory. These papers include:

Coleman, M.P., et al., [Socioeconomic inequalities in cancer survival in England and Wales](#). Cancer, 2001. 91(1 Suppl): p. 208-16.

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Cancer Research UK Cancer Stats. Cancer statistics on incidence, mortality, geography, deprivation, 1, 5 and 10 year survival, diet and family history.

National Cancer Intelligence Network. 2008. Cancer Incidence by Deprivation England, 1995-2004.

Coleman (et al). 2004. Trends and socioeconomic inequalities in cancer survival in England and Wales up to 2001. British Journal of Cancer (2004) 90, 1367 – 1373

Summary

Our Bowel Cancer Survivorship investigation has discovered a number of key themes of research to improve the experiences of bowel cancer survivors from the point of diagnosis. Improvements to quick and accurate diagnoses; access to adequate written and verbal information; emotional support for patients and carers; access to medical professionals (whether via 24 hours telephone advice or face to face); access to local support groups; and the equality of the follow up service need to be made.

According to our patients, the NHS does a lot of things extremely well. The treatment phase was almost universally praised as swift, professional and above all well executed by the MDTs. If the emotional and support side can be improved, then the bowel cancer patient survivorship pathway would appear much improved for everyone concerned.

As we've discovered throughout this survivorship project, there are, however, great gaps in existing research as a framework for tackling many of the issues raised. This is perhaps understandable as the initiative is so new to the cancer field. This fact in itself demonstrates that the initiative has great merit in being a driver for improving patient care.

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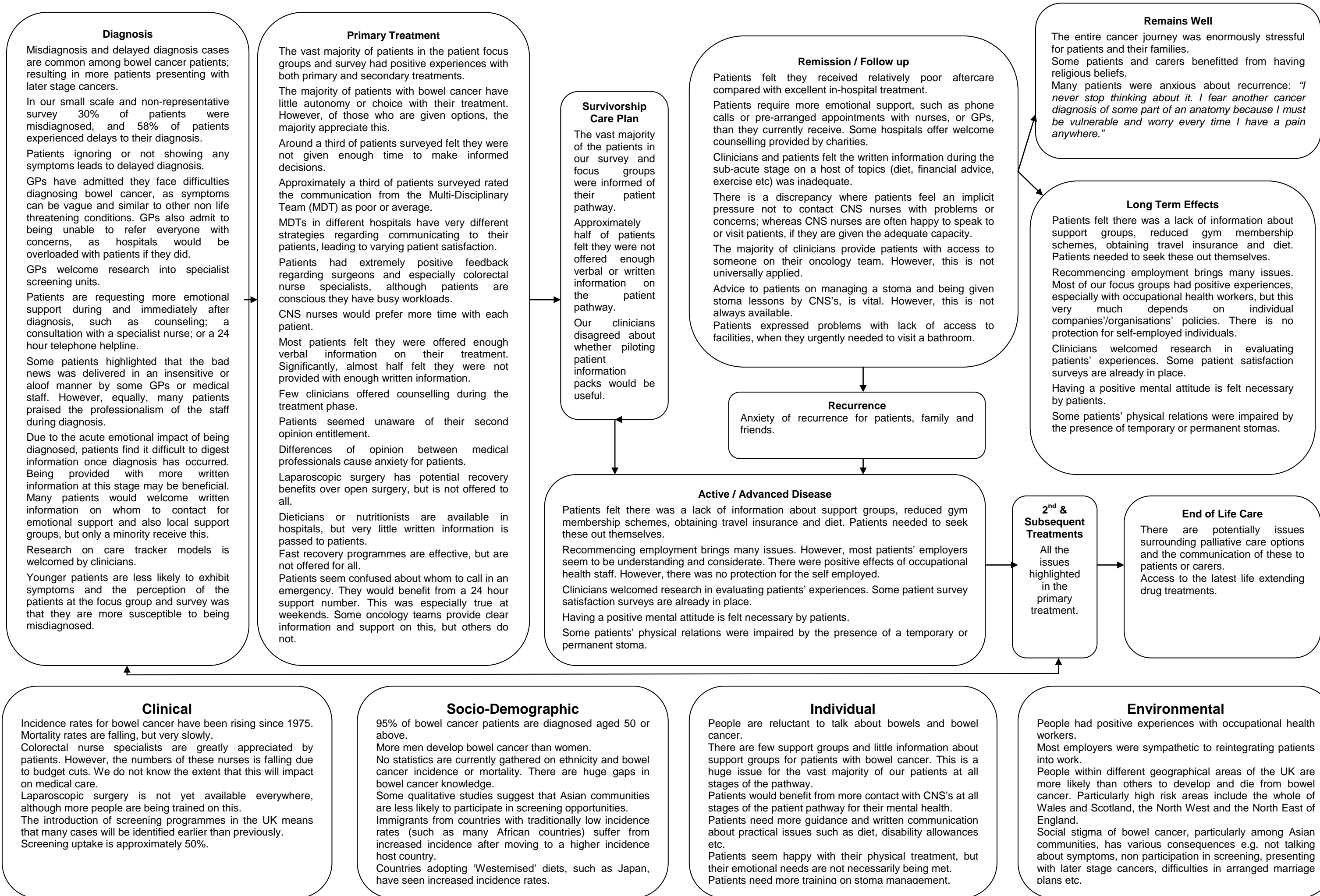
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Mapping the needs of breast cancer survivors: Information from qualitative stakeholder research and grey literature

Report for the Research Work Stream of the National Cancer Survivorship Initiative

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March 2009

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1. Background

Breast cancer is the most common cancer in the UK: in 2005 45,947 people were diagnosed with the disease [1]. Survival rates have been steadily increasing and current five year survival estimates within the UK are at least 80% [2-4]. It has also recently been estimated that 66% of Scottish breast cancer patients and 67% of English patients will be “cured”, which means that they will not have a reduced life expectancy due to a diagnosis of breast cancer [5].

The high incidence and survival rates for breast cancer have led to a large population of breast cancer survivors¹ within the UK. A 2008 estimate indicates that about 550,000 women are alive in the UK who have previously had a diagnosis of breast cancer [6]. Although many of these individuals may no longer be receiving primary treatment for their breast cancer, it is likely that a diagnosis of breast cancer will continue to impact on some or all aspects of their lives.

In order to provide detailed consideration of the services needed by cancer survivors, a National Cancer Survivorship Initiative (NCSI) was proposed as part of the Cancer Reform Strategy [7]. The Initiative will be jointly chaired by Professor Mike Richards, National Cancer Director, and Ciaran Devane, Chief Executive of Macmillan Cancer Support. The NCSI will consider a range of approaches to survivorship care and how these can best be tailored to meet individual patients' needs.

As part of its role on the NCSI Research work stream, Breakthrough Breast Cancer has been asked to map the needs of breast cancer survivors and determine areas of research to improve breast cancer-specific survivorship services and support. This report sets out the survivorship needs identified by breast cancer stakeholders and the relevant research questions that may help to address such needs.

2. Methodology

Due to the large amount of research into breast cancer survivorship that has already been carried out with breast cancer survivors, a more comprehensive picture of stakeholders' needs can be gained from reviewing a wide range of existing resources. Much of this evidence is not in the public domain but can be obtained through the analysis of the results of surveys, consultations and focus groups with stakeholders, as well as from relevant grey literature. Breakthrough Breast Cancer contacted breast cancer charities in the UK, USA and Australia, cancer support charities in the UK and other UK organisations whose work relates to cancer survivorship and asked that they share any relevant evidence.

The relevant information from all the received sources [8-26] was collated and analysed in order to determine the survivorship needs identified by stakeholders. These needs were classified according to the relevant stage, cross-cutting theme or factor identified in the agreed NCSI survivorship model (see Appendix, section 8). Research needs in each of these areas were identified by determining the gaps in the information obtained. It is possible that findings from published, peer-reviewed studies may have already addressed some of these needs, however it is not possible to determine this from the sources used in this analysis.

¹ Macmillan Cancer Support defines a cancer survivor as *someone who has completed initial treatment and has no apparent evidence of active disease, or is living with progressive disease and may be receiving treatment but is not in the terminal phase of illness (the last six months of life), or someone who has had cancer in the past.* [7]

Following identification of the research needs, two panels of relevant stakeholders (people affected by breast cancer and clinicians) were asked to prioritise the research via an e-mailed survey. The results of these prioritisation exercises are also reported below.

3. Mapping the breast cancer survivorship pathway research needs

Set out below are the

- survivorship needs identified by breast cancer stakeholders
- relevant research questions that may help to address such needs
-

for each stage, cross-cutting theme and factor of the agreed survivorship model (see Appendix, section 8).

3.1 Stages of the care and support pathway

3.1.1 Diagnosis

From the sources used for our analysis, people affected by breast cancer did not identify any aspects of a primary diagnosis of early breast cancer that needed modification in order to improve their survivorship experience. Please see sections 3.1.2 and 3.1.8 for an analysis of the research needs relating to a diagnosis of primary and secondary breast cancer respectively and section 3.3.3 for research needs related to psychosocial effects such as anxiety and depression.

3.1.2 Primary treatment and clinical factors

There is a lot of information available regarding the short-term, immediate adverse effects associated with individual treatment/therapy modalities, such as specific chemotherapy drugs or surgical procedures. Much of these can be found in published data from clinical trials and reviews and information from drug manufacturers [27, 28], as well as patient information resources [29]. However, there appears to be less information available on the long-term effects of primary treatment (see also section 3.1.6).

Within each treatment/therapy modality there are many different possible techniques or drugs that could be offered, depending on a number of factors including tumour biology, tumour stage and grade, co-morbidities/health status and patient choice. This means that there are a large number of primary treatment combinations for early breast cancer. Furthermore, the side-effects and impacts on quality of life that an individual breast cancer patient will experience are affected by the same factors that determine treatment choice and cannot currently be accurately predicted. The combination of these “unknowns” means that it is not possible to identify the short-, medium- and long-term adverse effects, impacts on quality of life or survivorship needs that an individual patient having a particular combination of treatments and therapies will experience.

Research into this area would lead to improved, personalised information on the impacts of primary treatment for breast cancer patients. This would potentially allow greater patient treatment choice and could also support more specific and responsive commissioning of care and services for patients with adverse treatment effects.

Research questions

- What are the adverse effects and impacts of different modalities of primary treatment (surgery, radiotherapy etc) and combinations of treatments on quality of life in the short-, medium- and long-term?
 - Are any groups more likely to have their quality of life significantly impacted (e.g. due to age, gender, ethnicity, other diseases etc)?
- What are the most common side effects associated with all the different possible combinations of primary breast cancer treatments, including
 - who is most at risk?
 - when are the effects likely to occur and how long are they likely to last?
 - possible methods of prevention
 - How prevalent are such effects in breast cancer survivors?
- How does tumour biology (stage, grade, receptor status etc.) impact on health status, quality of life and long term effects of treatment?

3.1.3 Survivorship care plan and self-management factors

From the stakeholder consultation sources used to inform this report, there was little discussion on the self-management of breast cancer or survivorship care plans and many survivors focussed on follow up (see section 3.1.4). This may indicate a lack of awareness or experience of the concept of “self-management”, but is also likely to be due to the lack of investigation in this area.

A focus group of women with gynaecological and breast cancers who had experience of follow up care [26] expressed the view that patient-managed follow up could not be the only form of follow up, particularly not immediately after treatment. However, there was a belief that some individuals may choose to manage their own follow up and that for these people it would be beneficial.

Overall, people affected by breast cancer had concerns regarding the care they would receive at a primary care level, particularly when they were no longer being treated or followed up in secondary care. Many breast cancer patients were unsure how much their GP knew about their breast cancer treatment in secondary care and voiced concerns about getting rapid referral/access to a secondary specialist via their GP. Rapid access to secondary care (either through contacting the specialist directly or referral through a GP) was viewed as important, and some survivors lacked confidence that they could rapidly access a specialist via their GP [19, 26].

The recently updated NICE clinical guidelines for early and locally advanced breast cancer [30] recommend that a written care plan should be agreed for all breast cancer patients and a copy sent to their GP. This plan should include

- designated named healthcare professionals;
- dates for review of any adjuvant therapy;
- details of surveillance mammography;
- signs and symptoms to look for and seek advice on;
- contact details for immediate referral to specialist care;
- contact details for support services, for example support for patients with lymphoedema.

However, the guidelines state that this recommendation is not based on any good quality data.

Research questions

- What information and support is needed to assist breast cancer survivors to self-manage their care, post-diagnosis?
- What specific information is needed in a breast cancer survivorship care plan? How is this best agreed with and communicated to the patient and all relevant healthcare professionals (such as the GP)?
- What are the best practice models for improving and joining up primary and secondary care pathways commonly experienced by breast cancer survivors and communication between primary and secondary care?
- What are the best practice models for rapid referral pathways from primary care back into secondary care when survivors present to their GP with possible signs of recurrence, secondary breast cancer or chronic/serious effects of treatment?

3.1.4 Remission/follow up

Follow up of early breast cancer patients after treatment is carried out with the aim of detecting a local recurrence of breast cancer (in the affected breast) or a new cancer in the other breast. It usually includes clinical examination and mammography as well as a review of ongoing adjuvant treatment and potential side effects, and any clinical trials a patient may be enrolled in. According to the most recent NICE clinical guidelines for early and locally breast cancer [30] follow up should also include advice on general health, diet and exercise.

People affected by breast cancer view follow ups as 'care after treatment' in the form of both scheduled check-ups and informal contact with a clinician or breast care nurse. Stakeholders point out that it is important for them to know not only what to expect during follow up appointments, but also what these appointments are for and why they end when they do. They put particular importance on follow up appointments that take place with a specialist in the secondary care setting in the first one to two years following primary treatment. However, not all breast cancer survivors have the same views on the remit of follow up care. One focus group involving breast cancer survivors reported that although some felt that ongoing treatment for side effects was distinct from their cancer treatment and therefore should be included in the definition of follow up care, others felt such treatment was part of the cancer treatment and follow up care should be provided after this was completed [26].

Stakeholders also believe that continuity of care is important, for example seeing the same nurse or consultant throughout both treatment and follow up. In addition, survivors have stated that it is important that they are given information on signs of recurrence or advanced disease to look out for in between follow up appointments. In one survey of English breast cancer patients, 57% of respondents were 'very' or 'a little' concerned about follow up services provided at the end of hospital-based treatment (including information on symptoms that may be of concern, emotional support, who to contact in between appointments and length of time between appointments) [17].

There appears to be a consensus among breast cancer survivors that follow up care should be tailored to the individual and that survivors should be fully involved in the decision making [19, 26]. Different models of follow up care have been proposed and survivors have differing views on the effectiveness of such models. For example, members of one focus group [19] felt that

group-based follow up could not possibly cover as many care issues as individual follow up and also had concerns that telephone-based follow up would miss important clinical indications that could only be identified in a face-to-face, clinical appointment. However, a small breast care nurse-led telephone intervention was shown to meet the information needs of women with breast cancer and to lead to a reduction in the reporting of physical problems at follow up [9].

The most recent NICE clinical guidelines for early and locally advanced breast cancer [30] make a recommendation that clinicians should “discuss with patients where they would like follow-up to be undertaken. They may choose to receive follow-up care in primary, secondary, or shared care”. However, participants of focus groups of breast cancer patients with experience of follow up agreed that they would not personally like to be seen by their GP for follow up [26] and that GPs would need further training if they were to take on this responsibility [19]. Furthermore, the NICE guidelines state that “there is little evidence that routine follow up of patients treated for early breast cancer to detect recurrence or new primary disease early is effective or offers any mortality benefit... The consensus of those providing breast cancer treatment is that routine follow up is beneficial for patient welfare and for monitoring effectiveness of treatment. There are few data on which to base guidelines on the most effective methods of providing follow up, how frequently and for how long” [30].

Finally, breast cancer patients view follow up care as important for meeting wider psychosocial as well as clinical needs. Participants in one focus group of breast cancer advocates [19] thought it was very important that follow up should include signposting to other services relevant to breast cancer survivors, such as lymphoedema clinics, complementary therapies and sources of further support.

Research questions identified by NICE

- What is the optimal frequency and length of surveillance of follow-up mammography for patients who have been treated for early invasive breast cancer or ductal carcinoma in situ?
- Prospective randomised comparative studies are required to ascertain the most effective methods for detecting recurrence and new primary disease, and should include:
 - how (by clinical examination and/or imaging and/or serum tumour markers)
 - different patient populations, depending on their risks and toxicities from treatment
 - where (in primary care and/or secondary care) and by whom (by patients, nurses or doctors) these should be provided
 - whether such care provides any benefits (such as reduced mortality, morbidity and treatment costs).

Research questions identified from stakeholder research

- There is a need to develop best practice models of follow up care that can be adapted to the individual to be developed and piloted, including
 - how follow up should be conducted (clinical examination, mammography etc)?
 - who should provide follow up care and where (GP, breast care nurse etc)?
 - needs of different patient populations (e.g. elderly, those with other diseases, patients in rural areas etc.)?
 - study into the benefits of different models of follow-up, e.g. on survival, quality of life etc.

- information patients need at different stages of follow up – what, from whom and when best to provide?
- how often should survivors have follow up appointments?

3.1.5 Remains well

There was no data from the stakeholder sources used to inform this report to indicate the survivorship needs of breast cancer survivors who remained well following breast cancer treatment. This may be because such individuals have not been specifically targeted for research or because they are less motivated to take part in research.

Research questions

- The research currently available does not differentiate between survivors who have no long-term effects of treatment and those who do. It will be important to determine their differing needs.

3.1.6 Long-term effects

Undergoing treatments for early breast cancer can be associated with long-term or chronic physical and psychosocial side effects, many of which are reported in the published literature. However, breast cancer survivors continue to have concerns about both long-term effects and related services and treatments.

Breast cancer survivors have concerns regarding body image, hair loss, sexuality and sexual problems following breast surgery and treatment. One report suggests that survivors of breast cancer experience more sexual problems than healthy friends including fatigue, depression, hot flushes and vaginal dryness [20]. However, breast cancer survivor-rated quality of life appears to improve over time with long-term survivors of breast cancer reporting similar quality of life scores to age and gender matched controls, particularly in those aged under 50.

It is thought that a significant proportion of breast cancer patients experience anxiety and depression as a result of the diagnosis of breast cancer. Long-term physical side-effects of cancer and its treatment have been associated with poorer quality of life and more psychological distress and sexual problems [20]. The most recent NICE clinical guidelines for early and locally advanced breast cancer [30] highlight that there is currently a variation in the provision and quality of psychological treatments and services offered to breast cancer patients. They state that cognitive behavioural therapy (CBT) is one form of psychotherapy that has been proven to treat and reduce depression but that there are no studies that compare CBT in breast cancer patients with other forms of intervention.

Following investigation of the debilitating long-term side effects experienced by a number of breast cancer survivors who were given radiotherapy treatment at a particular group of hospitals within the UK, a number of priorities have been identified [22]. These include:

- the need for a national register of consequences of cancer treatment;
- the need to support patients to recognise and understand changes in their health after cancer treatment, to provide the information and help they need to manage these and to understand when and from whom they should seek help, including appropriate face-to-face, written and web based information;

- the need to improve communication between primary and secondary care;
- the need to develop innovative ways to bring multidisciplinary specialist expertise to patients with rare, severe treatment-related chronic illness;
- the need for innovative commissioning models to help people with severe chronic survivorship illnesses get the care that they need;
- the need to develop an expert patient programme for chronic treatment related survivorship conditions.

This may include the need to educate survivors to recognise, record and report any problems they experience following breast cancer treatment so that unanticipated long-term effects could be identified earlier. One suggestion was for this to be included in the information given to people who have had treatment that might result in long-term effects, but services and support for self-management must also be provided to survivors who develop these effects [22].

One specific, chronic long term effect of breast cancer treatment can be lymphoedema. This is a long-term swelling that is caused by a build up of excess fluid in the tissues. After certain types of breast or axillary (armpit) surgery lymphoedema can occur in the arm, hand, breast, chest wall, back or armpit on the same side as the surgery. Lymphoedema can develop months or years after breast cancer treatment and, although it cannot be cured, the swelling can be reduced and controlled if managed effectively.

There is currently little consensus on the prevalence of lymphoedema or the incidence after breast cancer treatments and insufficient evidence on the most effective methods for preventing, diagnosing and treating the condition. Anecdotal evidence from survivors indicates that that referral pathways and services are lacking in some parts of the UK. A recent survey of English breast cancer patients indicated that 15% of respondents had developed lymphoedema [17]. Of these, a third (32%) reported that they did not receive practical support after developing symptoms of lymphoedema. Furthermore, nearly 1 in 3 respondents felt they received 'too little' information on ways to reduce the risk of lymphoedema developing and 53% felt there was 'too little' awareness surrounding the prevention and treatment of the condition. Respondents diagnosed with lymphoedema were significantly less satisfied with their overall care and treatment than respondents who had not been diagnosed with lymphoedema. 34% felt they did not have enough information on the impact upon their lifestyle and 19% felt they did not have enough information on where to find further information.

In April 2009 Breakthrough Breast Cancer, working with Breast Cancer Care and the Lymphoedema Support Network, will launch a campaign to improve the availability and access to services for people with lymphoedema following breast cancer. As part of this we will be highlighting the need for further research to determine the incidence and prevalence of lymphoedema after breast cancer and to gather evidence on the most effective methods for preventing, diagnosing and treating the condition.

Research question identified by NICE

- What is the effectiveness of CBT compared with other psychological interventions for breast cancer patients? (Other forms of psychotherapy include psychodynamic counselling, Gestalt therapy or any other psychological intervention. The comparison group could include support from the breast care nurse specialist, telephone support or pure counselling)

Research questions identified from stakeholder research

- What are the most effective methods for treating the psychosocial effects of breast cancer treatments e.g. cognitive behavioural therapy, drug treatments etc.?
- How does survivors' quality of life change over time? Are particular patient populations more or less likely to see an improvement?
- How do long-term side effects of treatment impact on quality of life, sexuality/sexual function and psychosocial distress?
- What are the most effective methods for treating menopausal symptoms in breast cancer survivors?
- What are the most effective methods of treating problems with sexual function or sexuality in breast cancer survivors?
- There is a need for a greater focus on lymphoedema research, including:
 - What is the incidence and prevalence of lymphoedema in breast cancer survivors?
 - Which populations of breast cancer survivors are most at risk of developing lymphoedema?
 - Which are the most effective treatments for lymphoedema?
 - How can the risk of developing lymphoedema be reduced?
- Clinical trials should include quality of life measures and follow-up of trial participants should include measurement of long-term effects
- A national system is required to record outcomes/long-term effects following cancer treatment – what is the best way to measure and record such effects?
- How are patients best supported to recognise and report long-term effects and to manage them?

3.1.7 Recurrence

None of the breast cancer survivors whose views and experiences were reflected in the sources used for this report mentioned survivorship issues related to a recurrence of breast cancer. It is unclear whether this is because they considered treatment for recurrence to be the same as treatment for early breast cancer (primary treatment), they had not experienced a recurrence of breast cancer or they were not asked about any such experiences. One review of the psychosocial implications of living with cancer indicates that little is known about the impact of cancer recurrence on long-term survivors [20].

3.1.8 Active/advanced disease and second and subsequent treatments

Women living with secondary breast cancer have many specific information, support and care needs that differ from those of women diagnosed with early breast cancer.

Qualitative work with women diagnosed with secondary breast cancer [25] indicates that they feel they are given very limited information about their diagnosis and about places to go for support. Almost all participants felt that there is a lack of written information about secondary breast cancer, particularly for women who have had primary breast cancer and younger women with secondary breast cancer [25]. There is a need for accurate and appropriate information for patients and their carers/families on the financial and emotional impact of secondary breast cancer, support available, palliative care, standards of care and relevant clinical trials [23, 25]. Secondary breast cancer patients who responded to a recent consultation also said they had

not been asked for their preferences on the level and type of information that they needed [12]. 38% of people with secondary breast cancer have also reported that the information and support they had received was 'significantly worse' or 'worse' in comparison to their primary diagnosis [17].

The NICE Guidelines on advanced breast cancer [31] made the following recommendations to clinicians on providing information and support for decision-making:

- Assess the patient's individual preference for the level and type of information. Reassess this as circumstances change.
- On the basis of this assessment, offer patients consistent, relevant information and clear explanations, and provide opportunities for patients to discuss issues and ask questions.
- Assess the patient's individual preference for how much they wish to be involved in decision making. Reassess this as circumstances change.
- Be aware of the value of decision aids and the range available. Make the most appropriate decision aid available to the patient.

There is a difference in the support available to primary and secondary breast cancer patients. Women with secondary breast cancer have highlighted that there is a current lack of access to a nurse specialist, or other key healthcare professional, with the skills and knowledge to manage metastatic breast cancer. Three quarters (74%) of secondary breast cancer patients recently consulted said that they do not have a key worker [12]. Similarly, most respondents had not had their supportive care service needs assessed either at diagnosis or at later time points.

A small study of the rehabilitation needs of women with secondary breast cancer [21] indicated that secondary breast cancer patients had a range of different physical, psychological and social rehabilitation needs throughout the course of their illnesses. Although their needs did not change, detection was low and referral to appropriate services usually did not occur. A third of patients in the study had anxiety and depression requiring treatment, and the levels of psychological distress were high, especially at the last interview before death.

These gaps in the provision of psychosocial support for patients and their families have been highlighted more recently by secondary breast cancer patients [23]. Many secondary breast cancer patients are not aware of the psychosocial support (such as emotional, financial, and employment support) available and the majority (76%) stated that they had not been given the support they wanted for planning end of life care [12]. Secondary breast cancer patients have also highlighted that they would like face-to-face counselling to enable them to come to decisions about their care [12] and that there is a need for improved management of metastatic breast cancer in the primary care and community settings [23].

Recommendations on community-based treatment and supportive care in the NICE guidelines for advanced breast cancer include:

- Healthcare professionals involved in the care of patients with advanced breast cancer should ensure that the organisation and provision of supportive care services comply with the recommendations made in 'Improving outcomes in breast cancer: manual update' (NICE cancer service guidance [2002]) and 'Improving supportive and palliative care for adults with cancer' (NICE cancer service guidance [2004]), in particular the following two recommendations:

- 'Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as diagnosis at commencement, during, and at the end of treatment; at relapse; and when death is approaching).'
- 'Mechanisms should be developed to promote continuity of care, which might include the nomination of a person to take on the role of "key worker" for individual patients.'

There is a wide range of treatment modalities for secondary breast cancer. Choice of treatment or therapy depends on many factors including the location of the secondary cancer(s), tumour biology, tumour stage and grade, co-morbidities/health status and patient choice. This means that there are a large number of treatment combinations for secondary breast cancer. Furthermore, the side-effects and impacts on quality of life that an individual secondary breast cancer patient will experience are affected by the same factors that determine treatment choice and cannot currently be accurately predicted. This means that it is not possible to identify the short-, medium- and long-term adverse effects, impacts on quality of life or needs that an individual secondary breast cancer patient having a particular combination of treatments and therapies will experience.

Research into this area would lead to improved, personalised information on the impacts of treatment for secondary breast cancer patients. This would potentially allow greater patient treatment choice and could also support more specific and responsive commissioning of care and services for patients with adverse treatment effects. Furthermore, there is no data on the incidence and prevalence of secondary breast cancer in the UK, and such figures are needed to inform commissioning and service provision.

Research questions

- There is a need for the determination of the incidence and prevalence rates of people with metastatic breast cancer.
- Development of an appropriate needs analysis to determine the services and support required by people with secondary breast cancer.
- What are the best methods for assessing the physical, psychological and social needs of people with secondary breast cancer (and their families/carers)?
 - When should these assessments take place? By whom?
- What are the best treatments/support services for secondary breast cancer patients with psychosocial problems? How can the long-term benefits of current interventions be improved?
- Which type of healthcare professional is best placed to act as a key worker for secondary breast cancer patients, by co-ordinating their health and social care at all levels?
- Which forum is most appropriate for the discussion and determination of care plans for people with secondary breast cancer? Is it the multi-disciplinary team?
- How can the information needs of people with secondary breast cancer and their families/carers best be met?
- How can people with secondary breast cancer be supported to "live well" (maintain a good quality of life)?

- How can GPs' awareness of the signs and symptoms of secondary breast cancer be improved?
- What are the impacts of different types of second/subsequent treatment (surgery, radiotherapy etc) and combinations of these treatments on quality of life in the short-, medium- and long-term?
 - Are any groups more likely to have their quality of life significantly impacted (e.g. due to age, gender, ethnicity, other diseases etc)?
- What are the most common side effects associated with all the different possible combinations of second/subsequent breast cancer treatments?
 - Who is most at risk?
 - When are the effects likely to occur and how long are they likely to last?
 - Possible methods of prevention
 - How do side effects impact
 - How prevalent are such effects in breast cancer survivors?

3.1.9 End of Life Care

Few of the resources used in this analysis focussed on the needs of breast cancer patients at the end of life. However, people with secondary breast cancer responding to a recent consultation stated that they had not been given the support they wanted for planning their end of life care [12]. Similarly, a survey of breast cancer advocates [15] indicated that there is a lack of joined up care between the NHS and social services at the end of life and that information for patients, carers and families on what to expect is lacking.

Research questions

- How can appropriate and timely information about what to expect at the end of life and where to get advice and care be best provided to patients and their families/carers?
- Developing and piloting models of joined-up health and social care for patients needing end of life care.

3.2 Cross-cutting themes

3.2.1 Work and finance

Although there have been some qualitative studies and surveys looking at the impact of a cancer diagnosis on work and finances, very few have specifically focussed on people affected by breast cancer. Much of the information and studies are based in the USA and Canada and it is unclear how relevant they are to breast cancer survivors in the UK.

A focus group of women with gynaecological and breast cancer highlighted that the main support they needed to return to work is information or a booklet to give to employers [26]. Such information would explain survivors' needs on returning to work and that they may need to take time off for follow up appointments. Furthermore, a literature review on returning to the workplace after cancer [8] indicates that women returning to work after breast cancer reported a lack of medical advice about work during and after their treatment. There was also a high level of apprehension among breast cancer survivors about returning to work because of lower confidence about job competency and fear that their ability to be productive might have declined.

A survey of English people affected by breast cancer indicated that 59% of respondents had 'too little' information on financial matters and sources of support and 58% had 'too little' information on employment advice [17].

Research questions

- How and when should information be provided to employers after an employee returns to work following breast cancer treatment? What specific information should be included?
- What medical needs do breast cancer survivors have on their return to work? Do they need specific medical advice or support?
- How and when should information on financial support and returning to work best be communicated to breast cancer survivors? What should this information include?

3.2.2 Self-management

See section 3.1.3.

3.2.3 Research

The opinions and views of breast cancer stakeholders used to inform this report have identified the areas of breast cancer survivorship where more research is needed. However, much information on breast cancer survivorship is also available in the published and grey literature. It is important that such research is not duplicated but that its findings are used to improve services and treatments for breast cancer survivors.

3.2.4 Information

Information is very important to people affected by breast cancer and is relevant to all stages of the care and support pathway. Studies indicate that breast cancer survivors experience a range of emotional problems and need effective communication and information to manage their psychosocial impact [9]. Although many sources of accurate and appropriate information exists, patients and survivors still highlight gaps in information provision and state that their needs are not being met. It is not clear whether these gaps exist because there is a lack of available resources or because existing information is not adequately provided to survivors.

For example, over a third (35%) of patients in breast units responding to a written survey [13] had not received written information about possible side-effects of treatment. Most patients also reported that they had not received information about local psychological, social, spiritual, cultural and financial support or complementary therapies. 63% of secondary breast cancer patients have reported that their information preferences and needs were not assessed (see section 3.1.8 for more information on the information needs of patients with secondary breast cancer). Patients also reported considerable differences in the amount of information they had received about their follow up care [26].

Many breast cancer survivors use the internet to support their information needs and therefore it is important that survivors are provided with signposting to sources of accurate internet-based information. Survivors would also appreciate more holistic information, for example on diet and complementary therapies, to help them manage their overall health and wellbeing [26].

Research is also needed into the best methods for delivering information, after a small study indicated that a breast care nurse-led telephone intervention could meet the information needs of women with breast cancer and lead to a reduction in the reporting of physical problems at follow up [9].

Finally, the information needs of specific populations of breast cancer survivors (such as those with learning difficulties, from black and minority ethnic groups, older women and those from socially disadvantaged backgrounds) and those of carers and family members are not known [11].

Research questions

- What information is available on the side-effects of drug treatments; psychological, social, spiritual, cultural and financial support; complementary therapies and diet/lifestyle after breast cancer; and secondary breast cancer?
 - Is it sufficient for survivors' needs?
 - At what stage(s) should this information be provided?
 - How should the information be delivered?
 - Who is best placed to provide such information?
- What are the information needs of families and carers?
- What are the information needs of hard-to-reach groups of breast cancer survivors?
- There is a need for the development and testing of an information needs assessment tool that would support healthcare professionals to provide relevant information to breast cancer survivors.

3.2.5 Commissioning

As outlined in sections 3.1.2 and 3.1.8, there is a lack of complete information on the side effects associated with breast cancer treatments (primary and secondary), their impact on patients' quality of life and the prevalence of such effects in breast cancer survivors. The incidence and prevalence of secondary breast cancer within the UK must be determined and there is also a need to develop innovative commissioning models to help people with chronic long-term effects of breast cancer treatment (such as lymphoedema) receive the care they need. Finally, more research evidence on the safety and effectiveness of complementary therapies is required. Such information would help to inform local commissioners and better determine the provision of services for breast cancer survivors.

Research questions

- What are the most common side effects associated with all the different possible combinations of primary and second/subsequent breast cancer treatments?
 - Who is most at risk?
 - When are the effects likely to occur and how long are they likely to last?
 - Possible methods of prevention
 - How do side effects impact on residual effects from initial/primary treatment?
 - How prevalent are such effects in breast cancer survivors?
- There is a need for the determination of the incidence and prevalence rates of people with metastatic breast cancer.

- There is a need to develop innovative commissioning models to help those people with severe chronic long-term effects (such as lymphoedema) receive the care they need.
- Greater research evidence on the safety and effectiveness of complementary therapies is needed to help commissioners make decisions about complementary therapy provision on the NHS.

3.3 Other factors that impact on survivorship

3.3.1 Clinical

See section 3.1.2.

3.3.2 Socio-demographic

Socio-demographic factors include age, gender, ethnicity, education and socioeconomic status. There is little information available on how these factors affect breast cancer survivorship and stakeholders have not identified the impact of such factors in most of the resources analysed. More in-depth analysis of the information, care and services needs of particular populations of breast cancer survivors is required and how different cultural and other factors impact on these needs. Similarly, the impact of such factors on the quality of life of breast cancer survivors is not known.

Research questions

- How do age, ethnicity, gender, education and socio-economic status impact on breast cancer survivors'
 - quality of life,
 - information, care and service needs?

3.3.3 Individual

Individual factors include coping responses (physical and psychological measures of wellbeing), health behaviours (such as diet, exercise, weight, stress etc.), disposition (for example optimism or problem solving) and transformative coping (spiritual and non-spiritual measures of health and wellbeing). The impacts of some of these factors on breast cancer survivorship, particularly coping responses and use of complementary therapies, have been studied, but survivors continue to have unmet needs and questions.

Breast cancer patients report having concerns regarding body image, hair loss and sexuality following breast surgery and treatment [13, 20]. However, the majority of patients in English and Welsh breast units stated that they had not received information about local psychological, social, spiritual or cultural support. Attendees of a focus group of women with breast and gynaecological cancers highlighted that psychological support needed to be available from the point of diagnosis onwards, including at follow up, and that services must be tailored to the individual [26]. Psychological support was also seen as important for family and carers [26]. There are also gaps in psychosocial support for secondary breast cancer patients and their families (see section 3.1.8).

A recent literature review indicated that the evidence on the effectiveness of interventions to provide emotional and psychological support to women with breast cancer was ambiguous and

contradictory. However, one consistent finding was that the beneficial effects of all interventions were modest and appeared not to be sustained over time [10]. There appears to be a lack of evidence regarding interventions to address psychosocial problems in the long-term [20].

A second literature review [20] has suggested that higher self esteem and greater belief in being in control are associated with better quality of life scores in breast cancer survivors. The belief that a breast cancer experience led to lasting harmful effects was associated with poorer quality of life. Breast cancer survivors were also seen to perceive the world as less controllable and more random than healthy women.

Studies have indicated that breast and prostate cancer patients are more likely than other cancer patients to use complementary therapies [16]. Complementary therapies are particularly used to provide psychosocial and emotional support, relieve the side-effects of treatment, hasten recovery and improve health and wellbeing [16, 18]. Visitors to Breast Cancer Haven centres reported that their use of complementary therapies had improved or alleviated their concerns about breast cancer-related fear and anxiety, general wellbeing, physical problems and conventional treatment [24]. Cancer patients in North London have expressed satisfaction and benefit from use of complementary therapies throughout their care and support pathway [18].

Although there is support from cancer patients and carers for complementary therapies to be integrated with conventional services [18], there is a lack of good evidence regarding the safety and effectiveness of complementary therapies for breast and other cancer patients. There is a need to determine which therapies are safe to use alongside conventional treatments and whether they are effective at alleviating treatment side-effects and improving wellbeing. Such information would be useful for both local commissioners and breast cancer survivors wishing to make an informed choice about the provision and use of complementary therapies.

Research questions

- What is the availability of psychosocial support and services available for patients across the UK?
- Development and testing of a tool to assess the emotional state of breast cancer survivors, both prior to and after using a psychosocial support service, in order to identify needs and evaluate outcomes.
- Which interventions are most effective to improve psychosocial problems and quality of life after breast cancer treatment?
- How do individuals' health behaviours, self-esteem and coping responses specifically affect quality of life and wellbeing after breast cancer?
- Interventions designed to address psychosocial problems in the long-term need to be developed and tested.
- Complementary therapies research questions:
 - Which complementary therapies are safe to use alongside conventional breast cancer treatments?
 - Are any complementary therapies effective at improving wellbeing, quality of life or the impacts of the side-effects of treatments?
 - Models of integrated complementary therapies/conventional services need to be developed and piloted.

- How do individual health behaviours, disposition and transformative coping specifically affect breast cancer survivors? What needs do breast cancer survivors specifically have in these areas?

3.3.4 Environmental

Environmental factors include geography/location, employment, family structures and social support. There is limited information on how such factors affect breast cancer survivors, with most focussing on the impact of breast cancer on relationships. It is also unclear which environmental factors are specific and important to breast cancer survivors.

A survey of female Australian breast cancer survivors indicated that the effects of a diagnosis of breast cancer on their relationships differed depending on the stage of the survivorship pathway [14]. Individuals' relationships were affected in differing ways, for example whilst some women reported that communication had improved, others said that it had deteriorated. Challenges that added stress to relationships included partners who also had illnesses and were undergoing treatments and supporting and caring for children [14]. A literature review of the psychosocial implications of cancer indicated that female breast cancer survivors expressed satisfaction with both social contact and marital relationships and reported that relatives were closer but friends often avoided them [20].

Research questions

- Which environmental factors are specific and important to breast cancer survivors?
- How do location (e.g. urban v rural), employment, family structures and social support impact on the breast cancer survivorship experience, including
 - relationships,
 - psychosocial needs,
 - access to and uptake of relevant support services,
 - quality of life?
- What is the impact of breast cancer on carers and families? What are their support needs?

4. Breast cancer stakeholders' research priorities

Two panels of breast cancer stakeholders were asked to prioritise the identified breast cancer survivorship research needs via an e-mailed survey. Stakeholders included members of Breakthrough Breast Cancer's Campaigns and Advocacy Network (Breakthrough CAN) Advisory Group and Clinical Expert Reference Group. The CAN Advisory Group is made up of ten people affected by breast cancer who play an active role in ensuring that Breakthrough Breast Cancer's influencing and campaigning agenda is effective and remains in tune with the views and priorities of people affected by breast cancer. Members of the Clinical Expert Reference Group are 40 healthcare professionals and experts working across a wide range of specialities who provide Breakthrough Breast Cancer with advice on many areas of work.

Members were e-mailed and asked to complete an online survey. The identified research questions were described for each of the stage, cross-cutting theme or factor in the survivorship model (see Appendix, section 8). Respondents were asked to rate the importance of each area on a scale of 0 (low priority) to 5 (high priority) and to choose an overall research priority from all of the areas. Six members from each panel responded.

It should be noted that neither panel is fully representative of either population of breast cancer stakeholders within the UK. This prioritisation exercise should be considered as an illustration of the views of some people affected by breast cancer and some breast cancer clinicians and not the results of a comprehensive consultation.

4.1 Results

4.1.1 Priorities of people affected by breast cancer

Members of the Breakthrough CAN Advisory Group rated all stages, cross-cutting themes and factors of the survivorship model as high priorities, apart from those related to work and finance, information and commissioning. When asked to choose their most important area for research, their responses were:

- Active/advanced disease and second and subsequent treatments (3 votes)
- Primary treatment and clinical factors (1 vote)
- Survivorship care plan and self-management factors (1 vote)
- Long-term effects (1 vote)

4.1.2 Priorities of healthcare professionals and experts

Members of the Clinical Experts Reference Group rated the survivorship care plan and self-management and socio-demographic, individual and environmental factors as high priorities. Opinion was split as to whether the other areas were high or low priority. When asked to choose their most important area for research, their responses were:

- Long-term effects (3 votes)
- Socio-demographic, individual and environmental factors (2 votes)
- Work and finance (1 vote)

4.1.3 Overall priorities

The top three priorities for breast cancer survivorship research identified by breast cancer stakeholders combined were:

1. Long-term effects
2. Active/advanced disease and second and subsequent treatments
3. Socio-demographic, individual and environmental factors

However, it should be noted that the two groups of stakeholders asked had very differing priorities for breast cancer survivorship research. For example, healthcare professionals and experts prioritised research related to long-term effects whereas people affected by breast cancer prioritised research gaps for active/advanced disease. Ideally, therefore, both of these areas of breast cancer survivorship research should be given equal priority and all of the areas specifically identified as important by stakeholders considered when determining research priorities.

5. Conclusions

Although much of the published survivorship research has focussed on the experiences of breast cancer survivors, it appears that people living with and beyond breast cancer still have unmet survivorship needs. From the stakeholder-focused information sources used to inform this report, a number of general research questions can be identified, although there are many specific questions to be answered. These general research themes are:

- Self-management and follow up, particularly continuity of care between primary and secondary care.
- Long-term effects of breast cancer treatment, including lymphoedema and improved surveillance.
- Services for people with secondary breast cancer, particularly those meeting information needs, assessing care and support needs (with a focus on psychosocial needs), identifying the most appropriate key worker and determining incidence and prevalence.
- Effective long-term interventions and support to treat the psychosocial impacts of breast cancer.
- The specific care and support needs of different populations of breast cancer survivors (i.e. the impact of socio-demographic factors), including those that are related to quality of life, short-, medium- and long-term side effects and information needs.

The majority of these themes have also been identified as important research priorities by two independent panels of Breakthrough Breast Cancer's breast cancer stakeholders.

Many of the research questions identified in this report may have been investigated and the results published in peer-reviewed journals. Any such investigations will not have been covered in the scope of this analysis, although they should be identified through the NCSI Research work stream's literature review. If this is the case, the findings of this report highlight that there remains a need to translate robust research findings into practice in order to improve breast cancer survivorship care and support services. Similarly, it will also be important that there are commitments to swiftly act on all knowledge arising from the results of survivorship research commissioned by the Research work stream so that it can be used to immediately and directly benefit survivors.

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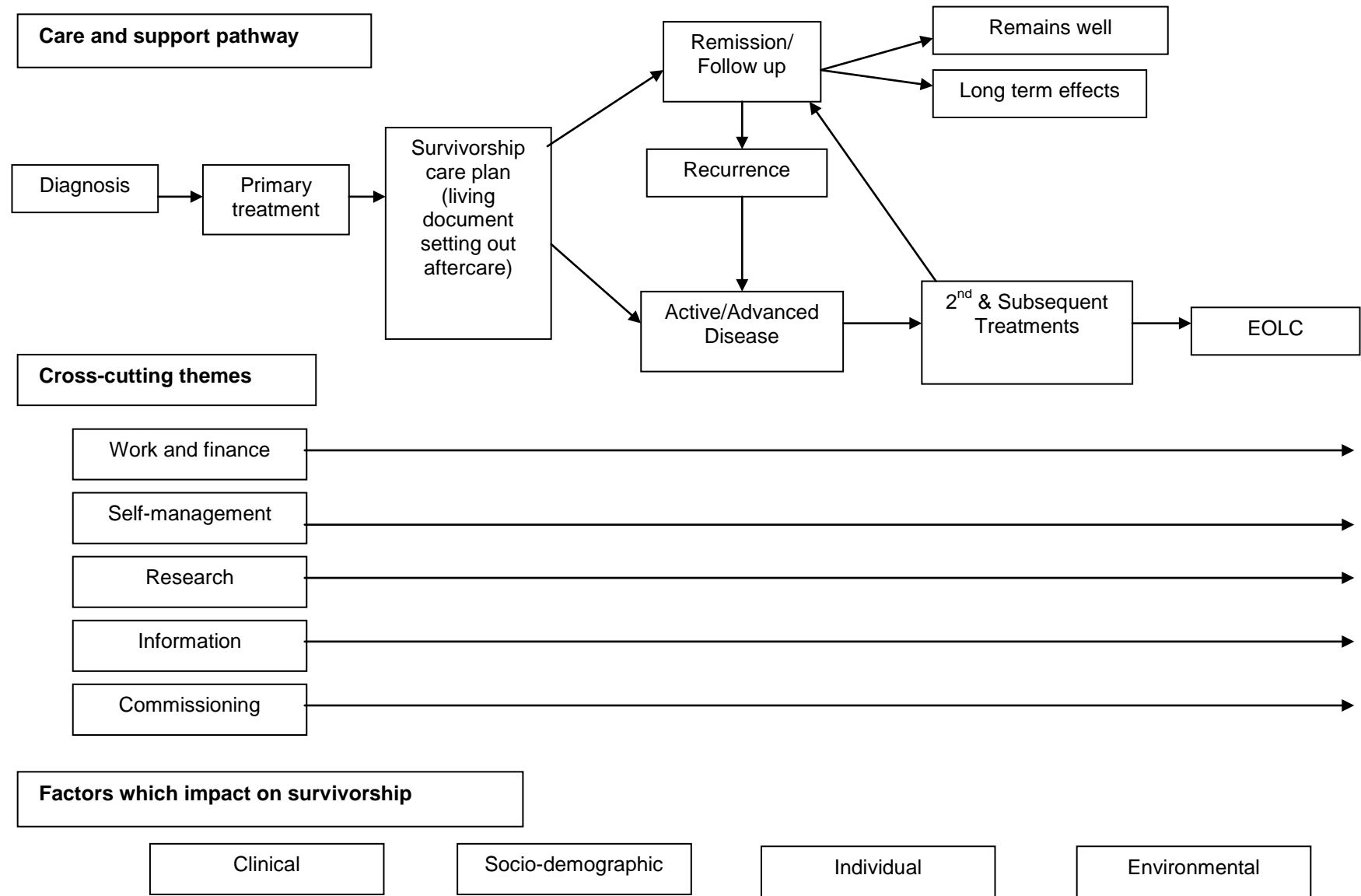
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7. Thanks

Breakthrough Breast Cancer would like to thank Julie Flynn at the National Cancer Research Institute for her help collating the information used to inform this report and to all of the organisations who shared their work and research in this area.

8. Appendix – NCSI survivorship pathway model

Adapted from “An overview of the National Cancer Survivorship Initiative (NCSI) - living with and beyond cancer”, Mike Richards and Ciaran Devane, January 2009.



9. Summary of research questions identified

This summary sets out the research question identified through the exercise undertaken by Breakthrough Breast Cancer on behalf of the National Cancer Survivorship Initiative (NCSI) Research work stream to map the needs of breast cancer survivors [see full report of same name]. Research questions were determined by identifying the gaps in knowledge obtained from analysing relevant stakeholder research and grey literature [refs 8-26 of full report]. Some of the questions may have been addressed by peer-reviewed, published research.

The questions are set out for each stage, cross-cutting theme and factor in the NCSI survivorship pathway model.

9.1 Stages of the care and support pathway

9.1.1 Diagnosis

No research questions identified

9.1.2 Primary treatment and clinical factors

- What are the adverse effects and impacts of different modalities of primary treatment (surgery, radiotherapy etc) and combinations of treatments on quality of life in the short-, medium- and long-term?
 - Are any groups more likely to have their quality of life significantly impacted (e.g. due to age, gender, ethnicity, other diseases etc)?
- What are the most common side effects associated with all the different possible combinations of primary breast cancer treatments, including
 - who is most at risk?
 - when are the effects likely to occur and how long are they likely to last?
 - possible methods of prevention
 - How prevalent are such effects in breast cancer survivors?
- How does tumour biology (stage, grade, receptor status etc.) impact on health status, quality of life and long term effects of treatment?

9.1.3 Survivorship care plan and self-management factors

- What information and support is needed to assist breast cancer survivors to self-manage their care, post-diagnosis?
- What specific information is needed in a breast cancer survivorship care plan? How is this best agreed with and communicated to the patient and all relevant healthcare professionals (such as the GP)?
- What are the best practice models for improving and joining up primary and secondary care pathways commonly experienced by breast cancer survivors and communication between primary and secondary care?
- What are the best practice models for rapid referral pathways from primary care back into secondary care when survivors present to their GP with possible signs of recurrence, secondary breast cancer or chronic/serious effects of treatment?

9.1.4 Remission/follow up

Research questions identified by NICE

- What is the optimal frequency and length of surveillance of follow-up mammography for patients who have been treated for early invasive breast cancer or ductal carcinoma in situ?
- Prospective randomised comparative studies are required to ascertain the most effective methods for detecting recurrence and new primary disease, and should include:
 - how (by clinical examination and/or imaging and/or serum tumour markers)
 - different patient populations, depending on their risks and toxicities from treatment
 - where (in primary care and/or secondary care) and by whom (by patients, nurses or doctors) these should be provided
 - whether such care provides any benefits (such as reduced mortality, morbidity and treatment costs).

Research questions identified from stakeholder research

- There is a need to develop best practice models of follow up care that can be adapted to the individual to be developed and piloted, including
 - how follow up should be conducted (clinical examination, mammography etc)?
 - who should provide follow up care and where (GP, breast care nurse etc)?
 - needs of different patient populations (e.g. elderly, those with other diseases, patients in rural areas etc.)?
 - study into the benefits of different models of follow-up, e.g. on survival, quality of life etc.
 - information patients need at different stages of follow up – what, from whom and when best to provide?
 - how often should survivors have follow up appointments?

9.1.5 Remains well

- The research currently available does not differentiate between survivors who have no long-term effects of treatment and those who do. It will be important to determine their differing needs.

9.1.6 Long-term effects

Research question identified by NICE

- What is the effectiveness of CBT compared with other psychological interventions for breast cancer patients? (Other forms of psychotherapy include psychodynamic counselling, Gestalt therapy or any other psychological intervention. The comparison group could include support from the breast care nurse specialist, telephone support or pure counselling)

Research questions identified from stakeholder research

- What are the most effective methods for treating the psychosocial effects of breast cancer treatments e.g. cognitive behavioural therapy, drug treatments etc.?
- How does survivors' quality of life change over time? Are particular patient populations more or less likely to see an improvement?
- How do long-term side effects of treatment impact on quality of life, sexuality/sexual function and psychosocial distress?
- What are the most effective methods for treating menopausal symptoms in breast cancer survivors?
- What are the most effective methods of treating problems with sexual function or sexuality in breast cancer survivors?
- There is a need for a greater focus on lymphoedema research, including:
 - What is the incidence and prevalence of lymphoedema in breast cancer survivors?
 - Which populations of breast cancer survivors are most at risk of developing lymphoedema?
 - Which are the most effective treatments for lymphoedema?
 - How can the risk of developing lymphoedema be reduced?
- Clinical trials should include quality of life measures and follow-up of trial participants should include measurement of long-term effects
- A national system is required to record outcomes/long-term effects following cancer treatment – what is the best way to measure and record such effects?
- How are patients best supported to recognise and report long-term effects and to manage them?

9.1.7 Recurrence

No research questions identified

9.1.8 Active/advanced disease and second and subsequent treatments

- There is a need for the determination of the incidence and prevalence rates of people with metastatic breast cancer.
- Development of an appropriate needs analysis to determine the services and support required by people with secondary breast cancer.
- What are the best methods for assessing the physical, psychological and social needs of people with secondary breast cancer (and their families/carers)?
 - When should these assessments take place? By whom?
- What are the best treatments/support services for secondary breast cancer patients with psychosocial problems? How can the long-term benefits of current interventions be improved?
- Which type of healthcare professional is best placed to act as a key worker for secondary breast cancer patients, by co-ordinating their health and social care at all levels?
- Which forum is most appropriate for the discussion and determination of care plans for people with secondary breast cancer? Is it the multi-disciplinary team?

- How can the information needs of people with secondary breast cancer and their families/carers best be met?
- How can people with secondary breast cancer be supported to “live well” (maintain a good quality of life)?
- How can GPs’ awareness of the signs and symptoms of secondary breast cancer be improved?
- What are the impacts of different types of second/subsequent treatment (surgery, radiotherapy etc) and combinations of these treatments on quality of life in the short-, medium- and long-term?
 - Are any groups more likely to have their quality of life significantly impacted (e.g. due to age, gender, ethnicity, other diseases etc)?
- What are the most common side effects associated with all the different possible combinations of second/subsequent breast cancer treatments?
 - Who is most at risk?
 - When are the effects likely to occur and how long are they likely to last?
 - Possible methods of prevention
 - How do side effects impact
 - How prevalent are such effects in breast cancer survivors?

9.1.9 End of Life Care

- How can appropriate and timely information about what to expect at the end of life and where to get advice and care be best provided to patients and their families/carers?
- Developing and piloting models of joined-up health and social care for patients needing end of life care.

9.2 Cross-cutting themes

9.2.1 Work and finance

- How and when should information be provided to employers after an employee returns to work following breast cancer treatment? What specific information should be included?
- What medical needs do breast cancer survivors have on their return to work? Do they need specific medical advice or support?
- How and when should information on financial support and returning to work best be communicated to breast cancer survivors? What should this information include?

9.2.2 Self-management

See section 9.1.3.

9.2.3 Research

No research questions identified

9.2.4 Information

- What information is available on the side-effects of drug treatments; psychological, social, spiritual, cultural and financial support; complementary therapies and diet/lifestyle after breast cancer; and secondary breast cancer?
 - Is it sufficient for survivors' needs?
 - At what stage(s) should this information be provided?
 - How should the information be delivered?
 - Who is best placed to provide such information?
- What are the information needs of families and carers?
- What are the information needs of hard-to-reach groups of breast cancer survivors?
- There is a need for the development and testing of an information needs assessment tool that would support healthcare professionals to provide relevant information to breast cancer survivors.

9.2.5 Commissioning

- What are the most common side effects associated with all the different possible combinations of primary and second/subsequent breast cancer treatments?
 - Who is most at risk?
 - When are the effects likely to occur and how long are they likely to last?
 - Possible methods of prevention
 - How do side effects impact on residual effects from initial/primary treatment?
 - How prevalent are such effects in breast cancer survivors?
- There is a need for the determination of the incidence and prevalence rates of people with metastatic breast cancer.
- There is a need to develop innovative commissioning models to help those people with severe chronic long-term effects (such as lymphoedema) receive the care they need.
- Greater research evidence on the safety and effectiveness of complementary therapies is needed to help commissioners make decisions about complementary therapy provision on the NHS.

9.3 Other factors that impact on survivorship

9.3.1 Clinical

See section 3.1.2.

9.3.2 Socio-demographic

- How do age, ethnicity, gender, education and socio-economic status impact on breast cancer survivors?
 - quality of life,
 - information, care and service needs?

9.3.3 Individual

- What is the availability of psychosocial support and services available for patients across the UK?
- Development and testing of a tool to assess the emotional state of breast cancer survivors, both prior to and after using a psychosocial support service, in order to identify needs and evaluate outcomes.
- Which interventions are most effective to improve psychosocial problems and quality of life after breast cancer treatment?
- How do individuals' health behaviours, self-esteem and coping responses specifically affect quality of life and wellbeing after breast cancer?
- Interventions designed to address psychosocial problems in the long-term need to be developed and tested.
- Complementary therapies research questions:
 - Which complementary therapies are safe to use alongside conventional breast cancer treatments?
 - Are any complementary therapies effective at improving wellbeing, quality of life or the impacts of the side-effects of treatments?
 - Models of integrated complementary therapies/conventional services need to be developed and piloted.
- How do individual health behaviours, disposition and transformative coping specifically affect breast cancer survivors? What needs do breast cancer survivors specifically have in these areas?

9.3.4 Environmental

- Which environmental factors are specific and important to breast cancer survivors?
- How do location (eg urban v rural), employment, family structures and social support impact on the breast cancer survivorship experience, including
 - relationships,
 - psychosocial needs,
 - access to and uptake of relevant support services,
 - quality of life?
- What is the impact of breast cancer on carers and families? What are their support needs?



Research • Prevention • Support

The National Cancer Survivorship Initiative (NCSI)

Lung Cancer Research Work Stream

FINAL REPORT

**Dr Rosemary Gillespie
Chief Executive
The Roy Castle Lung Cancer Foundation**

Introduction

Due to the lack of research into the impact of lung cancer on patients, carers, the NHS and society as a whole the Roy Castle Lung Cancer Foundation (RCLCF) was delighted to facilitate the Lung Cancer mapping exercise for the NCRI Research Work Stream.

With only 7% of people diagnosed with lung cancer still alive after 5 years it was important to clarify the definition of “Survivorship” in the context of a lung cancer diagnosis. The definition this work-stream has been working to is as follows:

Anyone who is living following a diagnosis of cancer can be described as a survivor, though many people prefer to think about this initiative in terms of “living with and beyond cancer”. Survivorship therefore encompasses patients who are undergoing primary treatment, those who are in remission following treatment and those with active/advanced disease.

Process

The RCLCF consulted with existing lung cancer patients and carers, recently bereaved carers as well as healthcare professionals and researchers with an interest in lung cancer.

Consultation with Patients / Carers

Due to the rapid changes in the NHS it is vital that views are sought from patients and carers who have had a relatively recent experience of services etc. Gaining opinion from current patients and carers affected by lung cancer from across the UK is a constant challenge due to the nature of the disease. Patients are often acutely unwell and caring for them is a 24 hour job. A popular way to engage with patients is to hold focus groups, however due to the nature of the disease current lung cancer patients are usually not fit enough to travel to a central location. Therefore as an organization we tend to consult with patients using a variety of methods, namely via telephone interviews, postal questionnaires or email where appropriate.

In order to populate the model we asked the patients / carers what their experiences and feelings had been through the different parts of their lung cancer treatment / disease pathway. In addition we also asked them about their perceptions of the “wider” arena in terms of stigma etc.

In addition to this process the RCLCF used information highlighted from its recent UK Lung Cancer Attitude Assessment Project to populate the model. From September to November 2008 The RCLCF canvassed opinion on a variety of issues amongst patients and carers at our National Lung Cancer Patient Meeting, held in Glasgow, September 2008; Clinical Nurse Specialists during the National Lung Cancer Forum for Nurses Annual Conference in Harrogate, November 2008 and Clinicians with an interest in lung cancer at the Lilly Oncology Practical Management of Thoracic Cancers, London, November 2008. A combination of keypad voting technology and written questionnaires were used. (1)

Consultation with healthcare professionals and those researchers with an interest in lung cancer

A letter was disseminated to all known interest groups requesting assistance with this project, in particular any unpublished work (grey literature) (Appendix 1).

As previously stated there appears to be little research available on the impact of lung cancer and even less addressing the relatively small numbers of individuals who are still alive one year after diagnosis.

The feedback from the letter was varied. There was generally an interest in the project however most of the documentation we received was in relation to early diagnosis rather than through the different parts of the lung cancer journey.

A great number of responses were in the shape of general comments regarding areas where there appears to be a lack of information / research. These comments were included into the model.

At each stage of the process the model was shared with all the participants asking for input and comments. A list of contributors can be found in Appendix 2. All participants would be happy to be contacted as part of the ongoing project.

1. DIAGNOSIS, INCLUDING SECONDARY CANCERS AND RECURRENCE – See model for detail (Refs 1, 2,3,4)

CLINICAL:

Lack of awareness of signs and symptoms in both the public and GPs at both initial diagnosis and signs of recurrence
Slow recognition of symptoms leading to Early Detection & Initial Diagnosis

SOCIO-CULTURAL:

Higher proportion of females smoking especially young females
Impact of lung cancer blame and stigma on early presentation
Lack of awareness of signs and symptoms
Services need to be tailored to meet the info and support needs of socially deprived people
Impact of deprivation
Impact of social inequalities

INDIVIDUAL:

Stigma affects lung cancer patients whether or not they have a smoking history
Fear due to the awareness of poor lung cancer statistics – “death sentence”
Guilt
Disease trajectory impact on patient and family
High likelihood of recurrence

ENVIRONMENTAL:

Blame – family
Financial difficulties

2. TREATMENT, INITIAL & SUBSEQUENT TREATMENTS – See model for detail
(Refs: 1, 5,6,7,8,10)

CLINICAL:

Access to oncologist with interest in lung cancer
Access to lung cancer clinical nurse specialist
Access to breathlessness support/clinics
Access to Smoking Cessation services
Access to lung cancer clinical trials
Effective side effect management – during/post treatment
Access to new treatments
Access to post treatment rehab/fitness planning
Access to dietary advice/nutrition

SOCIO-CULTURAL:

Impact of stigma on lung cancer patients / carers
Lung cancer patient barriers into seeking most appropriate care and support
Timing of services
Services need to be tailored to meet the info and support needs of socially deprived people
Impact of deprivation
Impact of social inequalities
Ethnic minorities – information in relevant language

INDIVIDUAL:

Stigma affects lung cancer patients whether or not they have a smoking history
Disease trajectory impact on patient and family
High likelihood of recurrence

ENVIRONMENTAL:

Peer support
Support groups
Employment Issues
Counselling – individual/relationship/family
Financial support
Family

3. ACUTE / IMMEDIATE POST TREATMENT – See model for detail (Ref:5, 7,8,10)

CLINICAL:

Continued access to oncologist with interest in lung cancer
Continued access to lung cancer clinical nurse specialist
Access to breathlessness support/clinics
Access to Smoking Cessation services
Effective side effect management – post treatment
Access to post treatment rehab/fitness planning
Access to supportive care within Primary Care setting

Access to dietary advice/nutrition
Access to psychological assessment & related support eg survivors guilt

SOCIO-CULTURAL:

Impact of stigma for lung on lung cancer patients / carers
Lung cancer patient barriers into seeking most appropriate care and support
Provision of local services
Services need to be tailored to meet the info and support needs of socially deprived people
Impact of deprivation
Impact of social inequalities
Ethnic minorities – information in relevant language

INDIVIDUAL:

Stigma affects lung cancer patients whether or not they have a smoking history
High likelihood of recurrence
Information provision after treatment

ENVIRONMENTAL:

Peer support
Support groups
Returning to work / Employment issues
Counselling – individual/relationship/family
Financial support
Family

4. SUB-ACUTE / REMISSION AND FOLLOW-UP – See model for detail (Ref 5,9)

CLINICAL:

Continued access to oncologist with interest in lung cancer
Continued access to lung cancer clinical nurse specialist
Access to breathlessness support/clinics
Access to Smoking Cessation services
Effective side effect management – post treatment
Access to post treatment rehab/fitness planning
Access to supportive care within Primary Care setting
Access to dietary advice/nutrition
Access to psychological assessment & related support eg survivors guilt

SOCIO-CULTURAL:

Impact of lung cancer stigma
Lung cancer patient barriers into seeking most appropriate care and support
Services need to be tailored to meet the info and support needs of socially deprived people
Impact of deprivation
Impact of social inequalities
Ethnic minorities – information in relevant language

INDIVIDUAL:

Stigma affects lung cancer patients whether or not they have a smoking history
High likelihood of recurrence
Managing long term effects affecting quality of life in survival
Information provision after treatment

ENVIRONMENTAL:

Peer support
Support groups
Returning to work / Employment issues
Counselling – individual/relationship/family
Financial support
Family

5. LONG TERM EFFECTS – See model for details (Ref: 8,10)

CLINICAL:

Access to breathlessness support/clinics
Access to Smoking Cessation services
Effective side effect management – post treatment
Access to post treatment rehab/fitness planning
Access to supportive care within Primary Care setting
Access to psychological assessment & related support eg survivors guilt

SOCIO-CULTURAL:

Lung cancer patient barriers into seeking most appropriate care and support
Services need to be tailored to meet the info and support needs of socially deprived people
Impact of deprivation
Impact of social inequalities
Ethnic minorities – information in relevant language

INDIVIDUAL:

Stigma affects lung cancer patients whether or not they have a smoking history
Likelihood of recurrence
Managing long term effects affecting quality of life in survival
Information provision after treatment

ENVIRONMENTAL:

Peer support
Support groups
Returning to work / Employment issues
Counselling – individual/relationship/family
Financial support
Family

1. **DISEASE FREE/ REMAINS WELL** – See model for details (Ref: 8,10)

CLINICAL:

Access to breathlessness support/clinics
Access to Smoking Cessation services
Access to supportive care within Primary Care setting
Access to psychological assessment & related support e.g. survivors guilt

SOCIO-CULTURAL:

Services need to be tailored to meet the info and support needs of socially deprived people
Impact of deprivation
Impact of social inequalities
Ethnic minorities – information in relevant language

INDIVIDUAL:

Managing long term effects affecting quality of life in survival
Information provision after treatment

ENVIRONMENTAL:

Peer support
Support groups
Returning to work / Employment issues
Counselling – individual/relationship/family
Financial support
Family

2. **END OF LIFE INCLUDING ADVANCED DISEASE** – See model for details

CLINICAL:

Access to specialist palliative care

SOCIO-CULTURAL:

Lung cancer patient barriers into seeking most appropriate care and support
Timing of services
Services need to be tailored to meet the info and support needs of socially deprived people
Impact of deprivation
Impact of social inequalities
Ethnic minorities – information in relevant language

INDIVIDUAL:

Concern for family

ENVIRONMENTAL:

Financial worry / support

APPENDIX 1



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www.roycastle.org

2 April 2009

Following the publication of the Cancer Reform Strategy for England in 2007, the National Cancer Survivorship Initiative (NCSI) was launched in March 2008. Co-chaired by Macmillan Cancer Support and the Department of Health, the NCSI aims to improve the quality of life for people living with or beyond cancer. The initiative focuses on seven work streams and The Roy Castle Lung Cancer Foundation (RCLCF) sits on the Research workstream steering group. The overall aims are

- To identify what is and what is not known about the health and well-being and the care and support of cancer survivors
- To prioritise a future research agenda to tackle the ‘not knowns’
- To work closely with the NCRI in informing the commissioning of a research programme to address key identified priorities

The Foundation has agreed to lead the development of a lung cancer-specific survivorship framework. Although the term survivorship may not be frequently used in relation to lung cancer, this project is based on the following assumption:

Anyone who is living following a diagnosis of cancer can be described as a survivor, though many people prefer to think about this initiative in terms of “living with and beyond cancer”. Survivorship therefore encompasses patients who are undergoing primary treatment, those who are in remission following treatment and those with active/advanced disease.

A review of published, peer-reviewed literature relevant to lung cancer survivorship will be commissioned by the work stream. However we felt that there may be unpublished (“grey”) research which could add a different dimension to this work. By including this information, we hope that we will be able to identify what is already known about lung cancer survivors’ experiences and needs and therefore we will be able to highlight the **gaps** in our knowledge. We would hope to then be able to better understand where research into this area needs to be directed.

In order to ensure that we have the most comprehensive picture of lung cancer stakeholders’ opinions and experiences of survivorship, we would like to collaborate with a number of organisations who may have previously conducted work in this area. We would be grateful if you would consider sharing results of any surveys, insight work, focus groups or other similar quantitative or qualitative research relevant to lung cancer survivorship that you may have carried out. Areas that are relevant to the framework include information on services, treatments, long-term effects (physical, psychosocial, spiritual etc), patient information, benefits or other relevant factors and variables (see framework for definitions).

Once we have collected all of the relevant information, RCLCF will analyse and summarise it in order to populate the framework. We will then identify where there may be gaps in our knowledge or where more in depth research may be required. We will present a summary of this work to the Research work stream steering group at the end of February 2009.

If you are able to share any relevant research or insight work with us, please could you send us details of the findings by **Friday 20th February 2009**. If you have any concerns regarding the use of confidential material, we would be very happy to discuss this further with you and to explore the different possibilities for using the material to better inform this work without publicising sensitive material.

Please contact Joyce Dunlop, Director of Patient Support who is co-ordinating this work on behalf of The Roy Castle Lung Cancer Foundation if you have any questions regarding this work.

Yours sincerely

A handwritten signature in cursive script that reads "Rosemary Gillespie".

Dr Rosemary Gillespie
Chief Executive
The Roy Castle Lung Cancer Foundation

APPENDIX 2 Contributors

Lung Cancer Patients/Carers and bereaved carers c/o The Roy Castle Lung Cancer Foundation

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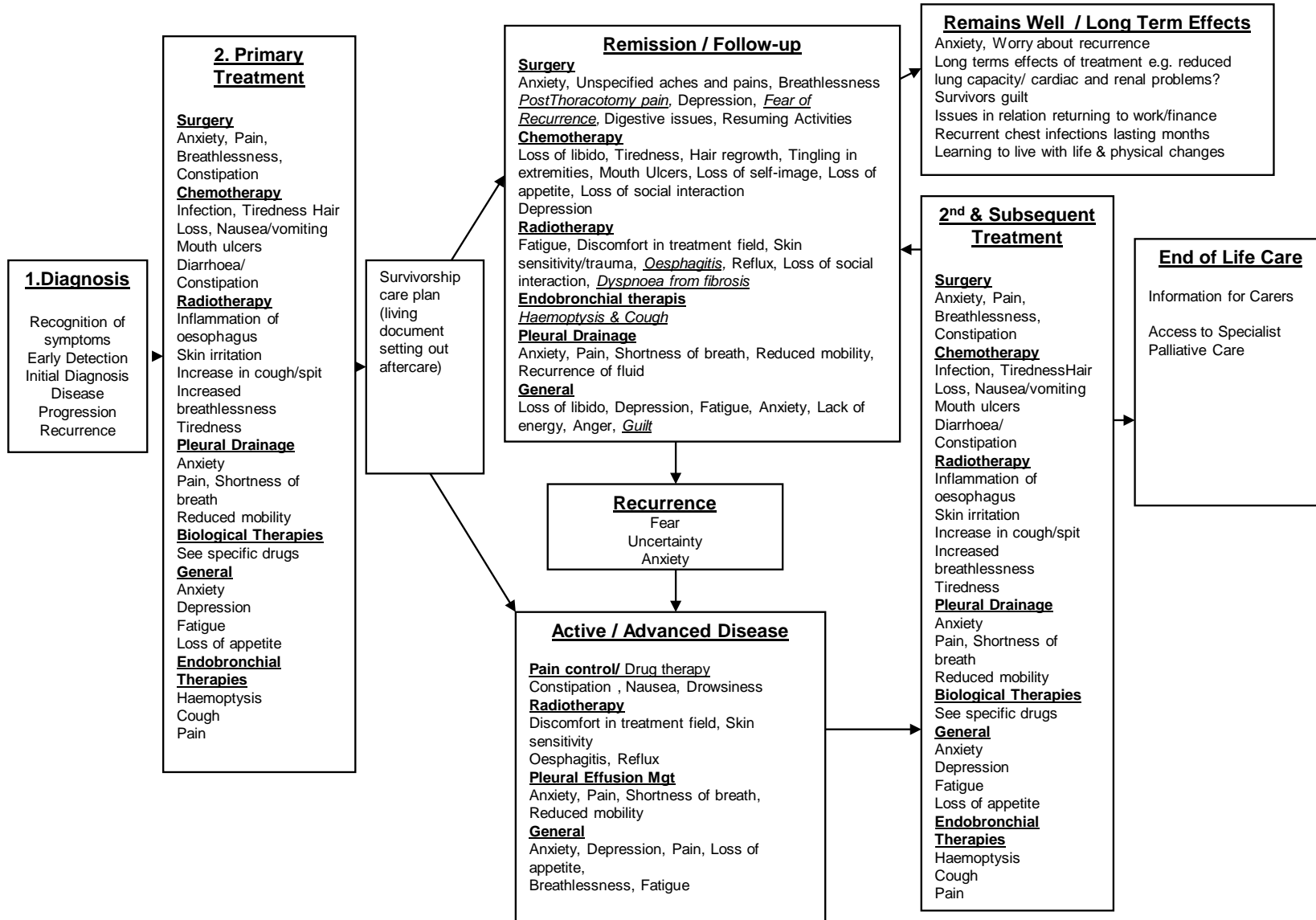
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APPENDIX 3 - Grey Literature References

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Lung Cancer Survivorship model



Factors which impact on survivorship on those affected by lung cancer

Clinical

Access to oncologist with interest in lung cancer
Access to lung cancer clinical nurse specialist
Access to breathlessness support/clinics
Access to Smoking Cessation services
Access to lung cancer clinical trials
Effective side effect management – during/post treatment
Access to new treatments
Access to post treatment rehab/fitness planning
Access to supportive care within Primary Care setting
Access to dietary advice/nutrition
Access to psychological assessment & related support e.g. survivors quilt
Access to specialist palliative care

Socio-demographic

Higher proportion of females smoking especially young females
Impact of lung cancer stigma on early presentation, research funding etc
LC patient barriers into seeking most appropriate care and support
Timing of services
Lack of awareness of signs and symptoms
Services need to be tailored to meet the info and support needs of socially deprived people
Impact of deprivation
Impact of social inequalities
Ethnic minorities – information in relevant language

Individual

Stigma affects lung cancer patients whether or not they have a smoking history

Disease trajectory impact on patient and family

High likelihood of recurrence

Managing long term effects affecting quality of life in survival

Information provision after treatment

Environmental

Peer support

Support groups

Returning to work / Employment issues

Counselling – individual/relationship/family

Financial support

Family



Identification of research needed into the experience of men living with and beyond prostate cancer

**Paper for the National Cancer Survivorship
Initiative – Research working group**

The Prostate Cancer Charity

March 2009

Introduction

This paper is a submission to the National Cancer Survivorship Initiative Research Work Stream on the survivorship research priorities for prostate cancer.

The overall aims of the research working group are:

- To identify what is and what is not known about the health and well-being, care, support needs and experiences of people living with and beyond cancer
- To prioritise a future research agenda to tackle the 'not knowns' about the health and well-being, care, support needs and experiences of people living with and beyond cancer
- To work closely with the National Cancer Research Institute (NCRI) to inform the commissioning of a research programme to address identified priority areas where research is needed.

The Prostate Cancer Charity was asked by the Research working group to complete the following activities:

- To map the 'survivorship journey' of men with prostate cancer.
- To identify new research that is needed to inform understanding of the experience, care, support and information needs of men living with and beyond prostate cancer

This paper explains the process undertaken by The Prostate Cancer Charity to identify the survivorship research priorities for prostate cancer and sets out the identified research priorities.

Process of identifying the research priorities for prostate cancer

Mapping the 'survivorship journey'

The Prostate Cancer Charity began the process of identifying the survivorship research priorities for prostate cancer by mapping the 'survivorship journey' of men with prostate cancer. This involved considering:

- The different stages of prostate cancer
- Treatment options and the associated side effects and late effects of treatment
- Socio-cultural variables – eg age, ethnicity, socio economic status, education
- Variables relating to the individual – coping response, health behaviour, disposition
- Environmental factors – geographic, work, family, social support

Mapping the survivorship journey allowed the Charity to consider all of the different survivorship needs that men with prostate cancer might have. The development of the pathway was carried out in consultation with our Specialist Nursing and Information Teams. The pathway can be found in appendix 2.

Internal consultation

To identify an initial list of key survivorship needs and potential areas for research the Policy & Campaigns Team reviewed existing evidence about the experience of men with prostate cancer from a national survey conducted by the Charity in 2005 '*The First National Survey*'¹ and a report from the Prostate Cancer Charter for Action '*Because men matter*'². We also considered evidence from key research papers on the needs of men with prostate cancer in the UK.

This initial list of potential areas for research was used as the basis for an internal consultation with the specialist prostate cancer nurses who staff our Helpline, our Healthcare Services Liaison Manager and our Information Team. The internal consultation led to a more detailed list of research ideas being developed which was then discussed with the organisation's Healthcare Professional Advisory Group and a couple of external researchers who work in the prostate cancer field.

External Stakeholder Consultation

The Charity arranged a stakeholder event on 6 February 2009 to consult with other stakeholders in the field of prostate cancer including men affected by prostate cancer, researchers, healthcare professionals and other charities on the research that should be carried out into the needs of men living with prostate cancer. The invite to the event was sent out to the Prostate Cancer Charter for Action (members of the Charter include patient groups, prostate cancer/cancer charities and health professional organisations), Prostate Cancer Voices (a network of people affected by prostate cancer), and researchers known to have experience of working in the field.

Around 30 people signed up to participate in the event but unfortunately due to heavy snowfall on the day only 21 people were actually able to attend alongside four members of the Charity's Policy & Campaigns Team. (See appendix 1 for full list of attendees.)

In preparation for the event attendees were sent a paper outlining the aim of the project and setting out the initial list of ideas about the research that is needed to inform our understanding of the experience (and needs) of prostate cancer survivors developed by the Charity. This paper contained details of 16 different potential research areas.

At the event stakeholders were divided into three small groups and asked to share their own ideas about the key issues that need addressing by the research community to inform improved care, support and experience of men living with and beyond prostate cancer. They were then asked to debate and refine the ideas put forward by the Charity and to prioritise the suggested research areas. When discussing the research ideas put forward by the Charity stakeholders were asked to consider the following questions:

- Has comprehensive research already been conducted in this area?
- Is there a pressing need to address this research idea?
- Is there anything missing from this list that you think should be added?
- Is there anything on this list that you think should be removed?

After the small group discussions the results from the three groups were compared and common priorities identified. Stakeholders were then given the opportunity to rate individually each research idea.

The discussion at the event was very informative, from the input provided by the participants we were able to refine the list of key research areas and select the top five priorities. The research topics selected are set out in the paper below. During the discussion at the event a number of research areas were discussed which the stakeholders felt were important but which were applicable to all cancers rather than prostate cancer specifically; these ideas have also been included in the paper. There are also a number of generic issues which stakeholders felt should be taken into consideration by the NCSI – Research working group which have been included.

Research needed into the experience of men living with and beyond prostate cancer

Top five research priorities

1. Psychosexual needs of men with prostate cancer

(Matrix - 3. Acute, 4. Sub-acute, 5. Long term effects

A. Clinical Residual symptoms, C Individual – coping behaviours)

A number of the treatments for prostate cancer can cause erectile dysfunction and hormone therapy can also cause a loss of sexual desire. There are erectile dysfunction services currently available to men but these services often only address the physical aspect of erectile dysfunction and not the psychological impact that erectile dysfunction or a loss of sexual desire can have on a man and his partner.

Participants at the stakeholder event felt that this was a priority area of research for men with prostate cancer. It was felt that there is a lack of research on how to combine the psychosexual and physical needs associated with erectile dysfunction. There is research into providing support for the physical aspects of erectile dysfunction for example through tablets, injections or implants but not how to combine this type of intervention with emotional needs, impact on masculinity or the effect on relationships. Participants felt that the impact of sexual function side effects on men is often underplayed and that the impact on masculinity has not been fully investigated.

Some participants also highlighted that most studies of psychosexual needs and interventions for men with prostate cancer have been conducted among men who have had a prostatectomy and have not included men who have received radiotherapy or hormone therapy.

The key research areas for ‘the psychosexual needs of men with prostate cancer’ were identified as:

- Research to investigate the impact of loss of sexual function and sexual desire on men; this should include the psychological impact and affect on masculinity.
- Research into appropriate interventions and forms of support for men experiencing loss of sexual function and sexual desire which address both the psychological and physical impacts. In particular interventions should consider the impact on relationships.

2. The support needs of men from black and minority ethnic groups (and their partners) (Matrix - B. Socio-Cultural – relevant to all stages of diagnosis and treatment)

Research has shown that black and minority ethnic (BME) groups can experience inequalities in healthcare³. However there has not been much research to investigate the specific support needs of men from BME groups affected by prostate cancer. In the UK, African Caribbean men are three times more likely to develop prostate cancer than white men, and are more likely to develop cancer at an earlier age. It is particularly important that more is known about the support needs of this group.

The participants at the stakeholder event felt that this was a priority research area and that there are considerable research gaps in terms of UK specific research.

The key research areas for the support needs of men from black and minority ethnic groups (and their partners) were identified as:

- Research to investigate the experience of having prostate cancer among different black and minority ethnic (BME) groups. This should include cultural perceptions of the disease.
- Research to investigate the experience men from BME groups have of accessing and using prostate cancer health and support services.
- Research to identify appropriate interventions to support BME men (and their partners) affected by prostate cancer.

3. 'Empowering' interventions.

(Matrix - 3. Acute, 4. Sub- Acute, 5. Long term effects
C. Individual health behaviours, Individual - Disposition)

Anecdotally we know that men frequently cite a feeling of 'loss of control' as a result of prostate cancer. Some men seek to gain a sense of control over the disease, through altering their diet, pursuing complementary therapies or through exercise. Research into the most effective ways of empowering men to regain a sense of control could improve the care of men with prostate cancer. This research would feed into the work of the NCSI - Self management working group.

The participants at the stakeholder event felt this was a priority research issue. It was felt to be important that men with prostate cancer can be empowered to be involved in decision making about their treatment and that they have access to information and support which can enable them to take some active control over their condition. Participants felt that the role of complementary therapies, exercise and diet in helping men manage their condition should be investigated.

The key research areas for 'empowering interventions' were identified as:

- Research to investigate the self management techniques which men are currently using to manage their disease and side effects and their effectiveness e.g. diet, exercise, and complementary therapy.
- Research to investigate the type of self management techniques that men with prostate cancer would find appropriate and use.

- Research to test /evaluate different self management interventions to help men manage their condition and treatment side effects.

4. Understanding the long term impact of treatment side effects to aid informed treatment decision making

(Matrix1. Diagnosis, 2. Treatment.

A. Clinical – Residual symptoms)

Men with prostate cancer have to make difficult decisions about which treatment option to have, particularly as treatment side effects can have a long term impact on quality of life. At the time of diagnosis it can be difficult for men to fully consider the long term impact that treatment side effects, such as erectile dysfunction and incontinence may have on them because they are still coming to terms with a cancer diagnosis. Some men later regret their treatment choice because of the significant impact of side effects on their quality of life. There is a concern that a lack of information on the long term impact of treatments side effects for prostate cancer can make it difficult for men to decide which treatment option to have.⁴

At the stakeholder event participants felt this was a priority issue. However some participants highlighted that a lot of evidence on the incidence and impact of side effects already exists, especially for localised prostate cancer from studies such as the ProtecT study. However, there may be less evidence about the incidence and impact of treatments for locally advanced or advanced prostate cancer. The participants felt that a greater issue might be how information on incidence and long term impact is being used and communicated to men when they are making treatment decisions.

The key research areas for ‘understanding the long term impact of treatment side effects to aid informed treatment decision making’ were identified as:

- Review of existing evidence on incidence and long term impact of treatment side effects to identify gaps in knowledge.
- Research into scale and long term impact of side effects where gaps have been identified through the review.
- Evaluation of how information on potential long term side effects of treatment is communicated to men making treatment decisions by healthcare professionals and identification of ways to improve this process.

5. Follow up systems and support for men on hormone therapy

(Matrix - 2. Treatment, 3. Acute

A. Clinical – Medical Care)

The follow up care of men on hormone therapy can be ad hoc and there are variations in how follow up care is delivered with some men being looked after in secondary care, whilst others are seen in primary care. These variations can impact on satisfaction with care and this is something that has been noted through calls to the Charity’s helpline. There may be a need for research to develop more systematic processes for follow up and support of men on hormone therapy.

The participants at the stakeholder event felt this was a priority area for research. There were concerns over the information given to men about the likelihood of side effects from

hormone therapy and how this information was communicated to men. Participants also raised concerns about whether the information and support needs of these men were being fully assessed and met during follow up.

It was also highlighted that there are research gaps in terms of what can be done to help men manage some of the side effects they experience from hormone therapy. It was also felt that where interventions do exist they are not always widely known about by all healthcare professionals involved in the follow up care of men on hormone therapy.

The key research areas for 'follow up systems and support for men on hormone therapy' were identified as:

- Research into the follow up experience of men on hormone therapy. In particular to find out how they feel about the follow up processes in place, how well they are communicated with and whether they are provided with information and support to cope with side effects.
- Research into best practice models of co-ordinated follow up for men on hormone therapy.
- Research into interventions that can support men to cope with hormone therapy side effects particularly the impact on sexual function/sexuality and mental wellbeing.

Other research priorities identified

Below are details of the remaining research areas identified. These issues were all felt to be important and have not been placed in an order of priority.

6. Development of an assessment tool to identify the survivorship needs of men affected by prostate cancer

*(Matrix - 3. Acute, 4. Sub-Acute, 5. Long term effects
A Clinical Residual symptoms)*

It is important to assess the survivorship needs of men affected by prostate cancer, particularly as they may have some specific needs relating to incontinence, bowel function or sexual function and desire. Assessing the needs of men with prostate cancer through a tool could ensure all needs are identified and that men receive the support they need.

Participants at the stakeholder event felt that the assessment of survivorship needs was important and that without this assessment some concerns affecting men may be missed. However, participants were aware that the NCSI already has a workstream looking at assessment and care planning. It was felt that research into this area might be dependent on the needs of the workstream looking at assessment and the gaps in knowledge this group felt existed. Some participants commented that there are already some needs assessment tools in existence and that the problem lies in the implementation of an assessment tool into common practice.

Some participants also felt that it might be helpful for men to have a self assessment tool to enable them to assess their own support needs and be empowered to raise issues of concern with their healthcare professionals.

The key research areas for 'the development of an assessment tool to identify the survivorship needs of men affected by prostate cancer' were identified as:

- Validation of a tool that specifically takes into account the survivorship needs of men with prostate cancer e.g. incontinence, impact on sexual function.
- An evaluation of the use of an assessment tool in practice, investigating barriers to implementation.
- Development of a self-assessment tool for men with prostate cancer.

7. Anxiety and depression among men living with and beyond prostate cancer

(Matrix - 5. Long term effects

A. Clinical Residual Symptoms)

There is little evidence on the level of anxiety and depression among men treated for prostate cancer.⁵ However, there is some evidence to suggest that psychological distress is currently not being assessed or managed well in men living with prostate cancer in England and that this contributes to the unmet supportive care needs of men with prostate cancer.⁶

The participants at the stakeholder event felt this was an area where more research was needed. In particular men experience anxiety in the lead up to the PSA tests they receive as part of regular follow up.

The key research areas for 'anxiety and depression among men living with and beyond prostate cancer' were identified as:

- Research is needed to identify the scale of anxiety and depression in men with prostate cancer and the main causes of anxiety and depression.
- Research to investigate effective interventions to help men manage anxiety and depression.
- Research into self management techniques to help men cope with anxiety around the time of their regular PSA tests.

8. Support needs of men on active surveillance

(Matrix - 2. Treatment.

A. Clinical – Medical Care)

There is a lack of research into the experience, psychological impact and support needs of men on active surveillance. It may also be beneficial to investigate how best to support men in making the decision about whether to choose active surveillance. Some men make the decision to undergo active surveillance but then change their minds and undergo another form of treatment without any sign of disease progression, often because of concerns about the cancer progressing. It would be helpful to investigate whether improved support for decision making would increase long term satisfaction with this treatment choice.

The key research areas for the 'support needs of men on active surveillance' were identified as:

- Research to investigate the experience of men undergoing active surveillance. This would include an investigation of why some men choose to leave active surveillance without disease progression.

- Research to investigate effective interventions to support men undergoing active surveillance.

9. Prostate cancer and gay men

(Matrix - B. Socio cultural – all stages of treatment and care)

It is not known how many gay men are living with and beyond prostate cancer in the UK, but given that prostate cancer is the most common male cancer, we can assume that a significant number of gay men are affected by the disease. Despite this a Department of Health (DH) review of Medline found no research on the disease among gay and bisexual men. The Department of Health state that “*gay men are more likely to have difficulty dealing with urologists and oncologists, who may assume a female partner, and the management of any subsequent sexually-related dysfunction may differ from that in heterosexual men.*”⁷

Very little is known about the experience of gay men living with prostate cancer or their support needs. Research is needed into the experience of gay men living with prostate cancer so we can ensure their needs are addressed. Participants at the stakeholder event agreed that this was an important research issue.

The key research areas for ‘prostate cancer and gay men’ were identified as:

- Research to investigate the experience of gay men with prostate cancer including their experience of using health and support services.
- Research to investigate the support needs of gay men living with prostate cancer.

10. Support needs of partners of men with prostate cancer.

*(Matrix - D. Environmental
3.Acute, 4. Sub-acute, 5. Long term effects)*

At the stakeholder event a number of participants raised the issue of the support needs of the partners of men with prostate cancer as an area that should be researched. This was felt to be a particular issue for prostate cancer because the treatment side effects can have a significant impact on sexual function and sexual desire and can therefore impact on men’s sexual and emotional relationships with their partners.

The key research areas for the ‘support needs of partners of men with prostate cancer’ were identified as:

- Research to investigate the impact of loss of sexual function or sexual desire through prostate cancer treatment on partners and relationships.
- Interventions that could support partners to cope with the impact of treatment side effects on their relationship.

11. Work, finance and social care needs of men with prostate cancer

(Matrix - D. Environmental – 5.Long term effects)

At the stakeholder event a number of participants raised the issue of the social care, work and finance related needs of men with prostate cancer. Participants felt that not enough is known about these needs among men with prostate cancer and that this is a research gap.

The key research areas for the 'work, finance and social care needs of men with prostate cancer' were identified as:

- Research to investigate the impact of prostate cancer on work and finance.
- Research to investigate the social care needs of men diagnosed with prostate cancer.

Generic Cancer Research Issues

1. Does age affect access to cancer care and support services?

(Matrix - B- Socio-Cultural)

There is some evidence to suggest that older people may be discriminated against when receiving healthcare, because of their age.⁸ Given that over 90 percent of men diagnosed with prostate cancer are aged over 65 years it is important that the support needs of older men are considered and that they receive appropriate levels of support. In particular, assumptions may be made about the impact of side effects on men's quality of life because of their age (e.g. impact of erectile dysfunction). However, it may also be the case that different age groups place different importance on certain side effects.

Participants at the event felt that the support needs of different age groups were an important research issue. However, they felt that the issue was a generic cancer issue rather than being specific to prostate cancer. Participants felt that all research carried out into survivorship should consider the needs of different age groups and in particular older men.

2. Information and support needs of people moving towards the end of life stage

(Matrix -7. End of life)

Every year 10,000 men die from prostate cancer in the UK. There may be a shortage of information and support for men (and their families) entering the advanced stage of advanced disease. Men need information about what they can expect when moving towards the end of life stage, for example, what they can expect to happen to their physical state. Research may be needed on the information and support needs of men (and their families) that are approaching the end of life stage.

The participants at the stakeholder event felt that this was an important area of research. However they felt this was a generic cancer issue and not specific to prostate cancer. Participants were also unsure if this was an issue for the National Cancer Survivorship Initiative or whether it was being looked at under the new End of life strategy work.

3. Access to support services

(Matrix - A. Medical – Medical care)

There is uncertainty about what support services currently exist across the country to support men living with prostate cancer and concerns that there may be inequalities in the availability of support services particularly for those living in more rural areas. A scoping study to assess the current level of support service provision for men with prostate cancer would be helpful.

Participants at the stakeholder event felt it would be important for the NCSI to scope the current provision of support services, however they felt this was a generic issue which should be looked at for all cancers rather than prostate cancer specifically.

4. Needs of single people living with cancer

(Matrix - B. Socio- Cultural)

At the stakeholder event a number of participants raised the issue of single men living with prostate cancer and whether they might have additional or specific support needs. In discussion it was felt that the support needs of single people was a generic cancer issue rather than specific to prostate cancer.

General issues for consideration by the NCSI Research Work Stream

1. Implementation of good practice

Overall participants at the stakeholder event felt that the implementation of research and good practice was an area that needs investigating. They felt that a lot of research already exists around the needs of people living with cancer and interventions that can be beneficial. However, this research did not always get implemented into practice within health care services.

It was felt that the NCSI needs to investigate the barriers to good practice being integrated into daily service delivery. In particular the NCSI should look at the methods through which research about new interventions or good practice gets passed to the NHS and whether training could support the roll out and implementation of new interventions. It was also felt that with more follow up care of cancer patients being provided within primary care it is also essential that knowledge about survivorship needs and interventions is reaching and influencing primary care.

2. Access to Clinical nurse Specialists

Many of the participants at the stakeholder event mentioned access to clinical nurse specialists as being an important issue which is related to the provision of support to men with prostate cancer because they often provide much of this support. There was recognition that there is an under provision of CNSs for men with prostate cancer and that this is an important issue to address if support needs are to be met in the future.

Appendix 1 – List of participants at the stakeholder event

- Mr Mick Barrow Prostate Cancer Voices
- Ms Markella Boudioni London South Bank University
- Mr Frank Chinegwundoh Cancer Black Care
- Professor Joan Curzio London South Bank University
- Ms Laura Dunkeyson The Prostate Cancer Charity
- Professor Sara Faithful University of Surrey
- Mr Tony Fisher Prostate Cancer Voices
- Mr Kenneth Jeffers Prostate Cancer Voices
- Ms Anna Jewell The Prostate Cancer Charity
- Dr Daniel Kelly Middlesex University
- Dr Athene Lane University of Bristol
- Ms Rebecca Leadley Macmillan Cancer Support
- Ms Katie Matheson The Prostate Cancer Charity
- Dr Rosaleen O'Brien University of Oxford
- Ms Sheba Qureshi The Prostate Cancer Charity
- Dr Emma Ream Kings College London
- Mr Tony Rickaby Prostate Cancer Voices
- Professor Clive Searle Queen Mary University of London
- Mr Andrew Scoones Mandate
- Mr Sandy Tyndale-Biscoe PCaSO
- Dr Emma Turner University of Bristol

Attendees from NCSI Survivorship Research Work Stream

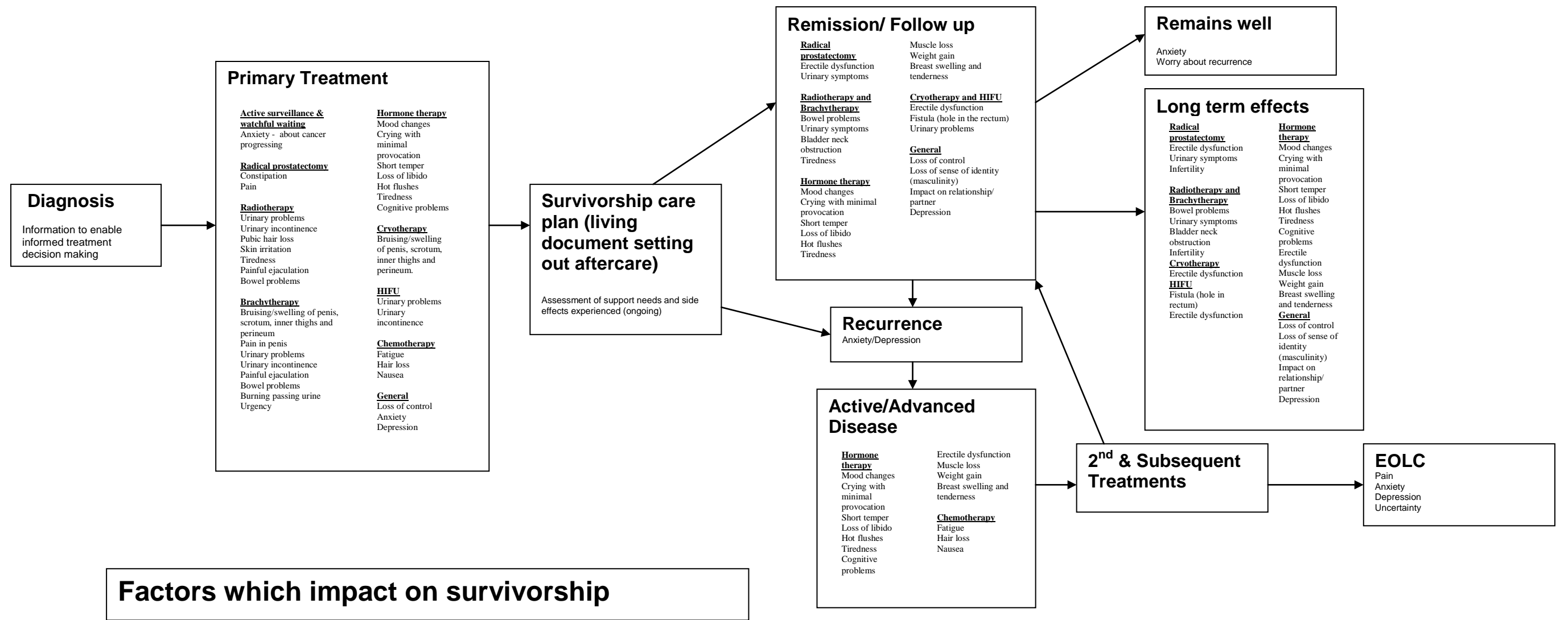
- Ms Julie Flynn NCRI
- Dr Sarah Cant Breakthrough Breast Cancer
- Mr John Gardiner Bowel Cancer UK
- Ms Rosalind Stroud Macmillan Cancer Support

Sent comments as unable to attend the event due to snow

- Mr Paul Sinfield University of Leicester

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- ⁷ Department of Health (2007) 'Gay men's health. Briefing for health and social care staff.'
- ⁸ BBC News online (2009) 'NHS age discrimination common'.
<http://news.bbc.co.uk/1/hi/health/7850881.stm>, 27 January 2009.



Clinical

Tumour biology:

- Pathology
- Response

Health status:

1. current health
2. other diseases – prostate cancer predominantly affects older men so co-morbidities are common. What impact does this have on survivorship?
3. past health

Residual symptoms – symptoms patient continues to experience after treatment:

- incontinence (bowel and urinary)
- erectile dysfunction
- muscle loss
- osteoporosis
- gynaecomastia
- fatigue
- depression
- pain
- cognitive limitations
- etc (as above).....

Medical Care:

- access, for example, to information, a clinical nurse specialist or erectile dysfunction services
- quality – how good is the care a man receives?
- Cost – some treatments not provided on NHS

Socio-demographic

Age

- Predominantly disease that affects older men – what impact can this have on survivorship? Do they face any barriers to appropriate care and support?
- What are the needs of younger men living with prostate cancer?

Gender

- Prostate cancer only affects men
 - Is more research needed into how men view/access cancer services?
 - Do services need to be tailored to meet the needs of men?
- A man's sense of identity/masculinity can be affected by prostate cancer and its treatments.

Ethnicity

- African Caribbean men
 - three times higher risk of developing prostate cancer
 - More research is needed around cultural perceptions of prostate cancer and its side effects and support needs of this group.
- Services need to be tailored to meet the information and support needs of Black and minority ethnic groups.

Education

- Do illiterate men or men with learning difficulties need specialist care and support?

Socioeconomic status

- Are there differences into the experience of men from upper and lower socio-economic background? Is there anything else we should be researching in this area?

Sexual orientation

- Little is known about the experience of gay men with prostate cancer – do they have different support needs?

Individual

Coping response:

- behavioural
 - How can we help men regain a sense of control that we often hear they feel they have lost as a result of prostate cancer and its side effects? – E.g. diet, exercise, information, peer support, psychosexual support. More research is needed in this area.
- response
 - Men are individuals so they react differently to the experience and the side effects of treatment.
 - Can we identify which men are likely to need psychological support through screening/assessment and put a support plan in place?
- cognitive
- biological –for example, each man's body will have an individual reaction to treatment and side effects can have different impact/ effect.

Health behaviours:

- diet
- exercise
- weight
- stress

How do these variables impact on a man's survivorship experience?

Disposition:

- problem solving
- optimism
- Often experience anxiety

Transformative coping:

- spiritual
- non-spiritual

Environmental

Geographic

- Do men in rural areas have the same choice of support services available to them as men in urban areas
- Do men in rural areas have particular transportation needs (which men)?

Work

- How does prostate cancer impact on a man's ability to work (if he is in work at the point of diagnosis)? What support do they need?

Family

- How do prostate cancer and the side effects of treatment affect a man's relationship with his partner? What support do they both need?
- Should relationship counselling be offered to all men (and their partners) after treatment for prostate cancer?

Social support

- What impact do support groups have on men who participate in them? Why don't some men choose to join support groups? Etc.
- How effective are peer support programmes for men living with and beyond prostate cancer?
- When does social care and health care need to be integrated to ensure the best support is available to men living with and beyond prostate cancer?