

Determining Research Priorities for Cancer Survivorship: consultation and evidence review

TECHNICAL APPENDIX: No. 2

Report on National Cancer Survivorship consultation on research priorities

Jo Armes¹
Alison Richardson²
Julia Addington-Hall²

¹Florence Nightingale School of Nursing & Midwifery, King's College London.

²Cancer, Palliative and End of Life Research Group, School of Health Sciences, University of Southampton.

December 2009

Final version following revisions agreed by NCSI research work stream March 2010

Introduction

This report presents findings from a consultation exercise to determine research priorities in the field of cancer survivorship in the UK. It complements two scoping reviews undertaken to identify problems faced by cancer survivors and the effectiveness of interventions designed to alleviate these problems.

Aims and research question

We were commissioned to undertake a consultation with researchers, commissioners and consumers of survivorship research to identify (a) what is known about the problems faced by cancer survivors and solutions tested (b) research projects in this field that are ongoing (c) future research priorities and (d) the availability of large data sets suitable for secondary analysis.

Overall Question

What are the future priorities for research in relation to cancer survivorship, taking into account existing evidence, current and planned research and identified priority areas?

Specifically, we aimed to consult the research community, voluntary organisations and statutory bodies with an interest in survivorship research in the UK to identify:

1. Their views on the most important questions pertaining to the health and well being of cancer survivors that merit research in future
2. Relevant unpublished reports and ongoing research
3. Large datasets that may be amenable to secondary analysis

Methods

Design

We undertook a national consultation and prioritisation exercise using a technique similar to that used by Shipman et al¹ in the recent consultation on priorities in End of Life Care. This took into account work already conducted by Macmillan Cancer Support and the National Cancer Survivorship Initiative research work stream.

The consultation exercise was conducted in two stages (see Figure 1). Stage 1 comprised an on line survey and stage 2 a face to face consultation event. Figure 2 provides a more detailed overview of processes involved in undertaking the consultation survey

¹ Shipman, C Gysels, M White, P et al Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups. BMJ 2008;337:a1720

Figure 1: Key stages undertaken during the consultation process

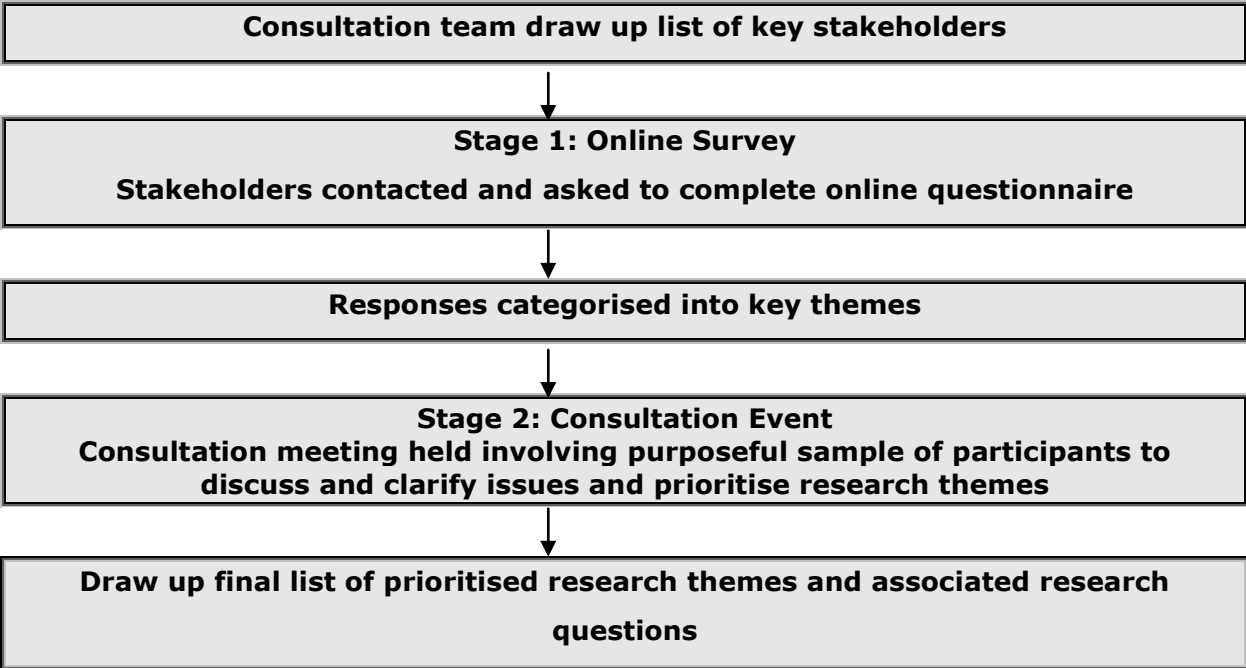
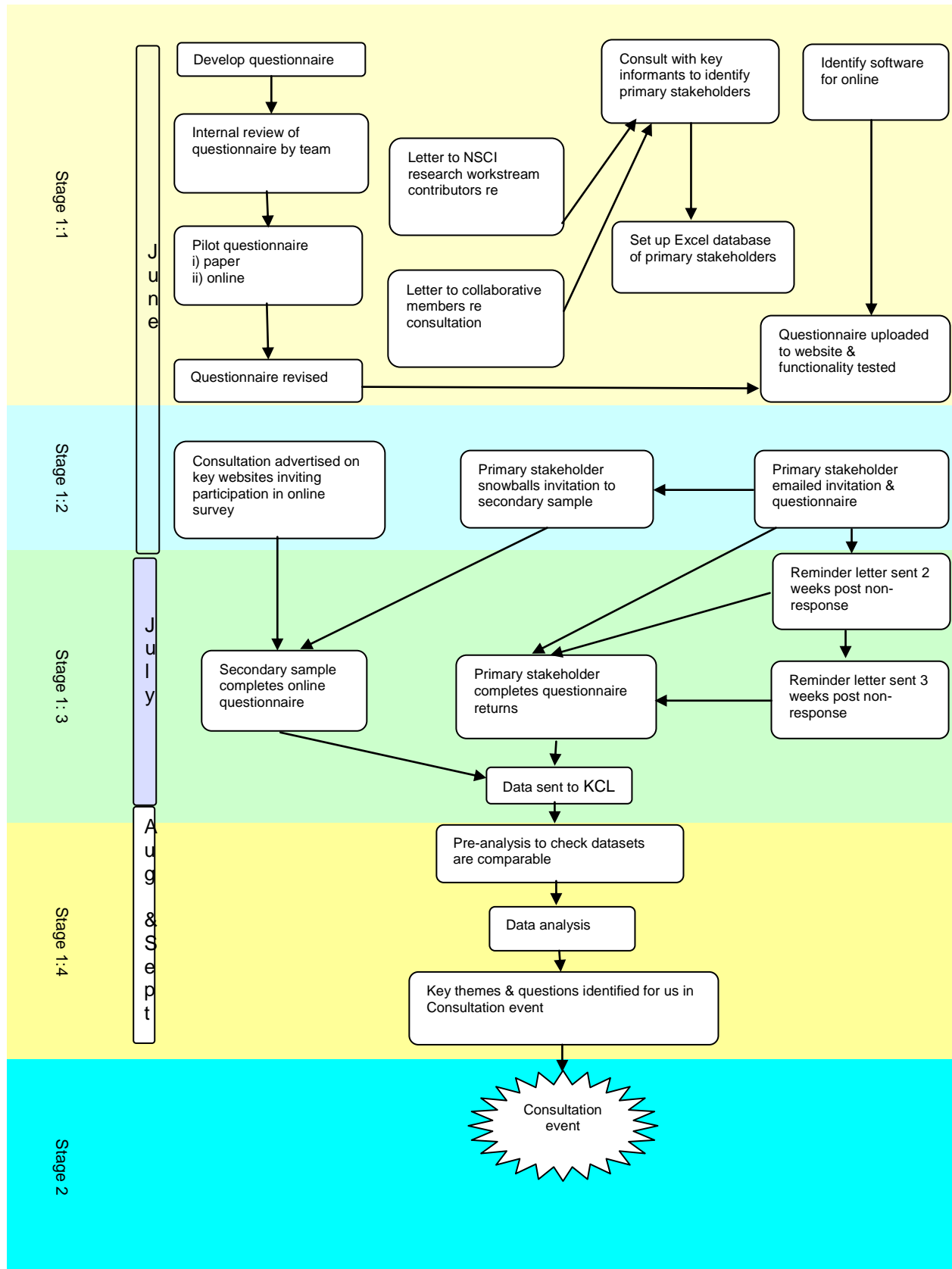


Figure 2: Flowchart of processes involved in undertaking the consultation survey



Stage 1: Questionnaire Survey

Participants

Two forms of recruitment were used. First, a primary group of key stakeholders were identified and personally invited, based on the judgement they were considered in some way 'expert' on survivorship research. The primary list of 'experts' was generated from a number of sources by contacting key stakeholders. These included: NCSI workstreams/crosscutting groups; NCRI Clinical Studies Groups (Psychosocial Oncology; Primary Care; Palliative Care; Complementary Therapies; Consumer Liaison; Survivorship); respondents to the NCRI Supportive and Palliative Care (SUPAC) survey conducted in 2004; members of CECO and COMPASS research collaboratives; key charitable and statutory organisations that fund research in this area; and user organisations. Secondly, a snowball technique was used, whereby the primary stakeholders were asked to pass on the invitation to participate to other relevant stakeholders (academic institutions, individuals and voluntary organisations) to ensure as wide range of views as possible were gathered in the time available. In addition advertisements inviting people to participate in the consultation survey were placed on four key websites – NCRI, NCRN, and the CECO and Compass collaboratives.

Data collection

A short, structured questionnaire was developed (Appendix A). This explored what participants perceived to be the most important and useful research needed to better support cancer survivors. Respondents were also asked to identify unpublished completed research, and any research underway or planned. The questionnaire was piloted with 5 individuals to ensure it met its purpose.

Both paper and online versions of the questionnaire were developed. Whilst the primary sample were sent and asked to return the questionnaire via email to facilitate calculation of a response rate, the snowball sample could return the questionnaire via email or complete it online using SurveyMonkey software. Use of the online questionnaire was developed and then piloted with 5 individuals for functionality. When requested copies of the questionnaire were also posted to potential participants.

Data were collected over a four week period between 14/7/09 - 12/8/09. Reminder letters were emailed two and three weeks after the questionnaire was distributed. Participants in the snowball sample were either invited to participate by a member of the primary stakeholder group or responded to a web advertisements to participate. As a consequence the research team did not know who or how many had received the invitation and it was not possible to send reminders to this group.

Data analysis

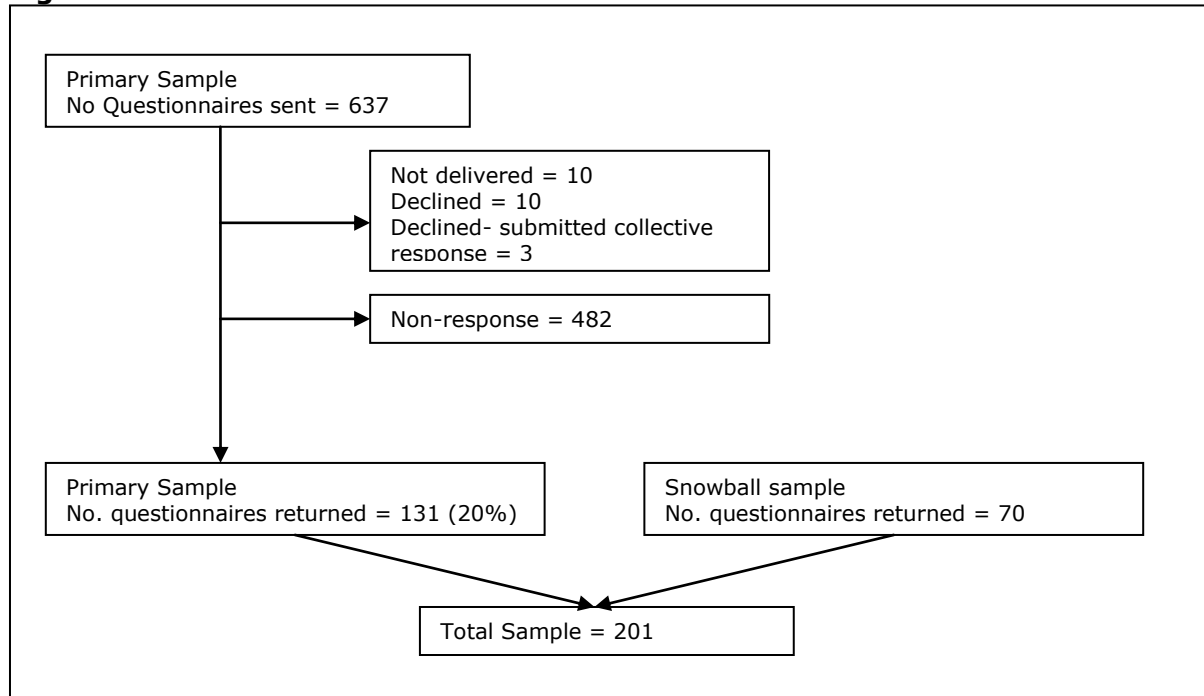
Thematic analysis of participants' responses was undertaken with the primary sample's data and a coding frame developed identifying main themes and sub categories. Subsequently the coding frame was applied to the snowball sample. This exercise revealed the two datasets were comparable in terms of responses and so were combined and results presented for the entire sample.

Responses to questions about ongoing or planned research were entered into an Excel database and analysed using descriptive statistics.

Results from survey

Figure 3 provides an overview of responses received for both primary and secondary samples.

Figure 3: Flowchart of data collection



Questionnaires were sent to a primary sample of 637 people. Of these 20% returned completed questionnaires. The majority of the remainder failed to respond. The fact the consultation period was short and took place during the height of the summer holiday period may account for the low response rate (a large number of automatic responses were received stating invitees were on annual leave). A further 70 people returned questionnaires as a result of a snowballed invitation. In total 201 people responded to the survey, most of whom were recruited from the primary sample (65%).

Characteristics of the sample

The greatest number of responses received was from academic researchers (32%). NHS researchers and charitable or voluntary organisations made up 25% of remaining responses. Just over a tenth of responses received were from patients or carers. Thirty-eight (19%) organisational responses were received. The characteristics of those making an individual response are outlined in table 2 by subgroup and total sample. The majority of the sample was female, aged 41-60 years and resident in England. Of those who made an organisational response the majority (N = 25, 66%) identified the nation they represented as England. Only 9 (25%) reported representing the whole of the UK and, with one exception, all were charitable organisations. There are few differences between the primary and snowball sample, the main ones being that the snowball sample was younger and less likely to provide information on their designation.

Table 2: Sample characteristics (n = 163)

Characteristic	Primary sample n = 93 n (%)	Snowball sample n = 70 n (%)	Total Sample n = 163 n (%)
Age			
18-40	18 (19)	25 (36)	43 (26)
41-60	60 (65)	38 (54)	98 (60)
61-80	5 (5)	4 (6)	9 (6)
Missing	1 (1)	3(4)	4 (2)
Gender			
Male	24 (26)	8 (11)	32 (34)
Female	61 (66)	59 (84)	120 (74)
Missing	2 (2)	3 (4)	5 (3)
Nation			
England	74 (80)	55 (79)	129 (79)
Scotland	8 (9)	5 (7)	13 (8)
Wales	1 (1)	2 (3)	3 (2)
N Ireland	0	5 (7)	5 (3)
Designation			
	n =131	n = 70	n = 201
Patient	9 (7)	9 (13)	18 (9)
Carer	6 (5)	0	6 (3)
Academic researcher	51 (39)	13 (19)	64 (32)
NHS researcher	19 (15)	10 (14)	29 (14)
Charity/voluntary org	21 (16)	3 (4)	24 (12)
Professional org/group	9 (7)	0	9 (5)
Other	16 (12)	0	16 (8)
Missing	0	38 (54)	38 (19)

Identified Research Priorities

Thematic analysis of responses identified two broad research priorities: studies to determine the prevalence of survivors' care needs and the development and evaluation of cost-effective interventions. In relation to interventions it was considered important to explore issues such as the content, mode of delivery and method of outcome measurement. There were also a number of issues that emerged that we categorised as cross cutting themes, factors that might moderate survivors' experiences and should be considered when formulating research. These three areas will now be described in more detail.

Prevalence of survivors needs

Many respondents were at pains to point out how little we know about the physical, psychological and social needs of survivors, let alone the best way of meeting these needs. It was recognised survivors are not a homogenous group and felt there was a need to undertake research to describe the incidence, prevalence and severity of needs over time whilst identifying variation by personal, social and clinical factors. It was envisaged this type of research would inform the second research priority: survivorship interventions through enabling the development of a risk stratification model to identify those 1) most in need and 2) those most likely to benefit from support/intervention.

Survivorship interventions/care

A large number of respondents identified survivorship care and interventions as a research priority and were concerned research should inform selection of the most effective and appropriate intervention for groups of individuals. Respondents particularly focused on the need for care/interventions demonstrate clinical and cost effectiveness. A few respondents expressed concern that evidence-based interventions were not currently being implemented in practice and this was an area that needed addressing.

The theme of intervention was very large and issues raised have been catalogued into three areas:

- 1) Content of interventions
- 2) Delivery of intervention
- 3) Outcomes of intervention

Content

This category refers to the focus and type of intervention. It was recognised that care and support of cancer survivors needs to encompass, as far as possible, the following goals: effective detection of recurrence; optimal detection and management of any consequences of treatment; promote rehabilitation and personal empowerment. Respondents identified seven main areas of supportive interventions in this category that warrant further research. These split into those that deal with the physical or psychological aspects of surviving cancer. Respondents also identified a number of different types of interventions they felt were promising as methods of supporting survivors.

Goal of supportive care interventions: Physical effects

Supportive interventions to alleviate the physical impact of cancer and its treatment on the health and wellbeing of survivors emerged as one of the dominant themes of the survey. A number of recurrent subthemes were identified.

- Consequences of cancer treatment
There is a growing recognition that cancer treatments can result in physical harm long after they were administered. These effects, commonly known as 'late effects', will be termed 'the consequences of treatment' and were, overall, the most frequently mentioned theme in the survey. Specific consequences of treatment most commonly mentioned were lymphoedema (not just for breast

cancer) as well as menopausal symptoms, peripheral neuropathy and arthropathy. The emphasis was on the need to undertake research to describe the prevalence of, and risk factors for, different consequences of treatment. Central to this research was the need to develop systematic methods of assessment both for the specific consequence of treatment and the impact it has on health outcomes. Both these activities were seen as fundamental to developing and testing effective management techniques as well as identifying methods to reduce the risk of or prevent survivors experiencing late consequences. Some suggested there was a need to undertake research to identify the late consequences of biological response modifiers now increasingly used to treat cancer. The need to evaluate new models of care for identifying and treating late consequence of treatment were also identified as a research priority.

- Surveillance for cancer recurrence (ie medical follow-up)
This was an important theme as a number of respondents felt current medical follow-up was unsustainable and ineffective, as many recurrences are identified by the patient between follow-up appointments. It was felt there was an urgent need to research new and effective methods of surveillance for cancer recurrence.
- Symptom assessment and management
Many of the symptoms experienced after the completion of treatment lack valid and reliable assessment tools, are under-recognised and poorly managed. Specific symptoms identified as requiring further research were fatigue (dominant) and sexual functioning.
- Return to work/education and financial matters
It was recognised this was an area where there was very little known and so much work needed to be done to identify the current state of play in order to develop models of vocational rehabilitation both for survivors and employers/statutory agencies.

Goal of supportive care interventions: Psychological support

This was the second most dominant theme of the survey and incorporates a number of subthemes:

- distress/depression,
- fear of recurrence and living with uncertainty,
- body image

Respondents identified the need for research to be undertaken to identify the best means of assessing and cost-effectively managing these issues. There was recognition that survivors develop their own coping strategies and that any interventions/care that are developed should build on these. Furthermore, it was felt important to research the full range of interventions needed to ensure psychological support is available to meet the different needs this group of people have.

Types of intervention

Respondents identified a number of approaches they felt may be particularly beneficial for survivors of cancer that warranted further investigation, the main one being self management. This was largely discussed in relation to assessing its effectiveness/cost-effectiveness in bringing about beneficial improvements to health outcomes. Few, however, discussed what self-management consists of or what skills are required to deliver self-management programmes. A small number felt that the cancer workforce lacked the necessary training and skills to offer such an approach. Two subsidiary themes were identified. Complementary therapies are used by a significant proportion of survivors and thus a need was expressed to establish their safety and effectiveness/cost effectiveness. Secondly, rehabilitation, mainly discussed in relation to promoting physical activity among cancer survivors and a debate over who should deliver such programmes.

Delivery

This theme encompassed the need to research the 'who', 'where', 'when' and 'how' questions about the delivery of supportive interventions to cancer survivors.

- Who
Who should deliver supportive interventions dominated discussion in this theme. Namely, under what circumstances should it be provided by nurses, allied health professionals, peers or general practitioners? Furthermore what training, education and support is needed to undertake this role? A number of respondents felt that in recognition of cancer fast becoming a chronic condition that research should address whether provision should be cancer-specific and explore whether accessing services available to people with other long-term conditions could be an effective and/or acceptable solution.
- Where
This refers to the need to undertake research to identify the optimal care location to deliver supportive interventions eg primary, secondary or a mixed model. In addition the need to investigate the role to be played by the voluntary sector was raised. Further research on how to ensure optimal professional co-ordination of services across primary and secondary settings was highlighted as a research priority.
- When
The need to identify the optimal timing for offering care/interventions to maximise improvements in health outcomes was identified as a research priority relating to the delivery of supportive interventions for survivors. Moreover, how do we best facilitate transition from treatment to surveillance was mentioned several times.
- How
This refers to the mode of delivering supportive interventions such as new media (online, web-based, mobile phone) or individual versus group and in particular the need to investigate efficacy and acceptability of different modes of delivery.

Health outcomes

As mentioned earlier care/interventions were frequently seen as a way of improving health outcomes. There is a lack of consensus on the best indicators of improved health outcomes. The issues raised were as follows:

- Patients need to be assessed in order to develop a plan of care.
- Choice of outcome measures need to take into account
 - Issues important to survivors, their carer/families as well as health professionals. This includes looking at positive personal growth that may have occurred as a result of having cancer.
 - Validity and reliability
 - Cancer survivor-specific or generic measures
 - Suitable for patients and carers
 - Acceptable method of assessment ie interviews, questionnaires, online, phone, how are those with low literacy levels assessed?
 - Optimal timing for assessment
- Should there be core, routinely collected outcomes nationally (ie minimum data set)?

Cross-cutting themes

Cancer survivors are not a homogenous group and there was recognition that a one-size-fits-all approach to survivorship care may not be appropriate. This also relates to a wider concern about equitable access to support for people from different groups. Respondents identified that research needs to be undertaken to identify whether and in what way care needs to be tailored for the following groups.

1) Disease-related factors

- Diagnosis – are there diagnosis-specific issues that require specific interventions eg alterations in appearance in head and neck cancers/neurological/musculo-skeletal, managing a stoma in colorectal cancer etc. Less support is perceived as

being available to those with rarer cancers with little understanding of their specific needs.

- Stage of disease – A number of respondents identified that some people may live for a long time with active/advanced disease and not require end of life care. Thus it is important the needs of this group are identified and met.
- Length of survival – how do care needs differ eg short term v long term? What are the care needs of people who, against the odds, survive a commonly fatal cancer eg lung, pancreas, stomach.

2) Socio-economic factors

- Disadvantaged groups – in relation to social & economic deprivation, disability, single people, BME and single parents

3) Personal factors

- Carers/Families – this was a dominant theme. Respondents felt there was a need to view the patient + family as a whole unit when assessing adjustment, uncertainty and economic effects
- Age
 - Children and teenagers – transition and co-ordination with adult services, impact on education, relationships, and finances. Prevalence, impact of consequences of. Less is known about teenage survivors.
 - Young adults – consequences of treatment, fertility & sexuality, relationships, education/work/finances, psychological impact, effect on those with young children.
 - Older adults – co-morbidity
- Gender – support requirements may vary by gender
- Black & ethnic minority groups – cultural perceptions about cancer, access and uptake of services, language difficulties, appropriate support.

Why are these research priorities important?

Respondents were asked to explain why they thought the research priorities they had identified were important. There was recognition that as cancer treatment becomes more successful, so the number of people surviving and living life after cancer increases. There was, however, a recurrent concern that although this group of people are 'cured' many experience physical and psychological problems that have a negative impact on their ability to resume prior activities (including work) and quality of life. This can have a deleterious effect on their families in terms of health and health being. At the same time there was a general acknowledgement of how little we know about the needs of this group of people. Research was needed to identify the number and type of unmet needs experienced by different diagnostic groups across the survivorship trajectory. The earlier detection of problems that prompt treatment may prevent issues becoming a chronic problem, and guide the development and implementation of evidence-based management strategies. This should lead to improvements in the care/support offered to survivors, which in turn would bring about improvements in their health outcomes. Supportive care for this group was often linked in discussions to the ongoing debate about whether medical follow-up is an effective vehicle for detecting recurrence, providing supportive care and identifying and managing late consequences of treatment.

Finally, a number of respondents highlighted that changes in supportive care for cancer survivors are set in a health policy landscape where there is a drive to shift the balance of care from the secondary to primary sector. At the same time there are significant economic constraints likely to get worse and so for services to be commissioned evidence is required on their cost-effectiveness.

Summary of research priorities identified through survey

From responses to the survey a list of ten themes was generated and used at the consultation event as a starting point for discussion and prioritisation of research in relation to survivorship.

- Epidemiological data on the prevalence and severity of psychological, social and physical needs
- Support for carers
- Identification and management of the consequences of treatment
- Cost-effectiveness of self management
- Models of surveillance for disease recurrence
- Return to work or education and financial matters
- Identification and management of the psychological impact of survivorship
- Organisation and delivery of services
- Health outcome measurement

Part 2: One-day consultation event

A one-day consultation meeting was held on 16th September 2009 at The Mary Ward House, London. It was facilitated by Professor Julia Addington-Hall. The programme for the consultation event can be found in Appendix B. Preliminary results from the evidence reviews and the research priorities identified from the consultation questionnaire were presented, discussed and reprioritised by invited stakeholders. The process and results from this day will now be outlined in more detail

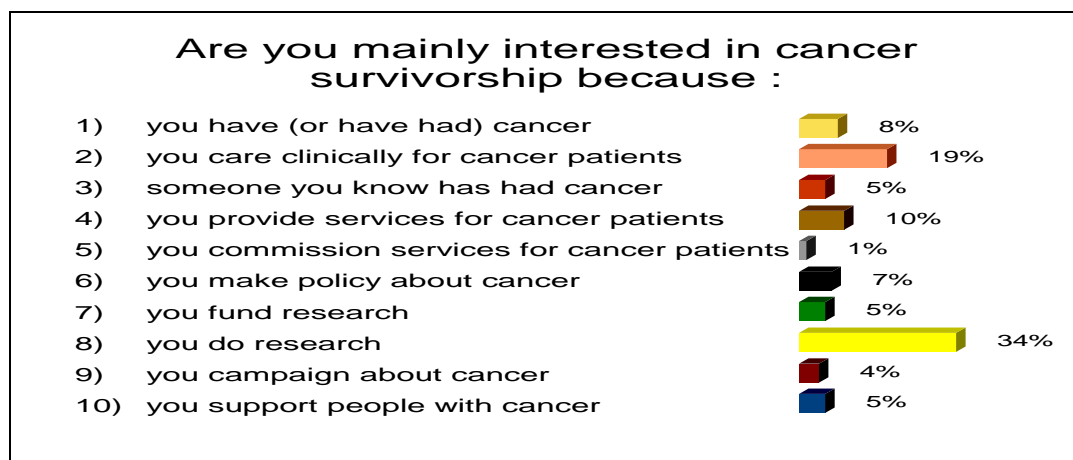
Participants

Participants at the consultation event were carefully selected by mapping invitees across the categories outlined below to ensure a broad range of opinion was gathered:

- NCSI work stream members
- NCRI Clinical Studies Group members
- SuPaC Collaborative members
- Patients & carers
- Cancer charities
- Cancer diagnoses
- Professional/speciality groups
- Funding organisations
- UK nations

On arrival participants were allocated to tables, according to a prearranged seating plan drawn up to ensure a broad mix of people. Figure 4 indicates reasons attendees gave as to why they are interested in survivorship research. Just over half reported that their main interest derived from either doing research or caring for cancer patients. Users and carers or family members made up 13% of participants.

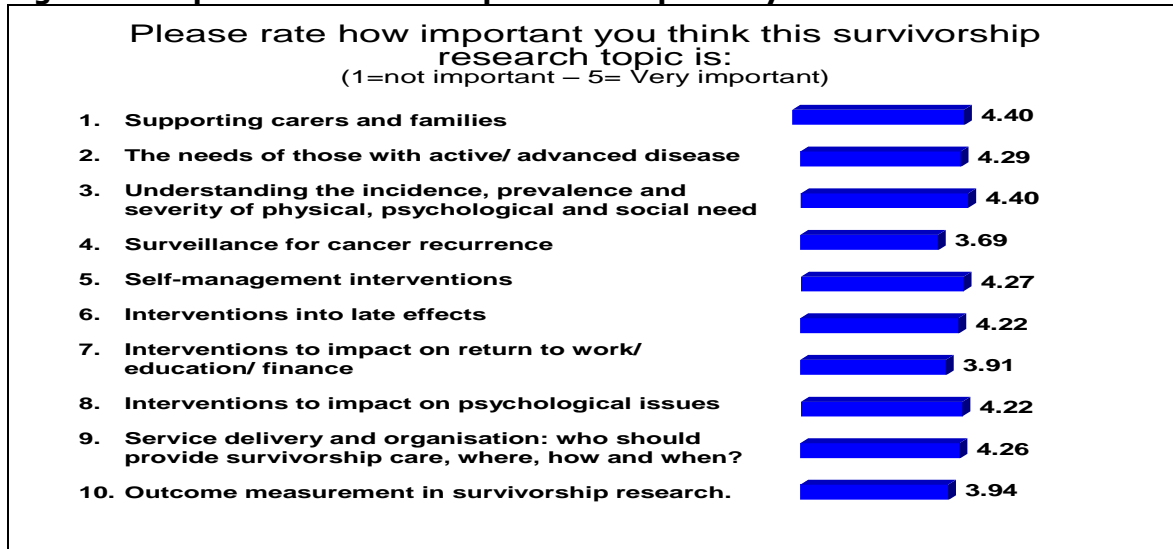
Figure 4: Reasons for interest in survivorship issues



Selection of research priorities

An initial introduction outlined the aims of the National Cancer Survivorship Initiative (NCSI), the work of the research workstream and the background to this piece of work. Thereafter the key research topics generated from the survey were presented. At this point participants were asked to rate the importance of the ten key topics from the survey, outlined above. Participants rated each topic on a scale of 1 (not important) to 5 (very important) using wireless digital voting equipment. This permitted almost instant presentation of the results of the voting procedure (see Figure 5). This demonstrated that scores varied very little between the topics and all were seen as being important when rated individually.

Figure 5: Importance of each topic rated separately



First weighted priority vote

Preliminary findings from the two exercises scoping the literature on factors influencing health and well-being and interventions to improve health and well being were then presented and discussed. Subsequent to this, another vote was conducted and participants chose their top three topics in order of preference and weighted according to order of importance (ie first choice scored 3, second choice scores 2 and third choice scored 1). Understanding the prevalence, severity and type of unmet need was identified as the top research priority by a fifth of participants (Figure 6). One in seven participants felt research investigating psychological issues, support for carers and families and self management were the next most important priorities for survivorship research, followed closely by consequences of cancer treatment.

Figure 6: First weighted vote for research priorities



Following the second vote participants were asked to discuss the results of the vote with the other people on their table and make suggestions for additional topics that replaced the five least popular research priorities on the existing list. Table discussions were recorded on flipcharts and feedback given to all participants (see Appendix C for a transcription of discussion topics recorded on flip charts). As a result the original list of research topics was amended and where overlap in topics was identified a number of topics were combined together.

The revised list for a further round of voting reflected seven items from the pre-existing topic list

- 1) Understanding need
- 2) Psychological issues
- 3) Carers and families
- 4) Self-management
- 5) Consequences of cancer and treatment
- 6) Service organisation and delivery
- 7) Outcome measurement

The following items were added to the topic list

- 1) Lifestyle management
- 2) Finance
- 3) Co-morbidities

Second weighted priority vote

A weighted priority vote was then conducted on the amended topic list (Figure 7). Although understanding the epidemiology of unmet need remained the top priority topic the next two most important research priorities changed at this point in the proceedings to consequences of cancer & treatment and the organisation and delivery of services. Researching psychological issues slipped from second to fourth place and support for research on carers/families reduced by a third, moving into fifth place.

Figure 7: Results of second weighted priority vote



In order to ensure participant views were heard and to take advantage of collected wisdom on the research priorities final table group discussion were held and recorded on flipcharts. Participants were asked to debate the following questions:

- What areas of the emerging consensus do you agree with?
- What, if anything, do you disagree with – and why?
- What areas are important but have not been discussed?
- What areas need further investigation or explanation?
- What should we consider when choosing between competing research priorities in survivorship research?
- What challenges do we face in survivorship research in the next 5 years? What are the solutions to these challenges?

Not all tables chose to discuss all questions, but from transcription of table discussions a number of key issues emerged. On the whole people agreed with the areas of emerging consensus. However, some felt that more categories should be collapsed to make them broader, whilst others were concerned this made the categories so broad as to render them meaningless. The majority of comments recorded focused on the last three questions: criteria for selecting priorities, future challenges and potential solutions. A consensus emerged on the most appropriate selection criteria to use when deciding research priorities. These were:

- Relevance of the topic to patients and carers
- What improvements the research would make on patient care
- Phased approach to ensure improvements in survivorship care in the short term (<5years) whilst also funding longer term projects.
- Ensure quick wins by identifying topics for which there is sufficient evidence to support implementation in practice in the near future and that would be easy to integrate into existing services.

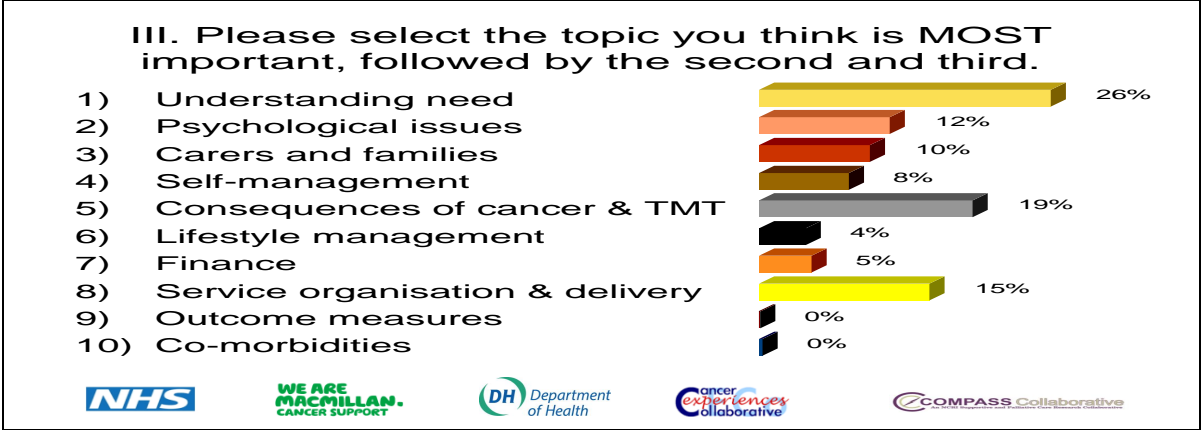
The implementation of research findings in practice was a commonly cited challenge with many participants expressing concern about the poor implementation of research at present. It was suggested, therefore, research should be conducted to investigate this topic. Nearly all the tables identified that funding of survivorship research would be problematic when competing against studies aimed at the cure or prevention of cancer. The need for an experienced research workforce working collaboratively on multicentre studies was recognised and concerns expressed about the limited number of people working in this area. It would therefore be important to increase research capacity in this field and nurture researchers of the future

It was recognised priorities might change over time, ie today’s priority might be assessment of needs whereas in 3 years time it may be the development of interventions. Therefore priorities should be reassessed on a regular basis.

Third weighted priority vote

Following, and in light of the broad ranging discussions outlined above, participants cast a third and final vote. The order and relative importance of the topics did not change from the previous vote (see Figure 8).

Figure 8: Results of final weighted priority vote



The top five research priorities identified from the consultation event were

- 1) Understanding the epidemiology of need
- 2) Identification and management of the consequences of cancer and treatment
- 3) Service organisation & delivery, including developing and testing of new models and modes of support
- 4) Psychosocial issues
- 5) Carers and Families

Ongoing or unpublished research

Data on ongoing and completed, but as yet unpublished, research were collected during the survey so such work could be mapped and taken into consideration in the final determination of survivorship research priorities by the NCSI.

Data were collected on 1) completed but as yet unpublished research, 2) research currently underway and 3) funded research at the set up phase. The results from this mapping are presented in a series of tables that relate to population of study, topic of study, themes and funder.

Table 3 describes studies by population of interest. The majority, be they completed, ongoing or in set up have been conducted with heterogeneous samples of cancer survivors. Where homogenous samples have been recruited these have focused on cancers of the breast, prostate, head and neck and central nervous system.

Table 3: Number of research studies by population

Population	Completed & unpublished	Ongoing	Set up	Total
Diagnosis				
Various	24	61	18	103
Breast	6	16	5	27
Prostate	6	5	2	13
Colorectal	1	4	2	7
Lung	0	4	0	4
Bladder	0	1	0	1
Gynaecological	2	5	0	7
Myeloma	0	1	1	2
Mesothelioma	0	2	0	2
Central Nervous System	4	8	1	13
Head & neck	3	7	1	11
Advanced cancer	0	3	0	3
Palliative care	2	5	1	8
Non-cancer	0	1	0	1
Haematological	1	2	1	4
Total	51	124	32	206
Sample characteristics				
Women	0	1	1	2
Men	1	1	0	2
Children	1	2	2	5
Teenagers	0	2	0	2
Carers/family	0	6	1	7
Professionals	0	0	3	3
BME	0	3	0	3
Total	2	15	7	24

The research studies were also categorised according to which problem they addressed - a list generated as a consequence of the evidence reviews and consultation event. The majority of survivorship research (see Table 4) addresses physical and psychological problems, the most frequently reported being general distress, functional impairment and sexual problems.

Table 4: Number of research studies that address physical, psychological, practical and social problems

Problem topic	Completed & unpublished	Ongoing	Set up	Total
Physical				
Neuropathy	1	1	0	2
Fatigue	3	4	0	7
Pain	0	0	0	0
Lymphoedema	1	1	0	2
Bladder problems	1	0	1	1
Bowel problems	0	2	0	2
Sexual problems	3	4	1	8
Sleep	0	0	0	0
Eating & weight	1	3	0	4
Breathlessness	0	2	0	2
Functional impairment	0	9	1	10
Menopausal symptoms	0	1	0	1
Other	6	17	4	27
Total	16	44	7	67
Psychological				
Depression	0	4	0	4
Anxiety	0	0	0	0
General distress	3	9	2	14
Fear of recurrence	1	0	1	2
Spirituality	0	0	0	0
Body image	0	1	1	2
Other	5	14	1	20
Total	9	28	5	42
Practical				
Financial	1	1	0	2
Employment	1	3	1	5
Information	0	3	0	3
Total	2	7	1	10
Social				
Family	2	5	3	10
Carers	3	4	1	8
Social Function	1	1	1	3
Total	6	10	5	21
Total	31	89	18	138

The studies were also catalogued according to certain cross-cutting themes: cancer type, stage of survivorship, inequalities, self management, service delivery, specific interventions and methodological issues (Table 5). This revealed little research is exploring issues around inequalities or explicitly addressing survivorship stage.

Table 5: Number of research studies that address cross-cutting themes

Cross-cutting theme	Completed & unpublished	Ongoing	Set up	Total
Problem				
Cancer type	11	27	2	40
Inequalities	0	6	0	6
Stage of survivorship	2	2	1	5
Total	13	35	3	51
Solution				
Self-management	2	4	2	8
Service delivery	5	30	8	43
Specific interventions	11	19	13	53
Total	18	53	23	94
Methodological issues¹	5	9	4	18
Total	36	97	30	163

¹Includes all pilot/feasibility studies

Finally, funders of survivorship research were examined and categorised (Table 6). Half the studies were funded by large funding bodies, including government organisations (NIHR, MRC, ESRC, Big Lottery, Scottish Office) and major charities. The remaining 50% were funded by a variety of local sources, including NHS trusts & PCTs, universities and charitable organisations/bequests.

Table 6: Source of funding for survivorship research

Funder	Completed & unpublished	Ongoing	Set up	Total
NIHR	3	6 ²	5	14 ²
NCRI	1	1	0	2
NCIN	0	1	0	1
MRC	0	2	0	2
ESRC	0	1	1	2
CR-UK	10	27 ³	1	38 ³
CR-UK & WCF	0	1	0	1
Macmillan Support	5	13	9	27
Marie Curie Cancer Care	0	3	2	5
Scottish Office	0	2	0	2
Big Lottery	0	1	0	1
Breakthrough Breast Cancer	0	1	0	1
Breast Cancer Campaign	1	1	0	2
Myeloma Foundation	0	1	1	2
Dimbley Cancer Care	2	2	4	8
Prostate Cancer Charity	3	0	0	3
Total	25	63	23	111
Misc¹	24	74	13	111
Total	49	137	36	222

¹ Local NHS trusts/PCTs, universities, charitable donations eg bequests

² 1 study was clinical/biological in nature

³ 7 studies were clinical/biological in nature

Conclusion

During the consultation event a degree of unease and/or lack of clear understanding emerged about what the exact focus of each research topic comprised. This created some tension when consensus was sought on future research priorities. Nevertheless, despite the addition of new topics and amending the focus of others during the voting process a clear consensus emerged over the front runners. These encompassed understanding survivors' needs; consequences of cancer; service organisation and delivery; psychosocial issues and carers and families. Underlying this list of priorities was the desire to seek a better understanding of survivors' needs, combined with a motivation to seek effective solutions to address these. There was also strong recognition that needs and solutions would be influenced by a number of moderating factors such as type of cancer and biographical factors.

There was a strong desire to see studies commissioned with the potential to develop our understanding of cancer survivors' needs and test interventions focussed on the consequences of cancer and cancer treatment (in particular psychological distress). The relative merits of different ways to organise and deliver services and interventions also needed to be explored through research. There was also a strong wish to better describe the needs of carers and the best means to support this group. Outcome measurement was identified as a key methodological challenge in this nascent field of research.

Appendix A: Consultation Questionnaire



Consultation to identify priorities for future research about cancer survivorship

We are conducting this study to find out what people interested in the health, well-being and care of cancer survivors think are the priorities for future research in this area. This consultation is funded by The National Cancer Survivorship Initiative, a partnership between The Department of Health and Macmillan Cancer Support that is supported by NHS Improvement. The findings will be used to inform the commissioning of research to answer the most pressing unanswered questions about people living with, and beyond, cancer. We hope to include the views of as many people interested in this subject as possible. We would, therefore, be very grateful if you could complete the questionnaire by typing your comments below each question.

For the purposes of the consultation, we have defined cancer survivors as:

Anyone living with and beyond cancer. This encompasses people who are coming to the end of primary treatment, in remission and living with active/advanced disease but who are not so unwell that they are receiving end of life care.

We are thinking particularly about what research needs to be done into their physical and psychological health, well-being and care.

At the end of the questionnaire we ask for some personal and/or organisational information to assist with analysis of your responses. All the information you give us will be treated as completely confidential. In the final report we will not link responses to individuals or organisations but we would like to include a list of individuals and organisations who contributed to the consultation.

Thank you very much for your support and taking the time to complete this questionnaire

If you have any queries please contact me, Jo Armes (jo.ames@kcl.ac.uk or 020-7848 3709).

1. Priority areas for survivorship research

- a) What, in your opinion, are the most important unanswered research questions in the field?

- b) Why, in your view, are these questions important?

- c) In your opinion, what contribution would research in these areas make to the care and support of cancer survivors?

2. Ongoing or unpublished research studies about cancer survivors

As part of this review we want to find out about all the research going on in this field to prevent duplication of effort. It would be very helpful if you could tell us about studies underway at the moment, are set up, are being planned or have not been published yet. Please use the tables below

Current research underway

Principal investigator	Centre	Title	Funding Source

Funded research in set up phase

Principal investigator	Centre	Title	Funding Source

Research being planned

Principal investigator	Centre	Title

Completed & not published

Principal investigator	Centre	Title	Funding Source

3. Existing datasets suitable for secondary analysis

Secondary analysis of existing datasets is likely to play an important role in understanding the experience of cancer survivors. For example, some centres routinely screen patients for anxiety and depression using the Hospital Anxiety and Depression Scale. Analysis of this data might help us better understand the impact of cancer on mood over time. If you are aware of any datasets that might be suitable for secondary analysis, subject to necessary ethical and other permissions, we would be grateful if you would list them below.

Centre	Contact person	Instrument name	Cancer diagnosis	Frequency of patient assessment

Please tick below which group best describes you:

- Academic researcher, please specify
Profession/occupation.....
- NHS researcher, please specify
Profession/occupation.....
- Cancer charity or voluntary organisation, please specify cancer diagnosis represented if specific to type of cancer
.....
- Individual patient
Please tell us what cancer you have/had and what year you were diagnosed
.....
- Carer or family member
Please tell us your relative's cancer diagnosis
.....
- Patient group, please specify.....
- Other, please specify

Are you responding on behalf of:

- Yourself
- An organisation

What gender are you?

- Male
- Female

What age group are you in?

- 18-40
- 41-60
- 61-80
- Over 81

In which UK region are you based?

- England Scotland Wales Northern Ireland

We would like to publish a list of those who participated in the consultation. If you are happy for us to include your name or that of your organization please tick the box below and provide your details

.....

Please tell us how you heard about this consultation

.....

Appendix B: Consultation Event Programme
National Cancer Survivorship Initiative
Review of Research into Cancer Survivorship

Consultation Event

Wednesday, 16th September 2009

Mary Ward House, 5-7 Tavistock Place, London WC1H 9SN

PROGRAMME

MORNING:

Registration and Refreshments: *Dickens Library (ground floor)*

Meeting: *Mary Ward Hall (first floor)*

- | | |
|------|--|
| 0900 | Registration and Coffee |
| 1000 | Welcome
– Professor Julia Addington-Hall (Chair) |
| 1005 | The National Cancer Survivorship Initiative
– Mr John Neate, Chair of Research Stream NCSI |
| 1015 | The NCSI Review of Research into Cancer Survivorship
– <i>(Professors Alison Richardson & Mike Sharpe)</i> |
| 1025 | Findings from the National Survey of Priorities in Survivorship Research
– <i>(Dr Jo Armes)</i> |
| 1055 | Voting Session 1:
<i>1) how important is each of 10 priority areas derived from the survey?</i>
<i>2) weighted priority voting of 5 areas</i>
<i>Immediate feedback and discussion</i> |
| 1105 | Coffee break |
| 1135 | Preliminary findings from the Review of Research Evidence in Survivorship |
| 1225 | Table Discussions 1
<i>An opportunity for participants to suggest topics which are missing from the list of 10 priority areas.</i> |
| 1245 | Feedback
<i>Suggestions from floor of areas to replace those priority areas which scored badly at Vote 1. Discussion of the overlap between areas. Which areas should go or stay. An indication of how difficult priority setting is.</i> |
| 1315 | Lunch |

AFTERNOON:

Refreshments: Dickens Library (ground floor)

Meeting: Mary Ward Hall (first floor)

- 1415 Voting Session 2
A weighted priority vote again, this time using the new list incorporating participants' priorities – but losing 'low scorers' at Vote 1.
- 1425 Table Discussions 2
What the priorities are, what the challenge to pursuing research in these areas might be, and how these might be overcome, and what should be the key issues in determining between competing priorities.
- 1510 Tea break
- 1535 Feedback from groups
- 1600 Final Voting Session
Again, weighted priority voting, taking into account everything they have heard and discussed about priorities and realities. Plus a second vote on priorities to achieve maximum impact in the NHS in the next five years.
- 1630 Next stages:
a) in the Review of the Research into Cancer Survivorship
b) in the NCSI Survivorship Initiative
- 1645 Close of meeting

Appendix C: Table discussion of alternative research priorities



National Cancer Survivorship Initiative Review of Research into Cancer Survivorship

Consultation Event feedback

Table discussion 1: Suggestions for additional/alternative research priorities in survivorship research

Table 1
<ol style="list-style-type: none">1. Isolation both geographic and by tumour type and how we can support people beyond initial treatment2. Affect of anticipatory grief on carers/families and impact on survivorship3. Inequalities in commissioned services across tumour sites – lots available for breast cancer patients a lot less for others eg ovarian

Table 2
<ol style="list-style-type: none">1. Pain & physical symptoms2. Maintaining financial stability3. Genetics4. Organisation & delivery5. Communication

Table 3

1. Translating evidence/individualising policy and approaches/implementing evidence, understanding change
2. Training health professional in identifying and screening for psychological problems
3. How to support self management of cancer/treatment related problems following primary treatment
4. Understanding experiences of survivorship over time – identifying who might be most in need of support and when
5. If these don't come under service delivery and organisation: Communications (primary – secondary – staff to patient); Staff burnout
6. Lack of specialist centres for LCCs main problem identified; isolation/psycho problems into support for carers; clinical trials/follow-up
7. Value of using web-based assessment tools
8. Use experience from other fields and QoS data
9. Research priority: to develop and use and validate a web tool that captures all survivorship issues, so can be tackled efficiently, tackles all 10 priorities; simple, practical, implementable, feasible, address weaknesses

Table 4**Overlapping and cross-cutting themes:****A 1. Not specific to cancer**

2. Co-morbidities
3. Secondary prevention and new diagnosis

To include self management and peer support/carers and families

B 1. Return to work

2. Practical coping
3. Psychological issues

C 1. Service provision; primary/secondary care

2. Equity and targeting of care
3. Roll out of excellence
4. Acknowledge patient preferences

Table 5

1. Combine psychosocial & consequences of treatment & work and finance (also a consequence of treatment) together
2. Also important to think about what we do wrong which may have a negative impact eg more opiates for pain; going back to work too soon. Needs consideration under each heading
3. Solution: Self management; Lifestyle management
Problem: Psychosocial; consequences of treatment (finances); co-morbidities
Infrastructure: Service delivery & organisation; outcome measures; understanding need; finance; carers & families

Table 6

1. Change late effects to consequences of treatment
2. Broaden definition of rehabilitation and add as a topic to include: return to work, adaptation to a new normal and inform service development
3. How to convert grey literature into quality evidence which will inform care
4. Develop a blue print for good research methodology in cancer survivorship

Table 7

1. Service delivery & organisation
2. Promoting achievement/adjustment to 'new normal'/return to normality
3. Keep and further endorse families and carers
4. Keep and further endorse return to work and financial matters
5. Surveillance for cancer recurrence – release money

Comments:

No particular order to above

Table 8

1. If have tighter definitions then the 10 could be 5
2. Everything is important, hard to prioritise, therefore focus on how to choose between competing priorities
3. Or focus on a cancer as a model and then apply to others later
4. Look at research that you can build on – need to get interventions out there
5. Patient involvement is essential
6. Involve NHS so only implementable work is done, and get health economics/feasibility of intervention
7. Learn from voluntary sector as well as patients eg Macmillan nurses and fund research collaboratively
8. Outcome measures are different for patients and the NHS – need to find common ground, need to understand each others priorities

Table 9

1. Secondary prevention/lifestyle changes - post diagnosis/treatment
2. Living with uncertainty
3. Needs of ethnic minority groups
4. Impact of co-morbidities on living with cancer
5. Role or peer support

Other comments:

'New normal'

Table 10

1. Care planning along the trajectory including diagnosis; early assessment; assessment on discharge; including recurrent/active disease
2. Service delivery – key workers role; models of care; how to improve cross boundary working eh primary/secondary care, health/social care, acute treatment/palliative care
3. Impact of symptoms on daily living eg QoL, family relationships and social functioning
4. Survivorship programmes – getting back to work; educational/instructional needs; information needs; needs of younger survivors; transition from childhood to adulthood
5. What are the practice barriers to implementing research into practice
6. incidence and management of long term effects eg hot flushes, breathlessness

Table 11

1. Training implications for HCPs arising from survivorship agenda
2. Supporting health professionals especially in secondary care with psychological support/clinical supervision to deliver better/effective care especially as future will be dealing with more acute phases
3. Support health professionals in better conversations/more effective interactions with patients
4. Communication skills training
5. Illness trajectories of each cancer – so to help categorise
6. Information access for patients/cares/HCPs; quality; methods; cost-benefit; outcomes
7. Transport to services
8. Implementation of good practice
9. Cost effectiveness of interventions
10. Impact of care in initial phases of illness on long-term

health/survivorship

11. How to identify impact of changes to FUP on patient well-being
12. Risk stratification – level of care
13. Culture – how to manage change
14. Developing interventions to improve negative consequences of cancer/cancer treatment
15. Service delivery
16. Type of contribution of non-NHS sources of support and care
17. Personal support network (not just carers and families)
18. Impact of lifestyle on survivorship
19. Inclusion of primary care NHS in deciding research priorities
20. Presentation of information; non-verbal narratives – is information/research biased to English language and words
21. What are the environmental contributions to causes of cancer eg pollutants
22. Survivorship boundaries – professional/patient/researcher/carer; shifting multiple roles
23. Outcome measurement
24. Recurrence/relapse – pathways into the system

Comments:

All above comments were on individual post-it notes

Table 12

1. Psychosexual issues, needs and interventions
2. Agree with all other priorities
3. Self management to include: diet nutrition, exercise
4. PROMS/user involvement
5. Decision making
6. Not rely on RCT – use other methodologies
7. Definition of terms very important – many categories overlapping
8. Hard to reach groups
9. Under psychological; managing fear and recurrence
10. Research which is practicable in the real world
11. Information and support services as an intervention

Appendix D: Notes from second table discussion



Table discussion 2

Questions:

- a. What areas of the emerging consensus do you agree with?
- b. What, if anything, do you disagree with – and why?
- c. What areas are important but have not been discussed?
- d. What areas need further investigation or explanation?
- e. What should we consider when choosing between competing research priorities in survivorship research?
- f. What challenges do we face in survivorship research in the next 5 years?
- g. What are the solutions to these challenges?

Table 1

We should consider:

- Where evidence exists that interventions are effective/guidelines are in place focus research on barriers to implementation/comparing methods of implementation
- In under-researched areas eg less common and rare cancers focus research on clinically relevant topics and those raised by patients and carers as important issues
- Groups with extensive needs and/or complex needs
- How follow up of cancer patients can improve or take away their quality of life – appropriate surveillance, assisted 'self management'
- Who and when – especially less common cancers
- Funding
- Self management – definitions
- Co-ordinated funding
- Skilled workforce
- Longitudinal
- Isolation
- Co-morbidities
- Less common and rarer cancers
- Transition points
- Communication/MDTs
- Assessment/H. outcome measures

Table 2

1. Understanding needs – important but with the proviso that it is taken forward towards an intervention/benefit, not just identifying need but must meet the need

2. Psychological issue – important but only support. More work if it moves it forward into benefiting patients; may be combined with pain and symptoms
- 4 + 6. Self-management and lifestyle management should go together as are of high priority
5. Consequences (concern that the category is too diverse) – add (10) Co-morbidities into this category.
7. Finances (not given high enough priority) but also goes with carers and family – could be family/social issues
8. Service organisation and delivery – agree high priority but must include independent sector charities etc
9. Outcome measures – agree low priority as long as what we already have are fit for purpose

Suggestions:

- Whatever the result of this exercise, it must be validated by patients and carers
- More refinement of categories

e. User's priorities

f. Funding; keeping up with pace of change in treatments, expectations, populations changes, service context

g. Getting money/funding

Table 3

a.

- Understanding need (who, when)
- Service organisation and delivery (specialist services for less common cancers)

b.

- Rather than throw out themes – merge into smaller number of themes
- Clarity around what theme captures
- Will meaning of themes be retained – list sub-themes

c.

- Communication (primary/secondary care/patients)
- Staff burnout/support/training
- Nature of studies (scale/focus/prospective)

d.

- Less common cancers
- Clarity around terms eg 'survivorship', themes'

e.

- Implementation
- Do-able
- Financially viable
- Relevant/important
- Potential solution (practical application)
- Clinically important/relevant

f.

- Finance
- Building on existing research or targeting new areas
- Definition of qual of survivorship
- Broadening research focus with less £
- Implementation of findings into practice
- Use of technology
- Incorporating grey literature

g.

- Greater co-ordination and so-operation (funding bodies)
- Less replication and more collaboration (continuing the collaboratives)
- Bringing together stakeholders
- Making use of technology
- Money

Table 5

e.

1. Impact on patients/carers (< 5 yrs)
2. Moves services forward (< 5 yrs)
3. Level of evidence existing - small push/big push – long term impact
4. Those that can be integrated/adapted into existing services

f - g.

Challenge	Solutions
Lack of funding for research	Different partners – community/TUC/chronic disease/combine
Lack of funding for actual implementation	- Results - Research that can fit in with existing services make better what we have rather than reinvent the wheel
Attitudes of funders - understanding realistic outcomes of research - methodological considerations	Educate funders re complex methodologies
Quality of research - small studies - dubious quality - often calls are too detailed; no applications	- big studies - centre of excellence - established expertise - funders need to be more flexible with calls

Table 8

e.

- Consider if the research is applicable to multiple cancers
- If the priority has come from collaboration between patients/carers and NHS/researchers then it is good (needs/feasibility/health econ)
- Consider if the area has evidence that can be built on – quick wins
- If project is on one cancer, still important because it could translate to others
- Is it a gap eg no lung cancer reviews
- Quick studies with impact vs long term studies or especially good if link the two eg looking at early predictions of late effects. Need to see some impact early to boost the field

f.

- Need to know where expertise is (ie methodologies, tools, end points) – develop database
- Consider qualitative and quantitative methodological support; and get qualitative outcome measurement tools
- Need to ensure survivorship prioritised with research funding organisations
- Engage with commercial sector eg for IT support or treatment/imaging support
- Need a figure head to promote importance of our research area to ensure survivorship maintained as priority even if change of government
- Engage with survivor and carer communities; ask question appropriately so get representative patient sample in studies.

Table 9

a.

- Broad agreement with top 4 topics
- Could psychological, finance, physical, social and spiritual issues be incorporated into consequences
- Everything over 10% as priority

c.

- Wider context eg public health/lifestyle choices

d.

- Clarification of self management and its remit
- All topics need thorough and coherent definition/explanation
- Require greater understanding of extent of problems

e.

- Relevant priority from a patient's perspective. What should be funded and over what timescale eg 3-5; 5-10; over 10 years
- Level of funding available
 - Quick wins – achievable over short-medium term
- Research that has the chance to be embedded in practice/ideas that come from practice

f - g.

- Funding – sustainability
- Competing priorities – competition with ‘cancer cure’ research
- Implementation of research findings
- Where are we going to ‘grow’ the next generation of H & SC researchers?
- The skill set of practitioners to deliver interventions/implement new/different services
- Collaboration
- Succession planning – leaders/lobbyists
- Clinical/academic careers – funding
- PPI

Table 10

- Need clarification of these headings eg (5) Does that include intervention and might it include self-management?
- Is there a phased approach to understanding our research priorities? Eg today’s needs for research might be about understanding needs/don’t want to keep reinventing the wheel. Tomorrow’s priority might be about implementation
- Why separate psychological issues from consequences – why separate?
- Keep it simple – why make it messy?
- Need a macro picture before refining it down in to the smaller areas
- Could have 2 more areas: (1) The consequences of cancer incorporating psychological needs; psychosocial needs; finance and work (2) The health professional response
- Each of these areas needs to be (a) identified and (2) addressed
- What is outcome of this day going to be/how will it drive the agenda for funding?
- Need to make sure research evidence is gathered before practice is changed – put resources into this
- Need to have realistic timeframes
- Need to improve action/practice research
- Resources to go towards improving practice/research links to make sure the right research is being done and practice change is being evaluated properly
- Sharing best practice. Do we have a way of co-ordinating how best practice is rolled out? Are there frameworks for delivery?
- But not a layer of bureaucracy
- How do voluntary organisations work with the more formal organisations? Eg partnering for delivery of service
- How do we even out the inequalities created by more affluent voluntary organisations
- How much of the research that is done is implemented? How do we know?
- How do we shorten the lead time between research and implementation
- Can research proposals be operationalised when solutions have been suggested ie implementation of outputs to be put into proposals
- How much influence does the research evidence have?
- Research into attitude change in health providers
- Research into training people to work in the right way

- Won't change practice unless we change the way health providers utilise research evidence
- Integration of practice/research
- Will there be top down implementation of research driven outputs and will it be up to individual trusts
- There is a big gap between research findings and implementation into practice. This is biggest need and answers are about education provision, better links with the clinical and academic

- Quite anxious about privileging one area of research over another so that resources would be directed in that way. If we wanted to direct resources, we would look at getting over the research/practice gap
 1. Difficulty with headings and priorities – keep it simple
 2. Could be classed into needs and interventions
 3. Moved from prioritising these to a wider view
 4. Phased approach – today's priority might be about needs, tomorrows should be interventions. Have to know first before intervention. Priorities should be re-visited.
 5. Big problem about practice changing before evidence available, therefore priorities need to be about improving practice/research collaboration; research into training and attitude change; research into helping health providers utilise research
 6. Without increasing bureaucracy, need to have a centralised way of gathering and disseminating and implementing research based improvements in practice. Audit of ongoing research.

Table 11

d.

1. Outcome measures

Validating appropriate OMs for full range of research in C.S. and service delivery

2. Terminology

Clear and consistent (and definitions)

e.

- Time frames – commissioning
- Replicability and transferability
- Interdependent and linked steps is immediate results but awareness of long term results/impact of research
- Targeting 'intervention' at best point, research etc, for maximum impact/people/influence/benefit
- Positive discrimination to address social exclusion
- Projects that give results that can inform other sectors
- Help commissioners understand relevance from across sectors/knowledge bases
- Dissemination strategy must be wide and included in all funded research
- Project team must include those who will disseminate projects' results
- Increase awareness/understanding of context (health) in research design

f.

- Challenge of late consequences is limited or no funding for longitudinal studies

- Need money and community of experts, to include practitioners (like COMPASS and CECo)
- Clash between academic and clinician communities
- Decreased profile and funding for psychological research. Programmes of, and not just individual studies are needed
- Recruitment of ss 70 yrs+
- Addressing needs of ageing population
- Recruitment of CS in acute phase

g. Solutions

- Include methodologies
- Political lobbying
- Economic evaluations included in research design
- Identify units/egs of best practice that cut across many sectors and build training and research around these
- Clinical/academic career pathways – more of these with increased parity with medical and nursing
- Greater transparency in research funding collaboration. How much do the different funders know of each other
- Commissioning and timescales

Table 12

a – c. Disagree/disappointment/needs further clarification

- Patient/carer representation in defining research areas
- Carers/psychological issues – undervalued/seem to get lost because of a lack of user involvement. Psychological issues is umbrella term for lots of interesting research areas ie fear of recurrence, sexuality, need. Nuances will be detected through mapping work and evidence review. To what extent will you use and preserve the info captured about where specific survivorship research is needed within the evidence review
- Definitions shift since session 1 – definitions almost meaningless – or too broad eg self management vs lifestyle management. Devaluing meaning because definitions are too broad now. How meaningful are these definitions?
- What does cancer generic approach actually achieve? There are specific issues for each cancer
- No mention of health economics – needs incorporating otherwise what's the point of identifying new interventions
- Methodological approach – ensure diversity of research approaches, not just RCTs (expensive)
- PROMS – patient experience must be valued and used equally with other outcome measures

d. Further investigation/explanation

- Psychological support needs unpicking – multi-faceted problem/issue
- Just want to be clear that this is an opportunity to do some research into patient experience of 'surviving' cancer. Clearly define survivorship vs other research around treatment and cure

e. Considerations for competing research priorities

- Get users involved – commissioning of research

f. Challenges

1. Generalising: trying to make survivorship a one size fits all issue for all cancers
2. Funding
3. Implementation: already knowns and new understanding; practical benefit to patients and carers

g. Solutions

1. Agree cross-cutting questions and broad concepts eg returning to work
 2. Identify site and issue specific research – smaller population but essential
- Needs mechanisms and funding processes to ensure this research is carried out
 - Rolling programme of survivorship research



Feedback from groups:

- Access to information re services, diet, lifestyle at all times/emotional support
- Impact of co-morbidity (managing other disease alongside cancer)
- More evidence for interventions and management of symptoms and side effects
- Research into 'how' we identify long term need
- Disadvantaged groups access to services and service delivery and organisation
- Return to work – info/support & remaining in work (strategies to promote); cross over with other chronic conditions (inc emotional support)
- Wellbeing of people receiving survivorship (start when diagnosed)

Don't forget:

- Cancer type
- Less common cancer
- What themes include
- User views
- Listening study