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# Doncaster Cancer Survivorship Programme: Evaluation Report, 2016

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18<sup>th</sup> March 2016 (v.22)

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## Executive Summary

### Background

This summary describes work carried out to provide evaluation findings for the Doncaster Cancer Survivorship programme. The evaluation was commissioned by RDaSH on behalf of the Doncaster Cancer Survivorship Strategic group and Macmillan Cancer Support to explore recent changes to service delivery funded by Macmillan.

Doncaster Cancer Survivorship Strategic group have been working with people affected by cancer and professionals to co-produce changes to service provision in Doncaster since September 2012. The work was driven initially by Macmillan Cancer Support who funded a series of teams across the region to respond to the Survivorship agenda. The Survivorship work has active commitment not only from Macmillan but also from People Affected by Cancer in Doncaster (PABC), Doncaster CCG, Doncaster Metropolitan Borough Council, RDaSH, Meeting New Horizons and Doncaster and Bassetlaw Hospitals NHS Foundation Trust.

The evaluation considered the whole system approach to survivorship including systems, processes and service delivery. Its aims, informed by stakeholder feedback were to;

1. Determine the Programme's effectiveness
2. Provide recommendations and identify learning to guide future programme development
3. To provide a legacy of evaluation approaches
4. To obtain information to assist in future commissioning
5. To identify the programme's efficiency

Theoretical development of the evaluation framework was based on Realist Evaluation methodology (Pawson & Tilley 1997). Context, Mechanism and Outcome configurations were proposed to explain theories of change (mechanisms) and how various influencing factors (contexts) act to result in specific outcome patterns. These theories guided the data collection and analysis. However, the identification and meeting of stakeholders' requirements is the primary focus of the evaluation. Therefore, elements of Utilization-Focused Evaluation methods (Patton, 1986) have been employed to ensure that key stakeholders' needs are taken into account.

Providing information to contextualise the current landscape and inform future planned changes to services is the secondary concern. Developmental Evaluation methods (Patton, 2011) therefore guide the evaluation to produce outputs that will steer local, regional and national developments.

Primary and secondary qualitative and quantitative data have been analysed to inform this report. 10 qualitative interviews were carried out with representatives from all key stakeholder groups. Two questionnaires were designed using feedback from 17 PABC and six members of the Strategic group who were not PABC. One questionnaire was for those experiencing cancer directly and one was for 'carers'. The 'user' questionnaire provided pilot data, achieving a response rate of 75% (18 people). A thematic scoping review of relevant literature investigated 80 sources. Primary and secondary documentary data were used to undertake an economic evaluation.

## Summary of Findings

The literature review produced refined topics within the I-statement themes, which could be used for future monitoring and service development purposes (e.g. table 3 in full report). Generally, the approaches taken by the programme were appropriate to address the identified needs. However, some aspects took time to develop; largely owing to the difficulties of the co-production approach. Some important areas of the programme also developed with a degree of serendipity; for instance engagement with employers.

In terms of the numbers of PABC accessing the survivorship programme: annual referrals into the Living Well (Hub) service equate to just over half of estimated annual incidences of cancer diagnoses in the borough of Doncaster (53.8%), and about 10% of the estimated number of cancer survivors (approximately 10,500).

Improving the attitudes and knowledge of employers has been shown to be crucial in order to improve the situation for PABC. However, change can be slow, unpredictable and hard to assess (one is reminded that not all that counts can be easily counted). There are important elements of the programme that rely to a greater extent than others on the input of PABC, and specifically PABC with other required knowledge and skills, which could present challenges for sustainability. Engagement with employers is one of these key areas. This was also an area where capacity did not meet needs, specifically as only certain types of employers were considered appropriate for the intervention as it is currently conceptualised and delivered.

Engagement with primary care (specifically GPs), was identified as important in the literature. Qualitative work indicated that this element of the programme was problematic in terms of access, influence and assessment of progress. This was supported by findings from the pilot questionnaire, which indicated that GP services could be an area which requires improvement. Indeed, awareness raising work with all clinical professionals was identified as an area that will require continued resources, at least until knowledge,

awareness and supportive processes are embedded and self-sustaining within organisations. This will require ongoing monitoring (potentially through analysis of referral patterns and questionnaire responses).

Various approaches were taken for the economic analysis. This was due to the variability of available data and issues regarding the complexity of the programme: different aspects of the programme thus required different economic models. The findings set out the current situation as far as possible; describing assumptions, limitations, cautions and considerations. This provides models, which can be improved upon for ongoing evaluation and monitoring. Recommendations are made for more advanced economic evaluation methods, which would improve reliability, accuracy and validity.

**For the Living Well Information (Hub) service**, a cost per referred service user was estimated at £18.23, which demonstrates good value for money when compared to similar alternatives (e.g. Primary care counselling services at £26 per half-hour). A key recommendation for further monitoring and evaluation is the introduction of a method to routinely collect and report on outputs related to referrals into the service (e.g. time spent with clients, number and type of actions taken on their behalf etc). In addition, some specific, measurable, appropriate outcome measures for clients that can realistically be influenced by the service within a defined timeframe would benefit ongoing evaluation and monitoring.

A preliminary cost benefit analysis (CBA) of the **Meeting New Horizons (MNH)** service was undertaken by attributing costs to the overall cost savings recorded. The findings, of a return of 46 pence for every pound invested should be taken with extreme caution. This exercise highlighted where there were potential knowledge gaps and areas where decisions about the relative value of potential costs and benefits need to be agreed by stakeholders within the programme. For instance, if volunteers were not utilised, what would be the alternative? It should also be noted that much of the work carried out by MNH, whilst supported by current evidence, does not relate to easily quantifiable/short-term financial benefits: benefits were therefore not fully included. It is recommended that a more granular approach to CBA be undertaken, which can isolate costs for activities with easily identifiable benefits, and the return on investment for other activities should be assessed qualitatively with a view to achieving longer-term benefits.

A cost effectiveness analysis of the **Cancer Buddies** service was undertaken. The cost for running the Cancer Buddies project over 12 months is £22,640, which resulted in 22 active buddies (at 7 months). This represents a cost effectiveness of £1,029 per active Buddy. Assuming all of the signed up Buddies (49) became active the costs increase to £30,057, but cost effectiveness increases to £613 per active Buddy. Much of the revenue cost is fixed and therefore increased activity would lower the cost per active Buddy. However, scaling-up could ultimately demand a step up in revenue costs at a certain point, in order to successfully manage a larger project.

Once all Buddies are trained it is likely that around 166 clients a year will access the service. This represents a cost effectiveness of £136.40 per client paired with a Buddy. As above, increasing the number of buddies and/or the average number of clients each buddy is in contact with will decrease this cost.

Annually a 1:1 ratio of client attrition was projected: whatever the number of clients considered optimal for the service, approximately the same number will need to be referred in to the service on an annual basis. Using this assumption, the number of clients accessing the service over one year will be roughly double the mean of active clients during that year.

## Selected Recommendations

Respondents felt a person centred holistic needs assessment, with follow-up, monitoring and signposting to other services was essential. The programme continues to improve by extending networks of support, and learning to better address needs for wellbeing and support.

Areas requiring continued effort:

- Continued work to persuade professionals to introduce the idea of survivorship early on, and in the long term, and to spread knowledge about what roles the programme performs
- Whilst the work to raise awareness amongst nurses was reported to be successful to an extent, the need for continued activities was recognised

Possible adjustments to the programme:

- Clients entering the information centre also required the services of MNH (would be useful to explore the frequency of these instances and whether functions might be combined, or streamlined)
- It was not clear whether the work with GPs had been successful (process/activity monitoring might be useful for this work-stream)

There were a number of recommendations associated with timing of Interventions. Early contact starting at the time of diagnosis was beneficial, although the type of information that people are able to manage at this time is likely to be limited:

- The key mechanism seems to involve early contact with limited intervention, but with an understanding that support is available when they are ready
- This will ensure timely access to appropriate services when needed
- Having multiple points in cancer pathways, where different clinicians etc. can introduce survivorship issues and signpost or refer to other services could be a useful approach

One area where the programme could develop is in the provision of services for carers or relatives/friends of PABC:

- Eliciting carers needs:

Despite no specific approaches or work-streams for carers within the programme, their needs were felt to differ from those of the person with a cancer diagnosis. There was felt to be a need for skilled and experienced workers to correctly identify all the carers' needs.

- CNS' do not refer carers in:

Although some lack of 'carer' awareness was thought to contribute; even when nurses are aware of carers and their needs, they do not have time to deal with them appropriately. This indicates that some awareness raising and simple referral systems might be required.

- Carers were often not felt to identify themselves as carers:

Appropriate services for carers were considered to already exist with the Doncaster area. However, family/friends of people affected by cancer are unlikely to self-identify as a carer, and therefore unlikely to seek out these support services.

- Programme and service marketing to carers was felt to require specific thought:

There are some specific difficulties in developing mechanisms to address these outstanding issues from identification (including self-identification), referral/signposting into appropriate first-point services,

elicitation of needs, and ongoing access to specific services. An additional complexity is the potentially changing and increasing needs of friends and family as the needs of the person with cancer change.

General recommendations for continued and additional effort:

- *All:* Introduce the idea of survivorship early on
- *All:* Identify carers for additional support and signpost to services (e.g. financial)
- *All:* Awareness and attention to holistic needs
- *All:* To get involved in the programme steering groups, and the professional engagement events; building networks, connections and relationships
- *All:* Be involved in creative problem solving and build trust between organisations and other professionals
- *All:* Identify and seek to improve communication difficulties with PABC
- *All:* Sharing treatment/discharge and care plans between all professionals involved and the PABC themselves
- *Doctors:* provide adequate information about the situation of PABC related to further support and self-care
- *Doctors:* more involvement and appropriate/individualised expectations of self-management
- *Clinical Nurse Specialists:* to encourage self-determination

The evaluation provided recommendations for further development of the questionnaire that was based on the I-statements:

- A large number of respondents indicated that employment support was not applicable for them. It is recommended to remove these respondents from calculations for wider use.
- 3/18 (16.6%) of respondents ticked more than one box when asked to identify what their current clinical situation was. All three of these respondents were having treatment in addition to another clinical situation.
  - Recommendation: identify if these data are required from future questionnaires, and redesign options.
- The questionnaire attempted to identify which services were felt most relevant. However, respondents often ticked more than one box. The data suggests a cause for this. It appears that support is being received 'across the board' - from all services for all I-statements.

It is important to note that the data suggests all services contributed, including GP's, Macmillan and the 'hospital'.

- Recommendation: identify if these data are required from future questionnaires. Adjust analysis methods to cope with multiple responses for services.
- When exploring the average agreement scores for I-statements per respondents, a lower agreement score appear associated with men. (Men=1.87 and women = 1.4). This may warrant further investigation. Due to the small sample used for the pilot questionnaire the statistical significance of this was not investigated.
  - Recommendation: Consider if any differences between men and women are worth investigating with a larger sample.

Also included in the full report are recommendations for improving methods for economic analysis of the three key services within the programme.

Living Well Information service:

- In order to carry out a cost benefit analysis, further investigation is required to establish a method to ascribe value to the results of referrals into the service (e.g. time spent with clients, number and type of actions taken on their behalf etc). In addition, some specific, measurable, appropriate outcome measures for clients that can realistically be influenced by the service within a defined timeframe would benefit ongoing evaluation and monitoring.

Meeting New Horizons:

- The further work (outlined in the full report) will be required in order to have confidence in, and accurately interpret the cost benefit analysis of the work of MNH with individuals.
- The work that MNH carries out with organisations has value that is difficult to measure, but is addressing a known and serious problem for cancer survivors. A possible solution for the purposes of future economic analysis would be to treat the individual advice and support work as a separate project to the cancer friendly organisations work.

Cancer Buddies:

- In order to establish outcome measures that could be used to determine benefits, qualitative work with clients to establish counterfactual data would be beneficial. For instance, might clients be likely to seek consultations with health care professionals (GP, consultant, cancer specialist nurse etc), would their wellbeing be affected, might they suffer mental health problems (e.g. anxiety, depression), would they contact other agencies etc? This evidence could be used to provide a straightforward cost comparison, for instance in saving mental health community provision (£167/contact).
- As the number of clients is probably too small to detect organisational or local population level benefits, evaluation would need to concentrate on gathering data directly from clients. This could be done using pre-post measures, such as health related quality of life (e.g. EQ-5D 5L).

## Full Report

### Introduction

This report describes work carried out to provide evaluation findings for Doncaster Cancer Survivorship Programme. In 2012, Macmillan Cancer Support funded changes to service delivery within Doncaster to address the Survivorship agenda. In addition to Macmillan, these changes had commitment from People Affected by Cancer (PABC) in Doncaster, Doncaster Clinical Commissioning Group (DCCG), Doncaster Metropolitan Borough Council (DMBC), Rotherham, Doncaster and South Humber NHS Foundation Trust (RDaSH), Meeting New Horizons and Doncaster and Bassetlaw NHS Foundation Trust.

The service delivery changes were guided by the Doncaster Cancer Survivorship Strategic group. They worked holistically with people affected by cancer (PABC) and professionals to co-produce changes to service delivery. The basis of these changes were eight I-statements, created with PABC within Doncaster between October 2012 and January 2013.

### Doncaster's Contextual Background

#### Doncaster's cancer experience

The local cancer intelligence 2013 figures show that the number of people per 100,000 diagnosed with cancer in the Doncaster Clinical Commissioning Group geographical area is higher than the national average.

Table 1: Cancer Diagnoses Doncaster

	Cancer diagnoses per 100,000 people (2013)
UK average	611
Doncaster	659

There are approximately 300,000 people registered in the borough of Doncaster, which equates to annual incidences of diagnoses of approximately 1,977.

Following national trends, it can be expected that this higher than average number of Doncaster residents diagnosed with cancer, are also living longer. It is expected that by 2030 the number of people living with and beyond cancer for up to 20 years will have risen from 8,700 in 2010 to 16,900. Predictions estimate the 2016 prevalence of people living with and beyond cancer in the borough of Doncaster at approximately 10,000-11,000 (Local cancer intelligence website).

### Doncaster's Cancer Survivorship Programme

#### Programme development

In response to this growing population of cancer survivors, increased demand on services and local and national research identifying unmet needs, Macmillan initiated the Doncaster Cancer Survivorship Programme in the spring of 2012.

The Doncaster Cancer Survivorship Programme was a two-phase, transitional model. Phase 1 ran from September 2012- July 2015. The programme moved into phase 2 in July 2015.

## Co-production approach

The Programme was unusual in that it was driven and co-produced by PABC, took a holistic approach and focused on supporting the ‘survivorship’ agenda. PABC within Doncaster were empowered and facilitated to set the Programme aims, suggest Programme activities, operational changes and solutions in order to improve the PABC experience. Macmillan and Programme partners then agreed to honour and action these service changes.

Key to the co-production approach taken in Doncaster was the Programme’s I-statements (see appendix ii). Facilitative work was done with PABC to create eight I-statements between October 2012 and August 2013. This facilitative work included two ‘open space public events’ and PABC membership of the Programme’s strategic group. These I-statements became the Programme aims and rationale.

## Programme partners

There were seven Programme partners who committed to delivering the I-statements. These were:

1. People Affected by Cancer
2. Macmillan
3. RDaSH (Living well hub)
4. Doncaster Clinical Commissioning Group
5. Doncaster Borough Council and Cancer Buddies
6. Meeting New Horizons
7. Doncaster and Bassetlaw Hospitals NHS Foundation Trust

## Programme activities

Key activities of the Programme resulting from PABC suggestions and the co-production work with them, included three new services, four operational changes and awareness/education work. They are listed below:

Table 2: Key Programme Activities

Type of activity	Key Programme activities			
New Services	<b>Living Well hub</b>	<b>Meeting New Horizons</b>	<b>Cancer Buddies</b>	
	(Holistic needs assessments, public awareness raising)	(Home visits/financial assessments/‘survivor friendly’ organisations)	(Peer support service for PABC)	
Operational changes	Ambition for a ‘one stop shop’ – PABC’s get into the system and the system does the rest	Creation of the holistic needs assessment	Promotion of moving on interviews	Promotion of treatment summaries

Awareness  
raising

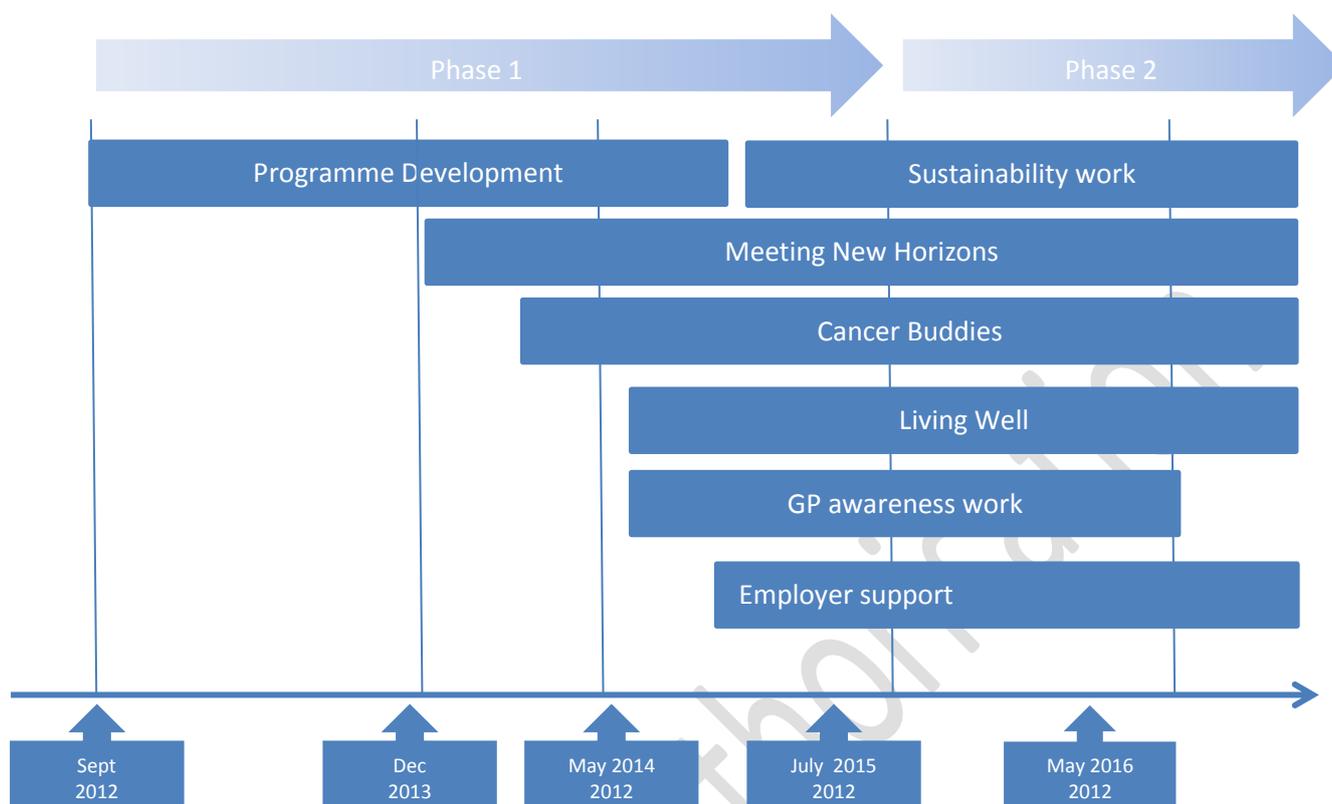
Awareness raising  
with and support for  
Doncaster employers

Strengthening links with  
Clinical Nurse Specialists  
(Cancer)

GP awareness work

DRAFT for Authorisation

Figure 1: Visual Representation of the Doncaster Cancer Survivorship Programme



### Background to the evaluation

The evaluation was commissioned by RDaSH on behalf of Macmillan Cancer Support and the Doncaster Cancer Survivorship Strategic group. It was carried out at the University of Sheffield's, School of Health and Related Research (SchARR) between September 2014 and February 2016. It was undertaken by Dr. Steven Ariss (Senior Research Fellow) Jennifer Read (Research Associate). Additional support was provided by Mr Nisar Ahmed (Research Assistant, University of Sheffield) and Mrs Heather Dunn (Research Assistant, University of Sheffield) with data analysis and literature reviewing respectively.

The evaluation's key aims and associated objectives were informed by stakeholder feedback. They were:

1. Determine the programme's effectiveness
  - Are 'I statements' being addressed?
  - Are the right people getting the right support?
2. Provide recommendations and identify learning to guide future programme development
  - Identify how to manage transition within the programme
  - Identify recommendations for programme sustainability
  - Identify recommendations for scaling the programme up
3. To provide a legacy
  - Provide knowledge/tools to assist with future programme evaluation
4. To obtain information to assist in future commissioning
  - Provide data on the programme's economic sustainability
5. To identify the programme's efficiency

- Identify the numbers of people accessing the programme

## Methods and methodology

The study used a mixed methods approach formed around five distinct work streams. The evaluation was more broadly informed by a theory driven approach using Realist Evaluation methodology to develop hypotheses about what works in what circumstances for whom and why. The 'I statements' were used to prioritise and thematically organise the evaluation. The five work streams form the basis of the reporting framework with each stream being reported separately.

1. Literature review
2. Data collection workshop
3. Qualitative interviews
4. Pilot questionnaires
5. Economic analysis

The literature review used the 'I statements' to broadly organise the evidence; more refined themes were explored within this organisational framework. The qualitative work was carried out in an incremental fashion. Informal discussions, reading documents and attendance at meetings began to develop an initial understanding of the whole programme. This was followed by more formal data collection activities. The data collection workshop was organised around uncovering Contexts, Mechanisms and Outcomes and underlying programme assumptions regarding causal links between these aspects of programme theory. This exploration was guided by prompts to uncover important features of the 'Business as Usual' compared to the 'New Delivery Model'. This approach was designed to fit with the 'New Economy' (HM Treasury, 2014) approach to ensure that the development and analysis of programme theory could be used to describe findings from the economic analysis. The questionnaires were developed using the 'I statements' as a starting point. Further discussions with programme members helped to define some of the more ambiguous terms in order to produce specific measurable concepts that could be measured.

Further details of methods are included in the descriptions of each work stream.

## Literature Review

### Methods

Due to the quantity of available literature it was not possible within the scope of this study to conduct a full systematic review. However, a large number of publications and some grey literature were identified and explored, and some of the stronger themes from this literature have been extracted and summarised.

Following preliminary discussions with programme members and initial scanning of available literature, several themes were identified and search terms derived from these themes. Where the numbers of returns were deemed manageable, they were all explored for relevance and either put forward for data extraction or rejected. However, when the numbers of returns were very large, several pages of titles were scanned for relevance, and literature that was not rejected was explored further to assess relevance for inclusion. Citation referencing was also carried out using recent literature, which had comprehensively reviewed previous work.

In total, 80 sources of literature were reviewed. The two main themes explored were *Co-Production* (47 papers reviewed) and *Cancer Survivors' Needs* (33 papers reviewed). Search and selection methods and numbers of returns are included in appendix i.

Data from this literature were extracted using a template based on the eight main I-statement headings. Themes within these headings were then developed and described.

### Cancer Survivorship Literature Review

Each of the I-statement categories had up to 4 themes (or sub categories), which are shown in the table below.

Table 3: Sub-Themes Within Each I Statement Category

	Sub-themes within each I Statement Category			
I Statement Category	Sub Cat 1	Sub Cat 2	Sub Cat 3	Sub Cat 4
<b>1 Money</b>	Medical bills	Insurance	Family provision	Information & advice
<b>2 Employment</b>	Cancer specific	Demographic	Service needs	
<b>3 Information</b>	Information Seeking	Unmet needs	Cancer specific	Interventions
<b>4 Health &amp; Well-being</b>	Psychosocial Needs	Access to services		
<b>5. Carers</b>	Involvement & Support			
<b>6. Support</b>	Under-utilisation	Cancer specific		
<b>7. Discharge</b>	Follow-up needs	Follow-up Barriers	Follow-up Facilitators	
<b>8. Role of Professionals</b>	Integration & Education	Accessibility & Continuity		
<b>9. Models</b>				

#### 1: Money

*Medical bills; health insurance; family provision; information and advice:*

Survivors across a number of cancer types highlighted issues relating to finance (Parry, 2012; Picker Institute, 2009; Thewes et al., 2004), which fall into four categories: issues with medical bills, obtaining health insurance, providing financially for family, and access to financial information and advice (e.g., benefits). Medical expenses were highlighted to a lesser extent by survivors in countries where care is free at the point

delivery e.g., the United Kingdom. A self-report survey of 477 adult leukaemia and lymphoma survivors found that lower income was related to greater unmet need (Parry, 2012).

The main financial issue expressed by patients and carers who had experience of gynaecological and breast cancer or prostate cancer was difficulty accessing advice about benefits (Picker Institute (2009), as many people with cancer were at risk of financial hardship. Similarly, younger premenopausal women were found to experience lifestyle, career and finance needs following breast cancer that were directly related to their younger age (Thewes et al., 2004). This highlights a need to provide young breast cancer survivors with access to financial and career advice counsellors.

## **2: Employment**

### *Cancer-specific:*

Whilst the majority of survivors of all cancer types surveyed in the USA (83.4%) did not perceive pursuing the career of their choice as problematic; 11.5% felt it moderately problematic, and 5.1% felt it was severely problematic (George Washington guide, 2013). Focus groups exploring patient and carers experiences (either gynaecological and breast cancer or prostate cancer) found that returning to work after treatment for cancer was difficult and the ease with which it happened depended largely on support provided by the employer (Picker Institute, 2009). There was agreement that information to raise employers' awareness of the issues involved would be helpful.

### *Demographic:*

Differences between men and women were found, with women experiencing more barriers to employment than men e.g., unmet child care needs (Parry, 2012; Thewes et al., 2004). Furthermore, younger women survivors of breast cancer highlight specific needs relating to pursuing and continuing their career that are directly related to being of younger age at the time of diagnosis (Thewes, 2004), which suggests younger women in particular may benefit from access to career counselling.

### *Service Needs:*

Employment status has been found to influence survivors' needs. A study of cancer patients' rehabilitation needs in Norway found that 63% of the 1,325 respondents reported a need for at least one rehabilitation service which was associated with employment status (Thorsen, 2011).

## **3: Information**

### *Information Seeking:*

In the USA, Fenlon (2015) found information seeking activity was greater in those with a family history of cancer. Furthermore, the percentage of cancer survivors who reported information seeking increased from 66.8 % in 2003 to 80.8% in 2013. Cancer information seeking was independently associated with age, education, and income; and was less likely among older adults, those with less education, and those with lower incomes. Respondents in 2008 were half as likely as those in 2003 to use the internet as the first source of cancer information compared to a healthcare provider; healthcare providers are an increasingly key source of health information for cancer survivors.

### *Unmet Needs:*

Of concern is the prevalence of unmet information needs for survivors of all demographics, and across all cancer groups (Fenlon, 2015; George Washington Guide for Delivering Quality Survivorship Care, 2013; Lewis et al., 2009), and specific information needs for survivors of lung cancer (Brown, 2014), thyroid cancer (Husson, 2015), head and neck (Luddenberg, 2015) and breast cancer (Fenlon, 2015; Luddenberg, 2015).

The Survivorship Care report (George Washington Guide, 2013) identifies many physical/medical, psychological, social, spiritual, financial and informational needs and concerns, and supports the need to identify long-term issues and assess adjustment over time. Current care does not address these issues, and written information consistently fails to reach all survivors across health care service providers and cancer types, which includes standard information such as summary care records and treatment regimes. A systematic review of the literature (Lewis, 2009) indicates that information about the effectiveness of follow-up is not given to patients, which would help them to cope and be more involved.

#### *Cancer specific:*

Among thyroid cancer survivors, findings indicate disparity in the amount of information received regarding; 1) different aspects of their disease, 2) medical tests, 3) treatment, and 4) aftercare. Almost half of the survivors (47%) were less than satisfied with the amount of information received; 31% found information not or a little helpful; and 34% wanted to receive more information (Husson, 2015).

Survivors of head and neck and breast cancer felt unprepared for the post-treatment period, and that their symptoms often remained unknown to care providers, and also mentioned a suboptimal referral pattern to supportive care services (Luddenberg, 2015).

Women with breast cancer needed help to regain control over their life, adapt to a changed body, and restore confidence (Fenlon, 2015). The need for supportive care among women with gynaecological cancer and their relatives during the pre-diagnostic period requires an overview of the treatment process supplemented with information, involvement, and help to prepare for treatment (Holt, 2014). Relatives need involvement, someone to talk to, an overview of the pre-diagnostic period, and advice on communication with young people in the family.

Survivors of gynaecological and breast cancer and prostate cancer (Picker Institute, 2009; Watson, 2015) and lung or colorectal cancer (Watson, 2015) would like to have received more information (particularly written information) about follow up care. It was suggested that health professionals only provided information to those that asked the right questions. Lack of information could lead to feelings of 'frustration' and 'isolation' (Picker Institute, 2009). Few differences emerged between age groups, although younger patients had more psychological and sexuality support needs than senior patients at 3 months post-diagnosis (Watson, 2015). Brown (2014) summarises current research that suggests lung cancer patients have high levels of need for information, physical, daily living, psychological and emotional support, yet underutilise available support resources e.g., support groups and helplines.

Most survivors expressed a need for more information about tests and treatments, health promotion, side effects and symptoms, and interpersonal and emotional issues e.g. counselling (Beckjord, 2008; Brown, 2014; and Burg et al., 2015). Specifically, Beckjord (2008) found younger, non-White survivors who had more comorbid health conditions, and who reported less than excellent quality of follow-up cancer care had more information needs; associated with worse perceived mental and physical health.

#### *Interventions:*

As most cancer survivors needed more information about maintaining good health, Beckjord (2008) suggests that communication interventions e.g. Survivorship Care Plans (SCP's) may address survivors' needs, improve follow-up care and health-related quality of life.

Holt (2014) suggests that internet information could be relevant in the pre-diagnostic period with gynaecological cancer; support of relatives and needs of families with children should be spotted in the early diagnostic phase; and more knowledge about the pre-diagnostic period should be made available as eHealth solutions.

Survivors of head and neck and breast cancer considered that an eHealth application may be a potential solution to meet their individual supportive care needs, including insight into the course of symptoms by monitoring, availability of information among follow-up appointments, receiving personalised advice and tailored supportive care (Luddenberg,2015).

#### **4: Health and Wellbeing**

One systematic review found that 20% to 30% of long-term survivors (5 years or more after treatment) reported physical and psychosocial problems (Brown, 2014). Although cancer survivors identified an approximately equal percentage of physical and emotional needs (George Washington Guide, 2013), research suggests, survivors have insufficient support to manage their psychosocial needs.

##### *Psychosocial Needs:*

Some evidence suggests health profiles of cancer survivors are broadly similar to those with a serious long-term condition, and individuals formerly diagnosed with cancer and who also report a chronic illness are in poorer health still (Richards, 2011; Elliott et al., 2011). Recovery from primary cancer treatment requires a rebuilding of confidence: however, loss of self-confidence may itself be a significant barrier to accessing support (Fenlon, 2011).

The health status, psychological morbidity, and supportive care needs of long-term survivors of breast, colorectal and prostate cancer in the UK found at least one unmet support need reported by 47.4% of survivors (Harrison, 2011). The most common was concerns about recurrence. Predictors of unmet needs were found to be trait anxiety, non-discharged status, dissatisfaction with discharge, and receipt of hormonal therapy, which may help identify individuals in need of targeted support.

A significant proportion of breast cancer patients experience psychosocial morbidity after treatment. Disease-free breast cancer survivors who were anxious or depressed reported over three and two and a half times as many unmet needs, irrespective of years since diagnosis (Hodgkinson,2007). Although most participants in a study of survivors of breast, colorectal and prostate cancer considered that they did not need active follow-up, some expressed a need for psychological services and information on possible long-term effects (Kahn, 2011).

Adult leukemia and lymphoma survivors who had completed treatment within the past four years reported need was highest regarding sexual issues, emotional difficulties, and relationships; suggesting overlapping areas of unmet need (Parry, 2012). Younger individuals were more likely to report needing help with emotional difficulties and family problems. Although cancer is the leading disease-related cause of death in adolescents and young adults (AYAs) many programs do not focus their specific needs, which are largely under-researched (Naas, 2015).

These findings support the need for a comprehensive and extended supportive care services to identify cancer survivors (especially survivors with psychosocial needs) that require supportive care interventions.

#### *Access to Services:*

Findings suggest that a lack of continuity within primary care, and lack of specialist knowledge made it difficult for survivors to talk about long-term issues with their GP (Kahn, 2011). Although survivors with specific emotional and physical needs could benefit from input from their primary care team, not all access their GP for long-term care. Better information planning is required from specialists in order to identify those who would benefit most. A study of post-diagnosis cancer survivors concluded that most needed more information about maintaining good health, which may be supported by the introduction of Survivorship Care Plans (Beckjord, 2008).

#### **5: Carers**

Holt (2014) investigated the need for supportive care among Danish women with gynaecological cancer and their relatives during the pre-diagnostic period. Relatives were found to need involvement, and help to prepare themselves including; someone to talk to, an overview of the pre-diagnostic period, and advice on communication with children and teenagers. Findings suggest women with gynaecological cancer should be encouraged to involve relatives in the pre-diagnostic period. Information about the pre-diagnostic period should be readily accessible at a time when the women and their relatives need this. Internet-based information could be a solution in the pre-diagnostic period.

Similar findings were found for participants with gynaecological and breast cancer, and also prostate cancer (Picker Institute, 2009). Participants identified the ongoing need for psychological support from the beginning, at diagnosis, right through to follow up care. They felt support should be provided on a range of issues tailored to individual needs. Survivors agreed there was a need for support for their partners, carers, family and friends. As well as emotional support, carers also discussed the need for help with more practical aspects of care.

#### **6: Support**

##### *Under-utilisation of available support:*

Supportive care is defined as “the provision of the necessary services for those living with or affected by cancer to meet their physical, emotional, social, psychological, informational, spiritual and practical needs during the diagnostic, treatment and follow-up phases, encompassing issues of survivorship, palliative care and bereavement” (in Brown, 2014). However, available research indicates that despite high levels of *need for information* (see I statement 3 - Information) there is a general underutilisation of available support resources by survivors across varied cancer groups e.g. support groups for lung cancer survivors (Brown, 2014).

##### *Support needs:*

A lack of provision of appropriate and needs specific support is also an issue, with support needs varying across survivor groups. In Norway survivors of all cancer types highlighted the need for support in the form of rehabilitation services, 40% identified unmet support needs (Thorsen, 2011). For survivors of breast, colorectal and prostate cancer there was a lack of support around managing concerns about cancer recurrence (Harrison, 2011), psychological support, and support for carers and relatives (Picker, 2009). In this cohort, few differences emerged between age groups, although younger patients had more psychological

and sexuality support needs than senior patients at 3 months post-diagnosis (Watson, 2015). Breast cancer survivors specifically identified the need for support around anxiety and depression (Hodgkinson, 2007). These needs are often unmet by oncology teams and they have to find other sources of support, such as self-help groups (Vivar, 2005).

Where independent self-management of activities of daily living was not possible, lung cancer survivors preferred to seek support from family over external organisations (Brown, 2014). There was a lack of supportive care among women with gynaecological cancer and relatives during the pre-diagnostic period, which would help them to prepare for treatment, and meet the specific needs of families with children (Holt, 2014).

Adolescent and young adult (AYA) survivors have been found to experience short- and long-term health and psychosocial consequences of cancer diagnosis and treatment (Nass, 2015). However, their support needs are under-researched. There is a need to develop educational programs for providers who care for AYA survivors, and to enhance the evidence base by facilitating participation in research.

## **7: Discharge**

### *Follow-up needs:*

Cancer survivors may continue to experience psychosocial and physical needs many years after treatment. A survey of the unmet needs of 1,514 post treatment survivors identified six main unmet needs, not found to be associated with the time since treatment (Burg et al., 2015). Burg found that breast cancer survivors identified more unmet needs than others, male survivors and especially prostate cancer survivors identified personal control problems as current needs, and older cancer survivors identified fewer unmet needs than younger survivors.

Survivors of rarer cancers with a clinical nurse specialist (CNS) reported they were well supported on return home and their needs were met (Griffiths, 2007). However, survivors referred to Primary Healthcare Teams found the service unsure of how to assess or support them. These survivors felt abandoned, suggesting a need for rehabilitation for rarer cancer to strengthen individual coping, and family and social support.

In a study of longer-term outcomes and supportive care needs in breast cancer, approximately two thirds of survivors reported at least one unmet need, most frequently concerning existential issues (Hodgkinson, 2007; Kahn, 2011). For survivors of at least 5 years following diagnosis (Kahn, 2011), and in a review of the literature (Lewis et al., 2009) perceived unmet needs included deficiencies regarding interactions with primary care.

### *Barriers to Follow-Up:*

Barriers to access follow-up care included the lack of: service co-ordination, local provision, integrated and holistic care, and specialised services either locally or, in some cases, nationally (Picker Institute, 2009). Reasons cited by survivors for not using GP services in relation to their cancer diagnosis: GPs were seen as non-experts in cancer; they were perceived as too busy; and a lack of continuity made it difficult to talk about long-term issues (Hodgkinson, 2007; Kahn, 2011). Findings suggest that better information care planning is required from secondary care specialists when discharging cancer survivors to primary care to identify those who would benefit most.

A report by the Picker Institute (2009) found that most patients described broadly positive experiences of follow up care, although patients living with the side effects of treatment highlighted particularly poor experiences. Those with 'best' access to follow up care described 'working hard' to get it, and concern was expressed that some patients might not be able to access specialist advice if they did not have certain personal attributes and skills, such as confidence or tenacity.

#### *Facilitators for follow-up:*

The preferred options for follow up of prostate cancer survivors found the majority wanted hospital follow-up with face-to-face consultation every six months (Viera, 2014). Nearly all survivors (95%) felt that it was important to have easy access to urology services, maintaining the traditional model of hospital based follow-up in specialist urology cancer clinics. Any new approach to follow-up should incorporate access to expert advice and support, and referral back to the urology team if required.

The impact of cancer and cancer treatment on the long-term health and quality of life of adult survivors is substantial, leading to questions about the most appropriate configuration of services and models of care for follow-up of post-primary treatment survivors (Howell, 2012). Survivors might benefit from coordinated transition planning that includes the provision of survivorship care plans as part of standard care (Howell, 2012), and early survivorship interventions to integrate palliative care into the treatment plan (Economou, 2014). Most survivors that expressed unmet information needs during follow up care were positive towards a proposed eHealth application (Luddenberg, 2015). From a policy perspective, the unmet psychosocial needs of survivors with and without other chronic diseases have been found to be significantly reduced following improvements in the quality of mental health care among cancer survivors (Whitney, 2015).

### **8: Role of professionals**

#### *Integration and Education:*

Economou's (2014) literature review highlights the importance of early integration of palliative care into cancer survivor care. Within the multidisciplinary team, specialist cancer nurses are considered best placed to anticipate and integrate palliative care into the treatment plan early in survivorship; supporting previous findings among rare cancer survivors (Griffiths, 2007). Women with breast cancer have also expressed unmet needs from oncology teams, and have obtained support from other sources e.g. self-help groups (Vivar, 2005). There is a need for information care planning from specialists in order to identify those who would benefit most (Naas, 2015). Furthermore, as unmet needs of survivors were identified in interactions with primary care services there is a need to educate professionals in this sector about how to support the needs of survivors.

As previously stated, the main reasons for not using GP services was that GPs were seen as non-experts in cancer; they were perceived as too busy; and had a lack of continuity (Griffiths, 2007; Kahn, 2011; Lewis, 2009; Picker Institute, 2009). Of the minority of survivors expressing a preference for accessing primary care, the main reason cited was the potential reduction in trips to hospital, particularly if the hospital was not easy to reach (Picker, 2009). One way to facilitate more GP follow-up is to expand the role of the CNS into the community, to share their specialist knowledge with GPs (Picker, 2009).

#### *Accessibility and Continuity:*

Most participants (Picker Institute Report, 2009; Viera, 2014) expressed a strong preference for having follow-up care delivered by a specialist at a hospital; very few patients, and no carers, raised concerns about being seen at hospital. However, practical difficulties in attending hospital appointments were often acknowledged. Issues included difficulty accessing or knowing who to contact, and many expressed the need for a single point of contact. When concerned, most made initial contact by telephone. It was considered very important to see the same specialist (either a consultant or nurse) at each appointment, and felt this beneficial to their care due to the specialist knowing their history. As many older survivors have chronic co-morbidities, most post-treatment survivors will require support from multidisciplinary teams, which poses challenges in relation to continuity of care (Rowland, 2014).

### **9: Models**

In 2009, the Picker Institute was commissioned by NHS Improvement (formerly the Cancer Services Collaborative 'Improvement Partnership') and Macmillan Cancer Support to examine patient and carer views of health and social care services following treatment for cancer. A number of similarities regarding follow up care were found across cancer groups. Three alternative models for organising follow up care were proposed: telephone follow-up (nurse led); patient managed follow-up; and group follow-up. Participants were generally resistant to these alternatives as replacements for existing models of follow-up care, and many foresaw potential problems, but there was support for their use to supplement gaps in current care, particularly in the areas of support provision and the exchange of information.

A supplementary article by Richards (2011) assessed health service utilisation among cancer survivors and highlighted five shifts in care and support suggested by Maddams and colleagues (2011); reflecting a move towards self-management and involvement in care, and integration and personalisation of services. Howell's (2012) literature review on the long-term health and quality of life of survivors leads to questions about the most appropriate configuration of services and models of care for follow-up of post-primary treatment survivors.

Cancer survivors might benefit from coordinated transition planning including the provision of survivorship care plans as part of standard care. Further research is needed to evaluate the efficacy of models of care in a broader population of cancer survivors with differing needs and risks. While the evidence is limited, there is research that may be used to guide the configuration of health care services and planning. The George Washington Guide for Delivering Quality Survivorship Care (2013) provides knowledge, tools and resources to deliver high-quality follow-up care. The Guide is divided into three sections: Defining Survivorship Care, Developing Survivorship Programs and Accessing Survivorship Centre Tools. Each section distils best practices, evidence-based interventions and lessons learned in delivering survivorship care and developing survivorship programs.

Others suggest a model of care for older cancer survivors which considers the role of carers, as carers might have conditions which require information and support regarding recovery, including help with practical issues (e.g. assistive technologies) and psychosocial demands (Rowland, 2014). Also, findings suggest that prostate cancer patients in England want to maintain the traditional model of hospital based follow-up in specialist urology cancer clinics (Viera, 2014). Alternative models to follow-up should meet the needs of patients by ensuring access to expert advice and support.

### **Survivorship Literature Review Summary**

Regarding financial issues, four categories were recognised: 1) medical bills, 2) obtaining health insurance, 3) providing financially for family, and 4) access to financial information and advice (e.g., benefits). Category 1

& 2 are less important in the UK context. For common cancer types, advice about benefits was most important. Lower income could relate to higher unmet needs, and there is a need to provide young breast cancer survivors with access to financial and career advice counsellors.

Returning to work could be problematic and depended on the attitude of employers. Information to raise employers' awareness of survivorship issues would be helpful. Differences between men and women were found, with women experiencing more barriers to employment than men e.g., unmet child care needs.

Cancer information seeking was less likely among older adults, those with less education, and those with lower incomes. More survivors seem to be seeking information, but fewer might be relying on the internet as a first source. There is a prevalence of unmet information needs for survivors of all demographics, and across all cancer groups. There are many physical/medical, psychological, social, spiritual, financial and informational needs and concerns, including information about the effectiveness of follow-up. Information fails to reach across all providers, cancer types, and stages of cancer journeys. There is evidence about the information needs for specific cancer types, some of which might be generalizable. There is a suggestion that communication interventions e.g. Survivorship Care Plans (SCP's) may address survivors' needs, improve follow-up care and health-related quality of life.

Research suggests, survivors have insufficient support to manage their psychosocial needs. Recovery from treatment requires a rebuilding of confidence: however, loss of self-confidence may be a barrier to accessing support; programmes to promote rehabilitation and self-management should take account of this. Approximately 50% of survivors could have an unmet support need. The most common was concerns about recurrence. Predictors of unmet needs were found to be trait anxiety, non-discharged status, dissatisfaction with discharge, and receipt of hormonal therapy, which may help identify individuals in need of targeted support. There is evidence of a correlation between unmet needs and anxiety and depression. Younger individuals were more likely to report needing help with emotional difficulties and family problems. Although cancer is the leading disease-related cause of death in adolescents and young adults (AYAs) many programs do not focus their specific needs. There are important barriers to survivors utilising primary care services.

Relatives were found to need involvement, and help to prepare themselves including; someone to talk to, an overview of the pre-diagnostic period, and advice on communication with children and teenagers. Findings suggest women with gynaecological cancer should be encouraged to involve relatives in the pre-diagnostic period. Survivors agreed there was a need for support for their partners, carers, family and friends. As well as emotional support, carers also discussed the need for help with more practical aspects of care.

The evidence indicates underutilisation of support services. Younger patients had more psychological and sexuality support needs than senior patients. Breast cancer survivors identified the need for support around anxiety and depression. These needs are often unmet by oncology teams and they have to find other sources of support, such as self-help groups.

Cancer survivors may continue to experience psychosocial and physical needs many years after treatment. Survivors of rarer cancers with a clinical nurse specialist (CNS) reported they were well supported on return home and their needs were met. However, survivors referred to Primary Healthcare Teams found the service unsure of how to assess or support them; 5 years post-diagnosis interactions with primary care remain an unmet need. Findings suggest that better information care planning is required from secondary care specialists when discharging cancer survivors to primary care to identify those who would benefit most.

Survivors might benefit from coordinated transition planning that includes the provision of survivorship care plans as part of standard care, and early survivorship interventions to integrate palliative care into the treatment plan.

Specialist cancer nurses are considered best placed to anticipate and integrate palliative care into the treatment plan early in survivorship. There is a need for information care planning from specialists in order to identify those who would benefit most. There is a need to educate primary care professionals about how to support the needs of survivors. GPs are seen as non-experts in cancer; they were perceived as too busy; and had a lack of continuity. One way to facilitate more GP follow-up is to expand the role of the CNS into the community, to share their specialist knowledge with GPs. There is a strong preference for continuity of care at hospital. However, practical difficulties in attending hospital appointments and difficulty accessing or knowing who to contact were often acknowledged.

In summary, whilst there are some key general themes and principles, these studies demonstrate that cancer survivors' needs differ by type of cancer, age, sex, race and ethnicity, and continue to change over time (including post-discharge): of concern is the evidence that these needs are frequently undetected and unmet.

### Co-Production Literature Review

Table 4: Co-production Literature: Sub-themes within each I Statement Category

Co-production: Sub-themes within each I Statement Category		
I Statement Category	Sub Category (a)	Sub Category (b)
<b>1 Money</b>	Personal Health Budgets	Investment & Savings
<b>2 Employment</b>	Benefits of Engagement	
<b>3 Information</b>	Service User & Provider Needs	
<b>4 Health &amp; Wellbeing</b>	Benefits & Boundaries	
<b>5. Carers</b>	Barriers & Facilitators of Engagement	
<b>6. Support</b>	Peer Support	

<b>7. Discharge</b>	Transitional Needs	
<b>8. Role of Professionals</b>	Barriers & Facilitators of Engagement	
<b>9. Models</b>	Appropriateness/Efficacy	Approaches & Implementation

## **1: Money**

### *Personal Health Budgets*

User-led approaches to inform commissioning and delivery of health services, and to create personal health budgets have been supported in diverse service user groups, examples of which are outlined in the DOH (2010) paper 'Practical Approaches to Co-production'. Subsequently, the London based Prosper initiative (Barret et.al., 2014) comprising of a self-directed network of people with experience of mental health problems, has used co-production, and recovery and social movement approaches to successfully support the development of personal health budgets, local commissioning, and consultancy.

### *Investment & Savings*

The initial funding of social care service user-led initiatives by health and social care commissioners has been found to successfully promote self-help, and collaboration with service providers to identify and deliver the specific service needs of people with mental health problems (Barret, 2014). With regard to economic cost savings, NESTA (2013b) report that user-led interventions resulted in 7 percent savings equivalent to £4.4bn across England on A&E attendances, planned and unplanned admissions, and outpatient admissions. The valuable resource of 'time' (sometimes referred to as time banking or time dollars) that is generously and freely donated to co-production by service users is a valuable resource that leads a growth in both economic and social capital (NESTA, 2013b; Powell & Dalton, 2003; SCIE 2013). However, limited resources have been found to pose challenges in the adoption of such initiatives within a community setting (e.g., Lashco, 2012).

It is suggested that for co-production to succeed there is a need for greater autonomy in budgets and decision making (Gannon & Lawson ,2014) and adequate investment in innovation at organisational level (e.g., Klerkx & Nettle, 2013: NCAG). However, this can be complex to achieve and may require a collaborative architecture between services including information technology, pooled budgets and integrated employment contracts (Pisano & Verganti, 2008). The National Co-production Advisory Group (NCAG) recommend investment should include: allocation for participants' fees and meeting their access needs, expenses, and the provision of easy read documents; and for frontline staff, sufficient time and flexibility.

## **2: Employment**

### *Benefits of Engagement*

A comprehensive study in the UK (Boyle, Clark & Burns, 2006) investigated whether co-production between public sector professionals and members of the public (especially those outside paid work) has the potential to capture and develop community members' contribution to their neighbourhoods. The study provided training to unemployed clients to enable them to play an active role as researchers on the project. Boyle's study found that such co-production can improve individual lives, improve social cohesion, broaden public services, and develop the relationship.

### **3: Information:**

#### *User and Provider Needs*

Findings suggest that the provision of training to support service users (Boyle, 2006) contributing to collaborative initiatives facilitates participants' ability to play an active role. Equally, the need for service provider training is required for successful information exchange (e.g., Klerkx, 2013; NCAG)

Within the present literature reviewed, none focus solely on the information required to facilitate co-production. Instead, a number of articles provide overall guidance for organisations, managers, and health professionals on the information needs of service providers and service users (including health and social services) and co-production stakeholders across a variety of services (e.g., Dixon & Sindall, 1994; Department of Health [DOH], 2010; Gannon, 2014; LGiU, 2012; NCAG; Needam, 2007; NESTA, 2012, NESTA, 2013a; NESTA 2013b; Phillips & Morgan, 2014; SCIE, 2013; Wilson et. al., 2012).

### **4: Health and Wellbeing:**

#### *Benefits and Boundaries*

Findings support the assumptions that co-produced projects have a significant positive impact on health, wellbeing and community cohesion and that co-production built around people rather than systems needs to be embraced across healthcare (Dineen, 2014), community healthcare (e.g., Munoz, 2013) and wider community settings (e.g., Lashko, 2012).

In contrast, there are scenarios where service user involvement in the co-production initiative may have a negative impact on the health and wellbeing of participants and/or is impractical. In terms of context, engagement in one remote rural community health care project induced feelings of pressure, strain and frustration among participants, and met with resistance to change and an allegiance to traditional provider led dynamic (Munoz, 2013). Alternatively, user-led engagement may only be inappropriate during specific aspects of service development. For example, a collaborative project to develop wound care products bespoke to people with the rare skin condition Epidermolysis Bullosa (EB) (that causes extensive skin blistering, wounds, pain and discomfort) required the use of surrogates during the testing phase of prototype dressings (Grocott et al., 2013): this was to protect patients with EB, but also to ensure the delivery of research and service outputs within pre-defined and limited time/resource constraints. Where surrogates are required, Grocott suggests ways to ensure that the spirit of co-production and the voice of service users remain intact.

### **5: Carers & Service Users**

#### *Barriers and Facilitators of Engagement*

In the present literature review, neither of the papers reviewed represented only the voice of carers regarding their views on inclusion/exclusion in the development of user-led service provision. However, a study conducted in Bristol (Hicks, Keeble & Fulford, 2015) identified carers' perceptions of health

professionals and organisational consultation with service users as: heard but ignored ('tick box exercise') and/or heard but dismissed by health professionals as lacking credibility.

This is of concern as 2 influential reports identify that sustainability of co-production approaches is dependent upon public engagement (NCAG 'Think local act personal', and the Local Government Information Unit [LGIU] 2012- 'Making Health and Social Care Personal and Local'). Both reports emphasise the importance of encouraging and maintaining the participation of more people e.g., by ensuring that their input results in the outcomes they most want, and by acknowledging and appreciating the contribution they make.

From a service user's perspective, people considered vulnerable or that lack capacity (e.g., people with learning disabilities, dementia, or the frail elderly) are generally excluded in the process of service development. However, engaging this cohort in co-production has proven successful in breaking down barriers to communication, developing service users' knowledge, skills and self-confidence, and has instilled a sense of social belonging (Gannon, 2014; Leone et. al., 2012; Network EoEsc; Roberts et. al., 2012; SCIE, 2013; Sang, 2009;Sangiorgi, 2009)

In response, initiatives to determine best practice when engaging diverse service user groups and carers in the development of services have begun to emerge that themselves adopt co-production approaches (see section 9b Models and Frameworks: Approaches to co-production). Needham (2007) emphasises that co-production should be a process of collective dialogue, rather than purely transactional and suggests that deliberative workshops may have the potential to facilitate collaboration, especially where poor relationships between officials and citizens exist. Needham also highlights the importance to be clear about the limitations of such exercises, to avoid raising expectations that cannot be fulfilled. Additionally, amidst the enthusiasm to promote the voice of service users, it is also important to avoid coercion and acknowledge and respect peoples' right to remain silent.

## **6: Support**

### *Peer Support*

Self-directed support groups often form due to a gap in, or user dissatisfaction with, the traditional service model (Slay, 2013). Slay 's review of the literature on peer support (limited to mental health settings) found groups often exist outside (and sometimes in opposition to) mainstream mental health provision. Although this affords greater freedom and flexibility, it also limits their capacity to co-produce with health professionals and services or access mainstream funding, or to alter the mainstream model of delivery. In contrast, models where service providers actively promote service users' delivery of peer support, such schemes have been found to have positive outcomes for people with mental health problems: yet peer support is often self-directed (e.g., Barret, 2014).

## **7: Discharge**

### *Transitional Needs*

Research has highlighting that patients particularly value relationships with health professionals that pay close attention to transitional health identities and the co-production of health-related decisions (e.g., Wilde, 2014). Although there is a paucity of literature relating to the use of co-productive approaches in the delivery of service users ongoing and transitional needs, literature offering information and guidance on co-

productive approaches is summarised: and may be applied to the provision of appropriate post-discharge service user support (see co-production literature sections 1-6, 8, and 9).

## **8: Role of Professionals**

### *Barriers and facilitators to engagement*

As previously highlighted by Wilde (2014) patients particularly value relationships with health professionals that engage them in the co-production of health-related decisions. Alongside, there is an increasing requirement for health professionals to support social inclusion in service provision. For this to succeed it is necessary to provide adequate education and resources to enable front line staff to facilitate service users in the co-production of services (e.g. Klerkx, 2013; Leone, 2012; NCAG).

Findings suggest a lack of provision to educate and inform professionals' understanding of co-production theory and practice, and a hierarchical failure to understand and appreciate the structure/agency dilemma that represents a barrier to engagement with service users to co-produce socially inclusive outcomes (e.g., Clifton et al., 2013; Dunston et al., 2009). Despite this, more programmes in the UK are being launched to evaluate and support co-production working in health and social care: for example, those conducted by the East of England Strategic Co-production Network (Network, EoEsc) with the National Development Team for Inclusion (NDTi) (Gannon, 2014); the Scottish Co-Production Network (Network, Sc); and the Bristol Co-production Group (Hicks, 2015).

The aforementioned studies suggest that it is necessary to acknowledge the limited extent to which health professionals and service users' engagement in co-production can overcome the socioeconomic, political and cultural structures that generate social exclusion. Within these wider constraints, for co-production to succeed, Gannon suggests there is a need for greater autonomy in budgets and decision making, the spread of good practice, knowledgeable and confident workers and users, and the time and space to innovate.

## **9: Models and Frameworks**

### *Appropriateness & Efficacy*

Some consider that the traditional concepts of 'market' and 'market management' are inappropriate and need to be modified within the public sector to accommodate collaborative relationships between multiple stakeholders (Bovaird, 2006; Bovaird, 2007; Hunter & Richie, 2007). Bovaird suggests this unique relationship is not otherwise addressed in collaborations involving relational contracting (single commissioners and contractors), partnership procurement (multiple commissioning bodies with a joint procurement policy) and distributed commissioning (multiple commissioning bodies with different procurement policies with one single purchasing body). Others suggest barriers to co-productive relationships are integral to the design and culture of public sector organisations (e.g., Hyde & Davis, 2004).

It is also suggested that the packaging of co-production and self-support as empowerment fails to recognise or understand the resulting pressures and practice it unfolds for both health professionals and service users (Iedema & Vejanova, 2013). For health professionals this includes issues such as how to manage risks when engaging with vulnerable groups, whether there are enough people willing or able to engage, and if so how best to reach them (Lashco, 2012). Nevertheless, successful outcomes have been achieved in co-production interventions, including those involving people considered to be vulnerable (for examples see section 5a: Carers and Service users: Barriers and facilitators of engagement).

As value creation remains one of the primary outcomes required of public sector organisations, an understanding of factors that facilitate value creation is required. Chew's (2013) literature review describes the underlying principles and mechanisms for value creation in organisations that collaborate either within or between organisations. Chew states that the value creation potential of an organisation is influenced by its network reach (extent of tie to external partners) its richness (value of network resources available) and its receptivity (capacity for resource sharing across network boundaries). Chew identifies that network ties are organised either loosely (flexible strategy) or tightly (efficiency strategy). Further, the capacity to create and sustain value is linked to the organisation structure, dynamic capabilities, and strategies: especially the leadership's ability to manage tensions between flexible and efficiency strategies. Finally, Chew describes that organisations may have open or closed boundaries and/or membership dependent upon its innovation strategy and associated organisational capabilities: value creation is enhanced by open boundaries where product-customer mapping is of low to medium complexity, and by closed boundaries where it is highly complex.

Considering Chew's findings, this poses a challenge to the delivery and/or enhancement of value creation in the public services arena, as product-customer mapping (service provision and service user needs) varies in complexity both within, and between service user groups. Additionally, as previously outlined (see 8a - Role of Professionals: Barriers to engagement) the wider contextual influences, and the traditional health professional/patient (dominant provider/passive recipient) model of health care provision is required if engaging service users in co-production is to succeed.

#### *Approaches & Implementation*

Most of the literature reviewed here supports that co-production represents equality of voice for all participants, and that service development should be collaborative and primarily user led (e.g., Barret, 2004; Dixon, 1994) although traditionally the top down (service provider led) model has been used for the delivery of health and social services. In practice many initiatives remain provider led (co-design) rather than user led (co-creation), or commonly a combination of the two depending on context (e.g., Coen et al., 2013). How to maintain equilibrium in co-production is one of the biggest challenges to successful implementation. Increasingly theoretical models and frameworks of co-production are tailored to specific contexts, and participants vary dependent on the specific user group.

*Implementation:* An exemplar of the shift in focus towards collaborative working in government policy is the Department of Health (DOH, 2010) guide 'Practical approaches to implementation', which has identified co-production as one of four elements that define successful change, alongside leadership, subsidiary, and system alignment. The DOH (2010) report outlines various approaches to and different aspects of co-production, and also considers the health policy context within which approaches are being developed; for instance, the NHS White Paper (Equity and Excellence: Liberating the NHS, 2010), the Public Health White Paper (A Vision for Adult Social Care: Capable Communities and Active Citizens, 2010) and the Partnership Agreement between government and the social care sector (Think Local, Act Personal). Additionally, the implementation document provides various definitions of co-production within health and social care and the principles underpinning co-production, a summary of legal frameworks that support co-production, and examples of where co-production has worked well at different levels of the social care system.

*Service-user Specific:* The DOH approaches to implementation paper also highlights different ways to involve people from diverse groups including: collaboration with user-led organisations (ULOs) and small social enterprises, engaging carers in co-production, and working with citizens to create Participatory Budgets. For

guidance on implementation, the following documents provide information for health and social care organisations, managers, and health professionals on how to begin the process of introducing co-productive approaches to service development (e.g., Dixon, 1994; DOH, 2010; Gannon, 2014; Glasby & Dickenson, 2014; LGiU, 2012; NCAG; Needham, 2007; NESTA, 2012, NESTA, 2013a; NESTA 2013b; Network EoEsc; Network Sc; Phillips et. al., 2014; SCIE, 2013; Wilson, 2012)

*Service Complexity:* In addition, other examples (see section 9 a: Models and Frameworks: Appropriateness/efficacy) demonstrate Chew's identification of the need to adapt different approaches to collaboration depending upon the variability in service type (see Needham, 2007 - Section 5a for a summary) and the complexity that exists both across and within specific service user groups. For example, engaging parents in the delivery of services for children and families is more complex where parents are estranged, and escalates where contact issues exist (Coen, 2013). Coen's evaluation found service user involvement in the delivery of the service was broadly professionally defined, and service delivery varied from family to family based on specific service-user involvement but still remained within the bounds of professional control. This variability between service user involvement (open boundaries) and professionally defined (closed boundaries) may, in circumstances where services are more complex, optimise organisational value creation.

*Service Location:* During implementation or co-productive approaches the location and evaluation of services also requires consideration: for example, community services (Dixon, 1994; and Lashco, 2012). Dixon highlights the need to recognise the specific dynamics that underpin community-led change ('lifeworld rationality'), externally initiated health programs and interventions ('formal rationality'), and the value dimensions behind such programs and interventions ('substantive rationality'). Also, Dixon suggests the health promotion standards and performance indicators of programs or interventions should be co-produced by all stakeholders utilising an ethnographic approach, rather than via community controlled process evaluations that coexist alongside expert-controlled impact evaluations.

### *Co-Production Literature Review Summary*

Relating to the I-statement 'money' there were two main categories outlined: 1) personal health budgets and 2) investment and savings. First, findings support that using co-production approaches can successfully support the development of personal health budgets in diverse user groups (including people with mental health problems), local commissioning, and consultancy. Second, the cost of service provision can be significantly reduced by promoting and supporting service user self-help initiatives, and through collaboration with service providers to identify and deliver the specific service needs. The contribution by service users of the resource of 'time' is a valuable resource that leads to not only growth in economic capital, but also social capital. However, limited resources have been found to pose challenges in the adoption of such initiatives, especially within a community setting. To succeed, it is suggested that greater autonomy in budgets and decision making and adequate investment in innovation at organisational level is a necessity. However, this can be complex to achieve and itself requires a collaborative organisational level infrastructure between services including information technology, pooled budgets and integrated employment contracts. At the point of delivery, investment should, for example include: allocation for participants' fees and meeting their access needs, expenses, and the provision of easy read documents; and for frontline staff, sufficient time and flexibility.

The limited references to the I-statement 'employment' in the literature reviewed generally outline the 'benefits of engagement' in co-production between public sector professionals and the general public:

especially people outside paid work. This is an important area for exploration as the ability to maintain a career or employment is often compromised due to ill health. Findings suggest that training skills of engagement to unemployed people and enabling them to play an active role in co-production initiatives (e.g., the role of researcher on projects) can improve individual lives, improve social cohesion, broaden public services, and develop the relationship between service providers and service users.

Similarly, within the I-statement 'information', literature supports that it is necessary to provide training for organisations and individuals, including health professionals, contributing to collaborative initiatives to facilitate their ability to play an active role, and for successful information exchange. Encouragingly, a number of articles were found to provide overall guidance for organisations, managers, and health professionals on the information needs of service providers and service users (including health and social services) and co-production stakeholders across a variety of services.

In terms of the impact on the 'health and wellbeing' (I-statement 4) of service users participating in co-produced projects, mixed reports suggest both positive and negative outcomes depending upon the context, stage of service development, and cohort involved. Within the community setting some studies have found positive impact on health, wellbeing and community cohesion, whereas others induced feelings of pressure, strain and frustration among participants, which may exacerbate resistance to change. Further, user-led engagement may be inappropriate during specific aspects of service development that and/or involving specific service user groups. For example, this may be for ethical reasons that protect patients, but also practically to ensure the delivery of research and/or service outputs within pre-defined policy, time/resource constraints. In such cases it is important to ensure that the spirit of co-production and the voice of service users remain intact: within the literature, guidance is provided on how to retain the values of co-production where surrogates are required.

Additionally, the voice of carers (I-statement 5) within the literature is largely under-represented, but where cited, carers' perceptions of health professionals and organisational consultation with service users reflects feelings of being heard but ignored by service providers, and/or heard but dismissed by health professionals as lacking credibility. To promote general public engagement the literature suggests ensuring that participants' input results in the outcomes they most want (this should reflect wider group needs and not just individual preferences), and the need to acknowledge and appreciate the contribution they make.

From a service user's perspective where the challenges of engaging vulnerable groups in the process of service development are overcome, initiatives have proven successful in breaking down barriers to communication, developing service users' knowledge, skills and self-confidence, and have instilled a sense of social belonging. Examples of best practice when engaging diverse service user groups and carers in the development of services emphasise that co-production should: be a process of collective dialogue, rather than purely transactional; be clear about the limitations of such exercises and avoid raising expectations that cannot be fulfilled; and continue to acknowledge and respect peoples' right not to engage should they so choose.

With reference to support (I-statement 6), self-directed peer support groups are less likely to succeed where they are not supported by service providers than those with service provider backing. This is because the latter improves the group's capacity to co-produce with health professionals and services, access to mainstream funding, and/or ability to alter the mainstream model of delivery. As peer support initiatives have been found to have positive outcomes for people, including those with mental health problems, service providers are encouraged to collaboratively support service user self-help groups. Furthermore, patients

have been found to particularly value relationships with health professionals that pay close attention to transitional health identities and the co-production of health-related decisions. The literature demonstrates the need to provide ongoing support for service users pre and post-discharge (I-statement 7), and provides information and guidance on co-productive approaches that may be applied to determining service users' support needs upon discharge.

With regard to the final I-statement ('role of professionals') there are a number of barriers and facilitators to health professionals' engagement with service users highlighted in the literature. At organisational level and the point of service delivery there is a lack of understanding of the theory and practice of co-production and the structure/agency dilemma faced by practitioners. There is also a need for greater autonomy in budgets and decision making, the spread of good practice, knowledgeable and confident workers and users, and the time and space to innovate. This requires adequate education and resources although, findings suggest there is currently a lack of such provision. It is also important to acknowledge the limited extent to which health professionals and service users engaged in co-production can overcome the wider socioeconomic, political and cultural structures that lead to social exclusion in the first place.

In addition to the I-statements, information was found in the literature relating to an further area that describes 'models and frameworks' of co-production applied in a variety of contexts. This literature was found to fall within two sub-themes: 'Appropriateness and Efficacy', and 'Approaches and Implementation'.

First, literature in 'Appropriateness and Efficacy' states that in the public sector the organisational design, culture, and traditional concepts of 'market' and 'market management' are inappropriate and need to be modified to accommodate collaborative relationships between multiple stakeholders. Also, despite evidence of successful outcomes of co-production, including value creation, others caution that the packaging of co-production and self-support as empowerment fails to recognise or understand the resulting pressures and practice it represents for both health professionals and service users.

However, the fact remains that value creation, which is facilitated by co-production, remains one of the primary outcomes required of public sector organisations, therefore an understanding of factors that facilitate value creation is required. Within organisations, the capacity to create and sustain value is linked to the organisation structure, dynamic capabilities, and strategies, and is enhanced by open boundaries where 'service provision'-'service user' mapping is of low to medium complexity, and by closed boundaries where it is highly complex. As the mapping of complexity within health and social care service provision varies both within and between service user groups, this poses a challenge to the delivery and/or enhancement of value creation in the public services arena.

Finally, under 'Approaches and Implementation' literature, most of the literature reviewed here supports that co-production represents equality of voice for all participants, but in practice many initiatives remain provider led (co-design) rather than user led (co-creation), or commonly a combination of the two depending on context. As co-production has been identified to be one of four elements that define successful change (alongside leadership, subsidiary, and system alignment) theoretical models and frameworks seek to tailor co-production principles to meet diverse service user needs. The two main considerations outlined are variability in service complexity, and the context in which services are delivered. From a positive perspective, the literature reviewed here suggests a burgeoning body of exemplars of successful co-production interventions for health and social care provision, and 'how to' guidance on implementation derived from research and practice across diverse sectors, organisations, and services. Despite the current enthusiasm for co-productive approaches to enhance public health and social care

provision, an underlying message of caution prevails, and emphasises the need to avoid over-promising and under-delivering on the rewards of service led collaboration by ensuring that adequate resources and support are available to all participants.

## Data collection workshop

A data collection workshop was undertaken by JR and SA on the 5.5.15. Members of staff from the three key Programme services attended; The Living Well hub (LW), Meeting New Horizons (MNH), Cancer buddies (CB), plus a Macmillan and Programme representative. It used a preliminary evaluation framework to gather data. This framework was based on documentary data, notes taken during the evaluator's attendance at fact finding and Programme meetings. The workshop collected data on contexts, mechanisms and outcomes prior (BAU) and post (NDM) the Programme's existence. These data were used to further refine the evaluation framework. The framework was used to design the qualitative interview schedule and informed the literature review and the economic evaluation.

## Qualitative interviews

### Methods

10 semi-structured interviews were carried out between the 25th June 2015 and 23rd October 2015 with key members of each stakeholder group including the Strategic group. Purposive sampling methods were used to identify one potential participant from each key organisation/membership group of the strategic group. Then snowball sampling after that with interviewees suggesting useful contacts (PABC, CNS and GP). The interview topic guide was based on initial programme theories for each of the eight I-statements. These programme theories consisted of contexts, mechanisms and outcomes (CMOs) and aimed to describe what was working, for whom, in what circumstances and why. These initial conjectures (CMOCs) were tested for face validity with the interviewees, and questioning was directed at further refining the programme theory. All interviews were face to face, except one which for practical issues had to be undertaken by telephone. They lasted between 1-1½ hours, were digitally recorded and transcribed verbatim. Field notes were also kept.

Transcripts and field notes were anonymised and added to the data analysis software (NVivo 10) to aid data management coding and reporting. Interview data were initially coded line-by-line according to the refined evaluation framework. However, discussions with key stakeholders suggested that the I-statements might provide a more relevant evaluation framework for discovering what was working, for whom, in what circumstances, and why. The I-statements are important criteria against which the programme would ultimately be assessed, so these were used as the coding structure for a second analysis.

Line-by-line, all responses were categorised to their relevant I-statement/s. Within these categorisations, data were coded thematically. Initial themes were developed from the data. Each unit of data (statements with relevant intrinsic meaning) was either: connected to an existing theme; or if sufficiently unique a new theme was created; or if the data were similar to a previous theme, then it would be added to this theme, but the description of the theme altered to accommodate the new data.

This approach offered two types of findings. The first relates to the programme as a whole, and further develops theories about what is working well and what issues remain about how mechanisms of change operate in particular contexts, in order to reach specific project outcomes. The second set of findings, being based on the I-statements, focus more on service-user centred outcomes and explores how these are viewed and the relationship between the programme and these statements.

## Findings Programme-Wide Themes

### *Moderating contexts*

Many wider contextual issues appear important to the Programme:

- Third sector competition
- The target population – increased rates of cancer and survivorship
- Poor starting position regarding cancer awareness and referral rates
- Trusted and ‘prestigious’ Macmillan brand
- Known ‘professionals’ with successful track records involved in the Programme (this allowed key partners to trust the Programme and its activities)
- The pre-existing NHS and commissioning landscape
- NHS staff have ideas, but structures, workloads and processes prevent them achieving change
- Low NHS staff moral and high workloads result in no motivation, time or energy to create, develop and implement change
- Traditional (paternalistic and medical model) NHS cultures and ways of working
- NHS priorities
- Changing NHS, social and 3<sup>rd</sup> sector landscapes
- Pre-existing discordancy within some teams
- Programme partners having different priorities, motivations, cultures and ways of working

### *Key programme activities*

The Programme’s overarching activity was its co-production. This included co-production with PABC, and co-production between various organisations and services. PABC were central to its design and implementation. They were facilitated and supported to create the programme’s aims (I-statements) and identify solutions to meet them. The PABC group were seen as equal partners within the strategic group and key Programme drivers. The programme had a centralised co-ordination and facilitation role, providing opportunities for partners to work together for the development of services.

### *Mechanisms*

#### *Power-shift and Empowerment*

One of the key overarching mechanisms for the programme could be summarised as ‘Power-Shift and Empowerment’; firstly, in terms of shifting some responsibility for the PABC from clinical services to survivorship services. This was reportedly being achieved through quality assurance of organisations, involvement of the Macmillan brand, and involvement of and engagement with clinicians.

Secondly, the programme aimed to empower PABC to self-manage by identifying them, easing access to advice and support services, helping to address basic needs and provide information and support to inform self-management.

Thirdly, the programme aimed to enable PABC to have a say in the direction of development of cancer services. This was approached by actively involving PABC in the development of the programme, and is being managed at a more sustainable level through the Cancer Survivor Action Group (CSAG) and links to the local cancer board.

## Community Resilience

The programme aimed to enhance community resilience by providing:

- A wide variety of potential contact points for information and support
- Network training events
- Survivor-friendly organisations
- Named individuals in organisations
- Employer engagement events
- Signposting to services where experiences can be shared (e.g. carer support group)
- General awareness raising activities

These programme processes could be understood to improve outcomes for PABC and carers by, for instance; reducing feelings of isolation, improving awareness of and access to support services, ensuring that the general population and employers treat PABC according to their needs.

## Learning from other organisations

The opportunity to learn from other individuals through meetings, events, and day-to-day working has been a key mechanism of the programme to contribute towards improving outcomes for PABC. This mechanism is particularly relevant for multi-organisational programmes. For instance, knowledge from MNH and the information centre has merged to provide both organisations with a better understanding of PABC, developing shared objectives and shared language, and resulting in unanticipated and emergent benefits.

## Feeling able to talk

A key mechanism for PABC, which was identified at the stakeholder workshop was the ability to 'talk openly and safely' about sensitive subjects to people who are removed from clinical care. Importantly, the access to people that PABC have no prior history with, and who won't be judgemental was considered important.

## Main Themes

Four key Programme process themes emerged from the data.

- Time
- PABC providing commonality
- Informal and creative networking
- Programme identity

### Time

Time appeared relevant to the Programme in three ways.

- Timing of the intervention and access to services
- Time taken by the programme to develop and evolve
- When in time does 'survivorship' start?

Timing of the intervention: There was repeated reference made to when PABC should be receiving support and services from the Programme. PABC were felt to need interventions early on, but not immediately post diagnosis as they often would be in shock. Timing had to be personalised and access to the Programme was required throughout the persons 'cancer journey' as needs changed according to time. This would blur the point of discharge from statutory services which was felt to be a good thing.

Time taken by the programme: It was felt that the Programme has taken time to evolve and processes are slowed due to culture and bureaucratic nature of statutory partners. This was in contrast to the relatively nimble 3<sup>rd</sup> sector organisations. Differences in response times did cause tensions and frustrations, but it appears that this time was needed to let networks develop and creative problem solving occur.

When in time does 'Survivorship' start? There was some discrepancy across the programme regarding the terminology of 'survivorship' as opposed to 'living with and beyond cancer', and the times that these different terms were considered appropriate. It was suggested that a focus on 'survivorship' was only appropriate some-time after initial treatment and potentially only for those with a prognosis for long-term survival. However, there was strong agreement that the programme had potential benefits when PABC were accessed as early as possible.

#### PABC providing commonality

PABC's being at the centre of the Programme appears to have provided shared values, goals, language and incentives. Without this, key partners might have struggled to work together because of organisational differences.

Involving people affected by cancer as quite a big group to; express what the issues are, and get involved at a strategic level has resulted in changing the way that executive and management level within commission and provider organisations have taken to making decisions. These changes have included:

- Much more open, plain English way of communicating
- More representative of a wider range of issues than having one representative
- Enabled better collaboration between different providers

It was reported that there is a need to try to nurture the involvement of PABC further. It was also noted that PABC need to have appropriate links to be able to make changes.

#### Informal and creative networks

Informal and creative networks and partnerships with win-win situations appeared key to the Programme. The networks (and the willingness to share and use them) that partners brought to the table meant the Programme was 'more than the sum of its parts'. The networking opportunities (formal and informal) that the programme provided, resulted in creative problem solving and collaborations.

A specific example of informal networks being used creatively to solve problems was the spreading of the connections with the Leisure Trust to improve access and offer reduced prices from different organisations within the programme.

MNH via their community (survivor friendly) work contributed significantly to the networks and partners the Programme had to draw on. In addition this work raised the profile and awareness of cancer, cancer services and the Programme within Doncaster; to employers, employees and the public and contributed towards meeting several I-statements. They created win-win situations for potential partners and identified and used a common link for potential partners.

#### Programme identity

Internal issues around Programme identity were evident in the data. Differences in definition of terms, outcomes, goals and aims were highlighted. Difficulties in not having a clear Programme 'leader' were also identified. However, if a clear leader had been present, the co-production and collaborative nature of the Programme may have been lost. Clarity and measurement of the I-statements contributed to internal Programme identity problems. They were felt to be complicated, often duplicated needs and were difficult to measure.

There were also some difficulties associated with the external identity of the programme. For instance marketing and branding issues were identified: no clear brand and marketing strategy was available for the

start of the programme. It was felt by responders that this had held the programme back as profile and awareness raising (internally and externally) was key to the programme's success. Struggles with branding emerged from the nature of multi-agency collaboration.

It was not always clear to patients, carers or people working in the sector that the elements of the programme were connected, and this lack of awareness was associated with time taken to establish programme branding and profile-raising activities. It was also recognised that the identity of the programme affected referrals into the programme services. Clinical Nurse Specialists are important referrers into the programme. However, they have seen many new initiatives come and go, and this could make them reluctant to refer patients until they have seen the programme demonstrate effectiveness and longevity. There were some differences of opinion as to the aims of the programme and whom it was intended to target.

### *Barriers to change*

Some important barriers to change have been identified elsewhere:

- Carers not identifying as carers
- Communication between services and agencies external to the programme
- Time and resource limitations of the programme and external agencies
- Marketing
- Availability of skills (e.g. communicating with employers)
- Involvement of big employers

Some additional barriers were also identified:

Environments that stifle creativity and innovation: It was highlighted that the bureaucracy, workloads, hierarchy and procedures within the statutory partners could stifle creativity and innovation. However the informality, networking and creative opportunities that the Programme provided appeared to counter balance these difficulties, which otherwise would have restricted Programme activity significantly.

Internal programme communication: Internal Programme communication was felt to be lacking at times, especially for those who could not attend the strategic groups. This was felt to contribute to misunderstandings especially regarding roles, programmes of work and inter organisational and partner trust.

Gaps in the programme: Concerns were raised over how the programme was meeting the needs of carers, people with rarer cancer types, seldom heard groups and BME communities. Carer contact was dependent on being referred, rather than them finding the programme when they were ready for it, which could be a long time after a diagnosis has been made. So as not to 'reinvent the wheel', it was considered to be best strategy to link up with existing carer services. Potentially, the role of the programme could be expanded to understand what services are available and actively identify carers, but then refer them on or signpost them to other services. Support for children carers was identified as a potential area of need.

### *Sustainability and improvement*

The following threats for programme sustainability were identified:

- Finances: convincing funders to continue supporting the programme

- People leaving, continuity (e.g. continuity of information, connections, processes)
- CSAG details of involvement will determine success (who are they representing, how do they establish authority/mandate)
- Debate about the importance of the single point of access into the programme (perhaps internal communication and processes to ensure clients receive appropriate services with minimal inconvenience is more important)
- The coherence of the profile of the programme (this can be an enabler for clinicians to refer in and client to self-refer). This relies on maintaining the project identity and continuing profile-raising activities
- Ownership of the programme (difficulties with ownership can result in competition for credit, and role conflict)
- External incentives to not fully collaborate (these could be emergent and the programme might have limited ability to control or respond to these pressures)
- Referrals from the acute services and primary care are reported to be difficult to encourage and maintain. Repeated contact could be a key function to enable sustainability of the programme
- A lack of effective communication between different agencies and services was reported as a problem; especially regarding patient/client experiences and roles and responsibilities
- The programme was reported to have limited contact with carers (it was suggested that enhanced efforts to connect with carers through acute services or to engage in marketing activities might be beneficial)

Other topics that were mentioned as areas of possible improvement by a small number of respondents:

- Pension and retirement advice
- Targeting resources/risk stratification
- Assessment for self-management
- Information supporter role & skills (mostly communication skills; covered elsewhere)
- Employer engagement & employment issues (covered in Employment section)
- Indicators of success
- Support services with wider appeal
- Information about effects of treatment
- Profile & awareness
- Bereavement support
- Awareness of survivorship issues for health professionals
- Locating the Living Well information service in the town centre
- Providing GP surgeries with paid locum time (not money) to free up clinical staff to commit to programme work
  - Establishing a GP 'community of practice' to foster and grow the 'head of steam' and motivation required for change

### **I-Statement Findings**

This set of findings relate to the programme I-statements. They are presented under the eight broad topic headings:

- 1) Money

- 2) Employment
- 3) Information
- 4) Health and wellbeing
- 5) Carers
- 6) Support
- 7) Discharge
- 8) Role of professionals

I-Statements 4 & 6 have been combined due to significant overlap of themes.

### **1: Money**

Relevant theories within the 'Money' theme overlapped significantly with employment, regarding the individual financial impact of cancer. There were also overlaps with the information theme, regarding employment and financial advice and support (e.g. claiming benefits).

Stopping work can result in higher utility bills. Additional assistance required with care activities and purchases such as equipment and special foods can also have a financial impact. Concerns about meeting basic needs can have psychological and emotional repercussions, and these concerns can be long-term and changeable. Financial solutions often lag behind the individual's needs.

Some moderating contexts, which might be amenable to change to address financial problems, are:

1. IT confidence and skills
2. Literacy level
3. Confidence with authority (Doctors, bank managers etc)

Mediating contexts that can affect the efficacy of interventions are:

1. Attitude and type of employer
2. Terms and conditions of employment
3. Financial situation prior to diagnosis
4. The impact of 'normal' life events, such as redundancy, family births, deaths and illness

For PABC referred into the MNH assessment and intervention service, respondents felt that I-statement aims were being met: indicating that the approach to the problem is appropriate. The use of well-trained volunteers was considered an effective model. However, a key limitation of the service was considered to be ensuring that people with financial needs access the service. There are three key mechanisms for improving access to the service:

1. Raising professionals' awareness of potential financial problems to increase referral rates
2. Raising awareness in other services for signposting into MNH
3. Raising public awareness of the MNH service to increase self-referrals

The data suggests that the following are important in delivering the service:

Attributes of the assessor/advisor:

- Holistic and empathetic in approach
- Treat all PABC as individuals
- Active listening skills

- Expert in financial issues
- Experience and understanding of the wider experience of cancer
- Skilled in conversation
- Instil confidence in their abilities, skills and knowledge

What the PABC needs:

- Provision of information to allow informed not 'desperate' decision making
- Provision of a holistic and individualised assessment
- Provision of ongoing support
- Someone to 'do things for them' rather than 'facilitating' or empowering
- Appropriately timed assessment and planning for the future (not too early/ too late, provide it at different times on their cancer journey)

Five main barriers to change were noted by respondents:

1. Culture and confidence of clinical services identifying financial needs
2. Shifting landscape /change fatigue
3. Low on organisational priorities
4. Programme lacking clarity (roles, definitions, processes) and profile (inconsistent awareness)
5. Gaps (e.g. people not eligible for benefits) and inequity (geographical, age and ethnic)

In terms of sustainability, there were some concerns that the service could be more targeted towards those most likely to gain the most benefit.

## 2: Employment

The programme theory, which was developed around employment issues, indicated that there were three key moderating contexts that were amenable to change, and which could make an important impact on the experiences of PABC and their families:

- 1) Survivor Knowledge: of rights and access to support
- 2) Employer Knowledge: rights and responsibilities
- 3) Employer understanding: circumstances of PABC

Some of the mediating contexts are not able to be easily addressed and can limit the potential to help some PABC:

1. **Illness variables:** Treatment and/or illness effects can be variable (good days/bad days) and might have a variable effect on ability to work (possibly over a long period of time)
2. **Employment variables:** Type of employment/organisation could be important in terms of access to flexible times, conditions and types of work, which might align well or poorly with PABCs needs and circumstances

However, the four key programme activities were appropriately targeted in terms of attempting to change the three contexts that are amenable to change:

1. General information about employment rights and employee responsibilities (e.g. Macmillan resources from the Living Well Information Centre)
2. More specific and targeted individual advice, guidance and support, provided by MNH

3. Accreditation of organisations as Cancer Friendly (through MNH). Named individuals in survivor friendly network
4. Events at which employers can be informed about employment issues relating to PABC

The following were considered important aspects of the programme to continue to focus on; things that are working well:

1. It was considered important to effect wide-scale culture change to prevent variation in people's experiences: The survivor friendly network was considered critical for this work.
2. It was also noted that, although PABC might be aware of sources of information and support, they will often need encouragement to access them: Provision and awareness of advice and support services might not be enough in itself. Appropriate first contact could be critical.
3. Generic advice and signposting should be mixed with expertise for very specific or specialised advice and support.
4. The experiences of people affected by cancer were considered important to add authority when talking to employers: It is important to maintain involvement of PABC with appropriate skills and experience of dealing with employers.

The following were considered to be important limitations of these approaches, which could be addressed as the programme develops:

1. Employer events: only suitable for certain types/sizes of organisations
2. Early difficulties identifying people with required skills and experience to engage with employers
3. Likelihood that hard to reach organisations were not being effectively targeted
4. Difficulty addressing mediating contexts: specifically problems for self-employed and people on zero hours contracts

### **3: Information**

There were a number of poor outcomes for PABC related to inadequate information provision including additional stress or fear, risk of physical harm or health problems, which were related to being unprepared for self-care, not knowing who to get solutions from, and difficulties in maintaining an income. The programme is seen as providing reliable, good quality information in contrast to the wide range of doubtful quality information available on the internet.

Communication skills were a strong topic within the 'Information' theme. The following were considered important factors for achieving desired outcomes within the programme:

- Ability to follow a systematic needs assessment; also actively listening and eliciting further information
- Training was recognised as a method for improving communication skills
- Ability to target specific information towards individual needs, rather than providing general and potentially not very useful information
- The facilitator role: helping people to understand what information might be important
- Benefits of information provided by a person with experience of cancer (could ask more questions and a stronger emotional connection).

Early difficulties with programme coherence and organisation were reported. However, whilst difficult to address, these were mostly resolved, but might require ongoing vigilance:

- Difficulties in aligning separate organisational priorities and ways of working
- The branding of the programme and discussions around having a shared website took a long time to resolve
- Onlookers had a view of the programme, which was not coherent with its joined-up, one-stop aspiration

There were a variety of views about what constitutes, or defines a good decision and how to help towards achieving this. A prominent view was: providing adequate information, in order to allow people to make decisions that they think are right for them. There was a tendency towards describing methods of empowerment through information provision. Helping to achieve a person's personal plan was also mentioned.

There were some moderating contexts, which might be amenable to change which are related to professionals' roles:

- Common for patients not to receive adequate information from doctors about their situation
- Professionals not identifying carers for additional support
- Clinical Specialist Nurses: 'overprotective', and do not tend to encourage self-determination
- Doctors: patients expect more involvement and less expectation of self-management

Views on the extent to which these negative contextual factors might be amenable to change varied amongst respondents. Some reported that the programme had little or no influence over the practices of many professionals. However, there were other respondents who drew attention to the work of the programme with GPs, and the activities carried out to increase the number of appropriate referrals from Clinical Specialist Nurses in acute services. A geographical anomaly was reported, whereby GPs outside of Doncaster were reported to be more engaged.

Recommendations:

- Persuading professionals to introduce the idea of survivorship early on, and in the long term, and to spread knowledge about what roles the programme performs
- Whilst the work to raise awareness amongst nurses was reported to be successful to an extent, the need for continued activities was recognised
- Clients entering the information centre also required the services of MNH (would be useful to explore the frequency of these instances and whether functions might be combined, or streamlined)
- It was not clear whether the work with GPs had been successful (process/activity monitoring might be useful for this work-stream)

There were a number of recommendations associated with timing of Interventions:

- Early contact starting at the time of diagnosis was beneficial
- The type of information that people are able to manage at this time is likely to be limited

- The key mechanism seems to involve early contact with limited intervention, but with an understanding that support is available when they are ready
- This will ensure timely access to appropriate services when needed
- Having multiple points in cancer pathways, where different clinicians etc. can introduce survivorship issues and signpost or refer to other services would seem to be a useful approach

Barriers:

- Organisational key performance indicators were considered to not actively encourage client centred interactions
- The programme was reported to have little or no influence over the behaviour of clinicians
- Location of the information centre at the hospice was considered a barrier to access, as the hospice was associated with dying rather than survivorship issues
- Regarding information for Carers: they often did not identify themselves with the role of carer: the term 'family member affected by cancer' was preferred. They were considered to not always be aware of available support services

#### *4 & 6: Health and Wellbeing, and Support*

I-statements 4 and 6 have been reported on together as their contexts, issues and themes were found to overlapping and link during data analysis. The general overall theory for how and why the programme engages with these issues is that promoting wellbeing and providing practical support to PABC can have a positive effect on physical and mental health and help them to live life to the full. This can have implications not only for survivors, but also for their families and friends.

#### *Key programme activities*

Overall, the co-production approach taken by the programme was seen to have influenced the focus on health and wellbeing, rather than medical needs.

The living well information service at St. John's hospice (the Hub) undertakes holistic needs assessments and 'outreach work' to raise awareness of cancer and survivor needs within the community and within health services. The Cancer Buddies peer support service, was intended to address general well-being and support issues by giving PABC access to volunteers with experience of cancer. The key mechanisms held in common for these two approaches to achieve improved outcomes are assumed to be:

- A source of information and reassurance to reduce fear and worry associated with the unknown
- A limited or general source of practical advice, for instance regarding employment and benefits issues
- Signposting to other services, giving awareness and access to a range of services for various specific needs

The cancer buddies service also relies strongly on the following mechanism:

- Somebody empathic to talk to, thereby reducing feelings of loneliness and isolation

The Living Well information service also relied on the following mechanism:

- Contact with health professionals to improve signposting and referral to support services, and educate about the holistic needs of PABC

Meeting New Horizon's service aimed to support PABC with health and well-being issues by:

- Assessing and meeting their practical, social, financial and occupational needs
- Making contact with local sports and leisure facilities, ensuring that organisations were 'survivor aware', and improving access (for instance by arranging preferential payment rates)

### Mediating contexts

The following health, wellbeing and support difficulties can be viewed as mediating contexts, which have an effect on outcomes, but are amenable to change due to programme activities:

1. Communication difficulties between PABC and 'professionals' were felt to exist pre-Programme. It was felt that PABC s were not listened to and often lectured at
2. There was a need for sharing treatment and care plans - between all professionals involved and the PABC themselves
3. Additional needs for holistic follow-up services that 'see the PABC first and the cancer second' and quality health and wellbeing information that educates and explains

### Moderating contexts

Four key contextual pre-programme issues were identified by respondents.

1. Organisational funding and resource constraints; for example, health care professionals were often seen as too busy to address health and wellbeing needs.
2. PABC might not have the financial resources available to address their general wellbeing needs (this links with the employment and money themes)
3. PABC personalities, preferences, attitudes and experiences meant that existing support groups were not felt to be suitable for all.
4. Individual attitudes and psychological needs of those affected by cancer were also felt to impact on health and wellbeing issues.

### Further theory refinements

- Holistic support (emotional, practical, social and occupational) was reported as crucial in being able to facilitate PABC to live their lives to the full.
  - Support to overcome negative emotions and reach acceptance
  - Finding appropriate travel insurance
  - Access to activities to promote wellbeing (e.g. sports, leisure, complimentary therapies, interest groups etc.)
- Honest and open discussions were felt to be important in order to address this I-statement. This worked two ways:
  - Providing PABC with the knowledge and information they required to make informed choices
  - Encouraging PABC to be honest and direct with others (e.g. health professionals, insurance companies etc.)
- The timing of assessment and support was felt by many respondents to be key to this I-statement. Needs were felt to differ according to where the PABC was on their 'cancer journey'. Therefore, monitoring was also felt to be important.

## Recommendations

Respondents felt a person centred holistic needs assessment, with follow-up, monitoring and signposting to other services was essential. The programme theory states how the programme is addressing needs by changing the context and promoting mechanisms of change to achieve relevant specific and general outcomes. The programme continues to improve by extending networks of support, and the theory refinements demonstrate ways that the programme is learning to better address needs for wellbeing and support.

## 5: Carers

### Key programme activities

The programme did not address carer issues specifically. It was felt that all services and support available to the person directly affected by cancer should be available to their carers. The term PABC within the Programme was used to define those with a cancer diagnosis and their carers/friends/family.

### Contextual issues

Prior to the introduction of the programme, there was a carer support infrastructure within Doncaster. However, several moderating contextual issues, which might be amenable to change, were identified:

- Carers not being identified by services
- Specific support needed for carers
- Support already exists but is underutilised

### Recommendations

- Eliciting carers needs:

Despite no specific approaches or work-streams for carers within the programme, their needs were felt to differ from those of the person with a cancer diagnosis. There was felt to be a need for skilled and experienced workers to correctly identify all the carers' needs.

- CNS' do not refer carers in:

Although some lack of 'carer' awareness was thought to contribute; even when nurses are aware of carers and their needs, they do not have time to deal with them appropriately. This indicates that some awareness raising and simple referral systems might be required.

- Carers were often not felt to identify themselves as carers:

Appropriate services for carers were considered to already exist with the Doncaster area. However, family/friends of people affected by cancer are unlikely to self-identify as a carer, and therefore unlikely to seek out these support services.

- Programme and service marketing to carers was felt to require specific thought:

There are some specific difficulties in developing mechanisms to address these outstanding issues from identification (including self-identification), referral/signposting into appropriate first-point services, elicitation of needs, and ongoing access to specific services. An additional complexity is the potentially changing and increasing needs of friends and family as the needs of the person with cancer change.

## 7: Discharge

### Key activities

Key activities within the Programme relating to discharge:

- Awareness raising
- Ensuring widespread use of treatment/discharge summaries
- Building networks, connections and relationships: it was considered beneficial for CNS' to get involved in the programme steering groups, and the professional engagement events to:
  - Raise awareness of the issues/problems being experienced
  - Provide opportunities to creatively problem solve and build trust between organisations and professionals
  - Result in programme staff being invited into the clinical areas by the clinical teams to help talk to patients alongside the clinical teams

### Moderating Contexts

Moderating contextual factors related to improving discharge from secondary care included:

- It was reported that PABCs' and professionals' had lack of awareness of, and difficulty accessing, services after discharge
- It was reported that because PABC had ongoing needs, discharge from health services felt like they were being abandoned
- Problems with communication between secondary and primary care on discharge from specialist services and inpatient care
- Professionals working with PABC had variable awareness of their holistic needs

### Key outcomes

Relationships between acute clinical staff and the survivorship programme were reported to encourage a more, holistic recovery attitude, and encourage collaboration with different providers from outside the acute service before the patient reaches clinical discharge. This can help prevent the abrupt step off, reported by patients and introduce a more holistic handover of support. However, several respondents provided examples of 'discharge failures'. These were situations when PABCs discharge from hospital needs were not met.

### Barriers

Some key barriers to optimal support around discharge from clinical services were identified:

- Responders noted that referrals into the programme were variable. The variance was by clinical teams, cancer types and over time. This was impacting on the demand for different parts of the Programme.
- Internal and external awareness of the Programme and its key organisations was also noted as inconsistent.
- Respondents expressed frustration at the lack of influence they had over NHS discharge procedures, attitudes and associated managers.

### **8: Role of professionals**

The roles of professionals featured prominently in a number of other I-statement sections. Some respondents reported that the programme had little or no influence over the practices of many professionals. However, there were other respondents who drew attention to the work of the programme with GPs, and activities carried out to raise awareness of the programme and increase the number of appropriate referrals from Clinical Nurse Specialists in acute services.

There were a number of professionals' roles that were identified as requiring some modification to improve outcomes for cancer survivors. The extent to which these require modification would need investigation, and most are being addressed to some extent within the programme activities. In some cases these would need to be approached with sensitivity: often limited resources rather than willingness or awareness are the most important barriers. Some of these suggested modifications could be considered to be recommendations as they might be able to be introduced without significant difficulty. However, other issues require careful consideration and might be difficult to implement:

- *All:* Introduce the idea of survivorship early on
- *All:* Identify carers for additional support and signpost to services (e.g. financial)
- *All:* Awareness and attention to holistic needs
- *All:* To get involved in the programme steering groups, and the professional engagement events; building networks, connections and relationships
- *All:* Be involved in creative problem solving and build trust between organisations and other professionals
- *All:* Identify and seek to improve communication difficulties with PABC
- *All:* Sharing treatment/discharge and care plans between all professionals involved and the PABC themselves
- *Doctors:* provide adequate information about the situation of PABC related to further support and self-care
- *Doctors:* more involvement and appropriate/individualised expectations of self-management
- *Clinical Nurse Specialists:* to encourage self-determination

### Incentives

Incentives were discussed in relation to gaining buy-in from professionals and organisations. The Macmillan brand, quality of its training, conferences and work was felt to be incentives to those working with PABC. Other incentives within the NHS were felt to be Key Performance Indicators, audit targets and financial incentives.

### Barriers to change

Key barriers to changing professional roles to further support PABC and join up services were:

- Limited NHS resources
- Incompatible communication systems and processes

## Questionnaire: development and pilot

### PABC Questionnaire

#### *Development*

Work on the PABC questionnaire started in July 2015 and for pragmatic ran concurrently alongside the qualitative data collection. Responding to stakeholder consultation, the questionnaire was based on the Programme's I-statements. Work done by PIRU (2014), suggested I-statements could be measured and this work was used as a foundation for the questionnaire development.

The questionnaire had three iterations. Each draft was amended following feedback from PABC and Programme members.

The first draft was created by reviewing the Programme's eight I-statements and sub-statements and summarising the main headings. Then the following methods were used:

- A 'weighting question was added to assess the relative importance of topics for individual respondents
- Sub-statements that were about current knowledge were removed as the weighting question was collecting this information
- Removed sub-section statements that had similar constructs/concepts within them
- Separated and defined sub-section statements that had more than one construct/concept within them
- Changed misleading I-statements and sub-statements to increase accuracy
- Removed I-statement on carers, as this would be collected using the 'carer' questionnaire
- A question regarding knowledge about involvement in improving cancer services was added as this was important to Programme members and the Programme's sustainability
- Gathered I-statement sub-sections focusing on the individual's perspectives and experiences of services and professionals to create a separate section as this was a stakeholder priority
- Moved some sub-section questions into more relevant sections
- Questions were weighted so the responder could indicate how much help had been required and this could be matched to their point on their cancer journey

Appendix iii shows which I-statement (and sub statement) relates to which question of the questionnaire.

#### *Methods*

Questionnaire packs were sent to 24 PABC. These potential participants were selected purposively to represent users of the Information Hub, MNH and Cancer Buddies by members of the survivorship programme and so were not a random sample. The questionnaire packs consisted of the questionnaire, a personalised covering letter, pre-paid reply envelope and participant information sheet.

## Feedback

**Iteration 1:** Work on this was completed in August 2015. It was sent electronically to representatives from all the key stakeholder organisations (LW, MNH, CB, DMBC, DBH, RDaSH, DCCG, Programme strategic group). It was sent electronically and provided in person to PABC. Stakeholders were asked to review the questionnaire and comment and the PABC were asked to comment after completing it. The following seven questions were asked:

1. Terminology – do you feel the terms used are meaningful and acceptable
2. Do you feel the questions are relevant and relate to people's experiences?
3. What are your thoughts on the way we are asking the questions
4. Are the questions specific enough? For example, should we be asking where people are getting support from specifically etc
5. Your views on the questionnaire's length
6. What are the priority questions if we need to cut it down?
7. Any other comments?

Feedback was obtained from 5/9 PABC and 6/10 stakeholders across all organisations, and the second iteration drafted.

**Iteration 2:** Feedback on the second draft was received from 13/24 PABC between December 2015 and February 2015. All had been sent the questionnaire, asked to complete and return it replying to the same additional seven feedback questions used previously. 12 completed the questionnaires and returned feedback. One respondent did not complete the questionnaire as they felt it did not relate to their experiences, but provided telephone feedback.

One 'carer' had been sent the questionnaire in error. They did not feel they could comment, but offered to be of assistance in reviewing the 'carer' questionnaire.

The PABC feedback is summarised below in Table 5 and was used to re-draft the questionnaire and to create the third iteration.

Iteration 3: This draft was used as the basis for the carer questionnaire in January 2016

**Table 5: PABC feedback for iteration 2 of the PABC questionnaires**

Overall feedback (total responders n=13 PABC )	Additional comments	
92% felt terminology was appropriate	/	/
77% felt the questions were relevant.	Some questions did not relate to my experience. Some questions too long.	I don't know
77% were happy with the way questions were asked	Some appear relevant, others not	Could be made simpler
77% felt questions were specific enough	/	/
77% felt the questionnaire length was appropriate	/	/
Suggested priority questions came from 3/13 responders	<ul style="list-style-type: none"> <li>• feelings of each individual</li> <li>• support they should be receiving</li> </ul>	

- information provided and needed
- help and support during and after treatment
- help after cancer

DRAFT for Authorisation

## Findings

Once the initial piloting and development work was completed, 24 questionnaires were sent out and 18 people completed and returned their questionnaire. This is a response rate of 75%.

### Respondents Characteristics (n=18)

Of the 18 respondents, all but one were white in ethnic background (one respondent identified as Asian/Asian British). Eight were women and 7 were men, with one responder not stating their gender (Fig. 2). All were aged 41-80 (Fig. 3).

Respondents were asked about their current situation regarding their clinical cancer experience. Three respondents were receiving treatment and another service, so ticked more than one box.

Geographically, there were no respondents from the D1 (city centre) post code area. However, there were responses from all the areas directly surrounding the city. There were no responses East or North of DN8.

Figure 2: Respondents' Gender

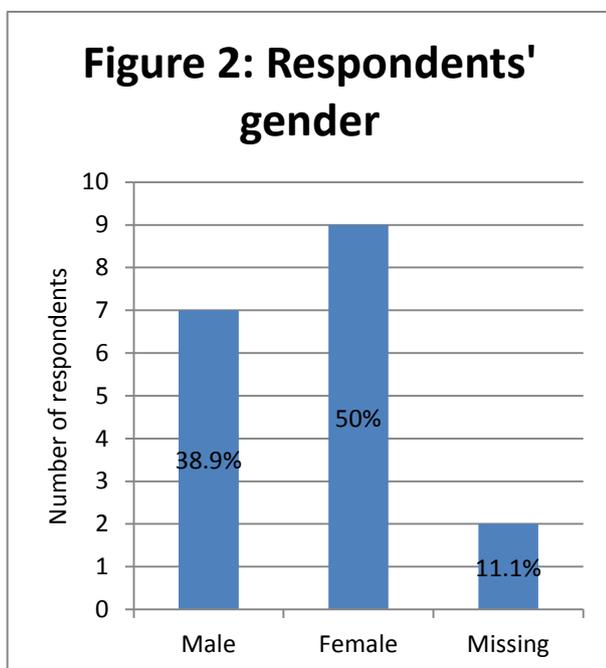


Figure 3: Respondents' age group

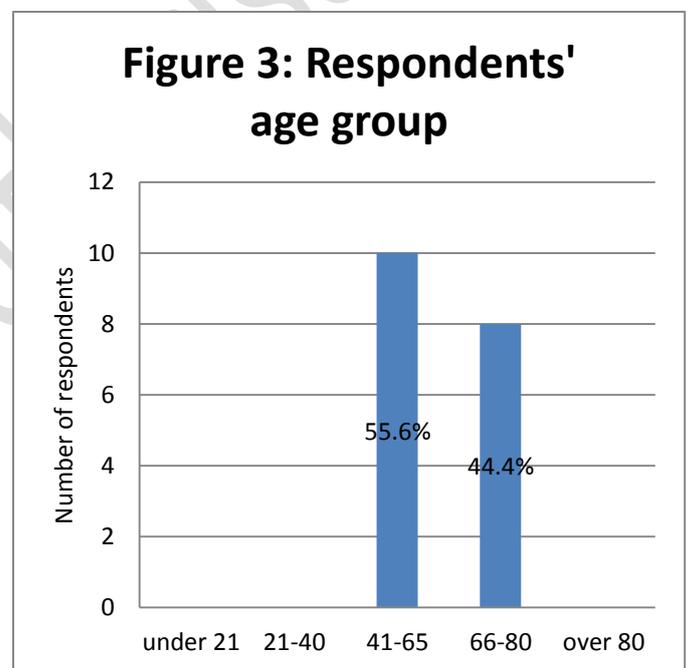


Figure 4: Respondents' postcodes

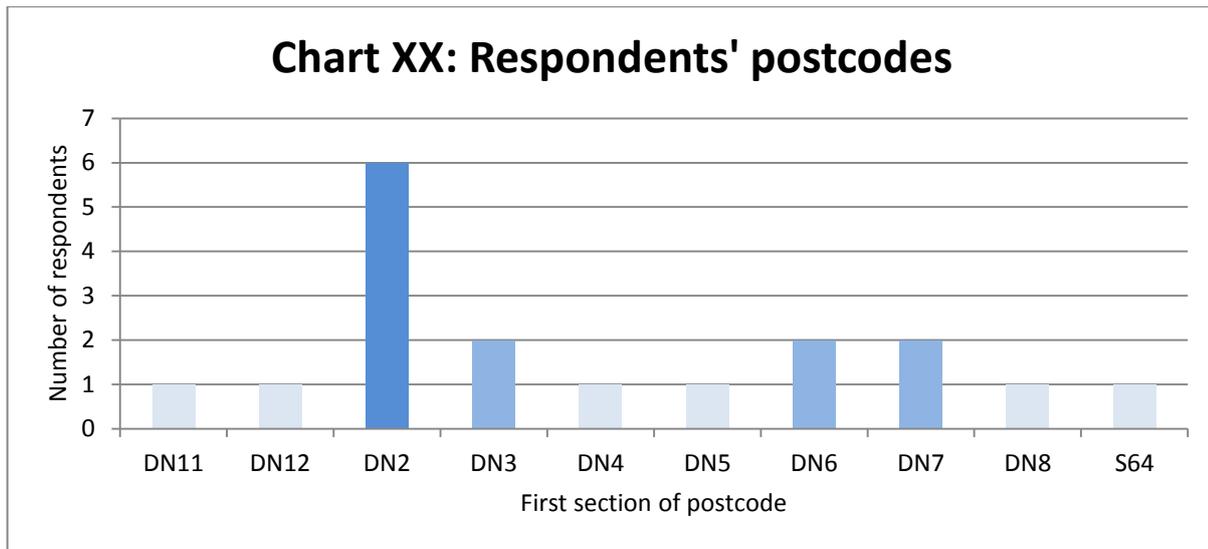
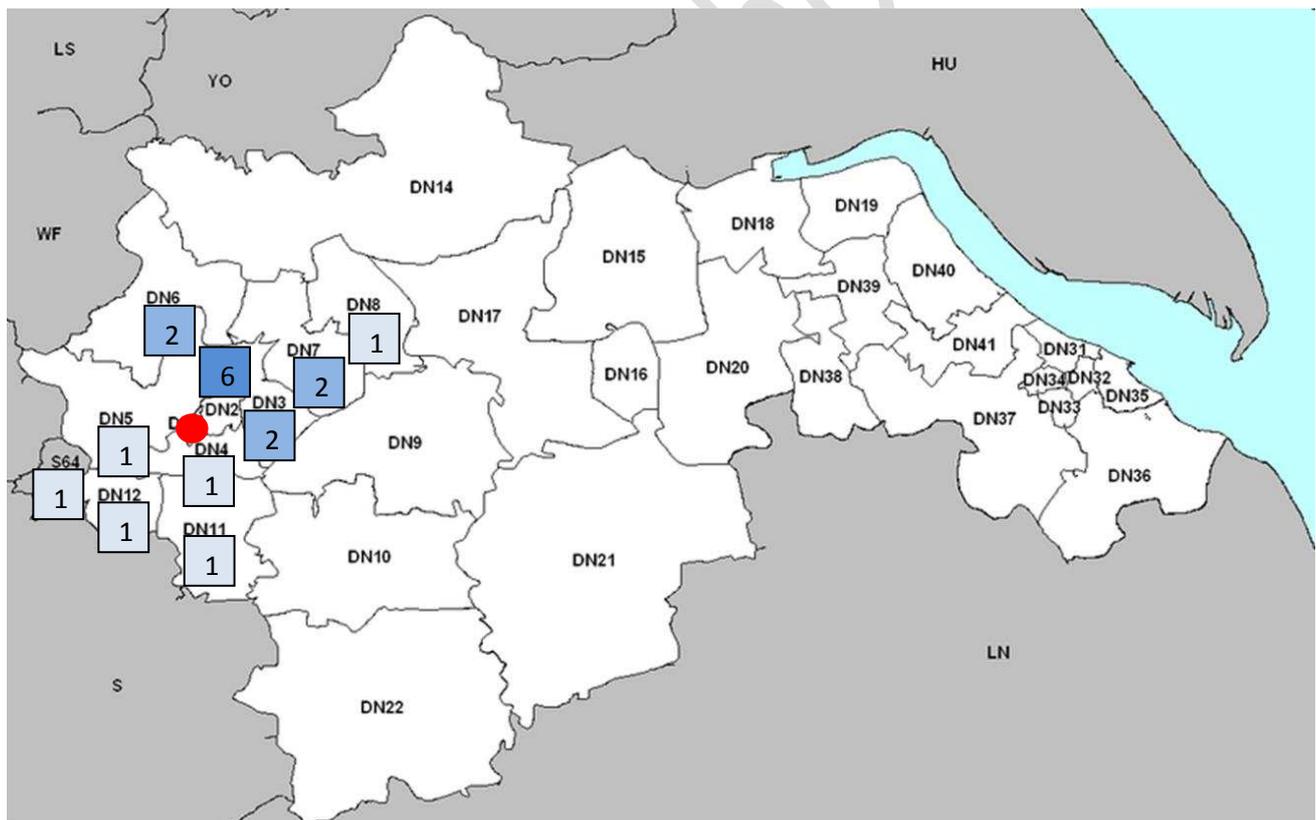
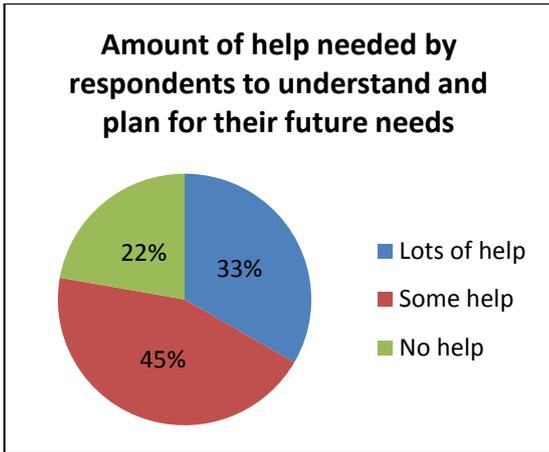


Figure 5: Pictorial representation the number of respondents per post code area



City Centre = ●





#### Mean responses

- I got the amount of help I needed = 1.5
- My carers know where to get information = 1.8
- Information required to make right choices was given the way I wanted = 1.35

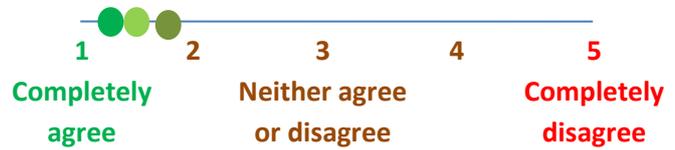
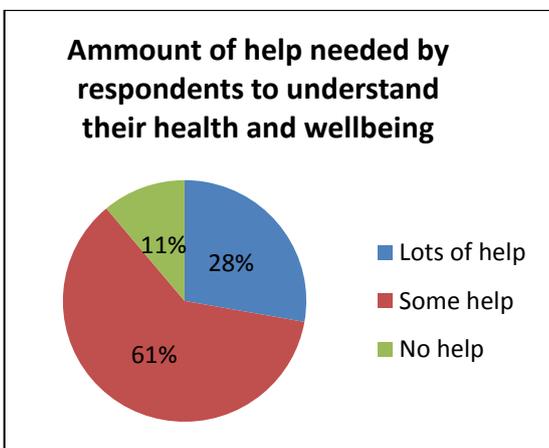


Figure 9: Questionnaire Responses, Health and wellbeing



#### Mean responses

- My needs are listened to, talked through and understood = 1.22
- I can have my say when planning treatment and support = 1.33

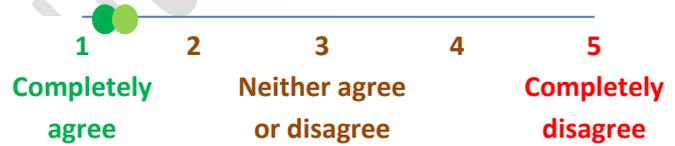
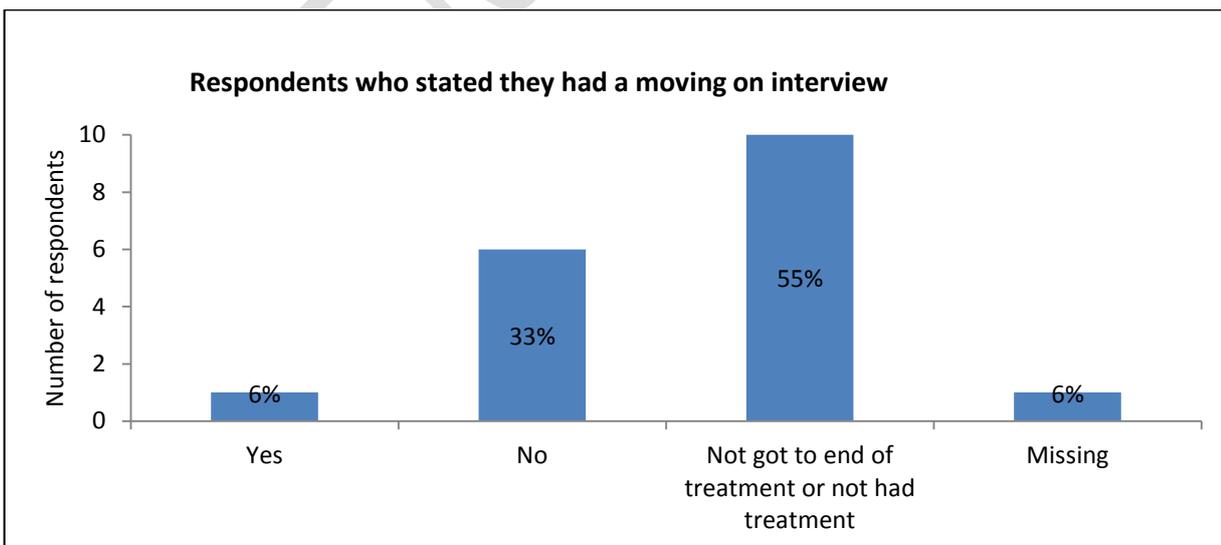


Figure 10: Respondents with moving on interview



The following table shows the numbers of respondents who stated they were given a written record and plan of their medical and non-medical needs at key-stages:

**Table 6: Written records and plans**

	<b>Number of respondents</b>	<b>Percentage %</b>
<b>Yes</b>	12	66.7
<b>No</b>	6	33.3

The following table shows the numbers of respondents who stated they were given a list of things to do to return to a fulfilling life:

**Table 7: List for return to fulfilling life**

	<b>Number of respondents</b>	<b>Percent %</b>
<b>Yes</b>	10	55.6
<b>No</b>	7	38.9
<b>Missing</b>	1	5.6

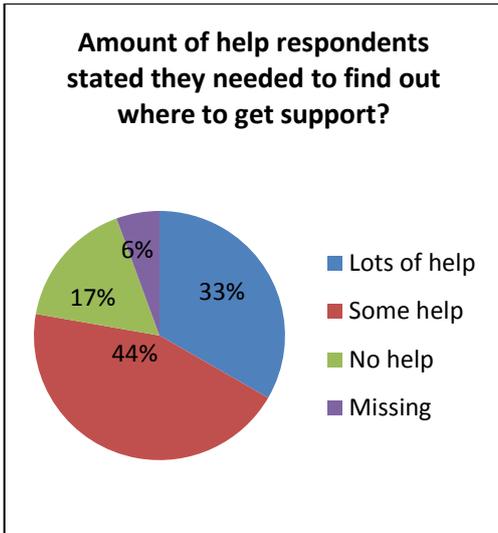
The following table shows the numbers of respondents who stated they were given information about how they could help to improve cancer services:

**Table 8: Information on how to help improve services**

	<b>Number of respondents</b>	<b>Percentage %</b>
<b>Yes</b>	9	50.0
<b>No</b>	9	50.0

I-statement 6: Support

**Figure 11: Amount of help needed, Support**



**Mean responses**

● I was helped to understand what support is available from professionals and others = 1.46

● I was helped to feel confident about getting support = 1.5

● I was helped to get support close to home = 2.42

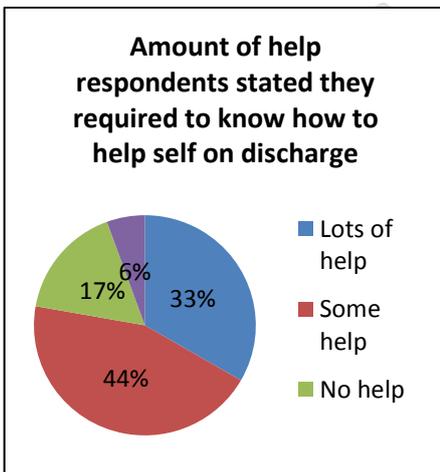


The following table shows the numbers of respondents who stated they had a written plan to help them understand where they could get support from before the end of their treatment.

Table 9: Written plan for support

	Number of respondents	Percentage %
Yes	4	22.2
No	5	27.8
Not got to end of treatment	9	50.0

Figure 12: Questionnaire Responses, Discharge



**Mean responses**

● I feel all members of my support team treat me like an individual = 1.1

● My support team talk to each other and know all about me = 2.15

● I know when and how to get practical help = 2.0

● I know when and how to get help form my GP = 2.2

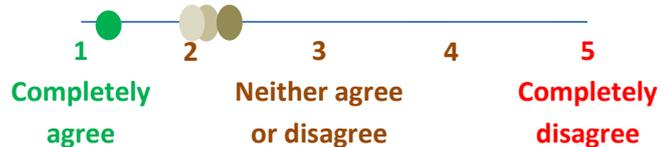


Table 10: Questionnaire Responses, Role of Professionals

Sub I -statement	Average (mean) of agreement
Supported by a team of people who work as one team	1.47
Support team ensure I get care and support I need to lead healthy life as possible	1.53
I usually see same members of my support team?	1.65
I am certain GP knows everything they need about my cancer treatment and care and knows how to support me	1.83
Other health professionals I meet understand my needs as a person affected by cancer and look out for signs of its return	2.0
All members of my support team treat me like an individual	1.11

Table 10 above shows the responses for each sub I-statement question (the nearer the mean is to 1, the more agreement with sub statement there is).

The following table shows the numbers of respondents who stated they received a written plan of medical and non-medical needs at key stages of their journey:

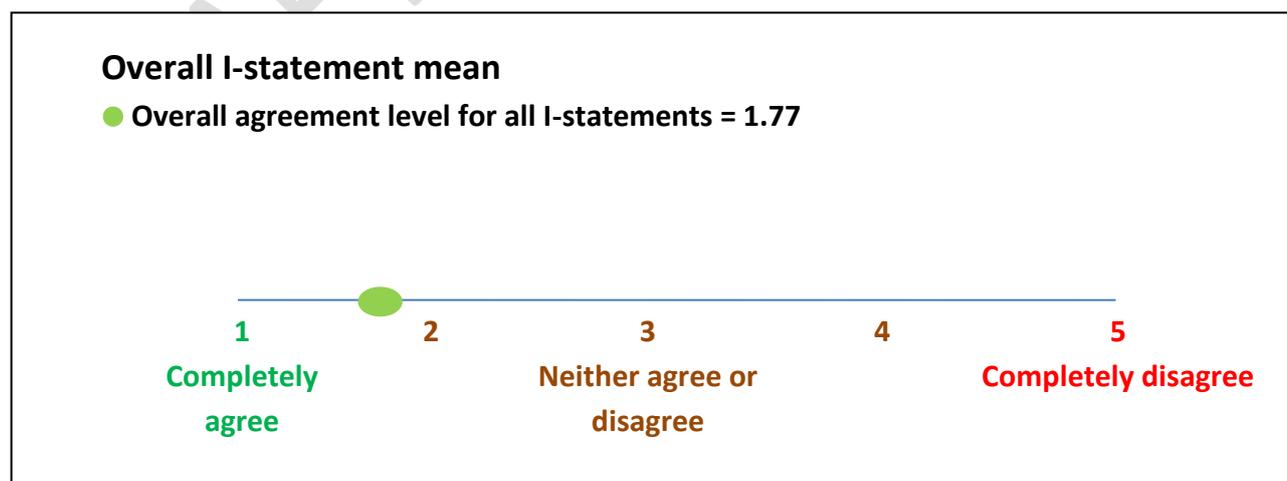
Table 11: Respondents receiving a written plan

	Number of responders	Percentage %
Yes	12	66.7
No	6	33.3

### Overall I-statements

The overall I-statement mean is 1.77. This is the average level of respondent agreement with all eight I-statement sub statements.

Figure 13: Questionnaire Responses, overall I-Statement level of agreement



## *Summary of Findings*

Respondents were at least 50% female, and aged between 41 and 80. 55% were between 41 and 65. The majority were from the DN2 postcode area. There was no representation from the North and East of the region. If conducted on a larger scale, the questionnaire would demonstrate the reach of the programme and indicate geographical gaps in service provision. 78% needed some or lots of help with issues related to money and agreement with ability to get clear and complete advice was good (1.5). Whilst only 33% needed some or lots of help regarding employment, for 56% this was not applicable. Agreement that employers understand their rights was low (2.0), and very low when asked if they had been helped to make a return to work plan (4.5). However, this anomaly is probably due to the high number of N/A responses, which should be removed for future calculations.

78% of respondents needed some or lots of help to understand and plan for future needs. The lowest scoring item in terms of agreement was related to carers knowing where to get information (1.8). 89% needed help to understand their health and wellbeing, and agreement with the individual statements was good (1.22 & 1.33). Only 6% of respondents had received a moving on interview, 33% of respondents reported not receiving a moving on interview, a further 55% had not reached the end of their treatment. One third of respondents were not given a written record and plan of medical and non-medical needs at key stages. 39% were not given a list of things to do to return to a fulfilling life. Exactly half of the respondents received information on how to help improve services.

77% needed some or lots of help to find out where to get support. There was an outlying result for the statement regarding being able to get support close to home (2.42). This is somewhat unexpected, particularly regarding the close geographical proximity of respondents to the city centre. It might be expected that if respondents had been from further afield, this would have further skewed the results towards dissatisfaction with this statement. Concerning respondents who reported receiving a written plan to understand where to get support before the end of their treatment; 50% reported not reaching the end of treatment, 22% had received a plan, and 28% had not.

77% reported requiring some or lots of help to know how to help themselves on discharge. Greatest disagreement was with statements related to support team talking to each other and knowing about the respondent (2.15), and knowing when and how to get support from GPs. Regarding the roles of professionals, the lowest agreement was for the statement related to other health professionals understanding the needs of the person affected by cancer and looking out for signs of its return.

The overall level of agreement with the statements was 1.77. This figure could be used as a crude measure to benchmark services. However, the detailed breakdown indicates areas which are working well and others which could benefit from efforts for improvement.

Apart from the theme concerning employment, those requiring a lot of help were fairly consistent and ranged from 28%-33%. Those not needing any help with specific topics ranged from 11% (health and wellbeing, employment) to 17% (discharge and support), and 22% (money, information).

## Conclusions

The questionnaire can be used as a tool to indicate the relative importance of I-Statement topics for respondents. When disaggregated to areas of service provision, findings can therefore be used to ensure

that the correct populations are being targeted with appropriate interventions. The level of agreement or disagreement with statements can be used as a monitoring and service improvement tool, which can indicate specific areas of improvement matched to the I-Statements.

### Analysis Comments and considerations

Several features of the analysis are of interest regarding the PABC questionnaire design.

- A large number of respondents indicated that employment support was not applicable for them. Owing to the very small remaining sample size, it was not considered useful to remove these respondents from calculations for items related to employment. However, this is recommended for wider use.
- 3/18 (16.6%) of respondents ticked more than one box when asked to identify what their current clinical situation was. All three of these respondents were having treatment in addition to another clinical situation.
  - Recommendation: identify if these data are required from future questionnaires, and redesign options.
- The questionnaire attempted to identify which services were felt most relevant to which question. However, despite clear instructions to tick just one box, respondents often ticked more than one. The data suggests a cause for this. It appears that support is being received 'across the board' - from all services for all I-statements.

There were obvious peaks, but due to the multiple responses noted and the low numbers of responders for the pilot, results have to be interpreted with caution. Peaks were noted in I-statement 1: money, 6: support and 7: discharge. I-statement 1 had a large proportion of respondents receiving support from MNH. LW also provided support, but it was approximately half that of MNH. Within I-statements 6 and 7, Consultants, CNS's and MNH appear to have been key. But again, it is important to note that the data suggests all services contributed, including GP's, Macmillan and the 'hospital'.

- Recommendation: identify if these data are required from future questionnaires. Adjust analysis methods to cope with multiple responses for services.
- When exploring the average agreement scores for I-statements per respondents, a lower agreement score appear associated with men. (Men=1.87 and women = 1.4). This may warrant further investigation. Due to the small sample used for the pilot questionnaire the statistical significance of this was not investigated.
  - Recommendation: Consider if any differences between men and women are worth investigating with a larger sample.

### 'Carer' Questionnaire

#### *Development and methods*

A 'carers' questionnaire was felt necessary, as most of the I-statements were not directly related to the carer experience.

Work on the 'Carer' questionnaire started on January 2016. It has had two iterations. Carer feedback was obtained on the first draft which informed the second. The carer questionnaire has currently not been piloted for data collection.

The questionnaire's structure was informed by the 3rd iteration of the PABC questionnaire. The content was informed by the following:

- *I-statements 1(money) and 5 (carers)*

These related directly to the carer experience.

- *Provisional qualitative findings*

These suggested it was important to establish if the carer was 'caring' for people not affected by cancer, which they lived with and their relationship to the person directly affected by cancer. These findings also suggested that it was important to obtain data on whether they viewed themselves as carers.

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- *Inclusion of the Carer Experience Scale (CES)*

This was devised to be a measure of care-related utility. It was developed in the UK using a meta-ethnography and semi-structured interviews with carers of older people. It was used as exploratory work, as it was devised for use with 'older' people specifically, but it does not rule out use with a younger population (Al-Janabi et al 2011).

### **Feedback**

The 'carer' questionnaire was sent electronically to two 'carer's' of PABC who had offered assistance to the evaluation team following PABC questionnaire development. Both completed the questionnaire and provided detailed feedback to the seven feedback questions used previously. Their comments can be seen in table 12 below:

**Table 12: Feedback for iteration 2 of the 'Carer' questionnaires**

Feedback question	Carer comments (responders n=2)
<b>Terminology?</b>	<ul style="list-style-type: none"> <li>• easy to understand</li> <li>• give the carer some options when answering the support questions, as they may not know what support is available</li> <li>• overall OK</li> <li>• found money question and impact on your life question unclear</li> </ul>
<b>Are questions relevant?</b>	<ul style="list-style-type: none"> <li>• the 'is there anything else you would like to tell us' box could give some examples of things which have caused stress and anxiety to the carer.</li> <li>• need to give opportunity to state the positives</li> <li>• overall felt that questions were relevant</li> </ul>
<b>How questions were asked?</b>	<ul style="list-style-type: none"> <li>• questionnaire's short length may improve response rate</li> <li>• unsure how answers will create change</li> <li>• comments that the CES section should be re-worded</li> <li>• overall OK</li> <li>• comment that the CES should have a different tense</li> </ul>
<b>Are questions specific enough?</b>	<ul style="list-style-type: none"> <li>• yes</li> </ul>
<b>Questionnaire's length</b>	<ul style="list-style-type: none"> <li>• just right</li> <li>• impact on your life question to long</li> </ul>

DRAFT for Authorisation

## Economic Analysis

### Scope of the Analysis

The evaluation of the economic impact of the Survivorship programme considers those costs and benefits that can be measured and valued. In principle an economic evaluation should consider the costs and benefits to all stakeholders affected by the intervention under consideration irrespective of whether they are 'cashable' or not. The evaluation has attempted to do this as far as the data allow. However, available data in some areas are problematic and the very nature of the benefits of a programme intended to address individual needs and promote the wellbeing of people surviving cancer makes valuation difficult.

Ongoing changes in the design of the programme and the relatively short period of implementation completed so far also mean that any conclusions about long term sustainability and value for money can only be tentative. Critically, the establishment of measurable target outcomes for the coming years should be pursued to inform further evaluation. In view of these limitations a major purpose of this evaluation has been to develop a model that can be adapted to assess future outcomes and to identify the data requirements for using the model in monitoring the ongoing progress of the programme.

### Methods

The economic evaluation was initially based on an approach set out in the HM Treasury/New Economy Cost Benefit Analysis (CBA) Guidance for Local Partnerships (HM Treasury, 2014). The method involves the development of a business as usual (BAU) model and a new delivery model (NDM) combined with assumptions about causal links between programme activities and comparable outcomes. The comparison between these two models can then be used to indicate economic outcomes of the programme of change including public value, benefit cost ratio, financial returns and budget impacts.

In practice, there were areas where the approach was straightforward to apply. However, there were also some significant difficulties resulting in incomplete models and limited access to data required to make calculations. We feel this demonstrates important learning for further implementation or sustainability of this or similar programmes.

One of the collaborating partners (Meeting New Horizons) has an organisational approach to assessing the economic benefit of their interventions, which is based on the New Economy benefit assumptions. However, this approach measures counterfactual cost prevention incidents and applies national-level fixed financial values to each incident. This approach is presented here, with some additional data and recommendations regarding interpretation of the results and requirements for further evaluation.

### Findings

Key gaps in the economic data were lack of economic data for the business as usual model (i.e. the situation prior to implementation of the programme), lack of benchmarked benefits data and difficulty establishing details of programme spending for the St John's Hospice/Living well information service.

#### *Living well information service*

The Living Well Information Service is based at St John's Hospice, and is intended as a contact hub to provide general information and to refer on to more specialist advice and support services. Before the survivorship programme, the Information service worked in a very different way and recorded service user contacts, which included health promotion interventions in the community. They also accepted referrals for non-

cancer patients, but from April 2015 this changed. Some new referral pathways were established and others were discontinued.

These significant changes meant that difficulties were experienced in establishing a useful business as usual service model, and seeking comparable outcomes with an equivalent user group. Therefore, an alternative approach to the planned cost benefit analysis was required. Difficulties in valuing comparative benefits of the service, but ease in counting process outcomes lends itself to cost effectiveness analysis, which is the approach that was taken.

Actual spend (Macmillan) was £69,000 for the enhanced service over the life of the programme, with approximately £1,000 per annum in-kind costs for line management and room hire. This equates to approximately £19,400 per annum. Referrals for the first three quarters of 2015 are shown below. Over this period approximately 34 referrals per month had received a DS 1500, which allows special provisions for benefit claims for the terminally ill. However, this was reported to be a feature that was actively managed in order to attempt to increase referrals for people without DS 1500 status who might be expected to survive cancer over a longer term.

**Table 13: Living Well Information Service Referrals for 2015 (Q1-Q3)**

	Referrals in	Referrals out	R. out as % of R. in
<b>Q1</b>	213	151	70.9
<b>Q2</b>	359	274	76.3
<b>Q3</b>	226	146	64.6
<b>Quarterly Mean</b>	266	190	71.6
<b>Monthly Mean</b>	88.6	63.4	71.6

In order to estimate the cost effectiveness of the service, costs were based on the additional contribution from Macmillan and in-kind costs mentioned above, which have been assumed as the present value (PV) of costs for the service. A projection of annual referrals into the service is based on the rates for the first three quarters of 2015 to give the present value of the number of referrals. Cost effectiveness was estimated over a one year period by dividing the present value of the number of people referred by the present value of costs. The cost per referral into the service is estimated at £18.23. If it is assumed that each referral takes half an hour of consultation: when compared to a similar type of service (e.g. Primary care counselling services at £26 per half-hour), the service appears to be relatively cost effective.

**Table 14: Cost effectiveness of referral into the Living Well service**

<b>PV of Costs</b>	<b>£19,400</b>
<b>PV of Referrals</b>	1,064
<b>Cost per referred service user</b>	£18.23

The annual referrals into the service equate to just over half of estimated annual incidences of cancer diagnoses in the borough of Doncaster (53.8%), and about 10% of the estimated number of cancer survivors (approximately 10,500).

A key limitation of this analysis is that we were unable to gather detailed data about the breakdown of costs for the service, but instead relied on gross measures of enhanced funding and some in-kind costs. Additionally, there have been significant changes to the type of work carried out, characteristics of service users and referral routes, which is likely to continue to change and might alter the effectiveness of the service and therefore the ability of this analysis to accurately predict future cost effectiveness. Another key limitation is that no information about the type or quality of intervention is included: each referral is assumed to have equivalent and unchanging value attached to the subsequent intervention.

### **Recommendations**

In order to carry out a cost benefit analysis, further investigation is required to establish a method to ascribe value to the results of referrals into the service (e.g. time spent with clients, number and type of actions taken on their behalf etc).

As effective referral onwards is vital to the success of the programme, it is important that referral-on costs are accurately identified. Ideally this would be by a detailed breakdown of referral destinations and reasons, with analysis of the costs of supporting agencies for these service users. However, in many cases this might not be possible, in which case a ready reckoner approach should be used.

In addition, some specific, measurable, appropriate outcome measures for clients that can realistically be influenced by the service within a defined timeframe would benefit ongoing evaluation and monitoring.

### **Meeting New Horizons**

Meeting New Horizons in Doncaster provide home visits offering support, information and advice. This includes financial assessments, benefits claiming advice, and signposting to other services. They also provide training and resources to organisations, that can be accredited as 'survivor friendly' organisations.

The organisation's in-house approach to CBA demonstrated cost savings related to 1) Housing (through services and support related to eviction, homelessness, and housing benefits) 2) Social Services (through intermediate care, family support workers and social workers) and 3) Health (through services for depression/anxiety and GP prescriptions). The CBA total for early December 2012 showed a value of £104,452.46 overall cost savings. However, project costs and number of volunteer hours do not appear to be included. These are critical to calculate the costs against which benefits are compared.

When the project costs are included in the model (at £226,000, Macmillan spend) the public value for money benefit cost ratio is less than one (0.46), which might indicate that the project costs more than it has achieved and is therefore not economically beneficial. However, these figures and underlying assumptions had not been validated with MNH at the time of this report publication, and therefore could be subject to adjustment. In addition, this would be a hasty conclusion to draw for a relatively new service model and there is significant uncertainty around the completeness of the figures in the current model. Further work is required to ensure that, for instance:

- Project cost estimates are accurate

- Timelines for cost and benefit calculations are aligned
- Risk and sensitivity tests are undertaken
- All benefits are appropriately accounted for
- Qualitative evidence is considered
- Strategic contribution is considered (e.g. improved reach, equality of access etc)
- One-off, capital costs are offset against projected benefits
- Projected increases in benefit realisation through project maturity are estimated

Our analysis identified additional in-kind costs of approximately £33,600 per annum, largely for volunteer training time and administration, which were not included in the model. Whilst these are opportunity costs for the programme, they could be considered as fiscal benefits for statutory organisations; for instance if an alternative to this service was for replacement services to be implemented. Therefore, a cost savings approach comparing the cost of volunteer activities to equivalent statutory services might be preferred.

The advantage of the counterfactual activity reporting approach used by MNH is that the spreadsheet can be regularly updated to demonstrate the current programme costs and benefits. Limitations of the approach are that: it can provide a narrow scope to the types of economic values included in the model; project timeframes and capital costs are not considered (thus payback periods are not calculated); it relies on assumptions about cost savings made by avoiding access to other services, and does not account for deadweight (i.e. costs and benefits that would have occurred anyway, without the programme).

A key component of the MNH intervention is the accreditation of cancer friendly organisations (>25). The benefits derived from this type of activity are problematic to measure. Perhaps the greatest benefits are related to cultural shifts in awareness and understanding across the locality, which can be slow to take hold, but can potentially provide significant improvements for large numbers of people. Our qualitative investigation and literature review indicate that resolving employment and financial issues following a diagnosis of cancer are key to reducing stress and promoting wellbeing.

The caution advised by the authors of the Treasury Guidance should be considered particularly relevant in this case: “CBA is not an exact science and its outputs are a guide to decision-making not a substitute for thought” (p.11).

### Recommendations

The further work, outlined above, will be required in order to have confidence in, and accurately interpret the economic situation in relation to the work of MNH with individuals.

The work that MNH carries out with organisations has value that is difficult to measure, but is addressing a known and serious problem for cancer survivors. In terms of the organisation’s own value for money analysis, the benefits of this work do not appear to be calculated. Therefore, the costs of both strands of work are calculated against the benefits derived from working with individuals only.

A possible solution for the purposes of future economic analysis would be to treat the individual advice and support work as a separate project to the cancer friendly organisations work. With the understanding that benefits derived from the work with organisations will be difficult to measure, and process outcomes might be all that is possible to quantify. A comparative case study approach for accredited and non-accredited organisations might provide qualitative evidence of benefits.

## Cancer Buddies

Cancer Buddies provide 1 to 1 emotional peer support to both those who have received a diagnosis and their family / friends. It was launched on March 6th 2014. A principal feature of the Cancer Buddies element of the programme is that no similar service existed prior to the programme. Therefore, there is no business as usual model cost. There are also difficulties in identifying pre-existing outcomes that can be observed to change. Therefore, a cost benefit analysis (CBA) was not considered feasible within the limitations of the study. Some different approaches were investigated and recommendations for possible future CBA are offered below. However, a cost effectiveness analysis was carried out.

The following table details project costs for the new delivery model. The total includes only annual costs. However, in addition to these costs, one-off costs will need to be repeated at intervals in order to provide training to refresh volunteers, and should be included in the model. However, this is an operational matter, which will be informed by experience of trainee throughput and strategic decisions regarding maintaining the preferred size of the project. Therefore, it was too early to assess attrition of trainees in order to include these costs in the model.

Table 15: Cancer Buddies Project costs

Description of cost	Data description & Confidence	Time period	Source	Total
Macmillan funding	Practitioner monitored costs (CG3) (includes training costs)	programme start - may 2015	Macmillan (actual spend, rather than contracted spend)	£9,400
<b>In kind costs</b>				
DBMC funding, Phones, admin In kind costs	Practitioner monitored costs (CG3)	programme start - may 2015	DBMC	£1,500
volunteer time (for training - 2 days face to face, 0.5 day on line) One off training for 16 volunteers	17.5 hours per person training (CG 3) X £11.75 =£205.63/person	One off		£3,290
Volunteer training travel and parking	4 trips @ £5.00 (CG6) £20 per person	One off	Volunteer	£320
Mobile phones (donated)	X 10 approximate cost (CG5)	One off	DMBC/TESCO	£250
Time from DBMC in kind costs	Formal service delivery contract costs (CG2). Half salary grade 7 (£21,000	Annual	DBMC	£10,500

	pro rata pa)			
Volunteer time (for buddying)	£11.57 per hour, 2 hours per month for 22 volunteers over 12 months (CG3, Practitioner monitored)	Annual		£6,109
Training venue hire	1 day a month= 48 months (£108 per day based on DMBC prices) = 48x£108 = £5184 (CG6)	Annual	DBMC	£1,296
Training time for volunteers Macmillan trainer 2 full days every six months	4 days/year @ £90/day (CG3)	Annual	Macmillan	£360
Admin staff time (2 hours per week) DMBC in kind	Full salary is £16,000, approx £8.80 per hour) 104 hours x 8.8 (CG4)	Annual	DBMC	£915
Supervision/mentoring costs	Salary (AFC band 6, 2 hours per week) £31,072 fte pro rata (approx £17 per hour) (CG4)	Annual	DBMC	£1,768
Support from public health	Salary (AFC band 5, top of scale, 2 hrs per week) £28,180 fte pro rata (approx £15.5 per hour) (CG4)	Annual	RDaSH	£1,612
<b>TOTAL ANNUAL COSTS</b>				<b>£22,640</b>

As we were able to obtain fairly detailed project cost information, this was used to estimate total project costs, rather than the level of project funding. The evaluators were unable to obtain up to date project activity data. Therefore, the cost effectiveness assumptions are made using projections derived from the quarterly report for 1<sup>st</sup> July to 30<sup>th</sup> September 2014, which is summarised below:

- Number of buddies signed up= 49
- Number of referrals= 73
- Buddies with clients= 22
- Buddies not presently allocated a client= 5

- Buddies awaiting training= 18
- Clients presently with Buddies= 37
- Mean clients per Buddy= 1.7

**Table 16: Breakdown of Buddies by Organisation**

Macmillan	Aurora	NHS	DMBC	Other
1	2	1	14	31

By the end of the following quarter (31<sup>st</sup> December 2014), 2 more clients (39) were receiving support from a buddy; 27 had received support, but it was no longer needed; and 5 had died. The number of Buddies (at 49) remained static being the same at 10 months as at 6 months.

The mean clients per Buddy (1.7) can be projected to estimate maximum capacity at this intensity for all signed-up buddies: 49 active Buddies x 1.7= 83 clients at any one time.

Attrition of clients can also be projected: 32 clients either die or no longer require the service after 10 months. This equates to 38 referrals per annum required to maintain a level of approximately 38 clients at any one time. This 1:1 ratio indicates that whatever the number of clients considered optimal for the service, approximately the same number will need to be referred in to the service on an annual basis. Using this assumption, the number of clients accessing the service over one year will be roughly double the mean of active clients during that year.

There is no information at this stage relating to attrition of volunteer Buddies. As mentioned above, this will have an economic impact on the service regarding the costs associated with recruitment, induction, initial training and one-off costs. Once the project has matured and this figure becomes stable, it can be added to the annual project maintenance costs.

The comprehensive economic cost for running the Cancer Buddies project over 12 months is £22,640, which resulted in 22 active buddies (at 7 months). This represents a cost effectiveness of £1,029 per active Buddy. Assuming all of the signed up Buddies (49) became active within this timeframe the costs increase to £30,057, but cost effectiveness increases to £613 per active Buddy. Much of the revenue cost is fixed and therefore would not increase with increased project activity: increased activity would increase the cost effectiveness, thereby lowering the cost per active Buddy. However, scaling-up could ultimately demand a step up in revenue costs at a certain point, in order to successfully manage a larger project.

Once all Buddies are trained, and the service is running at higher capacity, using the assumptions made above, around 166 clients a year will access the service. This represents a cost effectiveness of £136.40 per client paired with a Buddy. As above, increasing the number of buddies and/or the average number of clients each is in contact with will decrease this cost.

This analysis needs to be interpreted with caution as no up-to-date performance figures were available. However, the model could be used with more recent figures to provide a more accurate picture of cost effectiveness.

Another note of caution for the interpretation of the cost effectiveness of the Cancer Buddies service is related to the attribution of costs to the various collaborative organisations. This comprehensive economic analysis includes costs related to a number of organisations and individuals (Macmillan, DMBC, RDASH, volunteers). The costs are spread across stakeholders and are likely to be valued differently by each stakeholder group. The multiple stakeholders also create difficulties in defining in-kind costs. It could be considered that there is not one dominant organisation responsible for the project, and no organisations are being billed for the activities of another. Therefore whilst various organisations and individuals are contributing to the project, all costs related to the project as a whole could be considered in-kind.

For the purposes of future cost benefit analysis it should be considered that any realised benefits would relate differently to each stakeholder group, providing a mixed picture of returns on investments.

### Recommendations

In order to establish outcome measures that could be used to determine benefits, qualitative work with clients to establish counterfactual data would be beneficial. This would establish what course of action might be likely if the Buddies service was not available or not being effective, and therefore highlight preventative benefits. For instance, might clients be likely to seek consultations with health care professionals (GP, consultant, cancer specialist nurse etc), would their wellbeing be affected, might they suffer mental health problems (e.g. anxiety, depression), would they contact other agencies etc?

As the number of clients is probably too small to detect organisational or local population level benefits, evaluation would need to concentrate on gathering data directly from clients. This could be done using pre-post measures, such as health related quality of life (e.g. EQ-5D 5L). The EQ5D has the advantage that it is a utility measure, which can be used to calculate cost per quality adjusted life year (QALY). This can be compared to other services or used to monitor cost benefit ratios. Alternatively, a counterfactual survey (developed following appropriate qualitative investigation) could be used to make assumptions about what actions clients might have taken were it not for the Buddies service. This could provide a straightforward cost comparison, for instance in saving mental health community provision (£167/contact).

### Conclusions

Difficulties in establishing a business as usual model for each of the three main projects within the survivorship programme, and lack of good quality data regarding associated benefits; means that a credible cost benefit analysis is not currently possible. A cost effectiveness analysis was carried out for the Living Well information centre and Cancer Buddies. An assessment of the in-house cost benefit analysis was carried out for Meeting New Horizons.

**Living Well information centre:** costs were calculated as the sum of MacMillan additional funding and some identified in-kind costs. Working from reported data for the first three quarters of 2015; the cost per referral in to the service was £18.23. If a cost savings approach is taken, this service appears to offer good value for money compared to possible equivalent alternatives. Monthly mean referrals into the service were 89, of which 72% were referred onwards to other services. Annual referrals into the service equate to approximately 10% of cancer survivorship prevalence and 54% of annual cancer diagnoses for the CCG area.

There are a number of limitations of this analysis. A more accurate analysis would require:

- Actual costs for the project
- More detailed process data (e.g. time spent with clients, type of intervention, services provided etc)

- Details for onward referrals (to estimate comparative pathway costs)

A cost benefit analysis would require the establishment of specific, measurable, appropriate outcome measures.

**Meeting New Horizons:** An appraisal of cost benefit analysis data from the organisation indicated that the public value for money benefit cost ratio is less than one (0.46), which might indicate that the project costs more than it has achieved. However, there are significant limitations to this assessment. Eight steps are proposed to reduce the uncertainty of this analysis. Separating the economic analysis of work with individuals from work with organisations could also allow a more accurate representation of public value for money by associating the costs of specific activities with relevant activity measures or benefits.

**Cancer Buddies:** A detailed breakdown of comprehensive project costs, including in-kind and volunteer costs, was established at £22,640 per annum. This demonstrates estimated cost effectiveness for each active buddy of £1,029 for 22 buddies or £613 for 49 buddies. Projected cost effectiveness (for 49 active buddies) at current rates of client engagement (1.7 clients per buddy or 166 clients per year) equates to approximately £136 per client paired with a buddy. The annual recruitment ratio of new to existing clients is 1:1. The key limitation for this analysis is the lack of up-to-date service level data. An important consideration is the strategic appraisal of economic flows, and definitions of in-kind costs. For future cost benefit analysis, counterfactual or pre-post utility measures (compared to a control population) are recommended to estimate benefits.

### *Discussion*

This economic analysis has been undertaken utilising available data. It sets out the current situation as far as possible; describing assumptions, limitations, cautions and considerations. This provides a model, which can be improved upon for ongoing evaluation and monitoring. Recommendations are made for more advanced methods, which would improve reliability, accuracy and validity.

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## Glossary of terms and abbreviations

BAU	Business As Usual
CB	Cancer Buddies
CES	Carer Experience Scale
CMO	Context, Mechanisms, Outcomes

DBFT	Doncaster and Bassetlaw NHS Foundation Trust
DCCG	Doncaster Clinical Commissioning Group
DMBC	Doncaster Metropolitan Borough Council
DBH	Doncaster and Bassetlaw Hospitals (NHS Foundation Trust)
JR	Jennifer Read
LW	Living Well hub
Macmillan	Macmillan Cancer Support
MNH	Meeting New Horizons
NDM	New Delivery Model
PABC	Person Affected By Cancer
RDaSH	Rotherham, Doncaster and South Humber NHS Foundation Trust
SA	Steven Ariss
ScHARR	School of Health And Related Research
UoS	University of Sheffield
PV	Present Value
Q1 etc	Quarter 1 etc
R.	Referrals
CBA	Cost Benefit Analysis
fte	Full Time Equivalent
CG	Confidence Grade

## Appendices

### i) Literature Search Strategy and Tables of Reviewed Publications

The following tables ([a] Cancer Survivors; [b] Co-production) each show a list of literature that went through to the data extraction stage. The ticks indicate which I-statement topics relate to which piece of literature.

**Table (a) Literature Reviewed Relating to Cancer Survivors: By I Statement**

**Table (b) Literature Reviewed Relating to Co-production: By I Statement**

**ii) Doncaster cancer survivorship I-statements**

**Doncaster Cancer Survivorship Project: I-Statements**

**1. MONEY**

	<i>Headline I-statement:</i>
1.0	I fully understand how having cancer could affect my personal finances (whether as a patient or carer) and I have the information I need to plan how I will cope with any money problems.
	<i>Detailed I-statements:</i>
1.1	I have clear and complete advice right from the start about the costs of cancer and what support is available to help me deal with my money.
1.2	I can arrange to meet with a professional for an assessment and to talk about what benefits I might be entitled to, and for support with any concerns about money.
1.3	I know about what rights I might have to free prescriptions, council tax reduction, Macmillan grants, a temporary blue badge for parking and free hospital parking during treatment and follow-up.
1.4	The professionals who are supporting me give me accurate advice about benefits and earnings, or put me in touch with someone else who can.

**2. EMPLOYMENT**

	<i>Headline I-statement:</i>
2.0	I have the support I need to be in control and to make choices about my working life throughout my cancer journey.
	<i>Detailed I-statements:</i>
2.1	I understand my employment needs and rights from the point of being told I have cancer.

2.2	The professionals who are supporting me help me to make a written plan for my return to work before my treatment ends.
2.3	My employers understand my rights and do what they are supposed to for me as an employee, both during and after my cancer treatment.
2.4	The professionals who are supporting me give me accurate advice about work issues including retirement, or put me in touch with someone else who can.

### 3. INFORMATION

	<i>Headline I-statement:</i>
3.0	I understand my health and can make good decisions throughout my cancer journey.
	<i>Detailed I-statements:</i>
3.1	I am given information in the way I want, (or given reliable sources of information that are based on research), at the right time for me, that is easy to understand, relevant to my situation, clear and truthful.
3.2	I have the right information so that I fully understand what choices I can make about my care and treatment.
3.3	My carers know where and how to get information.

### 4. HEALTH AND WELLBEING

	<i>Headline I-statement:</i>
4.0	I understand my health and know what to do to keep myself healthy and to live my life to the full throughout my cancer journey.
	<i>Detailed I-statements:</i>
4.1	I feel that my individual needs are thoroughly listened to, talked through with me and understood.
4.2	At key points in my cancer journey, including at the end of treatment, I am given a written record of all my needs (not just the medical ones), and a plan showing how the professionals supporting me will help me to look after my health and live my life.
4.3	I feel that I can have my say, and be listened to, as much as I want to during the planning of my treatment and support.
4.4	I understand from my 'moving on' interview at the end of my treatment: <ul style="list-style-type: none"> <li>• how to manage my own condition,</li> <li>• how to manage stress and anxiety and</li> <li>• what important signs to look out for that mean I should get medical advice, and</li> </ul>

	where to get it.
4.5	<p>At the end of my treatment, I have a list of things that I can do to help me return to my 'normal' life, including:</p> <ul style="list-style-type: none"> <li>• how to take part in research,</li> <li>• how to take part in planning and improving the support for other people affected by cancer, and</li> <li>• how to become a volunteer and support other people affected by cancer through groups or by becoming a 'buddy'.</li> </ul>

## 5. CARERS

	<i>Headline I-statement:</i>
5.0	As a carer, I understand the effect cancer can have on important parts of my life including my relationship with the person I support, and I know how to help myself and who else can help me.
	<i>Detailed I-statements:</i>
5.1	As a carer, I understand how I fit in with the rest of the professional support team and I know how to get support for myself.
5.2	As a carer, I am given the chance to talk through my emotional, practical and financial needs, to feel that I have been listened to and understood and to know where to get support and information.
5.3	As a carer, I understand what will happen and when during the follow-up care for the person I support and I expect to get the right information at the right time in our cancer journey.
5.4	<p>As a carer, I know:</p> <ul style="list-style-type: none"> <li>• what quality of treatment and support I, and the person I support, should expect,</li> <li>• how to give feedback so that the quality of treatment and support can be improved,</li> <li>• what questions to ask and who to ask if I have any concerns.</li> </ul>

## 6. SUPPORT

	<i>Headline I-statement:</i>
6.0	I know how to help myself and who else can help me to stay as healthy and independent as possible throughout my cancer journey, and I am in control of my care and support.
	<i>Detailed I-statements:</i>

6.1	I understand what support is available from professionals, from the voluntary sector and from other people who have been affected by cancer.
6.2	I feel confident about when and how to get professional support and when to use the voluntary sector or peer support / buddying from other people affected by cancer.
6.3	Before the end of my treatment, I have a written plan that helps me to understand how to get support and where from.
6.4	I can get support from other people affected by cancer close to my home, rather than at the hospital.
6.5	As a peer supporter / buddy, I feel that I have been well-trained, I understand what I can and can't do as a volunteer and I feel that I get support too.

## 7. DISCHARGE

	<i>Headline I-statement:</i>
7.0	When being discharged after being in hospital as an inpatient, I know how to help myself and who else can help me.
	<i>Detailed I-statements:</i>
7.1	I feel that my support is joined-up and that the professionals in my support team from the health (primary, secondary and community), social care and voluntary sectors know about me as a person and understand my needs and how I prefer to be cared for and to live my life.
7.2	I know where and how to get support for practical issues such as childcare, cleaning, shopping, counselling and carer support.
7.3	I know when and how to get support from the team at my GP practice.

## 8. ROLE OF PROFESSIONALS

	<i>Headline I-statement:</i>
8.0	I get the care and support that helps me to live my life to the full throughout my cancer journey.
	<i>Detailed I-statements:</i>
8.1	I am supported by a team of professionals from social care, health and the voluntary sector who work as one team to make sure that I, and everyone else living with and beyond cancer, get the care and support needed to lead as healthy and active a life as possible, for as long as possible,
8.2	I usually see the same members of my support team.

8.3	I feel certain that my GP knows everything s/he needs to about my cancer treatment and that s/he understands how to support me during treatment and as a cancer survivor.
8.4	I feel certain that other health professionals in the wider NHS such as my dentist and pharmacist understand my needs as a cancer survivor and will look out for signs that might mean my cancer has come back.
8.5	At key points in my cancer journey, including before the end of the first phase of my treatment, I am given a written record of all my needs (not just the medical ones), and a plan showing how the professionals supporting me will help me look after my health and live my life.

ii) **PABC questionnaire**

iii) **PABC questionnaire questions matched to I-statements (for analysis purposes)**

iv) **'Carer' questionnaire**

DRAFT for Authorisation