Survivorship: Promoting Quality of Life in Cancer and Long-term conditions: Interim evaluation report

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Contents

1.0   Introduction

This interim report provides data on the evaluation of the delivery of a post-registration training module in survivorship which was delivered through the Continued Professional Development Centre at the University of Lincoln in 2013, and is part of a wider collaborative project between Macmillan Cancer Support and the University of Lincoln.

A more comprehensive evaluation which included a comprehensive literature review on the topic of survivorship, baseline measures of motivation amongst participants on the module and full analysis of a series of in-depth interviews exploration of practitioners' perceptions on the survivorship agenda (work conducted by Amanda Thompson under the supervision of Dr Ros Kane and Dr Ian McGonagle) has previously been reported back to Macmillan.

This current report aims to:
- Present data from the evaluation of the module
- Present key points from the in-depth interviews
- Provide an update of dissemination activities to date
- Outline the plans and timescale for the follow up outcome evaluation.

1.1   Background

1.1.1   Details of the course delivered

The short course: Survivorship: Promoting Quality of Life in Cancer and Long-term conditions, was built around the acknowledgement of the National Cancer Survivorship Initiative, launched in September 2008 and a key initiative of the Cancer Reform Strategy (2007) key areas for improvement of health services were needed in order to provide better support to cancer survivors. Specifically the NCSI acknowledged the need to:

- Move the focus from cancer as an acute illness to a greater focus on recovery, health and wellbeing after treatment.
- Plan an individual's care based on an assessment of their personally identified needs.

- Empower and support survivors to take an active role in their aftercare.
- Tailor aftercare support to enable earlier recognition of signs and symptoms of further disease.
- Measure experience and outcome for patients rather than measuring clinical experience

The short course was developed in collaboration with Macmillan Cancer Support who commissioned a formal module, be developed and delivered at master's level for senior clinicians, to compliment the work that had already been undertaken in this area. As such the module was validated as a 15 credit module with the option of studying at either Level 6 (degree level) or 7 (Master's level). This provided the opportunity for those wishing to undertake postgraduate study and also for those students studying at level 6, in order that expertise from both sets of students could be shared.

The teaching was delivered by a range of speakers from Macmillan Cancer Support and from other disciplines such as Occupational Therapy, Physiotherapy and Social Care. For the first cohort, Macmillan secured funding to offer the short course to 10 of their staff.

The short course utilised a number of different learning and teaching strategies including:

- Discussions – to allow exchange and development of attitudes, group dynamics, feedback and self-awareness.
- Lectures - giving a general background to a topic, transmitting current thinking and information giving.
- Seminar Presentations – to allow for exploration and sharing of personally researched and meaningful aspects of the course.
- Sharing of Practical Experiences – to allow exploration of factual, professionally relevant issues, raised and resolved utilising leadership skills.
- Self-directed Study – to allow exploration of the literature through a variety of open learning materials: (e.g: Library, IT, search engines, completion of assessments).

Whilst the main focus of the short course was around cancer survivorship, it also considered the similarities experienced by people living with a long term condition as many of their needs overlap.

1.1.2   Aims and Learning Outcomes of the module

The module aimed to provide students with the opportunity to critically examine the health and social care priorities when facilitating the improvement in outcomes for people living beyond cancer and with long term conditions. Students also had the opportunity to discuss how future services may need to be developed and their role in managing how such services may be implemented.

The learning outcomes and assessment requirements for both levels of the module are shown below.

	Level 6	Level 7
Learning outcome 1	Discuss the meaning of survivorship in the context of the national cancer survivorship initiative and long term conditions	Critically debate and apply the meanings of survivorship in the context of cancer and long term conditions in relation to health and social care provision
Learning outcome 2	Critically review the range of heath and social care services within the statutory and voluntary sectors required for the coordinated, effective facilitation of self-care	Evaluate the range of health and social care services within the statutory and voluntary sectors and critically discuss their role in developing a coordinated inter-professional approach towards the effective facilitation of self-care
Learning outcome 3	Appraise the importance of healthy living and the promotion of healthy lifestyles in the context of survivorship and long term conditions	Critically analyse their role in the coordination and development of services within health and social care aimed at healthy living and promotion of healthy lifestyles in the context of survivorship
Learning outcome 4	Discuss the impact of the late effects of treatment and/or the transition towards the end of life upon individuals and those significant in their life	Synthesise the impact of the late effects of treatment and critically discuss their role in the development and implementation of health and social care services required for the transition towards the end of life

| Assessment	Write a 3000 word case study critically analysing the health and social care implemented to sustain recovery, wellbeing and self-care in line with the module outcomes.	Part a Write a 3500 word critique of an identified health and/or social care need in relation to the module outcomes and critically discuss their role in the development and possible implementation of strategies to meet the identified need. (80%)
		Part b Deliver a 15 minute presentation discussing the identified need in part a to academic staff, clinicians and service users (20%)

1.1.3   Participant details

The module was attended by 8 health professionals with the following roles: Clinical Nurse Specialist, Survivorship; Macmillan Service Improvement Facilitator; Macmillan Support Services Coordinator; Macmillan cancer support information officer; Macmillan Clinical Nurse Specialist in Breast Care; Macmillan Information and Support Facilitator; Macmillan Project Manager – Living With and Beyond Cancer and a Macmillan Cancer Liaison Nurse. All but one were Macmillan employees. Participants were currently employed in Lincolnshire, Northumbria, Liverpool, Manchester and Rotherham. Their highest prior qualification ranged from Post-Graduate Certificate (PG Cert) to Masters' Level. Three people applied to study the short course at Level 7 with the remaining five at Level 6 however four participants went on to study at Level 7 and three at Level 6, indicating a change of study level for some throughout the process. Six participants passed the short course, one withdrew and one interrupter her studies, returning to complete a year later.

2.0   Evaluation of the module

The module was evaluated using a standard module evaluation form (Included at Appendix 1). Further in-depth evaluation was conducted by interviews with the participants and details of this are included in section 3.0 below.

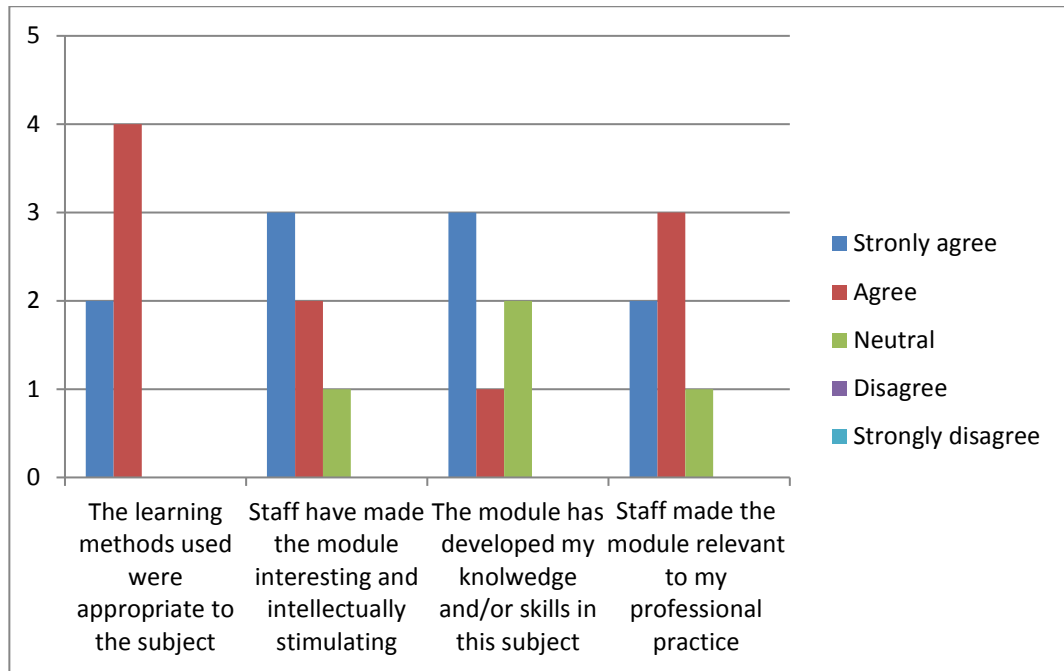Six evaluation forms were returned and the feedback is presented below in a series of self-explanatory bar graphs. In each graph, questions are replicated from the original evaluation form.

2.1   Module organisation
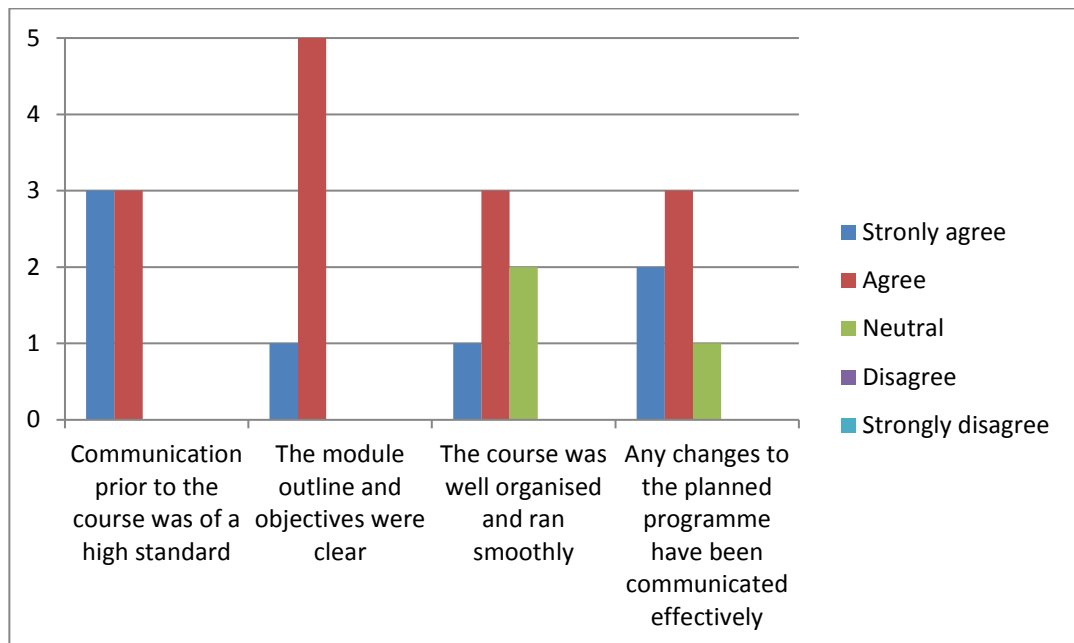
Additional comments: The university staff always responded to my queries promptly.

2.2 Teaching and learning

2.3 Academic support
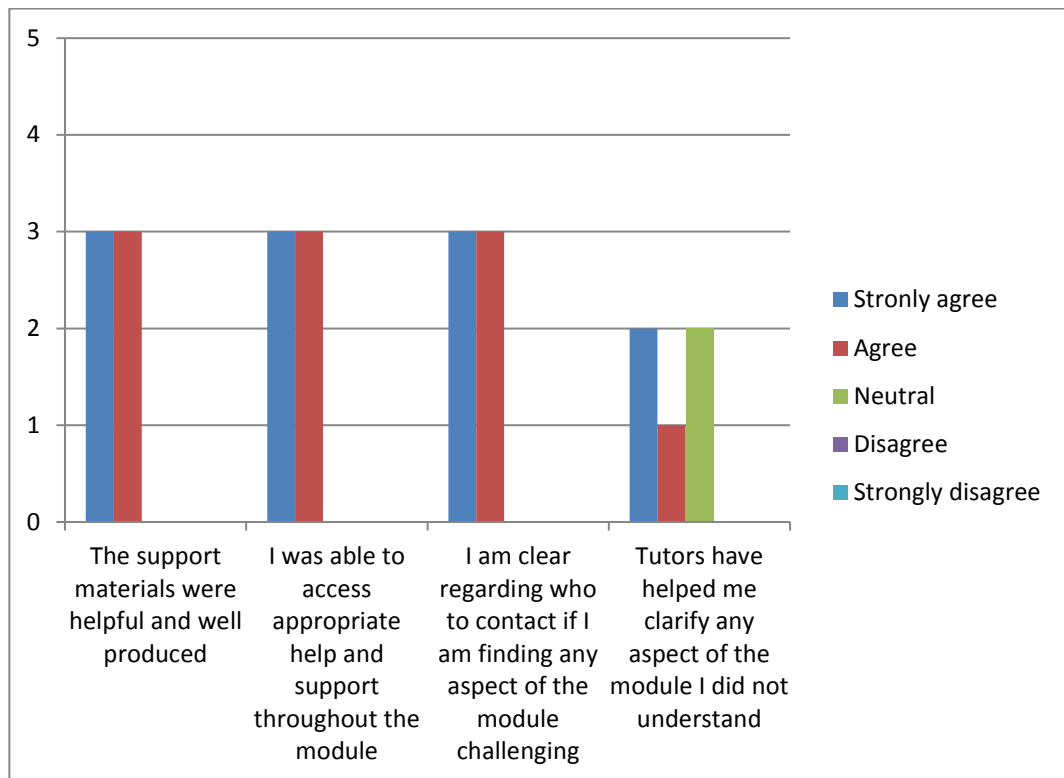
2.4 Assessment and feedback
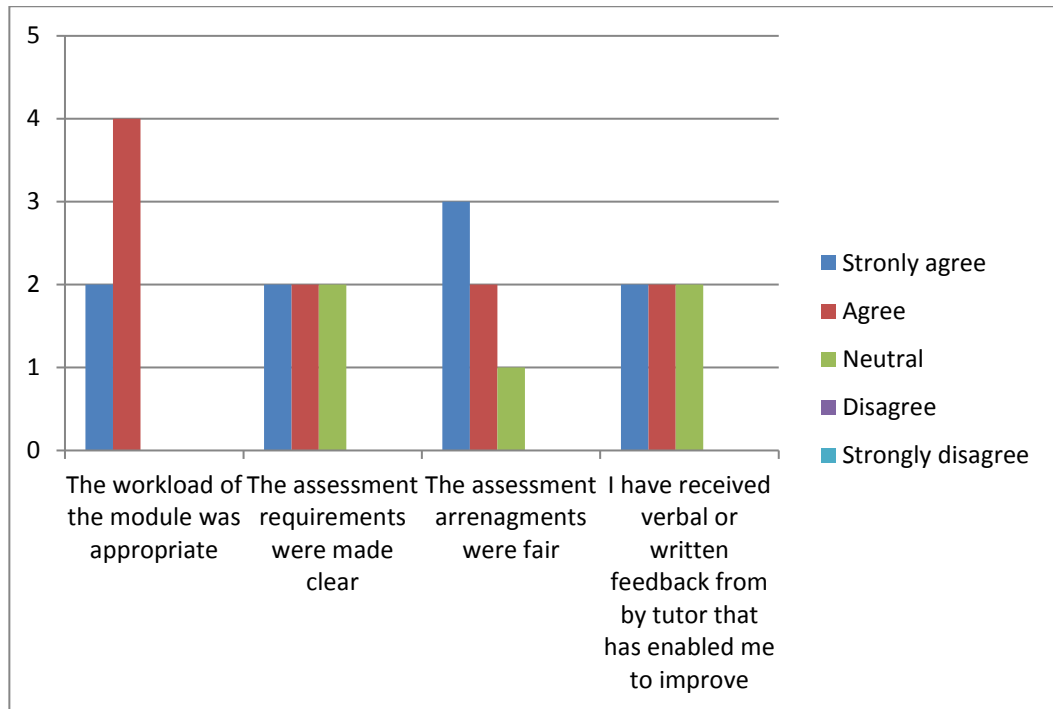
2.5 Learning resources
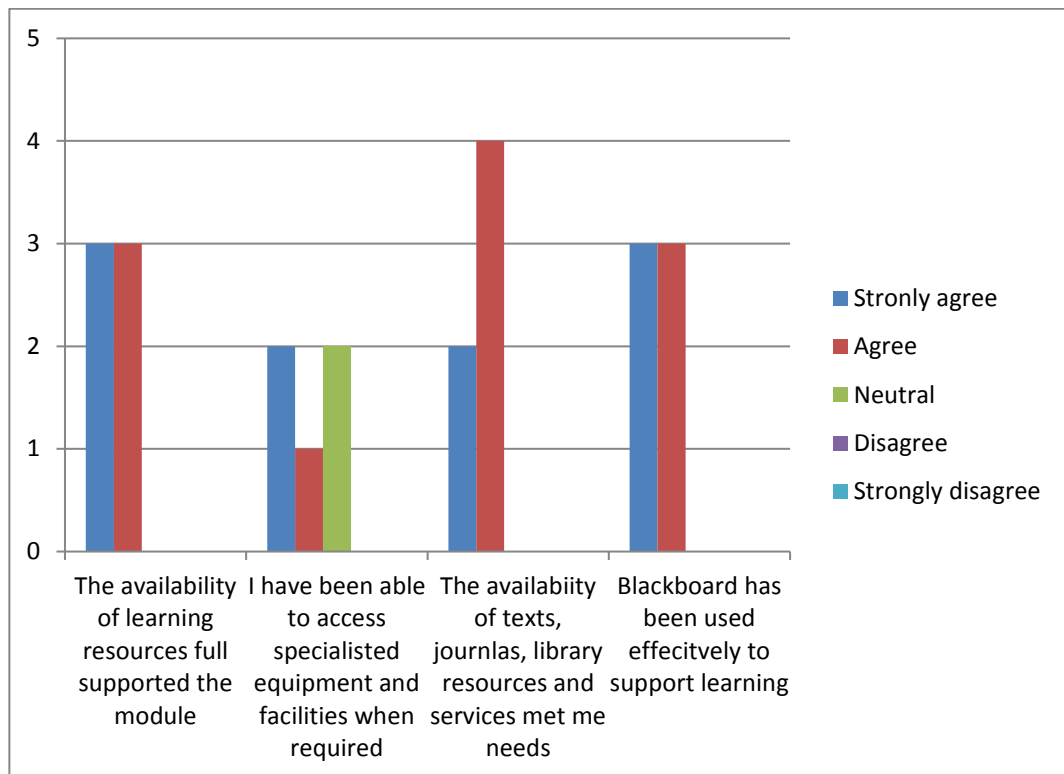
2.6   Overall evaluation
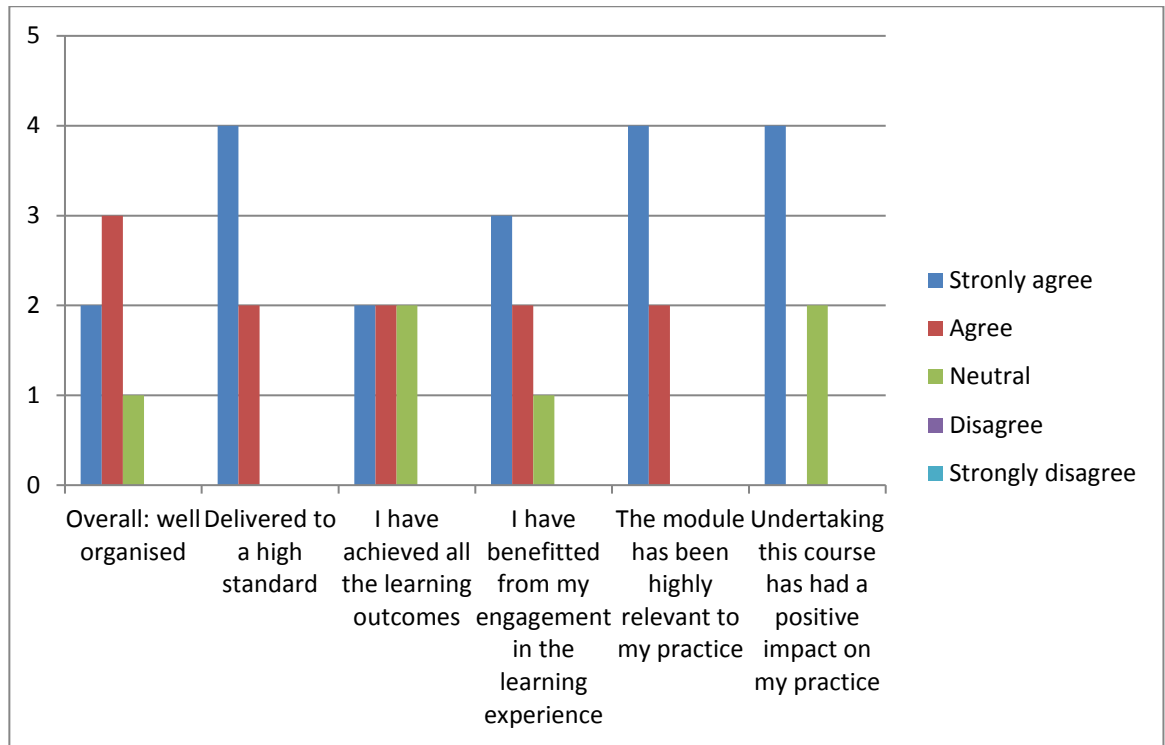
2.7   Qualitative responses to additional open ended questions

Did you undertake and work based learning days as part of the programme?

- Spent the day with health psychology in North Tyneside
- Yes – very helpful to have this as part of the programme
- Yes – activity programme
- Yes – I went to study with the bowel CNS and Stoma Nurses. I also spent the day with the local support group for colorectal cancer.

What did you like most about the module?

- I really enjoyed the motivational interviewing session and also the visit from [Name of service user]
- Networking opportunities
- New learning experiences
- Gaining further knowledge re all aspect of surviving beyond cancer
- Mindfulness

- Variety of Speakers
- Group members
- Carers insight
- Learning and sharing
- Opportunities to discuss with other professionals working in survivorship
- It has encouraged me to think more deeply about the recovery package.
- My fellow students and their visit presentations.

Which aspects of the module do you think could be improved?
- Perhaps pitched at a higher level? Although having not worked a lot at degree level I haven't got a good frame of reference.
- Information around treatment effects.
- I enjoyed every element of the module. I would have appreciated a longer session on motivational interviewing as I found this really interesting and very beneficial.
- Generally happy.

How will you apply the skills and knowledge you have gained to develop your practice?
- Not to take it at face value, to apply services to the individuals.
- The mindfulness and motivational interviewing will be put into practice.
- I am in the process of initiating a 'moving forward' programme and I have learnt so much from this module that I can use to guide this project.
- Gained much greater understanding re applying HNA to own practice especially – greater confidence.
- It has affirmed that we are doing the right thing!
- Affirming knowledge gained.

Overall the module was very well received by participants. The key strengths were the opportunity to network and learn from colleagues and the range of topic discussed. Specific feedback on both strengths and limitations will be useful in informing the content and delivery of future training programmes.

3.0   In-depth interviews with short course participants

Full details and justification of the methods have been reported elsewhere (Thompson 2015). Below the key details are presented.

3.1   Ethical approval

Ethics approval was granted from the School of Health and Social Care at the University of Lincoln on 18th February 2015 (Appendix 2).

3.2   Method

In order to accommodate participants and obtain rich and detailed data about their experiences of taking part in the module, the research team opted to undertake semi structured in-depth individual qualitative interviews.

3.2.1   Designing the topic guide

A topic guide was developed specifically for the interviews in this study and a copy is included at Appendix 3.

3.2.2   Collecting the qualitative data

Health professional who attended the module were invited to take part in an interview in which they could share their experiences of participating/learning. They were given a participant information sheet (Appendix 4) which they were able to read prior to agreeing to take part. Those who agreed to take part in the interview were contacted via email to arrange a convenient date. Two people agreed to be interviewed.

Prior to the interview participants were reassured that their participation was voluntary, results would be anonymous and they were able to withdraw at any stage if they wished to do so. They were asked to read and sign a consent form (Appendix 5). Interviews all took place in a private room on University premises during month 2014. They were digitally recorded and later fully transcribed verbatim.

The digital recordings and the transcriptions were assigned unique ID codes and any personal information removed.

Interviews were independently read by three members of the research team, analysed using the well established framework method for qualitative analysis (Ritchie, Spencer and O'Connor, 2003).

3.3 Key Results from the in-depth interviews

The data were analysed thematically and independently by three members of the research team. The interviews covered a number of related issues as the intention was also to gain insight into the potential for future courses and the extent to which respondents felt there was a need for service development and training in supporting those living with and beyond cancer. Four main themes emerged from the data.

1. Patient needs – statements around a wide range of perceived patient-needs related to adapting to the physical, psychological and social impacts of diagnosis and treatment resulting in altered function, identity and status.

2. Informational needs – frequently occurring perceptions of patient needs relating to support around transition and informational needs, respondents also recognised the informational needs of professionals in primary care settings.

3. Variation in attitudes and understandings – statements around variation in patient attitudes towards transition from secondary to primary care.

4. Variation in availability, up-take accessibility of supportive interventions.

5. The linking of cancer and other long term conditions

3.3.1 Patient-related needs

A sense of urgency was expressed about the necessity of service development to meet predicted future demand. Respondents recognised that current provision

is limited, and in need of a creative response to changing demographic and health profiles within a context of economic constraint.

Interviewees perceived a wide range of patient-related needs related to adapting to the physical, psychological and social impacts of diagnosis and treatment resulting in altered function, identity and status:

> *"…that can have effects on your self-confidence, your body image, your relationships, your loss of role, loss of income."*

Specifically, a perceived need concerned support with adjustment to changed circumstances:

> *"…they say 'I want to get back to normal' and I tend to say 'your normal perhaps has changed. You're on a new normal now.'"*

Respondents perceived that referral for specialist psychological support was sometimes required. One respondent made a distinction between her role - in one-to-one contacts and in support groups which offer help to overcome problems patients may experience through the use of listening skills - and more specialised assessment and support from clinical nurse specialists.

3.3.2   Informational needs – patient and professional

A perception related to information and support required for patients around transition between health services. Respondents also recognised the informational needs of professionals in primary care settings. Both patient and professional informational needs concerned the transition from secondary to primary care:

> *"It's got to be well followed up by the patient's GP … once they're out of the hospital system you lose contact … information and training for the GPs in the community as well."*

Respondents perceived basic information sharing about how services operate as necessary to ameliorate uncertainty, anxiety and disempowerment both at the stage of diagnosis and at the stage of transition from active treatment to follow up care. One respondent perceived informational provision about processes of screening, review and notification as "*massively lacking*" in a surveillance system with which she had been involved:

> "*… they'd have the mammogram and then they wouldn't know they didn't get the results on that day. Everything was up to that day for them in the whole year since they'd finished their treatment…*"

Perceptions relating to informational needs encompassed the need for conscious tailoring of information to meet individual needs according to what issues the patient presents, assessment of what information has already been received and how it has been understood, the need for information to be appropriately formatted (for example language translation or easy read versions for people with a learning disability – in this example the involvement of a specialist learning disability nurse to support both the patient and other professionals was highly valued.) Other issues raised were the importance of ensuring information resources used are aligned with the current evidence base and signposting to reliable sources. One respondent perceived the range of information sources and specialist practitioners as a "spider's web". This metaphor of a web or network of resources as a structural component of services will be expanded upon in the discussion section.

There emerged from the data a complex perception of informational and supportive care provision as a network which relies simultaneously upon health professionals engaged in survivorship maintaining knowledge and understanding of a broad range of potential needs encompassing medical, social, psychological, financial and practical issues. Within this broad range of knowledge professionals need to recognise when referral to professionals with more specialised knowledge is appropriate. The tension between these two levels was expressed by one respondent, speaking of how she supports patients to be generally mindful of any changes that may indicate recurrence:

"I'm not an oncology trained nurse, so I don't know that I've got the skills … I can do the basics …. but I don't know that I'm necessarily doing it right."

3.3.3   Variation in attitudes and understandings

Respondents perceived different support preferences:

"…like support groups are not for everybody, like you know one to ones aren't for everybody are they? But it's a way of starting."

Respondents perceived a variation in patient attitudes towards transition from secondary to primary care:

"Some people are fine, some people … can't wait to get out, shut the door, let me go."

Other patients are perceived as needing more help to increase confidence or to recognise their ability to manage beyond secondary care which is perceived as a safety net of monitoring and surveillance:

"… because you're safe in a hospital system aren't you?"

This variation in attitudes to leaving secondary care in the patient population is mirrored by one respondent's perception of colleagues' responses to changes to follow up. The delivery alterations left some staff being "*quite horrified*" and resistant to reduced dependence on specialist secondary care.

One respondent perceived a disconnect between the way professionals and patients understand and relate to the concepts of self-management:

"We get these terms don't we … and it doesn't always transfer to the person that we're trying to help."

and wellbeing:

> *"… if their self-perception is that they're unwell, before they've had a diagnosis of cancer and you give them a diagnosis of cancer and then you talk about them going a 'wellbeing' event."*

Variations in understandings and attitudes due to lay and professional differences in perception, and wider issues to do with cultural contexts and meanings will be considered in the discussion section.

Varying levels of commitment to specific self-care activities and confidence in ability to self-manage were perceived by respondents in regard to patients, and also variance in attitudes from primary care to participating in follow up survivorship care.

3.3.4 Variation in availability, up-take, accessibility of supportive interventions

Respondents commented upon information and support needs of availability and accessibility in terms of current provision: referral for psychological help and access to specialist dietetic and occupational therapy advice were particular areas perceived as inadequate.

Perceptions of what improved or ideal provision would look like were also shared:

> *"I think it's making sure you've got the right information there to support people when they want it. It's making sure that patients are – at each part of the pathway - really well informed what will happen next, to giving them the skills, the knowledge to know if there's been a recurrence …"*

The phrase "when they want it" within this quote implies the importance of recognising that patients' information requirements will vary, and that patients have should have some control over information-sharing processes.   This respondent also perceived the hospital basing of some information services as a barrier to access for some patients who may be reluctant to attend an acute

environment due to associations with negative experiences of diagnosis and treatment, which leads to another dimension – "where they want it?"- regarding the location of information and support services.

These variations in availability, up-take and accessibility expose potential gaps in current provision. One interviewee, speaking of a role expectation to compile an annual report on the user profile of her service:

> " … identifying what sort of categories if you like, of people who are using [the service], and therefore perhaps what aren't you meeting?"

Another interviewee, speaking about variation in up-take of wellbeing and exercise interventions:

> "… knowing there are individuals who perhaps won't access the different resources and perhaps may fall through the cracks."

Respondents saw holistic needs assessments (HNAs) as an important element in identifying patient needs and variations in need. The data suggested that in order for these assessments (and the care plans that are developed from them) to remain relevant and responsive, regular review is required *"because patients' needs will change at different points in their pathway."* Views were expressed on the need for further refinement (one respondent referred to a current piloting project) and standardisation in delivery to ensure equality of service. One respondent questioned:

> "… whether it's perfect for all patients because some people might not like to say in that way that they need help perhaps with different aspects that they might not say… I'd like to think that if a patient has face-to-face contact with somebody they might include more..."

This insight hints at both the exercise of patient control in choosing to disclose sensitive areas of concern and at the potential for face-to-face interactions to facilitate disclosure of such issues. The concept of assessor as "receptive

listener" and wider issues relating to power and control will be expanded upon in the discussion section.

Open access to informational services throughout survivorship was perceived as important by both respondents. One respondent described a potential project connected to her current role in improving follow up care: a structured telephone advice and support line to optimise utilisation of CNS expertise and their ability to function as a link between self-management and facilitating rapid re-access to secondary care if this is assessed as necessary.

3.3.5 The linking of cancer and other long term conditions

Asked to share their perceptions on the linking of cancer with other long term conditions one respondent identified a possible difference in patient perceptions of potential life limitation between the two in that a cancer diagnosis, despite increases in survival rates, automatically evokes considerations of life limitation that diagnoses of other long term conditions might not.

The other responded in terms of the potential for sharing resources between conditions (the example given was of cancer patients being able to access physical activity programmes which were designed for cardiac patients). This respondent perceived potential for increased take up of such interventions which would be advantageous in terms of efficiency and economics - exemplifying the creative response to economic constraints perceived as a general need in developing survivorship services - but also perceived potential barriers to resource sharing and opposition based upon territorial attitudes from service providers:

> "… my perception is that you know illnesses are kept to specific groups. … perhaps people– perhaps they don't want it mixing."

The transcript of the interview reveals that this perception was somewhat tentatively articulated, and reflects perhaps recognition of structural constraints arising from the way services are organised and also, as revealed below, how

they are funded and commissioned. Structural constraints will be explored further in the discussion section.

The same respondent perceived additional potential barriers to the implementation of new ways of delivering survivorship services from shifts in current funding and commissioning arrangements between hospitals and clinical commissioning groups (CCGs); the difficulty in measuring the efficacy of preventative interventions like exercise programmes in reducing the need for health service utilisation; and members of multi-disciplinary teams involved in survivorship services being managed separately.

4.0   Dissemination to date

The work has been disseminated through a number of mechanisms and similar activities will be sought after the outcome evaluation in 2017. Key outputs are categorised and listed below.

Presentation at international conferences

Trueman I, Kane, R and Sanderson, S (2016) *Collaborative working between higher education institutions and third sector charitable organisations.* RCN Education Forum national conference and exhibition: partners in practice, 15 - 16 March 2016, Telford.

Trueman, I., Kane, R., Sanderson, S., Nelson, D. (2016) *Collaborative Working between Higher Education Institutions and Charitable Organisations – an innovative approach.* NET Conference. Cambridge. September 2016.

Dissertation

Thompson A (2015) Study exploring perceptions of the survivorship agenda. Undergraduate Dissertation: BSc (Hons) Adult Nursing, University of Lincoln (Unpublished).

Presentation at internal conferences

Trueman, I (2016) *Learning Beyond Registration (LBR).* In: Thinking Forward, 22 February 2016, University of Lincoln.

Subsequent related research and outputs supported by Macmillan
Articles

Nelson, D. and Mansfield, P. and Kane, R. (2016) *Carers of people affected by cancer and other long-term conditions at end of life: a qualitative study of providing a bespoke package of support in a rural setting.* Palliative Medicine.

Reports

Nelson, D, Kane, R, Davies, H and Sinclair, C (2015) *The social care needs of people affected by cancer: a qualitative study in Lincolnshire.* Project Report. University of Lincoln.

Nelson, D, Kane, R, Mcgonagle, I, Thomson, A (2015) *Meeting the needs of carers of people affected by cancer (PABC) in Lincolnshire: an investigation to inform future service development and delivery.* Project Report. University of Lincoln.

Presentation at international conferences

Nelson, D, Kane, R, Davies, H and Mansfield, P (2016). *Exploring the social care needs of cancer patients and their carers in a rural setting.* In: International Scientific Conference Research and Education in Nursing, 16 June 2016, Maribor, Slovenia.

Nelson, D, Kane, R and Davies, H (2015) *Meeting the social care needs of people affected by cancer in Lincolnshire.* In: NCRI Annual Conference, 1-4 November 2015, Liverpool.

Nelson, D, and Kane, R (2015) *Supporting carers of people affected by cancer and other long-term conditions at end of life.* In: NCRI Annual Conference, 1 - 4 November 2015, Liverpool.

Nelson, D (2015) *Supporting carers of people affected by cancer in Lincolnshire: a qualitative study to inform future service delivery.* In: College of Social Science Research Conference 2015, 2 July 2015, University of Lincoln.

Presentation at internal conferences

Kane, R and Nelson, D and Boyer, C (2015) *University of Lincoln & Macmillan Cancer Support: a collaborative case study.* In: Involving Lincs & University of Lincoln: Academic & Voluntary Sector Networking Event, 10 November 2015, University of Lincoln.

Nelson, D (2015) *Supporting carers of people affected by cancer and other long-term conditions at end of life: an evaluation of an innovative intervention in Lincolnshire.* In: Lincolnshire Community Health Services (LCHS) NHS Trust Research Forum, 18th March 2015, Lincoln.

5.0   Next steps

5.1   Follow-up interviews with full cohort of participants

An ethical application has been submitted in November 2016 to re-contact all those who attended the survivorship short-course and to interview them 2 years post completion of the module. The aim of the outcome evaluation is to finalise the study with an exploration of outcome with a view to reporting back to the Macmillan with a comprehensive evaluation of the entire programme.

The aim of this strand of the research is to examine the ability of participants to adopt and apply elements of the training programme in their workplace and to examine the extent to which the training may have influenced new ways of working with people who live with or have recovered from cancer. The evaluation will involve an investigation of personal / professional development in the attitudes, knowledge and behaviours of a cohort of clinical practitioners engaged in the educational programme and explore potential facilitators of barriers to the transfer of their learning.

5.1.1   Project outcomes

An investigation into the views of previous participants of the short course of the extent to which they have implemented core aspect of the programme to their current clinical practice. Facilitators and barrier to transfer of learning will be explored.

5.1.2   Project outputs

1. A full scale programme (formative, process and outcome) evaluation available to project funders (Macmillan)
2. Information to aid development of future 'survivorship' training programmes.
3. Primary qualitative research dataset
4. A potential for publication as (an) academic paper(s)
5. Potential for presentation/poster displays at an appropriate academic conference

5.1.3 Methods

We intend to complete the following:

- A comprehensive review of the academic and policy literature relating to survivorship (NB this was completed on 2014 – we now deed to update it for final publication).
- Demographic data collection including a personal biography of clinically relevant research experience and interest of participants on the programme
- Analysis of module evaluation data – to be completed immediately at the end of the module.
- In-depth interviews with all participants who undertook and completed the initial training programme (n=5)   analysed using Framework Analysis

All interviews will the tape recorded (if permission is granted) and transcribed verbatim. Where consent to record is not given, extensive notes will be taken during the interview.

5.1.4 Timetable and milestones

Activity	2016		2017							
	Nov	Dec	Jan	Feb	Mar	Apr	May			
Submit ethics application	■									
Contacting the small sample students who undertook the training to invite them to take part in an in-depth interview		■								
Updating the literature review and conduct follow-up interviews			■	■	■					
Analysis and write up of post-training quantitative evaluation data (using a standard module evaluation questionnaire)					■					
Transcription and analysis of data						■				
Report writing						■	■			

Full details of the proposed follow-up evacuation and the proposed topic guide for the in-depth interviews are provided in Appendix 6.

6.0   References

Department of Health (2007) *National Cancer Strategy* [283524] London: Department of Health. Available from http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_081007.pdf

Ritchie, J., Spencer, L. and O'Connor, W. (2003) Carrying out qualitative analysis. . In: Jane Ritchie and Jane Lewis (eds.) *Qualitative research practice: a guide for social science students and researchers.* London: Sage, 219-262.

Thompson A (2015) Study exploring perceptions of the survivorship agenda. Undergraduate Dissertation: BSc (Hons) Adult Nursing, University of Lincoln (Unpublished).

Appendix 1: Module evaluation form

Professional Development Centre

Student End of Module Evaluation

To help us improve the student learning experience we would greatly value your feedback. Please take a few minutes to complete this form. All forms are collated anonymously, unless you specify you would like to discuss your individual feedback with your tutor or the Professional Development Centre.

ACADEMIC SUPPORT:	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The support materials were helpful and well produced					
I was able to access appropriate help and support throughout the module					
I knew who to contact if I found any aspect of the module challenging					
Tutors helped me to clarify any aspect of the module that I did not understand					

We ask that you think carefully about the comments you make as these may be used to develop and improve our provision. Any changes to a module resulting from student feedback will be communicated to your group and the next group of students on that module via blackboard, as well as to employers.
Thank you in advance.

Module title	Module code	Start date	Tutor

MODULE ORGANISATION:	Strongly	Agree	Neutral	Disagree	Strongly

	agree				disagree
Communication prior to the course was of a high standard i.e. emails, joining instructions					
The module outline and objectives were clear					
The course was well organised and ran smoothly					
Any changes to the planned programme have been communicated effectively					

TEACHING & LEARNING:	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The learning methods used were appropriate to the subject					
Staff have made the module interesting and intellectually stimulating					
The module has developed my knowledge and/or skills in this subject					
Staff made the module relevant to my professional practice					

ASSESSMENT & FEEDBACK:	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The workload of the module was appropriate					
The assessment requirements for the module were made clear					
The assessment arrangements have been fair					
I have received support to prepare for my assessment (s)					

LEARNING RESOURCES:	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
The available learning resources fully supported the module					

I have been able to access specialised equipment and facilities when required					
The availability of texts, journals, library resources and services met my needs					
Blackboard has been used effectively to support learning on the module					

OVERALL EVALUATION:	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
Overall the module was well organised					
This module was delivered to a high standard					
I have achieved all the learning outcomes for the module					
I have benefited from my engagement in the learning experience					
This module has been highly relevant to my professional practice					
Undertaking this course has had a positive impact on my professional practice					

Do you have any suggestions for improvement ?

What did you like most about this module?

COMMUNICATION:

If you wish to discuss any aspect of your feedback with a member of staff please include your name in the space   below. Please specify whether you would like to discuss this with your Tutor or the Professional Development Centre.

Student name:	
Name of staff to contact:	

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STAFF USE ONLY:		
Has the individual been contacted with regards to their feedback? YES / NO		
Staff initiating contact:		Date:
Summary of discussion:		
Follow up actions:		

Appendix 2: Ethical approval letter

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School of Health and Social Care Ethics Committee
College of Social Science
Bridge House
Brayford Pool
Lincoln
LN6 7TS

Telephone 01522 882000

18 February 2015

RE: Study exploring perceptions on the 'survivorship' agenda and motivations to engage with post-registration training in this area

Dear Amanda Thompson

Permission is hereby given for the above study, on the basis described in the EA2 application form and the documentation submitted.

1.   Participant Information Sheet
2.   Email recruitment.

The committee wishes you every success in your research.

Dr Zowie Davy
Chair Ethics Committee

Appendix 3: Interview Topic Guide

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Study exploring perceptions of the survivorship agenda

Topic Guide for qualitative interviews

(prompt and probe each response and ask participants to elaborate)

Warm up questions: current role and motivation to apply for survivorship module.

- Informational needs
- Emotional/psychological needs
- Self-management
- Wellbeing
- Linking of cancer to other long term conditions
- Service development and cultural change
- Survivorship care plans
- Multidisciplinary working

Open section

Final thoughts…

Is there anything else you would like to add?

Thank you!!

Appendix 4: Participant information sheet

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Study exploring perceptions on aspects of the 'survivorship' agenda

Participant information sheet
Thank you for your interest in the above study, I believe your participation will contribute to developing understanding of practitioners' perceptions of aspects of survivorship and their motivations to engage in training.

You have been selected to be approached to take part in this study due to your expression of interest in the educational programme on survivorship at the University of Lincoln.

Please note that it is entirely up to you whether you wish to take part in the study. If you require additional information about any aspect of the study, please contact Amanda Thompson (12300093@students.lincoln.ac.uk) or Ros Kane, research supervisor (rkane@lincoln.ac.uk; 01522 837326).

If you decide to take part, you will be asked to sign the consent form (a copy of which is attached to this information). You can choose to withdraw your interest and or consent at any time and no reason will be sought for your decision and it will have no detrimental effect on your participation in the survivorship module, or educational progress during the module.

The School of Health and Social Care Ethics Committee has approved this project. (The University of Lincoln's Ethical Principles for Conducting Research with humans is available from http://secretariat.blogs.lincoln.ac.uk/files/2013/09/UREC-Policy-Oct-2013.pdf). Though a novice researcher, I am fully guided by experienced research supervisors.

What is the purpose of the study?
There is a growing interest in understanding the experiences of people who are living with and beyond cancer, and in exploring how health and social care professionals and services can best support this group. This has come to be known as the 'survivorship' agenda. Research has revealed a level of patient dissatisfaction: that physical, emotional, and social needs which arise after completion of treatment are not being met. I am researching this topic in order to increase understanding of this relatively new area of practice.

I hope that findings from the study will help to shape the Lincoln University module in 'survivorship' by informing curriculum design (responding to what practitioners identify as relevant and necessary to develop their practice), and will ultimately contribute towards improving patients' experiences and outcomes.

What is involved?

The study is designed around in-depth confidential interviews with participants. In view of the distance some people may be travelling to Lincoln, I can offer various options for scheduling interviews as below:

1. Interviews at University on module days (including small group interviews of 2 or 3 if this is acceptable to participants, and matches their preferred times)
2. Individual interviews at a time/place convenient to participants
3. Telephone interview scheduled to best suit participants.

I would like to digitally record the interview to enable comprehensive capturing of data, but if participants do not consent to recording then detailed notes of interviews will be made instead.

The nature of the interview will be to explore practitioners' perceptions on the survivorship agenda, and their motivations to engage with post registration training in this area. Questions related to these areas will invite participants to reflect on experiences from practice; share thinking on how individuals and services can respond to meet these needs; and to explore what are perceived as enablers or barriers to progress in these areas.

The confidential interview will take about an hour, I do appreciate that this is a significant commitment of your time, but the actual timing of the interview will be planned to best suit you. I plan to conduct the interviews between now and early June.

What happens to the data?

The data collected from each interview will be added to data from other interviews to gain a deeper understanding of practitioners' perceptions and motivations. Findings from this analysis will be reported thematically and anonymously in my dissertation.

Data will be stored securely in locked cabinets at the university. All interview data in whatever form (audio or notes) will be anonymised and this anonymity will be maintained throughout the transcription (if applicable) and all subsequent stages of the study.

The data (if recorded) will be transcribed by myself. It will be analysed for items which appear to be significant in the understanding of the issues identified above with the intention of placing them within the body of my final BSc dissertation. Any themes which emerge through analysis and any direct quotes will be anonymised and you will not be identifiable.

Thank you once again for your interest

Yours faithfully

Amanda Thompson

Appendix 5: Consent form

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Study exploring perceptions on aspects of the 'survivorship' agenda

Consent form

I confirm that I have read the participant information sheet about this study and I am content that I understand the purpose and my involvement in the study.

I confirm that I have been provided with information about how I can seek additional information and to clarify the purpose and requirements of my involvement.

I confirm that my involvement is completely voluntary and that I understand that I can withdraw my involvement at any time without the need to offer a reason and with no ill effect on my standing on the programme, or educational achievement related to the programme.

I understand that all data relating to my involvement will be kept locked in a secure filing cabinet in accordance with the University of Lincoln ethical code for research.

I understand and agree that any data presented in the final dissertation will be anonymised.

I consent to the interview being recorded digitally.

I agree to take part in the above study.

I give consent for the findings to be potentially published in a reputable relevant journal.

Name of person consenting:
Date:
Signature:

Name of researchers: [*insert names here*]
Date:

Signature:

On completion: 1 copy to participant and 1 copy to secure research file.

Appendix 6. Ethics application and topic guide for outcome interviews

EA2

**Ethical Approval Form:
Human Research
Projects**

UNIVERSITY OF
LINCOLN

This form must be completed for each piece of research activity whether conducted by academic staff, research staff, graduate students or undergraduates. The completed form must be approved by the designated authority within the Faculty.

Please complete all sections. If a section is not applicable, write N/A.

1 Name of Applicant	Dr Ros Kane
	Department: School of Health and Social care ・ College: College of Health and Social Science
2 Position in the University	Reader in Healthcare
3 Role in relation to this research	Researcher (will work with colleagues Ian Trueman – Principal Lecturer in nursing - and Stacey Phillips – Clinical Academic Fellow) on overseeing the whole research process including recruitment, data collection, analysis, report writing and dissemination.
4 Brief statement of main Research Question	**Project title: An outcome evaluation of a new initiative: education and training in 'survivorship'.** **Project aim:** To conduct an outcome evaluation of a short programme of study exploring the concept of survivorship in people previously diagnosed with cancer or other long-term condition. Please note that this is a subsequent ethics application – to conduct the outcome element of an evaluation on a study which was previously approved and undertaken during 2014. The formative and process components of the evaluation have already been reported on. We now aim to finalise the study with an exploration of outcome with a view to reporting back to the funders with a comprehensive evaluation of the entire programme. We are now in a position to follow up participants 2 years post completion of their training programme. The initial approved ethics application is included with this current application for information. The main features of investigation will focus on the views of a cohort of participants on the above programme short which was first delivered by the University in 2014. The aim of this strand of the research is to examine the ability of participants to adopt and apply elements of the training programme in

their workplace and to examine the extent to which the training may have influenced new ways of working with people who live with or have recovered from cancer. The evaluation will involve an investigation of personal / professional development in the attitudes, knowledge and behaviours of a cohort of clinical practitioners engaged in the educational programme and explore potential facilitators of barriers to the transfer of their learning.

Project outcomes:
An investigation into the views of previous participants of the short course of the extent to which they have implemented core aspect of the programme to their current clinical practice. Facilitators and barrier to transfer of learning will be explored.

Project outputs:
6. A full scale programme (formative, process and outcome) evaluation available to project funders (Macmillan)
7. Information to aid development of future 'survivorship' training programmes.
8. Primary qualitative research dataset
9. A potential for publication as (an) academic paper(s)
10. Potential for presentation/poster displays at an appropriate academic conference

Timescale – December 2016 – May 2017

Brief description of the research project
Background:

Macmillan and the University of Lincoln have a formal agreement to work together in the development of local and national initiatives to support excellence in the care and treatment of cancer. The University of Lincoln and Macmillan Cancer Support formally agreed collaboration in November 2013, focusing on cancer survivorship. The collaboration is only the second of its kind between Macmillan, the UK's largest cancer care and support charity, and a university.

As part of the agreement, the University of Lincoln's Centre for Professional Development developed a new accredited education and training courses for health and social care professionals.

The first of these was this Survivorship programme. On this module delivered during 2014, speakers from Macmillan Cancer Support and from other disciplines such as Occupational Therapy, Physiotherapy and Social Care were invited to ensure that the module offered to inter-professional groups, was delivered by inter-professional groups.

Macmillan Cancer Support commissioned the development and delivery of this new education and training programme examining the concept of 'survivorship' in cancer. Currently there are two million people living with or beyond cancer in England (DoH 2013). With the development of new treatments it is expected that this figure will rise to four million by 2030 (DoH 2013). The national strategy for cancer (DoH 2007) calls for a culture shift in the role and behaviour of professionals towards shared decision making and recovery.

An emerging research literature has identified that people who live with or have recovered from cancer have significant unmet needs (Armes *et al* 2009). These needs emerge as:

- *Financial*: as a diagnosis and treatment for cancer may bring significant changes in job role or employability, thus potentially reducing household income. Recovery from cancer may require retraining for new work roles and possible challenges in entering the employment market.
- *Medical*: as the treatment for cancer may leave both short or long term side effects
- *Emotional:* This relates to the psychological adjustments to physical changes following treatment for cancer. Personal identity related to recovery from cancer and the consequences of living with the diagnosis are important factors. In addition the emotional investment by family and social network in the process of survivorship is an important area of investigation.
- *Practical:* This relates to access to information and support about living with and beyond their condition and the effects of cancer diagnosis on the lives of individuals.

The educational development programme consisted of;

This module aimed to allow students the opportunity to examine the health and social care priorities when facilitating the improvement in outcomes for people living beyond cancer and living with long term conditions. The module also considered the similarities experienced by people who are living with a long term condition as many of their needs appear to overlap.

Students had an opportunity to consider how services may need to be developed in the future. The module was delivered at both level 6 and 7 to enable a cross section of participants to benefit from each other's knowledge and experience.

The research proposal
The Department of Health (2007; 2013) has reiterated the need to develop a deeper understanding of the individual, social and national issues of survivorship in cancer. The psychological impact of 'recovery' (even if this means living with the disease) represents a significant reorientation of professional practice. This research initiative will explore these dimensions of professional practice and seek to understand the impact that an educational and training programme such as this may have in supporting aspects of the culture change in care provision. The formative and process elements of the module evaluation have already been undertaken. What remains is the outcome component following up the participants post-completion of their training.

The formative, process and outcome evaluation of training schemes such as the one outlined here represent an important element in learning about improvements to education and training and the barriers and drivers for change in professional practice. Programme evaluation can provide valuable insights on educational delivery; help share learning and make recommendations for future action. This proposed research initiative seeks to gain a detailed understanding on the attitudes, knowledge and behaviours of the participants on the survivorship training programme.

To complete the research aim we now intend to collect post-programme primary qualitative data (in-depth interviews) from participants.

Methods

We intend to complete the following:

- A comprehensive review of the academic and policy literature relating to survivorship (NB this was completed on 2014 – we now deed to update it for final publication).
- Demographic data collection including a personal biography of clinically relevant research experience and interest of participants on the programme
- Analysis of module evaluation data – to be completed immediately at the end of the module.
- In-depth interviews with all participants who undertook and completed the initial training programme (n=5)   analysed using Framework Analysis (Ritchie & Spencer 1994)

All interviews will the tape recorded (if permission is granted) and transcribed verbatim. Where consent to record is not given, extensive notes will be taken during the interview.

Time frame:

November 2016	Applying for Ethics/ research governance approval
December 2016	Contacting the small sample students who undertook the training to invite them to take part in an in-depth interview
January-March 2017	Updating the literature review and conduct follow-up interviews
March 2017	Analysis and write up of post-training quantitative evaluation data (using a standard module evaluation questionnaire)
February- April 2017	Transcription and analysis of data
May 2017	Report writing

Approximate Start Date:	Approximate End Date:
December 2016	May 2017

6 Name of Principal Investigator or Supervisor	Dr Ros Kane	
	Email address:	Telephone:
	rkane@lincoln.ac.uk	01522 837326
7 Names of other researchers or student investigators involved	1. Ian Trueman (Principal Lecturer) 2. Stacey Phillips (Clinical Academic Fellow)	
8 Location(s) at which project is to be carried out	University of Lincoln Brayford campus	

9 Statement of the ethical issues involved and how they are to be addressed –including a risk assessment of the project based on the vulnerability of participants, the extent to which it is likely to be harmful and whether there will be significant discomfort. **(This will normally cover such issues as whether the risks/adverse effects associated with the project have been dealt with and whether the benefits of research outweigh the risks)**	The ethical issues to account for are as follows: 1. There are potential risks and burdens placed upon the participants being interviewed for evaluation. There is a risk that participants may become distressed during the interview when reflecting on their involvement in the programme or their day-to-day practice. Particularly if they are not feeling positive about the impact or influence of the programme on their professional practice. 2. It is also important that all participants and researchers note the possibility of personal disclosure or the breaking of patient confidence anonymity during reflections on clinically relevant clinical incidents. At all times both researchers and participants will be reminded of the requirement to maintain confidentiality and anonymity during reflective discussions and a formal analysis Some of the research team lack experience in conducting primary research, however they will be supervised closely by experienced researchers over the life of this project. These members (as will all members of the team) will be abiding by NMC ethical codes of professional practice and conduct at all times. Participation is completely voluntary. Those engaged in the training programme on survivorship will be invited to take part but are under no obligation to do so. Their participation or otherwise or their sudden withdrawal from the study will not affect their position on the programme. They will not be asked to give a reason for withdrawal. Informed consent will be required before the interview in a prepared room where participants are given time to consider their participation (or otherwise) in the evaluation. The time for gaining consent and interview will be approx 90 minutes. There will be refreshments and comfort facilities available. This allows the participant to ask questions regarding the consent process consider their decision and withdraw if necessary. The interviews will not be conducted by anyone directly involved in the development of delivery of the training programme. The participants have a choice to either allow the interview to be recorded for transcription or for the interviewer to take comprehensive notes (see consent form). 3. There is concern that there will be a failure to recruit a varied sample group and there is a smaller concern that the individuals may not wish to participate. The programme leaders are confident that participants will consent to take part in the evaluation. All participants are to be informed that participation is voluntary and that they are free to withdraw at any stage without giving a reason. This will not impact in any way on their future participation in the training itself. 4. Confidentiality of participant data may cause an issue. However, participants taking part in the interview

| | process will be informed that their personal details such as neither their name, nor any other identifying information will only appear on the secure computer files and not on the subsequent transcripts from the interviews.

All data collected by the researcher will be made anonymous before the interviews are transcribed. This will enable the researcher to maintain confidentiality throughout the analysis and evaluation process.

All such data will be stored in a locked metal filing cabinet at the University of Lincoln. Furthermore, no identifiable data will be held on lap tops or other electronic media. All other research data collected through the interviews will be anonymised and stored for 7 years in accordance with health and university policies. |

Ethical Approval From Other Bodies

10 Does this research require the approval of an external body?	Yes ☐ No X
	If "Yes", please state which body:-
11 Has ethical approval already been obtained from that body?	Yes ☐ -Please append documentary evidence to this form. No X If "No", please state why not:- N/A **Please note that any such approvals must be obtained and documented before the project begins.**

<u>APPLICANT SIGNATURE</u>

I hereby request ethical approval for the research as described above.
I certify that I have read the University's ETHICAL PRINCIPLES FOR CONDUCTING RESEARCH WITH HUMANS AND OTHER ANIMALS.

_____

Applicant Signature   **Date 01 11 2016**

_____R Kane_____

PRINT NAME 45

FOR COMPLETION BY THE FACULTY RESEARCH ETHICS COMMITTEE

Please select ONE of A, B, C or D below:

☐ **A. The Faculty Research Ethics Committee gives ethical approval to this research.**

☐ **B. The Faculty Research Ethics Committee gives <u>conditional</u> ethical approval to this research.**

10 Please state the condition (inc. date by which condition must be satisfied if applicable)	

☐ **C. The Faculty Research Ethics Committee cannot give ethical approval to this research but refers the application to the University Research Ethics Committee for higher level consideration.**

11 Please state the reason	

☐ **D. The Faculty Research Ethics Committee cannot give ethical approval to this research and recommends that the research should <u>not</u> proceed.**

12 Please state the reason, bearing in mind the University's ethical framework, including the primary concern for Academic Freedom.	

Signature of the Chair of the Faculty Research Ethics Committee

_____   _____

Signature   **Date**

An outcome evaluation of a new initiative: education and training in 'survivorship'.

Individual Interview Guide

Introductions:

- Offer brief introductions
- Explain the aim and purpose of the research and provide a general overview of the topics to be discussed
- Revisit ethical aspects of the study and participant's participation
- Check participant's views and permissions regarding audio-recording of the interview
- Explain end product of research and obtaining final report

Discussion points:

a) Thank you again for agreeing to talk with me. The first question relates to you understanding of the role of the nurse/Allied health professional in Survivorship.

- Can you tell me your understanding of this?

Offer a prompt on elements of nurse/AHP role if participant is not sure:

b) It might be argued that this focus on survivorship in clinical practice is new or somehow different in the NHS".

- What are your views on this?

c) What personal difference do you think being engaged on the Survivorship training programme made in the following areas:

- Your confidence?
- Your personal ability?
- Your influence at work?
- Your motivation to achieve?
- Any other?

For each of the above ask the participant to provide examples of their behaviour to demonstrate the points being made.

d) Can you tell me about the impact your completion of the survivorship module has had on your team?

e.) Can you tell me about the impact your completion of the survivorship module has had on your organisation?

f) Can you tell me about the impact your completion of the survivorship module has had on your professional discipline?

g) Can you tell me about the impact your completion of the survivorship module has had outside your organisation?

h) Can you tell me how having the qualification has changed your practice?

Offer a prompt if participant is not sure:

Prompts:
- Opportunity to act as a role model?
- Barriers to implementation of training?
- Facilitators to implementation of training?
- External NHS/Non-NHS pressures?
- Team pressures?
- Any other?

For each of the above ask the participant to provide examples of their behaviour to demonstrate the points being made.

j) We are interested in learning more about patient care in the NHS and the role of training in survivorship in supporting people living with and beyond cancer and those with other long-term conditions. Can you tell us your thoughts and actions to support enhancement of patient care since undertaking the survivorship module?

Note to interviewer: focus on behaviours

Thank you, have you anything else to add?