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# Learning and Development in People Living with and Affected by Cancer

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## **EXECUTIVE SUMMARY**

### **Background**

In order to support people throughout their cancer journey, the UK charity, Macmillan Cancer Support offers a range of free courses, training opportunities, workshops and e-learning for people living with and affected by cancer, including carers, family members, volunteers and community members.

Macmillan asked the University of Lincoln to carry out a study around Learning and Development (L&D) provision focusing on (although not exclusive to) the Midlands region of England.

### **Methods**

The study collected quantitative and qualitative data from August to November 2019. This was done using an online survey (N=119) that asked people living with and affected by cancer questions on demographics and L&D provision. Participants could select multiple responses to the majority of questions. In addition, a series of semi-structured interviews (N=10) were conducted with a range of Professionals who were involved in supporting people living with and affected by cancer. Qualitative data were analysed using thematic analysis.

### **Results**

There was demand for L&D to be delivered face-to-face (N=74), as well as, online (N=66). Participants reported that they would like Health and Social Care Professionals (N=54) and people with a personal experience of a cancer diagnosis (N=64) to do facilitate the L&D. The most popular settings for L&D to be delivered were: in the community (N=75) and online (N=47) although some participants also reported wanting clinical or healthcare settings (N=38).

There were four themes from the qualitative data with Professionals (1) Setting (2) Including the Lived Experience (3) Communication and Inclusiveness and (4) Tailoring to Individual Needs.

## **Conclusion**

Macmillan should ensure that their future L&D offer is available face-to-face, as well as, online. Although the mode of delivery is likely to be dependent on the L&D on offer. Where L&D is delivered face-to-face, there would appear to be demand for this to be held in both a clinical and community setting. Where appropriate this should be facilitated by experienced Health Professionals and people with lived experience.

## **ACKNOWLEDGEMENTS**

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Finally, we are extremely grateful to the people living with and affected by cancer who completed the online questionnaire and the professionals who gave up their valuable time to be interviewed. We hope that the findings in this report can be used to inform future service provision to improve the lives of people living with and affected by cancer.

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## 1.0 INTRODUCTION

In the UK, there are two and a half million people living with and beyond cancer and this is set to exceed five million by 2040 (Maddams et al, 2012). This can be attributed to a range of factors, such as, increases in incidence due to an ageing population and advances in screening, and improved survival as a result of earlier detection and improvements in and access to treatment (Calman and Foster, 2018; DeSantis et al, 2014).

Whilst increases in survival are a positive long-term outcome of improvements in care, they present a range of challenges for the patient, their family, as well as the wider health and social care system. Indeed, this generates a growing population of cancer survivors, many of whom have unmet survivorship needs (Parry et al, 2011) particularly at the end of treatment, including, for example, psychological distress (Foster et al, 2009) and fear of recurrence (Armes et al, 2009) which can impact negatively on quality of life. Studies suggest that people with a diagnosis of cancer report more comorbid conditions and poorer physical and mental health compared to those without cancer (Smith et al, 2008) and they are more likely to suffer from fatigue (Corbett et al, 2016), anxiety (Greer et al, 2011), depression (Pasquini and Biondi, 2007), as well as, being at an increased risk of developing secondary tumours (Mariotto et al, 2007).

A considerable challenge now is to find new and innovative ways to treat, support and care for this emerging population from diagnosis through to treatment and beyond, when they can have a range of complex medical and psychosocial needs. As a response to the growing number of people surviving cancer, Calman and Foster (2018) have noted an increasing focus on not just the quality of survival, but also the number of disease-free years. Nonetheless, it should not be assumed that just because an individual is free of disease, that they are entirely cured of the consequences of a cancer diagnosis with some of the considerable and long-term impacts including emotional distress (Deimling et al, 2006), relationship and sexual problems (Badr and Carmack Taylor, 2009; Candy et al, 2016), as well as financial difficulties (Foster et al, 2009; Marti et al, 2016). In some cases, the consequences of cancer can emerge five to ten years after treatment and these 'late effects' have a



notable impact on individual health and wellbeing (Calman and Foster, 2018). For example, some chemotherapy drugs can cause heart or lung problems later in life or even early menopause and infertility (Macmillan Cancer Support, 2018). Additionally, many people living with and beyond cancer may suffer from several other health problems that have been exacerbated or caused by a cancer diagnosis and its subsequent treatment (Edgington and Morgan, 2011).

In order to support people throughout their cancer journey, the UK charity, Macmillan Cancer Support offers a range of free courses, training opportunities, workshops and e-learning for people living with and affected by cancer, including carers, family members, volunteers and community members.

Macmillan asked the University of Lincoln to carry out a study around Learning and Development (L&D) provision focusing on (although not exclusive to) the Midlands region of England.

The purpose of the study was to find out what types of L&D and training support people living with and affected by cancer would find most beneficial. A team of researchers from the School of Health and Social Care at the University of Lincoln conducted an online questionnaire with people living with and affected by cancer, as well as, a series of telephone interviews with a range of Macmillan and Health professionals who were involved with L&D and wider support for people affected by cancer. The findings will be used to inform Macmillan's L&D strategy across the Midlands and beyond as well as ensuring that future service provision is informed by people's needs.

It should be noted that the term "Learning and Development" (L&D) was used for consistency throughout the study documentation and when reporting the results. However, in the questionnaire and interviews, it was acknowledged that use of this terminology might mean different things to people affected by cancer and healthcare professionals. Therefore, the terms 'education' and 'training' were also utilised to evoke broader responses in relation to supporting people affected by cancer with their learning needs.

## **2.0 METHODS**

### **2.1 Ethical Approval**

An application was made to the University of Lincoln Human Ethics Committee (REF: 2019-Jul-0749) on 16<sup>th</sup> July 2019 via the LEAS (Lincoln Ethics Application System). A favourable opinion was received on 26<sup>th</sup> July 2019 and a copy of the approval letter can be found at Appendix: **1 University of Lincoln Ethical Approval Letter**. All participants (questionnaire and interviews) read and signed a consent form prior to participation. Physical and digital data were anonymised and stored securely at the University of Lincoln, Brayford Campus on a password protected PC and locked filing cabinet in the Principal Investigator's office which remained locked when not in use. When reporting data all identifiable personal information was removed.

### **2.2 Study Design**

The study collected both quantitative and qualitative data and was cross-sectional in design meaning that data were collected at one point in time for each participant. Data were collected from August to November 2019.

This was done using an online questionnaire designed using Qualtrics software, Version [2019] of Qualtrics. The questionnaire asked people living with and affected by cancer questions on demographics, their experiences of cancer and L&D provision. The questionnaire was piloted with a Macmillan volunteer and suggested changes adopted where appropriate. The questionnaire can be found at Appendix: 2. The online questionnaire was advertised on Macmillan's social media accounts in the Midlands (Facebook and Twitter) and actively promoted by two Macmillan Engagement Leads with their professional networks. Quantitative data were reported on using frequencies and percentages and free-text responses analysed thematically.

A series of semi-structured interviews (telephone and face-to-face) were conducted with a range of Macmillan and other Health Professionals who were involved with L&D provision and supporting people living with and affected by cancer. In the first instance, participants were contacted via email by a senior member of Macmillan's L&D team to

ascertain their interest in supporting the research. They could then self-select to take part by making contact with the research team. In order to best accommodate participant's busy schedules, they were also given the option to complete an email questionnaire when they could not commit to a telephone or face-to-face interview. The topic guide and email questionnaire were piloted with a range of Macmillan Professionals prior to wider data collection. The interview topic guide can be found at Appendix: 3. Interview data were digitally recorded and transcribed verbatim. Data were analysed using Braun and Clarke's (2006) approach to thematic analysis.

### **3.0 RESULTS FROM THE QUESTIONNAIRE**

#### **3.1 Characteristics of Questionnaire Participants**

Given the questionnaire was posted online we were unable to calculate a response rate. Furthermore, the number of responses to each question varied as some were recorded as missing. The data reported on below were from 119 responses.

The majority of respondents were aged 55-74 (N=72) and female (N=89). The overwhelming majority reported their ethnicity as White British (N=108). In terms of highest educational attainment, twenty eight per cent (N=33) were educated to A level or equivalent and four per cent reported having no qualifications (N=5). Forty six per cent (N=54) were retired and twelve per cent said they were unable to work (N=14).

With regard to their cancer experience, ninety six respondents said that they had a personal diagnosis of cancer and forty five stated that they had cared for or supported a friend/partner/family member with their cancer. For those that had a personal diagnosis, forty three stated that it had been over five years since they were diagnosed. Table 1 below presents the Characteristics of Questionnaire Participants.

**Table 1: Characteristics of Questionnaire Participants**

		<b>N (%)</b>
<b>Age</b>	25-34	2 (1.69)
	35-44	17 (14.41)
	45-54	19 (16.10)
	55-64	37 (31.36)
	65-74	35 (29.66)
	75-84	8 (6.78)
<b>Gender</b>	Female	89 (74.79)
	Male	30 (25.21)
<b>Ethnicity</b>	White British	108 (91.53)
	White Irish	2 (1.69)
	Other White	4 (3.39)
	Mixed/Multiple - White and Black Caribbean	1 (0.85)
	Mixed/Multiple - White and Asian	1 (0.85)
	Other Asian	1 (0.85)
	Black/African/Caribbean/Black/British – Caribbean	1 (0.85)
<b>Educational Attainment</b>	Postgraduate Degree or Equivalent	29 (24.58)
	Degree or Equivalent	31 (26.27)
	A level or Equivalent	33 (27.97)
	GCSE or Equivalent	20 (16.95)
	No qualifications	5 (4.24)
<b>Employment Status</b>	Employed Full-Time	21 (17.80)
	Employed Part-Time	15 (12.71)
	Self-Employed	8 (6.78)
	Retired	54 (45.76)
	Not employed	6 (5.08)
	Unable to Work	14 (11.86)
<b>Experience with Cancer*</b>	I have been diagnosed with cancer	96 (67.61)
	I have cared for or supported a partner/family member/friend who has been diagnosed with cancer	45 (31.69)
	I have not been diagnosed with cancer and have not supported or cared for someone who has been diagnosed with cancer	1 (0.70)
<b>Treatment Status</b>	I have received a diagnosis of cancer and have not started treatment	1 (0.99)
	I am currently under active surveillance or watchful waiting	7 (6.93)
	I am currently undergoing treatment (e.g. surgery, chemotherapy, radiotherapy, hormone therapy, immunotherapy)	13 (12.87)
	I have completed treatment (e.g. surgery, chemotherapy, radiotherapy, hormone therapy, immunotherapy)	43 (42.57)
	I have completed treatment (e.g. surgery, chemotherapy, radiotherapy, hormone therapy, immunotherapy) but am taking hormones or other medication for cancer.	27 (26.73)
	Other	10 (9.90)
<b>Time Since Diagnosis</b>	0-6 months	4 (3.92)
	6-12 months	11 (10.78)
	1-2 years	15 (14.71)
	2-3 years	17 (16.67)
	3-4 years	6 (5.88)
	4-5 years	6 (5.88)
	Over 5 years	43 (42.16)

\*Percentages equal >100 as participants could select multiple responses

For those who were diagnosed with cancer, the most frequently reported cancer types were breast (N=39), brain, other central nervous system (CNS) and intracranial (N=33) and bowel (N=10). It should be noted that participants could select multiple options had they received more than one diagnosis. See table 2 below for the cancer types of Questionnaire Participants.

**Table 2: Cancer Type of Questionnaire Participants**

<b>Cancer Type*</b>	<b>N=</b>
Breast	39
Prostate	8
Lung	5
Bowel	10
Melanoma Skin Cancer	3
Non-Hodgkin Lymphoma	4
Kidney	1
Head and Neck	8
Brain, Other CNS and Intracranial Tumours	33
Bladder	1
Uterus	2
Leukaemia	7
Oesophagus	1
Ovary	3
Liver	3
Myeloma	2
Thyroid	2
Other sites	4

*\*Participants could select multiple options if they had received multiple diagnoses*

In relation to where participants said they resided, the most frequently reported responses were Lincolnshire (N=28), Shropshire (N=17) and Staffordshire (N=16). Despite the study primarily focusing on the Midlands region of England, respondents resided across a range of locations in the United Kingdom as evidenced in Table 3 below.

**Table 3: Residence of Questionnaire Participants**

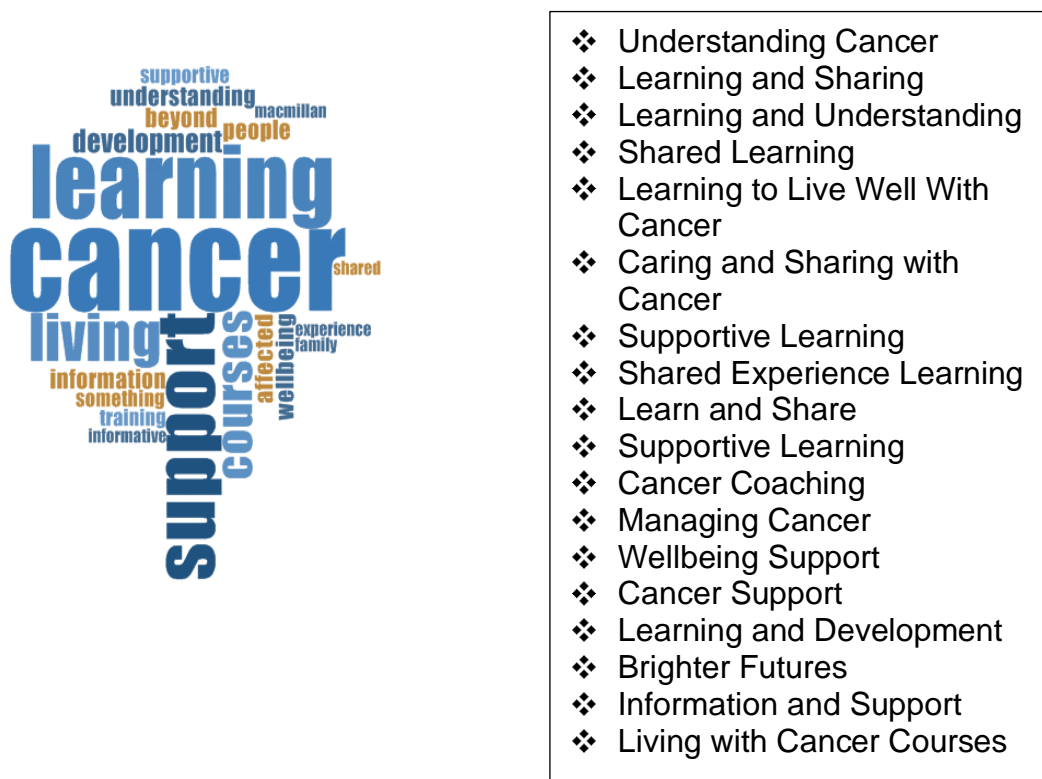
<b>Area</b>	<b>N=</b>
Lincolnshire	28
Northamptonshire	6
Derbyshire	3
Leicestershire and Rutland	3
Staffordshire	16
Warwickshire	7
Shropshire	17
Herefordshire	6
Worcestershire	3
Somerset and Gloucestershire	8
Hampshire	4
Dorset	4
Sussex	2
Cheshire	1
Lancashire	1
Devon	1
Surrey	1
West Yorkshire	1
Wales	1
Scotland	1
Other*	4

*\*Participants wrote in 'West Midlands' as other*

### 3.2 Naming of Learning & Development Courses

Questionnaire respondents were asked what they felt education, training and learning and development courses should be called. Figure 1 below presents a word cloud with the twenty most frequently used words with at least five characters, as well as, a selection of full responses in the text box. The five most frequently used words were cancer (N=29), learning (N=21), support (N=18), living (N=13) and courses (N=10).

**Figure 1: Word Cloud of Most Frequent Words and Selected Responses**



### 3.3 Mode of Delivery of Learning & Development

Participants were asked how they would like to receive training and learning and development support. The results are presented in Table 4 below. The most frequently reported categories were face-to-face (N=74), group format (N=69) and online (N=66). Telephone (N=18) was the least selected mode of delivery. One of the participants who selected other felt that people should be *'given a choice as everyone is individual'*. Interestingly, when breaking this question down by age there was not a significant preference for online and digital support with younger participants.



**Table 4: Mode of Delivery of Learning & Development**

<b><i>Mode of Delivery*</i></b>	<b><i>N=</i></b>
Online	66
Digital App	29
Face-to-face	74
Telephone	18
One-to-one	49
Group format	69
Printed materials	52
Other	6

*\*Participants could select more than one option*

### **3.4 Facilitator of Learning & Development**

The questionnaire respondents were asked who they felt should deliver training courses and L&D support and the results are presented in Table 5 below. Macmillan Professionals (N=73) and people with a personal experience of cancer (N=64) were the most frequently reported options. Some of those who selected other reported that it should be *'different people at different times'*, *'a mix'* or *'combination'* of those listed. One participant said it should be delivered by *'teachers and lecturers'* and another reported that *'professionals should learn to work together with cancer patients in recovery and not think they know best'*.

**Table 5: Facilitate the Delivery of Learning & Development**

<b><i>Facilitator of L&amp;D*</i></b>	<b><i>N=</i></b>
Health and Social Care Professionals	54
People with a personal experience of a cancer diagnosis	64
People affected by cancer	46
Macmillan Professionals	73
Volunteers	24
Other	11

*\*Participants could select more than one option*

### 3.5 Location of Learning & Development

The questionnaire asked respondents where they felt training and L&D support for people living with and affected by cancer should be delivered. The most popular preferences were in the community (N=75) and online (N=47). Some of those who selected other felt that this should be delivered in ‘universities’, a ‘nurturing environment’ that was ‘comfortable’ and ‘social’, as well as, in ‘different settings at different times’. Response Frequencies are presented in Table 6 below.

**Table 6: Location of Learning & Development**

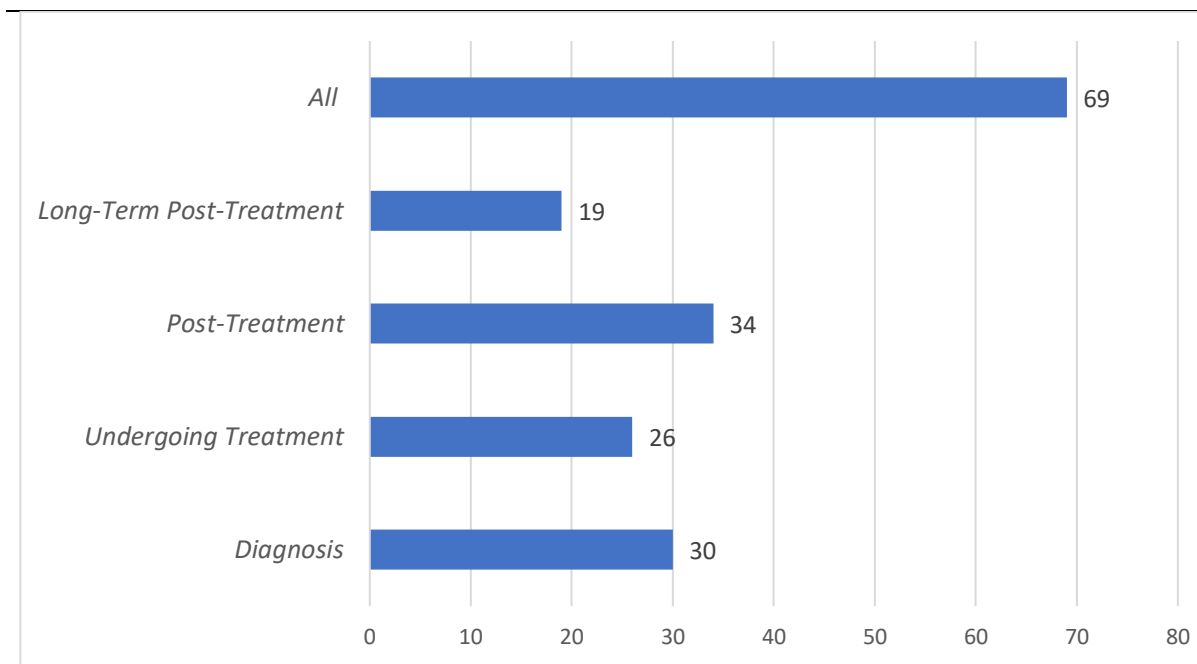
<b><i>Location of L&amp;D*</i></b>	<b><i>N=</i></b>
Community	75
Clinical or Healthcare Setting	38
Home	33
Online	47
Other	9

*\*Participants could select more than one option*

### 3.6 Timing of Learning & Development

Participants were asked the question ‘at what times in the cancer journey do you think people living with and affected by cancer most need access to training and learning and development support?’ The most frequently reported response was ‘all of the above’ (N=69) indicating a preference for learning at all stages of the cancer journey and is demonstrated in the Timing of Learning & Development reported in Figure 2 below.

**Figure 2: Timing of Learning & Development**



Note: Participants could select more than one option

### 3.7 Length of Learning & Development

Respondents were asked how long they felt education and training that is delivered to people living with and affected by cancer should last and the results are presented in Table 7 below. The most frequently reported responses were 1-2 hours (N=40) and half a day (N=38). The least popular response was that this should last a full day (N=14). A selection of the responses for other included depending ‘on what stage the person was at’, ‘what the session is and how far I would have to travel’ and ‘the content and mental capacity of attendees.’

**Table 7: Length of Learning & Development**

<b>Length of L&amp;D*</b>	<b>N=</b>
1-2 Hours	40
2-3 Hours	22
Half Day	38
Full Day	14
Other	9

\*Participants could select more than one option

### 3.8 Time of Day for Learning & Development

Participants were asked at what time of day they would like L&D to be delivered and the responses are presented in Table 8 below. With regard to the timing, the morning (N=59) and afternoon (N=52) were the most frequently reported responses with only twenty participants selecting that they would like this to be delivered in the evening. In relation to the day of the week, more people wanted this delivered on weekdays (N=67) as opposed to on the weekend (N=23). When examining these responses based on employment status, it should be noted that there was more demand for courses to be held at the weekend and evening with those who were in full-time employment although we would need more data before we could say anything definitively as the increase in preference was marginal.

**Table 8: Time of Day for Learning & Development**

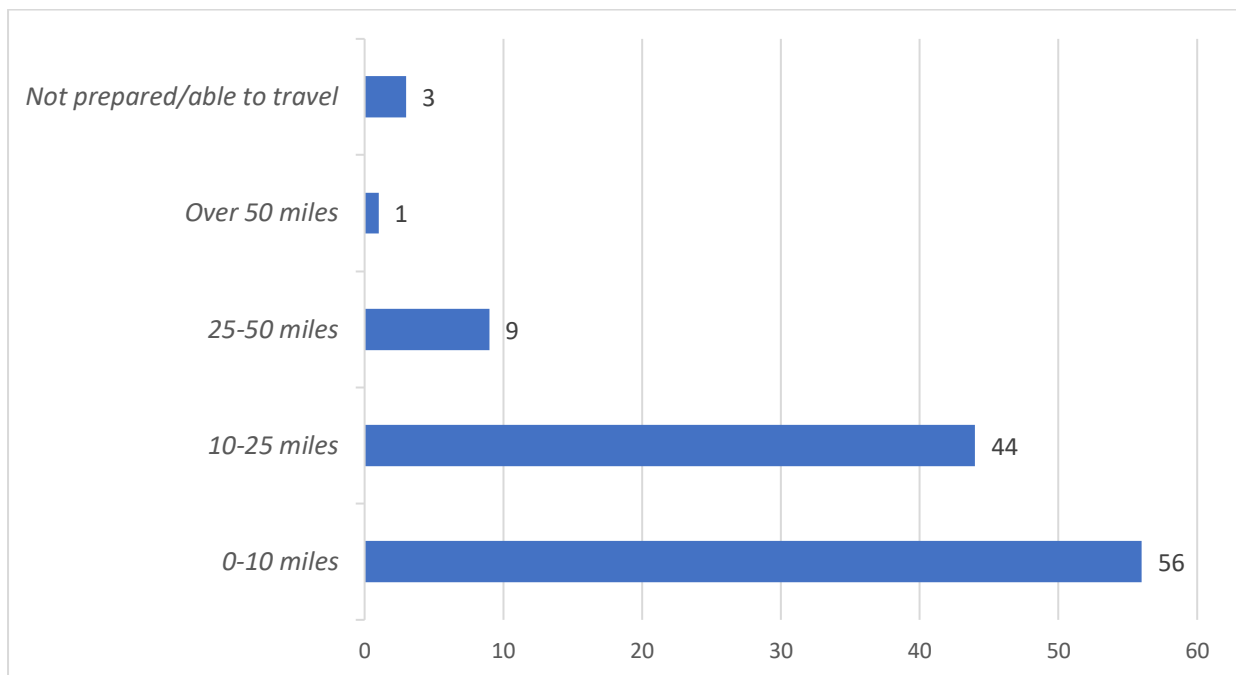
<i>Time of Day</i>	<i>N=</i>
Morning	59
Afternoon	52
Evening	20
Monday to Friday	67
Saturday or Sunday	23

*\*Participants could select more than one option*

### 3.9 Travel Distance for Learning & Development

The questionnaire asked participants how far they would be prepared to travel to attend an educational or training course for people living with and affected by cancer. Three respondents selected that they were not prepared or able to travel. The least frequently reported response was over 50 miles (N=1) and the most frequently reported distance was 0-10 miles (N=56). Findings are presented in Figure 3 below.

**Figure 3: Distance Prepared to Travel for Learning & Development**

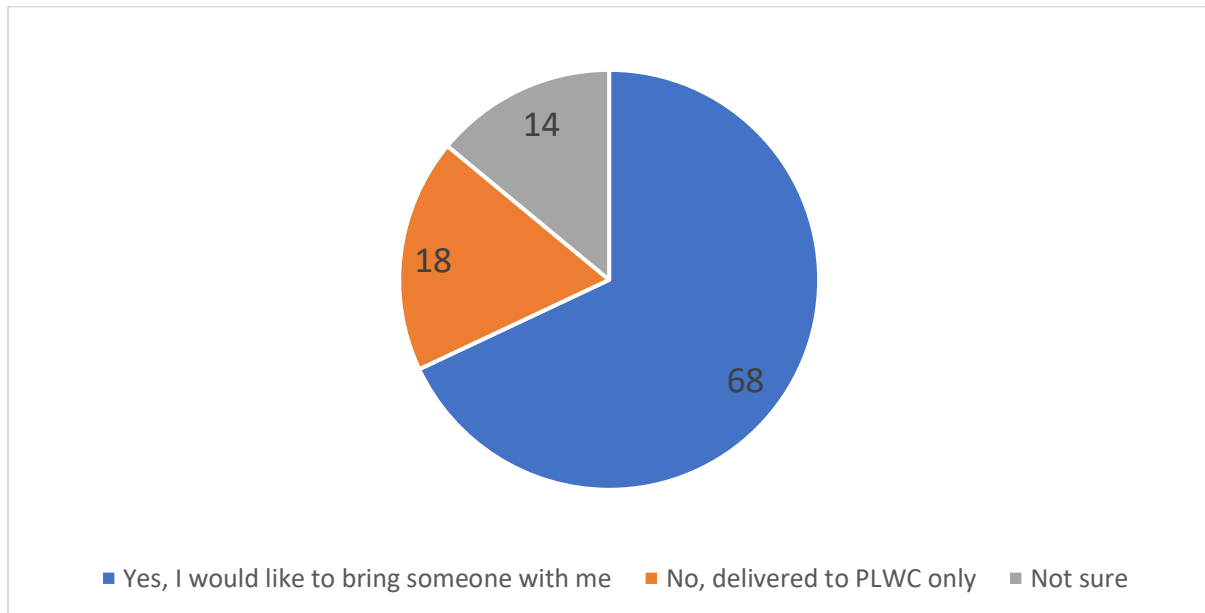


*Note: Participants could select more than one option*

### **3.10 Attendance Preference for Learning & Development**

Respondents were asked the following question ‘If you have been diagnosed with cancer and were to attend an educational or training course would you like to bring a partner/friend/family member with you to the course?’. Sixty eight per cent (N=64) selected that they would like to have the option to bring someone with them to a course and eighteen per cent (N=17) would prefer these to be delivered to people living with cancer only. The results are presented in Figure 4 below.

**Figure 4: Attendance Preference at Learning & Development for People Living with Cancer (reported in %)**



### **3.11 Most Beneficial Learning & Development**

The questionnaire asked participants what types of training, educational and L&D support they felt people living with and affected by cancer would find most beneficial. There were three themes that emerged from the data (1) Coping with Cancer (2) Emotional Support and (3) Peer Support. These are summarised below.

#### *3.11.1 Coping with Cancer*

Participants reported that L&D that would help them to *'cope with cancer'* in both the short and longer-term would be beneficial. To do this, they felt they needed support on managing side effects, finances and employment, diet and nutrition, emotional wellbeing, exercise, as well as, relationships and talking to friends and family members about cancer. Notably, many reported that L&D that would support *'confidence building'*, and *'coping mechanisms'* along with *'future planning'* that would *'enable them to be involved'* in their recovery and help to *'move forward positively'* would be beneficial to people living with and affected by cancer. Finally, some respondents maintained that L&D should be *'clear and concise'*, *'informal'* and *'easy to understand'*

and that courses could incorporate *'personal interests'*, *'computer skills'*, *'crafts'* and *'art therapy'*.

### 3.11.2 Emotional Support

Emotional and psychological support was a prevalent theme in the data. Participants reported that they wanted *'basic mental health first aid'*, advice on *'keeping mentally healthy'*, as well as, learning and support that would facilitate the understanding and management of the emotional and psychological consequences of cancer. Respondents specifically said they would find support on coping with fear of recurrence, stress, and anxiety beneficial. A number of participants felt that mindfulness was a helpful strategy that people affected by cancer could benefit from adopting.

### 3.11.3 Peer Support

Peer support was a prominent theme within the data and many participants felt that *'general discussion with like-minded individuals'* and *'meeting with other similarly-afflicted cancer patients'* as well as *'help and talking to people who have been through the same thing'* would be a positive form of support and learning for others. Cancer often put a significant strain on respondents' personal relationships, and some reported having difficulty opening up to close friends and family, therefore, they felt that exposure to other people's experiences of cancer beneficial when it came to coping with their own situation, as reported by the participant below:

*"Personally, I have found understanding other people's journeys and experiences of cancer helpful in enabling me to come to terms with my own situation. I found it helpful to talk to others who have been in a similar situation to myself. I think this is because during the cancer journey one can feel very isolated".*

### 3.12 Positive Experiences of Learning & Development

Next, respondents were asked the following question ‘In terms of the learning and development and training course provision that is already out there, what do you think is being done well?’ Three themes were generated from the thematic analysis (1) Awareness and Engagement with L&D (2) Written Material and (3) Face-to-Face Support.

#### 3.12.1 Awareness and Engagement

For many of the participants, there was limited awareness and/or engagement with L&D and training support and as such, they felt ill informed to give a comprehensive answer to the above question. This was evidenced by a number of responses indicating that ‘*I haven’t personally had any training*’ or ‘*I haven’t attended any so I can’t comment*’ or ‘*I have not really heard of much available*’. Others said that ‘*this is the first time I have heard this [L&D] is available*’ and that ‘*it [L&D] is rarely advertised and people don’t know about most of it*’ and that ‘*I know of no courses currently on offer in my region*’. Other participants stated that there is ‘*not enough on offer but also what is on offer is not communicated enough*’ or is ‘*inaccessible*’. The following participant felt advertising from Macmillan in relation to L&D was lacking and said that they preferred ‘*going to a learning day/event and I’ve not seen much coming from Macmillan in a long time, I have learnt a lot from the Cancer Research training days and conferences though*’. The following participant who was caring for their husband reports negatively on how they were not aware of L&D opportunities or non-clinical support, she stated:

*“We received no learning or development opportunities while my husband was being treated (finished in 2014), so as far as we are concerned, NOTHING is being done well. We couldn’t fault the treatment my husband received, but the total lack of non-clinical support was awful. We have no family or close friends in the area, so I as a carer, felt as if everything was my responsibility, and that I had no right to expect to be able to enjoy my “normal” activities, inside or away from our home”.*



### 3.12.2 Written Material

Participants reported positively on much of the written material that was currently available. Specifically, the printed literature, most of which was provided by Macmillan was perceived as *'excellent', 'well written in an accessible format'* and *'very informative'*. At the same time, some of those who reported positively on the written material acknowledged that *'perhaps there is too much of it'* and it could be *'overwhelming'* and that they found it *'difficult to stop reading'* where it would sometimes cause *'anxiety arising from the unknown'*. Additionally, there were further positive comments about the Macmillan website and the online and community forums.

### 3.12.3 Face-to-Face Support

In addition to written material, there were positive responses surrounding face-to-face provision, for example one respondent said that *'many forms of support in different formats – one-to-one, groups, workshops etc. - are very friendly and helpful with providing support'*. Others commented that *'current Macmillan courses are done well'* as well as, face-to-face provision from other cancer charities such as Breast Cancer Care, Cancer Research UK and Penny Brohn. Of particular note, participants commented positively on programmes such as *'Get Active Feel Good'*, *'Living with and Beyond Cancer'* and *'Look Good Feel Better'*. There were also answers expressing good experiences of local support groups and The Relate Macmillan Counselling Service. Another participant reports positively below on a range of face-to-face activities that they thought were done well, she stated:

*"I really liked the counselling, the art classes, the reflexology, the return to fitness and the make-up classes. They were all delivered professionally and in a timely manner. I had to go to the Penny Brohn Centre (private) to get some 'me' time away from the family and learn a lot".*

In addition to the above, telephone support was highly regarded by some participants, and considered to be done well when it came to L&D, training and education support. Participants spoke favourably of 1:1 phone calls with a Macmillan nurse, as well as,

the Macmillan helpline which was considered to be *'very helpful'*, *'have a good reputation'* and *'be highly trusted and staffed by people who have a lot of experience.'*

### **3.13 Improving Learning & Development**

The next question asked participants to consider what they felt could be done better in the future with regard to L&D and training course provision for people living with and affected by cancer. There were two themes from the data (1) Promotion and Marketing (2) Encouragement and Support

#### *3.13.1 Promotion and Marketing*

Given the lack of engagement with formal L&D provision and the limited awareness of support that is currently available (see 3.12.1), it was not surprising that many participants felt that promotion and marketing efforts should be enhanced to raise awareness with patients at all stages of the cancer journey. Participants stated that it should be *'accessible'* and *'better promoted'* with *'more marketing'* and to *'advertise a wider range of courses more clearly'* at a local level. Respondents felt that *'public awareness of what is available through hospitals/hospices/GP surgeries and general communications'* could be improved, as well as, *'more awareness by consultants and CNSs of what support is available'*. The following participant when referring to the HOPE (Helping Overcome Problems Effectively) self-management course maintained that there was a lack of knowledge surrounding its availability and *'like a lot of Macmillan information, its very existence does not get to all patients'*. Furthermore, another participant explained the importance of the terminology that is used for L&D and training support, in order to facilitate an open access programme of resources, and as such, this should be considered with future promotional and marketing efforts.

#### *3.13.2 Encouragement and Support*

The responses highlighted instances where participants felt that people needed to be supported with engaging in L&D and training. One participant maintained that *'when you feel a part of something you feel motivated and like you belong'*. They went on to say that *'this makes you feel positive'* and that people should be supported and

encouraged whilst they are participating in L&D activities. Others felt that organising networking groups to attend courses together could be *'self-supporting'* and done better. Another participant maintained that people need easier access and support to apply for courses. Other responses highlighted that support for those struggling mentally could be better, and that there should be recognition that *'we all learn in different ways and need different things at different times'* we therefore need a *'suite of resources that people can choose from and be signposted to'*.

### **3.14 Barriers to Learning & Development**

Questionnaire respondents were asked about their perceived barriers to accessing current L&D and training support. There were two themes from the data (1) Information and Awareness and (2) Accessibility.

#### *3.14.1 Information and Awareness*

For those that wanted information, they reported *'not knowing about it'* and that there was *'not enough'* or a *'lack of information'* and that *'finding what was out there'* as well as *'where to find it'* was a barrier to accessing current provision. In line with previous comments on promotion and marketing, one participant felt that *'inadequate advertising'* was a barrier to accessing information on L&D, although they maintained that *this was 'understandable with limited budgets'*. For others, they did not know how to find information and respondents said that *'signposting'* was a problem and that there was a lack of input from specialist staff, one respondent commented that there was *'no information provided by doctors and consultants'*. For others an *'overload of information at diagnosis'* was a perceived barrier to accessing L&D. However, some felt that *'individual attitudes and responses towards asking for and seeking help'* were a barrier as opposed to awareness, and that *'sometimes the patient does not want to access training with other cancer sufferers, as they prefer not to know about the side effects that they are going through'*. The following respondent comments on the lack of awareness around L&D and support in general, which they feel is down to ineffective communication, they stated:

*“Awareness that they are available. When you consider many people affected by cancer are not even aware of the existence of Information and Support Centres in their own hospital, there is a gap in communicating provision”.*

### 3.14.2 Accessibility

Accessibility was a prevalent theme in the questionnaire data. Respondents reported that courses were not accessible to them within their local area and that having to travel a considerable distance for support was a barrier to engaging with L&D. For some, suffering from other health conditions and disabilities, as well as undergoing individual treatment regimens and treatment related side effects, such as fatigue and incontinence, made travelling to physical courses problematic. In some cases, participants did not have access to a vehicle or resided in a remote area with limited transport links. With regard to cost, participants stated that having *‘no financial support’* and *‘travel costs’* impeded on their ability to attend courses. Others maintained that the time of day at which the courses were held or the fact that they were in full-time employment also meant they were unable to attend the sessions. Those who had returned to work suggested that training should be made available at weekends. Participants also felt that *‘many older people are not computer literate and do not want the added stress of trying to learn to use this sort of learning support’* and that there was an *‘overreliance on IT’* and that L&D needs to *‘include those who may not be able to use or have access to a computer’*.

## **4.0 RESULTS FROM THE INTERVIEWS**

### **4.1 Characteristics of Interview Participants**

A total of ten participants who were involved in supporting people living with and affected by cancer took part in an interview. They had a range of roles including Clinical Nurse Specialists (CNSs), Macmillan Engagement Leads, HOPE Workshop Facilitators, Macmillan Information and Support Officer, Macmillan Community Facilitator and a senior member of the L&D team. In some cases, participants had more than one role within their professional remit. For example, one was a CNS and a HOPE Facilitator, another was a Macmillan Volunteer and a HOPE Facilitator and finally, one was a Macmillan Information and Support Officer, as well as, a HOPE Facilitator. They were asked a series of open-ended questions via telephone (N=5), email (N=4) and face-to-face (N=1).

### **4.2 Results from the Interviews**

There were four themes in the data (1) Setting (2) Including the Lived Experience and (3) Communication and Inclusiveness and (4) Tailoring to Individual Needs.

#### *4.2.1 Setting*

Participants had a range of opinions and experiences with the delivery of L&D in both a clinical and a community setting, with a mixture of views over the optimal location for delivery. However, it was widely acknowledged that people would like courses to be local to them within their county and that they did not want to travel too far. For some, delivering L&D in the clinical or hospital setting offered familiarity and a sense of security in a trusted environment where people affected by cancer had already established relationships and rapport with staff. This was particularly salient around the period of initial diagnosis, as well as when undergoing treatment. However, others remarked that once participants had completed their treatment, they would prefer this type of support to be delivered in the community as they did not want to return to the place where they had received their treatment.

Regardless of setting, initiatives such as HOPE, were highly regarded by professionals and people affected by cancer, as programmes that supported self-management and recovery. Professionals reported L&D needs around self-management, fatigue, physical activity, managing long-term side effects and support with moving on with their lives. HOPE was therefore a highly sought-after programme, although it was not always readily available in individuals' particular geographical settings. Engagement Leads commented that HOPE '*would be of value to many people but is only available in certain areas*' and that it is '*limited in [the] numbers that it reaches and is only available face-to-face.*' Despite the small number of attendees, the following participant who was involved with delivering HOPE in the community stated:

*"The feedback was phenomenal. It was generally, right everybody should have one of these as a matter of course...the dynamic of having the HOPE course out of the clinical setting was a real help for at least two of the participants. Actually, getting them out of the house and doing some independent travel to come to the venue, that was massive for them, even before they started on the course"* **Macmillan HOPE Facilitator and Volunteer.**

At the same time, it was acknowledged that delivering L&D in the community could be hindered by geography, notably in rural and remote areas where transport links were poor and people had to travel considerable distances to access provision. One participant who worked in a predominantly rural county as a community facilitator suggested that '*work needs to be done with CNSs to refer more people onto the course*'. Equally, for those organising and facilitating the course, establishing and maintaining professional links for community venues also proved problematic and costly. It was suggested that more facilitators would need to be recruited and trained in order to support the delivery of L&D in harder-to-reach areas.

Within the hospital setting, one HOPE Facilitator explained how the programme had been very successful in terms of the number of attendees, as well as the number of facilitators available to deliver the course. They explained how they had received additional training to support them in their role as a facilitator and that they were now able to assess new facilitators, of which at the time of data collection, they had nineteen. Furthermore, another participant commented that HOPE had been

successful in the clinical setting as when it is kept in-house clinical staff and the Information and Support Centres are able to signpost potential participants to it. At the same time, they commented that *'parking is costly'* for attendees and that *'transport can also be a problem'* when trying to access the hospital.

In some cases, support in the community in a rural setting was well attended and proved beneficial to those that engaged with it. The following participant explained how Macmillan *'Living Well'* sessions that were created to help and support people affected by cancer with issues such as fatigue, nutrition, exercise and emotional wellbeing were positively received in the community. They stated:

*"Living Well sessions are now being run in community venues. These have proved much more successful in attracting patients than when run at the hospital".* **Macmillan Engagement Lead.**

There were instances in the data where facilitators of L&D in both the community and clinical setting, reported positive experiences of delivering it: *'it was a fantastic feeling to do it, I got an awful lot from it...and I know that they did as well'*. Another facilitator who was from a clinical setting remarked that delivering L&D was *'very rewarding'* and *'powerful'*. Notably, in both the clinical and community settings, past recipients of L&D initiatives such as HOPE, had expressed an interest in becoming a facilitator themselves, with some going on to be trained and eventually taking up the role.

#### *4.2.2 Including the Lived Experience*

There was a consensus amongst the majority of participants that L&D provision needs to incorporate the lived experiences of people living with and affected by cancer. This should be considered when providing both interactive online and face-to-face support. It was acknowledged that a mixed approach to L&D should be adopted whereby it is delivered by both professionals and peers where appropriate. For example, the participant below commented on how using speakers with a personal experience of cancer worked well at past events in their area:

*“The contribution of two speakers with lived experience of cancer was very well received at Living Well sessions”* **Macmillan Engagement Lead.**

Another participant who worked in the community felt that people living with cancer would like to receive L&D *‘face-to-face with other people that have been through cancer’*, as well as, online. They went on to comment that L&D provision needs to be informed and make use of people’s lived experience prior to development and implementation. They said:

*“I definitely think more insight needs to be given to what is offered and this should be done with people that have lived experience”* **Macmillan Community Facilitator.**

Furthermore, professionals felt that the involvement of people with lived experience did not always have to be in a formal capacity such as a speaker or facilitator; it could be extended to more informal group discussions at events where there were reports that *‘people really enjoyed meeting and talking to others, they benefited greatly from tips and ideas’* as well as, the social element of having *‘contact with others’*.

In terms of emotional support, bringing people together to share their cancer experience was thought to relieve feelings of isolation:

*“I think that people that have been through similar experiences sometimes do like to come together because I think that gives people the opportunity to realise that other people are feeling similar to how they might be feeling and therefore it gets rid of that sense of isolation, that I am the only one in the world, feeling like this.”* **Macmillan Education Delivery Lead.**

Another one of the Engagement Leads commented that they *‘would like to see Macmillan offering a buddy support service where they buddy people up with somebody going through something similar’*.



As mentioned earlier, some past participants of the HOPE course went on to receive training and become facilitators themselves. This was another way that the lived experience could be used to directly inform the delivery of L&D. The following participant who was a CNS and a HOPE facilitator explained how using people with a personal experience of cancer as facilitators has had a positive impact on course provision. They stated:

*“...it is very rewarding two nurses doing it, but when you have got a patient...we have three of them that have attended the HOPE training to become facilitators and we have run a couple of courses with them now and the patients that actually attend the course, oh wow, the connection they have with those facilitators, we are literally just there sitting in the corner going, wow, it is amazing to watch and see”* **Macmillan CNS and HOPE Facilitator.**

#### *4.2.3 Communication and Inclusiveness*

A further theme in the data was communication and inclusiveness, specifically around how L&D was advertised and promoted to people living with and affected by cancer from a range of backgrounds. It was widely acknowledged that more could be done to reach out to those that may not have a good command of the English language or be computer literate, as well as, those with learning disabilities and mental ill-health. Therefore, information around L&D needed to be communicated in a variety of formats in order to make it more universally accessible . The below participant felt that poor communication preceded issues around accessibility and so good communication was imperative. They stated:

*“Communication is the first barrier – if we are not communicating with them, then we are not necessarily going to know about accessibility”* **Macmillan Engagement Lead.**

Another participant explained how they felt the HOPE course albeit very successful involved a lot of reading and writing and was not as well suited to people who do not speak English. They stated:

*“Well ethnicity is definitely an issue, because we feel that the HOPE programme is very much geared towards white, almost middle-class people, because there is such a lot of reading and writing involved. We have people from different ethnic background who attend the course, but they have always been people with a really good understanding of English...the people who don't speak English very well there isn't a lot out there”* **Macmillan Information and Support Officer and HOPE Facilitator.**

A further professional felt that efforts should be made to ‘reach out to people who may not be literate as well as those with mental health needs and the elderly.’ One of the engagement leads felt that people who attended existing courses were mostly well educated and articulate and more needs to be done to communicate L&D to the public as a whole. They said:

*“I find that the patients I encounter who access Macmillan courses are generally articulate, educated and actively involved with a number of organisations and causes. Our courses do not seem to land well, when I am promoting them, with patients who have low confidence, are not well connected socially or who experiences additional difficulties like mental health, learning difficulties, language barriers etc. I think more needs to be done to make our courses more appealing to the general public at large”* **Macmillan Engagement Lead.**

Furthermore, there was some discussion around the terminology and language that is used to communicate service provision. Professionals felt that this needed to be accessible and lay friendly and there were positive reports by some of the professionals that much of the printed materials to support people living with cancer is in a readable format. However, it was suggested that the term “L&D” itself was too formal and an ‘unusual title to refer to’ as well as being a ‘funny concept’ that might not be relatable to people living with and affected by cancer. There was a consensus that L&D provision that is communicated from inception to delivery should consider the language that is used and be applicable to people from different demographic and cultural backgrounds.

Professionals who had experience working with people from rural and remote areas commented that internet access and digital inclusion were pertinent considerations when it came to delivering L&D. Additionally, one professional maintained that Macmillan's current online offer was '*not attractive and difficult to navigate*'.

Another participant felt that Macmillan as an organisation needed to make more efforts to communicate their local activities in those respective areas. They stated:

*"I think it would be nice to see obviously not on TV but somehow some form of communication, maybe billboards or bus stops, posters or something of what Macmillan are doing locally because that makes people feel a bit more involved or thought of by a big national name, that they are focusing on what is going on in Leicester or Lincolnshire or Cambridgeshire or whatever. I think for me that makes me feel that they have been reached personally"* **Macmillan Palliative Care CNS.**

#### 4.2.4 Tailoring to Individual Needs

Interview participants commented that people have a range of different needs and preferences with regard to learning and would like to receive L&D in a way that suits them, be that online, face-to-face or via the telephone. Therefore, L&D provision needs to acknowledge this and provide bespoke support that is tailored to individual needs. It was felt that it could be difficult for someone to walk into a room full of strangers or to travel to a new place, particularly when they are feeling vulnerable, so in these instances, online support might be preferable. However, several participants commented that face-to-face support and human interaction could prove beneficial for people living with and affected by cancer. That said, the participant below felt that non-engagement with face-to-face support did not mean that people did not want to be supported and that online methods might better suit their needs. They commented:

*"Some people do not want to sit and share those things together. Not everybody is comfortable doing that. That does not necessarily mean that they are not keen to feel supported. They might prefer to do things that are sort of distance*

*learning or online learning as opposed to being in a group”* **Macmillan Education Delivery Lead.**

Participants commented that age could influence the emotional management of cancer in addition to the type of L&D that is requested:

*“Generally, the older cancer patients seem to be accepting of their cancer diagnosis and treatment whereas younger patients seem to struggle more with being able to move on from their diagnosis, treatment and side effects”*

**Macmillan Engagement Lead**

Those who were younger and still in employment needed to be considered when it came to having L&D that they could engage with and it was suggested that courses need to run at different times of the day to accommodate them. That said, one of the HOPE facilitators maintained that when they *“tried later in the evening, but that was the worst attended course, so we went back to our afternoon slot”*.

Furthermore, some professionals commented that the needs of people in rural and urban areas could differ greatly, as well as, within different cities and town. Therefore, L&D that works in one part of a county or region might not necessarily work elsewhere and should be tailored accordingly. Other professionals commented that deprivation should also be considered and that the needs of people living with and affected by cancer were different in these areas as opposed to those in more affluent areas. Specifically, financial constraints meant that these people might not be readily available to engage with existing course provision. Moreover, needs were different for those who were suffering from other co-morbidities and it was suggested that L&D provision should also consider this.

It was acknowledged that people had different L&D needs based on where they were at in their own personal cancer journey. Equally, it was felt that needs could differ based on the type of cancer and the treatment that the person had received. Notably, a CNS who worked in Palliative Care reinforced how the L&D needs for patients in receipt of palliative care will be somewhat different to others. A professional who worked in the community felt that *‘based on my experiences of working with people*

*with cancer the main L&D need would be around treatment and anything related to aiding recovery*'. Another participant who worked in an Information Centre in a clinical setting felt that people needed support with their lives following the completion of primary treatment. They said:

*"I think that a lot of their needs are around once they have finished treatment or nearing the end of treatment: how do they get on with the rest of their lives? I think we have got key workers and doctors and radiographers and all the rest of it who are very skilled at treating people through their treatment phase, but I think the bit the patients need help with is afterwards."* **Macmillan Information and Support Officer and HOPE Facilitator.**

Furthermore, in order to meet people's needs, it was suggested that more could be done by offering shorter courses alongside the six-week HOPE course. One of the HOPE facilitators commented that *"there might be courses they could come to if it was just a day, or morning, or afternoon rather than the six-week course"*.

## **5.0 RECOMMENDATIONS AND CONCLUSION**

### **5.1 Recommendations**

In line with the previously reported data a number of recommendations have been formulated to inform the future delivery of L&D provision to people living with and affected by cancer. These are reported on below:

#### *5.1.1 Face-to-Face and Online*

The questionnaire highlighted preferences for L&D that was available both face-to-face, as well as, online. Therefore, Macmillan should prioritise delivering L&D in both of these formats. Equally, there was a consensus amongst professionals that people affected by cancer wanted to be able to access L&D in a format that suited them and providing both digital and physical (printed materials) support offers more choice. However, it should be acknowledged that some courses may work better digitally as opposed to face-to-face and vice versa. Notably, in hard to reach and rural areas, online provision that is interactive could have the potential to act as a form of peer support and relieve social isolation.

#### *5.1.2 Clinical and Community Setting*

The results from the questionnaire indicated that people living with and affected by cancer would like L&D that was delivered in both the clinical and community setting. Although the questionnaire findings highlighted that the community was the most frequently selected location, and this perhaps was best suited to delivering L&D post-treatment. Indeed, the professionals that were interviewed reported positive experiences where provision had worked in both the clinical and community setting. It should be acknowledged that where a course is delivered will be dependent on a number of factors (e.g. access to a suitable venue, course content, availability of trained professionals etc.) but it was apparent that L&D needs to be offered in both of these settings to improve accessibility and meet individual preference.

### *5.1.3 Course Content*

Whilst L&D needs will be dependent on the individual and the stage of the cancer journey, there was a consensus from professionals and patients that course provision needs to focus on 'coping with cancer' 'aiding recovery', 'self-management' and promoting health and wellbeing. For the most part, people felt that L&D was a particularly salient concern when individuals were post-treatment. The content of the existing HOPE programme appears to be a good fit with the questionnaire responses and is already delivered successfully in some areas. Furthermore, it appears to be well regarded amongst the professionals that were interviewed. That being said, it is not readily available in all geographic regions. Therefore, Macmillan should aim to increase their face-to-face provision of HOPE in both the clinical and community setting, as well as, the newly launched digital version, iHOPE.

### *5.1.4 Facilitated by Health Professionals and People with Lived Experience*

Macmillan's L&D offer should make efforts, where appropriate, to involve people with lived experience in the delivery of face-to-face and online courses. The questionnaire data emphasised a demand for L&D that was facilitated by people with lived experience, as well as, health professionals. Indeed, the interview data also reinforced that professionals felt that people benefited significantly through peer support. Given the success in training past participants of the HOPE programme as future facilitators, this could be a potential recruitment stream that is prioritised to involve those with lived experience in future provision. Equally, it is vital that courses are facilitated by trained and knowledgeable professionals who have past experience of delivering L&D.

### *5.1.5 Communication Strategy*

For many of the questionnaire respondents, there was limited awareness and/or engagement with current L&D provision. Equally, it was not surprising that many felt that promotion and marketing efforts should be enhanced to raise awareness with patients at all stages of the cancer journey. Macmillan needs to consider how it communicates its L&D offer (that is delivered to people living with and affected by

cancer) with professionals and the public, to promote inclusiveness, as well as, increasing awareness and engagement. Communication efforts need to consider different demographics at a local, regional and national level. L&D should be accessible and in a range of formats that are in line with population need. Furthermore, consideration needs to be given to how L&D is communicated and delivered in areas that have a high proportion of people who are non-English speakers.

#### *5.1.6 Branding of 'Learning and Development'*

Whilst it was used for consistency in reporting these findings, 'Learning and Development' can be considered a formal title that lends itself to education that is delivered solely to professionals. Interestingly, some of the professionals that were interviewed for this research did not identify with the term when it came to supporting people living with and affected by cancer. Whilst it is acknowledged that Macmillan have not universally adopted this term when it comes to communicating with patients, they should however, give careful consideration to what their 'L&D' 'education' 'training and learning' offer as whole is branded as, as well as, to the naming of individual courses and workshops.

#### *5.1.7 Further Research*

The questionnaire responses came from people who were predominantly white and well educated which limits their generalisability to the wider population. Additionally, the findings from professionals highlighted issues around inclusivity with different ethnic groups and those who had limited English language skills and learning disabilities. Future research should make efforts to purposively recruit from these underrepresented populations in order to ascertain their views on L&D so that this can be used to inform and improve Macmillan's L&D offer.



## **5.2 Conclusion**

This report has presented the findings from a research study that examined L&D provision that is delivered to people living with and affected by cancer in the Midlands region (although not exclusive to) of England. The quantitative and qualitative data illustrated a demand for L&D that was delivered both face-to-face and online where appropriate. There is no one size fits all approach to its delivery and patients and professionals alike acknowledged that people learn in different ways. Therefore, support should be tailored to individual needs and people would like this delivered in both a clinical and a community setting. Finally, L&D should make efforts, where appropriate, to involve people with lived experience in the delivery of face-to-face and online courses.

## 6.0 REFERENCES

- Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., Palmer, N., Ream, E., Young, A., and Richardson, A. (2009) Patients Supportive Care Needs Beyond the End of Cancer Treatment: A Prospective, Longitudinal Survey. *Journal of Clinical Oncology*, 27(36), 6172–6179. doi: 10.1200/jco.2009.22.5151.
- Badr, H., and Taylor, C. L. (2009) Sexual dysfunction and spousal communication in couples coping with prostate cancer. *Psycho-oncology*, 18(7), 735–746. doi:10.1002/pon.1449.
- Braun, V., and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. doi: 10.1191/1478088706qp063oa.
- Candy, B., Jones, L., Vickerstaff, V., Tookman, A., and King, M. (2016). Interventions for sexual dysfunction following treatments for cancer in women. *Cochrane Database of Systematic Reviews*. Issue 2. Art. No.: CD005540. doi: 10.1002/14651858.cd005540.pub3.
- Calman, L., and Foster, C. (2018) Cancer Survivorship in G. Velikova, L. Fallowfield, J. Younger, R. E. Board, & P. Selby (eds.), *Problem Solving in Patient-Centred and Integrated Cancer Care*. Witney, UK: EBN Health, 39-44.
- Corbett, T., Groarke, A., Walsh, J. C., and McGuire, B. E. (2016) Cancer-related fatigue in post-treatment cancer survivors: application of the common sense model of illness representations. *BMC Cancer*, 16(1), 919. doi: 10.1186/s12885-016-2907-8.
- Deimling, G. T., Wagner, L. J., Bowman, K. F., Sterns, S., Kercher, K., and Kahana, B. (2006) Coping among older-adult, long-term cancer survivors. *Psycho-Oncology*, 15(2), 143–159. doi: 10.1002/pon.931.
- DeSantis, C. E., Lin, C. C., Mariotto, A. B., Siegel, R. L., Stein, K. D., Kramer, J. L., Alteri, R., Robbins, A. S., and Jemal, A. (2014) Cancer treatment and survivorship statistics, 2014. *CA: A Cancer Journal for Clinicians*, 64(4), 252–271. doi: 10.3322/caac.21235.

Edgington, A., and Morgan, M. A. (2011) Looking Beyond Recurrence: Comorbidities in Cancer Survivors. *Clinical Journal of Oncology Nursing*, 15(1), e3-e12. doi: 10.1188/11.cjon.

Foster, C., Wright, D., Hill, H., Hopkinson, J., and Roffe, L. (2009) Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence. *European Journal of Cancer Care*, 18(3), 223-247. doi: 10.1111/j.1365-2354.2008.01001.x.

Macmillan Cancer Support (2018) *Late effects of chemotherapy*. Available from <https://www.macmillan.org.uk/information-and-support/treating/chemotherapy/side-effects-of-chemotherapy/late-effects-chemotherapy.html> [accessed 3rd June 2019].

Maddams, J., Utley, M., and Møller, H. (2012) Projections of cancer prevalence in the United Kingdom, 2010-2040. *British Journal of Cancer*, 107(7), 1195–1202. doi:10.1038/bjc.2012.366.

Mariotto, A. B., Rowland, J. H., Ries, L. A., Scoppa, S., and Feuer, E. J. (2007) Multiple Cancer Prevalence: A Growing Challenge in Long-term Survivorship. *Cancer Epidemiology Biomarkers & Prevention*, 16(3), 566–571. doi: 10.1158/1055-9965.epi-06-0782.

Marti, J., Hall, P. S., Hamilton, P., Hulme, C. T., Jones, H., Velikova, G., Ashley, L., and Wright, P. (2016) The economic burden of cancer in the UK: a study of survivors treated with curative intent. *Psycho-Oncology*, 25(1), 77–83. doi: 10.1002/pon.3877.

Parry, C., Kent, E. E., Mariotto, A. B., Alfano, C. M., and Rowland, J. H. (2011) Cancer survivors: a booming population. *Cancer epidemiology, biomarkers & prevention: a publication of the American Association for Cancer Research, cosponsored by the American Society of Preventive Oncology*, 20(10), 1996–2005. doi:10.1158/1055-9965.EPI-11-0729.

Pasquini, M., and Biondi, M. (2007) Depression in cancer patients: a critical review. *Clinical Practice and Epidemiology in Mental Health*, 3(2). doi:10.1186/1745-0179-3-2.

Smith, A. W., Reeve, B. B., Bellizzi, K. M., Harlan, L. C., Klabunde, C. N., Amsellem, M., Bierman, A.S., and Hays, R. D. (2008) Cancer, comorbidities, and health-related quality of life of older adults. *Health Care Financing Review*, 29(4), 41–56.

# Appendices

## Appendix: 1 University of Lincoln Ethical Approval Letter



### Application Details

Ethics Reference 2019-Jul-0749  
Title of Project L&D in People Living With and Affected by Cancer: A Service Evaluation across the Midlands.  
Lead Researcher Mr David Nelson  
Committee Human Ethics Committee (PR)  
Date of Ethical Opinion 26 July 2019

### Favourable Opinion

Thank you for your revised submission. The further information has been considered on behalf of the committee and I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form and supporting documentation.

The favourable ethical opinion provided is conditional to the following requirements:

- The following must be added to any recruitment materials: including posters, adverts, social media posts 'The project [insert study title] contributes to research conducted on behalf of the University of Lincoln and has received a favourable ethical opinion by a University Research Ethics Committee (Insert Ethics Reference - given at the top of this letter) in accordance with the Guidelines for research recruitment materials (available on the ethics portal page).
- Risk Assessment: In accordance with H&S policy and guidance a risk assessment should be completed or existing risk assessment reviewed/updated before data collection commences. A copy of the risk assessment should be retained with your research data.

### 1. Commencement of the research

1.1 It is assumed that the research will commence within 12 months of the date of the favourable ethical opinion.

1.2 If the research does not commence within 12 months of the favourable opinion being issued, the lead applicant (and academic supervisor for student research) should send a written explanation for the delay. A further written explanation should be sent after 24 months if the research has still not commenced.

1.3 If the research does not commence within 24 months, the REC may review its opinion.

### 2. Duration of favourable opinion

2.1 The favourable ethical opinion of the REC for a specific research study applies for the duration of the study, as detailed in your application (or any subsequent amendments).

### 3. Amendments

3.1 If it is proposed to make an amendment to the research, the lead applicant (authorised by the academic supervisor for student research) should submit an amendment to the REC by accessing the original application form on LEAS and creating an amendment form.

### 4. Monitoring

4.1 Research Ethics Committees may review a favourable opinion in the light of progress reports and any developments relevant to the study. The lead applicant and academic supervisor (for student research), is responsible for ensuring the research remains scientifically sound, safe, ethical, legal and feasible throughout its duration. The lead applicant and academic supervisor (for student research) should submit a progress report to the REC 13 months after the date on which the favourable opinion was given. Annual progress reports should be submitted thereafter.

4.2 Progress reports should be completed and submitted using the forms in LEAS.

### 5. Conclusion or early termination of the research

5.1 The Lead Applicant should complete the End of Study Form in LEAS once the study has completed. It is also their responsibility to inform the Committee of early termination of the project or if the work is not completed.

### 6. Long Term Studies

The lead applicant and academic supervisor (for student research) is responsible for ensuring that the study procedures and documentation are updated in light of legislative or policy changes and also for reasons of good practice (e.g. standards for supporting documentation). This should be documented in the progress report to the REC (see above) and, where necessary, an amendment (see above) should be submitted to the REC. The REC may review its opinion in light of legislative changes or other relevant developments.

Additional guidance may be found at [here](#)

### Statement of Compliance

The Committee is constituted in accordance with the University of Lincoln [Research Ethics policy](#) and [E-QMS SOP E-01 Ethics Committee Operations](#).

Yours Sincerely

A handwritten signature in black ink, appearing to read 'David Mullineaux'.

Professor David Mullineaux

On behalf of Human Ethics Committee (PR)

## Appendix: 2 Online Questionnaire

*Please note that the formatting has changed from the online version (designed in Qualtrics) when exporting to Microsoft Word.*

# Learning and Development (L&D) in People Living with and Affected by Cancer

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### Start of Block: Consent

Q1 Please read and click each statement below to indicate that you agree to take part in the questionnaire.

- I confirm that I have read the information sheet dated (25/07/19) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. I understand that should I withdraw then the information collected so far may not be erased and that this information may still be used in the project analysis.
- I understand that all the information I give will be STRICTLY CONFIDENTIAL and that results from this study will only be presented in an anonymous form.
- I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers.
- I agree to take part in this study.

### End of Block: Consent

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**Start of Block: SECTION 1: ABOUT YOU**

Q1 Please select your age category from the list:

- 18-24
  - 25-34
  - 35-44
  - 45-54
  - 55-64
  - 65-74
  - 75-84
  - 85 years and older
- 

Q2 Which one of the following best describes your gender?

- Female (including transgender women)
- Male (including transgender men)
- Prefer not to say
- If you describe your gender with another term (e.g. non-binary, gender fluid, gender), please provide this here:

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Q3 Please specify your ethnicity:

- White - English/Welsh/Scottish/Northern Irish
  - White - Irish
  - White - Gypsy or Irish Traveler
  - Any other White background (please specify)
- 

- Mixed/Multiple - White and Black Caribbean
  - Mixed/Multiple - White and Black African
  - Mixed/Multiple - White and Asian
  - Any other Mixed/Multiple ethnic background (please specify)
- 

- Asian/Asian British - Indian
  - Asian/Asian British - Pakistani
  - Asian/Asian British - Bangladeshi
  - Asian/Asian British - Chinese
  - Any other Asian background (please specify)
- 

- Black/African/Caribbean/Black British - African
  - Black/African/Caribbean/Black British - Caribbean
  - Any other Black/African/Caribbean background (please specify)
- 

- Arab
  - Any other ethnic group (please specify)
- 

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Q4 Please select the area below that you live in:

- Lincolnshire
  - Northamptonshire
  - Derbyshire
  - Nottinghamshire
  - Leicestershire and Rutland
  - Staffordshire
  - Warwickshire
  - Shropshire
  - Herefordshire
  - Worcestershire
  - Other (Please specify)
- 

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Q9 What is the highest level of qualification that you have obtained?

- No qualifications
  - GCSE or equivalent
  - A Level or equivalent
  - Degree or equivalent
  - Postgraduate Degree or Equivalent
- 

Q10 What is your current employment status?

- Not employed
  - Retired
  - Employed Full-Time
  - Employed Part-Time
  - Self-Employed
  - Unable to work
-

Q5 What is your experience with cancer (please select all that apply):

- I have been diagnosed with cancer
- I have cared for or supported a partner/family member/friend who has been diagnosed with cancer
- I have not been diagnosed with cancer and have not supported or cared for someone who has been diagnosed with cancer

Q6 What type of cancer have you been diagnosed with? (please select all that apply)

- Breast
  - Prostate
  - Lung
  - Bowel
  - Melanoma Skin Cancer
  - Non-Hodgkin Lymphoma
  - Kidney
  - Head and Neck
  - Brain, Other CNS and Intracranial Tumours
  - Bladder
  - Pancreas
  - Uterus
  - Leukaemia
  - Oesophageous
  - Cancer of Unknown Primary
  - Ovary
  - Stomach
  - Liver
  - Myeloma
  - Thyroid
  - Other sites (please specify)
- 
- Not applicable

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Q8 If you have been diagnosed with cancer which of the below applies to your current situation:

- I have received a diagnosis of cancer and have not started treatment
- I am currently under active surveillance or watchful waiting
- I am currently undergoing treatment (e.g. surgery, chemotherapy, radiotherapy, hormone therapy, immunotherapy)
- I have completed treatment (e.g. surgery, chemotherapy, radiotherapy, hormone therapy, immunotherapy)
- I have completed treatment (e.g. surgery, chemotherapy, radiotherapy, immunotherapy) but am taking hormones or other medication for cancer
- Other (please specify)  
\_\_\_\_\_
- Not applicable

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Q27 Again, if you have been diagnosed with cancer, how long has it been since you were first diagnosed?

- 0-6 months
- 6-12 months
- 1-2 years
- 2-3 years
- 3-4 years
- 4-5 years
- Over 5 years
- Not applicable

End of Block: SECTION 1: ABOUT YOU

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**Start of Block: SECTION 2: LEARNING AND DEVELOPMENT SUPPORT**

Q15 Macmillan currently offers a range of free courses, workshops and e-learning for people living with and affected by cancer. This includes people living with cancer, carers, family members, volunteers and community members. Their aim is to help bring together people who are just like you to learn and share with each other so that everyone can get more out of life. This support is often referred to as Learning and Development (L&D), education or training courses. What do you think this type of support should be called:

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Q11 How do you think people living with and affected by cancer would most like to receive training courses and learning and development support? (please select all that apply)

- Online
  - Digital App
  - Face-to-face
  - Telephone
  - One-to-one
  - Group format
  - Printed materials
  - Other (please specify) \_\_\_\_\_
- 

Q12 Who do you think people living with and affected by cancer would like to deliver training courses and learning and development support? (please select all that apply)

- Health and Social Care Professionals
  - People with a personal experience of a cancer diagnosis
  - People affected by cancer
  - Macmillan Professionals
  - Volunteers
  - Other (please specify) \_\_\_\_\_
-

Q13 Where do you think people living with and affected by cancer would like to receive training courses and learning and development support? (please select all that apply)

- Community
  - Clinical or Healthcare Setting
  - Home
  - Online
  - Other (please specify) \_\_\_\_\_
- 

Q14 At what times in the cancer journey do you think people living with and affected by cancer most need access to training and learning and development support (please select all that apply)

- Diagnosis
  - When undergoing treatment
  - After the completion of treatment
  - After the long-term completion of treatment
  - All of the above
- 

Q25 If you were to attend an educational or training course for people living with and affected by cancer how long would you like this to last? (please select all that apply)

- 1-2 Hours
  - 2-3 Hours
  - Half Day
  - Full Day
  - Other (please specify) \_\_\_\_\_
-

Q30 If you were to attend an educational or training courses for people living with and affected by cancer how far would you be prepared to travel? (please select all that apply)

- 0-10 miles
  - 10-25 miles
  - 25-50 miles
  - Over 50 miles
  - Not prepared/able to travel
- 

Q26 Again, if you were to attend an educational or training courses for people living with and affected by cancer when would you like this to take place? (please select all that apply)

- Morning
  - Afternoon
  - Evening
  - Monday to Friday
  - Saturday or Sunday
- 

Q29 If you have been diagnosed with cancer and were to attend an educational or training course would you like to bring a partner/friend/family member with you to the course?

- Yes, I would like to have the option to bring a partner/friend/family member with me
  - No, I would prefer that the course is delivered to people living with cancer only
  - Not sure
  - Not applicable
- 

Q24 What type of training, educational and learning and development support do you think people living with and affected by cancer would find most beneficial?

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Q19 <p>In terms of the learning and development and training course provision that is already out there, what do you think is being done well?</p>

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Q20 <p>With regards to learning and development and training course provision, what do you think could be done better in the future?</p>

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Q16 What do you think are the barriers to accessing current learning and development and training support provision?

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Q21 Finally, is there anything else you would like to add with regards to learning and development, education and training support provision for people living with and affected by cancer?

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End of Block: SECTION 2: LEARNING AND DEVELOPMENT SUPPORT

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## Appendix: 3 Qualitative Interview Topic Guide



### Learning and Development (L&D) in People Living With and Affected by Cancer

#### Topic Guide for Telephone Interviews with Macmillan/Healthcare Professionals

Introduce the study; consent; confidentiality; timing (approx. 30min).

Outline structure.

Give participant time to ask any questions. Re-iterate that participant can refuse to answer any questions and is free to terminate the interview at any time. Use probing throughout where appropriate.

#### INTERVIEW BEGINS

1. *Please introduce yourself and tell us about your current role?*
2. *What involvement (if any) do you currently have with L&D provision (courses, workshops, e-learning, HOPE, Mindfulness etc.) for people living with and affected by cancer?*
3. *What do you think are the L&D needs of people living with and affected by cancer? How, if at all, do these differ (age, gender, ethnicity, cancer type etc.)?*
4. *How do you think people living with and affected by cancer would like to receive L&D support? (e.g. online, face-to-face, telephone, group, individual etc.) Who do you think they would like to deliver this? (health professionals, peers, volunteers etc.)*
5. *Where do you think people living with and affected by cancer would like to receive L&D support? (e.g. community, clinical setting)*
6. *At what times in the patient journey do you think people living with and affected by cancer most need L&D support? (e.g. diagnosis, treatment, post-treatment and beyond, ALL of these)*
7. *In terms of L&D provision, what do you think is currently being done well?*
8. *With regards to L&D provision, what do you think could be done better in the future?*
9. *What do you think are the barriers to accessing Macmillan's current L&D provision?*
10. *Is there anything that currently doesn't exist that you would like to see in place with regards to L&D provision (local/regional/national level)?*
11. *Finally, is there anything we have left out that you would like to add?*

Many thanks for your time.

#### INTERVIEW ENDS



