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A descriptive survey of cancer helplines in the UK: who they are, the services offered and accessibility of those services

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Keywords:	cancer, Oncology, helplines, telemedicine, cancer information, cancer support

Title: A descriptive survey of cancer helplines in the UK: who they are, the services offered and accessibility of those services

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Abstract

Background: There are over 1500 UK health helplines in operation, yet we have scant knowledge about the resources in place to support the seeking and delivering of cancer-related telephone help and support. This research aimed to **identify and describe** cancer and cancer-related helpline service provision: the number of helplines **available**, **the variety of** services provided **and accessibility of those services**.

Method – Online national questionnaire survey sent to 95 cancer and cancer-related helplines in the UK

Results – 69 (73%) of 95 surveyed cancer and cancer-related helplines completed the survey. Most helplines/organisations were registered charities, supported by donations. 73.5% of helplines had national coverage. Most helplines served all age groups, ethnic groups, and men and women. Only 13.4% had a number that was free from landlines and most mobile networks and 56.6% could only be contacted during working hours. Over 50% of helplines reported no provisions for callers with additional needs. 55% had no clinical staff available to callers. Ongoing support and training for helpline staff was available but variable.

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Conclusion – While cancer helplines in the UK offer reasonably broad coverage across the country, there are still potential barriers to accessibility. There are also opportunities to optimise the training of staff/volunteers across the sector. There are further prospects for helplines to enhance services and sustain appropriate and realistic quality standards.

Keywords: cancer, helplines, telemedicine; cancer information; cancer support

Background:

Every year 250,000 people in England are diagnosed with cancer. An estimated 130,000 will die from the disease whilst 1.8 million people are living with or beyond a cancer diagnosis (1). Helplines are one way of providing patients, and others impacted by a cancer diagnosis, with the opportunity to seek information and support outside of the National Health Service and between appointments (2). Helplines have become a core feature of the UK health care system and the importance of them has been acknowledged by the Department of Health as a key way to promote a supported self-management approach to living with cancer (3).

In 2009 the Telephone Helplines Association (now Helplines Partnership) estimated there were over 1500 health related helplines in operation in the UK (4). Despite the popularity of helpline services in general, and cancer helplines in particular, we currently have little systematic knowledge of the types of cancer helplines in the UK, their purpose, and the scope of services provided.

This paper describes the results from a national survey of UK-based cancer and **cancer-**related helplines. As services increase in number, it may become difficult for service commissioners, and existing and start-up helpline organisations, to gain a strategic overview of the cancer helpline landscape to identify gaps in service, points of overlap and possibilities for co-ordination or integration. This survey aimed to provide useful information in this regard.

Aim: To identify and describe cancer and cancer-related helpline service provision both in terms of the number of helplines available, the variety of services provided and accessibility of those services.

1 Methods:

1.1 Inclusion criteria

The national survey aimed to identify all helplines operating in the UK with a cancer-specific or cancer-related remit. A telephone helpline service was defined as an impartial and confidential service that provides information, advice, listening, support or onward referral through a telephone service (normally offered free of charge) (5).A mixed approach was used to determine eligibility, involving screening all available websites for relevant information and speaking with a representative at each of the helplines to establish how they provide their service and whether they viewed their service as meeting our eligibility criteria (in a few cases screening for eligibility was performed by email). Organisations were excluded if they provided a support service such as one-to-one telephone buddy schemes or telephone support groups set up to supplement local group support meetings.

The study focused on helplines that had a cancer-specific remit – either covering specific types of cancer (e.g. breast cancer, colon cancer) or providing more generalised support to those affected by any type of cancer (e.g. Macmillan Cancer Support). Some helplines were not cancer-focused but often took calls from individuals affected by cancer – for

example Cruse Bereavement Helpline and Pain Concern. This paper will refer to these as "cancer-related" helplines.

1.2 Identification of participants

To identify eligible helplines, an online search was undertaken to identify organisations that might provide cancer-specific or cancer-related helpline services (6-16). This included generalised searches on publicly available search engines, including 'google', 'yahoo', 'bing', 'Ask' and using terms such as "cancer helpline services" or "cancer helpline", as well as specific searches related to the twenty most common cancer types in the UK (17). Established directories such as were also consulted (4, 18, 19).

In total, 152 organisations were identified and assessed according to the eligibility criteria. Fifty-one were excluded because when contacted it was established that they did not provide a helpline service. Six helplines had closed – the researcher attempted to contact them but the telephone number was no longer in service and no alternatives could be found. This provided 95 cancer or cancer-related helplines eligible for participation. A database was compiled of the organisations identified as eligible to receive the questionnaire survey.

Each helpline was contacted, the research explained and a lead individual responsible for managing and overseeing the helpline identified at all eligible organisations. This person was contacted by the researcher to confirm that they were interested in participating and that they were the most appropriate individual to complete the survey. The survey was designed to be completed by a single individual, but they were encouraged to consult colleagues or documents if they were unsure of any answers.

Ethics approval was obtained from the University of Southampton (reference: SOMSEC060.10).

1.3 Questionnaire development

The questionnaire items were developed by the research team in consultation with the steering group, two Telephone Helpline Association (THA, now Helplines Partnership) staff and the relevant literature (20-29). The survey was administered online to identified participants using SurveyMonkey (30). Paper based copies and telephone support from the research team were available on request.

The survey was sent to the 95 participants in May 2011 and they were asked to complete it within two weeks. A total of two reminder emails (in weeks 3 and 4) were sent and the completion period of the survey was extended for three weeks to increase the participation rate. Any remaining non-responders were telephoned from week 5 to ascertain whether they required assistance completing the survey.

1.4 Data analysis

All surveys were completed online and the data was extracted from the SurveyMonkey website into Excel. No paper versions were requested. Data were analysed descriptively in SPSS v.21.

2 Results:

2.1 . Helpline characteristics

Of the 95 eligible helplines, 69 (73%) completed the questionnaire. Not all questions were mandatory so not all participants completed all questions. The main characteristics of participating helplines are summarised in **Table 1**. The majority of respondents stated that provision of the helpline was one of their organisation's primary functions (65%). .

Most of the responding helplines (59.7%) reported providing support for specific cancers, with only a third providing general support for all cancer types. 73.5% (n=50) provided national coverage and almost all helplines stated that they aimed to serve all age groups, ethnic groups, and men and women.

2.2 Services offered

The helplines offered a wide range of services as set out in **Figure 1**. Almost all helplines, 63 out of 69 (91.3%), stated that they provide emotional support to callers and signposted to other external services, most commonly Macmillan Cancer Support, Breast Cancer Care, Cancer Research UK and the Lymphoma Association. Other services offered included the provision of information and practical support, referral to other services and referral to specialist cancer nurses who provide information on the signs/symptoms of cancer, cancer prevention, treatments and prognosis.

2.3 Accessibility

Hours of operation and out of hours service provision

Approximately half (56.5% n=35) of the helplines operated between 9am and 5pm or 6pm, Monday to Friday. Some (14.5% n=9) helplines were able to offer longer hours, closing between 8pm and 11pm but fewer than 10 helplines opened on a Saturday and those that did tended to operate a reduced service, typically closing around 2pm. While 8 helplines stated that they were open 24 hours a day, seven days a week some of these only provided an answerphone service.

Helpline access numbers

Relatively few helplines could be contacted free of charge. Only 13.4% provided a 0808 80 number that could be contacted free from both landlines and (most) mobile networks. Another key feature of this number range is that the calls do not appear on bills, offering greater confidentiality to callers living in shared households. A further 16.4% reported providing numbers that could be called free from most landlines only. Most commonly (44.8%), helplines could be contacted on standard geographic numbers beginning with 01 and 02.

Provisions for non-English speakers

Two-thirds (n=47) of helplines had no provision in place for callers who prefer to speak a language other than English. The remaining third were able to make arrangements, which could include the use of a generic 3-way interpreting service (n=10), referral to helplines with an interpreting service (n=3), assistance from staff and volunteers who speak other languages (n=6), provision of translation services if advance notice is given (n=6), and provision of materials printed in other languages (n=1).

Specialist provisions

Similarly, over 50% of helplines reported that they had no provisions in place for callers with hearing impairments, speech impairments, communication difficulties, visual or other physical impairment, or learning difficulties. Fourteen (21.2%) helplines had provisions in place for callers with physical impairments, twelve helplines (18.2%) for callers with learning disabilities, and eleven for callers with visual impairment. Only four had provisions for those with hearing impairments and only three had provisions for those with speech impairments. However, 14 helplines (21.2%) were able to provide services on request and/or make use of other channels such as email or instant messaging. Many helplines noted that they tried to be as accommodating as possible and would work with individuals to ensure their needs were met.

Use of social media

Helplines were also asked about the use of media other than the telephone, including email, SMS and social networking sites. Nearly all (94.1%) used email as a communication channel to support their helpline service. 79% sent letters to enquirers and 45.6% used web forums. Although many helplines (43.9%) did not use social networking sites, 34 respondents stated that they had a proactive presence on Facebook and 21 had a presence on Twitter. Others stated that although they currently did not use these sites, they were working towards doing so in the future.

2.4 Staffing and training/support

2.4.1 Staff

As shown in **Table 2**, at the time of the survey most helpline staff were full-time employees or volunteers at the organisation. Very few helplines provided welfare, benefits, or legal specialists (21.6%). 55% (28/51) of the responding helplines did not have doctors or nurses on their staff. This may indicate a need for cancer helplines to have greater awareness of other services that offer specialist health care professional provision in order to refer a caller appropriately.

2.4.2 Training

Almost two-thirds of helplines (64.6%) reported that staff received helpline-specific induction training for their role. Eleven helplines responded that they provided a general induction course or that they organised external training, such as the courses provided by Macmillan Cancer Support.

Induction training most commonly consisted of a 3-4 week induction period whereby staff working on the helpline received an introduction to the organisation, specific training in call handling and management, introduction and training on cancer and in some cases, more specific training on specific cancers. Further aspects of induction training included communication and listening skills training, assessment of calls, and call shadowing. Many organisations stated that training was an ongoing process but did not provide further details.

2.4.3 Support and supervision.

Forty (59.7%) helplines reported that supervision and support were available to staff. Most commonly, this was in the form of debrief or offloading sessions at the end of a call

with another member of staff or a supervisor. The other common formal method of support was allowing staff to take a break from answering calls as needed. However, a total of 22 helplines (32.8%) reported that they had no formal systems in place.

2.5 Helpline monitoring and assessment

There are a number of forms of accreditation available to helplines. However, 36 out of 64 helplines (56.3%) stated that they had no accreditation. Of those helplines that did have some form of accreditation, this tended to be the THA quality standard (n=9), the Information Standard (n=8), Investors in People (n=5), and PQASSO (n=3).

Most helplines were neither members of the THA nor holders of the THA Quality Standard. Most (61.9%, n=37/59) were aware of the THA and the Quality Standard (52.5%, n=31/59) and twenty two (37.3%) reported that they were members of the THA. 25.9% reported that they were working towards the Quality Standard or re-accreditation.

2.6 Challenges identified

Respondents were asked to provide details of any challenges facing their service. This was an open-ended question and 25 helplines responded. Four individuals (16%) mentioned the challenges posed by advances in technology enabling callers to seek information via the Internet prior to calling the helpline. Some callers were worried by information from online sources which were inaccurate or provided poor quality information. It was suggested by one respondent that the Internet contributed to reduced call volume, as people seek information and support online instead of using a telephone service, though 3/25 (12%) helplines indicated that they were experiencing increasing call volumes, which they were finding challenging.

Ensuring adequate funds to keep the service going was a key challenge for 7/25 (28%) of respondents. This is particularly difficult as there are a number of helplines offering similar services. Whilst not strictly in competition with one another, there is an overlap of some services, which means that some providers may not need to or be able to grow/sustain the helpline service.

3 Conclusions:

3.1 Study limitations

The study team identified 95 helplines operating in the UK. Whilst every effort was made to contact all cancer and cancer-related helplines, it is possible that some smaller, specialist services may have been missed. The survey response rate (73%) was high given the completion time of 30 to 40 minutes. Every effort was made to follow up non-responders but it is possible that those who chose not to take part offer different services and face different challenges to those outlined.

The questionnaire was designed for this specific study and as such could not make use of validated questions from previous surveys. The questionnaire was designed to be answered by one key person within each helpline organisation. Therefore, the information provided may not have been representative of all aspects of service provision; respondents were encouraged to consult with colleagues or records, it is possible that some respondents did not. Additional efforts were made to facilitate ease of completion for respondents such as

being able to save and return to the questionnaire later and to receive the questionnaire in paper form. The deadline for the online survey was also extended to enable participants who needed extra time to complete the survey.

The questionnaire did not ask helplines whether they screen callers for distress (e.g. using a validated distress thermometer). This would have been useful to know given that there is some evidence to suggest that screening can improve communication between patients and clinicians and may enhance onward referrals (31, 32).

The time elapsed between data collection and the reporting of findings may mean that the data gathered is not up-to-date. However, there remains a dearth of information on the available cancer and cancer-related helpline services in the UK and this study provides important comprehensive information on what services exist, what they do and the challenges they are likely to face going forward.

3.2 Discussion

The majority of participating organisations offered national coverage, served all ethnic groups and were not gender-specific. However, there were a number of potential barriers to access. First, services tended to be available on weekdays and during the typical 'in hours' working day. Some helplines addressed this by having a standard voicemail system, providing a call-back facility to out-of-hours callers. But individuals are likely to want to talk about cancer-related issues outside of working hours at times that are amenable to them. An interview study with callers to cancer helplines indicated that the most commonly suggested improvement was longer opening hours, particularly in the evening to allow individuals to call when they had time and when they felt most at risk of emotional distress (33). However, funding pressures can have a significant impact on provision and this was identified as a key operational challenge for helplines in this study. There is evidence that between 2009-2011 helplines experienced a 4% reduction in national government funding and a 6.6% reduction in local government funding. (34). A 2014 survey of helplines by the Helplines Partnership (the national membership body for helplines in the UK) identified that helplines of all sizes face problems with call volume and answering calls (35). Limited resources may mean that helplines answer as many calls as they can within their financial and staffing constraints rather than meeting the overall level of demand.

Approximately 30% of helplines had a number that was free to call from most landlines and/or mobiles. Extending the use of free or reduced-cost telephone numbers could help to improve accessibility. But some research suggests that cost is a barrier for helplines seeking to move to free-to-caller number ranges (35) .The situation became more complex in July 2015 as a result of telecoms industry and regulatory changes which meant that all UK calls via a mobile to a 0800 number will be free of charge, but it is likely that helplines using 0800 ranges will see an increase in costs. This may lead to helplines migrating to number ranges where the caller pays for the call which could in prove a barrier for some people.

Many helplines were unable to assist people who require specialist provisions, but were keen to adapt services to meet individual needs. But it must be remembered that, many helplines grow organically from demand in a community and are provided by non-profit and voluntary sector organisations (36). Community language and accessible service

provision can also support caller**s** to access a confidential service independently from family, friends or carers.

Many helplines provided email communication and some were expanding into social networking media. The increased presence of helplines on social networking sites may help to reach a broader demographic e.g. "hard to reach" / "hidden groups" / **and** those of younger ages. There is some evidence of growth in the number of helplines offering multi-channel communications using newer forms of technology such as Skype, social media, email, text and instant messaging (35). The move towards email support has been a particularly strong trend, which can be seen across the helpline sector in general supporting a wide demographic of users (personal correspondence Helplines Partnership). To some extent, the Internet/social media and other "new" technologies may help to overcome obstacles in communication**.**

Just over half of the helplines were staffed by people without a clinical background and so it might be they cannot answer callers' medically related questions. Most helplines did not offer legal, welfare, or benefits advice. Induction training tended to be short and variable, with some reporting limited or no training on providing the type of emotional support that callers may require. Interview~~s~~ with helpline callers suggests that the call handler's knowledge and ability to display empathy are key factors in terms of whether their encounter with a helpline was viewed as successful (33) . It is vital that the training for helpline staff, whether they are paid staff or volunteers, equips them with the confidence and skills necessary to deal with caller's sometimes complex, sensitive and emotional needs. Whilst a minority of helplines did offer ongoing training and indicated that they were constantly evolving the training available, most did not. It may be as demand increases and the significance of the helpline sector grows that cxternal validation of an organisation's internal training provision through a robust quality standard will be needed to limit variation and optimise the experience for callers and call handlers.

Helpline staff may need to "offload" or debrief following calls and many helplines provided this opportunity, but at a number of helplines, there was no formal supervision or support available (37). In addition to presenting a risk to helpline staff, this can also impact on the quality of service offered. Helplines are not formally regulated and although there are a number of forms of voluntary accreditation in place, more than half had no accreditation. Just **as** the information that individuals **access on** the internet **varies**, **so too** the information and support obtained on contacting a helpline may be of variable quality. In the absence of regulation, there is great opportunity for helplines to share knowledge to optimise services, and agree and sustain appropriate and realistic quality standards. There is a particular opportunity to share learning around the areas that offer most challenges, such as providing services to groups who are at risk of not being supported. Helplines are a core part of the support and information available for people affected by cancer, and this is a sector that is likely to continue to grow and continue to be a vital service in the landscape of supportive care in cancer. This paper offers insight into the varied and important work they do and some of the key challenges they face while doing so.

3.3 Future Research

Further research in partnership with helplines is required on how best to train and support staff. This is central to the provision of safe and effective services. Whilst larger helplines

may be well placed to access externally accredited training provision, smaller organisations are likely to have to evolve their own training systems and more work exploring the actual processes of helpline delivery is required, along with the actual benefits of cancer helplines through systematic measurement of caller outcomes and through intervention-focussed studies (38).

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Tables and Figures

Table 1. Characteristics of participating helplines

Helpline is one of the primary functions of organisation?	44/68 (64.7%)
Main source of income for helpline*	
• Central government	2/69 (2.9%)
• Local authority	5/69 (7.2%)
• NHS organisations	8/69 (11.6%)
• Private sector	9/69 (13.0%)
• Donations	56/69 (81.2%)
• Other	22/69 (31.9%)
Date established	
• Pre 1990	16/68 (23.5%)
• 1991 – 1995	7/68 (10.3%)
• 1996 – 2000	15/68 (22.1%)
• 2001 – 2005	15/68 (22.1%)
• 2006 – 2011	15/68 (22.1%)
Type of support offered	
• Site-specific cancer (e.g. breast, lung, bowel, etc)	40/67 (59.7%)
• All cancer types	21/67 (31.3%)
Provide national coverage	50/68 (73.5%)
Support all age groups	49/68 (72.1%)
Support all ethnic groups	65/68 (95.6%)
Support both genders	65/69 (97.0%)

*Multiple response item

Table 2. Numbers of staff employed directly by the helpline

	None	1 – 5	6 or more
Nurses	29 /51 (59.6%)	16/51 (31.4%)	6/51 (5.9%)
Doctors	34/40 (85.0%)	4/40 (10.0%)	2/40 (5.0%)
Other full time staff and volunteers	3/54 (5.6%)	31/54 (57.4%)	20/54 (14.8%)
Allied Health Professionals	31/36 (86.1%)	5/36 (13.9%)	-
Welfare and Benefits professionals	29/37 (78.4%)	7/37 (18.9%)	1/37 (2.7%)
Legal professionals	28/31 (90.3%)	3/31 (9.7%)	-

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Abstract

Background: There are over 1500 UK health helplines in operation, yet we have scant knowledge about the resources in place to support the seeking and delivering of cancer-related telephone help and support. This research aimed to **identify and describe** cancer and cancer-related helpline service provision: the number of helplines **available**, **the variety of** services provided **and accessibility of those services**.

Method – Online national questionnaire survey sent to 95 cancer and cancer-related helplines in the UK

Results – 69 (73%) of 95 surveyed cancer and cancer-related helplines completed the survey. Most helplines/organisations were registered charities, supported by donations. 73.5% of helplines had national coverage. Most helplines served all age groups, ethnic groups, and men and women. Only 13.4% had a number that was free from landlines and most mobile networks and 56.6% could only be contacted during working hours. Over 50% of helplines reported no provisions for callers with additional needs. 55% had no clinical staff available to callers. Ongoing support and training for helpline staff was available but variable.

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Conclusion – While cancer helplines in the UK offer reasonably broad coverage across the country, there are still potential barriers to accessibility. There are also opportunities to optimise the training of staff/volunteers across the sector. There are further prospects for helplines to enhance services and sustain appropriate and realistic quality standards.

Keywords: cancer, helplines, telemedicine; cancer information; cancer support

Background:

Every year 250,000 people in England are diagnosed with cancer. An estimated 130,000 will die from the disease whilst 1.8 million people are living with or beyond a cancer diagnosis (1). Helplines are one way of providing patients, and others impacted by a cancer diagnosis, with the opportunity to seek information and support outside of the National Health Service and between appointments (2). Helplines have become a core feature of the UK health care system and the importance of them has been acknowledged by the Department of Health as a key way to promote a supported self-management approach to living with cancer (3).

In 2009 the Telephone Helplines Association (now Helplines Partnership) estimated there were over 1500 health related helplines in operation in the UK (4). Despite the popularity of helpline services in general, and cancer helplines in particular, we currently have little systematic knowledge of the types of cancer helplines in the UK, their purpose, and the scope of services provided.

This paper describes the results from a national survey of UK-based cancer and **cancer-related** helplines. **As services increase in number, it may become difficult for service commissioners, and existing and start-up helpline organisations, to gain a strategic overview of the cancer helpline landscape to identify gaps in service, points of overlap and possibilities for co-ordination or integration. This survey aimed to provide useful information in this regard.**

Aim: To identify and describe cancer and cancer-related helpline service provision both in terms of the number of helplines available, the variety of services provided and accessibility of those services.

1 Methods:

1.1 Inclusion criteria

The national survey aimed to identify all helplines operating in the UK with a cancer-specific or cancer-related remit. A telephone helpline service was defined as an impartial and confidential service that provides information, advice, listening, support or onward referral through a telephone service (normally offered free of charge) (5).**A mixed approach was used to determine eligibility, involving screening all available websites for relevant information and speaking with a representative at each of the helplines to establish how they provide their service and whether they viewed their service as meeting our eligibility criteria (in a few cases screening for eligibility was performed by email).** Organisations were excluded if they provided a support service such as one-to-one telephone buddy schemes or telephone support groups set up to supplement local group support meetings.

The study focused on helplines that had a cancer-specific remit – either covering specific types of cancer (e.g. breast cancer, colon cancer) or providing more generalised support to those affected by any type of cancer (e.g. Macmillan Cancer Support). Some helplines were not cancer-focused but often took calls from individuals affected by cancer – for

example Cruse Bereavement Helpline and Pain Concern. This paper will refer to these as "cancer-related" helplines.

1.2 Identification of participants

To identify eligible helplines, an online search was undertaken to identify organisations that might provide cancer-specific or cancer-related helpline services (6-16). **This included generalised searches on publicly available search engines, including 'google', 'yahoo', 'bing', 'Ask'** and using terms such as "cancer helpline services" or "cancer helpline", as well as specific searches related to the twenty most common cancer types in the UK (17). Established directories such as were also consulted (4, 18, 19).

In total, 152 organisations were identified and assessed according to the eligibility criteria. Fifty-one were excluded because when contacted it was established that they did not provide a helpline service. Six helplines had closed – the researcher attempted to contact them but the telephone number was no longer in service and no alternatives could be found. This provided 95 cancer or cancer-related helplines eligible for participation. A database was compiled of the organisations identified as eligible to receive the questionnaire survey.

Each helpline was contacted, the research explained and a lead individual responsible for managing and overseeing the helpline identified at all eligible organisations. This person was contacted by the researcher to confirm that they were interested in participating and that they were the most appropriate individual to complete the survey. The survey was designed to be completed by a single individual, but they were encouraged to consult colleagues or documents if they were unsure of any answers.

Ethics approval was obtained from the University of Southampton (reference: SOMSEC060.10).

1.3 Questionnaire development

The questionnaire items were developed by the research team in consultation with the steering group, two Telephone Helpline Association (THA, now Helplines Partnership) staff and the relevant literature (20-29). The survey was administered online to identified participants using SurveyMonkey (30). Paper based copies and telephone support from the research team were available on request.

The survey was sent to the 95 participants in May 2011 and they were asked to complete it within two weeks. A total of two reminder emails (in weeks 3 and 4) were sent and the completion period of the survey was extended for three weeks to increase the participation rate. Any remaining non-responders were telephoned from week 5 to ascertain whether they required assistance completing the survey.

1.4 Data analysis

All surveys were completed online and the data was extracted from the SurveyMonkey website into Excel. No paper versions were requested. Data were analysed descriptively in SPSS v.21.

2 Results:

2.1 . Helpline characteristics

Of the 95 eligible helplines, 69 (73%) completed the questionnaire. Not all questions were mandatory so not all participants completed all questions. The main characteristics of participating helplines are summarised in **Table 1**. The majority of respondents stated that provision of the helpline was one of their organisation's primary functions (65%). .

Most of the responding helplines (59.7%) reported providing support for specific cancers, with only a third providing general support for all cancer types. 73.5% (n=50) provided national coverage and almost all helplines stated that they aimed to serve all age groups, ethnic groups, and men and women.

2.2 Services offered

The helplines offered a wide range of services as set out in **Figure 1**. Almost all helplines, 63 out of 69 (91.3%), stated that they provide emotional support to callers and signposted to other external services, most commonly Macmillan Cancer Support, Breast Cancer Care, Cancer Research UK and the Lymphoma Association. Other services offered included the provision of information and practical support, referral to other services and referral to specialist cancer nurses who provide information on the signs/symptoms of cancer, cancer prevention, treatments and prognosis.

2.3 Accessibility

Hours of operation and out of hours service provision

Approximately half (56.5% n=35) **of the** helplines operated between 9am and 5pm or 6pm, Monday to Friday. Some (14.5% n=9) helplines were able to offer longer hours, closing between 8pm and 11pm but fewer than 10 helplines opened on a Saturday and those that did tended to operate a reduced service, typically closing around 2pm. While 8 helplines stated that they were open 24 hours a day, seven days a week some of these only provided an answerphone service.

Helpline access numbers

Relatively few helplines could be contacted free of charge. Only 13.4% provided a 0808 80 number that could be contacted free from both landlines and (most) mobile networks. Another key feature of this number range is that the calls do not appear on bills, offering greater confidentiality to callers living in shared households. A further 16.4% reported providing numbers that could be called free from most landlines only. Most commonly (44.8%), helplines could be contacted on standard geographic numbers beginning with 01 and 02.

Provisions for non-English speakers

Two-thirds (n=47) of helplines had no provision in place for callers who prefer to speak a language other than English. The remaining third were able to make arrangements, which could include the use of a generic 3-way interpreting service (n=10), referral to helplines with an interpreting service (n=3), assistance from staff and volunteers who speak other languages (n=6), provision of translation services if advance notice is given (n=6), and provision of materials printed in other languages (n=1).

Specialist provisions

Similarly, over 50% of helplines reported that they had no provisions in place for callers with hearing impairments, speech impairments, communication difficulties, visual or other physical impairment, or learning difficulties. Fourteen (21.2%) helplines had provisions in place for callers with physical impairments, twelve helplines (18.2%) for callers with learning disabilities, and eleven for callers with visual impairment. Only four had provisions for those with hearing impairments and only three had provisions for those with speech impairments. However, 14 helplines (21.2%) were able to provide services on request and/or make use of other channels such as email or instant messaging. Many helplines noted that they tried to be as accommodating as possible and would work with individuals to ensure their needs were met.

Use of social media

Helplines were also asked about the use of media other than the telephone, including email, SMS and social networking sites. Nearly all (94.1%) used email as a communication channel to support their helpline service. 79% sent letters to enquirers and 45.6% used web forums. Although many helplines (43.9%) did not use social networking sites, 34 respondents stated that they had a proactive presence on Facebook and 21 had a presence on Twitter. Others stated that although they currently did not use these sites, they were working towards doing so in the future.

2.4 Staffing and training/support

2.4.1 Staff

As shown in **Table 2**, at the time of the survey most helpline staff were full-time employees or volunteers at the organisation. Very few helplines provided welfare, benefits, or legal specialists (21.6%). 55% (28/51) of the responding helplines did not have doctors or nurses on their staff. This may indicate a need for cancer helplines to have greater awareness of other services that offer specialist health care professional provision in order to refer a caller appropriately.

2.4.2 Training

Almost two-thirds of helplines (64.6%) reported that staff received helpline-specific induction training for their role. Eleven helplines responded that they provided a general induction course or that they organised external training, such as the courses provided by Macmillan Cancer Support.

Induction training most commonly consisted of a 3-4 week induction period whereby staff working on the helpline received an introduction to the organisation, specific training in call handling and management, introduction and training on cancer and in some cases, more specific training on specific cancers. Further aspects of induction training included communication and listening skills training, assessment of calls, and call shadowing. Many organisations stated that training was an ongoing process but did not provide further details.

2.4.3 Support and supervision.

Forty (59.7%) helplines reported that supervision and support were available to staff. Most commonly, this was in the form of debrief or offloading sessions at the end of a call

with another member of staff or a supervisor. The other common formal method of support was allowing staff to take a break from answering calls as needed. However, a total of 22 helplines (32.8%) reported that they had no formal systems in place.

2.5 Helpline monitoring and assessment

There are a number of forms of accreditation available to helplines. However, 36 out of 64 helplines (56.3%) stated that they had no accreditation. Of those helplines that did have some form of accreditation, this tended to be the THA quality standard (n=9), the Information Standard (n=8), Investors in People (n=5), and PQASSO (n=3).

Most helplines were neither members of the THA nor holders of the THA Quality Standard. Most (61.9%, n=37/59) were aware of the THA and the Quality Standard (52.5%, n=31/59) and twenty two (37.3%) reported that they were members of the THA. 25.9% reported that they were working towards the Quality Standard or re-accreditation.

2.6 Challenges identified

Respondents were asked to provide details of any challenges facing their service. This was an open-ended question and 25 helplines responded. Four individuals (16%) mentioned the challenges posed by advances in technology enabling callers to seek information via the Internet prior to calling the helpline. Some callers were worried by information from online sources which were inaccurate or provided poor quality information. It was suggested by one respondent that the Internet contributed to reduced call volume, as people seek information and support online instead of using a telephone service, though 3/25 (12%) helplines indicated that they were experiencing increasing call volumes, which they were finding challenging.

Ensuring adequate funds to keep the service going was a key challenge for 7/25 (28%) of respondents. This is particularly difficult as there are a number of helplines offering similar services. Whilst not strictly in competition with one another, there is an overlap of some services, which means that some providers may not need to or be able to grow/sustain the helpline service.

3 Conclusions:

3.1 Study limitations

The study team identified 95 helplines operating in the UK. Whilst every effort was made to contact all cancer and cancer-related helplines, it is possible that some smaller, specialist services may have been missed. The **survey** response rate (73%) was high given the **completion time of** 30 to 40 minutes. Every effort was made to follow up non-responders but it is possible that those who chose not to take part offer different services and face different challenges to those outlined.

The questionnaire was designed **for this specific study and as such could not make use of validated questions from previous surveys**. **The questionnaire was designed** to be answered by one key person within **each** helpline organisation. Therefore, the information provided may not have been representative of all aspects of service provision; respondents were encouraged to consult with colleagues or records, it is possible that some respondents did not. Additional efforts **were made to facilitate ease of completion** for respondents

such as being able to save and return to the questionnaire later and to receive the questionnaire in paper **form**. The deadline for the online survey was also extended to enable participants **who needed** extra time to complete the survey.

The questionnaire did not ask helplines whether they screen callers for distress (e.g. using a validated distress thermometer). This would have been useful to know given that there is some evidence to suggest that screening can improve communication between patients and clinicians and may enhance onward referrals (31, 32).

The time elapsed between data collection and the reporting of findings may mean that the data gathered is not up-to-date. However, there **remains** a dearth of information on the **available** cancer and cancer-related helpline services in the UK and this study provides important comprehensive information on what services exist, what they do and the challenges they are likely to face going forward.

3.2 Discussion

The majority of participating organisations offered national coverage, served all ethnic groups and were not gender-specific. However, there were a number of potential barriers to access. First, services tended to be available on weekdays **and during the typical 'in hours' working day**. Some helplines address**ed** this by having a standard voicemail system, providing a call-back facility to out-of-hours callers. But individuals are likely to want to talk about cancer-related issues outside of working hours at times that are amenable to them. An interview study with callers to cancer helplines indicated that the most commonly suggested improvement was longer opening hours, particularly in the evening to allow individuals to call when they had time and when they felt most at risk of emotional distress (33). However, funding pressures can have a significant impact on provision and this was identified as a key operational challenge for helplines in this study. **There is evidence that between 2009-2011 helplines experienced a 4% reduction in national government funding and a 6.6% reduction in local government funding. (34).** A 2014 survey of helplines by the Helplines Partnership **(the national membership body for helplines in the UK)** identified that helplines of all sizes face problems with call volume and answering calls (35). Limited resources may mean that helplines answer as many calls as they can within their financial and staffing constraints rather than meeting the overall level of demand.

Approximately 30% of helplines had a number that was free to call from most landlines and/or mobiles. Extending the use of free or reduced-cost telephone numbers could help to improve accessibility. But **some** research suggests that cost is **a** barrier for helplines seeking to move to free-to-caller number ranges (35) .The situation **became** more complex **in July 2015** as a result of telecoms industry and regulatory changes **which meant that a**ll UK calls via a mobile to a 0800 number will be free of charge, but it is likely that helplines using 0800 ranges will see an increase in costs. This may lead to helplines migrating to number ranges where the caller pays for the call which could in prove a barrier for some people.

Many helplines were unable to assist **people who require specialist provisions**, but were keen to adapt services to meet individual needs. **But it must be remembered that**, many helplines grow organically from demand in a community and are provided by non-profit and voluntary sector organisations (36). Community language and accessible service

provision can also support callers to access a confidential service independently from family, friends or carers.

Many helplines provided email communication and some were expanding into social networking media. The increased presence of helplines on social networking sites may help to reach a broader demographic e.g. "hard to reach" / "hidden groups" / **and** those of younger ages. **There is some evidence of** growth in the number of helplines offering multi-channel communications using newer forms of technology such as Skype, social media, email, text and instant messaging (35). The move towards email support has been a particularly strong trend, which can be seen across **the helpline sector in general** supporting a wide demographic of users (personal correspondence Helplines Partnership). **To some extent, the Internet/social media and other "new" technologies may help to overcome obstacles in communication.**

Just over half of the helplines **were** staffed by people without a clinical background **and so it might be they can**not answer callers' medically related questions. **M**ost helplines did not offer legal, welfare, or benefits advice. Induction training tended to be short and variable, with **some reporting limited** or no training on providing the type of emotional support that callers may require. Interview~~s~~ with helpline callers suggests that the call handler's knowledge and ability to display empathy **are** key factors in **terms of** whether the**ir** encounter with **a** helpline was viewed as successful (33) . It is vital that the training **for** helpline staff, whether they are paid staff or volunteers, equips them with the confidence and skills necessary to deal with caller's sometimes **complex, sensitive** and emotional **needs**. **Whilst a minority of helplines did offer ongoing training and indicated that they were constantly evolving the training available, most did not. It may be as demand increases and the significance of the helpline sector grows that c**xternal validation of an organisation's internal training provision through a robust quality standard **will be needed to limit variation** and optimise **the experience** for callers and call handlers.

Helpline staff may need to "offload" or debrief following calls **and many helplines provided this opportunity,** but at a number of helplines, there was no formal supervision or support available (37). In addition to presenting a risk to helpline staff, this can also impact on the quality of service **offered**. Helplines are not formally regulated and although there are a number of forms of voluntary accreditation in place, more than half had no accreditation. Just **as** the information that individuals **access on** the internet **varies**, **so too** the information and support obtained on contacting a helpline may be of variable quality. In the absence of regulation, there is great opportunity for helplines to share knowledge to optimise services, and agree and sustain appropriate and realistic quality standards. There is a particular opportunity to share learning around the areas that offer most challenges, such as providing services to groups who are at risk of not being supported. **Helplines are a core part of the support and information available for people affected by cancer, and this is a sector that is likely to continue to grow and continue to be a vital service in the landscape of supportive care in cancer. This paper offers insight into the varied and important work they do and some of the key challenges they face while doing so.**

3.3 Future Research

Further research in partnership with helplines is required on how best to train and support staff. This is central to the provision of safe and effective services. Whilst larger helplines may be well placed to access externally accredited training provision, smaller organisations are likely to have to evolve their own training systems and more work exploring the actual processes of helpline delivery is required, along with the actual benefits of cancer helplines through systematic measurement of caller outcomes and through intervention-focussed studies (38).

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Tables and Figures

Table 1. Characteristics of participating helplines

Helpline is one of the primary functions of organisation?	44/68 (64.7%)
Main source of income for helpline*	
• Central government	2/69 (2.9%)
• Local authority	5/69 (7.2%)
• NHS organisations	8/69 (11.6%)
• Private sector	9/69 (13.0%)
• Donations	56/69 (81.2%)
• Other	22/69 (31.9%)
Date established	
• Pre 1990	16/68 (23.5%)
• 1991 – 1995	7/68 (10.3%)
• 1996 – 2000	15/68 (22.1%)
• 2001 – 2005	15/68 (22.1%)
• 2006 – 2011	15/68 (22.1%)
Type of support offered	
• Site-specific cancer (e.g. breast, lung, bowel, etc)	40/67 (59.7%)
• All cancer types	21/67 (31.3%)
Provide national coverage	50/68 (73.5%)
Support all age groups	49/68 (72.1%)
Support all ethnic groups	65/68 (95.6%)
Support both genders	65/69 (97.0%)

*Multiple response item

Table 2. Numbers of staff employed directly by the helpline

	None	1 – 5	6 or more
Nurses	29 /51 (59.6%)	16/51 (31.4%)	6/51 (5.9%)
Doctors	34/40 (85.0%)	4/40 (10.0%)	2/40 (5.0%)
Other full time staff and volunteers	3/54 (5.6%)	31/54 (57.4%)	20/54 (14.8%)
Allied Health Professionals	31/36 (86.1%)	5/36 (13.9%)	-
Welfare and Benefits professionals	29/37 (78.4%)	7/37 (18.9%)	1/37 (2.7%)
Legal professionals	28/31 (90.3%)	3/31 (9.7%)	-

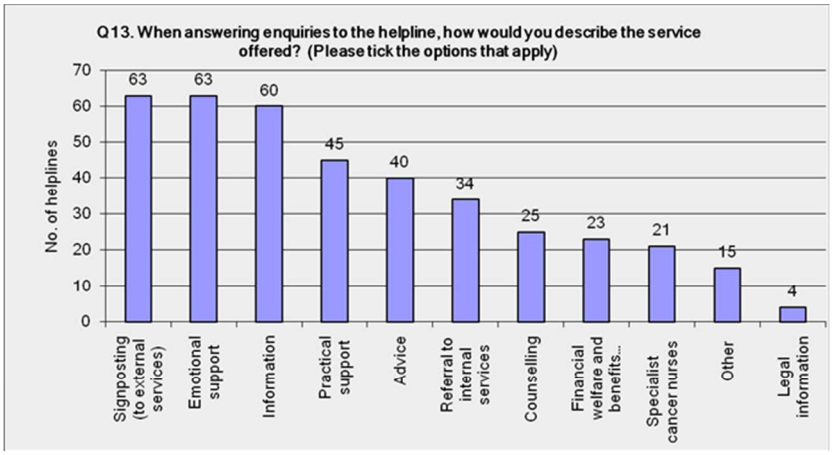

Figure 1. Services provided by participating helplines

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