



Coping with cancer

Supporting young people's resilience

Summary

Coping with cancer explores the help-seeking behaviour and information needs of young people with cancer, and examines how this links to the concept of resilience. This report aims to raise awareness among health and social care practitioners and policy makers of the support, advice and information needs of young people with cancer, highlighting existing good practice and suggesting ways forward.

About CLIC Sargent

Every day in the UK, 10 children and young people are given shocking news that will change their lives forever. They are told they have cancer. Treatment normally starts immediately, often happens many miles from home and can last for up to three years. A cancer diagnosis affects the whole family in many different ways as the emotional, practical and financial implications can be intensely challenging.

CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide clinical, practical and emotional support to help them cope with cancer and get the most out of life.

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Policy and influencing

CLIC Sargent works to raise awareness, influence change and help lessen the impact of childhood cancer. We undertake research into the impact of cancer on children and young people and use this evidence to raise awareness and to seek to influence government and policy makers, and those who provide public services across the UK, to help change things for the better for children and young people with cancer.

Young People's Health Partnership



Young People's
Health Partnership

CLIC Sargent is a member of the Young People's Health Partnership, a seven-strong consortium of organisations working with the Department of Health, Public Health England and NHS England as strategic partners to raise the profile of the health agenda across the voluntary youth sector. CLIC Sargent draws on the experience and contributions of the young people we work with to ensure that their views are taken into account in the partnership's activities, so that we can influence policy makers on their behalf and find ways to improve the services and support available to them. For more information and for a full list of the organisations that are leading strategic partnerships, visit www.gov.uk

Foreword

I was really pleased to be asked to write the foreword to this report. As a member of CLIC Sargent's Young People's Service Development Group, I know that support for 16 to 24-year-olds with cancer is a crucial part of the charity's services strategy. Through this group, I have been able to share my experience and be a voice for other young people with cancer.

This research looked at how young people like me look for information, support and advice, and how this can help them cope with a cancer diagnosis and life afterwards. I know how important this is - the support I received from CLIC Sargent was invaluable. Jude, my CLIC Sargent Young People's Social Worker, helped me to feel more confident to deal with my diagnosis, treatment and future. She enabled me to deal with challenges and this helped me to successfully cope with what I was experiencing - it helped me to be resilient.

The research also showed that being able to get information, support and advice from different people like friends or professionals, and in different ways like online or face-to-face, is really important to young people like me.

I know one of the ways CLIC Sargent is taking this work forward is through the development of an online community. I'm really excited about these plans to develop new ways of supporting young people online. I was there when the online community was first talked about, and it's been exciting to watch and help shape its development, along with other young people.

Everyone's journey is different, and it's rare that we get a chance to find other people who we can share experiences with and ask 'is it normal to feel like this?'



Ceinwen Stone (24 years old)

Member of CLIC Sargent's Young People's Service Development Group



Hanifa, who was diagnosed with leukaemia at 23, with her CLIC Sargent Social Worker Tricia



CLIC Sargent undertook this research to better understand the help-seeking behaviour and information needs of young people with cancer, and how quality support

and information can help them to build and maintain resilience. We looked at the existing evidence base in this area and consulted with 138 young people aged 16 to 24 who have, or have had cancer. We also interviewed experts who work with young people with cancer and who study resilience.

We found that enabling young people to deal with the issues they face during their cancer journey can support their resilience now and in the future. Young people told us they value face-to-face support from health and social care professionals and that this is a vital source of support and information.

Through this research we've also compiled evidence demonstrating the importance of the internet as a key source of information and support for young people with cancer in this digital age (96% of those surveyed use the internet to look for information and advice for themselves) and how, in particular, they value peer support accessed through social media and online communities.

This research has given CLIC Sargent the opportunity to take a fresh look at the suite of services we offer to young people with cancer - for example the face-to-face work of our young people's care professionals as well as financial assistance and information resources provided on our website.

We also believe it delivers a message to our colleagues across the health and social care sectors, from the practitioners to the policy makers and the politicians: together we can and must build the resilience of young people with cancer, through research, culture change and the continual improvement of the way we provide services including information, support and advice.

Moving forward, CLIC Sargent will continue to provide the crucial responsive services it offers to young people with cancer, and will work in partnership with others to raise awareness of the need to build their resilience, to help them to get the most out of their life during cancer and beyond.

Thank you Ceinwen, and to all the young people and professionals who made this report possible.

Lorraine Clifton
Chief Executive

Introduction

Every year around 2,200 16 to 24-year-olds are diagnosed with cancer in the UK (CRUK, 2014). A cancer diagnosis has a huge impact on a young person and can significantly disrupt their journey into adulthood. It can also affect their future. As well as the potential long-lasting physical effects of treatment, research has shown that a cancer diagnosis can impact on long-term emotional wellbeing, and education and employment prospects.

Our previous research found that many young people were anxious about the future and highlighted the impact of the cancer journey on their confidence. To explore these issues in more depth, we undertook further research on how young people seek support, information and advice to cope with cancer and develop self-confidence, looking in particular at how this might be linked to the notion of resilience.

The key objectives of this research were therefore to:

- Explore how young people with cancer seek help and what sources of support they value
- Understand what resilience means for young people, in particular young people with health conditions such as cancer
- Identify good practice examples of how face-to-face support, information and online resources and support can help build resilience

- Identify ways in which CLIC Sargent and the wider health and social care sector can move towards a system of support that fosters resilience in young people with health conditions such as cancer.

We believe that our findings will highlight and contribute to an evolving evidence base on how young people cope with cancer, and how they can best be supported to become resilient. The growing literature on resilience has, we think, great potential to inform work with young people with cancer. This has implications for the development of services at CLIC Sargent and for colleagues working with and on behalf of young people with cancer across the health and social care sector.

Key findings

- Access to quality information is key to helping young people with cancer feel confident in managing their illness and building resilience. Young people can feel anxious when their treatment ends and need more information and support at this point of their cancer journey
- Young people seek different information on different topics in different ways throughout all stages of their cancer journey. The source they choose depends on the topic. Providing young people with a suite of support options gives them the freedom to make the choice which suits them best
- Most (96%) of the young people surveyed use the internet to look for information and advice for themselves
- Online resources and support, however, cannot replace face-to-face support. Three quarters (74%) of the young people would want to speak to a healthcare professional if they had a health problem that was worrying them, and two in five (41%) young people would want to speak to someone from CLIC Sargent for emotional and practical support
- Nearly four in five (78%) young people with cancer who seek help online want to connect and interact online with other young people in similar situations, using social media and forums to share experiences and advice
- It's useful to conceptualise resilience as an outcome: the outcome of successfully coping with stressful experiences. The literature on resilience and experts in the field often link it to notions of coping and competence
- There is evidence of a range of effective approaches to building resilience. These include approaches focused on the individual, skills-based approaches and approaches taking the wider health and social care system into account (known as the community approach)
- Both individual and community approaches to resilience are relevant to young people with cancer. Practitioners on the ground are applying the principles at an individual level, while community-level approaches to resilience can impact on the strategic planning of how support is delivered for young people throughout their cancer journey.

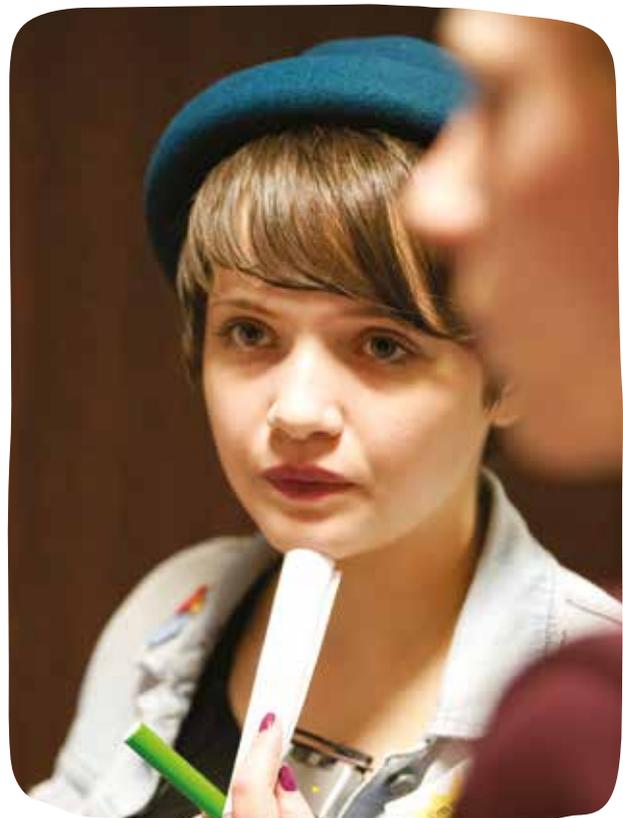
Context

As young people transition from being children to young adults they face complex biological, psychological and social changes (Schonert-Reichl & Muller, 1996). Having cancer during this time brings additional difficulties and disruption (Harvey & Finch, 2008). Treatment can last as long as three years and this, as with the cancer itself, can cause ongoing issues such as chronic fatigue, attention and concentration difficulties and psychological and emotional problems.

Previous CLIC Sargent research has shown the significant impact that cancer can have on a young person's education (CLIC Sargent, 2010; 2011; 2013b) and their employment and training (CLIC Sargent, 2013c). *No young person with cancer left out* (CLIC Sargent, 2013c) showed that many young people were anxious about the impact of cancer on their future prospects and highlighted the emotional impact of the cancer journey on their confidence. Academic research has also shown that a cancer diagnosis can impact on future emotional wellbeing (Schwartz & Drotar, 2006), education (Lancashire et al., 2010) and employment prospects (Kirchhoff et al., 2010).

A young person's resilience is an important factor in determining how they deal with the experience and move forward.

Not all young people with cancer will survive (around 80% of teenagers and young adults diagnosed with cancer survive their disease for at least five years (CRUK, 2013)). This research does not explicitly explore the resilience of young people with cancer receiving palliative care. However, we expect that the issues covered in this report will be relevant for these young people.



Policy context

The focus of this report relates to a number of different policy areas including health, welfare and education.

Health and wellbeing

Cancer

Cancer remains a priority for policy makers across the UK. In England, cancer policy is driven by *Improving Outcomes: A Strategy for Cancer* (Department of Health, 2011). The *Cancer Service Framework* (Department of Health, Social Services and Public Safety, 2011) sets standards for cancer prevention, treatment and care in Northern Ireland. *Better Cancer Care, An Action Plan* (The Scottish Government, 2008) outlines how cancer services are required to support all those in Scotland who are living with and beyond cancer. In Wales, *Together for Health, Cancer Delivery Plan for the NHS to 2016* sets the agenda for NHS Wales, working with its partners to tackle cancer (Welsh Government, 2012).

Young people's health and wellbeing

In 2013, the Department of Health in England published a 'system-wide pledge' entitled *Better health outcomes for children and young people: Our Pledge* and the *Children and Families Act 2014* which introduced duties on health bodies to meet the needs of children with disabilities including young people with cancer. A 10-year strategy for children and young people in Northern Ireland entitled *Our Children and Young People - Our Pledge* was published in 2006 (Office of the

First Minister and Deputy First Minister, 2006). The Scottish Government adopted the *Getting it right for every child* approach to children and young people's policy (Scottish Government, 2012) and the *Children and Young People (Scotland) Act 2014* places duties on public bodies to coordinate planning, design and delivery of services for children and young people with a focus on wellbeing outcomes. *The National Service Framework for Children, Young People and Maternity Services* (NHS Wales 2005) sets out the quality of services that children, young people and their families have a right to expect and receive in Wales.

Resilience and mental health

Promoting resilience is part of Public Health England's vision for health improvement in England and work is ongoing to explore how this can fit into the government's young people's health and wellbeing framework. The *Better health outcomes for children and young people* pledge stated the determination of system-wide partners in the NHS in England to 'improve the mental health of children and young people by promoting resilience and mental wellbeing and providing early and effective evidence-based treatment for those who need it' (Department of Health, 2013).

Mental health is a major policy priority for government departments across the UK (Department for Health, 2014), for example it is flagged within NHS England's 2014 *Five Year Forward View*. Framed as 'everybody's business', government strategies are beginning to stress that mental health must

have equal priority with physical health. There is also a growing focus on children and young people in mental health strategies across the UK; in its 2002 and 2008 concluding observations on the UK, the Committee on the Rights of the Child expressed serious concern at the levels of mental ill health among children and young people and the inadequate provision of appropriate services for them (United Nations, 2008). Scotland, for example, has indicators specifically for children and young people's mental health and promoting mental health, and with the *Schools Effectiveness Framework* (Welsh Assembly Government, 2008) wellbeing in schools is becoming recognised as a core element of education settings in Wales.

Welfare

Young people who are unable to work due to cancer can access financial support through the benefits system. They can also access non-means tested disability benefits which help to address the cost of care during treatment and take into account any ongoing effects that treatment may have.

Welfare policy is not a devolved issue, so the changes introduced by the *Welfare Reform Act 2012* are being implemented in the same way across the UK. Disability Living Allowance (DLA) is gradually being replaced with Personal Independence Payment (PIP) for working age adults (these changes in

Northern Ireland are subject to approval by the Northern Ireland Assembly and the Northern Ireland Executive).

CLIC Sargent is monitoring the impact of the new benefit on young people with cancer. Early indications show that many are experiencing significant delays receiving a decision on whether or not they have been awarded PIP.

Education

Substantial policy reforms which relate to children in education with health conditions such as cancer are also underway. Under the *Children and Families Act 2014*, Statements of Educational Needs (SEN) are to be replaced with more integrated Education, Health and Care Plans. These plans will continue into further education and training, and for some young people up to the age of 25. The Welsh Government is currently consulting on the *Legislative proposals for additional learning needs White Paper*, which outlines the proposals to introduce a new legislative framework for supporting children and young people with additional learning needs (Welsh Government, 2014).

Our research methodology

The research aimed to explore help-seeking, information needs and resilience among young people with cancer. Mixed methods of research were employed to encourage a range of stakeholders to participate.

First, a review of relevant literature was undertaken in order to understand the evidence base and its applicability to young people with cancer. This involved a systematic review of the current knowledge base on help-seeking and resilience, collating evidence from a range of sources including academics, government reports and other charitable organisations.

Next, drawing from the findings of the literature and previous studies, young people with cancer were consulted through an online survey and a focus group, where the survey findings were discussed in more detail. Young people were involved in the design and testing of these research outputs

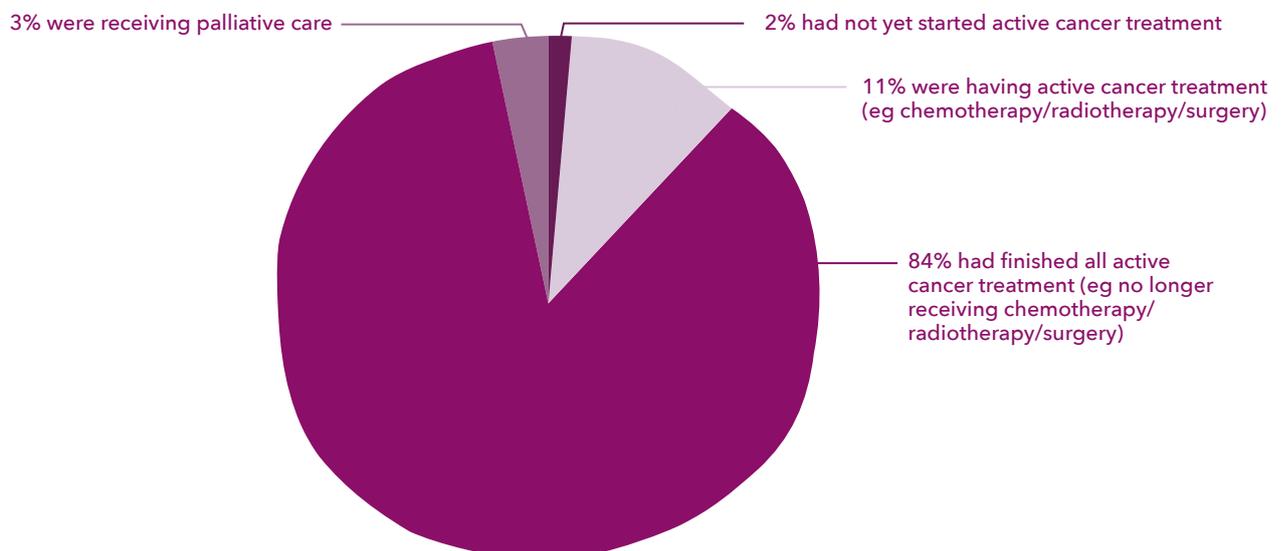
which asked 16 to 24-year-olds with experience of cancer to reflect on their help-seeking behaviour and how being able to access support can help them build resilience. A total of 138 young people participated in the study - 124 responded to the survey and 14 took part in the focus group. All participants were self-selecting and were sourced through CLIC Sargent's networks, our care professionals, as well as through social media. They had all been diagnosed with cancer in the UK between the ages of 16 and 24.

Next, interviews were carried out with academics and practitioners, including CLIC Sargent care professionals, to identify their expert views and contextual understanding of help-seeking behaviour and resilience among young people with cancer.

The findings of all stages of the research are presented in the next two sections.

Figure 1

Of the 124 young people who completed the online survey:



Young people and help-seeking behaviour

The research sought first of all to understand the nature of young people's help-seeking behaviour and the subsequent impact of cancer.

Young people encounter a number of stressors (issues causing stress or anxiety) as they transition to adulthood, such as negotiating relationships (with family, peers and partners) and navigating the academic domain (concerning both current achievement and its impact on future employment prospects) (Persike & Seiffge-Krenke, 2012). Seeking help is one way of coping with problems and stressors that arise in life (Rickwood, 1995).

Garvey et al. (2008) suggest that young people access a range of different people and sources of help, support and information depending on the nature of their needs. Those in low distress (eg every day or minor worries) may seek information from the nearest available source. If in moderate distress, they may engage in self-evaluation and seek help from friends, family and social networks. Those in high distress may consider professional advice or psychological treatment.

Other research on young people and help-seeking behaviour highlights several potential barriers to seeking help. These include the perceived need for help, the perceived benefit of seeking help, ease of access,

confidentiality (Czyz et al., 2013; Kuhl et al., 1997), the style in which the help is given, and any stigma attached to the topic (Garvey et al., 2008). There is also evidence to suggest that those experiencing the highest levels of distress are less likely to seek help at all (Sawyer et al., 2012). Among adults it has been found that socio-economic status impacts on help-seeking behaviour (Kuhl et al., 1997) and it is well established that females seek help more than males (Compas et al., 2001; Persike & Seiffge-Krenke, 2012).

Compas et al. (2001) note that the skills and strategies children and adolescents develop to cope with stress at a younger age can impact on their ability to manage stressors in the future. This suggests that successful management of problems creates greater resilience. Resilience may therefore be seen as an outcome of coping successfully with adversity. Indeed there is evidence that seeking help and advice from people in one's social support network is a coping strategy which results in better adjustment (Billings & Moos, 1981; Compas et al., 2001).

Young people with cancer

Aside from dealing with the challenges of becoming an adult, having a serious health condition such as cancer is clearly a significant additional stressor for a young person, for which they are likely to need information, support and advice.

In their survey of cancer patients aged 12 to 28, Groszmann et al. (2013) found that almost all went to professionals for information about cancer and treatment. However, almost half also used websites to gather the information, and the majority used laptops and smartphones to go online generally. About a third had gone online to find out about

their hospital. The research, which was paper-based as well as online, suggests that young people with cancer use the internet as an anonymous, accessible and convenient way to access health information for chronic conditions.

To build on this evidence, between April and May 2014, we consulted 138 young people who have, or have had, cancer on how they seek information, support and advice, using an online survey and a focus group. The survey found that young people with cancer want information and support on topics ranging from physical health, to cancer and treatment, sexual health and family relationships.

Our survey also found that the source of help varies according to the topic. Respondents would rather speak to friends about sex and relationships or go to an online information source. For general health, cancer and treatment issues they would opt to speak to a professional. They would go to their parents, friends or professionals to discuss bereavement issues. Interestingly, online information was not a major source for any one topic; however, this is not to say that the internet cannot be useful in enabling young people to have the conversations that they want to have with peers or professionals. These findings were corroborated by the focus group participants.

Figure 2

What sort of help and advice are you looking for?

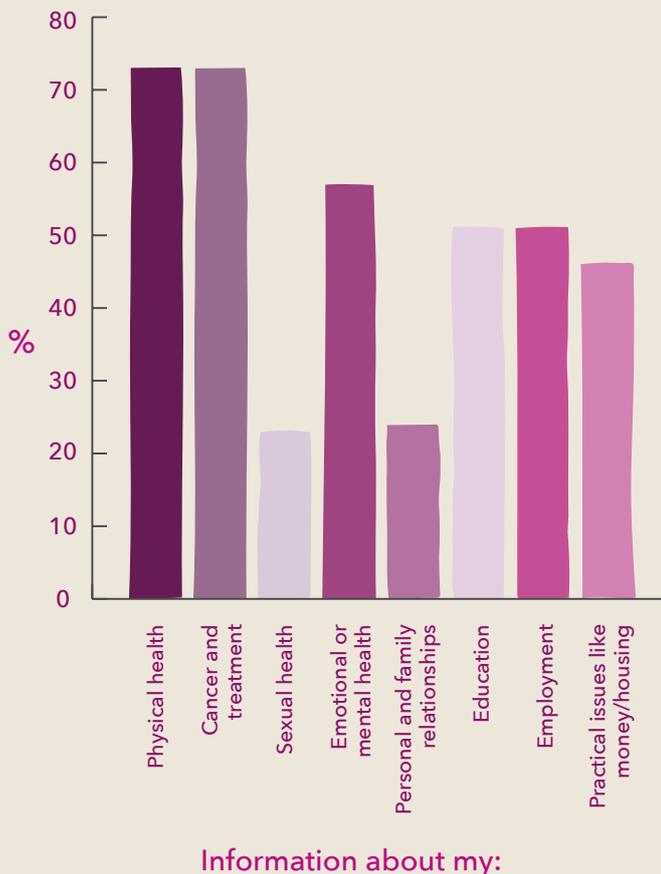
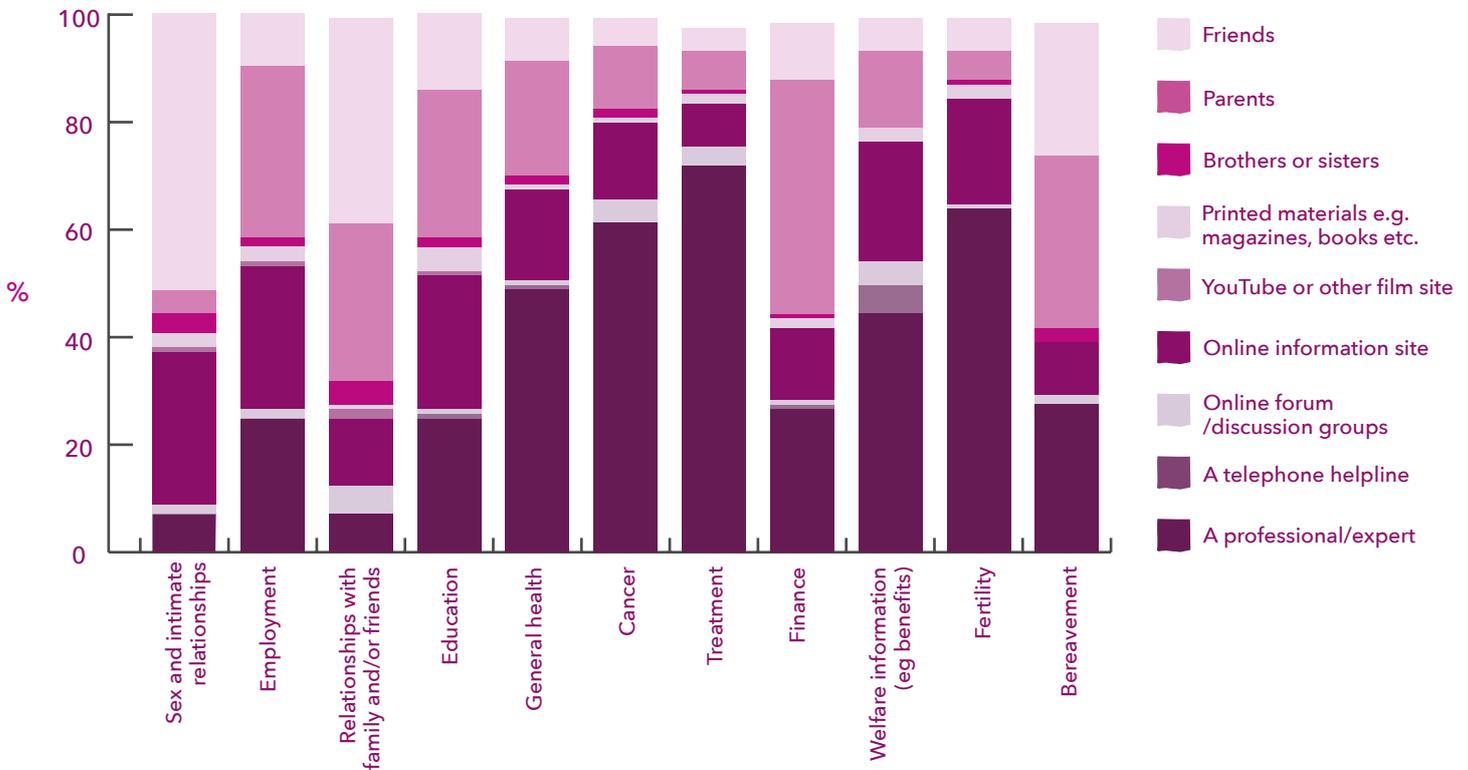


Figure 3

Which of the following sources would you be most likely to turn to for information or advice about the topics below?



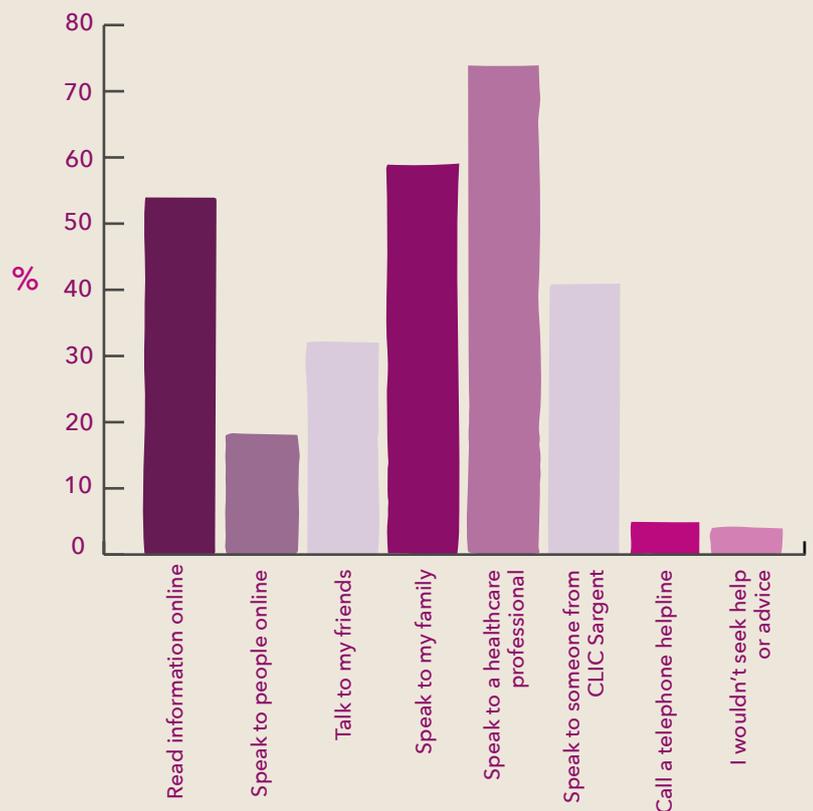
Face-to-face support

Face-to-face support is important to young people with a health condition, although the barriers to accessing such support can range from lack of availability to a desire for anonymity, plus the issues mentioned above.

Three quarters (74%) of the survey respondents indicated that they would want to speak to a healthcare professional (eg doctors and nurses) if they had a health problem that was worrying them. However, they would also use other sources, such as family and the internet. Two in five (41%) young people said that they want to speak to someone from CLIC Sargent for emotional and practical support.

Figure 4

If you had a problem that was worrying you, how would you prefer to seek help or advice?



In 2013 our *No young person with cancer left out* survey found that 95% of young people 'strongly agreed' or 'agreed' that CLIC Sargent had helped them to build their confidence, with 78% suggesting that face-to-face support had helped them to develop their future goals (CLIC Sargent, 2013c). The focus group found that young people recognise and appreciate the respective benefits of seeking advice from different groups, including from peers and care professionals such as CLIC Sargent's young people's social workers and community workers. They noted the practical help provided by our care professionals as well as the emotional support extended to the whole family.

"My young people's social worker was really great: she wrote letters to my university, helped me to get petrol money to travel to hospital, and even spoke to my mum on her own quite a few times which I think she needed."

Our young people's social workers and community workers provide much-needed practical and emotional support to help young people with cancer cope. They work with each young person according to their individual needs, focusing on emotional wellbeing and resilience and helping them to feel less isolated. They also provide specialist information and financial support, from diagnosis onwards, help young people keep in touch with their education if they are at school or college, and their jobs if they are in employment.

Our young people's social workers can offer in-depth emotional support to young people with complex needs, including those in crisis situations. Our young people's community workers help with emotional wellbeing and resilience, with a particular focus on education, employment and training issues. They provide individually-tailored support, close to where the young person with cancer lives or is being treated, on their terms.

Focus group participants described the anxiety they felt when their treatment ended, signalling the point when much of the professional support they were receiving would no longer be available. They were clear that they need more information and support post-treatment.

"After treatment finished I felt like I lost a blanket. I thought 'What do I have to look for that's going to show if I'm getting cancer again?'"

Hough et al. (2013) also identify a support and information need for young people and parent carers at the end of treatment.

Online support

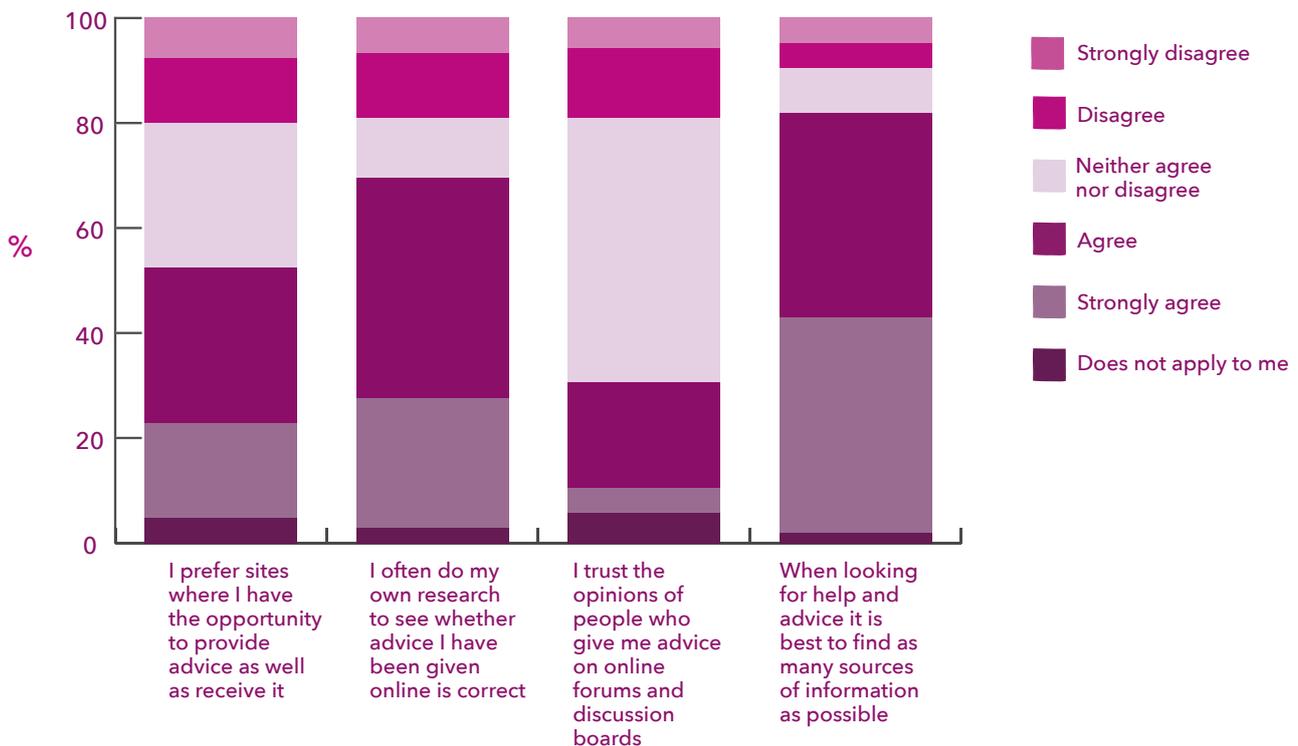
Young people with cancer value face-to-face support and information from health and social care professionals, and it's likely that this will continue to be a very important way in which they access support. However, it's also evident that there is a place for online support and information. These young people have grown up interacting with the digital world (YouthNet, 2009). In 2014, 82% of households in Great Britain had internet access (Ofcom, 2014) and in 2013 young people aged 15-24 were found to spend an average of 40 hours online per month (Ofcom, 2013).

Of the young people with cancer consulted by Groszmann et al. (2013), 70% said that digital communication was 'essential' in their life. CLIC Sargent's research echoes this: 91% of survey respondents said they use a smartphone to access the internet more than

once a day. As one participant said: "If it's not on my phone, I don't want to know". Groszmann et al. conclude that while face-to-face support cannot be replaced, digital communications are important for young people with cancer, with a significant proportion wanting more online resources. There is clearly an opportunity to respond to evolving digital needs.

Exploring help-seeking behaviour online, research carried out by Professor Hulme (YouthNet, 2009) found that 82% of young people had used the internet to look for advice and information for themselves, rating it alongside family and friends as a source of advice in stressful situations. While the research itself was carried out online, and will therefore have generated an internet-active respondent base, it is nonetheless notable that the single most important reason for using the internet for advice-seeking in stressful situations was the anonymity.

Figure 5
How far do you agree with the following statements?



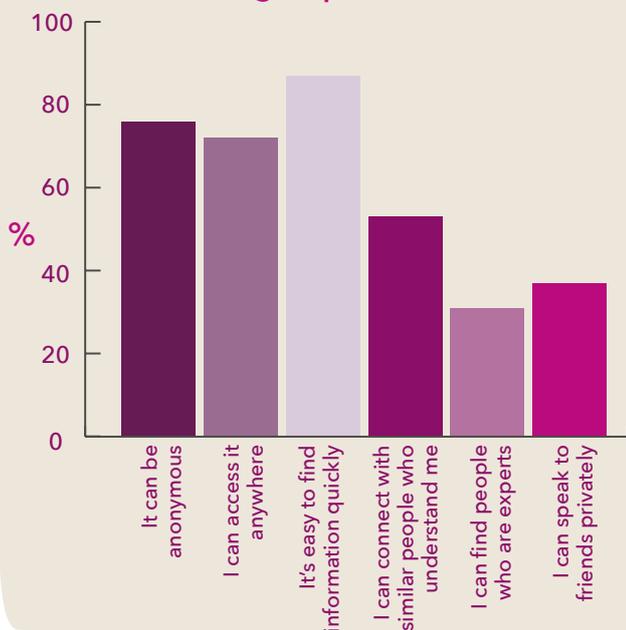
The research also highlights that 43% of young people prefer sites where they have the opportunity to provide advice as well as receive advice.

Of the young people that responded to our survey – also carried out online – the vast majority (96%) said they would use the internet to look for information and advice for themselves, over half (55%) used it to give advice to others and just under half (48%) said they used it to discuss issues and concerns with other people.

They also indicated which aspects of seeking information online they most valued, particularly emphasising access and anonymity:

Figure 6

What do you like about the internet when seeking help or advice?



The focus group participants suggested that using online social networks helped them to keep in touch and feel less isolated. They described using the internet to find specific information which they did not want to 'bother' their

doctor with (for example symptoms and side-effects of treatment). They felt there were websites that they could trust to provide reliable information such as Cancer Research UK, CLIC Sargent, Macmillan, NHS Direct, and Teenage Cancer Trust. Participants in the focus group however flagged that there can be practical barriers when accessing the internet, particularly if a young person is being treated in hospital on an adult ward where they may have to pay for internet access, if available.

"During my treatment, I'd google things like side-effects, so I felt reassured that other people had gone through that and it wasn't really weird. The internet is useful if you want information that you feel petty contacting the doctor about."

Both the focus group and the survey participants noted the benefits of interacting online with peers. Of those who said they would seek help and advice online, the majority wanted to interact with 'other people in the same situation as me' (78%) and 'people who have been in my situation before' (79%). The focus group participants felt that their 'cancer friends' – the term they used to describe friends they met as a result of having cancer – could empathise and enable them to share things that they were not always comfortable doing with other friends.

Disadvantages of the internet as an information source were also discussed at the focus group. For some young people, it can be overwhelming and unclear. Being able to access cancer survival statistics could be uncomfortable and finding age-appropriate information was a challenge.

While social networks could be a source of peer support, they could also be isolating, with online forums sometimes being prone to scaremongering. Our survey revealed a degree of ambivalence about the reliability of information on online forums and discussion boards, with 50% neither agreeing nor disagreeing that they could trust it. Safeguarding is a clear consideration when developing self-directed support resources.

Young people's information needs will vary throughout their cancer journey. Participants in the focus group said that they often found it difficult to obtain information from their GP or from healthcare professionals in the initial stages of their diagnosis, so turned to the internet, despite feeling overwhelmed and alarmed by some of the information they found. During treatment they used the internet less for information purposes and more for

distraction, support and staying in touch with friends and family. After treatment, they used the internet more to look for information about symptoms and signs of relapse, and long-term effects. They felt that there was less professional support available at this stage, which led to them having to seek out information, support and advice on their own.

The internet is obviously a major source of health information for young people, accessible in ways that face-to-face services may not be (Kauer et al., 2014). It should not be assumed however that all young people have access or are comfortable with online information (Smith et al., 2012).

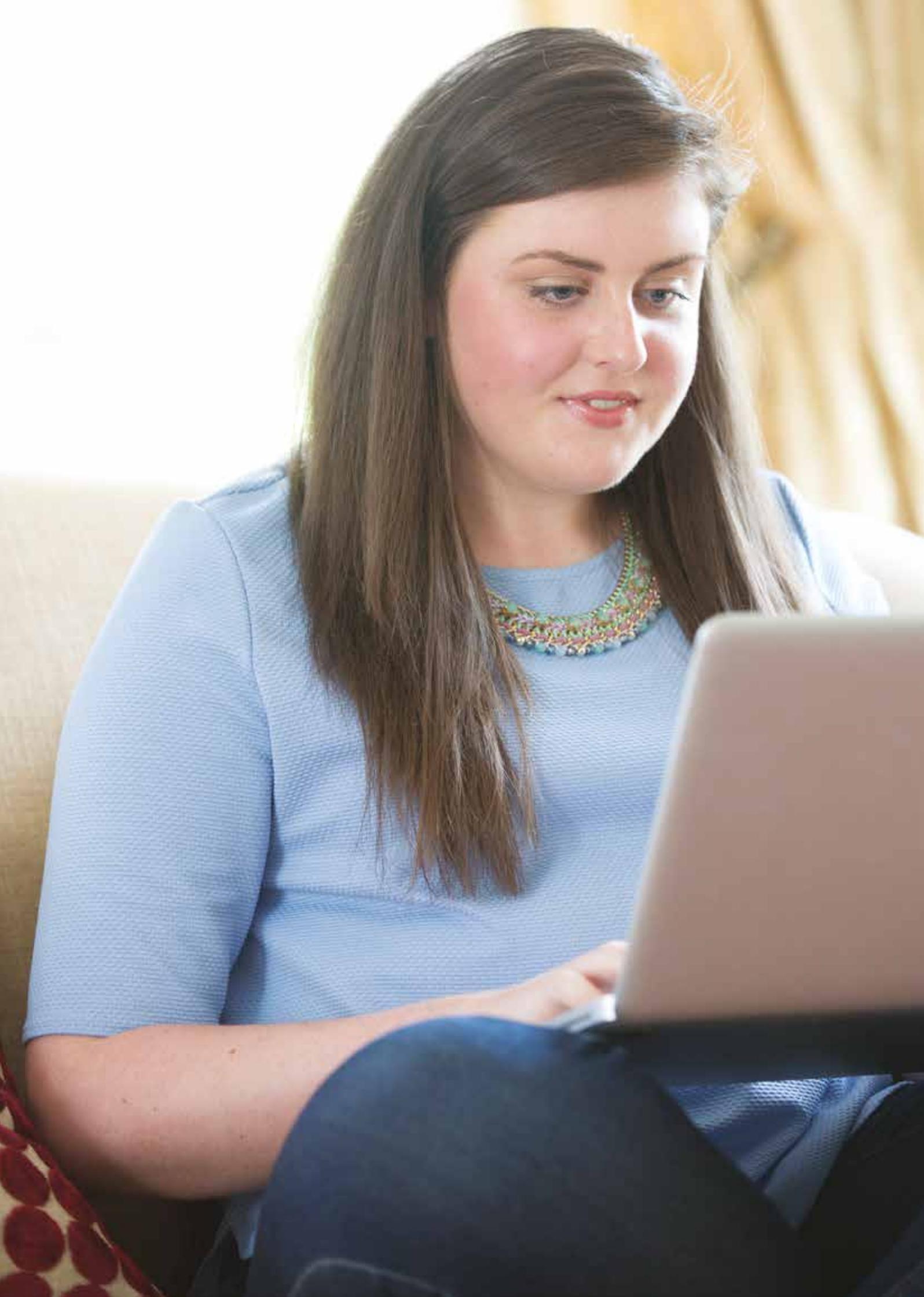
The next section explores the relationship between help-seeking and young people's resilience.

**Expert view: Hon. Professor Michael Hulme,
Senior Centre Director, Social Futures Observatory**

"It's important to understand how the digital media experience is part of an ongoing conversation and the conversation has different levels or elements. Part of the conversation may be seeking out online information, part of it might be using social media and part of it will be face-to-face.

Even when looking for professional advice there are moments when people want to search for something anonymously, or be involved in a conversation from a distance. If they are seeking information then they may do that more anonymously on their own, and when they are seeking some specific advice for themselves from professional sources, face-to-face interaction is hugely beneficial.

There is no substitute for face-to-face, but it's about allowing the opportunity for the individual to choose the mode of conversation that they want at the point that they want it. I would have thought that this will be of particular importance for young people with cancer."



Help-seeking and resilience

Help-seeking can be an effective way of coping with problems. How a young person (including a young person with cancer) copes (and is enabled to cope) with problems is key to how they will impact on them both now and in the future.

The evidence suggests that the ability to cope is a means of generating resilience. Resilience is often linked to notions of coping and competence (Compas et al., 2001). Taking this a step further, resilience can be conceptualised as an outcome – the outcome of successfully coping with stressful experiences.

“Resilience can be defined as reduced vulnerability to environmental risk experiences, the overcoming of a stress or adversity, or a relatively good outcome despite risk experiences.” (Rutter, 2012)

The evidence base for resilience is growing rapidly and there are many documented approaches to building resilience. These include individual approaches, focusing on the

vulnerabilities and protective factors (the attributes which help to deal with stressful events) of an individual, skills-based approaches, and wider approaches such as building resilient communities. Resilience is a broad topic, so we have reviewed relevant literature and, where it has direct application to building resilience in practice for young people with cancer, used it to inform our findings and guide our conclusions.

Resilience is often seen as a person’s capacity to cope with stressful situations and bounce back from setbacks. Personal characteristics such as self-determination and the ability to form positive relationships with others, as well as problem solving and communication skills, are often associated with individual resilience. These qualities can clearly help young people to manage their illness.

However, academics have challenged the view that resilience resides solely in individuals (Boingboing, 2014). A wider model of resilience looks at both internal capacities and external resources.

Expert view: Dr Rachael Hough, Teenage and Young Adult Oncologist, University College London Hospital

“Young people move through certain emotional and psychological stages as they travel towards adulthood. If you are diagnosed with cancer in the middle of that it’s extremely challenging.

Our aim should be to ensure that young people are appropriately supported as they go through these stages and feel empowered to navigate their way through services. Joined-up support is needed across the whole pathway - from point of diagnosis to post treatment and late effects. We need to ensure that there is sufficient support available for those who experience late effects so that we can ensure young people are able to remain resilient throughout their cancer journey and beyond.”

The community approach to resilience looks more widely than the individual. The *Communities that care* programme aims to 'help children and young people to grow up in safer and more caring communities' by focusing on what communities can do to reduce the risks facing children, young people and their families, to enhance protective factors and promote their wellbeing (France & Crow, 2001).

If the community approach was applied to health, the system itself would

have a role to play in developing the resilience of young people with cancer through multi-disciplinary support delivery throughout their cancer journey. Dr Ann Hagell advocates:

"A public health perspective doesn't just rest resilience within the individual. It's not just about changing children [and young people], it's also about changing society and social support systems."
(Hagell, 2014)

**Expert view: Dr Ann Hagell, Research Lead,
Association for Young People's Health**

"A lot is said about promoting resilience in young people, but it seems particularly salient for young people facing a huge challenge like cancer. Promoting their resilience is not just about helping them to develop coping skills, it's also about improving the support we provide and the way we respond to their particular needs."



Helping to build resilience in young people

Research has shown that there are developmental benefits from meeting and successfully coping with challenges (Rutter, 2012). This includes competence in dealing with problems by help-seeking (Murphy et al., 2013). Professionals who support young people can play a key role in building these skills and enabling them to successfully cope with challenges. Having access to quality information is integral to developing young people's problem-solving skills.

Other characteristics of young people which are associated with resilience include (ibid.):

- **Relationships with caring adults.** Apart from parents and caregivers, positive relationships with adults outside of the family are associated with resilience. Professionals working with young people can provide this important 'trusted adult' relationship
- **Cognitive skills.** Supporting young people to identify goals, plan and work towards achieving them can help to develop their skills
- **Social competence.** This involves applying problem-solving skills to interpersonal problems, showing empathy and helping others. Professionals working with young people can help to develop these skills, as can information resources, and the opportunity to interact with peers in a supportive environment
- **Confidence.** Confidence and self-belief are integral to young people being able to successfully deal with issues and problems that they encounter.

These characteristics are helpful when coping with stressors, however the ability to display these characteristics is often significantly impacted by a cancer diagnosis, which highlights the need to actively build this capacity in young people with cancer.

Resilience can help a young person to cope with stress, but stress can also build resilience and enhance that young person's ability to robustly face adversity and challenges in the future (ibid.). In previous research carried out by CLIC Sargent (2013c), some young people reported that their cancer experience had made them feel like they could 'deal with anything' in the future, which in turn gave some an increased drive to succeed. They had also developed skills through their experience, such as communicating with care professionals, which could help them in the future.

Not every young person who experiences stress will become resilient as a result. Individuals cope differently, which is why it's important to offer a choice of support networks to build skills and capacity for resilience.

The next section explores how CLIC Sargent approaches this.

How CLIC Sargent supports resilience

CLIC Sargent provides practical, financial and emotional support to young people with cancer across the UK to help them cope with the impact of a cancer diagnosis and its treatment.

We provide:

- **A wide range of information** for young people with cancer, to help them navigate their way through diagnosis, treatment and life after treatment. This includes online information and resources, videos and booklets. Our award-winning resources cover a range of topics from information about treatments and their side-effects, to handling money issues, to coping with changing relationships with family and friends
- **Financial support**, including grants and referral to a specialist CLIC Sargent welfare advice service, to help young people deal with the financial difficulties a cancer diagnosis can bring
- **Face-to-face practical and emotional support** to help young people, and their families, cope with the impact of a cancer diagnosis and its treatment
- **Free accommodation** at our nine Homes from Home – close to

specialist hospitals where families can stay during treatment, and patients too when treatment allows

- **Free specialist short breaks** away from the everyday challenges of cancer, giving young people the opportunity to spend time with others who are going through a similar experience.

Our care professionals

Care professionals such as CLIC Sargent Young People's Social Workers and Young People's Community Workers play an important part in building the confidence of the young people they support, helping them to have the self-belief they need to deal with the challenges they experience. They help to build resilience.

In 2013, 85% of young people told us that the emotional support from their young people's community worker had been extremely important to them (CLIC Sargent 2013a).

The young people who took part in the focus group for this research valued the practical help and the emotional support that a care professional can give. They noted the value of meeting face-to-face but added that it was

Expert view: Tracy Rodger, CLIC Sargent Young People's Community Worker

"My work is very much tailored to the individual but it tends to be around education and employment goals, personal development and life skills. Cancer can really knock a young person's confidence and some just don't know where to start again. As well as emotional support I offer practical support – for example I might help young people access information by signposting or by sending them internet links, helping them with their personal profile or helping them to freshen up their CV. It's a time to reflect on the skills and qualifications that they already have, establishing the gap between that and where they want to be.

Young people tell us that having professionals who believe in them helps them to believe in themselves. They appreciate the joined-up support we offer. They also benefit from the support that we offer through the peer support groups. We help to remind them of everything that they can do – that in itself can create a resilient state of mind."

important to also be able to contact them via text message or email. They recognised that these professionals could not always meet them outside of hospital, although they would have often preferred this. This highlights the importance of support in the community, or a location of their choice.

Online support for young people with cancer

The internet can be a useful tool to supplement and complement face-to-face support services. Prior to this research CLIC Sargent had identified the value of an online space for young people. The additional evidence identified through our research is being used to inform its development.

Alongside face-to-face support, we want to provide other options which

meet the clear demand for anonymous enquiry, peer support and instant access, including through mobile phones. CLIC Sargent's new online community for young people will be launched in early 2015. This will be a supportive virtual space where 16 to 24-year-olds who have, or have had, cancer can talk to other young people in a similar situation. It will be focused on enabling peer support. Young people who become members will be able to engage with other community members, and ask questions. A community moderator will also signpost young people to resources on the CLIC Sargent site, or to those provided by other organisations.



Conclusion and recommendations

This research was undertaken to better understand the help-seeking behaviour of young people with cancer. It examined how information and support can help develop their self-confidence and ability to manage their illness and its associated challenges. The research highlighted the synergy between 'help-seeking' and 'resilience'.

A review of existing research and consultations with young people with cancer and experts working with them were carried out. This enabled an analysis of young people's help-seeking preferences. It found that both online and face-to-face support have a role to play in meeting the needs of this group, and that they can both result in greater resilience.

The research has also raised questions for policy makers and practitioners in the health and social care system, including charities supporting children and young people with health conditions such as cancer, which we believe need further consideration and discussion:

- How can health and social care services (both public and charitable) take a more strategic approach to building resilience in children and young people?
- Can resilience be measured as an outcome and, if so, what approach should this take?

- How can the internet's potential to provide information, advice and support to young people with cancer be maximised, acknowledging risks and limitations of self-directed support online?
- How should the enabling of resilience and self-directed support be balanced with safeguarding?

While this research intends to help develop the evidence base specifically with regards to help-seeking and resilience among young people with cancer, we believe the findings (and the questions above) are relevant to all young people with health conditions and the professionals working with them.

The research has enabled CLIC Sargent to reflect on its services and continue to develop and improve how we support young people to meet their identified needs. We are also proposing a number of priorities for change for the wider health and social care sector, to move us all towards a system of support that fosters resilience in young people with health conditions such as cancer.

Priorities for change: building resilience in young people with health conditions such as cancer through the health and social care system

1) Research priorities

Further exploration into what works in building resilience in young people with specific health conditions is needed to better understand the services that impact them. In particular we recommend that academic institutions and national intelligence centres for young people and for cancer consider commissioning research in the following areas:

- Young people with cancer and resilience
- Survivorship and resilience
- Resilience in young people receiving palliative care
- The impact of age-appropriate care.

2) Culture change priorities - policy and practice

Young people aged 16 to 24 should be considered as a specific group within the health system, and measures should be put in place to ensure that young people can smoothly transition from children's to adult services. Responding appropriately to their needs should be made a priority. Central and local government policy across the UK can help to set the direction and to begin to change culture. In order to take this forward, we recommend that:

- Government and NHS agencies in each of the UK nations should adopt the principle of promoting resilience, including through

support, information and advice as part of a holistic approach to help young people cope with adversity – for example by developing and maintaining positive mental health, skill development and becoming financially stable

- Government and NHS strategies for cancer and young people's health in each of the UK nations should include priorities which help to establish an optimal cancer journey for children and young people, from routes to diagnosis to long-term effects, promoting more effective coordination between health, social care, education, financial support and employment services
- Initiatives that promote the integration of health and social care should target young people with health conditions, making it easier for them to navigate through the system and transition between specialist centres and local support.

3) Information and advice improvement priorities

Being able to access appropriate and timely information and advice is vital in enabling young people to be resilient. To ensure that they can access information and advice we recommend that:

- Priority should be given to maximising and, where possible, improving digital access within hospital settings to help ensure young people are able to stay connected digitally with their networks and to access information, advice and support online
- NHS information and advice strategies in each of the nations

of the UK should prioritise the development of information specifically for young people across a wide range of topics encompassing online, face-to-face and peer-led information

- In line with promoting resilience, government and NHS agencies should provide guidance for those developing information, advice and online support for young people to help ensure that they take into account how young people seek and prefer to access information throughout all stages of their illness.

4) Priorities for CLIC Sargent - expanding our young people's services

The learning from this research will inform our drive to develop our young people's services strategy and work. We know that there are many young people, particularly those in hospitals without age-appropriate services, that we do not reach or where we can only deliver a limited service. We have ambitious and innovative plans to extend this support to all young people diagnosed with cancer who need it. We'll do this by expanding our face-to-face services and complement this with on and offline information and resources. In particular we'll:

- Extend our quality face-to-face support to all 16 to 24-year-olds that need this service. This is an important part of CLIC Sargent's services strategy and we're committed to expanding our young people's service throughout the UK so that practical and emotional support is available to every young person with cancer who needs it. These services will offer

evidence-based support options that focus on building resilience

- Launch a peer-led, online community that provides a supportive space where young people with cancer can share experiences and support one another. It will be informed by the evidence base resulting from this research and further shaped by the young people who use it
- Explore how technology can support young people with cancer. CLIC Sargent will keep abreast of online developments which can be built into the suite of services we offer. We'll continue to monitor trends in digital technology and utilise this to ensure that our online support remains fresh and fit for purpose
- Provide on and offline information advice and guidance resources throughout young people's cancer journeys to help them feel supported at all stages of their illness. CLIC Sargent will continue to produce quality, age-appropriate information resources and to signpost young people to resources and information provided by other organisations. We'll also explore ways to better enable young people to share information with peers.



References

- Billings, A G & Moos, R H (1981) The role of coping responses and social resources in attenuating stress of life events. *J. Behav. Med.*, 4, 139-157
- boingboing (2014) Resilience research and practice. www.boingboing.org.uk
- CLIC Sargent (2010) More than my illness - delivering quality care for young people with cancer (Policy Research Report). London: CLIC Sargent
- CLIC Sargent (2011) Counting the costs of cancer (Policy Research Report). London: CLIC Sargent
- CLIC Sargent (2013a) Young People's Community Worker pilot - evaluation report. London: CLIC Sargent
- CLIC Sargent (2013b) No teenager with cancer left out (Policy Research Report). London: CLIC Sargent
- CLIC Sargent (2013c) No young person with cancer left out (Policy Research Report). London: CLIC Sargent
- Compas, B E, Conner-Smith, J K, Saltzman, H, Thomsen, A H, & Wadsworth, M E (2001) Coping with stress during childhood and adolescence: Problems, progress, and potential in theory and research. *Psychological Bulletin*, 127, 87-127
- CRUK (2013) Five-year survival. 10 September 2014, www.cancerresearchuk.org/cancer-info/cancerstats/teenage-and-young-adult-cancer/survival/#Five-year
- CRUK (2014) Teenage and young adult cancer statistics. 1 September 2014, www.cancerresearchuk.org/cancer-info/cancerstats/teenage-and-young-adult-cancer/
- Czyz, E K, Horwitz, A G, Eisenberg, D, Kramer, A, King, C A (2013) Self-reported barriers to professional help-seeking among college students at elevated risk for suicide. *Journal of American College Health*, 61(7), 398-406. doi:10.1080/07448481.2013.820731
- Department of Health (2011) Improving outcomes: a strategy for cancer. www.gov.uk/government/uploads/system/uploads/attachment_data/file/213785/dh_123394.pdf
- Department of Health (2013) Better health outcomes for children and young people: our pledge. www.gov.uk/government/uploads/system/uploads/attachment_data/file/207391/better_health_outcomes_children_young_people_pledge.pdf
- Department of Health (2014) Closing the gap: priorities for essential change in mental health. www.gov.uk/government/uploads/system/uploads/attachment_data/file/281250/Closing_the_gap_V2_-_17_Feb_2014.pdf
- Department of Health, Social Services and Public Safety (2011) Cancer service framework. www.dhsspsni.gov.uk/service_framework_for_cancer_prevention_treatment_and_care_-_full_document.pdf
- France, A & Crow, I (2001) CTC: the story so far: an interim evaluation of Communities that care. York: Joseph Rowntree Foundation
- Garvey, B, Madden, M, Violi, C, Spigelman, A, and Tracey, G (2008) Help-seeking behaviour in young adults (Research Report). London: nfpSynergy
- Groszmann, M, Aref-Adib, G, Abrol, E, Wimalsingham, G, Lasker, R, & Dawood, T (2013) Digital communication survey [PowerPoint slides]. www.londoncancer.org/media/61813/michael-groszmann-digital-communications.pdf
- Hagell, A (2014) What do we know about young people's resilience in a health context. [Presentation to Public Health England, London 3 Feb]
- Harvey, N, & Finch, A (2008) Supportive care for adolescents and young adults during cancer treatment. In Kelly, D, & Gibson, F (Eds.), *Cancer care for adolescents and young adults* (pp. 23-43). Oxford: Blackwell
- Hough, R, Elfer, J, Finch, A, Vernon, M, Collison, D, & Riley, V (2013) Audit of TYA cancer patient's views on supportive services offered by UCLH [PowerPoint slides]. www.londoncancer.org/media/61834/wilson-eglin_tya-support-audit.pdf
- Kauer, S D, Mangan, C, & Sancu, L (2014) Do online mental health services improve help-seeking for young people? A Systematic Review. *J Med Internet Res*, 16(3), e66. doi:10.2196/jmir.3103

- Kirchhoff, A C, Leisenring, W, Krull, K R, Ness, K K, & Friedman, D (2010) Unemployment among adult survivors of childhood cancer: a report from the childhood cancer survivor study. *Med Care*, 48(11), 1015-25
- Kuhl, J, Jarkon-Horlick, L, Morrissey, R F (1997) Measuring barriers to help-seeking behavior in adolescents. *Journal of Youth and Adolescence*, 26(6), 637-647
- Lancashire, E R, Frobisher, C, Reulen, R C, Winter, D L, Glaser, A, & Hawkins, M M (2010) Educational attainment among adult survivors of childhood cancer in Great Britain: a population-based cohort study. *Journal of the National Cancer Institute*, 102(4), 254-70
- Murphy, D, Barry, M, & Vaughn, B (2013) Positive mental health: resilience. www.childtrends.org/wp-content/uploads/2013/03/Child_Trends-2013_11_01_AHH_Resilience.pdf
- NHS England (2014) Five Year Forward View. <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>
- NHS Wales (2005) National service framework for children, young people & maternity services. www.wales.nhs.uk/sites3/docmetadata.cfm?orgid=441&id=46873
- Ofcom (2013) Communications market report. London: Ofcom
- Ofcom (2014) Communications market report. London: Ofcom
- Office of the First Minister and Deputy First Minister (2006) Our children and young people - our pledge. www.delni.gov.uk/ten-year-strategy_1_.pdf
- Persike, M, & Seiffge-Krenke, I (2012) Competence in coping with stress in adolescents from three regions of the world. *J Youth Adolescence*, 41, 863-879. Doi:10.1007/s1094-011-9719-6
- Rickwood, D J (1995) The effectiveness of seeking help for coping with personal problems in late adolescence. *Journal of Youth and Adolescence*, 24(6), 685-703
- Rutter, M (2012) Resilience as a dynamic concept. *Development and Psychopathology* 24, 335-344. doi:10.1017/S0954579412000028
- Sawyer, M G, Borojevic, N, Ettridge, K A, Spence, S H, Sheffield, J, & Lynch, J (2012) Do help-seeking intentions during early adolescence vary for adolescents experiencing different levels of depressive symptoms? *Journal of Adolescent Health*, 50, 236-242. doi:10.1016/j.jadohealth.2011.06.009
- Schonert-Reichl, K A, & Muller, J R (1996) Correlates of help-seeking in adolescence. *Journal of Youth and Adolescence*, 25(6), 705-731
- Schwartz, L, & Drotar, D (2006) Post-traumatic stress and related impairment in survivors of childhood cancer in early adulthood compared to healthy peers. *J Pediatr Psychol.*, 31(4), 356-66
- Smith, J, Skrbis, Z, & Western, M (2012) Beneath the 'Digital native' myth: understanding young Australians' online. *Journal of Sociology*, 49(1), 97-118. doi:10.1177/1440783311434856
- The Scottish Government (2008) Better cancer care: an action plan. www.scotland.gov.uk/Resource/Doc/242498/0067458.pdf
- The Scottish Government (2012) A guide to getting it right for every child. www.scotland.gov.uk/Resource/0045/00458341.pdf
- United Nations (2008) Convention on the rights of the child. www2.ohchr.org/english/bodies/crc/docs/AdvanceVersions/CRC.C.GBR.CO.4.pdf
- Welsh Assembly Government (2008) School effectiveness framework. www.wales.gov.uk/docs/dcells/publications/091020frameworken.pdf
- Welsh Government (2012) Together for health, cancer delivery plan for the NHS to 2016. www.wales.gov.uk/docs/dhss/publications/120613cancerplanen.pdf
- Welsh Government (2014) Legislative proposals for additional learning needs - White paper. www.wales.gov.uk/consultations/education/proposals-for-additional-learning-needs-white-paper/?lang=en
- YouthNet (2009) Life support: young people's needs in a digital age (Research Report)

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