

Macmillan's website: An evidence review

Introduction

Macmillan helps meet the information and support needs of people affected by cancer in a variety of ways including through the support and funding of local cancer information and support services, the production and distribution of high quality information and advice materials, and directly through our website and telephone helpline.

Macmillan's website provides high quality, up to date information for cancer patients, families and carers. It also meets financial, support and emotional needs, offers access to online communities, signposting to support groups and access to financial advisers.

We ensure both our virtual and telephone information services and our Macmillan supported services work to the same high standards and use common resources. We also enable referral to local support services where appropriate across all types of information provision to ensure the customers' needs are met.

Summary of Key Findings

80% of adults in the UK regularly use the internet and this is estimated to increase by 4.3million people by 2013. In 2012, 21 million households in Great Britain (80 per cent) had Internet access, compared with 19 million (77 per cent) in 2011. However 9.2 million people in the UK are still offline and of these 40% are from deprived groups. There is a danger that as more services and opportunities are delivered online, those who lack online access or the skills needed to take advantage of it, will be further disadvantaged.

Increasingly the internet is being used to access health related information and support online, with almost half of adults using the internet for this purpose. It is accessible 24 hours a day, can be used anonymously, in confidence and from the comfort of your own home. Cancer patients who are confined to their home or struggle to discuss issues face to face find this particularly appealing.

The internet enables cancer patients to obtain the information they need to self manage their condition and feel more in control. The support of online communities and networks provides emotional support, which in turn can lead to reduced anxiety, stress and depression.

1. Background on internet usage in the UK

It is estimated that in 2012 80% of UK adults use the internet (67% use it daily or almost everyday)³ and this figure is set to increase over the next few years by 4.3million people.¹ The Government's Broadband Strategy aims to provide 90% of all UK households with broadband internet access by 2015 allowing faster connection speeds and greater download capacity.²

The proportion of households able to access the internet varies between UK regions. In 2010 London had the highest level of internet access at 83%. The North East had the lowest proportion of households with internet access at 59%.³

Internet usage has risen over the last decade in all age ranges but especially among young people with 99% of 16-24 yr olds using the internet in 2010. However, proportionally, the largest growth area is in the > 65 yr old age range, with 46% having accessed the internet recently, up more than 10% from 2009.³

Even though the majority of people in Britain have access to the internet 9.2 million remained offline in 2010.³ It was estimated in 2009 that 4 million of those offline were the most socially and economically vulnerable.⁴ 97% of adults with a degree or equivalent qualification were estimated to live in a household with internet access. Those with no formal qualification were least likely with just 45% having access at home.³

There is a clear link between social status and digital exclusion and there is a danger that as more services and opportunities are delivered online, those who lack online access or the skills needed to take advantage of it, will be further disadvantaged.⁵

2. Why is the internet important in health and social care?

The internet has wide ranging appeal notably that it is a valuable means of communicating, gathering information, shopping and socialising with the added benefit of being easily accessible and available 24 hours a day. It does not discriminate and can be used anonymously and in confidence. For many people it is easier to connect to the internet than it is to find a bookshop or library.⁶

At least 47% of UK adults use the internet to search for health related information.⁷ A similar study showed that this usage was consistent across all age ranges.²

Not only does the internet serve as a robust source of both general and specific information, it also permits access to the most current information with considerable ease.⁹

The quality of health information found on the internet is highly variable and the risks of searching for information online are widely understood by internet users. Signposting to trusted sites is therefore valued. One survey of breast and prostate cancer patients established that websites attached to recognised centres of excellence such as universities or well known medical journals were preferred sources of health information. Non-commercial sites for health information were also favoured.⁸

For some people the internet is their only means to communicate with the outside world.⁹ One patient housebound through suffering with HIV made the following comment:

*'So many people have computers nowadays, you haven't actually got to leave your house, it doesn't matter how you are feeling. You don't even have to get dressed; you can just, you know, log on and you can get the information. Which I think is going to do absolutely nothing but help people'*¹¹
Cancer patients are often confined to their homes as a result of their cancer and its treatment and as such this is likely to also be applicable to them.

A study of HIV sufferers showed the value placed on being able to access the internet while housebound:

*'In situations where you can't do a lot of walking and getting out and stuff, having a terminal can be a life saver because you can get information and services without making a lot of effort, endangering your health.'*⁹

For some a lack of mobility, financial difficulty caused by an illness or the responsibility of caring for a child or elderly family member reduces the ability to leave the house and places a bigger reliance on the internet. One study found that online support groups were particularly popular with women from rural locations who did not have ready access to other forms of support.¹⁰

*'I was real, real sick and I was desperate for information. Driving was out of the question. I was able to get what I needed off the internet.'*⁹

The internet alleviates the need to speak to someone face to face about issues which people affected by cancer may feel uncomfortable or embarrassed about. This particularly appeals to young men, who are worried about their health but reluctant to visit the doctor.¹¹

3. Why do people affected by cancer use the internet?

Cancer patients use the internet for a wide range of information and support needs, many of which are unlikely to be met through conventional healthcare.¹¹ Internet use by patients at all stages of cancer care is now widespread, from early investigations to follow-up after treatment.¹²

One survey of people affected by cancer listed a number of the key reasons for accessing the internet. These are detailed below¹¹:

- To access a wealth of knowledge and information on their condition and treatment (*Please refer to 'Information and support- An evidence review' found on the Impact webpage for more information on this area.*)

- To find alternative and complementary treatments

*'Quite a lot is written and discussed on the internet about alternative treatments, and if conventional treatments stopped working I would obviously examine some of those.'*¹¹

- To raise awareness about cancer through instant communication with a large numbers of people

*'I know there are other people out there and we can get something done'*⁹

- To seek support from peers

*'It's not just the medical information aspect; it's just a kind of support, moral support, which is very, very important when you've had a diagnosis of cancer.'*¹¹

An added benefit of the internet for this purpose is the ability to access support when needed rather than having to wait until a scheduled meeting time.²⁸

- To make social connections

*'People log on because they've either got something to say or else an ear to lend to those who do'*⁹

*'There are friendships and camaraderie that you get from the internet. There's a community of us who are always on the internet. Nine times out of ten, I'm closest to people who are on the internet.'*⁹

- To tackle isolation

*'It's just very good to know that other people have been through this and to kind of share the experience with other people, and you feel much less isolated...'*¹¹

4. How does Macmillan provide people affected by cancer with online support?

In 2011 we estimated that Macmillan support online (www.macmillan.org.uk) reached 3.9 million people in the UK via our website, which is up 15% on 2010 figures.¹³ At a cost of 16p per reach it the cheapest of Macmillan's services to fund in terms of cost per reach.¹⁴

The reliability and accuracy of the health information found on the internet more globally is highly variable. Cancer patients searching for information may come across potentially dangerous drugs, treatments that cannot be financed on the NHS, unethical or unproven alternative treatments and information that could be damaging to their mental well-being.⁶ The importance of quality assured online information provision is therefore paramount.

Macmillan's website provides high quality, up to date information for cancer patients, families and carers. The information provided on the website is written and reviewed by specialists to ensure it is of the highest standard.¹⁵

The website contains a wealth of information covering over 56 different cancer types, causes and risks, treatments, tests and screening, how to cope with living with cancer, as well as information on end of life care and supportive information for carers and family members.¹⁵

Information on financial assistance in the form of grants and benefits is provided on line, allowing cancer patients to determine whether they might be eligible for disability living allowance and directing them towards Macmillan's benefits advice helpline and grants team. In addition there is signposting to external sources of financial advice and support such as the CAB.¹⁵

The website has an online community for social networking and gaining support and advice from fellow cancer patients, families, carers and Macmillan professionals. In addition to the online support the website provides signposting to local support groups.¹⁵

5. What impact does Macmillan's online support have on people affected by cancer*?

i) The impact of the website on user satisfaction and experience

One of the benefits of Macmillan's website is that it reaches people who might not seek information and advice elsewhere – for example – in 2011, 61% of users are friends and family members of people living with cancer and 14% were carers.¹⁶

A survey carried out in 2008 found that around 70% of people found Macmillan's website very or fairly easy to use to find the information they were looking for. Over half found the website comprehensive and containing all the information they were looking for.¹⁷

72% also found additional useful information that they had not been originally looking for (particularly the online forums and information about emotional support).¹⁸

As a result 95% are very or fairly likely to recommend the website to others and 92% are very or fairly likely to re-contact Macmillan in the future.¹⁹

* Please refer to 'Information and support- An evidence review' and 'Financial benefits advice services- An evidence review' found on the Impact webpage([link below](#)) for more information on the impact of providing information, support and financial advice

A 2012 online survey of visitors to the Macmillan website found that 90% rated the website excellent or good for 'easy to find what I needed' and 94% rated the clarity of information excellent or good. 93% found the information useful and 89% found the site engaging and interesting.²⁰

ii) The health and wellbeing impact of accessing information and support

56% of people accessing the Macmillan website do so to find information about cancer or a particular treatment for cancer.²¹

Patients who have a better knowledge and understanding of their cancer and treatment are found to be more positive and less depressed.¹²

In addition, cancer patients who are well informed are better able to understand and participate in their health care plan, experience less anxiety and more likely to cope with their illness.²² They are also better equipped and prepared with questions for consultations with health professionals.²³

Informed patients take a greater degree of ownership and responsibility for their care and are better equipped to manage their own symptoms.¹² With the right information and support patients can look after themselves more efficiently and their quality of life is much improved.²⁴ There is evidence that internet usage enables people to enhance their sense of autonomy.⁶

One study of the effect of computer support on younger women with breast cancer found that those who used a computer based support system were significantly more competent at seeking information, more comfortable participating in care and had greater confidence when speaking to doctors than those who didn't have access to information and support online.²⁵

For 50% of those completing the survey it was the first time they had used the Macmillan website and the majority had found the website through a search engine such as google.²⁶

iii) The health and wellbeing impact of access to social networking sites and online communities offering support and advice

Accessing social networking sites and online communities reduce feelings of isolation and loneliness. It can also alleviate the feeling that you are on your own and that nobody else has been through a similar experience.¹¹

*'The neat thing about the internet is that you can actually hook up with people that have gone through the same experiences, that do understand what you're talking about, that have been there.'*⁹

One study of the use of the internet to counteract social isolation after breast cancer found that by being able to exchange knowledge and experiences with other internet users the women concerned felt more empowered. The study also found that internet support groups have important potential for aiding rehabilitation.²⁷ Peer support has also been shown to improve a patient's ability to cope with their disease.²⁸

Recent research in the US found that spending time online reduces depression and increases cognitive brain function among senior citizens. Levels of depression were thought to have decreased by as much as 20%. Potential reasons include the fact that internet usage increases cognitive decision making and the ability to make social connections.²⁹ A second study confirmed these findings stating that cognitive behaviour interventions are effective in reducing and managing psychological distress in cancer patients.³⁰

*'Being involved takes your mind off the horror of it, and you immediately begin the process of fighting the disease.'*¹¹

One evaluation of the positive effect of peer support on the well-being of breast cancer sufferers reported improvements for patients on trauma symptoms, emotional wellbeing, confidence and self-belief. It was found that the opportunity for cancer patients to talk through their experience with someone who has gone through a similar experience could have real therapeutic benefits and positive health consequences.³¹

Users of Macmillan's online community made the following comments about how the service has improved their lives:

'I have been posting on this site for around a year now after having lost both my parents within a very short time of each other. It has been my life line and I don't know what would have happened to me without the support of the others. I live in Aberdeen and last weekend I travelled to Southampton to meet up with some of the others-a very emotional experience. Through this site I have now made friends for life and I just wanted to say thank you so much for helping me carry on after losing the two most precious people in my life. Keep up the brilliant work.'

'My partner has cancer and we have been terrified up until we found this site...we had no support or guidance and I can honestly say its brought out the best of the worst situation...I don't know what we would have done without this site...it's helped us to find all the positives... and there are some very sad stories but it has showed us how to cope....'¹⁵

'The site has truly helped me, it has helped me to gain some perspective and make me realise that I am not alone and to enjoy the moment instead of worrying what the next step is or what tomorrow or next week may hold'¹⁵

'Some days I get strength from seeing that people have the same feelings as me and it gives me comfort when I'm feeling like I'm the only person in the world to feel like I do. Other days it picks me up because I can share my feelings and thoughts which will hopefully give others comfort as well.'¹⁵

iv) The impact of financial support and advice

After information on cancer and its treatment searching for information on practical, emotional and financial support is the most popular.³²

Cancer patients are often unaware of the financial benefits that they are entitled to and there is widespread under-claiming of welfare benefits by those eligible for them.³³ There is considerable evidence that cancer patients experience substantial stress around financial issues.³⁴ Once the financial stress is removed, they are more able to deal with their illness and treatment.

Macmillan information and support services provide a vital signposting facility, referring patients to appropriate financial advice and assistance services. Macmillan-funded research has shown that all patients claimed that benefits received as a result of welfare advice funded by Macmillan helped to reduce stress levels, which can in turn aid recovery.³⁵

Conclusion

The internet is an extensively used resource for communication, accessing information and seeking social support through online communities and networking groups.

The internet is becoming increasingly accessible and widely used across all age ranges especially in the >65 yr old age range. Many people predict that the future of health care will heavily involve the use of the internet whether for booking appointments, delivering care plans or for self management.

It is essential that as more and more people turn to the internet for health advice that reliable sources are used. Macmillan's website provides a wealth of high-quality up to date information and signposting to support as well as access to online communities. The website could therefore play an increasingly important part in improving the lives of people affected by cancer going forward.

There is evidence that using the internet for health information generally can improve the health and wellbeing of people affected by cancer. We know that 3.2 million people in the UK have used Macmillan's website and there has been much positive feedback from the users of the Macmillan online community.

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- ¹ <http://www.newmediatrendwatch.com/markets-by-country/18-uk/148-usage-patterns-and-demographics>
- ² http://www.culture.gov.uk/what_we_do/telecommunications_and_online/7763.aspx
- ³ Office for National Statistics (2012) *Internet Access: Households and Individuals*. UK
- ⁴ <http://www.21stcenturychallenges.org/focus/digital-divide-in-britain/>
- ⁵ Office for National Statistics (2009) *Internet Access: Households and Individuals*. UK
- ⁶ Theodosio L et al. (2003) *Emerging challenges in using health information from the internet*. *Advances in Psychiatric Treatment*. UK
- ⁷ <http://consumers.ofcom.org.uk/2010/05/uk-internet-users-becoming-more-security-conscious/>
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- ¹⁵ www.macmillan.org.uk
- ¹⁶ Macmillan Cancer Support (2011) *Reach Figures*
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