



What are they?

Meeting other people with similar experiences can be invaluable when you are affected by cancer. Self-help and support groups offer a chance for people to talk to others and come together with people who understand how they are feeling, share concerns and get advice from those who have gone through similar experiences.

Macmillan supports independent cancer self-help and support groups and organisations across the UK by providing grants, a range of free publications and workshops to help set up cancer self-help and support groups.

'I could never adequately describe the benefits a support group gives to patients, carers and professionals alike. A friendly, informal, supportive atmosphere really helps to boost confidence, provide insight and establish long-lasting friendships for all involved.' **Therapist**

This Impact Brief is part of a suite of Impact Briefs which provide evidence about the impact of Macmillan's direct and indirect services, available at www.macmillan.org.uk/impactbriefs

Need



Over the next ten years, patient self-management must improve to provide more tailored care and reduce NHS expenditure.³



43% of patients in one study said that they would like to get more information about one or more aspects of their condition.⁷

Reach



In 2014 self-help and support groups who received Macmillan funding reached **12,760** people affected by cancer.¹⁶



By the end of 2014, Macmillan had provided set-up grants to around 900 Self-Help and Support Groups across the UK.¹⁷

Impact



Every £1 of investment by Macmillan in its start-up and grants programme for self-help and support groups could save the government as much as £76.08.¹



Self-help and support groups contribute to NHS priorities by providing improved patient experience, better quality of life and compassionate care.²¹

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SELF-HELP AND SUPPORT GROUPS

INTRODUCTION

People, who are affected by cancer, can significantly benefit from opportunities to meet and talk with others who have similar experiences. Self-help and support groups (SHSGs) provide space to share concerns with others that understand how they are feeling. These groups can offer physical, emotional or practical help depending on specific needs of attendees.

There are all sorts of self-help and support groups that people can get involved in. Some support those from a specific community or with a particular type of cancer, while others are designed to help carers and loved ones. Essentially, these groups give members a chance to meet up and chat in a safe and understanding environment.

KEY FINDINGS

- **Demand for self-help**
With a mismatch between NHS resources and demand over the next decade, it will be increasingly necessary to improve patient ability to self-manage conditions and free up health and social care resources. SHSGs can contribute towards this goal.
- **Services offered by SHSGs**
Typical services offered include the provision of cancer information materials, peer and informal support, training, social activities and telephone helplines.
- **Cost**
The main cost to support groups is the day to day running. Some SHSGs undertake fundraising to help meet this need. Macmillan offer grants to help cost such as the set up and development of groups.
- **Type of groups**
SHSGs can be organised by cancer type, location, community or user type, e.g., cancer patient, carer or friends. Some others are more generic and offer support to all people affected by cancer.
- **Government cost saving**
By providing support to those affected by cancer, Macmillan funded SHSGs can result in government health care cost savings.

1. What is the issue?

As well as receiving health care and support from the NHS, cancer patients in the UK are also supported by other organisations and groups that contribute to the prevention and treatment of cancer. SHSGs are one such group that play an important role in supporting cancer patients.¹

Various policy makers claim that the NHS will have to find a way to make significant savings in the future. Over the next 15 years health outcomes will need to improve significantly, but delivered with the same resources. The expenditure on cancer treatment is increasing because cancer patients live longer and it is becoming major medical spending in developed countries.² In the next decade healthcare will need to develop an approach to improving the capacity of patients to self-manage their conditions and to better manage their own healthcare to provide more tailored care and reduce spending in hospitals for care which can be provided elsewhere.³ Research shows that self-help groups can contribute to positive wellbeing and they should be offered to cancer patients.⁴ Therefore, SHSGs can potentially free up resources in health and social care and improve the quality of care for people affected by cancer.¹

Importance of cancer support

Every stage of the cancer journey can be challenging for patients as well as for carers, family and friends. Although many people find that they receive support from their healthcare team during treatment, the emotional and financial impact of cancer can be as great as the physical effects. Some people may have close friends or family who can provide support but people living with cancer can sometimes feel guilty about the emotional and physical impact that their cancer might have on those around them. There are people who can also feel as though they do not have anyone they can speak to about their experiences because they feel that nobody understands them.¹

SHSGs can provide opportunities to meet with people who have had similar experiences related to cancer as well as give specific information and support to those affected by cancer. Typical services offered by these groups include:

- Cancer information materials
- Peer and informal support
- Social activity i.e. day trips
- Telephone helplines
- Complementary and dietary therapy
- Home and hospital visiting
- Help with internet use
- Activity based support e.g. film making clubs
- Provision for the visually impaired
- Provision for the deaf and hard for hearing
- Written and spoken translation services.⁵

SHGSs are usually activity based initiatives that bring together people with similar interests which makes it easier for people to share their experiences. A Macmillan survey of SHGSs revealed that 69% of users mainly required befriending and information on cancer.⁵

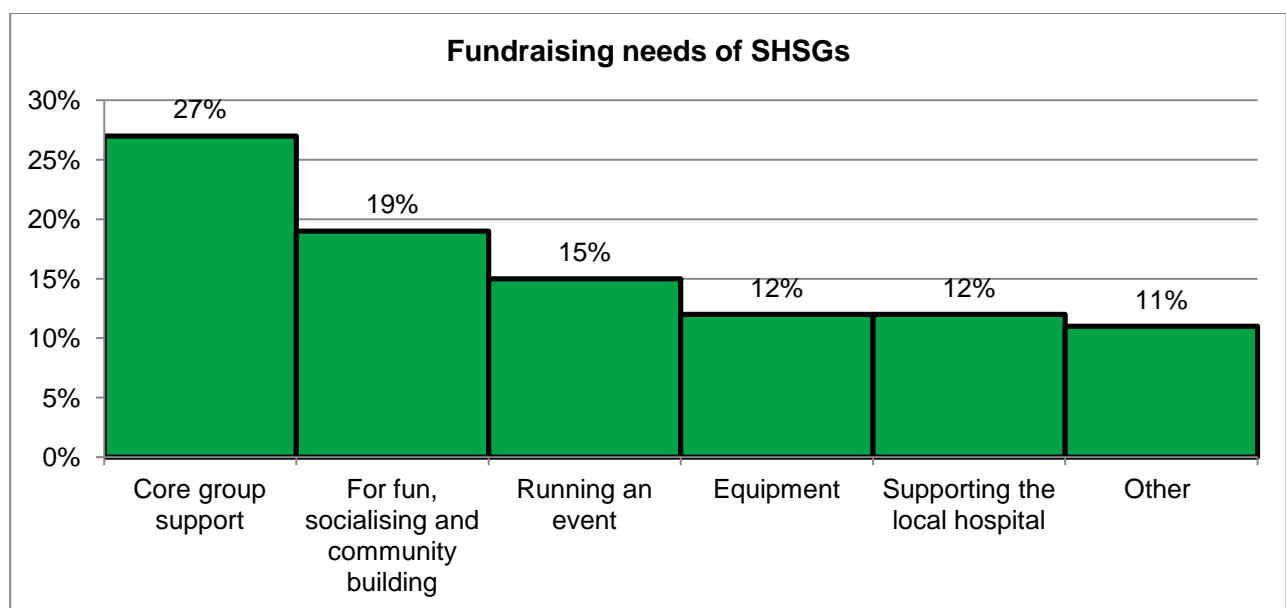
A cancer diagnosis presents a significant level of stress to patients, particularly women and younger patients.⁶ Information provision is a key service and a need that is not properly met by healthcare providers. Most people affected by cancer who want information receive it from healthcare professionals at the point of initial diagnosis. However, when some patients and their families first receive a diagnosis, they may not initially understand what the healthcare professional has told them. Studies have shown that 43% would like more information than they are given and 21% did not know a named healthcare professional who they could contact about their condition.⁷ 45% of cancer patients have not been told of consequences of their chemotherapy and only 41% had written information about the treatment.⁸ In addition, the same survey showed that 40% reported that

their families or someone close to them had not received all the information they needed to look after them at home.⁸ Clinicians may underestimate how much information the patient wants and sometimes patients may not ask all questions which they would like to ask. 87% of cancer patients want to know more about their disease, particularly, about prognosis, while older patients need more opportunities to ask questions.⁹ A Macmillan survey of SHSGs in Manchester and Cheshire found that 100% of group members reported unmet information needs, at every stage in the cancer journey.¹⁰ Some people affected by cancer do not know that they can claim benefits, even at a time when they have completed initial treatment and may feel more able to deal with their financial issues.¹¹

Cost and financial need

Only 15% of groups in a Macmillan survey of SHSGs charged a membership or attendance fee. Some undertake fundraising mainly to cover core group costs. The chart below gives details of other areas of fundraising need identified. Those groups that selected the 'other' option below gave answers that included fundraising for one-off events, advertising their groups and creating educational programmes^{5,12}

Figure 1. A range of typical SHSGs fundraising needs



A 2005 Macmillan evaluation of cancer support groups in Manchester and Cheshire found that the reason members joined the group was for mutual aid. People left the group for a variety of reasons including if they no longer needed support, had returned to work or if a member had died.¹⁰

Online

With an increasing number of people being able to access the internet, the online support groups also offer support for those affected by cancer.

In 2007 approximately only one in five adults (18%) used the internet to access health information, however by 2013 this proportion increased to 43%. The figure was even higher amongst those aged 25 to 34, the rate of use for this age group increased to nearly 6 in 10 (59%) in the same period.¹³ In 2014 more than 4 million people used Macmillan's website to seek various information related to cancer.

US support group NCCN highlights the advantages of effective online support. They state that effective online support groups offered by knowledgeable, skilled staff from reputable organisations can be especially helpful for people in rural areas, those who are too ill to attend a meeting in person, or those who without access to transportation. Online support groups can also provide anonymity and 24-hour availability, as well as bringing together individuals from different geographic areas.¹⁴

You can read more about Macmillan's online support through the Online Community Impact Brief which can be found at www.macmillan.org.uk/impact_briefs.

Research has suggested that men and women access support differently, and that male help-seeking behaviour is typically different to that of women. It is hypothesised that internet support groups may be more acceptable to men because those affected by cancer focus on obtaining information and education rather than on kinship and mutual aid. Research shows that men (with prostate cancer) were significantly less likely than women (with breast cancer) to participate in support groups. Whilst women coping with cancer tend to use friends and family for emotional support, men are less likely to use these resources and less likely to express their feelings to other men or where they do so the tendency is to rely on their partner, or one person, to act as sole confidante.¹⁰ It also important to note that the internet support is more prevalent among people who have higher-social status.¹⁵

2. What is Macmillan doing to address the issue?

Meeting other people with similar experiences can be invaluable for people affected by cancer because it offers an opportunity to share concerns with others who understand and who have been through different aspects of cancer treatment.¹⁶

In 2014, the self-help and support groups, who have had Macmillan funding, reached over 12,760 people affected by cancer.¹⁶

Results from the 2013 Macmillan survey of 177 cancer SHSGs showed that a wide range of Macmillan resources were used by the groups. 'General information and advice' was the most popular Macmillan service with 90 groups receiving this from Macmillan. 70 groups received support through Macmillan information resources including booklets, leaflets and posters giving cancer related information, and 52 received Macmillan support for learning, training and development.⁵

Macmillan offers a lot of cancer related information online which can be digitally accessed or ordered in print. The Macmillan website provides a wealth of information on cancer types and treatments, and emotional, practical and financial issues. Be.Macmillan has an option to order handbooks, while Macmillan Learn Zone features information on a range of free courses and workshops. Many SHSGs make use of these resources and can be seen as an effective conduit to get these resources out to those who need them.

Financial support

In 2014, Macmillan gave funding to 50 new SHSGs as well as awarded grants to over 150 organisations and groups.¹⁷

37 of these were new groups receiving start up grants, and 117 were existing groups receiving development grants. By the end of 2014, in total Macmillan provided set-up (first-time) grants to around 900 SHSGs across the UK.¹⁸

Grant applications include differing needs such as help with starting up a new group, support and the further development of a current SHSG or particular resource, extend reach or to help pay for group members to develop their skills to help support others.⁵

New group start up support

Starting a group can be a very daunting task, from securing funding and managing the finances, deciding on a name and how the group will be managed, to promoting, recruiting and sustaining members.

Macmillan grants can help relieve groups of the financial pressures of setting up and sustaining a support group.¹ Both individuals and organisations supporting people affected by cancer can apply to the following grants:

- Start up funds – to support the start up of a new self-help and support project for people affected by cancer. Macmillan offers up to £500 to applicants looking to start up a cancer support group.
- Development funds – to support the ongoing activities and development of self-help and support projects for people affected by cancer for at least a year or more. Grants of up to £3000 are available to develop a group’s activities and resources.
- User Involvement Grants – to encourage the involvement of people affected by cancer in the design and improvement of cancer services.
- Individual Development Grants – to enable people affected by cancer to develop their skills and use their cancer experience to help support others affected by cancer.

Training and workshops

SHGSs can be led by volunteers or professionals, provide services or not, and they can be very structured while others can be less formal. Macmillan provides a range of training courses aimed at equipping group leads and members with relevant self-help and support skills. For example, the Cancer Support Course provides training to people supporting others affected by cancer. The course covers effective communication techniques, induction to counselling, working with loss and bereavement as well as cancer awareness which discusses key medical issues related to cancer.



In addition, Macmillan offers all new groups:

- a one-day workshop in listening and responding
- a two-day workshop on good practice in starting a new group or activity
- a buddy: someone who has had experience of setting up or being part of a support group or service who will help and offer support over six months.^{1,19}

Cost of running a typical Macmillan information and support centre²⁰

Macmillan helps to fund and support SHGSs for people affected by cancer. Typical costs for 2014 are listed below:

Macmillan support	Cost
Helps a SHSG hold their first meeting.	£40
Could pay a speaker to deliver a talk (for example, about symptom management).	£50
Could pay for a mobile phone and some start-up credit for a SHGS which would help the members to keep in touch.	£75

Could pay for a SHGS to set up its own website to promote itself, list meetings dates and encourage members to keep in touch and chat online.	£250
Could pay for the hire of a room for a year so a SHGS could hold regular meetings.	£370

*For more detailed costs of these and other Macmillan services visit be.macmillan.org.uk to download [The Cost of Macmillan Services factsheet](#).

Services offered

In a Macmillan survey of SHSGs the following common services were delivered in addition to information needs identified above:

Phone lines

Almost one in every five (18%) of groups offered a phone line service, and of these 45% offered members a daytime service, seven days a week. Almost a third of groups with a phone service operated it 24 hours per day.⁵

Leadership and Training

- 64% of groups are led by volunteers
- 32% are led by a healthcare professional, with only 4% being led by a counsellor
- Only one in five volunteer leaders (20%) have no training
- Those that do have some training have a spread of formal skills, but listening is the most common (27% of groups responding to the question), followed by group work (25%).

Member profile

Most groups in Macmillan's survey had between 11-15 members, followed by 16-20 members and then between 36-50 members.¹²

Most groups were run by a small number of dedicated people, usually two people.⁵

Time

Approximately half of all groups held meetings for an average of between 2-3 hours. 70% of the groups stated that they held meetings monthly.¹

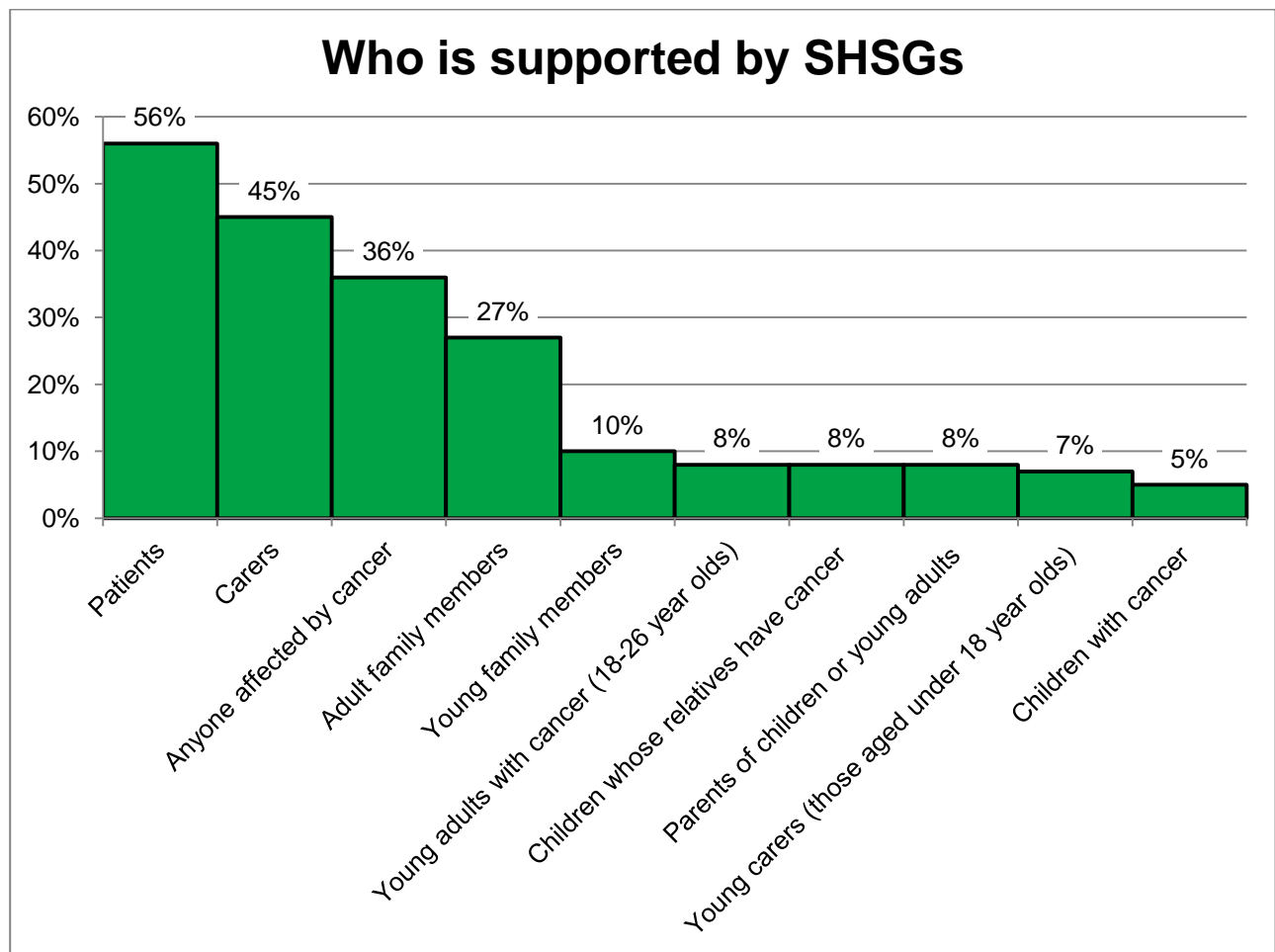
Approximately 32 hours of support are provided for group members each year through meetings alone, this does not take into account wider activities and services provided which are now a core part of many support groups.²¹

Additionally, at least 5,600 hours of volunteer time is spend in helping member every year through meetings alone.

Types of support group

There are SHSG's organised by cancer type; location; by age; by role such as cancer patient's carer; age; gender; sexual orientation and ethnicity.⁵

Figure 2. Proportion of cancer SHSGs according to their specialisations



Cancer Type

Given that breast and prostate cancer are the most commonly diagnosed cancers in women and men respectively, groups supporting people with these cancers are the most prolific.²¹ Some groups are generic and are open to everyone who is affected by cancer including carers, family and friends; whilst others are established for people affected by a particular type of cancer. The generic groups are especially useful for people that have recently received a cancer diagnosis and are undergoing complex, invasive treatments, because generic groups can focus on the more common issues and difficulties.¹⁰

Location

Some cancer support groups are national in their focus, whilst others have developed to respond to locally identified needs. The majority (79%) of groups in a Macmillan survey of support groups stated that they served a mixed area, 18% described their area as urban, and 9% as rural.⁵

3. What is the impact of effective cancer support groups?

A survey of self-help and support groups in the UK shows the impact that self-help and support groups can have:

- They help individuals when they are at their most vulnerable, by providing support to help them cope with a cancer diagnosis and to begin a process of recovery

- Form part of the fabric of strong communities that brings people from different backgrounds together to share experiences and find support by helping others
- Help to maximise the work of the NHS by supporting patients, their relatives and carers once formal care has been completed
- Contribute to NHS priorities in terms of improved patient experience, quality of life and compassionate care.²¹

Support groups can help people affected by cancer during and through challenging times. They can help people regain a sense of control over their lives. Cancer SHSGs can also reduce people's sense of isolation, and offer people a safe, confidential environment where they can talk openly about their cancer and express their emotions to someone who has had similar experiences.¹

Supporting carers, friends and relatives

Carers, relatives and friends of cancer patients may also need support in coming to terms and coping with a diagnosis. They can struggle with complex emotions including guilt, anger, sadness and denial. 41% offered support to carers of cancer patients and 40% specifically to relatives. As well as offering support and advice SHCGs can also provide a distraction from the day-to-day difficulties of coping with a cancer patient's treatment and care.¹

Case Study: "Hammer Out Brain Tumours" self help and support group²¹

'The event enabled brain tumour families to meet together in a safe environment, providing opportunities for them to meet with clinicians away from the clinical setting. Speakers facilitated workshops on different types of brain tumours, clinical trials, research and held a question and answer session. Workshops promoting fun through therapy had everyone participating and enjoying themselves no matter how ill they were. The support the families showed each other was everything Hammer Out was hoping to achieve.'

Cost benefits

In one year the equivalent cost to the state of SHSG of meetings is approximately £902.89, based on an average of 15 meetings a year. Support groups help to support the health and wellbeing of individuals affected by cancer in a variety of ways, including through dietary and nutritional support, reducing loneliness and improving psychological wellbeing, this can in turn mitigate long term NHS costs.²¹

Meeting cost²¹

Equivalent cost of one group meeting	Equivalent cost of meetings of one group over the course of a year	Equivalent cost of meetings of 800 groups over one year (estimated number of support groups known to Macmillan in the UK at the time of the study)
£61.07	£902.89	£722,150

This estimate is based on the equivalent cost of volunteer time at SHSG meetings. It does not take into account the other wide range of activities and services provided by SHSGs which are more difficult to evaluate but which would undoubtedly increase the overall value generated by groups. The figures above also do not take into account the role of groups in supporting the health and wellbeing of individuals affected by cancer, which can in turn mitigate long term NHS costs.

Equivalent costs of one-to-one support from a professional counsellor

If the amount of contact, support and services provided by Macmillan funded cancer support groups were replaced with a professional counsellor at £44 per hour that would have cost the government £4.77 million in 2010 and £8.32 million in 2009. During this time period, every £1 of investment by Macmillan in its self-help and support group start-up and grants programme could have saved the government as much as £76.08 in 2010 and £75.08 in 2009 respectively, although some groups will receive funding from other sources.¹

Macmillan grants given to SHSG¹

Year	Total amount of Macmillan grants per year on group development	Equivalent cost of professional counsellor providing one-to-one support per year	State saving per pound of Macmillan support
2010	£62,654	£4,766,696	£76.08
2009	£110,817	£8,320,576	£75.08

Whilst the exact saving to the state as a result of Macmillan's involvement in support groups is difficult to quantify, it is likely that the minimum amount that support groups saved the state in 2010 was over £642,000. Some people need more intensive support there could actually be a significantly higher cost to the government.¹

The future for self-help and support groups

As the NHS is focussed on delivering £20 billion in efficiency savings,²² it is likely that the role of self-help and support groups will become more important in the future to ensure that emotional and practical support is available to people affected by cancer.

CONCLUSION

Self-help and support groups provide invaluable services and support for people affected by cancer. Often the only reason that these groups exist and sustained is down to the passion and commitment of individuals giving up their time to run these groups. Financial support from organisations like Macmillan allows these groups to develop and support many more people. In the future, there is a critical role for self-help and support groups as more patients will be learn how to provide self-help to address their cancer needs.¹

SHSGs help to meet NHS aims of improving patient health and wellbeing and also save the government money by providing support outside of formal NHS support structures.

Macmillan urgently needs more charitable donations to allow this service to continue supporting cancer patients and their families. Go to www.macmillan.org.uk/donate or call 0300 1000 200 to make a donation.

REFERENCES

- 1 Macmillan Cancer Support. *A Whole Society Approach to Tackling Cancer*. 2011.
- 2 Sullivan R, Peppercorn J, Sikora K, Zalcborg J, Meropol NJ, Amir E, et al. *Delivering affordable cancer care in high-income countries*. The Lancet Oncology Commission. 2011;12(10):933–80.
- 3 NESTA, PPL, Innovation Unit. *The Business Case for people powered Health*. 2013.
- 4 Slesina W, Rennert D, Weber A. *Visits to Cancer Patients in Hospital by Members of Cancer Self-Help Groups in the Context of Visit Programmes - Process and Outcome Indicators*. Gesundheitswesen. 2014;76(12):847-55.
- 5 MHP. *Key Findings Support Group Survey*. 2013.
- 6 Linden W, Linden W, A Vodermaier A, MacKenzie R, Greig D. *Anxiety and depression after cancer diagnosis: Prevalence rates by cancer type, gender, and age*. Journal of Affective Disorders. 2012;141(2-3).
- 7 Sheldon H, Sizmur S. *An Evaluation of the National Cancer Survivorship initiative test community projects. Report of the baseline patient experience survey*. 2009. Picker Institute Europe.
- 8 NHS England. *Radiotherapy Patient Experience Survey 2013. National Report*.
- 9 Jenkins V, Fallowfield L, Saul J. *Information needs of patients with cancer: results from a large study in UK cancer centres*. *British Journal of Cancer*. 2001.
- 10 Ryan-Woolley B. *An Exploration of the Role and Impact of Self-help and Support Groups for People Affected by Cancer in Greater Manchester and Cheshire*. 2005. Macmillan Cancer Support, The University of Manchester.
- 11 Macmillan Cancer Support. *Cancer's Hidden Price Tag: Revealing the Costs Behind the Illness*. 2014.
- 12 MHP. *Additional Findings - Support Group Survey*. 2013.
- 13 ONS. *Internet Access Households and Individuals, 2013*.
- 14 NCCN. *Finding Support Systems for People with Cancer*.
- 15 Hoybye, MT et al. *Supportive care in cancer. Social and psychological determinants of participation in internet-based cancer support groups*. 2010;18(5).
- 16 Macmillan Cancer Support. *The Reach of Macmillan's Services factsheet*. 2015
- 17 Macmillan Cancer Support. *Supporting You to Help Others Grant 2015*.
- 18 Macmillan Cancer Support. *Handbook for Self-Help and Support Groups*.
- 19 Macmillan Cancer Support. *Start Your Own Group*.
- 20 Macmillan Cancer Support. *The Cost of Macmillan's Services factsheet*. 2015.
- 21 Macmillan Cancer Support. *Realising the value of self help and support groups*. 2013.
- 22 Department of Health. *The Spending Review settlement*.