Provision of information for cancer patients: an appraisal and review

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This article is based on an appraisal of Cancer Information and Support Services in Britain supported by the UK-based charity Macmillan Cancer Relief. Commissioned in 2002, the appraisal formed part of a wider review aimed at extending knowledge about Cancer Information and Support Services. It was also designed to ensure that the Macmillan Cancer Information and Support Service Model continues to reflect the needs of people whose lives are affected by cancer. The individual services reviewed for the appraisal vary widely in terms of resources, staffing and organizational structure, but many common themes emerge. The importance of outreach and networking are highlighted, along with the problem of isolation. Many post-holders saw a need to include a hospital base, while the role played by volunteers is widely acknowledged. A key aim of the review was to start to identify the factors that contribute to the success of a service, and a number of these emerge from the study. The creation of a culture that enables such a service to thrive appears to be as important as securing financial and other resources. The contribution made by Macmillan is explored, and ways in which the organization can support the dissemination of knowledge are put forward.

Keywords: information, service, cancer patients, access, provision

INTRODUCTION

Macmillan Cancer Relief is a charity that works to improve the quality of life for people living with cancer. The charity's vision is for everyone in the United Kingdom (UK) to have equal and ready access to the best information, treatment and care for cancer. It is working for change with the government, the National Health Service (NHS), and others, to make this a reality.

Macmillan offers life support by providing the expert care and practical support that makes a real difference to people living with cancer. A range of innovative cancer services are offered and are at the heart of improving cancer care throughout the UK. Macmillan funds specialist Macmillan nurses, doctors and other health professionals who deliver the best in cancer care. The charity funds and guides the building of vitally needed cancer care centres, and give financial support to those who need it most. A range of information and support services are provided, including the Macmillan CancerLine (a telephone helpline), useful publications and local cancer information centres. Support is also given to local self-help and support groups.

This article looks specifically at the Macmillan Information Service, which was established in 1999, and informed directly by commissioned research identifying what potential service users wanted from Cancer Information and Support Services (BMRB 1999). The findings were, broadly, that people affected by cancer wanted access to a range of services including:

- *Information* about cancer, treatment and care, the available services, financial issues, diet, etc.
- *Support*, including emotional support, opportunities for contact with others affected by cancer, support groups, counselling and complementary therapies.

The development of the Macmillan Cancer Information and Support Service Model (Fig. 1) was based on these findings, and continues to provide a blueprint for new services.

Almost 6 years on, there are now around 60 open Macmillan supported Cancer Information and Support Services in Britain and many more in development. To ensure their continued relevance and responsiveness, in 2002 Macmillan Cancer Relief commissioned a review of the Cancer Information and Support Services that it had supported.

From the outset, importance was attached to obtaining a rounded perspective of Cancer Information and Support Services, and so the review sought to reflect the views, needs, knowledge and experience of people affected by cancer, and also those of the post-holders working in these services. So the review was made up of two key components, an *assessment* of the Macmillan Cancer Information and Support Service Model developed in 1999 (Macmillan Cancer Relief Information 1999) and an *appraisal* of a sample of Information Services (Smith 2003). The assessment involved conducting a series of focus groups with people affected by cancer, and was

undertaken by the British Market Research Bureau (BMRB). The appraisal entailed visits and interviews with information post-holders across a sample of Cancer Information and Support Services. It is the main findings from the *appraisal* that are presented and discussed in this article, though reference is also made where pertinent to the BMRB research findings (Smith 2003).

The intended outcomes of the review as a whole were:

- to contribute to the knowledge base about cancer information and support services;
- to inform the development of Macmillan's strategy for supporting these services and, specifically, to ensure that the Macmillan Cancer Information and Support Service Model continues to reflect the needs of people affected by cancer;
- to contribute to the sharing of good practice across cancer information and support services and Service Development.

METHODS AND SAMPLE

The appraisal was undertaken using a variety of methods including, analysis of data and information held by Macmillan Information Services at UK Office, semi-structured interviews with information service post-holders, and observation. In addition, a few interviews were conducted with key external stakeholders in order to gauge their perspective on the development of information services generally. The sample of cancer information and support services comprised all open information services, and those in development within the East Midlands and Northern England Macmillan region. The region has a range of services across community, primary, secondary, and tertiary settings and urban and rural locations. This sample therefore ensured that a cross-section of services was appraised and, by focusing on a geographical area, meant they could be considered more effectively within their local and regional context. A cancer network project and two specialist projects in the region were also included.

A discussion brief was used as a prompt and *aide-mémoire* with information post-holders. However, all interviewed were encouraged to give their views and comments in their own way and order of priority.

PROFILE OF SERVICES

At the time of the appraisal, in the East Midlands and Northern Region there were 10 open cancer information and support services, with two more in development.
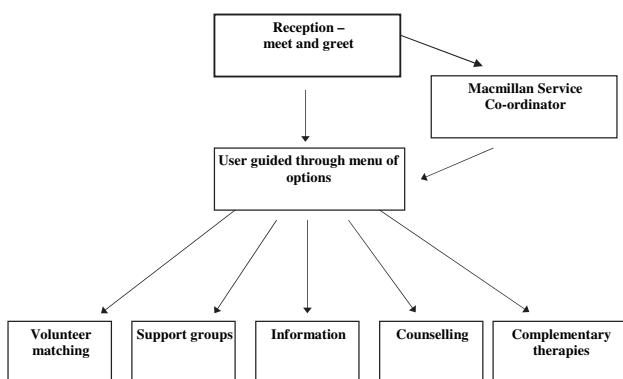

Figure 1. Macmillan cancer information and support service model (1999).

There was also a cancer network project and two specialist projects. For completeness, all these services – open and in development, and the specialist projects were visited as part of the appraisal. Eight of the open services were in hospital settings, one was in a library, and there was an outreach service hosted by a Primary Care Trust. The two services in development were to be hospital-based and the cancer network project was managing the development of a hub and spoke model of information services across the network area. Two specialist information projects have also been supported in this region – the Mesothelioma Information Service and the PIES (Personalized Information, Education and Support) project. The Mesothelioma Information Service (then based at the Cookridge Hospital, Leeds) was set up to provide a national information and support service by telephone to people diagnosed with mesothelioma. The Service also provides information for health professionals and has supported and trained a national network of specialist nurses to improve the quality of information available locally. The PIES project (based at the Trent Palliative Care Centre, Sheffield University) aims to establish the need and potential uptake for electronic patient information, including video telephone consultations. This is currently a regional project, but one with potential for national application.

The hospital-based open services visited included two hospital-based purpose built centres with a team of staff, one of which was in the process of opening a second centre at a neighbouring hospital to provide a district-wide service, and six further hospital-based services with one or two staff. Two of these six had a twinning arrangement whereby the post-holders split their time between them, and they also had a link to the library-based service which operated as a satellite of these services. Two other services were managed by the same post-holder and supported by the network project. Visits were also made to the library-based service, the network project already mentioned, the primary care-based outreach service, and a planned hospital-based service that was still in development.

FINDINGS

All of the static services visited aspired to provide a comprehensive information and support service to users, act as a navigator of the health and social care system, and to signpost on if services required were not available directly.

Post-holders felt that certain key resources and inputs were needed for them to fulfil their roles (see Table 1).

A number of other themes emerged, as set out below.

Accommodation and environment

Almost all post-holders stressed the importance of creating an informal, unhurried environment, clearly differentiated from the clinical setting.

Any service will appear more accessible and inviting if the premises include a foyer and a communal area. There should be space to display and dispense information, office space, and a separate room where privacy and quiet can be ensured. These facilities should be within close proximity. Ideally, there should also be a separate room for therapy or groupwork. These findings are concurrent with those of BMRB (2003).

Location

Many post-holders explained that there was a clear need to start with a hospital-based service. From a system's

Table 1. What post-holders need to provide a good service

Equipment and training
   Access to a computer from starting post
   Training (including training on project management/business planning and marketing/promotions, developing IT skills)

Information and orientation
   Information about local services and agencies, other information and support services, relevant policy initiatives, Macmillan Cancer Relief

Marketing and promotions
   Signage – ensuring that the host organization had adequate signage to a centre
   Leaflets – early availability of a leaflet to promote a service

Resources
   Access to revenue and administrative support
   Adequate staffing for anticipated levels of activity

Management and support
   Active management
   Steering group
   Mentoring/supervision – according to the nature of the project
   Peer support

perspective, this was found to work best, both for users and for health professionals. The reasons most commonly given were, first, that the key points when such a service was most needed – at the time of diagnosis, or while a person is undergoing tests or treatment – tend to take place within a hospital setting. Second, the professionals caring for people at these crucial stages also need to have ready access to information and support services, so that they could be supported in their role, are up-to-date and integrated with the information and support that is available, and can signpost onto the service as needed.

Respondents also felt that if the introduction of outreach, primary care and community-based services was supported by a core of hospital-based information and support, these services could then be more effective than they might be as 'stand alone' initiatives.

Networked approaches

An indicator of how services were evolving was the emergence of networked approaches – services working together within a locality or cancer network area. Post-holders explained that a networked approach could help them meet user needs and be more responsive to local community needs, gain peer support, enhance service capacity, and take a more strategic approach to service provision.

Most services had a number of links with professional groups, voluntary groups, individuals and agencies. These included NHS bodies and employees, other agency workers, voluntary groups and community organizations. However, there was also an awareness of the need to be sensitive to professional boundaries if good networking relationships were to be developed and maintained. For example, many post-holders found it necessary to disabuse Clinical Nurse Specialists of the notion that they were trying to take over their roles. Clear lines of communication were recognized as being essential to productive working relationships.

Inclusive approaches

Most post-holders identified the issue of inclusion, and there was an awareness that services were not being used by all sectors of the local community. Some services had identified outreach as a means of becoming more inclusive and responsive to issues around diversity, and a couple were looking at using information technology (IT) to extend accessibility. Others, without access to additional resources, seemed to think that enhanced capacity and

ready access to funds were needed to address this issue effectively.

Staffing and volunteers

Across almost all the services appraised, limited staffing appeared to be a key pressure. Those post-holders who were working in a team or job-share arrangement benefited from the skills mix and ready access to peer support. However, they were in a minority, and single-handed post-holders, especially those with non-clinical backgrounds, were at risk of isolation. Those services that had the potential to fare better were staffed by a manager, a volunteer co-ordinator and had access to administrative support.

The use of volunteers varied enormously, ranging from those services that saw them as an integral part of the service to those who were less certain of their role. In some cases post-holders were unsure of their service's suitability for, or capacity to sustain, volunteers. Some of the services, however, had been most imaginative in their use of volunteers. Examples included giving volunteers responsibility for maintaining information, or arranging for them to have links with a particular ward and visit on a regular basis. In the larger scale services, there were opportunities for volunteers to undertake a wide range of roles.

Some volunteers had been directly affected by cancer themselves, something that was valued by the respondents in BMRB's (2003) research. Post-holders felt that the presence of volunteers not only helped create a more informal atmosphere, it also added to the skills mix, and gave users of the service a feeling that the service must be of real value for people to give their time on a voluntary basis. Those post-holders who used volunteers emphasized this special value they brought to a service, a finding mirrored by the BMRB research.

Management and support

While most of the post-holders appeared very self-sufficient, they often expressed a desire to be managed actively. Most post-holders seemed to want managers who were well placed within the host organization to guide and support their service. Where a host organization had a steering group in place to oversee the service, this was viewed very positively.

Issues around peer support, mentoring and supervision were mentioned frequently. This was often in the context of the newness of the service being provided, the varied nature of the workload and the risk of becoming organizationally and personally isolated. All post-holders

welcomed any opportunities to link up with peers in comparable positions, and most were in contact with other post-holders in the region.

The perceived role of Macmillan

The appraisal provided an opportunity to find out more about how post-holders viewed Macmillan and also the views of external stakeholders. It should be emphasized that this was a small sample and was not designed to be representative of Macmillan's stakeholders.

Generally, Macmillan was perceived as flexible and responsive. Almost all the post-holders interviewed had found the support of the Macmillan Service Development Team and the Information Consultancy to be beneficial. A few went so far as to describe them as providing 'a lifeline'. Post-holders also liked the regional and national dimensions of the Macmillan Information Service team's employees and valued how this gave opportunity for different skills to be made available as well as facilitating networking around the UK.

The support of a national organization was seen as particularly helpful. However, many respondents felt a more structured overview of Macmillan as a whole would be useful, in order to be clearer about how the different departmental roles fitted with each other, and what resources and additional support might potentially be available to them.

Identifying success factors

It became apparent that the presence of certain 'success factors' (see Table 2) could make a significant contribution to the development of responsive, patient-centred and sustainable cancer information and support services.

The 'success factors' identified in Table 2 indicate that being patient-centred is not merely about resources. Fundamental to development of a successful service is the ability to create the right philosophy, environment, attitude and approach.

DISCUSSION

Across the services there were quite varied levels of planning and preparation prior to a service opening. Where it was evident that planning had been limited, this was for a range of reasons. Primarily it seemed to relate to the general state of flux within the NHS, and the new nature of these services meaning there is a lack of familiarity with the level of planning a cancer information and support service needs. Where there was a lack of, or more limited planning or preparatory work, the burden then fell mainly upon the post-holder to make good the deficit. Every post-holder talked of the significant amounts of time that need to be invested to plan, establish and develop a service. Most post-holders mentioned the need to forward plan so that the future of services could be protected and plans developed in a considered way.

Given that so many post-holders were developing these services with quite limited resources, there seemed to be a prevailing view that much more could be achieved easily and quickly with these inputs. In the case of the network project, some of these inputs were already available to services in this area, and this seemed to give them an easier start.

One aim of the review had been to 'start to identify the factors that contribute to the development of a successful Macmillan Information and Support Service'. As indicated in Table 2, those services that seemed to be doing well were those that were well integrated with their host organization, stayed user-focused and responsive to the needs of the communities they were serving, while also collaborating with other agencies and services to make the most of existing resources, skills and experience. Those services and projects that Macmillan has supported so far, have made collectively a significant contribution to information and support services and have raised awareness about their importance and relevance as an integral function in health and social care. Such an achievement is admirable especially given the staffing, resource, and management issues to be overcome. Networked approaches to the provision of information and support are now needed if can-

Table 2. Developing a successful service: key factors

- Planning a service based on an assessment of need (including an estimation of the likely usage of the proposed service by people affected by cancer) and having adequate and sustainable capacity (staffing and resources) to deliver an inclusive, holistic service.
- Creating a non-clinical environment, where people affected by cancer can be supported by a team of paid workers, volunteers, and clinical staff as needed.
- Creating a service that optimizes the physical space available and is not bound by it – developing in-reach as well as outreach approaches to a service that is networked into its local communities.
- Creating a service that is integrated into and supported by its host, and still has an external, user-centred focus – building its capacity through other community agencies to extend reach.
- Creating a service that builds on existing initiatives and skills available within the host organization, and optimizes the contribution of external agencies and individuals.

cer information and support services are to be developed further and sustained. Hospital-based services should be a key component of this approach to ensure that user need is addressed, the profile of information and support is maintained, and health professionals are supported and integrated effectively with services.

Following a stronger networked approach to service provision, designated services could be earmarked to act as a hub or 'engine room' for a network of services. Facilitators working at a cancer network level, facilitating links across services, keeping a strategic focus, and linking to the national agenda could augment this activity. The intention of such a design would not be to create rigid structures, but rather to encourage links between existing services and identify ways of optimizing resources. Macmillan could support this approach by continuing to support services at an operational level, influencing their strategic development at a cancer network and national level, investing further in monitoring, evaluation and development. Specifically, at an operational level, Macmillan could identify with host providers the expectations and inputs needed in order to offer a good cancer information and support service and ensure sustainability. Additionally, quality indicators could be more formally stipulated to support services and host providers in focusing and benchmarking activity.

The findings suggest that, in order to target need and address equity, outreach strategies are needed. These should build on existing services and be part of a wider network, rather than set up as stand alone initiatives. In addition, preparatory work, such as needs assessment work and planning, gives a service firm foundations and ensures that both users and professionals understand its remit and purpose from the start. This groundwork also helps to identify the minimum level of staffing capacity and revenue required to deliver an effective and equitable service and manage demand.

The appraisal highlighted the value brought to a service by its volunteers. Care needs to be taken to preserve this special quality and to ensure that the role of the volunteer is protected. The preoccupation of many services on fundraising for revenue has the potential to deflect both volunteers and post-holders from their main purpose and, if not carefully monitored, can become an inappropriate use of their time and skills.

Quality indicators could be used in a more formal way to support services and host providers in focusing and benchmarking activity. Evidence about specialist projects needs to be recognized and harnessed, and perhaps supported and taken forward by Macmillan at a national level. This approach would encourage learning to feed directly into the charity's research and development function, and increase the likelihood of successful projects being sustained, developed and, if appropriate, replicated.

The findings from this study can be set in a wider UK context and reflect a gradual recognition, over the past decade, of the importance of effective information and communication with patients if the NHS is to deliver patient-centred care (National Cancer Alliance 1996; University of York 2000; Holmes-Rovner *et al.* 2001). It has also been noted that because this area of activity may sometimes still be viewed in the NHS as a non-essential activity, there is often confusion about whose responsibility it is, with a consequent risk that information needs are marginalized or ignored (Smith 2000).

During this period, national policy has started to recognize information as an area of growing priority (Expert Advisory Group on Cancer 1995; DH 2000). To support the implementation of The NHS Cancer Plan (DH 2000) in March 2004, the National Institute for Clinical Excellence issued Supportive and Palliative Care Guidance with a series of recommendations that concentrate on aspects of services that are likely to have a significant impact on health outcomes (NICE 2004). One of the key recommendations on information is that:

> Commissioners and provider organizations should ensure that patients and carers have easy access to a range of high quality information materials about cancer and cancer services. These materials should be free at the point of delivery and patients should be offered appropriate help to understand them within the context of their own circumstances. (NICE 2004: Information, Key Recommendation 8)

Notably, the guidance states that 'within acute hospitals, this might be achieved through a dedicated cancer information centre, or through a facility that encompasses information for a broader range of diseases'. (NICE 2004: 4.20, p. 68)

It is encouraging that there is growing awareness of the need to focus as much on the method of delivery, to ensure patient access, as on the content of the information itself, and that this is a function worthy of attention in its own right. This concurs with Macmillan Cancer Relief's research and experience of developing information services.

CONCLUSION

The flexible and responsive approach taken by Macmillan to support new and existing services and projects has encouraged a creative approach to development. Mac-

millan now needs to find ways of consolidating the knowledge gained and disseminating it to post-holders and more widely.

The appraisal highlighted the need for effective knowledge management so that post-holders and others could build on and contribute to a collective knowledge and evidence base. This is particularly pertinent for IT-based projects and initiatives to improve accessibility and quality assurance. The time may also be right for drafting an information and support service pathway so that key stages, processes, inputs and priorities can be mapped and used as a guide and checklist for developing services. In addition, consideration could be given to establishing minimum inputs needed, in terms of staff, space, and resources for a range of services to be established and delivered successfully. This approach could allow Macmillan to identify with host providers the expectations and inputs needed in order to offer a good cancer information and support service, and ensure sustainability.

In undertaking the appraisal visits, it was impressive to see the level of commitment, motivation, professionalism, and wide range of skills across all the services and projects. There was a great willingness and generosity around sharing ideas, experience, and expertise and an eagerness and enthusiasm to learn from each other. With these foundations, there is a real opportunity to continue to shape these services to ensure they continue to meet need and strengthen and enhance their role and contribution within the health and social care system. For this to succeed, a cultural shift is needed to engender widespread recognition that the provision of information and support is a prerequisite for the delivery of an effective health service, and not a discrete activity or superfluous extra.

REFERENCES

British Market Research Bureau (BMRB) (1999) *Developing Information for Cancer Patients. Report for Macmillan Cancer Relief, June 1999.* BMRB, London, UK.

British Market Research Bureau (BMRB) (2003) *Review of Macmillan Information and Support Services.* BMRB, London, UK.

Department of Health (DH) (2000) *The NHS Cancer Plan: A Plan for Investment, a Plan for Reform.* Department of Health, London, UK.

Expert Advisory Group on Cancer (1995) *A Policy Framework for Commissioning Cancer Services.* A report to the Chief Medical Officers of England and Wales (The Calman Hine Report). Department of Health, London, UK.

Holmes-Rovner M., Llewellyn-Thomas H., Entwistle V., Coulter A., O'Connor A. & Rovner D.R. (2001) Patient choice modules for summaries of clinical effectiveness: a proposal. *British Medical Journal* **322**, 664–667.

Macmillan Cancer Relief Information (1999) *Macmillan Quality Toolkit – Ensuring Quality in Macmillan Cancer Relief Information and Support Services.* Macmillan Cancer Relief, London, UK.

National Cancer Alliance (1996) *Patient-Centred Cancer Services? What Patients Say.* The National Cancer Alliance, Oxford, UK.

National Institute for Clinical Excellence (2004) *Guidance on Cancer Services: Improving Supportive and Palliative Care for Adults with Cancer, the Manual.* NICE, London.

Smith C. (2000) The role of health professionals in informing cancer patients: findings from The Teamwork Project (Phase One). *Health Expectations* **3**, 217–219.

Smith C. for Macmillan Cancer Relief Information and Support Services (2003) *Information and Support Services: An Appraisal.* Macmillan Cancer Relief, London, UK.

University of York, NHS Centres for Reviews and Dissemination (2000) Informing, communicating and sharing decisions with people who have cancer. *Effective Health Care Bulletin* **6**, 6.