Connecting through communities:
how a voluntary organization is influencing
healthcare policy and practice

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ABSTRACT   In recent years, the UK charity Macmillan Cancer Relief has been developing
innovative ways of stimulating learning – among health professionals, patients and carers – to
improve the experience of people living with cancer. In essence what it is doing is to create and
support a number of groups and communities that "float" around its organization structure and
extend its reach far beyond its formal boundaries. Because these groups are not part of the
formal structure, they cannot be "managed" like normal organizational teams. Nonetheless, the
conversations and stories shared in them generate new ways of thinking and practising, and may
also result in tangible "products", such as documents, standards or major programmes. This
way of working through groups of people, which is informed by relational theories of learning
and change and insights from complexity theory, contrasts with attempts by many organizations
to base their knowledge management on technology alone. It enables Macmillan to stay
connected with the experience of hundreds of doctors, nurses and others directly affected by
cancer. Relationships established in this way often live on long after the formal relationship
with the organization finishes. And these relationships, combined with the more tangible
outputs of the groups, help Macmillan influence thinking and practice in the National Health
Service. This kind of work cannot be measured satisfactorily by traditional methods, and the
second part of this article, to appear in a future issue, will explore some innovative methods
being developed by Macmillan to evaluate and learn from its experience with communities.

KEY WORDS: communities of practice, organizational learning, complexity,
knowledge management, conversation, stories

Introduction

Macmillan Cancer Relief, one of the best known charities in the UK, is commonly
associated with its "Macmillan nurses". There are around 2,500 of these today in the
UK's National Health Service (NHS), guiding cancer patients through the maze of
different services and helping them cope with the symptoms associated with treatment
and disease. Many people are unaware that the charity funds other posts and
programmes for the benefit of people affected by cancer – for example, it provides
funding to more than 300 doctors in the UK, including specialist consultants and
general practitioners (GPs), to enable these Macmillan "post-holders" to develop
cancer-related services.

Perhaps least known is the way it is beginning to work, not just with individual post-
holders, but also with groups and communities of doctors, patients and carers. The
purpose is to draw on the experience of these groups, so that these key stakeholders

can help the charity influence the NHS, for the ultimate benefit of people living with cancer. This article explores this aspect of the organization's work.

Learning through interaction

To help improve the lives of people living with cancer, Macmillan aims to create and share knowledge from a wide range of sources. It also seeks to influence policy and practice in the NHS, a vast and complex organization (the largest organization in Europe, according to the NHS website). To understand how Macmillan can work through communities to achieve these aims, we have drawn on some of the literature on organizational learning and change.

A relational view of learning and change

Over the last 10 to 15 years, many organizations have attempted to "manage knowledge" by focusing on information technology investments, in the hope that large databases would be the answer. While technology can play a valuable role, we take the view that learning and change arise above all in human interaction (Stacey, 2001, 2003; Shaw, 2002; Lave & Wenger,1991) – that is, learning and change are social, or "relational", rather than purely individual, processes.

Complexity theory, though based on insights from computer modelling, offers useful metaphors for understanding organizational change (Plsek & Greenalgh, 2001; Shaw 2002; Stacey 2000, 2003, 2005). Essentially, it indicates that *interaction itself gives rise to patterning*. Relating this to human interaction, we can view conversation as "a process of communicative action which has the intrinsic capacity to pattern itself" (Shaw, 2002). As we go on to explain, patterning paradoxically involves both continuity and change.

First, by its nature, pattern formation includes some continuity or repetition. Organizational culture, for example, can be viewed as recognisable patterns of behaviour that are repeatedly recreated in people's interactions. However, wherever there is interaction, there is also potential for change. In conversation, it is through the presence of difference – e.g. in the form of different personal histories and different ways of thinking and speaking – that change emerges.

Furthermore, change is non-linear – small disturbances can lead to widespread change, or they can peter out. For example, a small shift of understanding might occur in one specific conversation, and this new understanding may then be amplified as it spreads or ripples through a whole chain of subsequent conversations. Alternatively, the new understanding may cause little or no further disturbance. We never know in advance which changes will be amplified and which will peter out. What does seem plausible, nonetheless, is that learning and change only have a chance if there are opportunities for interaction. In the examples developed in this article, we will try to bring these abstract concepts to life.

Stories told in groups and communities

In viewing learning and change as social activities, we are particularly interested in exploring how these processes occur in *communities of practice* (Lave & Wenger 1991; Wenger 1998; Wenger, McDermott & Snyder 2002; McDermott 2004). Indeed,

Wenger argues that it is by engaging in the practices of their communities that people learn. For organisations, this means that:

> *"...learning is an issue of sustaining the interconnected communities of practice through which an organization knows what it knows and thus becomes effective and valuable as an organization."* (Wenger 1998: 8)

In practice, much of the value of the groups and communities stems from people learning from one another by sharing stories from their experience (Denning, 2001; Snowden, 2001; Weick, 1990). These stories, told in the conversations between group members, help reveal the patterns, problems and solutions observed or experienced by community members. Furthermore, the stories and ideas are constantly subject to testing by peers, because it is members of a community rather than isolated individuals who are sharing their experience. This lends the stories and ideas validity and allows the organization, in this case Macmillan, to use its influence more confidently knowing that it is reflecting a "collective voice".

Cultivating groups and communities

In essence, then, what we are saying is that learning and change emerge in human interaction, and what Macmillan is trying to do is to give this process a little encouragement by cultivating communities and fostering the connections through which learning and change can occur.

Before describing these relatively recent attempts, it is important to acknowledge that the charity has long been closely connected with health professionals. Traditionally, it has worked in what it calls a "pump-priming" capacity – e.g. paying a nurse's salary for a few years, after which the nurse is taken on permanently by the NHS. From this point onwards, even though Macmillan no longer funds these individuals, it continues to have a relationship with them. Nonetheless, the 2,500 Macmillan nurses do not represent a cultivated community in the sense explored in this article.

The communities described here consist mainly of General Practitioners (GPs), patients and carers (with one exception – the Nursing Reference Group mentioned below). Macmillan has been focusing particularly on these groups in recent years for a number of reasons. First, there has been widespread acknowledgement in the UK that patients' voices have not been clearly heard in the health sector. Second, the voice of GPs – typically the first professional whom a person with possible cancer symptoms consults – was barely audible for years, either within Macmillan, which only began to fund GP time in the 1990s, or in the wider cancer care environment, which was dominated by the secondary (i.e. hospital) sector.

The groups and communities Macmillan is presently cultivating take three main forms:

1. "Reference groups". Each of these has come into being in a particular context, with a different purpose. Two examples include:
- A Patient and Carer Group (described below) with about 12 members, created to inform Macmillan's strategic thinking around its work with GPs
- A Nursing Reference Group with about 30 members at time of writing, set up to help Macmillan implement a programme (Macmillan's Gold Standards

Framework Programme) that introduces systematic processes to GP practices to help them improve the support and care they give to cancer patients, especially in the last year of life. (This reference group has no formal connection with the Macmillan nurses, though there is some cross-membership.)

2. Larger communities of health professionals, such as:
- Macmillan GPs – currently about 100 GPs most of whom receive funding or "protected time" from Macmillan. This typically gives them one day a week to stimulate learning about cancer care in their region, identify issues amongst peers, help test solutions to problems and build relationships with hospitals and hospices.
- Primary Care Cancer Lead clinicians (PCCLs) – about 250 health professionals, of whom about 75% are GPs, the rest predominantly nurses. These professionals are funded by the NHS and receive significant support from Macmillan (mainly in the form of conferences and a programme of learning and development).

3. Smaller "distilling and connecting groups". These are needed because the members of the two communities of professionals mentioned above are relatively large and work primarily to stimulate learning at local level, yet Macmillan is keen to get the collective voice heard and to promote improvements at national or UK level. Two groups deserve mention (the second is in the process of formation):
- GP Advisor Group – since 1994 there has been a small group of GP Advisors (described below) to support the Macmillan GP community and advise Macmillan on cancer and palliative care priorities in the primary sector.
- Macmillan is currently inviting Primary Care Cancer Lead clinicians (PCCLs) to form a similar small group to distil experience and connect Macmillan with this community.

By working with all these groups, Macmillan supplements its relatively small number of employees (about 580) through an extensive network of post-holders and ex-post-holders (including nurses, doctors, and other health and social care professionals) and people affected by cancer – and, in turn, the many people connected with those individuals. In other words, through human relationships, many of which are long-term, the organization can punch above its weight (see Figure 1).

What are the tangible results?

One of the main "results" of a group or community's work is the conversations and stories themselves, which have the potential to disturb wider patterns of thinking and practice. In other words, the sharing of problems, ideas and solutions can itself stimulate learning and change. In addition, a number of tangible "products" have also emerged from Macmillan's work with groups, ranging from major programmes through systematic procedures to written guides – for example:

- Major programmes: Macmillan's GP community and GP Advisor Group both contributed to the creation of the role of Primary Care Cancer Lead clinician, now established in the NHS all over the UK (as explained below).

- Systematic approaches: A GP who had been a Macmillan GP and later became a Macmillan GP Advisor developed a systematic approach to palliative care in the community called the Gold Standards Framework (GSF).
- Useful documents: The Patient and Carer Group described below helped Macmillan create a widely-used document called "Our principles of people-centred care". Similarly, another group, the Expert Carer Group, created a booklet for carers called "Hello and how are you".
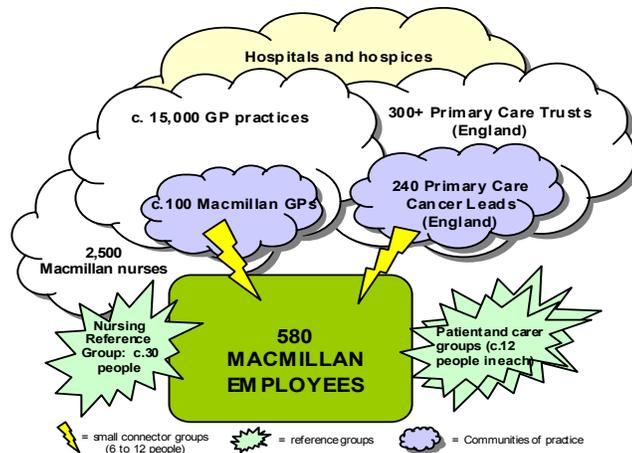
Figure 1. A range of groups and communities "floating" around the formal structure

Engaging with a group of patients and carers

The story of how "Our principles of people-centred care" came into being illustrates well how a tangible "knowledge product" emerged through collaboration between Macmillan and one of its existing reference groups. The Patient and Carer Group was originally set up in the first half of 2003 to participate in and contribute to Macmillan's thinking on how it works with doctors (part of Macmillan's work known internally as the "medical strategy"). Once created, the group started to meet regularly and its discussions were co-ordinated and facilitated by a Macmillan employee, a member of the organization's medical services team.

The document in question emerged almost by accident. The phrase "patient-centred care" was central to the medical strategy, and the medical services team decided to explore what it really meant, from the perspective of cancer patients, by conducting a literature review. The task fell upon a member of the team, who was to condense the findings into five or six bullet points. She rapidly realised that such an abstract summary would not be very useful. Meanwhile, she consulted Macmillan's User Involvement Advisor, who suggested widening the investigation to encompass the whole cancer care pathway (otherwise known as the patient's "cancer journey"), all the way through from prevention through to dying and bereavement. What ultimately emerged was an A3-size document laying out the cancer journey in 10 stages, with a multitude of quotes under each heading.

Macmillan decided to test the information gathered in this way with the Patient & Carer Group to refine the quotes and check that the language was comfortable for them. As a result, one of the document's most distinctive features was its plain language. The earliest drafts had contained a good deal of medical jargon, and the group helped Macmillan find language that ordinary people could relate to. For example, instead of "discharge" they came up with "going home".

The group also added their own further thoughts to the document, and they took early versions to other groups they were involved in and gathered a range of comments. For example, one member was part of the Anglesey Breast Care Focus Group, a group of women on the island who were concerned about the lack of emotional support in the community for people affected by cancer. The issues this group raised in meetings were passed back to Macmillan. Next, four members of the group worked with Macmillan's Corporate Communications Team to find a design and layout for the document to make it both practical for users and recognisable as a Macmillan product.

In the meantime, entire statements from the document had already found their way into an important Macmillan/NHS joint publication ("Cancer in Primary Care: a guide to good practice"), thanks to connections between Macmillan's medical services team and the NHS. Thus, the work of the Patient and Carer Group contributed directly to the NHS definition of "what users want".

Reflections on the social life of a document

The story of the Patient and Carer Group stimulates a number of reflections about working with groups:

1. *Not part of the group's original stated purpose.* The account shows how a valuable product that is not an explicit part of a group's original purpose or terms of reference can emerge unexpectedly.

2. *The value of a document created by users.* The document was created in close collaboration between Macmillan and the very kinds of people who were likely to benefit from any improvements in cancer care it might prompt. This experience echoes the story told by Brown & Duguid (2000) about how photocopier company Xerox decided to replace the documentation it had created centrally for its repair people with a peer-reviewed database which grew out of their own tips and became an indispensable tool for them. In other words, if the people likely to use and/or benefit from a document are actively involved in creating it, it typically becomes far more valuable than one created for them.

3. *The value of keeping the document alive.* Even before the redesigned version was ready, the group played an active part in getting the document into use for the benefit of patients, carers and health professionals. These uses were many and varied: nurse training; other professional training; Cancer Network patient forum meetings; input into hospital standards; a Macmillan services planning meeting; displaying local services in a drop-in centre; and simply giving patients and carers words to express their needs. Participants gave the document to friends, relatives, nurses, GPs, local support groups, patient groups, oncologists, hospice staff and volunteers. Thus, far from getting lost in a filing cabinet or database, this document developed a lively

"social life" (Brown & Duguid 2000). The danger for such documents otherwise is that, after all the excitement and hard work in creating them, they linger or die in a filing cabinet. In this case, the written product was "resurrected" every time somebody took it to a meeting, showed it to a friend, or used it as a poster or presentation. Ong points out one of the paradoxes of writing is that:

"The deadness of the text, its removal from the living human lifeworld, its rigid visual fixity, assures its endurance and its potential for being resurrected into limitless living contexts by a potentially infinite number of living readers." (Ong 2002: 80).

Indeed, since the story told here, the document has been used yet again, this time at a Macmillan GP conference – to start a debate about how GPs can best work with other professionals, including nurses and pharmacists, at each stage of the cancer journey, a debate which is topical given the pending shortage of experienced GPs in the UK and the nature of the new collective contract between GPs and the NHS.

4. *Combination of transient and tangible results.* Finally, the account throws light not just on a tangible product but also on the more ephemeral aspects of the group's work – the informal conversations and stories shared among the participants that can "ripple out" through their personal networks in unpredictable, uneven (non-linear) ways as each person talks to further people beyond the group. In the case of the Patient and Carer Group, it was the combination of tangible product and transient conversation that spread ideas and learning for the benefit of people living with cancer.

A medical community of practice

If the conversations of a relatively small group can produce the kind of learning and influence described, what is the potential for a much larger community to disturb patterns of behaviour across the health service? The Macmillan GP community is an example.

A community is born and grows
Today there are around 100 Macmillan GPs, but it is instructive to retrace the community's evolution since, like most communities, it neither came into being overnight nor did it retain a completely fixed membership or way of working.

The community's origins go back to debates around cancer and palliative care in the 1980s. At that time, with the hospice movement growing steadily, there was a desire to improve the quality of care at home, and widespread acknowledgement that there was scope for GPs to get better at caring for and communicating with cancer patients.

The difficulty was that it was not easy for GPs to develop and maintain palliative care skills, given that most saw just a few palliative care patients each year and had many other competing work commitments. The Macmillan GP Facilitator Programme came into being in the early 1990s to meet this need, based on the premise that the best people to provide education to GPs are their peers. It was Macmillan's then Medical Services Director who approached the Royal College of General Practitioners (RCGP - the academic organization in the UK for General Practitioners) to discuss what could be done to improve GPs' skills in palliative care. As a result, over the next few months,

the chairman of one of the RCGP's divisions worked with Macmillan to design a programme. As a GP himself, he knew very well how valuable this might be:

> "When I became a GP, whenever I managed a dying patient, I did my very best, and there were several occasions when I couldn't do my very best because I didn't know how to, I didn't have enough knowledge or experience… I worked out a lot of it myself because in those days, the early 1980s, there were no books on it…So I said to myself, 'I've got to do something about learning for myself and changing things."

As a result of the collaboration, in 1992 Macmillan appointed six GPs with an interest and some expertise in palliative care to act as "Macmillan GP Facilitators". These individuals remained practising GPs, employed by the NHS, but received funding for one day a week (this came to be known as "protected time") to facilitate learning and improve collaboration with specialist palliative care providers (e.g. local hospices). This pilot programme was funded jointly by Macmillan and government health departments in England and Scotland. Between them, each of the six Facilitators represented one region of the UK.

The original six GP Facilitators remained in post for two years until 1994, after which Macmillan decided to expand the programme, the stated aim of which was and remains: "to develop the continuity and quality of cancer and palliative care by providing protected time for experienced General Practitioners to work with GPs and primary care teams and others involved in cancer care in an educational capacity and as agents of change". Today the GP Facilitators are simply known as "Macmillan GPs".

Activities and outcomes

Macmillan GP activity remains wide-ranging, reflecting different local contexts and preferences. Nonetheless, the main areas of work are educational events (e.g. "Basics of Palliative Care" courses, or multidisciplinary meetings on "Breaking bad news") and visits to other practices. The latter enable Macmillan GPs to hear about problems faced in many different practices and link these problems with solutions. Other activities include networking with fellow professionals and working on guidelines (Shipman et al, 2001).

An evaluation undertaken between 1998 and 2000 in England and Scotland indicated that the Macmillan GP activities had increased both awareness of palliative care services and use of palliative care guidelines. There were also improved relationships between the GPs and their specialist palliative care colleagues, making it easier for GPs to access specialist knowledge. This "bridgebuilding" role was seen as especially important, because one of the main barriers to continuity and quality of care had been poor relationships between GPs and their colleagues in hospitals. (Shipman et al, 2001)

Another evaluation, undertaken in Powys, Wales, between 1999 and 2002, found that each of the 17 Macmillan GPs interviewed there "had added substantially to their knowledge and experience of palliative care and palliative care education, the majority to the extent of successfully completing a university diploma in palliative medicine" (Clark et al, 2002). Moreover, the very existence of Macmillan palliative care GPs in Wales "had brought the issue of palliative care into the spotlight". (Clark et al, 2002)

In the words of two GPs who have been closely involved with the community for years, each Macmillan GP:

> *"... has made a difference in their own community by creating a ripple effect of improving patient care by encouraging best practice and facilitating change. There are many 'vignettes', such as the debriefing of a troubled district nurse following the care of a dying child, the round-table discussions with two neighbouring hospices who had not talked for ten years, the increase in appropriate referrals from practices that had never previously referred, the gentle support for a burnt out GP in a state of collapse met on a routine visit, and the patient who died in pain in the private hospital whose charitable trust now provides palliative care drugs bags and crisis advice packs for the out-of-hours service." (Thomas & Millar, 2001)*

This quote gives some concrete examples of local changes sparked by the work of Macmillan GPs. However, there are other examples where the sharing of experience can be linked to wider changes. For example, Macmillan GPs collectively identified an "out-of-hours" problem – some cancer patients were being moved into hospitals or hospices during periods when the general practice surgery was closed, despite the patients' wishes to remain at home as long as possible. The Macmillan GP community raised this issue up the agenda and this led to the development of practical guidelines for health professionals to ensure that patients' wishes regarding their care were respected, day or night.

Supporting Macmillan GPs as a community

Macmillan does far more than simply fund sessions for the GPs, invaluable though this "protected time" is. The charity also gives them an opportunity to gather together as a whole group twice a year, in addition to their more frequent regional meetings. At this national GP meeting, participants talk informally, discuss their issues in small groups, and hear keynote speakers on topical cancer-related subjects. In other words, as well as pursuing educational activities in their local "patch", Macmillan GPs meet regularly and share experiences with peers from around the UK. They are therefore more than simply a collection of individual post-holders.

Even after Macmillan funding runs out, typically after three years, many employers fund the protected time themselves, once they have seen the value of the role (though this is not a precondition for the Macmillan grant). These GPs then tend to remain connected with the Macmillan GP community.

Other forms of support from Macmillan include:
- A regional steering group, which may include representatives of the local health authority, the primary care trust, a palliative care specialist, a Macmillan GP Advisor, and the local Macmillan Service Development Manager – these groups work well at least in some areas
- Induction packs, videos, other information, access to Macmillan library
- Email group for Macmillan GPs UK-wide
- Administrative, secretarial, educational and travel-related support.

In return, Macmillan (through the GP Advisors) typically asks Macmillan GPs to produce an annual report describing: whom they have been in contact with, including

general practices and other health professionals; what kind of educational activities they have run; what feedback and stories they have heard; and how they have increased their own skills or qualifications.

Thus, Macmillan has created and continues to support a community of GPs that is spreading learning about cancer and palliative care. The charity also supports GP academic posts in medical school departments, and a few members of the Macmillan GP community hold such positions.

The community is linked into Macmillan in a number of ways, so that the organization can benefit from the stories told and lessons learned. One connection is through the charity's regional "service development teams" around the country. Another is through Macmillan's GP Advisors, one of the above-mentioned "distilling and connecting groups".

Emergence of a distilling and connecting group

In 1994, the six original GP Facilitators had been in post for two years and Macmillan wanted to expand and continue supporting the community. It decided to create the new role of "GP Advisor" to help it do so. There were just two GP Advisors until 1999, when Macmillan's newly appointed Chief Medical Officer proposed the group be expanded: the community had grown too large for two Advisors to support and, equally important, GPs still lacked an audible voice within Macmillan.

Thus, by the beginning of 2000, Macmillan had five GP Advisors, each of whom was responsible for a specific region of the UK. The role was and remains, in part, a "pastoral" one – they look after the Macmillan GPs in their geographical "patch". In effect, they are facilitators of regional communities of practice. In addition, as a group the GP Advisors are responsible for preparing the twice-yearly Macmillan GP Conferences.

However, there is more to it than a pastoral job. With the growth of the Macmillan GP community, the challenge is: how can Macmillan learn from the experience of such a sizeable group? From the organization's point of view, part of the purpose of the GP Advisors is therefore to act as a "distilling and connecting group" to channel the collective voice of the community and influence the wider health agenda in the NHS. The GP Advisors not only help to link Macmillan GPs to other local influencers, such as Primary Care Cancer Lead clinicians and lead nurses and doctors in the local Cancer Networks (responsible for planning cancer services). As we shall see now, they have also acted as a link with national and UK-level discussions around cancer and palliative care.

Collective voice promotes major projects

Around the year 2000 there was a unique opportunity for Macmillan to influence public policy on cancer and palliative care in the UK. The Government had appointed a "Cancer Tsar", Professor Mike Richards, and set up the Cancer Services Collaborative and the Cancer Action Team. Macmillan was increasingly being invited to contribute to UK-wide thinking on cancer and palliative care issues.

Against this background, over the next few years the joint efforts of Macmillan GPs and GP Advisors gave rise to some major projects designed to improve the experience of patients and carers. For example, the idea of establishing Primary Care Cancer Lead (PCCL) clinician posts around the country had initially grown out of conversations among Macmillan GPs. However, it really took off after the Cancer Tsar invited members of the GP Advisor Group to his office to work out a plan for the role. The group next gave one of its members the task of defining the role more precisely. That member commented:

> *"I always put [my papers] to the Macmillan GP Advisor Group for comment first and adapted them in the light of the group's suggestions... To say 'the GP Advisor Group agrees that...' is much more powerful than saying 'I think that…'."*

Because the idea of the PCCL role was distilled from the Macmillan GP experience, there was relatively quick agreement about how it should work. The plan was that it should be funded by the Department of Health, with Macmillan giving the PCCLs opportunities to get together and share learning plus additional support for their personal development. In other words, Macmillan decided not to go for "ownership" of the PCCLs, but instead to seek to connect with them and support them. By the end of 2004, the role was well established, with 230 out of 303 Primary Care Trusts in England having a PCCL.

The GP Advisors, none of whom are Macmillan employees, are generally funded for two days a week by the charity. Since 2003 the group has been supported within Macmillan by a team known as the medical services team, one of whom organises and facilitates the group's meetings. Another is a senior manager, with extensive contacts in the NHS, who can take up ideas generated by the group and turn them into properly organised and funded programmes. The third is Macmillan's Medical Advisor, who provides leadership for the group and is its main connection with the organization's executive board.

As we have seen, the distilling and connecting function of the group has evolved over time. Like so many interesting and valuable developments, it was not the product of a "grand plan".

Lessons learned about cultivating communities

Through its work with communities of practice and other groups, Macmillan has been developing practical ways of staying connected with experience "on the ground" so that it can bring improvements to people affected by cancer. The experience has also revealed a number of issues that managers might want to consider when attempting to foster learning by working with communities and reference groups – starting with the relationship between the groups and the organization itself.

Relationship with the sponsoring organization

The groups and communities described here are not part of Macmillan's formal reporting structure – their members are not employees. This has a number of consequences. First, while Macmillan can and does support and facilitate the groups, it cannot "manage" them in the way it might an internal department or team. Macmillan relies on the members' interest and enthusiasm – as Wenger and Snyder put it, "… the

success of [a] community will depend on the energy that the community itself generates, not on an external mandate" (Wenger et al, 2002). The members need to see personal value in being part of the group, otherwise they will vote with their feet.

Given these characteristics, it is difficult – and possibly unhelpful – to define precise terms of reference at the outset. In the case of the Nursing Reference Group, Macmillan managers and the group's facilitator took a conscious decision to let the group get started by simply meeting and sharing experience. Managers can propose what they would like to see emerge from a group, or even define a specific goal, such as a document, but ultimately a sense of purpose emerges from the conversations and work of the group, often aided by a skilled group facilitator.

The biggest investment of time and effort to establish a successful community tends to be in the first year or two of operation when key relationships develop. Once the group is working well Macmillan has an asset it can use for many purposes. For example, the organization has decided to continue supporting the Nursing Reference Group, but it is no longer tied into the original programme it was created to contribute to. It has effectively evolved into a broader Macmillan nursing reference group.

Participation in a community is often an attractive personal development opportunity for the members. However, many of the people who take up this opportunity are liable to become overloaded, so acknowledgement and support are crucial. Macmillan's people have learnt that the relationship between the organization and the members of these voluntary groups and communities needs constant care and attention. These members are giving considerable time and effort to the organization – for example, the members of patient and carer groups give their time typically out of a sense of commitment to other patients and carers, while GP Advisors commonly sit up late at night responding to email requests from their local Macmillan GPs.

Last not least, the fact that such communities are not part of the normal organizational structure can lead to misunderstandings and tensions in the organization. One person described this as the Macmillan "fog". The medical services team is therefore keen to develop a shared language to describe and explain these fluid and largely invisible processes and what they can give back to the organization. We will explore this further in our next article.

Membership

As we have seen, the groups described vary in size. In all cases, however, group facilitators constantly have to bear in mind that not every member will manage to attend every meeting so the make-up of the groups is somewhat fluid.

While the groups supported by Macmillan bring together diverse experiences and points of view, they are largely unidisciplinary – e.g. consisting of just GPs or just nurses or just carers. Our experience suggests that each profession or group can best find its collective voice when it has a chance to meet exclusively – unconstrained by the presence of other groups – before opening its doors more widely. The Nursing Reference Group members, for example, said they found it beneficial to be able to discuss issues with fellow professionals who had a common language and culture, equipping them better to contribute to their local multidisciplinary teams.

One exception to the unidisciplinary rule is the community of Primary Care Cancer Leads (PCCLs), mentioned earlier. PCCLs can be doctors, nurses or other professionals and retain their allegiance to their own professional group, but they also have an identity and well-defined role as PCCLs.

Finally, in order to stay focused on patient needs, there may be a case for always involving patients and/or carers in some way, even in single profession groups. The Nursing Reference Group, for example, always has a few representatives of patient and/or carer groups at its meetings, and Macmillan always invites patients and carers along to conferences of PCCLs and Macmillan GPs. The PCCL community also has its own patient and carer group.

Process and support

One thing that any community needs is the opportunity to communicate regularly, and all the groups described have regular meetings or conferences at least twice-yearly, in some cases more frequently. In addition, most groups have email contact between meetings – the Nursing Reference Group maintains a constant exchange of emails, in which the group's facilitator plays an active role, about a whole range of issues relating to cancer care. Another factor that increases the connections is cross-membership: for example, many of the PCCLs are also current or former Macmillan GPs.

In addition, each of the groups and communities described has one or more people who provide it with a link into Macmillan the organization. We have come to distinguish between the "facilitator" and the "sponsor" role, although in some cases the sponsor and the facilitator may be the same person. For example, the Nursing Reference Group and the Patient and Carer Group each has a Macmillan facilitator. Such facilitators have to be multi-talented: they need to have excellent interpersonal skills, be a natural networker and connector, be good at planning and organising, computer literate if appropriate, understand the "what's in it for me", and obviously have good group facilitation skills. An important role of the organizational sponsor is to communicate the intended role of the group to the rest of the organization to allay suspicion and mistrust.

Finally, Macmillan provides such groups with a range of facilities:
- A budget (to pay travel expenses and, in the case of the professional communities, protected time)
- Spaces to meet, whether face-to-face, by teleconference, by videoconference, or virtually through a web site or email list
- Information – e.g. some GP Advisors provide their local Macmillan GPs with an induction pack when they are first appointed.
- Macmillan administrative staff to support the work of the groups – e.g. to take notes at meetings and to make sure travel expenses are paid.

* * * * *

All in all, through this work, Macmillan is managing to stay connected with the experience of hundreds of doctors, nurses and others directly affected by cancer. It is reaching out far further than the limited number of its employees might suggest, and it has established networks and relationships that live on even after Macmillan funding finishes. This way of working through groups of people contrasts strongly with

attempts by many organizations to base their knowledge management on technology alone. It potentially represents an imaginative and efficient way to invest the charity's funds – in people and relationships rather than in technology – to help achieve real improvements for people living with cancer.

Macmillan is still very much in the process of developing its thinking about how it can best work with groups and communities of this kind. One particular challenge, given the transient nature of much of the work in communities, is how to describe and evaluate the approach. Can ephemeral conversational processes be "measured" to demonstrate their value? How can the organization "capture" the learning from these processes? How can Macmillan (or more precisely the relevant "organizational sponsor" within Macmillan) make the processes and benefits "visible" to people inside and outside the organization? Macmillan is developing some innovative ways of addressing these questions, which we intend to explore in part two of this article.

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