



The collective voice

Bringing practitioners together to influence policy and practice

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The notion of practitioners joining to defend their rights and influence those in power goes back centuries. It is worth taking a fresh look today at how to develop a collective voice, in the form of a sustained network or community of practitioners, to improve services.

This is something that UK charity Macmillan Cancer Support has been doing for several years, as a recent book demonstrates (Donaldson et al, 2011a, 2011b). The book illuminates how hundreds of people (mainly health professionals but also people living with cancer) have worked together over time, with Macmillan's support, to improve care. The story told is at the same time about how

people (health professionals and/or patients) developed a collective voice to press for improvement, and about the role of a non-profit organisation in encouraging and supporting such work.

This article aims to give a flavour of what this involved and to draw out practical ideas that may be relevant and helpful for those in comparable fields.

Small beginnings

The seeds of the story go back to 1992, when the charity (best known for its nurses) funded 'protected time' to six GPs with experience of, or an interest in, palliative care. This released them from clinical responsibilities typically for one day a week.

While these individuals remained practising GPs, they could use their protected time to develop their own skills, raise awareness about palliative care, and provide education, advice and support for other GPs. In addition, they could take steps to improve collaboration with hospitals and specialist palliative care providers, such as hospices.

The 'Macmillan GPs' typically visited general practices in their 'patch', listened to what other GPs had to say about trying to care for cancer patients, and developed educational materials.

When their Macmillan-funded protected time came to an end

(usually after three years), many found local funding to continue the work, but still referred to themselves as 'Macmillan GPs' and remained connected with the charity and its GP community.

From the very beginning, the Macmillan GPs met regularly as a group, and by 2004 (when we started reviewing their work) there were some 100 of them. As well as sharing ideas for improving care locally, the community contributed to two national developments:

- The spread of systematic processes in palliative care (eg to encourage general practices to keep a register of people diagnosed with cancer and to meet regularly as a team to co-ordinate their care)
- The development of a new role in the NHS, the primary care cancer lead.

The latter was typically a GP or a nurse who worked at a more strategic level than the average Macmillan GP, seeking to influence the quality of care for patients at every stage of their 'cancer journey', starting with possible cancer symptoms.

Today, Macmillan GPs and cancer leads form a combined 200-strong Macmillan primary care community. This continues to be valued as a collective voice and source of knowledge by both the funding organisation and government policy makers,

taking up a range of issues that matter to people living with cancer, including earlier detection of disease and better support for survivors.

Out of these early experiences of developing the collective voice of professionals, a number of other groups and communities of influence emerged.

Macmillan also worked with groups of patient advocates to influence the NHS. Interestingly, one of the inspirations for developing the GP community had been some experiences with self-help groups in the 1990s, which had provoked the question: 'If we have effective, influential patient groups, why couldn't we do something similar with GPs?'

We do not have space here to describe all of the Macmillan-sponsored communities, but one more example would be a collaborative group of researchers with clinical backgrounds that was set up by the charity in 2004 and which is still going strong today.

Value of hybrid identities

The group was set up to evaluate services offered to cancer patients, providing much-needed evidence about the value of supportive care. More specifically, the intention was to test whether academics with clinical backgrounds could do research that could be rapidly translated

into service improvement, while also developing collaborative relationships over time.

The group represented six universities in England and Scotland. In the early years, it comprised seven researchers with a track record in working to improve services for people affected by cancer, plus two people affected by cancer.

We call it a 'hybrid' group because the multiple identities of its professional members meant that they were used to talking to and influencing academics, clinicians, patients, policy makers, managers and service developers.

The group we are describing is called the Macmillan Palliative and Cancer Care Research Collaborative. After some seven years of working together, it has absorbed new members and expanded its influence by creating and disseminating useful evidence about supportive care, influencing education and training, developing helpful new tools and generating further funding for research in this important but under-researched field. The collaborative now stands ready and can be called on to evaluate new services for people living with cancer.

Practical steps

For those interested in developing a community of influence, we suggest paying special attention to the following areas.

Convening an influential group

Assuming you have an issue in mind that is ripe for influence, a first step might be to think about what kind of practitioners could be brought together as a group, community or network to improve policy and practice in this area.

The group could include people from one or more professions, or with hybrid identities. Members need to be good at networking and influencing (or at least have that potential), so they should not be chosen only as 'representatives' (eg of departments, professions or social groups). The group may also benefit from including service users.

In our experience it is vital to give them opportunities to meet face to face in an environment that is conducive to sharing ideas, engaging in dialogue and building trust. A new group may need expert facilitation to enable it to develop the feeling of a community and not simply another taskforce or work team.

Making the invisible visible

From the beginning, it is worth giving thought to how the group can become and stay visible. Otherwise, the conversations that are the lifeblood of any community may remain ephemeral. Even worse, the group may look to others like a talking shop or a clique.

We have used written narrative accounts to explain what difference our groups have made. These can capture complex stories and leave a visible record. We have also made use of pictures, video and internet (see: www.cancerconsequences.org).

Negotiating joint purpose

Even with a clear issue identified, people brought together as a group for the first time may not be comfortable with free exploration. They may welcome it if you offer a specific focus.

Once they feel they have made some initial progress, they may be more inclined to explore and reflect on their experience, which is an important part of being a community. Do not be surprised if they do not accept your proposal – they may want to take time to adapt it to fit their own interests. This is perfectly reasonable for a community of this kind.

'A community of influence is not a one-off initiative'

Giving documents a social life

One particularly satisfying product for members can be a set of guidelines that they have created together. A guide compiled for practitioners by practitioners can be extremely useful. But if it is to influence practice, it will need 'a social life'. Look out for opportunities to introduce it to relevant practitioners or other key influencers.

Playing a long game

It is worth bearing in mind that a community of influence is not a one-off initiative. If it is to be supported and sustained effectively, it requires long-term funding. Working with such groups also means taking relationships seriously, recognising that individuals may come and go, and being prepared to rekindle relationships when the circumstances are right, or otherwise part-ways satisfactorily.

Portrait

To provide a human face to communities of influence, we include the story of one person who has taken part in no less than three of the Macmillan-sponsored groups (see Box 1). A number of themes emerge:

- Someone with a hybrid identity can act as a bridge between worlds of research, education and clinical practice
- Long-term relationships between practitioners and organisations can bear fruit
- A collaborative group can provide opportunities to become more influential.

Reference

- Donaldson A, Lank E, Maher J. (2011a) *Communities of influence: improving healthcare through conversations and connections*. Oxford: Radcliffe.
- Donaldson A, Lank E, Maher J. (2011b) *Communities of influence*. See: www.communities-of-influence.co.uk (accessed 1 Sept 2011).

Box 1. Portrait: one member of a community of influence

Stephen Barclay's working life has spanned patient care, research and education. His interest in palliative care goes back to early life experiences – his mother died when he was seven, and as a medical student he found himself caring for patients in a hospice.

In 1995, Stephen became one of a group of six GPs who received funding from Macmillan for a few hours of protected time each week. Among other things, he embarked on a survey of GPs and district nurses in the Cambridge area, alerting him to their different perspectives on palliative care and laying the ground for later, wider-scale research. Stephen took up a new three-year post as Macmillan clinical fellow in 2002, based at the University of Cambridge. Macmillan funded 1.5 days per week to provide academic support to Macmillan GPs, introduce medical students to palliative care and develop his own research. He benefited from meetings in which Macmillan and university representatives explored how to support his fellowship and ease the tensions of combining a clinical and academic career.

In 2003, when the Macmillan Palliative and Cancer Care Research collaborative group was being formed, Stephen was a natural candidate. He came to value being part of a peer group where he could regularly share ideas in a 'friendly but not uncritical environment'. In 2006, the group supported Stephen in his application for a competitive Department of Health postdoctoral research fellowship (funded by Macmillan), which gave him five years to pursue a programme of research focused on understanding patient preferences in primary palliative care. More recently, he has secured a permanent post (clinical senior lecturer) at the University of Cambridge, allowing him to continue combining research, teaching and clinical GP work. Stephen says, 'The support of Macmillan has led on to the award of substantial competitive national research funding', including £9.5million from the National Institute of Health Research for collaborations in the Cambridge and Peterborough area.