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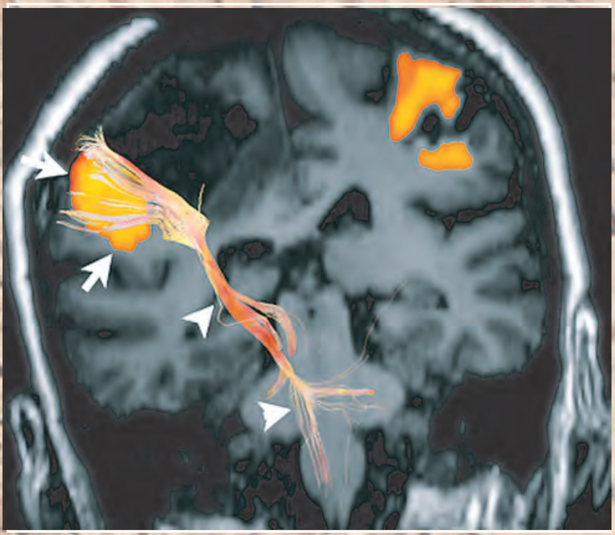

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Patient Advocates and Guideline Development: Token Involvement or Meaningful Input?

Kathy Oliver

Clinical practice guideline (CPG) development is thriving across Europe.

We are moving toward consensus on the treatment of all kinds of cancer – from the very common to the very rare – reflecting the fact that treating cancer patients today requires a complex multidisciplinary approach.

At a recent "Forum on Multidisciplinary Clinical Guidelines in Oncology" hosted by the European CanCer Organisation (ECCO), over a dozen major medical societies – who among them have created more than 175 sets of clinical practice guidelines – met to debate the possibilities of greater cooperation and harmonisation in the development of European guidelines. The aim is to increase their quality and use.

But international harmonization of CPGs is a substantial challenge. A 2011 editorial in the *Annals of Oncology* explained that homogeneity among the developmental processes relating to internationally available guidelines does not exist [1].

Furthermore: *"In a recent report, nine well-known CPGs (ASCO, ESMO, NICE, SIGH, START, NHMRC, NCI, NCCN and CCO) and three representative tumors (advanced breast, lung and colon cancer) were selected and scrutinized. Results have shown that a diverse heterogeneity in development, structure, target user and endpoints were prominent among them"* [1, 2].

Of course, the creation of any CPG does not necessarily guarantee its full implementation across all treatment centres even in any one country. Compliance is a thorny issue and the tough economic times in which we now live, among other reasons, may preclude full adherence by cash-strapped health authorities.

An example of non-uniform compliance is the "Improving Outcomes Guidance for Brain and other CNS Tumours" published by the UK's National Institute for Health and Clinical Excellence (NICE) in June 2006 [3].

This crucial document sets out 11 key recommendations for delivering a high standard of care and support to this group of patients in England and Wales within the overall context of the UK National Cancer Action Plan.

But 6 years later, these multidisciplinary guidelines are still not uniformly in place across all English and Welsh treatment centres.

Another barrier to compliance is the challenge of dissemination. Guidelines are sometimes slow to pass into standard practice simply because they are not efficiently distributed and publicised.

The same *Annals of Oncology* editorial mentioned above describes the European Society of Medical Oncology's (ESMO) long-standing and successful association with the development and dissemination of clinical guidelines [1].

ESMO's dissemination of its CPGs relies on a variety of different methodological tools such as *"the translation of ESMO's CPGs into various languages"*; *"the organization of the ESMO interactive sessions during the ESMO Congresses"*; and the *"publication of editorials or articles [about CPGs] in oncology journals"*. Future ESMO plans for increasing implementation and dissemination of CPGs include pocket-sized booklets, slide sets, and mobile apps.

It is important for clinical guideline developers to utilise patient advocates who can play an important role in contributing to the success of CPGs, from their very inception to their successful dissemination and implementation. Currently, input into guidelines from patient advocates seems to range from involvement at the outset to simply reading the finished product and commenting.

As NICE itself states: *"Patients and carers can help those responsible for developing a clinical guideline to understand what it is like to live with a medical condition ... and what different forms of treatment and care mean to them ... This can include information about what patients want from their treatment and care, the acceptability of different treatments and their preferences for different treatment options"* [4].

In the brain tumour community, patient advocates are a relatively numerous, outspoken group, considering that CNS tumours are a rare disease.

Brain tumour patient advocates can help with scoping the objectives of a set of CNS CPGs. They can assist with defining key research questions. They can write and review recommendations. They are crucial in developing patient versions of CPGs, too.

Brain tumour patient advocates were involved in the creation of clinical practice guidelines with the British Neuro Oncology Society (BNOS) in collaboration with the UK National Cancer Action Team (NCAT) who developed CPGs for 4 very rare brain tumours: adult PNET, primary CNS lymphoma, pineal and optic pathway glioma [5].

In recognition of the important role that brain tumour support, advocacy, and information groups play, these 4 sets of guidelines also included an appendix listing the major brain tumour patient groups in the UK. We believe that this inclusion gave added value to the guidelines.

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According to the ECCO Patient Advisory Committee (PAC) Chair, Ian Banks: *"An added benefit of patient involvement in the design of clinical practice guidelines is that the relationship between medical teams and their patients can improve as a result of this collaboration. Patients' involvement in guidelines may also increase concordance with therapy requirements."*

Brain tumour patient advocates can also assist CPG developers with dissemination of guidelines throughout the brain tumour community. In the UK alone, nearly 50 brain tumour charities represent thousands of patients and their caregivers. These groups are potential conduits for spreading the word about clinical practice guidelines.

The IBTA has identified an additional 20 brain tumour patient organisations across Europe that could help with the dissemination of CPGs. There are also various online forums for European brain tumour patients plus a number of major brain tumour e-newsletters which provide substantial communication channels. The IBTA's mailing list for its monthly e-newsletter includes nearly 2000 European subscribers plus another 5000 people outside Europe.

Involvement of brain tumour patient advocates in the creation of CPGs does require, however, a commitment to appropriately train those advocates and provide clear guidance as to exactly what is expected of them.

Finally, it is important that brain tumour clinical practice guidelines fully reflect the collaboration and multidisciplinarity that is so crucial to successful treatment. To achieve truly patient-centric clinical guidelines, patient advocates should be involved in their creation, compliance, and dissemination. This involvement should not simply be tokenistic but should embrace real and meaningful input from the relevant patient community.

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