

## How would you ensure that we listen and respond to the voice of patients in Ophthalmology?

### People, Not Patients

Medical-school notebook clutched tightly, I observed the ophthalmology registrar, fast and focused, speed through her seemingly-endless glaucoma list: she tinkered with drops, listed operations, completed reams of paperwork. Perhaps I looked like an approachable target for one elderly patient: on hearing that her visual fields were now too significantly reduced for driving, she asked me, despairingly, how she would manage the daily visits to her disabled son's residential home in another town. Caught off-guard, I could only mumble sympathetically as she shuffled out into the bustling corridor, token leaflet in hand, and the next patient took their place at the slit-lamp.

Clinicians are privy to only fleeting snapshots of patients' real lives, via sporadic ten-minute consultations. We are task-focused, making objective decisions in patients' best interests, every choice strongly guided and supported by the safe maxims of evidence-based medicine (EBM). But how, I wondered, would EBM resolve this lady's wider predicament, help her visit her son, do her weekly shopping, manage the myriad quotidian tasks necessary to maintain her 'normal' life?

The impact of a simple, three-letter-diagnosis of eye disease can be catastrophic – practically, financially, socially, and psychologically. Encouragingly, yesteryear's paternalistic practice is steadily evolving into purposeful 'patient-centred medicine', as we actively aim for a holistic healthcare approach. Indeed, our inherent, Hippocratically-bound aim of prioritising patients' interests was reinforced in 2010 with formal legislation: the *Equity and Excellence* paper directs that "*no decision about me, [is] to be made without me*"<sup>i</sup>. The UK's Medical Research Council guidelines have also recently been updated, stipulating that patient involvement should be encouraged in as many stages of study design and delivery as practically possible<sup>ii</sup>. Additionally, layperson representatives are now routinely included in many professional committees, directors' boards, and clinical commissioning groups, e.g. Cancer Research UK<sup>iii</sup>.

But, if we are to listen and respond to patients genuinely - and effectively - perhaps 'patient-**centred**' should evolve into 'patient-**powered**' medicine. This process must be underpinned by three rudimentary steps: asking patients what they want, both individually and collectively; listening; then actively responding.

### PROMs, PPIs, COS

A strong clinical 'culture' of listening thus must be engendered routinely in all aspects of ophthalmology.

Currently, individual feedback is somewhat irregularly garnered. For instance, patients are commonly asked post-operatively to complete anonymous 'Family & Friends' questionnaires. Enthusiastic junior doctors might also complete audits/ Quality Improvement Projects (QIPs) to gather patients' views. Many hospitals also elicit feedback via text message – a convenient and quick way to assimilate simple responses. This information, shared regularly in departmental meetings, allows evaluation of practice and implementation of appropriate changes. Yet such small-scale, localised, and not necessarily regular, feedback processes are inherently limited.

One difficulty in creating effective, wide-scale mechanisms for productive feedback is a relatively poor understanding of how to conduct rigorous qualitative research to yield valid data in a world dominated by quantitative methods<sup>iv</sup>. Qualitative studies – which tend to establish **aims** but not hypotheses - tend to be deemed a 'softer science', and are thus, perhaps, overlooked in the world of lucrative, **hypothesis**-driven randomised controlled trials (RCTs)<sup>v</sup>.

The relatively recent advent of specific research tools, however, should potentially boost the standard of qualitative research: PROMS and PREMS (patient-reported outcome/experience measures) ascertain the collective patient voice by collating patients' views regarding specific treatments. Targeted use of these could effectively enhance the value of individual feedback. The most commonly used ophthalmological PROM is the National Eye Institute Visual Function Questionnaire (NEI VFQ 25), utilised to supplement findings of gold-standard RCTs across a number of sub-specialties, such as the ANCHOR<sup>vi</sup> and MARINA<sup>vii</sup> studies (AMD), and the CIGTS<sup>viii</sup>, EMGT<sup>ix</sup> and EAGLE studies<sup>x</sup> (glaucoma). These studies use PROMs to tie their primary endpoints (e.g. objectively-measured change in

visual acuity) with the perceived impact upon patients' quality of life, and thus focus clinicians firmly on the **real** impact of research upon individual lives. However, rather than using PROMs as a **reactive** measure, perhaps researchers should instead seek to use patients' views **proactively** to guide research agendas.

Patient and Public Involvement events (PPIs), which typically collect together patients, carers, charity sector workers, and additional service-users to elicit opinions, also potentially offer a positive way forward. PPIs eschew the traditional structure of research carried out 'by us' (clinicians, scientists) 'for them' (patients), instead promoting a horizontal hierarchy of open dialogue where patients' views become central to the "*identification of research priorities, the planning, funding, running and evaluating of clinical trials, and the dissemination of findings*"<sup>xi</sup>. Such methods of engaging patients are reflected in the Royal College of Ophthalmologists' curriculum, which stipulates that ophthalmologists have a professional duty to "*understand the importance of research and seek to promote it where possible (while) ensuring that the patient feels valued and important*"<sup>xii</sup>.

A pioneering PPI was held in 2014 for patients with Thyroid Eye Disease (TED)<sup>xi</sup>. The researchers invited lay people to attend an event featuring stalls, focus-group sessions, individual interviews, and an "*interactive voting wall to determine research priorities*". The authors state that the event was "*successful in engaging patients, researchers and clinicians in a two-way discussion about research priorities and improved study design*"<sup>xi</sup>, and proffered invaluable insight into patients' needs for better quality life. It particularly highlighted patients' concerns regarding the lack of available psychological support, and of the poor understanding of TED among other medical professionals. The primary advantage of conducting PPI events is the capturing of genuine data from key potential stakeholders **prior** to research agendas being created: adopting such strategies could ensure that future research truly echoes patients' views, changing 'patient-centred' to 'patient-powered'.

However, despite yielding evidential information, the complex planning and delivery of PPIs may be criticised as unworkably labour-intensive. A more practical means of allowing patients' views to steer future research could be to use "Core Outcome Sets" (COS)<sup>xiii</sup>. By standardising outcome measures, these ensure that **all** research addresses common fundamental principles. Ideally, within ophthalmological research, COS topics should include 'consideration of a patient's ability to carry out activities of daily living' and 'assessment of patients' key concerns regarding sight' within the study's outcome measures – the areas determined by clearly-focused collection of patients' own experiences.

## Community Collaboration

Engaging a broad multi-disciplinary team to respond to the patient voice is paramount. Ophthalmologists are just one instrument in the multi-modal orchestra of patient care – we cannot possibly address each aspect of patients’ concerns ourselves, and must embrace the wider team of optometrists, nurses, community support workers, counsellors, and voluntary networks who may be better suited to respond to particular needs<sup>xiv</sup>. My own experience of SomersetSight, a charity supporting visually impaired patients in South West England, testifies to the effectiveness of third-sector organisations. They provide wide-reaching, varied support, such as counselling for those with recent diagnoses, and help reinforce an invaluable sense of ownership by patients of their conditions. I witnessed the positivity generated by their efforts while joining a team of volunteers running the Bath Half Marathon with visually-impaired runners. The group’s energetic zest was inspirational, exemplified by one individual’s light-hearted attitude: “It’s easier for me, I can’t see how long we’ve still got left to run!” Encouragement of such upbeat attitudes can prevent patients becoming overwhelmed by bleak diagnoses, and thus genuinely contribute to general well-being.

Technology should be harnessed to include the wide spectrum of individuals affected by eye disease, both directly (i.e. patients themselves) and indirectly (e.g. relatives, carers). For instance, online support groups for certain conditions, e.g. Birdshot Uveitis Society (BUS), are being established as communication hubs, a means for patients, carers, researchers and clinicians to instantaneously share experiences with many other inter/national users<sup>xv</sup>. Their forums showcase individual blogs: as these societies are universally-accessible, monitoring them (with consent) would provide yet another avenue to listen to patients’ voices.

As technology develops further, new resources will become available. For example, tentative steps are being made towards the eventual use of ‘artificial intelligence’ in interpretation of optical coherence tomography scans, potentially facilitating rapid access to treatment for community-based patients<sup>xvi</sup>. The creation and application of such technology would be undeniably time-consuming and expensive initially, but has huge potential in facilitating patient-professional communication in the future.

## Conclusion

Acknowledging the human side of ophthalmology, empathising with the individual - not just treating the patient - is crucial to overall patient care and their understanding of potentially personally-devastating conditions. Formally, this should be incorporated into research strategies using PPIs and robust feedback mechanisms to sculpt research agendas.

Moreover, we should aim to acknowledge that we are perhaps not **fully** qualified to cope with **all** the emotional and psychological demands a patient and their family might present. Instead, we must recognise any available external sources and technological advances that might allow us to optimise an effective listening process. Finally, such an open-minded and listening attitude should be reflected by enriching the College curriculum with, for instance, lectures by counsellors or visits to blind schools, to help instil this sense of holistic awareness in the future generation of Ophthalmologists.

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