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Guest Editorial



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Patient Power

We hear often about patient-centred care and patient involvement, but how aware are you really of the experiences and needs of the patients you serve? Do you know their views of health services and systems they navigate, beyond your experiences of individual interactions or information reported in patient 'satisfaction' surveys? To what extent do patients in your hospitals and communities understand and take part in discussions about improving healthcare for everyone, against a backdrop of rising costs, restricted budgets, innovative (yet expensive) medicines and diagnostics, and rising demand?

At the International Alliance of Patients' Organizations (IAPO) we seek to answer these questions and to identify effective examples and models for improvement, and support improvement locally, nationally and globally. Our vision is a world where patients are at the very heart of health, from global policy-making to decisions made locally and within healthcare teams. Our member patient groups are all patient led, and can be small grassroots organisations led by volunteers, national level disease-specific bodies, or associations crossing regions and continents. Presently we have 250 members covering around 65 different disease areas and countries. We fundamentally believe that communication and collaboration are at the core of the challenges to meaningful patient involvement, and that this is also where solutions will be found.

We aim to be a voice for patients at the global level, advocating and collaborating on World Health Organization (WHO) projects and on pan-European projects. For example, this year we are working with academics, physicians and medical student representatives as part of a WHO project to deliver an online training resource for health professionals about the social determinants of health. At the European level we are working with health professionals, researchers, regulators, pharmaceutical companies and payers to test different ways to bring new and better medicines to professionals and patients faster.

At the individual level, informed and empowered patients are able to make choices about their treatment options, and many patients can and do take responsibility for their health and management of conditions. With all countries facing ever-increasing demand for services and rising costs for chronic condition management, new technologies offer patients more options to selfmanage and to truly have a partnership with their healthcare team. However, this can only work effectively within systems that support patients' right to be involved. Trust and open dialogue is needed, alongside access to advice and support about medicines, treatment and how to recognise and respond to any problems. Online 'apps' already empower many patients to manage their own conditions and are a good example of how new technology can assist the healthcare team and patients by offering the potential for sharing data, improving communication and shared decision-making, as well as the opportunity to tell industry what patients and professionals really need to help improve condition management.

Patients and patient groups are increasingly involved in hospital boards and committees, staff training and open days, or patient advocacy groups. In some hospitals and jurisdictions patients are involved in the review of and decisions about new medicines. Members have been involved with reviewing research proposals and patient information leaflets, and in specific disease areas patients have completed surveys on weighing up the benefits and risks of different treatment options. However, meaningful patient involvement remains inconsistent, and often no feedback is provided about what difference their input has made. There are clues about where further gains can be made. For example, a patient representative told us that if she was involved in the earliest stages of forming research questions, she would highlight a group of women who are not having their needs met by research or clinical practice. And we have heard examples where clinicians are wary about benefit/risk preference elicitation surveys, because the survey presents treatment options to patients that may not been discussed.

Patient representatives can also add value to improvement initiatives in healthcare services, because they are often closest to a patient and their whole experience. When mapping the patient journey and showing it to clinicians, patient representatives can shock health professionals with the complex, time-consuming and overlapping interventions and pathways. Health professionals often only see the part of the patient experience that overlaps with their own focus. Health is a human right and patients are the ones who bear the impact of many decisions made without them. Better services can be designed and outcomes delivered by communicating more openly and effectively, listening to and involving patients at all levels, and feeding back to patients on changes, improvements and ongoing challenges. We appreciate the journal's willingness to promote discussion and encourage you to seek further information on IAPO and our partners, guidance, toolkits and activities at iapo.org.uk

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