**EBN Opinion: The Expert Patient**

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**Background**

The European Patients’ Academy (EUPATI) is a pan-European Innovative Medicines Initiative project of 33 organisations, led by the European Patients’ Forum with partners from patient organisations (the European Genetic Alliance, the European AIDS Treatment Group, and EURORDIS), universities and not-for-profit organisations, along with a number of European pharmaceutical companies. EUPATI aims to help patients to be more educated and involved in the research and development process of new medicines, by offering reliable, objective, comprehensive lay-friendly information and training on the research and development process of medicines. EUPATI increases the capacity of patients to be effective advocates with meaningful involvement in areas like drug discovery and non-clinical testing, planning and conduct of clinical trials, regulatory affairs, assessment of safety of medicines, benefit-risk assessment, as well as principles of health technology assessment. The first EUPATI Patient Expert Training Course was launched in October, 2014 and the new web-based educational toolbox is being launched in January, 2016 hosting educational material in English, Italian, Spanish, Polish, German, French and Russian aiming to reach 12,000 patient advocates across Europe. <http://www.patientsacademy.eu/index.php/en/>

**Key messages from the Twitter Chat (#ebnjc)**

Participants agreed that there should be greater collaboration between patients, academia and industry in the area of medicines research and development. It was noted that expert patients currently have roles inter alia on Research Ethics Committees, the European Medicines Agency, Regulatory Affairs, Health Technology Assessments and on local, national and European research projects. The importance of shared decision-making with patients during medicines research and development was acknowledged by participants as being crucial as this allowed different perspectives to be taken into account (Coulter et al, 2008).

Participants suggested that social media is opening up greater access to clinical trial information. Social media could potentially be used to recruit participants to clinical trials. Other participants suggested that the public are only interested in medicines research and development if they have personal or family experience of illness. Significantly, some participants revealed personal details about their own experiences of taking part in clinical trials during the Twitter Chat which humanised the topic. It was remarked that patients can lose a sense of involvement in a clinical trial as it progresses suggesting there is a need for better communication with these patients particularly with regards to the publication of results. Participants stated that lay patients require further education and training in pharmaco-vigilance matters so as to ensure that there are safer medicines for everyone.

Participants in the Twitter Chat felt patients need to be recognised and valued as experts. Whilst, healthcare professionals may be an expert in the disease, patients are experts by experience. Expert patients contended that they can add value, influence, educate and inspire others to change the status quo in healthcare. Increased collaboration with many stakeholders can lead to more meaningful decisions if the patient’s voice is included and provided all parts of the system are willing to listen. The argument was put forward that patients who are experts by experience can collectively address the “blind spots” that evidence based medicine cannot cover, namely – the impact of “living” with a long term condition. Patient empowerment is a progressive and collaborative journey that we all need to follow to ensure improved health outcomes for everyone.

**What can you do?**

As noted above the patient is an expert by experience. While this is acknowledged by many professionals across healthcare and academia, it does not always translate into practice (Nelson et al, 2015). This Twitter Chat has highlighted the importance of collaboration in, not only medicines research, but also in relation to the general care afforded to all patients. Academics, healthcare educators, doctors, pharmacists, nurses and other allied health professionals have a key responsibility in advocating for the active inclusion of patients within their healthcare system. This is because expert patients provide a meaningful and a unique perspective about living with a particular illness. These patients can therefore illuminate aspects of practice which are helpful but also those which can be improved in the future (Parsons et al, 2016).

**References**

1. Coulter A, Askham J, Parsons S (2008) ‘Where are the patients in decision making about their own care?’ WHO Regional Office for Europe, 1–14.
2. Nelson EC, Eftimovska E, Lind C, et al (2015) Patient reported outcome measures in practice. BMJ 2015;350:g7818. doi:10.1136/bmj.g7818
3. Parsons, S., Starling, B., Mullan-Jensen, C., Tham, S., Warner, K. and Wever, K. (2016) ‘What do pharmaceutical industry professionals in Europe believe about involving patients and the public in research and development of medicines? A qualitative interview study’, BMJ Open. <http://bmjopen.bmj.com/content/6/1/e008928.full?sid=e9547d90-0de6-4078-ae92-7dc3ab76d742>

**Screenshot from Twitter-Chat**

