

EUPATI: Patient engagement through education as an important contributor to shared decision making

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Abstract

Building knowledge and capacity for patients and their advocates about the “systems” of healthcare is empowering for patients. The European Patients’ Academy (EUPATI) was established across Europe in 2012 to provide education and training to patients and their advocates. Initiatives like EUPATI have broken new ground in terms of patients’ education and learning opportunities. Taking their knowledge back into decision making bodies like the UK’s National Institute for Health and Care Excellence (NICE) can lead to a greater focus on the issues that matter most to patients. That focus on the outcomes and issues of concern to patients give those of us working in this field the opportunity to take population-level recommendations as the basis for individualised decisions, shared between patient and clinician.

EUPATI

The European Patients’ Academy (EUPATI)¹ was established across Europe in 2012 to provide education and training to patients and their advocates. The purpose of the initiative (part of the Innovative Medicines Initiative²) was to increase patients’ understanding of and contributions to medicines research and development, and to improve the availability of objective, reliable, and patient-friendly information for the public. Its aim was also to build capacity in Europe and beyond to accelerate patient engagement in all aspects of the development of medicines.

As a founding member of EUPATI’s multi-stakeholder consortium (which brings together patients, pharmaceutical industry, academia, non-profit organisations, regulators, and health technology assessment [HTA] bodies), it has been an extraordinary privilege for me to see the successful graduation of more than 200 EUPATI scholars over the years, knowing that the cascade of their knowledge and experience is being felt worldwide.

What does EUPATI offer its students?

The EUPATI syllabus covers several modules under the following broad headings: introduction to medicines R&D, non-clinical development, clinical development, regulatory affairs, and health technology assessment. Further details about the modules can be found in their current brochure.³ EUPATI’s website contains much information which is free to use, including the toolkits which form essential content for its formal students. People have the option to use this content as a guest but to become a registered EUPATI fellow one needs to become a “formal learner”. The content for formal learners remains free to use, but there is a small (8 Euro) charge to cover assessment costs for each module. Anyone with an interest can register to become a formal learner.

The EUPATI course has moved predominantly online to the platform called the “Open Classroom”⁴ with some face-to-face and streamed sessions, all of which comprise a mix of taught and interactive modules, with opportunities for discussions and practical exercises (Figure 1). EUPATI offers most of the course on a flexible and “on-demand model”, allowing the students to study around their other commitments.

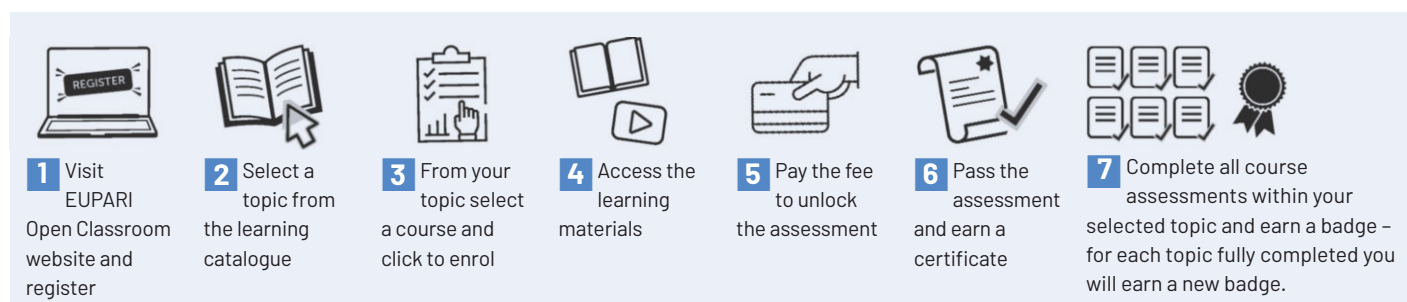


Figure 1. How does EUPATI Open Classroom work?



Health technology assessment

One of the key parts of the EUPATI training is the module on HTA⁵ and the role that patients, carers, and the public can play in shaping these evaluations. As explained in this module, the UK's National Institute for Health and Care Excellence (NICE) has responsibility for delivering HTA recommendations for the health service in England.⁶ NICE's Public Involvement Programme supports the involvement of patients and the public in this work⁷ that is integral to how NICE operates across all its programmes.

The recommendations that NICE produces as part of its HTA programmes are designed to support the health service in England by identifying the technologies that deliver effective treatments for patients in terms of improving people's outcomes. The NICE recommendations also include interventions that deliver cost-effectiveness (or, in essence, value for money) for the UK healthcare system.

Evidence-based decisions for broad populations

The EUPATI initiative was established as a means to educate patients on the life cycle of

medicines, to give patients an understanding of the process of taking a medicine to market, and to understand the broad mechanisms by which patients can be involved in all stages of medicines development. Part of this process is the identification, analysis, and appraisal of the best available evidence – including evidence generated about and by patients.

However, one of the limitations of evidence-based medicine – and its application in the HTA process in particular (exemplified by NICE) – is that the recommendations developed are based on standardised care for broad populations of patients. Individual decision making (and by association, key aspects of personalised medicine), and the science of how we make decisions about our care, have not routinely been considered as part of this approach. Some new initiatives at NICE are paving the way for formally translating these population-level decisions into mechanisms for individual patients to make individual decisions about their care.

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These have included to date the development of patient decision aids for a number of topics,⁸ and the identification of “preference-sensitive” decisions during the development of recommendations. These decisions may be preference-sensitive due to a lack of evidence, the uncertainty of evidence, or – most importantly – where a person's individual circumstances, experiences, values, and preferences would lead them to make individual choices.

Shared decision making (SDM)

The concept of patients and clinicians working together to jointly decide on the best course of action for that particular patient is not new. Indeed, it is at the heart of what we would all hope for from a successful consultation with a health professional. There are circumstances when all of us would like others to act in our best interests, and we hope that they use the best available evidence to make decisions on our

behalf. However, in most clinician/patient interactions and in many clinical circumstances, there are opportunities for a considered approach to the evidence where the treatment options can be weighed up and patients and clinicians can discuss, as equals, the best option for the individual in question.

We all have different attitudes to risk, and when presented with the same clinical options, we might make different choices to one another. It is important that we have access to standardised information about our treatment options so that we can reach a decision about what would best reflect our own values and preferences and be able to discuss these with our clinicians.

The value that patients' understanding and involvement brings to these processes, by identifying the issues that matter most to them and the questions they wish to pose to their clinicians, is unique and vital. NICE's longstanding involvement of patients in its guidance development, and latterly in its work around shared decision making, demonstrates time and again this added value.⁹

We know from a recent Cochrane review¹⁰ that tools to support these individual discussions and decisions (e.g. decision aids, patient decision aids, option grids) can make people more knowledgeable, better informed, and clearer about their values – and in all likelihood, they will have a more active role in decision making and more accurate risk perceptions.

These tools also support clinicians by providing easy access to standardised information that they can share with their patients in pursuit of a shared decision about treatment. Shared decision making is still not embedded in routine clinical practice, and Joseph-Williams et al¹¹ have articulated why this might be (e.g. assumptions that patients are not interested in making decisions, that there are not the tools to support it, not knowing how to measure it, etc.) and how the barriers to integration might be overcome.

We are hopeful that the work that NICE is currently developing in this field will also add to the tools that support a change in culture whereby shared decision making is not only a

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part of routine care but is also part of our approach to developing evidence-based guidance and HTA recommendations.

We have produced a set of guideline recommendations on good practice in shared decision making.¹²

Alongside this, we have collaborated with Keele University to develop an online learning package to support clinicians in delivering a shared decision making approach.¹³

We have published a quality framework for people who are decision aid users and developers, whether they are patients or clinicians.¹⁴ This piece of work was commissioned from NICE by NHS England.¹⁵

Finally, as part of NICE's five-year strategy,¹⁶ we will be developing mechanisms by which shared decision making can form an integral part of NICE's methodologies and processes.

Conclusion

Both the EUPATI initiative and the two decades of patient and public involvement at NICE have demonstrated the value of enhancing patients' understanding of the processes by which treatments and interventions make their way into health care systems. These processes have typically stopped short of including an analysis of the science of decision making and of the potential tension between recommendations intended to realise benefits at a population-level and the choices and potential benefits for the individual.

NICE is aiming to help resolve this tension by incorporating shared decision making into its methods and processes, providing a quality framework for decision aids, and continuing to support clinicians, patients, and the general public in participating in shared decision making. In this way, NICE hopes to draw together the need for population-level, evidence-based recommendations and the importance of individualised personalised decision making.

Disclaimers

The opinions expressed in this article are the author's own and not necessarily shared by her employer.

Conflicts of interest

The author is employed by the National Institute for Health and Care Excellence. She is also part of the founding consortium for the European Patients Academy on Therapeutic Innovation.

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Victoria Thomas, MSc (Dist), has worked for NICE since 2001 and has been Head of its Public Involvement Programme since 2009. She has an international reputation in relation to patient and public involvement approaches and has a long-standing interest in the relationship between evidence-based initiatives and personal decision making.