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Individual or organisation response: Organisation

Permission given to the Academy to publish response: Yes

How does society use evidence to judge the risks and benefits of medicine?

The Academy of Medical Science should carefully consider the definition of evidence that frames your review, before specific questions are considered. Traditionally, the concept of evidence has focused on clinical and economic forms of knowledge. While these forms of evidence are very important, changes in society and the nature of disease and ill-health mean a wider view of evidence is required. The research questions that researchers attempt to answer are changing. The need for a broader view has been recognised by organisations such as NICE in some of their work. For example, the production of NICE Guidance on patient experience was underpinned by a vision of evidence that not only included clinical and economic forms of evidence, but also identified the importance of patient-based evidence, which includes experiences and outcomes from a patient perspective (Staniszewska et al 2014). In addition, the importance of patients and the public as active collaborators in shaping evidence has evolved in the last decade; with patients and clinicians working together to identify key research questions (NIHR 2015). More recently, a new journal focusing on the co-production of evidence has been launched, with academics working in partnership with patients, reflecting the significant changes taking place in the creation and publication of evidence (Stephens and Staniszewska et al 2015). Deliberation of evidence is also important and the concept of colloquial evidence is emerging, recognising the significant social context of evidence production (Sharma et al 2015).

In line with such deliberations, research designs are also evolving. In an attempt to try and capture the emerging complexity, we recognise that more flexible approaches are required that account for context, mechanism and outcome, as contained in the Medical Research Council Complex Interventions Guidance (MRC 2012). How randomised controlled trials will evolve in the future, to evaluate interventions in a real world setting, is an important challenge.

Reviews of effectiveness are not designed to directly address many issues of importance to patients and there is an increasing acknowledgement that primary qualitative research (Garner et al 2007) and particularly syntheses of qualitative research may be able to help to fill this gap (Glenton et al 2013). Qualitative synthesis is being used increasingly in HTA and health services research and its role and contribution seems likely to grow as awareness increases and methodological advances occur [GRADE working group; Tong et al 2012]. Indeed, the availability of qualitative syntheses and secondary analysis of qualitative data as methods to gather patient evidence may be able to strengthen the patient and carer voice in policy development, and go some way to counter the dismissal of methods of gathering patient experience as 'unrepresentative' (Ziebland & Hunt 2014; Hansen et al 2011). This may encourage an increasingly nuanced view of the risks and benefits of medicine, which incorporates patient preferences, and the unique contribution of different types of evidence (Walach & Loeff, in press), more fully.

In conclusion, we would urge the Academy to adopt a wider view of evidence to include patient-based evidence, alongside clinical and economic forms of evidence (Staniszewska et al 2015). We would also encourage the academy to recognise the importance of research designs that consider applicability with a wider context for evaluating effectiveness of interventions. Finally, the importance of involving patients and the public as active collaborators in the identification of evidence generation is vital (Staniszewska et al 2012).

References

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