

INVOLVEMENT OF PATIENTS AND CITIZENS: HTAi EXPERIENCE

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Health technology assessment (HTA) aims to support rational decision making in health care policy and practice through robust assessment of evidence and knowledge in the national/regional context. Given the current political emphasis for patient-centred care; shared decision making between physician and patient; and accountability of health care systems to their owners (i.e. citizens), involvement of patients and citizens in HTA would seem essential. However, 'involvement' can be defined in many ways and can be seen as a 'box ticking' exercise.

The HTAi Interest Group on Patient/Citizen Involvement in HTA provides guidance to those undertaking HTA to show how they can effectively involve patients and citizens in their work. Many of the ideas are relevant to guideline development and so HTAi is pleased to have a close working relationship with GIN on these issues.

Focus to date has been on including patients' perspectives, in two quite different ways through:

1. generation of robust evidence about patients' views on the consequences of using a technology and living with the illness
2. involvement processes that support patients to participate fully in the deliberative processes of HTA.

As evidence on patients' views may arise from primary studies or systematic reviews, considerations of quality and applicability of the evidence are similar to those made in the clinical effectiveness assessment of an HTA or guideline. The challenge is that the majority of studies which provide this evidence are from the social science or humanistic research field and the involvement of professionals with such social science training is not common place in assessments.

Many studies describe the barriers to patient/citizen involvement in HTA, but few give practical advice on how it can be achieved. The HTAi Interest Group has developed a comprehensive glossary for use with patients involved in HTA, promotes a guide from Health Equality Europe on HTA that is for use by patient organisations and is developing other support materials.

The next question is what more is needed to move from the ticking the box for consumer involvement to making sure that patients participate fully in our evidence based work and measuring the impact of this?

ABOUT THE PRESENTER

Karen Facey PhD is an Honorary Senior Research Fellow in the Department of Public Health and Health Policy at the University of Glasgow and Honorary Member of the Faculty of Public Health in the UK. Following a career as a statistician in the pharmaceutical sector, Karen has worked for the past nine years in health technology assessment (HTA), which provides a bridge for evidence and knowledge to inform healthcare policy. She has developed a passion for bringing patient perspectives into the HTA process and since its inception in 2005 has chaired the Interest Group on Patient/Citizen Involvement in HTA for Health Technology Assessment International (HTAi).