

ABSTRACT

CHOOSING OUTCOMES AND MEASURES – FOR DOING AND USING RESEARCH

The responsibility for choosing outcomes and measures may be shared for ethical reasons or in order to choose and measure outcomes better. Responsibility may be shared for choosing aspects of health to be assessed, developing and applying the measures, and making decisions for either individuals or groups of patients.

Advances in each of these tasks have been led by researchers, practitioners and patients. We can learn from this experience by considering who's involved in each task, in which steps, what knowledge they bring, what other knowledge they need, how they share what they know between them and build new knowledge. This is more than user participation in research, it is user participation in studying research methods – methods for measuring and methods for participation – and it brings new challenges for users and researchers.