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Public awareness of and attitudes to clinical guidelines: a systematic review

Background

Clinical practice guidelines are typically written for health care professionals but there is increasing interest in producing versions for the public, patients and carers. This review looked at the literature describing the public's attitudes towards clinical practice guidelines and evidence-based recommendations, together with their general awareness of clinical guidelines.

Methods

We included quantitative and qualitative studies of any design reporting on public and patient awareness, attitudes and knowledge of guidelines. We searched electronic databases including MEDLINE, PSYCHINFO, ERIC, ASSIA and the Cochrane Library from 2000 to 2012. We also searched relevant websites, reviewed citations and contacted experts in the field. At least two authors independently screened, abstracted data and assessed the quality of studies.

Results

We reviewed 5415 records and included 26 studies (10 qualitative studies, 13 cross sectional and 3 randomised controlled trials) involving 24 887 individuals. Studies were mostly good to fair quality.

Awareness that clinical guidelines exist at all ranged from 0% to 79%. Once people were made aware of guidelines though, they generally wanted a copy.

Four main themes emerged (see box). Overall, participants had mixed attitudes towards guidelines. Some participants found them empowering but many saw them as a way of rationing care. Patients want to be seen as individuals with unique experiences and health care needs but do see that guidelines can help both them and health professionals.

Applicability of guidelines

- Will the information be applicable to me?
- Do I trust the guideline as much as my own judgement, or my friend?
- Purpose of guidelines for patient
- A tool to provide information.
- To support discussion with health professionals
- To support self care
- Empowerment: making sure patients are offered the care they need
- Purpose of guidelines for the health care system
- A way to keep health professionals up to date
- Rigid rules that must be followed
- A way of restricting care
- Must be engaging to read
- Properties of guidelines
- Formatting is importantNeed to get a sense that the
 - information is trustworthy
 - Should say something about uncertainty

Guideline producers need to make clear how guideline-derived information for the public is relevant to the reader and how it can be used to support their decisions. Awareness of guidelines is low and guideline producers cannot assume that the public has a more positive perception of their material than of alternative sources of health information.



