

SHORT ORAL PRESENTATIONS

001 DECIDE: USER INVOLVEMENT IN GUIDELINE DEVELOPMENT

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The European Union funded project, DECIDE aims to improve the dissemination of evidence based recommendations by building on the work of GRADE. Work Package 3 aims to identify approaches to effective dissemination and use of research evidence by the general public, in order to improve shared health-care decision making and person-centred care. This part of the study explores public understanding of clinical guidelines and preferences over future presentation. Focus groups were carried out, to discuss specific guidelines (depression, diabetes, flu vaccination and cervical cancer), and with professionals working in science communication and young people. Questions were informed by a systematic literature review. Data were analysed using the Framework method. Those with experience of a specific illness were better informed and more likely to have actively sought out information than those targeted for screening. Themes emerged including: participants not understanding the concept of 'strong' and 'weak' evidence; participants feeling information should be presented more clearly with emphasis on self-management and side effects; concern expressed that treatment decisions were based on cost rather than evidence; and participants wanted more general information on the condition. Aspects of the content and presentation of guidelines are not relevant or understood by the public. Several different versions of these guidelines have been created based on these results and user testing is ongoing. Current clinical guidelines will need to be adapted substantially before they are appropriate for the public, and the public should be involved in guideline development on an ongoing basis.

002 PUBLIC ATTITUDES TO AND KNOWLEDGE OF HEALTHCARE GUIDELINES, AND METHODS TO COMMUNICATE GUIDELINE RECOMMENDATIONS TO PATIENTS AND THE PUBLIC – A SYSTEMATIC REVIEW

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Background Improving patient versions of guidelines is one way to support an increasing role for patients in health decision making.

Objectives To evaluate evidence on the public's attitudes and knowledge of clinical practice guidelines AND what strategies have been used to communicate guideline recommendations to this group.

Methods We conducted a systematic review of public attitudes and knowledge of clinical practice guidelines to inform the development of dissemination strategies for this population. We searched health databases from 2000 to 01/2013, grey literature, and we contacted guideline producers. Two reviewers independently abstracted, coded, synthesised themes from the studies.

Results We included 25 published studies and three reports (CCPG, NICE, SIGN). There was a huge variation in the

public's awareness of guidelines (12 studies) from 25–75%. The key themes to communicate guidelines (15 studies) to the public included, predictive factors (amount of education), personalisation, access to care, trustworthiness (evidence behind recommendations), and self-management.

Discussion Although there were few studies for thematic analysis there were recurrent themes. When developing patient versions, the danger could be to focus on detailed formatting instead of fundamental issues around whether patients dismiss guidelines as not applicable to their unique situation and restricts care. The results will inform work focused on the public and patients being done in EU FP7 DECIDE project.

Implications Guideline producers will need to increase the public's awareness of clinical guidelines and developing communication strategies that are clearly personally applicable, trustworthy and useful for patients and carers managing their care.

003 TOWARDS OPTIMAL PATIENT INVOLVEMENT IN GUIDELINE DEVELOPMENT GROUPS

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Background The involvement of patient representatives in guideline development groups (GDGs) could increase legitimacy and quality of clinical practice guidelines (CPGs), since the experiential knowledge of patients could complement scientific evidence. By their involvement, patients have the opportunity to share (consultation) and incorporate their views and experiences into CPGs (decision-making). Although the importance of this approach is emphasised, little methodological support and systematic reflection exist on effective strategies.

Objectives To gain insight in how patient involvement in GDGs can be optimised in order to develop strategies which can be implemented in practice.

Methods The evaluation consisted of a desk study and 23 semi-structured interviews with stakeholders in CPGs, including patient representatives. The acquired insights were used to develop an evaluation framework, which guided monitoring and evaluation of four ongoing oncological guideline development processes. Validation took place through a triangulated approach (e.g. observations, document-analyses, interviews). Two patient representatives were included in the research team.

Results The evaluation revealed that successful patient involvement in GDGs depends on a broad scale of factors (e.g. members of the GDGs, support of patient representatives) which could facilitate or constrain patient involvement. The factors were used to develop practical strategies for patient involvement, ranging from preparation meetings to regular reflections with the patient representatives and dialogue sessions with patients.

Discussion The strategies could lead to more successful patient involvement in GDGs and provide valuable insights on how to involve patients in guideline development processes on other disease areas.

004 PARTNERING TO TRANSFORM CLINICAL RESEARCH INTO EVIDENCE-BASED HEALTH CARE GUIDELINES

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