

## Oral presentation Cochrane Colloquium 2013

**Title:** Knowledge translation with consumers: lessons from the IN-DEEP project

**Topic category:** Knowledge Translation and Advocacy for Evidence-Based Decision-Making

**Topic sub-category:** Internet and social media

### ABSTRACT

**Background:** The IN-DEEP project, Integrating and deriving evidence, experiences and preferences: Developing research-based health information applicable to decision making and self-management by people with multiple sclerosis (PwMS), is a collaboration between research teams in Australia and Italy, undertaking two parallel projects. The aim is to make high quality evidence accessible and meaningful to PwMS and their families.

**Objectives:** to discuss the implications of our project findings for the provision of evidence-based information to consumers.

**Methods:** The Australian and Italian teams each conducted a mixed-method study; drawing upon the information needs of PwMS to create a web site that presented Cochrane reviews (CR) of MS treatments. Extensive formal and informal user testing with consumers and other stakeholders was undertaken during development. The web sites went live in 2012 with an online evaluation survey.

**Results:** Due the iterative nature of the projects and differing information needs, the Australian and Italian web sites took different approaches, but both were strongly endorsed by consumers. The Italian web site as a first topic covered a CR on the effects of recombinant interferons for MS with additional methodological information. The Australian web site included a number of different CRs. Lessons learnt include the importance of understanding consumer needs, the complexity of being faithful to the volume and quality of the evidence and to say it clearly, and effective strategies to involve lay people in the selection of treatment topics and in the production and dissemination of evidence-based information.

**Conclusions:** preparing accessible summaries of the evidence for consumers identifies potential improvements for Cochrane reviews, eg the importance of Summary of Findings tables, but also the challenges of providing the full range of information which people need to manage their health. Working in partnership with consumer organisations will aid this process.

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