

# Integrating and deriving evidence, experiences and preferences (IN-DEEP): developing research-based health information applicable to decision making and self-management by people with multiple sclerosis

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## Parallel research stages in Australia and Italy

### Background:

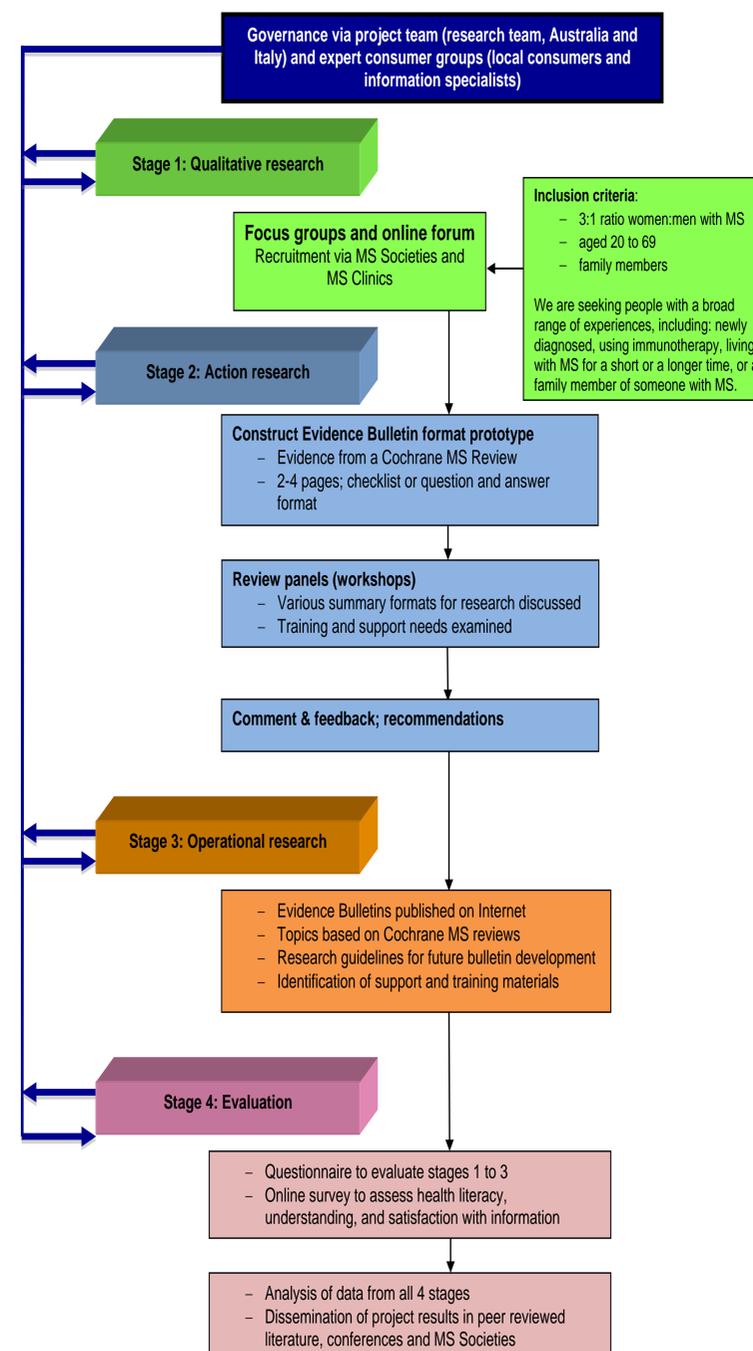
Access to accurate, relevant and easily understood information facilitates informed decision making, all of which improves disease management for consumers and their physicians.

### Objectives:

To make high quality evidence more accessible and meaningful to consumers and their families for use in their self-management decisions. Internet-based information on evidence from systematic reviews of treatments for multiple sclerosis (MS) is the initial focus.

### Methods:

The project realises collaboration between international researchers, with Italian and Australian consumers, and Italian and Australian MS Societies playing a major partnership role. The research has four stages (Figure 1), each step building on the last. In the first stage, we will explore with people with MS and their families how they find, assess and use health information from research about the effectiveness of treatments. Drawing from people's experiences, in the second stage we will develop a template for writing summaries of the latest research in a format that enables people using the information to make it applicable and meaningful for their personal circumstances. In the third stage, we will develop a model for presenting the information on the Internet aimed at people with MS and their families. The fourth stage is to evaluate the model to ensure that it meets people's needs and helps them find and assess information for managing their health. We plan to conduct the research both in Australia and Italy and compare findings for a fifth stage, in particular, any similarities and differences in people's information needs, and the implications for The Cochrane Collaboration and *The Cochrane Library*, such as translation of summary formats.



### Intended outcomes:

The project will lead to the provision of high quality research-based information for people with MS and their families that is responsive to their expressed need. It will be used to guide future strategies by MS Societies and the development and translation of Cochrane summary formats.

### Conclusions:

The potential significance of this research is learning how people integrate research information into their decision making and how they assess and make sense of new information. It will provide an international model for sharing and exchanging information and expertise where the primary focus is information and education for people with MS.



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