

# Development of a Web-based Palliative Care Registry in General Practice Settings



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## Background

Routine assessment and feedback is recognized as an important approach for dynamically monitoring health care quality and policy development, and has been widely used in health care research. However, in Australia, there are no processes to determine what and how care is provided for end of life patients, or the quality of this care, in general practice settings. This lack of information is noteworthy given that GPs undertake the majority of end of life/palliative care, and a number of barriers in the provision of palliative care in general practice have been identified in previous studies.<sup>1</sup>

## Aims

To develop a Web-based Palliative Care Registry (WPCR) in General Practice Settings.

## Methods

The first step is to establish a palliative care questionnaire based on a literature review and expert interviews. A systematic review of instruments assessing palliative care from the general practice's perspective was conducted. Additional background was obtained from focus groups with GPs and in-depth interviews with other stakeholders such as policy makers, palliative care specialists and nurses. In the second step, the list of questions to be included will be refined through a consensus process which will involve 20 experts mainly consisting of GPs and palliative care researchers. The third step will convert the questionnaire into the WPCR configured for use with electronic medical record system. Once a death is notified in medical record, the WPCR will be automatically activated and some core data fields will be automatically populated, with additional questions about the care provided being part of a drop-down questionnaire to be completed by GPs.

## Key learning

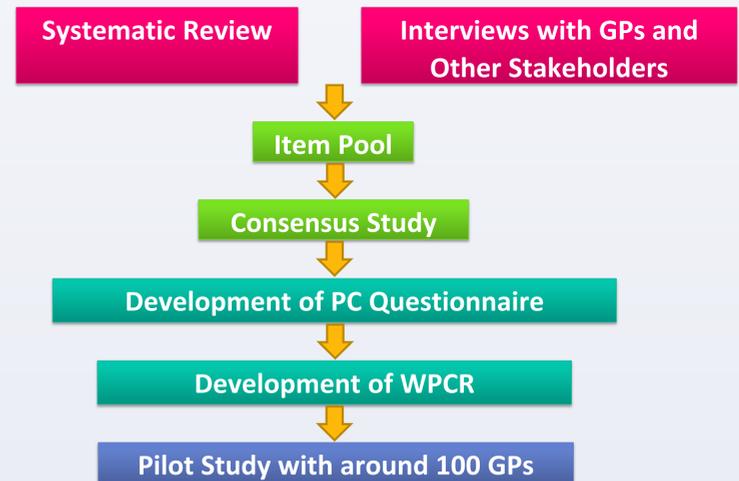
Our systematic review identified 21 relevant instruments in which a broad range of questions were extracted and would inform the development of our questionnaire. These questions were most commonly referred to the following three domains:

- physical, psychological and spiritual aspects of care
- coordination and continuity of care
- information-sharing and communication with patient and family

Preliminary findings from our qualitative analysis indicated:

- a high level of commitment by GPs in the provision of high-quality palliative care
- a desire for coordination with multidisciplinary team
- delay or difficulties in recognizing EOL patients and introducing palliative care
- difficulty in keeping GPs engaged in the patient's care after referral
- lack of financial support for case conference and home visit
- problems with accessing necessary medications.

## Research design



## Conclusions

Several successful palliative care audit programs were identified in the literature review and opinions obtained from interviews.<sup>2,3</sup> These results confirmed the significance, feasibility and acceptability of our design idea of configuring WPCR for use with an electronic medical record system.

## Research and practice implications

This registry will be pilot tested with around 100 GPs in next step, and further developed into a national palliative care audit network, with the ultimate aim to contribute to quality improvement through informing policy development, evidence-based benchmarks and feedback to GPs.

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