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Clinical practice guidelines and principles of care for people with dementia: a protocol for undertaking a Delphi technique to identify the recommendations relevant to primary care nurses in the delivery of person-centred dementia care

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ABSTRACT

Introduction Nationally and internationally it is well recognised that dementia is poorly recognised and suboptimally managed in the primary care setting. There are multiple and complex reasons for this gap in care, including a lack of knowledge, high care demands and inadequate time for the general practitioner alone to manage dementia with its multiple physical, psychological and social dimensions. The primary care nurse potentially has a role in assisting the general practitioner in the provision of evidence-based dementia care. Although dementia-care guidelines for general practitioners exist, evidence on resources to support the primary care nurse in dementia care provision is scarce. The 'Australian Clinical Practice Guidelines and Principles of Care for People with Dementia' provides 109 recommendations for the diagnosis and management of dementia. This protocol describes a Delphi study to identify which of the 109 recommendations contained in these multidisciplinary guidelines are relevant to the primary care nurse in the delivery of person-centred dementia care in the general practice setting.

Methods and analysis Using a Delphi consensus online survey, an expert panel will grade each of the recommendations written in the 'Clinical Practice Guidelines and Principles of Care for People with Dementia' as high-to-low relevance with respect to the role of the primary care nurse in general practice. To optimise reliability of results, quality indicators will be used in the data collection and reporting of the study. Invited panel members will include Australian primary care nurses working in general practice, primary care nursing researchers and representatives of the Australian Primary Health Care Nurses Association, the peak professional body for nurses working in primary healthcare.

Ethics and dissemination This study has been approved by The University of Newcastle Human Research Ethics Committee (HREC) (H-2019-0029).

Findings will be published in a peer-reviewed journal and presented at scientific conferences.

Strengths and limitations of this study

► The Delphi consensus method is useful to solicit expert opinion and build knowledge in areas where limited evidence exists.
► Content validity is increased with selection of panel members with knowledge and interest in the roles of primary care nurses in general practice.
► Reliability of study findings are optimised using defined methodologic criteria for data collection and reporting in Delphi studies.
► The findings of this Delphi study will inform a qualitative interview study of Australian primary care nurses aimed at validating and refining the recommendations selected by the Delphi expert panel.

INTRODUCTION

Nationally and internationally, primary care, and in particular the general practitioner (GP), is responsible for the majority of screening, on-going management and care of people living with dementia (PLWD).[1,2] However, it is well recognised that dementia is poorly recognised and suboptimally managed in the primary care setting.[3,4] There are multiple and complex reasons for this gap in care, including a lack of knowledge, high care demands and inadequate time for the GP to manage dementia with its multiple physical, psychological and social dimensions.[1,5,6]

Primary care nurses (PCNs) are significant contributors in the delivery of primary care nationally and internationally[7–10] and have a key role in supporting the work of the GP.[11] It has been acknowledged that the PCN potentially has a role in supporting the GP in the better recognition and management

of dementia in general practice.[12–14] However, a review of recent literature shows that PCNs have limited knowledge in relation to the recognition of cognitive impairment and care planning for PLWD[15] suggesting that they will need support if they are to have a role in assisting the GP to provide optimal care to PLWD.

Clinical practice guidelines aim to support health practitioners with best-practice decision-making[16] thereby improve quality of care, patient outcomes and cost effectiveness.[17 18] Although dementia care guidelines and pathways of dementia care delivered by GPs exist, there is little evidence on models of care or clinical practice guidelines that support the PCN in dementia care provision in general practice.[19]

The recently published 'Australian Clinical Practice Guidelines and Principles of Care for People with Dementia'[20] (henceforth referred to as 'The Guidelines') provides 109 recommendations for the optimal diagnosis and management of dementia. The Guidelines are written for doctors, nurses, allied health and care workers who work with people in community, residential and hospital settings in Australia.[20]

The most effective clinical practice guidelines are those that are specific to the end-user and incorporate implementation frameworks.[16 21 22] Therefore, to optimise effectiveness of The Guidelines in supporting PCN delivery of dementia care, the 109 recommendations in The Guidelines need to be distilled down to those relevant to the PCN and barriers and enablers to the PCN implementation of these recommendations identified. This article describes a protocol for a Delphi technique that will identify the recommendations in The Guidelines that are perceived, by a panel with expertise in primary care nursing, as relevant to the PCN in the provision of evidence-based person-centred dementia care.

Findings from this Delphi process will inform the development of a future qualitative interview study with Australian PCNs to critically review the selected recommendations for delivering person-centred dementia care and identify barriers and enablers to their implementation in the general practice setting.

This study serves as an important first step to develop a primary care nursing model of care for the provision of dementia care in general practice, specific to the PCN role, and that also incorporates information on their implementation.

METHODS AND ANALYSIS
Aim
To identify which of the 109 recommendations contained in the 'Clinical Practice Guidelines and Principles of Care for People with Dementia' are relevant to the PCN in the delivery of person-centred dementia care within general practice.

Design
A Delphi consensus technique[23] engaging an expert panel to reduce the number of recommendations to those applicable to PCN provision of dementia care will be used.

Sample
The expert panel is a purposive sample of people who have a minimum of 1 year's experience in research or clinical practice in the area of primary care nursing. Panel members invited to participate will include Australian practice nurses, primary care nursing researchers and representatives of the Australian Primary Health Care Nurses Association.

There is little agreement about the optimal size of the expert panel for a Delphi study[23] and as described in Keeney et al[24] this decision is often based on funding, logistics of data handling and inclusion criteria. Jorm[25] describes stability in findings with panels of around 20 or more members. This study will aim for 20 panel experts, assuming a 30% rejection rate, 27 experts will be invited to participate in this study.

Participants will be anonymous to each other but not to the researcher. Panel members will be assured all information will be confidential and comply with the University of Newcastle research data security policies.

At the conclusion of the process, participants who have responded in each round will be offered the choice to remain anonymous, or receive acknowledgement in the publication for their participation.

Recruitment
Delphi participants will be invited to participate via email. The invitation to participate will include a personalised letter including a description of the study, its importance and the valuable contribution the panel member can make, the online Delphi process, expected time commitment and research contact details and a consent document. Written consent will be obtained by return email. After consent is provided, the first survey, round 1, of the Delphi will be sent to participants. Figure 1 describes the panel recruitment process.

Enhancing response rate
Strategies to aid the inclusion and commitment from panel members will include the following: electing panel members who are willing to participate and have knowledge of the relevant topic; communicating the ongoing importance of each individual panel member's contribution to the research process and that each round is constructed entirely on their response to previous rounds; limiting the number of rounds to reduce panel fatigue; quick turnarounds in data collection to enhance enthusiasm and maintain commitment, and consideration of panel members work and holiday schedules.[23 26]

The Delphi online survey
The Delphi online survey will be formatted using Research Electronic Data Capture.[27] The online survey will list each
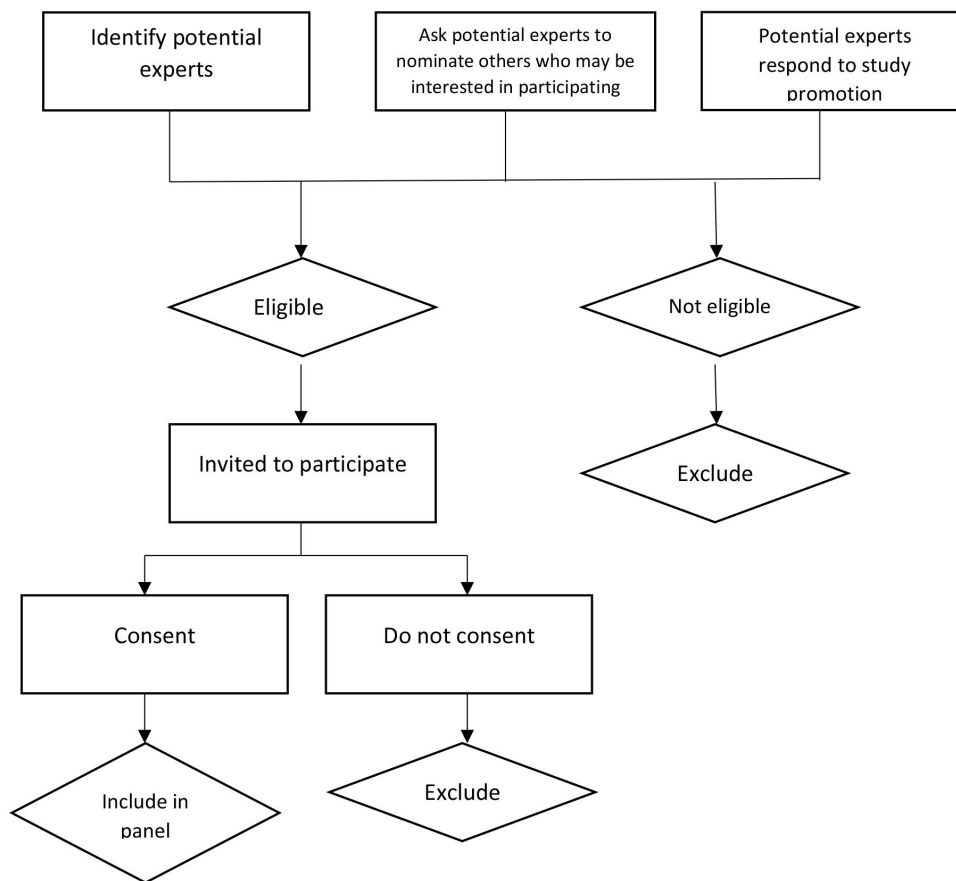
Figure 1 Expert panel recruitment process.

recommendation as written in The Guidelines. Each recommendation will be graded from high-to-low relevance using a five-point Likert scale in response to the question 'Is this recommendation relevant to the PCN in the provision of person-centred dementia care?' Suggestions for additional recommendations will not be sought as this study is limited to identifying those recommendations contained in the most recent Australian best-practice guidelines for dementia care that are relevant to the PCN.

The survey rounds
The round 1 survey will include all 109 recommendations and will take <60 min to complete with subsequent rounds taking less time to complete as the number of recommendations for consideration become fewer.

Following the initial invitation, panel members will be given 10 days to provide their consent to participate and 2 weeks to respond between each round. Two reminders will be sent, the first at 1 week after the round is sent with the second reminder sent 2–3 days prior to the due date of the round.

The Delphi process will run until consensus is met or for a maximum of three rounds as response exhaustion usually occurs within several rounds with 'busy' clinicians.[24]

Returning data
The responses from each round will be aggregated and fed back to the panel members anonymously in the next

round. Group feedback will list the recommendations to be included, recommendations to be re-rated and recommendations to be excluded. Each panel member will also be provided with their individual responses and asked to reconsider the recommendations for which consensus has not been reached. Figure 2 illustrates the process of progression through the rounds and returning data.

Consensus
This study will use 75% agreement on the rating of relevance of the recommendation to the role of the PCN for determining consensus. Consensus refers to a certain percentage of the vote falling within a prescribed range[23] or statistical analysis such as measures of central tendency mean and median and mode. In a systematic review on consensus in Delphi studies the median threshold, when specified, for determination of consensus was 75%.[28] Those recommendations which are not excluded by consensus will be deemed as relevant.

Data analysis
The SPSS Statistics 25[29] will be used for data analysis. A master code will be linked to each expert panel member. Each recommendation in The Guidelines will be a separate variable in SPSS. Frequencies run on entire dataset will provide the percentage of each overall response to each recommendation. The median will provide data on group opinion and the SD indicates level of agreement
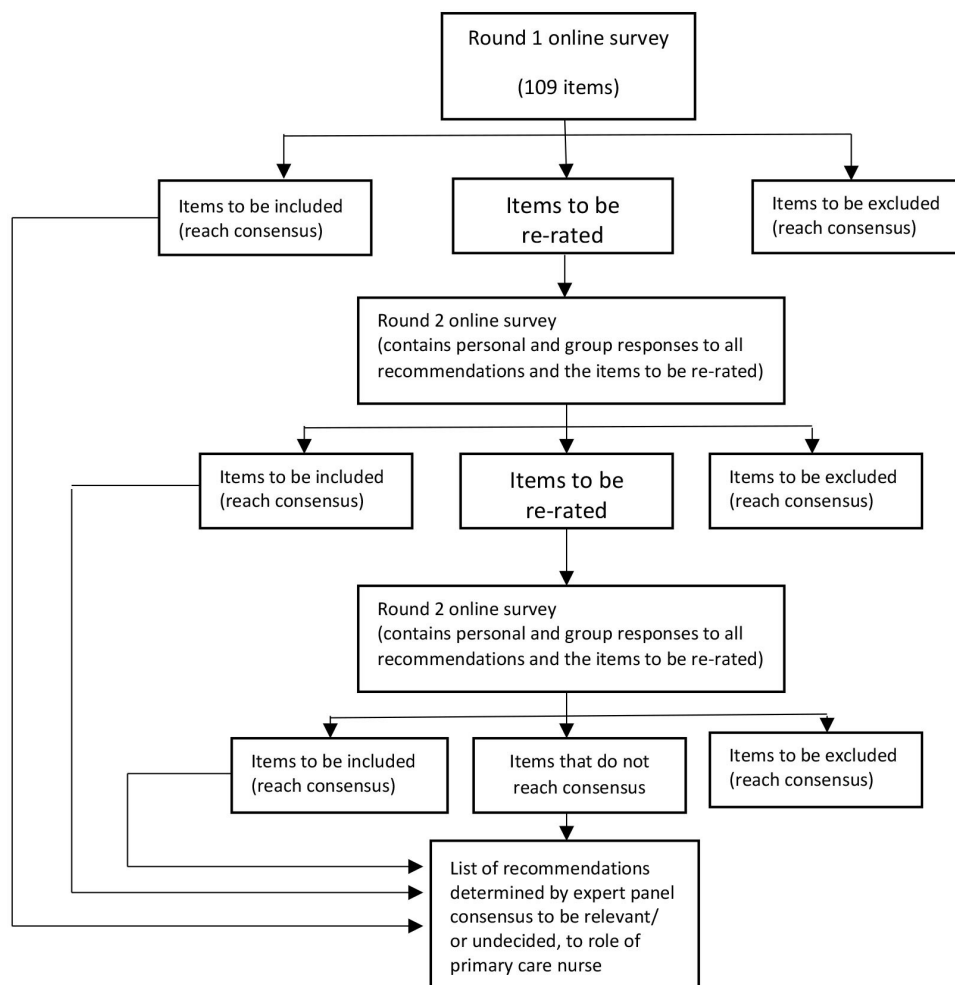
Figure 2 Progression through the rounds.

among the panel members. The mean will be used to rank the guidelines in order of relevance.

A descriptive analysis of the demographics of the expert panel will provide a profile overview.

Quality and reporting

This study will use quality indicators for reporting Delphi studies. The four quality indicators require a clear description of (1) the aim of the Delphi study including how it will address consensus, (2) participant inclusion and exclusion criteria, (3) the definition of consensus used and (4) the Delphi process with criteria for dropping items and determining when Delphi process to be stopped.[28]

Patient and public involvement

Development of this study protocol did not involve direct public participation; however, consumers of dementia care were involved in the development of the Clinical Practice Guidelines and Principles of Care for People with Dementia[20] which is central to this study.

DISCUSSION

This protocol describes the Delphi consensus technique that will be used to identify which of the 109 recommendations included in the 'Clinical Practice Guidelines and Principles of Care for People with Dementia' are agreed, by an expert panel, as relevant to the role of the PCN in the delivery of person-centred dementia care in the general practice setting.

The Delphi approach is appropriate as the research question does not lend itself to precise analytical techniques but can benefit from subjective judgements.[28] This study design will overcome the significant constraints to surveying a large sample of PCNs. Namely, achieving a response rate to allow generalisability of the findings could be difficult with 109 items and the clear irrelevance of many items to the practice of PCNs in general practice.

The expert panel will be comprised of primary care nursing key stakeholders, including researchers, clinicians and representatives of primary care nursing associations. The criteria used for an 'expert' in this study is based on French et al,[30] and is defined as an individual who has knowledge and experience about the subject of inquiry; is willing to express opinions about the subject of the inquiry and is able to express opinions about the subject of enquiry.

Validated quality indicators for Delphi studies are lacking,[24] therefore, in an attempt to mitigate this limitation, in this study we will use the Delphi methodologic criteria for reporting of Delphi studies proposed by Diamond *et al*.[28]

There are several expected limitations to using a Delphi method. Bias may result as selecting the experts cannot be random.[24] Those who do participate are the most likely to be interested and not be truly representative of the larger population.[24] However, content validity is increased by the use of participants who have knowledge and interest in the topic.[31] Validity maybe compromised due to panel members changing highly relevant views in the face of a different view from the main body of the panel.[32]

Keeney *et al* and Powell suggest that even when consensus exists, it does not indicate that an irrefutable fact has been achieved.[23 32] The primary impact of achieving consensus is building new knowledge in an area of uncertainty using expert opinion. The findings of the Delphi consensus method can be enhanced with further research.[32] Findings from this study will inform a qualitative interview study of Australian PCNs to determine which of the selected recommendations they perceive as applicable to their role in delivering person-centred dementia care and the feasibility of implementation in the general practice setting. Findings from this broader study will influence the development of an optimal primary care nursing model of care for people with dementia and support person(s) receiving care in the general practice setting.

ETHICS AND DISSEMINATION

This study has been approved by The University of Newcastle HREC (H-2019-0029).

Findings will be published in a peer-reviewed journal and presented at scientific conferences. The findings may also be presented to healthcare providers and consumers of dementia care in primary care settings via education forums, websites and social network services.

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