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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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Keywords:	Dementia < NEUROLOGY, PRIMARY CARE, Protocols & guidelines < HEALTH SERVICES ADMINISTRATION & MANAGEMENT

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7 undertaking a Delphi technique to identify the recommendations relevant to primary care
8 nurses in the delivery of person-centred dementia care
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ABSTRACT

Introduction

Better utilisation of the primary care nurse may improve recognition and management of dementia in General Practice. While 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 provide 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 multi-disciplinary guidelines are relevant to the primary care nurse in the delivery of person-centred dementia care.

Methods and analysis

A Delphi consensus online survey will be developed. Invited panel members will include Australian Practice Nurses, primary care nursing researchers and representatives of Australian primary care nursing peak bodies.

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.

Article Summary

Strengths and Limitations of this study

- The Delphi technique is useful to solicit expert opinion in areas of little knowledge
- Methodologic criteria for data collection and reporting are employed to optimise reliability of study findings
- Content validity is increased by use of participants with knowledge and interest in the topic

- Consensus does not mean the correct answer is found
- Results from this rigorous Delphi consensus study will be enhanced as the findings will inform a survey of Australian Practice Nurses asking which of the reduced recommendations they perceive as relevant to their role

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Introduction

Australian and international literature (1, 2) reveal a significant gap in the delivery of dementia care in the general practice setting. There are multiple and complex reasons for this gap, including a perception by the General Practitioner that nothing can be done and that support options are lacking (1-3). As people living with dementia have increased rates of other chronic illnesses (4-6) and the presence of dementia can undermine their ability to understand or follow agreed plans to manage these conditions (4, 7) barriers to the identification, diagnosis and management of dementia need to be addressed.

It is acknowledged that nurses are significant contributors in the delivery of primary care nationally and internationally (8-11). The primary care nurse is likely to have established a therapeutic relationship with people with cognitive decline through routine primary care treatment, chronic disease management, health assessment and health promotion activities. It follows that better utilising the primary care nurse has the potential to improve recognition and management of dementia in General Practice (3, 12, 13).

While dementia care guidelines and pathways of dementia care delivered by General Practitioners exist, there is little evidence on models of care or clinical practice guidelines that support the primary care nurse in dementia care provision (14).

Recently published Australian Clinical Practice Guidelines and Principles of Care for People with Dementia (15) (henceforth referred to as The Guidelines) provide 109 recommendations for the optimal diagnosis and management of dementia for health practitioners who work with people living with dementia and their support person(s) in community, residential and hospital settings in Australia. As guidelines that are specific to the end-user have been identified as being the most successful (16-18) this study will identify which recommendations in the Guidelines are most relevant to the role of the primary care nurse.

This paper describes a protocol for a Delphi technique that will identify the recommendations in the Guidelines that are perceived, by an expert panel, as relevant to the primary care nurse in the provision of evidence-based person-centred dementia care. Those recommendations which are not excluded by consensus will be deemed as relevant. Findings from this Delphi process will inform the development of a survey of Australian

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3 Practice Nurses to garner which of the guidelines they perceive as most relevant to their
4 role in delivering person-centred dementia care and how feasible is it to implement them in
5 the General Practice setting.
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10 **Methods and analysis**

11 **Aim**

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13 To identify which of the 109 recommendations contained in the Clinical Practice Guidelines
14 and Principles of Care for People with Dementia are relevant to the Practice Nurse in the
15 delivery of person-centred dementia care.
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24 **Design**

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26 A Delphi consensus technique engaging an expert panel to reduce the number of
27 recommendations to those applicable to primary care nurse provision of dementia care will
28 be used.
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35 **Sample**

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37 The expert panel is a purposive sample of people who have a minimum of one year's
38 experience in research or clinical practice in the area of primary care nursing. Panel
39 members invited to participate will include Australian Practice Nurses, primary care nursing
40 researchers and representatives of Australian primary care nursing peak bodies.
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46 This study will aim for 20 panel experts, assuming a 30% rejection rate, 26 experts will be
47 invited to participate in this study.
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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 on-line Delphi process, expected time commitment and research contact details. After consent is given to participate, Round 1 of the Delphi will be sent. Figure 1 describes the panel recruitment process.

Enhancing response rate

Strategies to aid the inclusion and commitment from panel members will include: 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 (19, 20).

The Delphi on-line survey

The Delphi online survey will be formatted using Research Electronic Data Capture (RedCap)(21). The on-line survey will list each 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 Primary Care Nurse in the provision of person-centred dementia care?"

The rounds

Round 1 will include all 109 recommendations and will take no more than 60 minutes to complete with subsequent Rounds taking less time to complete as the number of recommendations for consideration become fewer.

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3 Following the initial invitation panel members will be given 10 days to provide their consent
4 to participate and two weeks to respond between each Round. Two reminders will be sent,
5 the first at one week after the Round is sent with the second reminder sent two to three
6 days prior to the due date of the Round.
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11 The Delphi process will run until consensus is met or for a maximum of three rounds as
12 response exhaustion usually occurs within several rounds with 'busy' clinicians (22).
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16 17 18 Consensus

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20 This study will use 75% agreement on the rating of relevance of the recommendation to the
21 role of the Practice Nurse for determining consensus. Consensus refers to a certain
22 percentage of the vote falling within a prescribed range (20) or statistical analysis such as
23 measures of central tendency mean and median and mode. In a systematic review on
24 consensus in Delphi studies the median threshold, when specified, for determination of
25 consensus was 75% (23).
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35 Returning data

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37 The responses from each round will be aggregated and fed back to the panel members
38 anonymously in the next round. Group feedback will list the recommendations to be
39 included, recommendations to be re-rated and recommendations to be excluded. Each
40 panel member will also be provided with their individual responses and asked to reconsider
41 the recommendations for which consensus has not been reached. Figure 2 illustrates the
42 process of progression through the rounds and returning data.
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51 Data analysis

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53 The Statistical Package for Social Scientists (SPSS) (24) will be used for data analysis. A
54 master code will be linked to each expert panel member. Each recommendation in The
55 Guidelines will be a separate variable in SPSS. Frequencies run on entire dataset will
56 provide the percentage of each overall response to each recommendation. The median will
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3 provide data on group opinion and the standard deviation indicates level of agreement
4 amongst the panel members. The mean will be used to rank the guidelines in order of
5 relevance.
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9 A descriptive analysis of the demographics of the expert panel will provide a profile
10 overview.
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13 14 15 16 Quality and reporting

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18 This study will use quality indicators for reporting Delphi studies. The four quality indicators
19 require a clear description of (1) the aim of the Delphi study including how it will address
20 consensus (2) participant inclusion and exclusion criteria (3) the definition of consensus
21 used, and (4) the Delphi process with criteria for dropping items and determining when
22 Delphi process to be stopped (23).
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31 Quasi-anonymity

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33 Participants will be anonymous to each other but not to the researcher. Panel members will
34 be assured all information will be confidential and comply with the University of Newcastle
35 research data security policies.
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40 At the conclusion of the process, participants who have responded in each round will be
41 offered the choice to remain anonymous, or receive acknowledgement in the publication
42 for their participation.
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48 Ethics and dissemination

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50 This study has been approved by The University of Newcastle HREC (H-2019-0029).
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53 Findings will be published in a peer-reviewed journal and presented at scientific
54 conferences. The findings may also be presented to healthcare providers and consumers of
55 dementia care in primary care settings via education forums, websites and social network
56 services.
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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 (15) which is central to this study.

Discussion

This protocol paper describes the Delphi consensus technique that will be utilised 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 Practice Nurse in the delivery of person-centred dementia care.

The Delphi approach is appropriate as the research question does not lend itself to precise analytical techniques but can benefit from subjective judgements (23). This study design will overcome the significant constraints to surveying a large sample of primary care nurses. 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 primary care nurses in General Practice.

The expert panel will be comprised of primary care nursing key stakeholders. The criteria used for an 'expert' in this study is based on French et al., (25) 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 are able to express opinions about the subject of enquiry.

Validated quality indicators for Delphi studies are lacking (22), 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. (23)

There are several expected limitations to using a Delphi method. Bias may result as selecting the experts cannot be random (20). Those who do participate are the most likely

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3 to be interested and not be truly representative of the larger population (22). However,
4 content validity is increased by the use of participants who have knowledge and interest in
5 the topic (26). Validity maybe compromised due to panel members changing highly relevant
6 views in the face of a different view from the main body of the panel (20).
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11 Keeney et al., (20) suggest that even when consensus exists, it does not indicate that the
12 correct answer has been derived, and further research will often be required to enhance the
13 findings of a Delphi study (27).
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17 Findings from the study described in this protocol paper will inform a survey of Australian
18 Practice Nurses to determine which of the selected guidelines they perceive as relevant to
19 their role in delivering person-centred dementia care and the feasibility of implementation
20 in the General Practice setting. Findings from this broader survey will influence the
21 development of an optimal primary care nursing model of care for people with dementia
22 and support person(s) receiving care in the general practice setting.
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31 **Declarations**

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33 Ethics approval and consent to participate

34 This study has been approved by The University of Newcastle HREC (H-2019-0029).
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39 Consent for publication

40 Not applicable
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44 Availability of data and materials

45 Not applicable
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50 Competing interests

51 The authors declared no conflicts of interest.
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57 or not-for-profit sectors
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Author contributions

CG conceived the study. CG, DG, DP and MY contributed to the study design. CG and DG drafted the manuscript and MY and DP provided critical commentary on subsequent versions of the manuscript. All authors have read and approved the final version.

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Figure 1 – Expert panel recruitment process

Figure 2 – Progression through the rounds

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Figure 1 Expert panel recruitment process

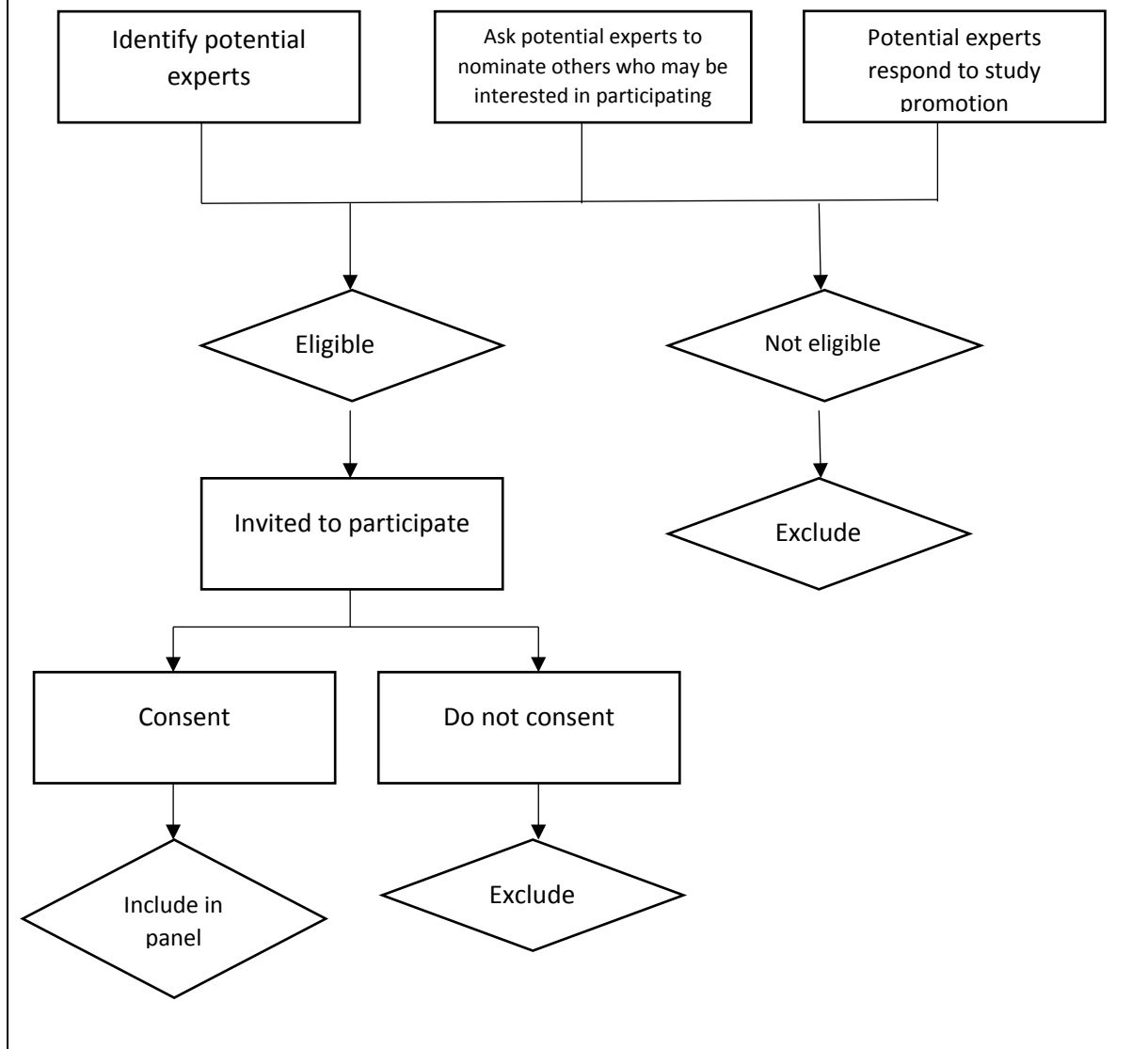
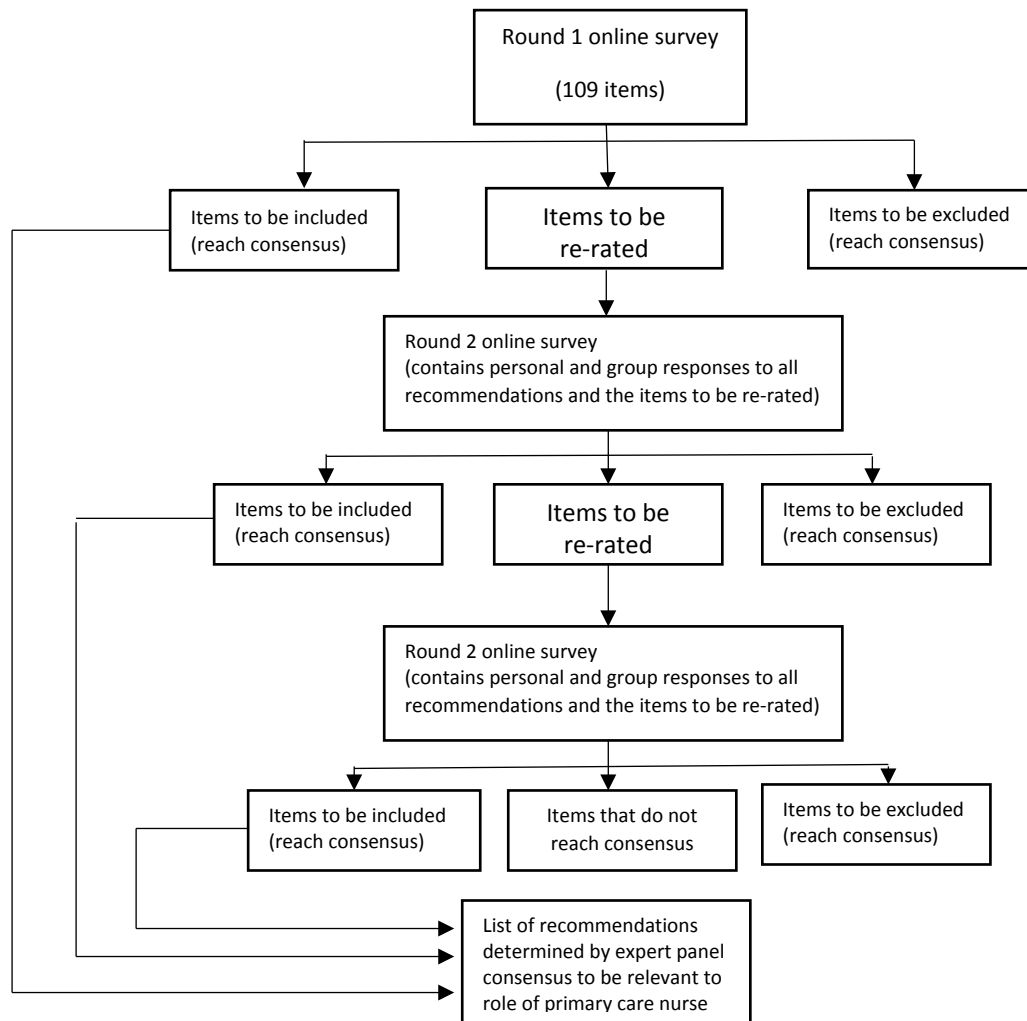


Figure 2. Progression through the rounds



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Primary Subject Heading:	General practice / Family practice
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ABSTRACT

Introduction

Nationally and internationally it is well recognised that dementia is poorly recognised and sub-optimally 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. While 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' provide 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 multi-disciplinary 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 health care.

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.

Article Summary

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 sub-optimally 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 (PCN) 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 PCN's 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 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) While 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) provide 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

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3 and barriers and enablers to the PCN implementation of these recommendations identified.
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5 This paper describes a protocol for a Delphi technique that will identify the
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7 recommendations in The Guidelines that are perceived, by a panel with expertise in primary
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9 care nursing, as relevant to the PCN in the provision of evidence-based person-centred
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11 dementia care.
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14 Findings from this Delphi process will inform the development of a future qualitative
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16 interview study with Australian PCNs to critically review the selected recommendations for
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18 delivering person centred dementia care and identify barriers and enablers to their
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20 implementation in the General Practice setting.
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23 This study serves as an important first step to develop best-practice guidelines for the
24
25 provision of dementia care in General Practice, specific to the PCN role, and that also
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27 incorporates information on their implementation.
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30 **Methods and analysis**

31 **Aim**

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33 To identify which of the 109 recommendations contained in the 'Clinical Practice Guidelines
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35 and Principles of Care for People with Dementia' are relevant to the Primary Care Nurse in
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37 the delivery of person-centred dementia care within General Practice.
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44 **Design**

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46 A Delphi consensus technique⁽²³⁾ engaging an expert panel to reduce the number of
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48 recommendations to those applicable to primary care nurse provision of dementia care will
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50 be used.
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54 **Sample**

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56 The expert panel is a purposive sample of people who have a minimum of one year's
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58 experience in research or clinical practice in the area of primary care nursing. Panel
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3 members invited to participate will include Australian Practice Nurses, primary care nursing
4 researchers and representatives of the Australian Primary Health Care Nurses Association.
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7 There is little agreement about the optimal size of the expert panel for a Delphi study(23)
8 and as described in Keeney et al(24) this decision is often based on funding, logistics of data
9 handling and inclusion criteria. Jorm describes stability in findings with panels of around 20
10 or more members.(25) This study will aim for 20 panel experts, assuming a 30% rejection
11 rate, 27 experts will be invited to participate in this study.
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17 Participants will be anonymous to each other but not to the researcher. Panel members will
18 be assured all information will be confidential and comply with the University of Newcastle
19 research data security policies.
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24 At the conclusion of the process, participants who have responded in each round will be
25 offered the choice to remain anonymous, or receive acknowledgement in the publication
26 for their participation.
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31 Recruitment

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33 Delphi participants will be invited to participate via email. The invitation to participate will
34 include a personalised letter including a description of the study, its importance and the
35 valuable contribution the panel member can make, the on-line Delphi process, expected
36 time commitment and research contact details and a consent document. Written consent
37 will be obtained by return email. After consent is provided, the first survey, Round 1, of the
38 Delphi will be sent to participants. Figure 1 describes the panel recruitment process.
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46 Figure 1 Expert panel recruitment process
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50 Enhancing response rate

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52 Strategies to aid the inclusion and commitment from panel members will include: electing
53 panel members who are willing to participate and have knowledge of the relevant topic;
54 communicating the ongoing importance of each individual panel member's contribution to
55 the research process and that each round is constructed entirely on their response to
56 previous rounds; limiting the number of rounds to reduce panel fatigue; quick turnarounds
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3 in data collection to enhance enthusiasm and maintain commitment, and, consideration of
4 panel members work and holiday schedules.(23, 26)
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10 The Delphi on-line survey

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12 The Delphi online survey will be formatted using Research Electronic Data Capture
13 (RedCap).(27) The on-line survey will list each recommendation as written in The Guidelines.
14 Each recommendation will be graded from high to low relevance using a five-point Likert
15 scale in response to the question “Is this recommendation relevant to the Primary Care
16 Nurse in the provision of person-centred dementia care?” Suggestions for additional
17 recommendations will not be sought as this study is limited to identifying those
18 recommendations contained in the most recent Australian best-practice guidelines for
19 dementia care that are relevant to the PCN.
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30 The Survey Rounds

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32 The Round 1 survey will include all 109 recommendations and will take no more than 60
33 minutes to complete with subsequent Rounds taking less time to complete as the number of
34 recommendations for consideration become fewer.
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39 Following the initial invitation panel members will be given 10 days to provide their consent
40 to participate and two weeks to respond between each Round. Two reminders will be sent,
41 the first at one week after the Round is sent with the second reminder sent two to three
42 days prior to the due date of the Round.
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47 The Delphi process will run until consensus is met or for a maximum of three rounds as
48 response exhaustion usually occurs within several rounds with ‘busy’ clinicians.(24)
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51 Returning data

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53 The responses from each round will be aggregated and fed back to the panel members
54 anonymously in the next round. Group feedback will list the recommendations to be
55 included, recommendations to be re-rated and recommendations to be excluded. Each
56 panel member will also be provided with their individual responses and asked to reconsider
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3 the recommendations for which consensus has not been reached. Figure 2 illustrates the
4 process of progression through the rounds and returning data.
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7 Figure 2. Progression through the rounds
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10 11 12 Consensus

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

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31 The Statistical Package for Social Scientists (SPSS)(29) will be used for data analysis. A
32 master code will be linked to each expert panel member. Each recommendation in The
33 Guidelines will be a separate variable in SPSS. Frequencies run on entire dataset will
34 provide the percentage of each overall response to each recommendation. The median will
35 provide data on group opinion and the standard deviation indicates level of agreement
36 amongst the panel members. The mean will be used to rank the guidelines in order of
37 relevance.
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44 A descriptive analysis of the demographics of the expert panel will provide a profile
45 overview.
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51 Quality and reporting

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

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12 Development of this study protocol did not involve direct public participation, however,
13 consumers of dementia care were involved in the development of the Clinical Practice
14 Guidelines and Principles of Care for People with Dementia(20) which is central to this
15 study.
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23 Discussion

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25 This protocol paper describes the Delphi consensus technique that will be utilised to identify
26 which of the 109 recommendations included in the 'Clinical Practice Guidelines and
27 Principles of Care for People with Dementia' are agreed, by an expert panel, as relevant to
28 the role of the PCN in the delivery of person-centred dementia care in the General Practice
29 setting.
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35 The Delphi approach is appropriate as the research question does not lend itself to precise
36 analytical techniques but can benefit from subjective judgements.(28) This study design will
37 overcome the significant constraints to surveying a large sample of primary care nurses.
38 Namely, achieving a response rate to allow generalisability of the findings could be difficult
39 with 109 items and the clear irrelevance of many items to the practice of PCNs in General
40 Practice.
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47 The expert panel will be comprised of primary care nursing key stakeholders, including
48 researchers, clinicians and representatives of primary care nursing associations. The criteria
49 used for an 'expert' in this study is based on French et al., and is defined as an individual
50 who has knowledge and experience about the subject of inquiry; is willing to express
51 opinions about the subject of the inquiry and is able to express opinions about the subject
52 of enquiry(30).
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3 Validated quality indicators for Delphi studies are lacking(24), therefore, in an attempt to
4 mitigate this limitation, in this study we will use the Delphi methodologic criteria for
5 reporting of Delphi studies proposed by Diamond et al(28).
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9 There are several expected limitations to using a Delphi method. Bias may result as
10 selecting the experts cannot be random(24). Those who do participate are the most likely to
11 be interested and not be truly representative of the larger population.(24) However,
12 content validity is increased by the use of participants who have knowledge and interest in
13 the topic(31). Validity maybe compromised due to panel members changing highly relevant
14 views in the face of a different view from the main body of the panel.(32)
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21 Keeney et al., and Powell suggest that even when consensus exists, it does not indicate that
22 an irrefutable fact has been achieved.(23, 32) The primary impact of achieving consensus is
23 building new knowledge in an area of uncertainty using expert opinion. The findings of the
24 Delphi consensus method can be enhanced with further research.(32) Findings from this
25 study will inform a qualitative interview study of Australian Primary Care Nurses to
26 determine which of the selected recommendations they perceive as applicable to their role
27 in delivering person-centred dementia care and the feasibility of implementation in the
28 General Practice setting. Findings from this broader study will influence the development of
29 an optimal primary care nursing model of care for people with dementia and support
30 person(s) receiving care in the general practice setting.
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42 Ethics and dissemination

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44 This study has been approved by The University of Newcastle HREC (H-2019-0029).
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47 Findings will be published in a peer-reviewed journal and presented at scientific
48 conferences. The findings may also be presented to healthcare providers and consumers of
49 dementia care in primary care settings via education forums, websites and social network
50 services.
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56 **Declarations**

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3 Consent for publication

4
5 Not applicable
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9 Availability of data and materials

10
11 Not applicable
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15 Competing interests

16 The authors declared no conflicts of interest.
17
18

19
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23
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27 Author contributions

28 CG conceived the study. CG, DG, DP and MY contributed to the study design. CG and DG
29 drafted the manuscript and MY and DP provided critical commentary on subsequent
30 versions of the manuscript. All authors have read and approved the final version.
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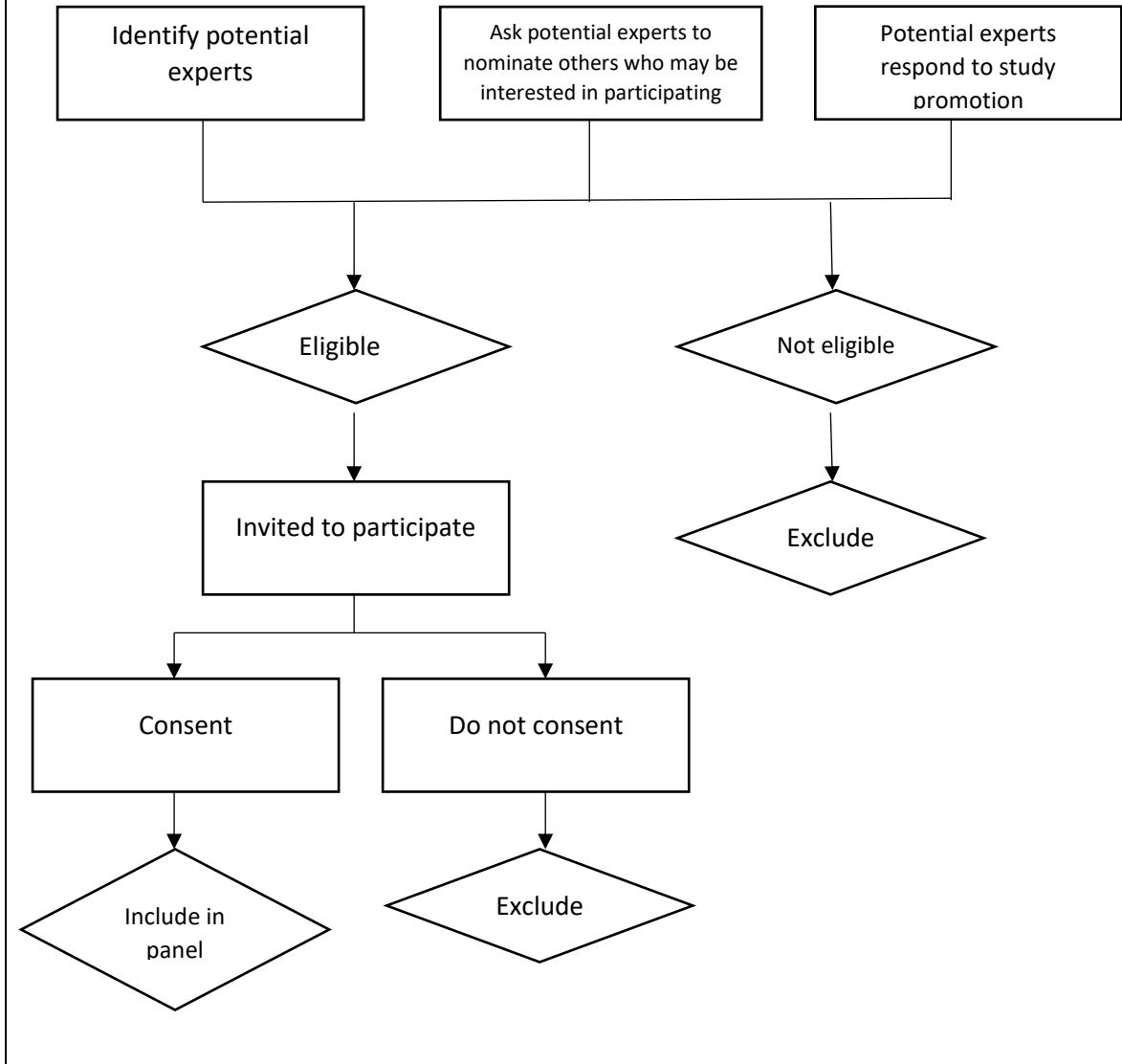
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Figure 1 Expert panel recruitment process



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