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SHORT COMMUNICATION

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Partnering with a stakeholder steering group to co-design the PRIME deprescribing conversation tool: Reflections and recommendations

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1 | INTRODUCTION

Empowering people living with dementia to be active partners in conversations about their medicines is imperative. Consumers, people living with dementia and their carers, have reported limited confidence to start conversations with their healthcare professional (HCP) about deprescribing, reducing or stopping, their medicines.[1] Co-design is the process of co-producing an output by engaging end users throughout the entire project.[2] To co-design impactful, usable, healthcare tools with real-world relevance, key stakeholders should be engaged in the research, not just as participants but as true partners. To our knowledge, deprescribing tools that are co-designed with consumers to meet their individual preferences and beliefs, are currently unavailable in the public domain.[3]

To address this gap, we established an 11-member stakeholder group (SG) consisting of consumers and HCPs from heterogenous backgrounds in Australia and the United States of America (USA) and worked alongside this group to co-design the PRIME tool. The PRIME tool is a conversation-starter, communication tool that stands for "**PR**eparing people living with dementia and their carers to **I**nitiate deprescribing conversations about **Me**dications." The PRIME tool's design and utility is based on the implementation science theory of "nudging."[4] Consumers using the PRIME tool in practice will provide subtle cognitive cues (i.e., nudges) to their HCP to review the ongoing need of their medicines during a shared decision-making consultation. In this short communication, we focus on reflecting on our partnership with our SG to support our co-design process. Specifically, we aim to:

1. Describe our steps to establish a SG.
2. Present reflections about the process of co-designing the PRIME tool.
3. Outline learnings from challenges related to SG engagement and pragmatic recommendations to address these challenges.

We hope this knowledge will accelerate and inform the uptake of co-design methodologies amongst researchers to co-develop impactful deprescribing research resources alongside consumer groups.

2 | METHODS

To achieve our aim of co-designing the PRIME tool, we conducted steps summarised in Table 1 and described below:

Step 1. Form stakeholder group (SG)

Our project is a collaboration between a research team and a SG from Australia and the USA. Our research team consists of three clinician-researchers who are pharmacists and a health literacy expert. Guided by the framework for stakeholder engagement in Comparative Effectiveness Research,[5] we established a diverse SG from Australia and USA. Our SG includes two people living with dementia, four carers, three geriatricians, a nurse practitioner and a social worker. Altogether, our research team's expertise and our HCP SG members enabled us to capture an interdisciplinary perspective of using the PRIME tool in practice.

We used the Comparative Effectiveness Research framework and leaned on our previous co-design research experience[6] to invite our SG. Specifically, we employed two approaches:

1. We leveraged existing relationships with local hospital networks, and personal contacts to identify suitable HCPs and consumers.
2. We approached a consumer representative liaison at Dementia Australia, a peak consumer organisation in Australia, to identify and build new relationships with consumers. This liaison advertised our project on Dementia Australia's website to consumers. The principal investigator met individually with potential SG members who expressed interest in our research. Whilst we are unable to form a SG representative of all consumers and HCPs internationally, we purposively chose our final SG members to capture the views of diverse people (e.g., from various geographical states, mixture of people living with dementia and carers, people who have different types of dementia) to diversify the user experience of our tool.

Step 2. Conduct SG meetings

To date, we have held six stakeholder steering group meetings and plan on holding two further meetings (Table 1).

Step 3. Co-design the tool

As a research team, we collated a list of potential key elements to include in the PRIME tool based on existing literature.[1] During Meeting #2, SG members broke off into smaller groups using Zoom's break-out room function to discuss the key elements. Each group was assigned a research team member to facilitate the discussion. The SG members then discussed their feedback as a whole group, which we used to create the first draft of the PRIME tool. During Meeting #3, SG members

TABLE 1 Steps to establish the stakeholder steering group (SG) and co-design the PRIME tool.

Step 1: Form SG (August 2021–October 2021)
We employed different approaches to establish our 11-member international SG including leveraging our networks with established consumer advocacy groups, personal contacts and relationships with health providers.
Step 2: Conduct SG meetings (October 2021–present)
We conducted the following meetings to date: 1. Introductions and familiarisation to the project 2. Reviewing key elements (e.g., sections) of the PRIME tool 3. Further reviewing and finalising key elements of the PRIME tool 4. Finalising the discussion guide to interview consumers and healthcare professionals about the tool's usability and comprehensibility 5. Discussing preliminary findings from interviews; iterative changes to the PRIME tool 6. Discussing revisions to the PRIME tool after feedback incorporation and pilot study planning Future meetings include: 7. Discussing preliminary findings from the pilot study (e.g., outcomes of interest; updates on recruitment) 8. Discuss final revisions to the PRIME tool based on the pilot study
Step 3: Co-design the tool (October 2021–present)
We gathered input from SG members to select key elements to include and refined them to create a PRIME tool draft ready for further testing. Examples of key feedback that we incorporated included: • Providing specific examples with infographics to describe concepts such as medicine-related harm (e.g., listing falls, hospitalisations). • Mentioning "goals of care" when describing the process of reviewing medicines • Describing clinical situations when deprescribing a medicine could be considered (e.g., the medicine is no longer beneficial) • Including a text box as a reminder to review medicine lists and medicines they purchase over-the-counter • Perfecting key phrases included for consumers to start conversations about medicines Cultural and language differences were noted between the US and Australia. For example, in Australia the term "carers" is used and in the US "caregivers" is used. Additionally, the scope of practice of specific HCPs (e.g., nurse practitioners) may differ depending on the country and the healthcare setting. We are considering these differences as we finalise the PRIME tool. Overall, the discussion between SG members was rich. Some members had opposing views which created a range of possible options. For example, there was discussion about whether to create tailored versions of the PRIME tool for subgroups in the future (e.g., people living with dementia and carers separately; various healthcare settings).

provided feedback on wording and formatting of the tool. Meeting #4 focused on reviewing a guide to test the tool's usability and comprehensibility via interviews and focus groups with people living with dementia, carers and HCPs. Meetings #5 and #6 discussed interview findings and further revisions to the tool. We also elicited feedback from our SG to co-design the design of the pilot study in Meeting #6. Our pilot study aims to test the feasibility of implementing the PRIME tool in practice. The methods and findings from our alpha-testing (interviews, focus groups) and beta-testing (pilot study) will be published separately.

2.1 | Results: Reflections, learnings and recommendations

Overall, SG members were engaged and enjoyed the co-design process of the PRIME tool. For example, one SG member stated, "*It has been an absolute delight being a part of this design consultative group*." The SG members also reported that they believed the tool would address an unmet need for resources to encourage and enable consumers to engage in medicine reviews. There was consensus amongst SG members to include three sections: (a) **Background**: information about reviewing medicines and medicine-related harm; (b) **Self-reflection**: questions from the Revised Patients' Attitude Towards Deprescribing (rPATD) questionnaire for people with mild cognitive impairment and mild-to-moderate dementia (rPATDcog),[7] which invites consumers to answer how willing they are to have one or more of their medicines deprescribed if recommended by a doctor; (c) **Call-to-action**: example phrases to empower consumers to start deprescribing conversations.

To improve the content of the tool, our SG put forward several suggestions (Table 1), which we implemented to improve the PRIME tool's usability in practice.

Whilst we successfully engaged our SG to co-design the PRIME tool, engaging SG members in a true co-design process can be challenging. Therefore, we outline our unique learnings from challenges we experienced during the co-design process along with potential recommendations:

1. **Identifying meeting times**: People living with dementia may have limited times in the day when they have more energy (e.g., in the morning or the middle of the day).[8] These times often clash with HCPs' schedules who may be busiest at those times. Given this, identifying convenient times to meet was challenging.
   Recommendation(s): We recommend gathering individuals' preferences to meet using a Doodle poll. We offered times that are early in the morning to accommodate both consumers' and HCPs' preferences. If members were unavailable to attend the

meeting, we provided them the opportunity to meet separately at a different time.

2. **Incorporating cultural and language differences**: We noticed cultural and language preference differences (Table 1).
   Recommendation(s): We recommend taking full advantage of incorporating the SG's diverse and rich feedback by using a framework for guidance. To achieve this, we used the Comparative Effectiveness Framework to ensure the tool's relevance to an international audience.
3. **Forging connections between a new group of people**: Given that our SG had a mixture of HCPs and consumers, the potential for a "power imbalance" to exist was present.
   Recommendation(s): We recommend working as a research team to facilitate communication between the group to hear and include every member's voice. We also recommend orientating the members in the first meeting by facilitating introductions of SG members, explaining co-design concepts, familiarising members with the project and encouraging their feedback. We also recommend using break-out rooms with a small number of people[3–6] to allow people to get comfortable with other members. These recommendations along with maintaining values such as respect and transparency translated into members' comfort to speak up even within the larger group.
4. **Engaging the SG**: Maintaining interest and engagement of the SG over an extended period (1–2 years) of research is challenging.
   Recommendation(s): We recommend transparently providing SG members with an upfront timeline. We also recommend informing people, as soon as feasibly possible, when meetings would be. We aimed to have one meeting every 3–4 months to maintain engagement. We also recommend regular correspondence with SG members via email to provide updates and communicate potential delays in the progress of research plans.
5. **Considering SG members' capacity to be involved**: Overtime, SG members might experience changes to their health or caring responsibilities, which impacts their involvement.
   Recommendation(s): We recommend employing a flexible approach by providing them the opportunity to end their involvement at any time. We also recommend collecting their feedback via practical avenues, such as e-mail correspondence.
6. **Fairly remunerating SG members**: Limited guidance exists for researchers to achieve fair remuneration.
   Recommendation(s): We recommend checking local guidance regarding consumer renumeration. We were guided by South Australia health consumer guidelines and chose to remunerate both consumers and HCPs equally.[9] We incorporated SG payment into our grant's budget to ensure the project's feasibility.
7. **Determining the size of the SG and managing the SG's diversity**: It can be challenging to determine the ideal size of a SG, and appropriate diversity between SG members, for maximal knowledge exchange.
   Recommendation(s): We recommend leaning on similar co-design research to guide the size of your SG for effective engagement.[6,10] Taking this into consideration, we aimed to invite up to 12 members in total, the majority of whom are people with lived experiences with dementia and some HCPs. To bridge members' variability of health information and experiences, we recommend developing and using consumer-facing materials, such as PowerPoint presentations, to guide discussion. These strategies along with our SG members being respectful of other members' opinions, even when they differed from their own, enabled us to facilitate a rich discussion.
8. **Deciding the number of SG members and meetings needed:** To ensure there is ample opportunity for all members to provide feedback, an adequate number of SG meetings is needed. This decision needs to be balanced against budget considerations and avoiding overburdening the SG.
   Recommendation(s): Based on previous similar research, we recommend holding between six to eight meetings whilst taking into consideration meeting research goals and budget targets.

2.2 | Considerations and summary

Previous research has shown that consumer engagement through the provision of health information can be a successful deprescribing strategy.[11] Similarly, partnering with our SG enabled us to successfully co-design a deprescribing communication tool for people living with dementia and their carers. We will continue to work alongside our SG to complete our research program's next steps. These include feasibility and pilot testing the implementation of the PRIME tool in clinical practice followed by the pragmaticly embedding the PRIME tool in various healthcare settings. Once ready for use, we will widely disseminate the PRIME tool, in collaboration with partner organisations, so that it may reach all end-users who may benefit the most from its use.

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CONFLICT OF INTEREST STATEMENT

Dr Reeve receives honoraria for co-authoring a chapter on deprescribing in UpToDate and from the Society of Hospital Pharmacists of Australia (leading workshops on deprescribing).

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