**Partnering with a stakeholder steering group to co-design the PRIME deprescribing conversation tool**

**Short running title:** Partnering with a group to codesign a deprescribing tool

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**Keywords:** Codesign; deprescribing; dementia; health information; consumer engagement

**Introduction**

Empowering people living with dementia and their carers as active partners in conversations about medicines is imperative. People living with dementia and their carers have reported limited confidence to start conversations about deprescribing their medicines with clinicians (1). Deprescribing tools codeveloped alongside consumer groups are limited and such tools are especially valuable if they incorporate consumers’ individual preferences and beliefs. To address this gap, we are undertaking a research program funded by the US Deprescribing Network (National Institute of Ageing:1R24AG064025) to co-design a conversational tool called the PRIME (**PR**eparing people living with dementia and their caregivers to **I**nitiate deprescribing conversations about **ME**dications) tool.

Co-design is the process of co-producing an output by engaging end users throughout the entire project (2). To create impactful healthcare tools with real-world relevance, key stakeholders such as consumers and healthcare professionals (HCP), should be involved, not just as participants, but as true partners to increase the tools’ acceptability and accessibility. Carefully engaging consumers to improve the uptake of deprescribing in practice is important considering consumers’ heterogenous lived experiences. The National Health and Medical Research Council in Australia highlight various ways to involve consumers (3); one of which includes establishing a stakeholder steering group (SG). We implemented this strategy to co-design the PRIME tool by establishing an international, 11-member SG with consumers and HCPs from Australia and the United States of America (USA). In this short communication, we aim to:

1. Describe our steps to establish a SG.
2. Present direct learnings from co-designing the PRIME tool.
3. Outline potential challenges and solutions related to SG engagement.

Altogether, we hope this knowledge will accelerate and inform the uptake of co-design methodologies amongst researchers to co-develop impactful research outputs alongside consumers.

**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 SG**

This project is a collaboration between researchers from Australia and the USA. Guided by the framework for stakeholder engagement in Comparative Effectiveness Research(4), we established a diverse SG from Australia and USA with 6 consumers (two people living with dementia and four carers), two geriatricians, a nurse practitioner, a social worker, and a public health physician. We used this framework and leaned on our previous co-design research experience (5) to maximize knowledge exchange.

To invite and engage SG members, we employed two approaches. The first approach involved leveraging existing relationships with local hospital networks, and personal contacts. The principal investigator sent potential SG members an email with a lay summary describing the research project and the role of SG members.

The second approach involved culminating new relationships with consumer representatives interested in participating in research. We approached a consumer representative liaison at Dementia Australia, a leading peak consumer organisation in Australia. This liaison advertised our project on Dementia Australia’s website with instructions for consumers to express their interest in participating. Twelve consumers were interested in joining our SG and contacted us. The principal investigator organised a teleconference call with each potential SG member to confirm their interest. We 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**

Meetings were held via Zoom given the geographically diverse nature of the SG. To date, we have held six stakeholder steering group meetings and plan on holding two further meetings (Table 1).

**Step 3: Codesign the tool**

Based on existing literature and input from the research team (1), the principal investigator collated a list of potential key elements to include in the PRIME tool. The PRIME tool was co-designed based on the concept of “nudges” which are subtle cognitive cues to frame information in a way that can change behaviour (6). These were grouped into three sections: a) Background: information about reviewing medicines and medicine-related harm b) Self-reflection: Questions from the rPATDcog (7) inviting consumers to answer how willing they are to have have one or more of their medicines deprescribed c) Call-to-action: Example phrases to empower consumers to start deprescribing conversations.

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. This information was used by the principal investigator to create the first draft of the PRIME tool. During meeting #3, SG members provided feedback on the tool’s wording and formatting. Meeting #4 then focused on reviewing the interview guide for testing the tool’s usability and comprehensibility via interviews with people living with dementia, carers, and HCPs.

**Results**

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 a review of their medicines.

There was consensus amongst SG members to include three sections (background; self-reflection; call-to-action). Suggestions by the SG to improve the content of the tool are summarised in **Table 1**. These were taken into consideration to refine the PRIME tool so that it was ready for further testing. Engaging SG members in the co-design process can be challenging. Below, we outline some potential challenges we experienced and possible solutions:

* Meetings’ timings: Given our SG members lived in different time zones, and variability between HCPs’ and consumers’ availability, identifying convenient times to meet was challenging. We gathered the preferred time to meet using a doodle poll. If members were unavailable to attend the meeting, we provided them the opportunity to meet separately at a different time.
* Cultural and language differences: Whilst we noticed cultural and language preference differences, we took full advantage of incorporating the diverse and rich feedback we received (Table 1). This ensured the tool’s relevance to an international audience.
* 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. As a research team, we facilitated communication between the group aiming to hear and include every member’s voice. To achieve this, during the first meeting, the principal investigator facilitated introductions, explained codesign concepts, familiarised SG members with the project, and encouraged their feedback. We also used small break-out rooms to allow people to get comfortable with the other members. This along with maintaining values such as respect and transparency translated into members’ comfort to speak up even within the larger group.
* Engaging the group: Maintaining interest and engagement of the SG over an extended period (1-2 years) of research is challenging. To address this, we transparently provided a timeline up front. As soon as feasibly possible, we informed people when meetings would be. We aimed to have one meeting every 3-4 months to maintain engagement. In between meetings, the principal investigator corresponded with SG members via email to provide updates.
* Considering SG members’ capacity to be involved: Overtime, SG members had changes to their health or caring responsibilities which impacted their involvement. To address this, we employed a flexible approach where we collected these members’ feedback via email and gave them the opportunity to end their involvement at any time.
* Research team’s capacity to fairly remunerate SG members: We incorporated SG payment into the grant’s budget to ensure the project’s feasibility. Limited guidance exists for researchers to achieve fair remuneration. We were guided by South Australia health consumer guidelines and chose to remunerate both consumers and HCPs equally (8).
* Managing the SG members’ diversity: Taking into consideration the members’ variability of health information and experiences, we developed materials, such as power point presentations, to facilitate discussion. Our SG members were very respectful of other members’ opinions, even when they differed from their own.
* Deciding number of meetings needed: An adequate number of meetings is needed to ensure that ample opportunity is provided to members to provide feedback. Determining this was difficult and had to be balanced against budget considerations and avoiding overburdening our SG.

**Discussion**

To date, consumer engagement through health information such as the PRIME tool has proven to be a successful deprescribing strategy (9). Given that “nudges” are more likely to be successful when they are embedded into the clinical workflow, our program’s next steps include pilot testing the implementation of the PRIME tool in outpatient geriatric clinics and aged care.

**Considerations and summary**

Despite the challenges, partnering with our SG to codesign a usable deprescribing conversation tool was an invaluable experience. In future steps, we will draw from our SG’s experience as dementia research advocates to involve people living with dementia and carers ethically and genuinely during the dissemination of the PRIME tool and related research findings.

**Table 1:** Steps to establish the stakeholder steering group (SG) and co-design the PRIME tool

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| **Step 1: Form SG (Aug 2021-Oct 2021)** |
| We employed different approaches to establish our 11-member international SG |
| **Step 2: Conduct SG meetings (Oct 2021-present)** |
| We conducted the following meetings to date:   1. Introductions and familiarization to the project 2. Reviewing key elements for the PRIME tool 3. Reviewing key elements for the PRIME tool 4. Finalizing the discussion guide to interview consumers and HCPs 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   We also plan to conduct at least two other meetings which include:   1. Discussing preliminary findings from the pilot study (e.g., outcomes of interest; updates on recruitment) 2. Discuss final revisions to the PRIME tool based on the pilot study |
| **Step 3: Co-design the tool (Oct 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 USA and Australia. For example, in Australia the term “carers” is used. In the USA, the term “caregivers” is used instead. We are considering language and cultural differences as we finalise the PRIME tool.  Overall, the discussion between SG members was rich. Some 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; different healthcare settings). |

**Acknowledgements:**

We would like to acknowledge Dementia Australia and our stakeholder steering group members who supported this research.

Funding: Dr Ailabouni is supported by the US Deprescribing Network, National Institute of Ageing (NIA: ). Dr Reeve is supported by an NHMRC Investigator Grant (GNT1195460) and grants from the US National Institutes of Health (R33-AG057289 and R01-AG070047-01).

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

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