Stakeholder engagement in participatory action research to codesign a core outcome set for routine care provided to people living with dementia.

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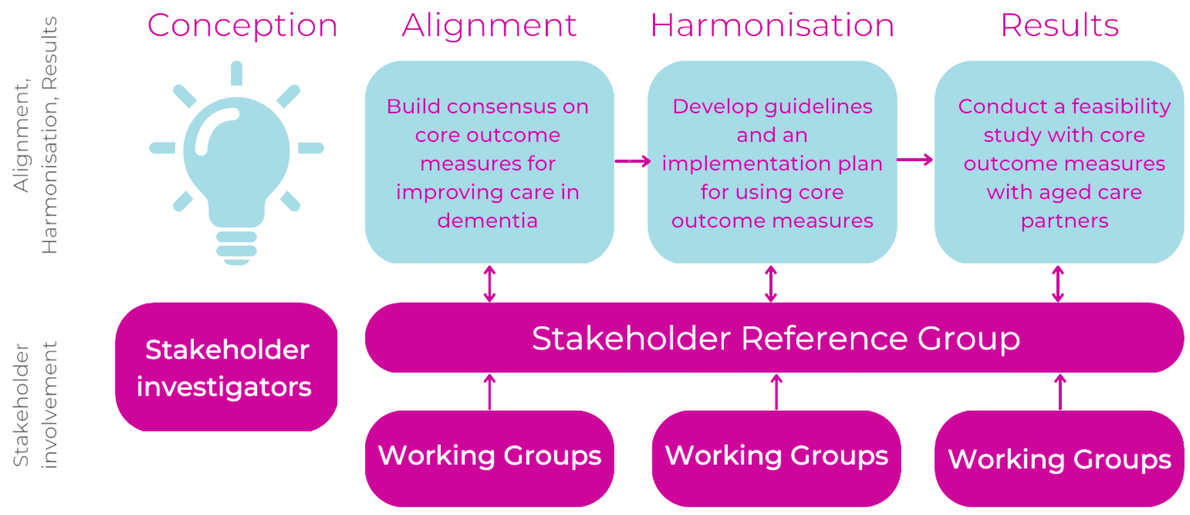

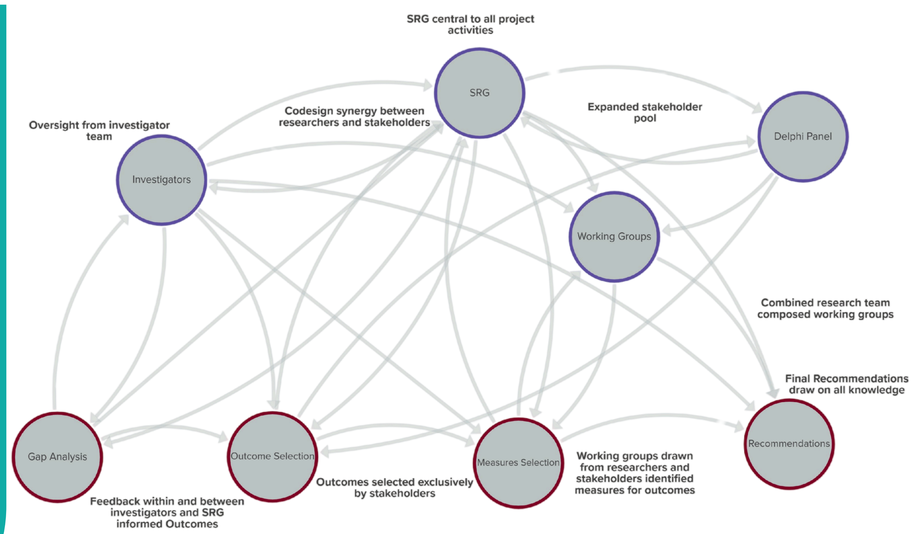

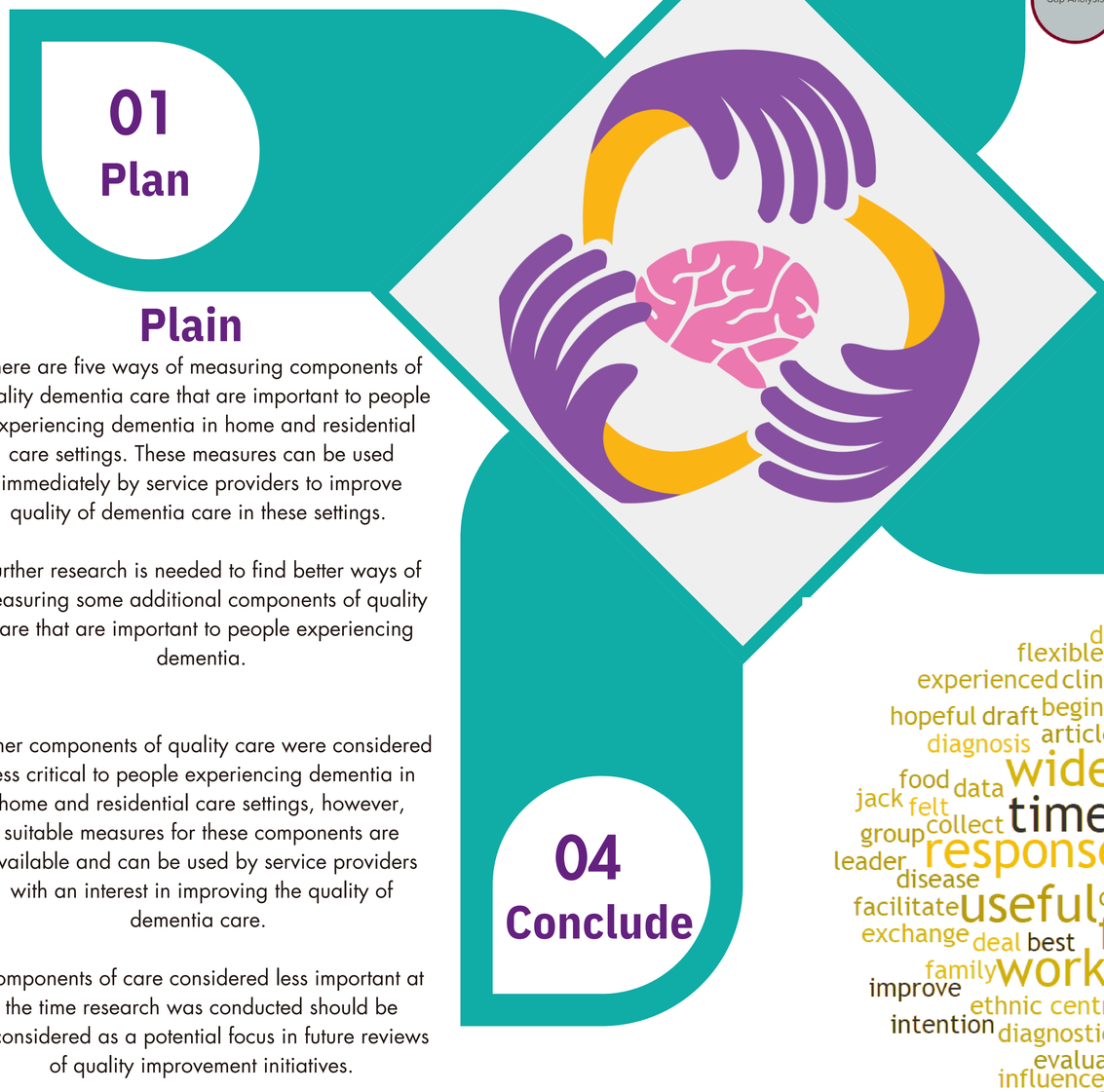

Academic

1. Identified core outcome measures be implemented by service providers as a minimum standard of care quality audit.
2. Further research is required to develop and validate appropriate measurement instruments directed at the outcomes highlighted by stakeholders as being core to quality care provision (i.e., suggested outcomes).
3. Validated measures for outcomes not considered core should be made available for service providers with an interest in improving quality of dementia care in those areas.
4. Outcomes identified as important but not core should be discussed as potential areas for care quality improvement in home care and residential aged care settings. These items may be considered core items in future.
5. Core outcome measures for improving care for people experiencing dementia in home care and residential aged care should be reviewed periodically for relevance and currency.

Plain

There are five ways of measuring components of quality dementia care that are important to people experiencing dementia in home and residential care settings. These measures can be used immediately by service providers to improve quality of dementia care in these settings.

Further research is needed to find better ways of measuring some additional components of quality care that are important to people experiencing dementia.

Other components of quality care were considered less critical to people experiencing dementia in home and residential care settings, however, suitable measures for these components are available and can be used by service providers with an interest in improving the quality of dementia care.

Components of care considered less important at the time research was conducted should be reconsidered as a potential focus in future reviews of quality improvement initiatives.

Improving the care of people experiencing dementia in home care and residential aged care settings requires ongoing periodical reviews incorporating perspectives of stakeholder groups in the pursuit of meeting evolving societal expectations of quality health care.

"Personally rewarding to work in participatory co-design project where 'consumer' experiences are considered equally valuable in conjunction with input from researchers, policy makers, clinicians. The changing direction of the project over time required me to maintain patience and flexibility, adapt expectations (which I can do when required), to believe in the process and to trust in the research leaders' expertise to enable me to remain focused on my role and work towards an end point, despite the changes." Stakeholder Feedback

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