

Successfactors Dementia Friendly Communities: Mentality

ZonMw Memorabel project

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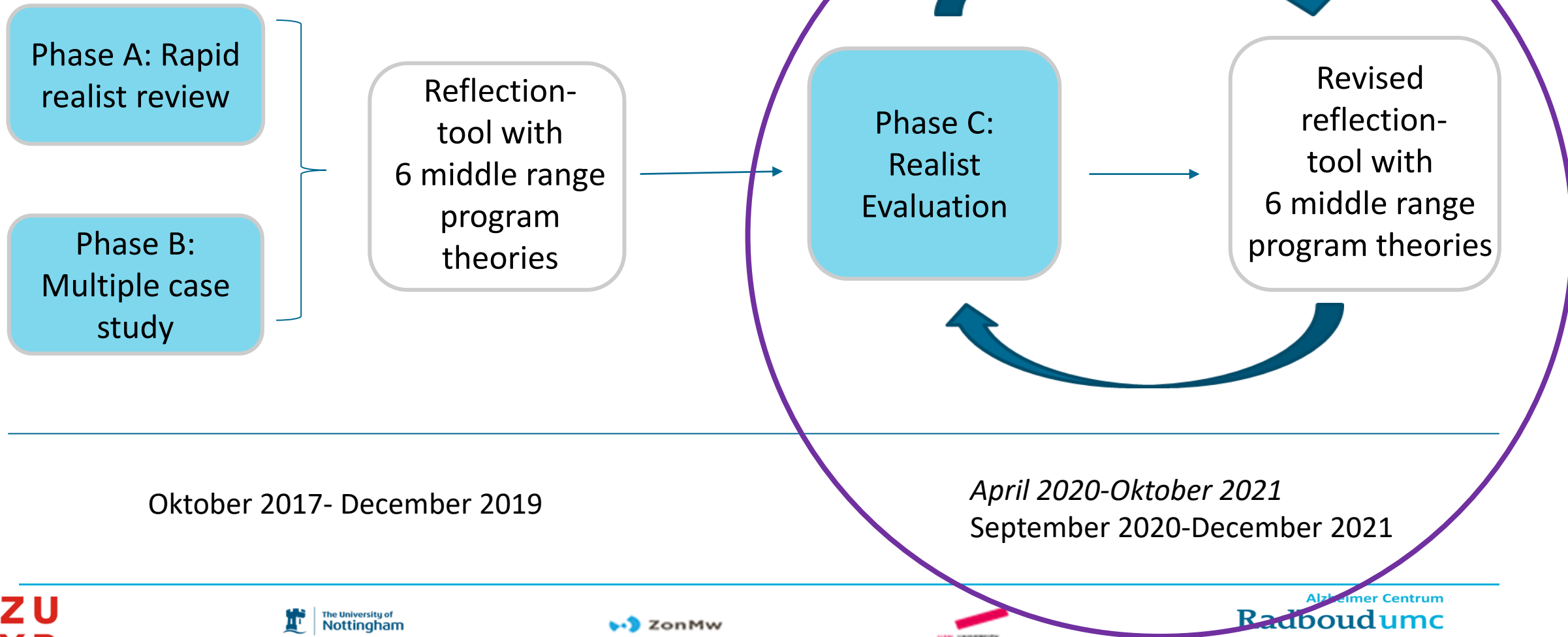
Dementia friendly communities: why-how?

- Aim: Living with dementia is normalised into a community's culture, language, infrastructure and activities.
- Concern with the role of people with dementia as a citizen-not a patient.
-> People with dementia should not be defined by their diagnosis and that there are multiple assets and strengths that people can draw on to maintain their identity, key relationships and achieve personal growth.
- Dementia friendly communities are not bound by geographic boundaries per se; it may also be a community of shared interest.
- Dementia friendly communities often start with local dementia friendly initiatives on a local or small scale; f.e. a sports club or neighbourhood.

Overview presentation

- Phase A&B: 6 Middle range program theories
- Focus on the architecture of phase C; realist evaluation
- Impact of Corona on phase C; realist evaluation
- Challenges and choices during phase C; realist evaluation
 - Testing theories
 - Datacollection
 - Timeframe and collaboration with stakeholders

Phases in the project



Theories from phase A & B.

Middle range program theories

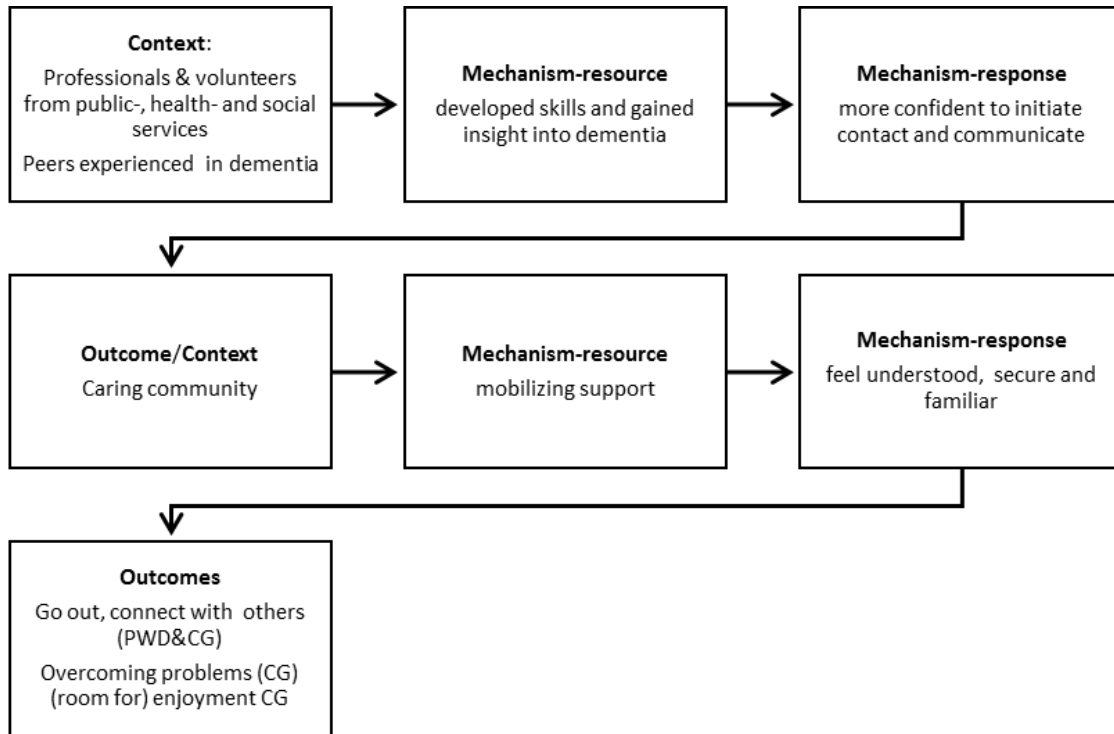
- 3 middle range program theories about the outcomes of initiatives, mostly from perspective of people with dementia and their caregivers.
- Caring community and its outcomes
- Stimulating community and its outcomes
- Activating community and its outcomes

Results B: Multiple case study

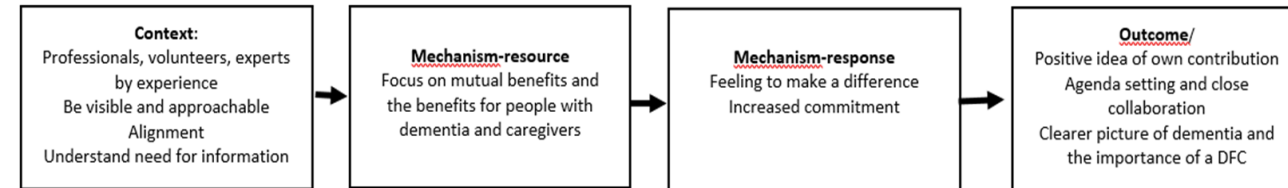
- 3 middle range program theories about the development of initiatives, from perspective of professionals and volunteers
- Creating public support for initiatives
- Development and sustainment of dementia friendly initiatives
- Taking part in initiatives by people with dementia, caregivers and community members

Examples middle range theory phase A & B

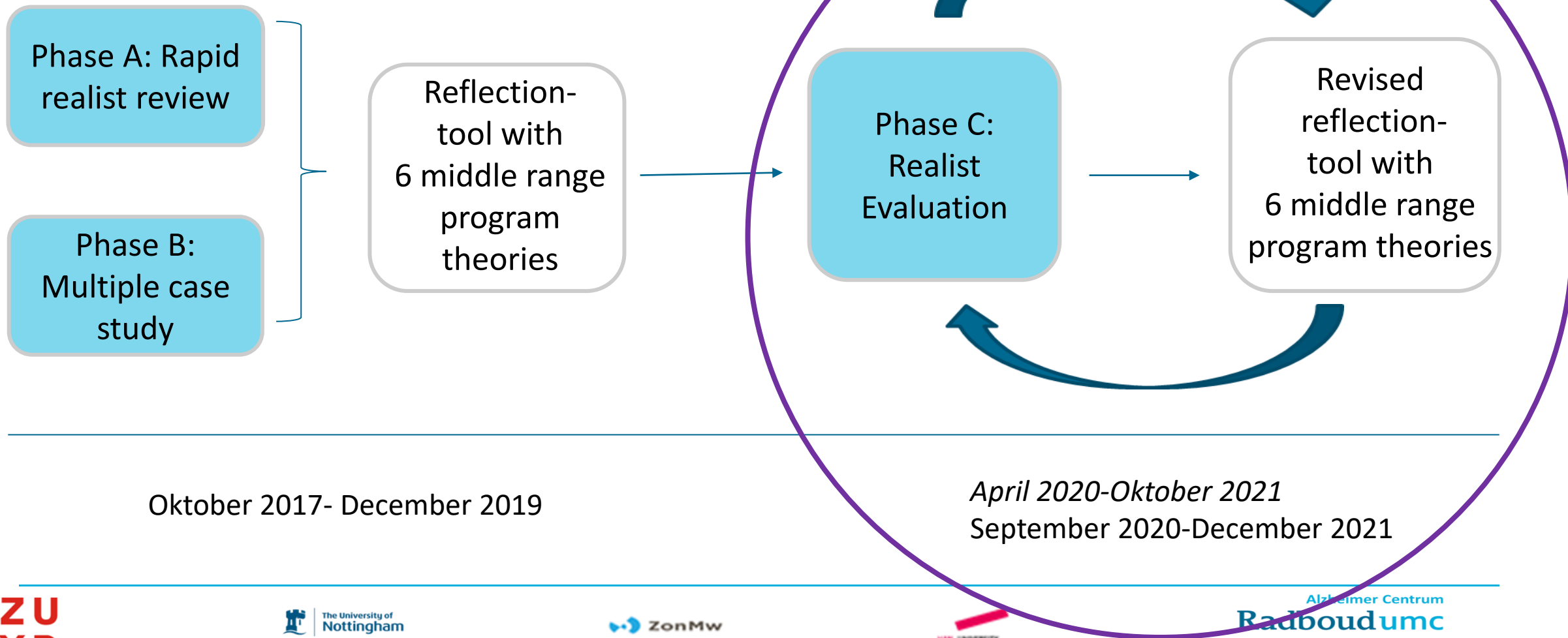
A: 'caring community'



B: 'creating public support'



Phases in the project



Characteristics realist evaluation

- Explanatory focus
- Investigate linked configurations of context(s), mechanism(s) and outcome(s)
- Use multiple, mixed methods of data collection
- Include stakeholder involvement and engagement
- Aiming for data cumulation rather than replication

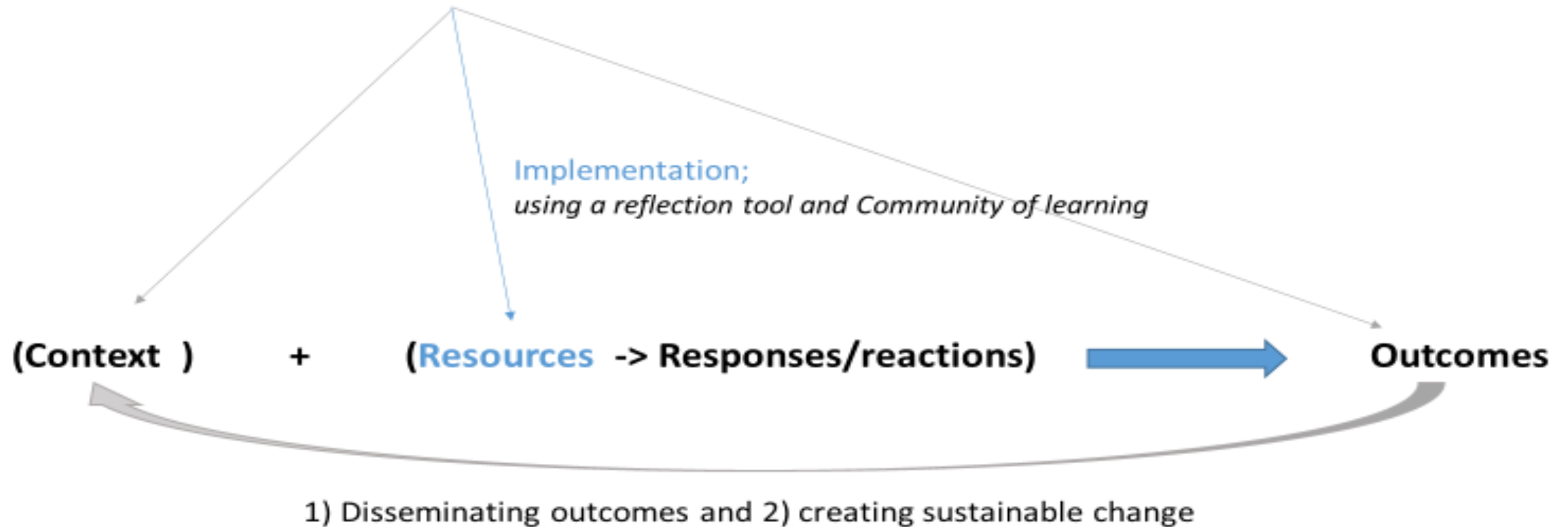
(Marchal et al., 2012; R Pawson & Tilley, 2004; Salter & Kothari, 2014; Westhorp, 2014)

Modelling the architecture of phase C: realist evaluation

Adapted from Pawson, R. and Tilly, N. 1997 [2003] Realistic evaluation. Thousand Oaks. CA. Sage Publications

Middle Range Program Theories

described in the narratives of phase A&B



Impact Corona on realist evaluation

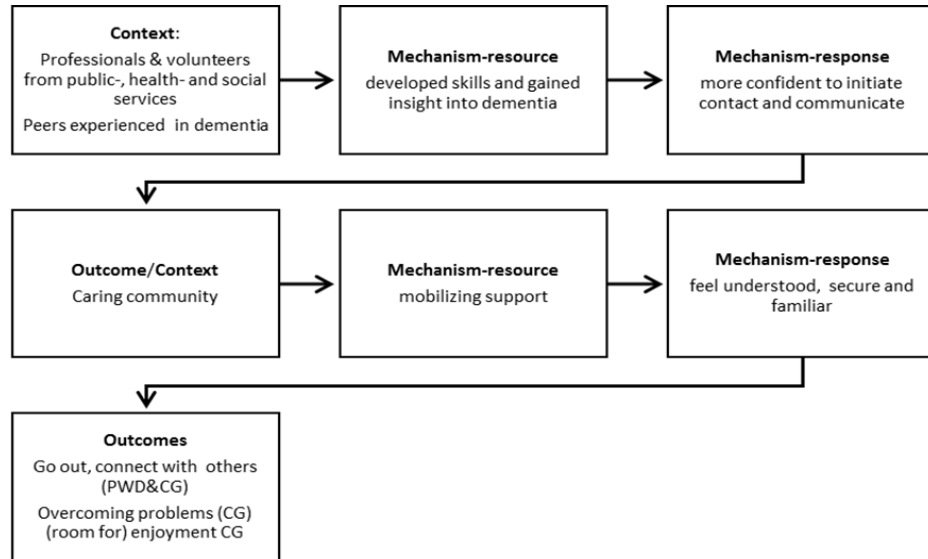
- Change of context in which theories will be tested (No time to develop new theories)
 - People with dementia and caregivers are advised not to ‘go out ’ , or are anxious, which is in contrast of the outcomes of initiatives. (‘go out-connect’)
 - Probable shortage of time for datacollection due to a three-month- break.
- + Increased urgency:
- Pilot regions focus also on ‘well being’, next to basic medical needs. ‘We have to do something; what are we going to do?’ Wish/call for solutions
 - For caregivers, outcomes such as ‘feeling relieved’ and ‘room for enjoyment’ have become extra important because lack of daily support and a very high burden.

Choices and challenges in testing theories

- Testing current middle range program theories
-> Need to broaden definition 'dementia friendly initiatives'?
- Some MR-PT are more easy to test; like caring community'while an activating community, is not.
- Expand and refine thinking about the role of context in both delivering and developing initiatives; focus on taken-for granted-aspects of contexts.
- Implied change from focus and definitions in current theories
 - Public-private
 - Role daycare
- Interviews-observations-documents
- Ask open-ended interview questions about how current context is having effects and glean new theoretical insights through an inductive approach.
- Input from macro-meso level

Choices and challenges in data collection

- What to do with outcomes for people with dementia and caregivers? Focus on the mechanisms instead?



- Interviews, if possible with a diary approach, with attention for burden.
- Survey for people with dementia to understand mechanisms, with attention for causation.
- Focus on Context-mechanisms and outcomes for caregivers?

Choices and challenges in time frame and collaboration

- Cumulate data collection instead of reproduction

Planning data collection; analysis and re-directing research ->

- Impact on stakeholders and researchers

Thank you very much for your attention and feedback 😊

please feel invited to contact

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For more information about Mentality: <https://mentality.space/> (..unfortunately in Dutch..)

Choices and challenges for discussion paper

- Testing current theories is not relevant due to change in destinations and infrastructure; abstract more general principles
- Ask open-ended interview questions about how current context is having effects and glean new theoretical insights through an inductive approach.

Use middle range theories instead of current middle range program theories