



Constructing the long list of outcomes: what can we learn methodologically?

Neighbourhoods and Dementia programme study:

Core Outcome Set (COS) for People with Dementia Living at Home

Lancaster University: Hazel Morbey, Faraz Ahmed, Siobhan Reilly

University of Liverpool: Paula Williamson

University of Manchester: David Challis, Linda Davies, John Keady, Reena Lasrado, Iracema Leroi, Caroline Swarbrick
Yingying Wang, Carol Opdebeeck

Linköping University, Sweden: Ingrid Hellström, Lars-Christer Hydén

The support of the Economic and Social Research Council (ESRC) and National Institute for Health Research (NIHR) is gratefully acknowledged.
This work forms part of the ESRC/NIHR Neighbourhoods and Dementia mixed methods study.

Overview of the Presentation

- Background
- Study overview
- Developing the 'long list'
- Delphi design

Background: Outcomes in dementia research

- Inconsistency across trials of outcomes measured in non-pharmacological interventions for dementia so difficult to compare across studies
- Current outcomes measured may not reflect what outcomes are important to people with dementia as there has been little input by people with dementia or those involved in their day to day lives.
- Nearly two thirds of people with dementia live at home but outcome measures in existing studies don't necessarily reflect the right outcomes from dementia care in community settings
- Current investigations focus on **how** measured rather than **what** measured.

Research Questions

1. Which outcomes should be measured from the perspective of **people with dementia**, care partners, health and social care professionals and policy makers, service commissioners, and research leaders?
2. How should such outcomes be measured?

Developing the Core Outcome Set

Phase 1

Focus groups & interviews

A review of existing & registered studies

Phase 2

Delphi surveys (and consensus meeting)
An agreement on a list of outcomes that are important to people with dementia

Phase 3

Systematic review to identify how outcomes identified as important should be measured

Phase 4

Stated preference survey to explore the preferences of key stakeholders for different aspects of outcomes

Developing the Core Outcome Set

Phase 1

Focus groups & interviews

Review of existing & registered studies

Phase 2

Delphi survey (and consensus meeting)
Agreement on a list of outcomes that are important to people with dementia

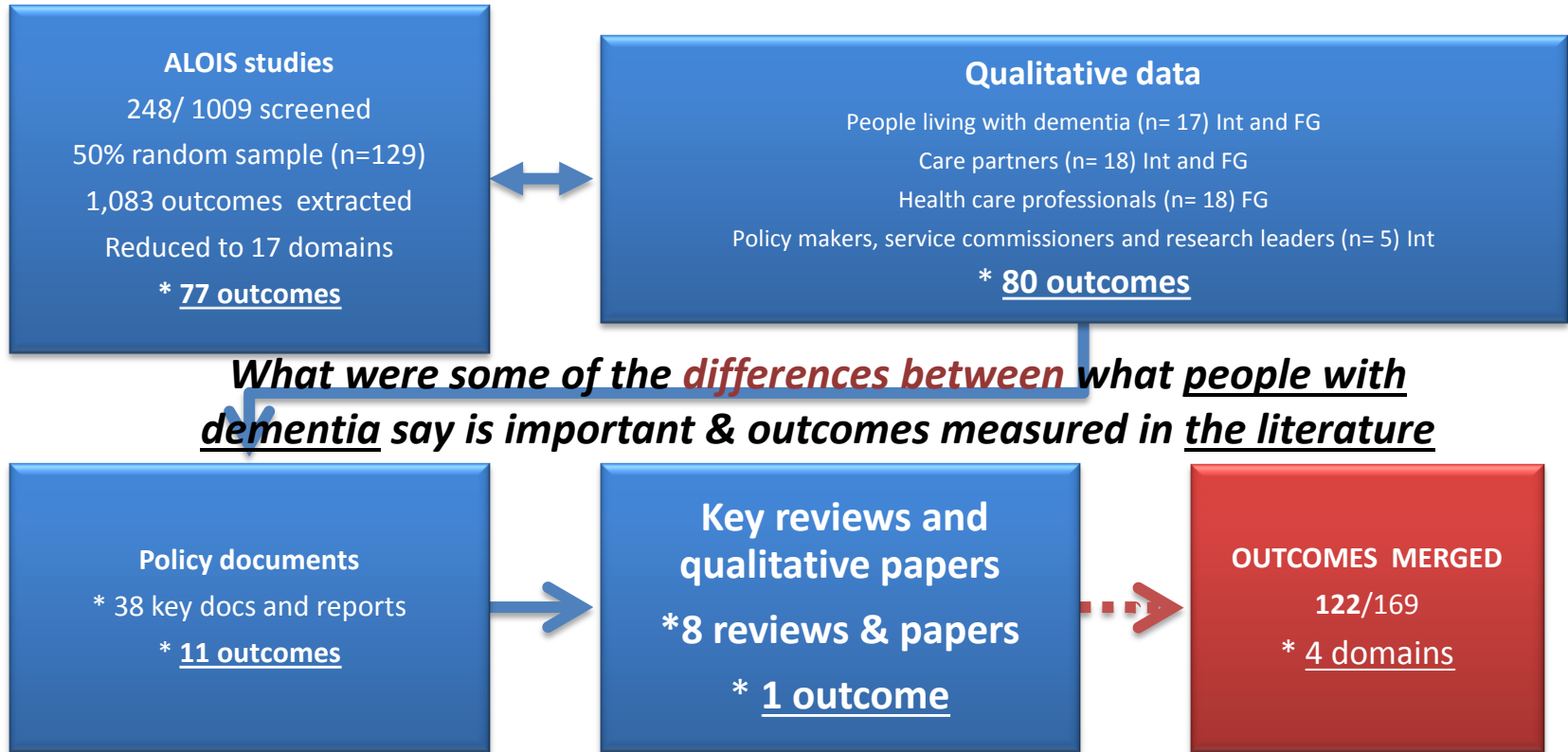
Phase 3

Systematic review to identify how outcomes identified as important should be measured

Phase 4

Stated preference survey to explore the preferences of key stakeholders for different aspects of outcomes

Summary: outcome extraction & developing the long list



Literature outcomes & what people with dementia say

From literature		From qualitative data	
Outcome	Emphasis	Outcome	Emphasis
Activities	Frequency	Activities	Meaningfulness
Relationships	Quality	Relationships	Quality
Safety/risk	Actual safety or risk e.g. falls	Feeling safe and secure	Person with dementia's feelings of safety or security

Literature outcomes & what people with dementia say

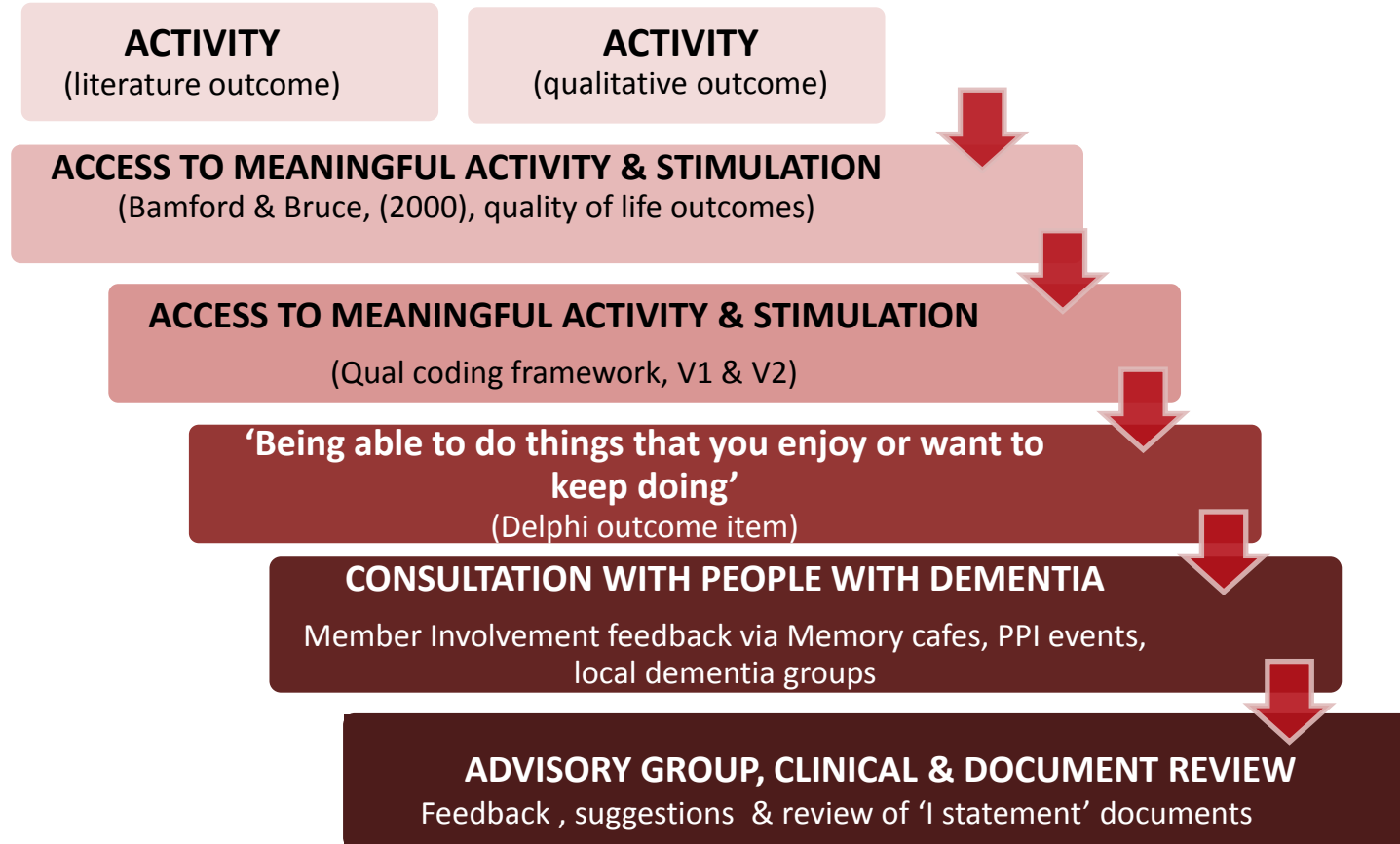
From literature		From qualitative data	
Outcome	Emphasis	Outcome	Emphasis
Activities	Frequency	Activities	Meaningfulness
Relationships	Quality	Relationships	Quality
Safety/risk	Actual safety or risk e.g. falls	Feeling safe and secure	Person with dementia's feelings of safety or security

Activities

From literature		From qualitative data	
Outcome	Emphasis	Outcome	Emphasis
Activities	Frequency	Activities	Meaningfulness

“Yeah... not all the games, I must admit, not all the games but, well, they get very boring really.... Well, it’s all children’s games really.” (Paul)

Outcome translation in consultation with people with dementia

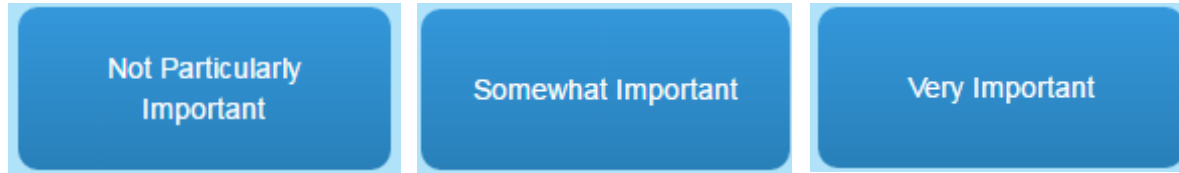


Phase 2

- We will ask all stakeholders to rate the importance of each outcome using a **2-round Delphi survey**.



- Rating scale**



- If **70%** rate as **very important** the outcome will go to R2, if **70%** rate as **not particularly important** the outcome will be discarded.

Methodological questions



What is the best way to achieve consensus on accessible outcome item descriptors?



What is the best way of including people with dementia in Phase 2 of the study (2 round Delphi survey)?



We welcome your questions

Thank you for listening

For further information please contact:

s.reilly@lancaster.ac.uk

h.morbey@lancaster.ac.uk

idclancaster@lancaster.ac.uk

The support of the Economic and Social Research Council (ESRC) and National Institute for Health Research (NIHR) is gratefully acknowledged.

This work forms part of the ESRC/NIHR Neighbourhoods and Dementia mixed methods study.

