

# Life through a Lens

## Participatory action research to collaboratively implement non-drug interventions with people who have a learning disability and dementia

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### Background

People with a learning disability now have a longer life expectancy than ever before. In addition to typical age-related conditions, we know that some people with a learning disability are at increased risk of dementia at a younger age. Whilst research evidence is increasing in relation to non-drug interventions for the general population of people with dementia, previous studies have not included people with a learning disability.

This three-year inclusive research project will use a participatory action approach to implement non-drug interventions with people who have a learning disability at different stages of dementia.

### What are the interventions?

Interventions will be personal to participants with a learning disability and dementia. Each is determined at individual 'goal setting' meetings using a Goal Attainment Scale. Interventions may include:

- music
- reminiscence-based activities
- design or environmental changes
- technology



Actors engaged in photography as part of Jenny's Diary dissemination grant\*

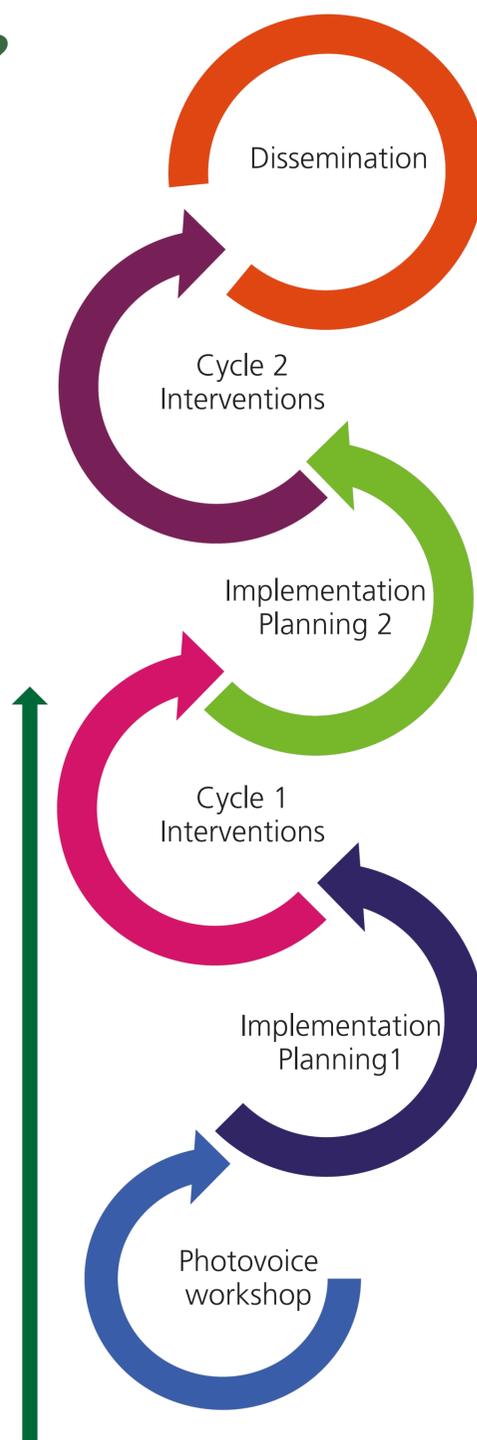
### Study Design

Participants are:

- family members and social care staff who provide support to people with a learning disability and dementia.
- people with a learning disability and dementia who take part in interventions.
- people with a learning disability (not dementia) who live, work or socialise with peers who have a learning disability and dementia.

Mixed-method data collection methods are:

- Goal Attainment Scale
- Photovoice (use of photography and digital story methods to facilitate inclusion of co-researchers with a learning disability)
- Semi-structured interviews
- NPI-Q scale
- QUALID tool (cycle 2 only)



**Dissemination:** Digital story of the research, end of project event and provision of accessible information.

**Cycle 2:** Individualised interventions with participants who have advanced dementia, data collection and analysis.

**Planning 2:** Learning from Cycle 1 and individual goal setting with different participants who have advanced dementia.

**Cycle 1:** Individualised interventions with participants who have a recent diagnosis of dementia, data collection and analysis.

**Planning 2:** Individual goal setting with participants who have a learning disability and a recent diagnosis of dementia.

**Photovoice workshops:** Co-researchers with a learning disability (not dementia) trained in photovoice methodology and take part in pilot.

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