

# Improving hospital outpatient care for people with dementia

## Co-designing and testing a toolkit and accompanying resources



Led by the [Centre for Dementia Research](#), Leeds Beckett University, in partnership with people with lived experience of dementia and NHS staff

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## The toolkit and example resources

1 The toolkit contains 5 sections:

- Identifying dementia and the person's needs
- Helpful information ahead of appointments
- Support during appointments
- Involvement and support of carers
- Environments and accessibility

2 Each section contains top tips e.g.

**TOP TIPS**

### Identifying dementia and the person's needs

**IDENTIFY DEMENTIA EARLY IN THE APPOINTMENT**

Ask about additional needs when people 'check in'.\*

Display posters to invite people to self-identify memory problems or dementia.\*

See the 'Resources' section for example posters that could be used or adapted.

3 And resources to help implement the top tips e.g.

**RESOURCES**

### Do you have memory problems or dementia?

Please let a member of staff know

You could also complete a 'Things you need to know about me' card to share your needs with staff

Staff will be happy to discuss your needs and any support that might be possible during your appointment

Posters offering the option to self-identify

### Things you need to know about me

Name: \_\_\_\_\_

Completed by: \_\_\_\_\_ Date: \_\_\_\_\_

Patient  Relative or friend  Professional carer

Complete this card to help staff understand your needs and how they can help

I describe myself as having:

Memory problems  Cognitive difficulties

Dementia  Alzheimer's Disease

Other: \_\_\_\_\_

This affects me in the following ways:

\_\_\_\_\_

You can help me during my appointment by:

\_\_\_\_\_

Making decisions during my appointment:

I can make my own choices about my care. Please fully involve me.  I need help to make decisions about my care. Please involve me and anyone supporting me.  I find it hard to make decisions about my care. Decisions may need to be made in my best interests.

I have a Lasting Power of Attorney for health and welfare:  Yes  No

My supporters:

I attend appointments with a supporter:  Yes  No

Their name(s) and relationship to me: \_\_\_\_\_

Cards to share the person's needs

Each hospital department chose which resources they wanted to implement over a 5-month period.

## Introduction

- People living with dementia (PLWD) regularly use hospital outpatient services for conditions like heart disease, fractures and diabetes
- Limited existing research suggests they may experience challenges accessing outpatient services and receiving good care and support

## Study Aims

- To explore experiences of outpatient care for PLWD and their families, including good practice and potential improvements
- To design and test a toolkit to improve outpatient care for PLWD

## Study Design

### Stage 1: Ethnographic study and scoping review

Explored experiences of care and potential improvements via observations, conversations and interviews with 12 PLWD, 12 relatives and 22 hospital staff and a review of existing research.

### Stage 2: Co-design

Co-designed a toolkit and accompanying resources via 12 workshops with PLWD, families and staff using Stage 1 findings

### Stage 3: Testing and refining

Tested the toolkit in two hospitals. Feedback was sought via observations plus discussions with 5 PLWD, 11 relatives and 22 staff.

## Results of the initial testing found:

The toolkit was feasible and acceptable to, and valued by, PLWD, families and staff, with important refinements identified.

There was expected, context-dependant variability in whether and which elements were of use, reinforcing the choice the toolkit offered.

The stigma associated with dementia was a barrier to acceptability in some cases, requiring further consideration of the language used.

"It's pretty easy... 'Here's a pack, it might help you, things to fill out if you need... just bring it back to your next appointment, and there's some resources in there to help'" (Staff)

"I flashed it [personal information card] to everyone... they moved us on pretty quickly." (Relative)

**NEXT STEPS**

Refining the toolkit based on the feedback given

Disseminating the toolkit - contact [r.kelley@leedsbeckett.ac.uk](mailto:r.kelley@leedsbeckett.ac.uk) for a copy!