

Supporting people living at home with dementia and continence problems

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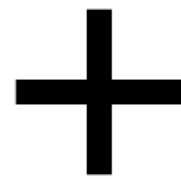
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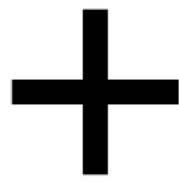
Why is incontinence a problem for people with dementia?



PHYSICAL CAUSES



DEMENTIA CAUSES



MANAGEMENT CHALLENGES



INCONTINENCE ASSOCIATED WITH DEMENTIA IS DIFFERENT

Biggest incontinence related care challenges

Relationship problems

Protecting dignity

Negative emotions

Workload & physical toll

Lack of support/information

Behaviours that challenge

Maintaining hygiene

Damage to home

Financial cost

Stopping socialising and going out

Smell

1. Stay independent with toilet use
2. Achieve social continence
3. Cope with incontinence



How are we doing it? (Working with people living with dementia, carers and other stakeholders throughout)



- Interviews (n=45)
- Survey with 113 family/friend carers

Detailed practical guide for carers

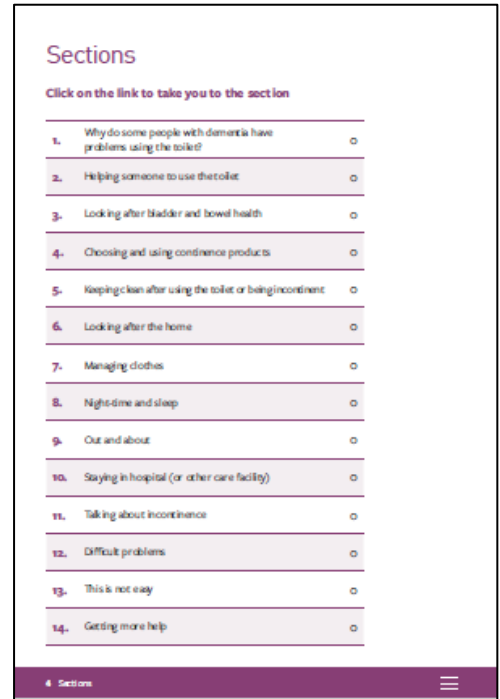
- Interviewed 31 primary and community HCPs
- Reviewing similar resources for 'lessons learned'
- Developing resources

Evaluate with up to 60 people living with dementia, carers and HCPs

- Interviewed 14 homecare workers'
- Working with stakeholders to plan resources
- Develop, evaluate and implement resources

Web-based information

1. For carers
2. For healthcare professionals
3. For homecare workers



Non-pharmacological interventions delivered to/by healthcare professionals in primary or community care to support people living at home with dementia: Findings from the literature
The DemCon Study



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Review Question

To identify and synthesize ‘lessons learnt’ from available literature on non-pharmacological interventions delivered to or by healthcare professionals in primary or community settings to support people living at home with dementia, their carers and homecare workers to inform the development and implementation of a continence support intervention.

Study selection, data extraction and synthesis

- Interventions comprising information, education or training relating to supporting people living with dementia at home with activities of daily living
- Systematic searches and inclusion/exclusion criteria applied
- 11 articles selected for data extraction
- Narrative synthesis of the literature undertaken
- Guided by the person-based approach to planning, optimising, evaluating and implementing health interventions

Use of the Person-Based Approach

Aim is to “ground the development of behaviour change interventions in a profound understanding of the perspective and psychosocial context of the people who will use them.”

(Yardley et al., 2015 p.2).

More details about the approach:

<https://www.personbasedapproach.org/index.html>

This literature review (together with stakeholder/PPI consultations and interviews) has been used to develop ‘guiding principles’ and inform an ‘intervention planning table’ recording the rationale and evidence-base for specific elements of the intervention.

Preliminary findings – initial themes

1. Value of online interventions
2. Appropriate, targeted and tailored information/resources
3. Content, format and visual presentation (design principles)
4. Credibility of information/resource
5. Importance of user involvement in developing content and presentation
6. Role of (healthcare) professionals
7. Strategies to encourage uptake/signposting to resources by professionals

Some reflections

- The searches revealed many studies relating to interventions for people with dementia in care homes (fewer relating to people with dementia living in the community)
- Lots of studies related to testing therapies, exercise/physical activity, use of devices/technology
- Few studies related to the provision of practical information, education or training (formal and informal) to caregivers to help them to support people living with dementia at home with activities of daily living
- Where studies exist often the actual intervention, its development and delivery are not well described

Thank you

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<https://www.kcl.ac.uk/hscwru>



DemCon Study – Interviews

Semi-structured interviews to identify:

- What the resource content should include
- How and when the resource is likely to be used
- What are the likely facilitators and barriers to uptake

Interview Participants (n=45)

- *Homecare Workers*
- *Healthcare Professionals - primary and community care*

Challenges to recruitment:

- *Care Agency diversity*
- *Healthcare Professional engagement*
- *Expressions of interest - conversion rate*

Participant Sample

Homecare Workers, n=14 – keen to be heard

5 private care agencies: (n.b. sample representation)

Healthcare Professionals, n=31 – various roles

13 organisations: Community Trusts; Primary Care

Community Nurses; District Nurses; Practice Nurses; Continence Specialist Nurses; Consultant Nurse - Dementia and Frailty; Specialist Nurse - Older People; Paramedic; Social Prescriber; GPs; Care Home Co-ordinator; Occupational Therapists; Physiotherapist

Findings - Thematic Analysis

Overarching Themes



**Continence
Conversations**

**Caring
Issues**

**Resource
Uptake**

Continence Conversations

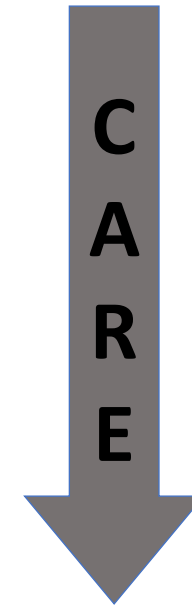
- Avoidance
- Confidence
- Nobody's business - passing the buck
- Assumptions around willingness of PLWD / carers to engage



“Jack of all trades”



'Human Signposts'



Homecare Workers

Caring Issues

“Everyone is a person and everybody is different. It is the understanding that something that might work for one will not work for another and that sometimes it’s about a compromise” (HCW 2)

- Subject-specific knowledge
- Accessing equipment / products
- Relationship building
- Individuality of PLWD
- Staffing considerations

Engaging with New Resources

- Design, delivery and content
- Barriers to engagement
- Facilitators to engagement

Easily accessible

Awareness

Subject-specific

Stress the importance

Useful

User-friendly

Length and depth

Encourage engagement

Homecare Workers - Content

- Person living with dementia
 - support network; what to expect
- Family carers
 - practical information
- Home care professionals
 - educational material

“It’s a softer message for the client, a more pragmatic message for the carer and, I guess, a more empathetic message for the family”
(HCW 5)

Homecare Worker Engagement

- Online accessibility
- Access during visits - discuss with client
- Educational - enhance their knowledge



“So, I’d look at it at home and think: Oh, right, yes this looks useful. I will take my computer and when I’m in with my client tomorrow morning I’m going to play this. We can do this, I think it’s going to help us, and if it does, brilliant! If it doesn’t, OK, such is life, we’ll carry on as we were. So I think initially I would use it as a training tool, train myself, show myself what’s happening and then take it out to the clients and use it for real” (HCW 4)

Designing the Intervention

Person-Based Approach (Yardley *et al.*, 2015)

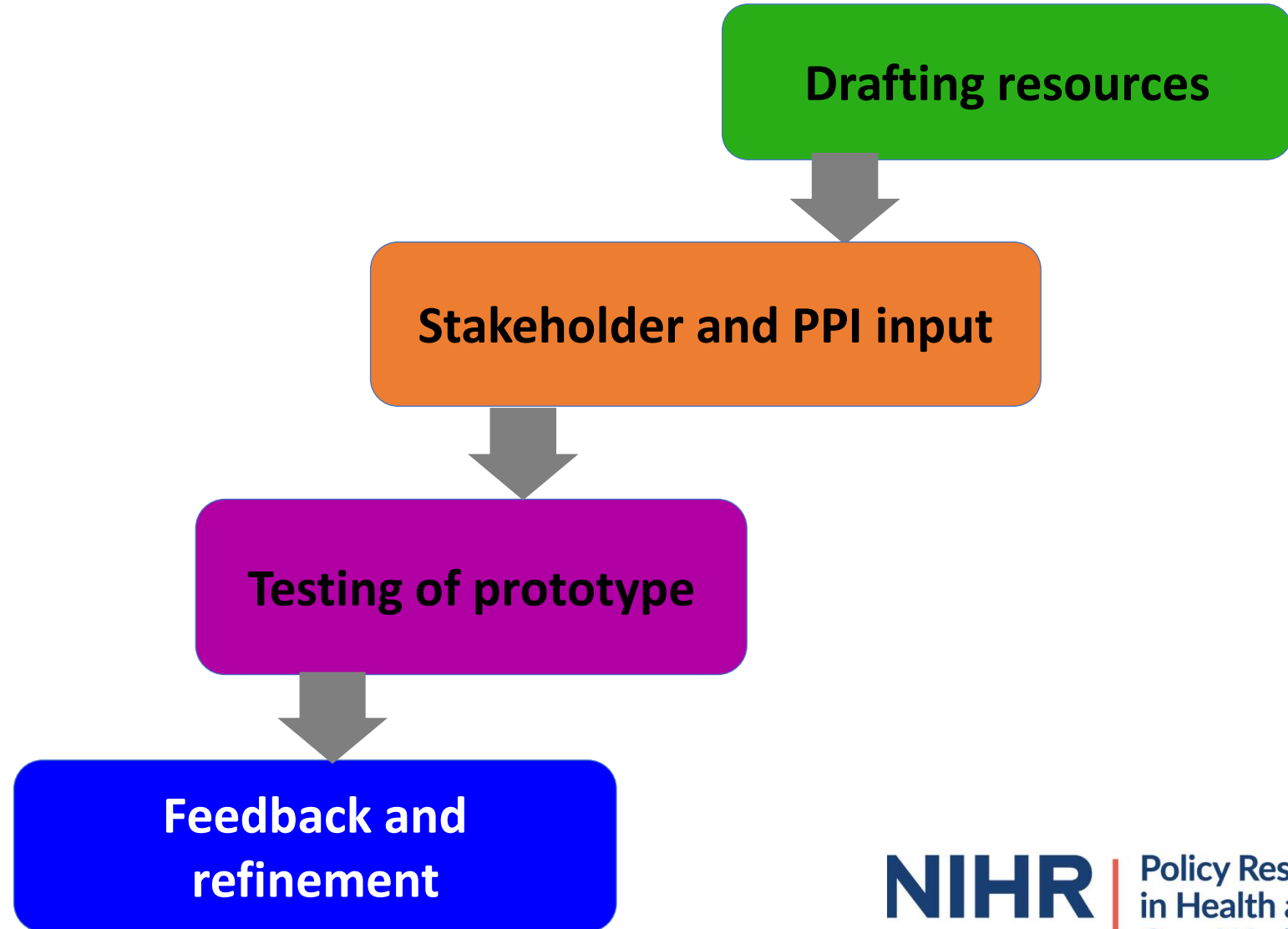
Guiding Principles

- Design objectives
- Key features of intervention

Intervention Planning Table

- Target behaviour
- Features to overcome barriers and promote facilitators

Next Steps



DemCon Homecare

Funding to plan the development, evaluation and wide-scale implementation of bespoke continence care resources for Homecare Workers

- Identify content of a practical guide for Homecare Workers to:
 - Enhance their knowledge in caring for PLWD
 - Promote continence independence for their clients
- Develop a plan to create and evaluate the resources

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- Stakeholder involvement
 - Advise on content, style and implementation
- Stakeholders: Homecare Workers; Homecare Agency managers; PLWD; family carers; organisations (e.g. Home Care Association)
- Time commitment
 - Stakeholder meetings × 2: 1.5 hours each (Sept / Nov 2023)
 - Preparatory reading × 2: 1 hour each
- Reimbursement for time: NIHR standard rates

DemCon Homecare

Key next step: stakeholder selection

If you would like to be involved, or know someone who may wish to, please get in touch with Barbara:

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