



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC



WS4

Post-diagnostic dementia care: efficient and sustainable models

Professor Louise Robinson
&
Dr Heather Yemm





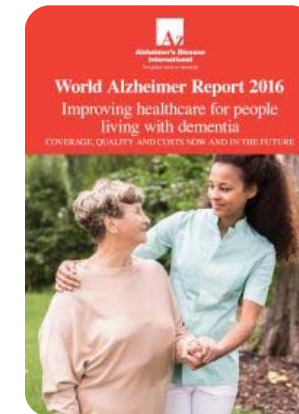
Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC



**National Institute for
Health Research**

WS4 Overview

- Addresses the 2016 World Alzheimer Report recommendations for efficient, task-shifted dementia care, and a competent workforce to deliver such care



Prince et al. (2016)



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

WS4 Overview

- Two core components:
 - WS4.1: Developing efficient, feasible and sustainable dementia care pathways
 - WS4.2: Building the workforce to deliver future dementia care



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Dementia Training & Awareness

- Aim to provide resource(s) to raise awareness of dementia, particularly for carers (formal and informal)
- Development of an online course focusing on the dementia journey, from diagnosis to death, and aimed at carers

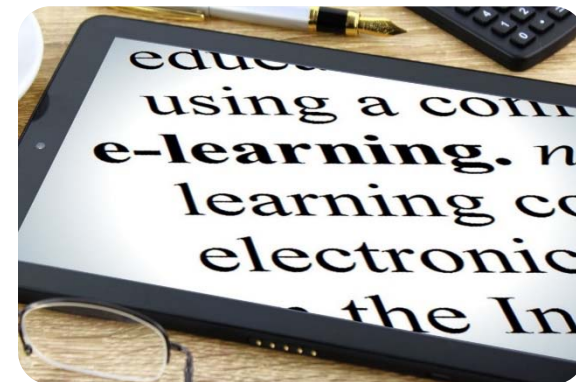


Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Proposed MOOC

- Massive Open Online Course (MOOC)
- Free to access
- Available online via the FutureLearn platform
(www.futurelearn.com)
- 3 week course
- Due to start April 2019





Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

MOOC Aim and Objectives

To support informal carers of people living with dementia to prepare for the future as dementia progresses

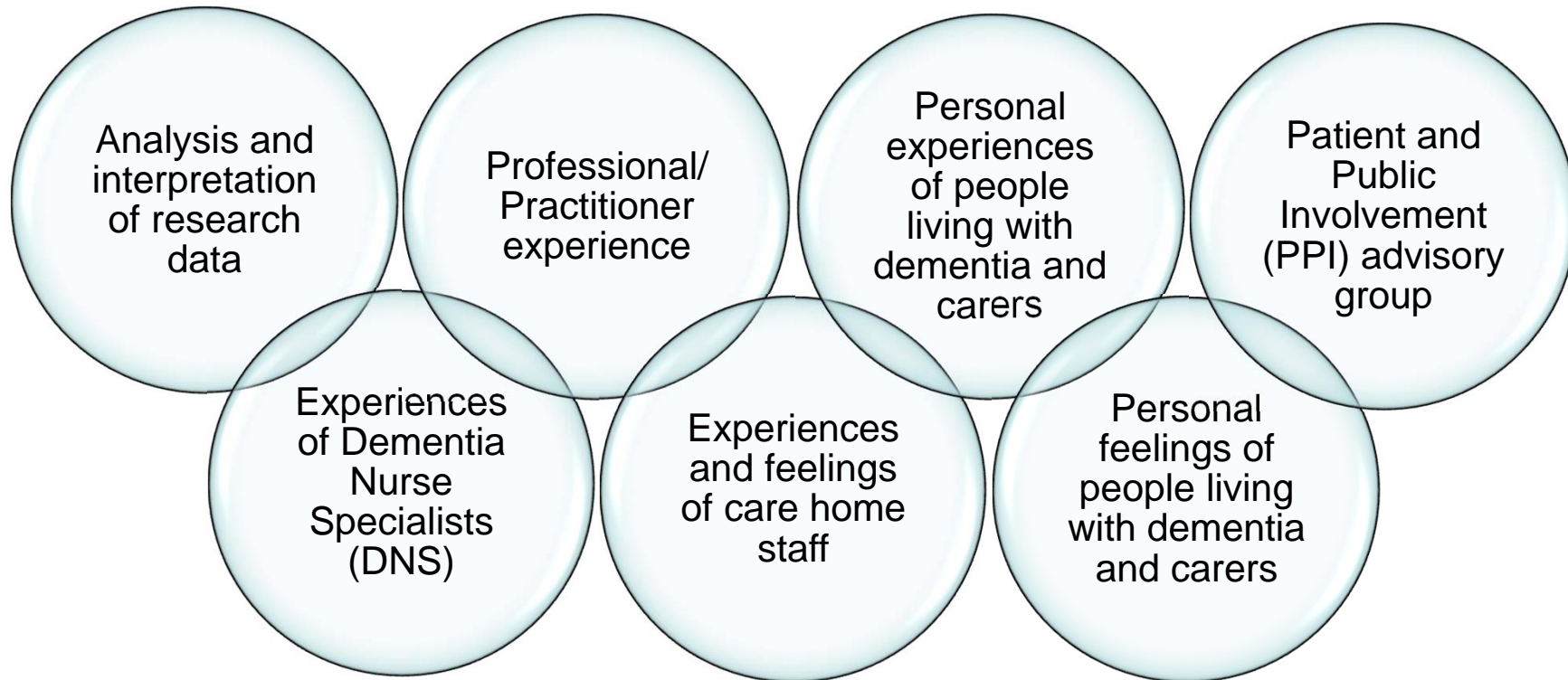
- Promote the importance of planning ahead appropriately
- Reinforce comfort care planning for people with advancing dementia
- Help carers to consider their own needs as well as the needs of the person living with dementia, and how both their needs may change
- Encourage broad access and reach to information
 - carers can do this at home in their own time
 - facilitates access for an international audience



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC



What has informed the content?



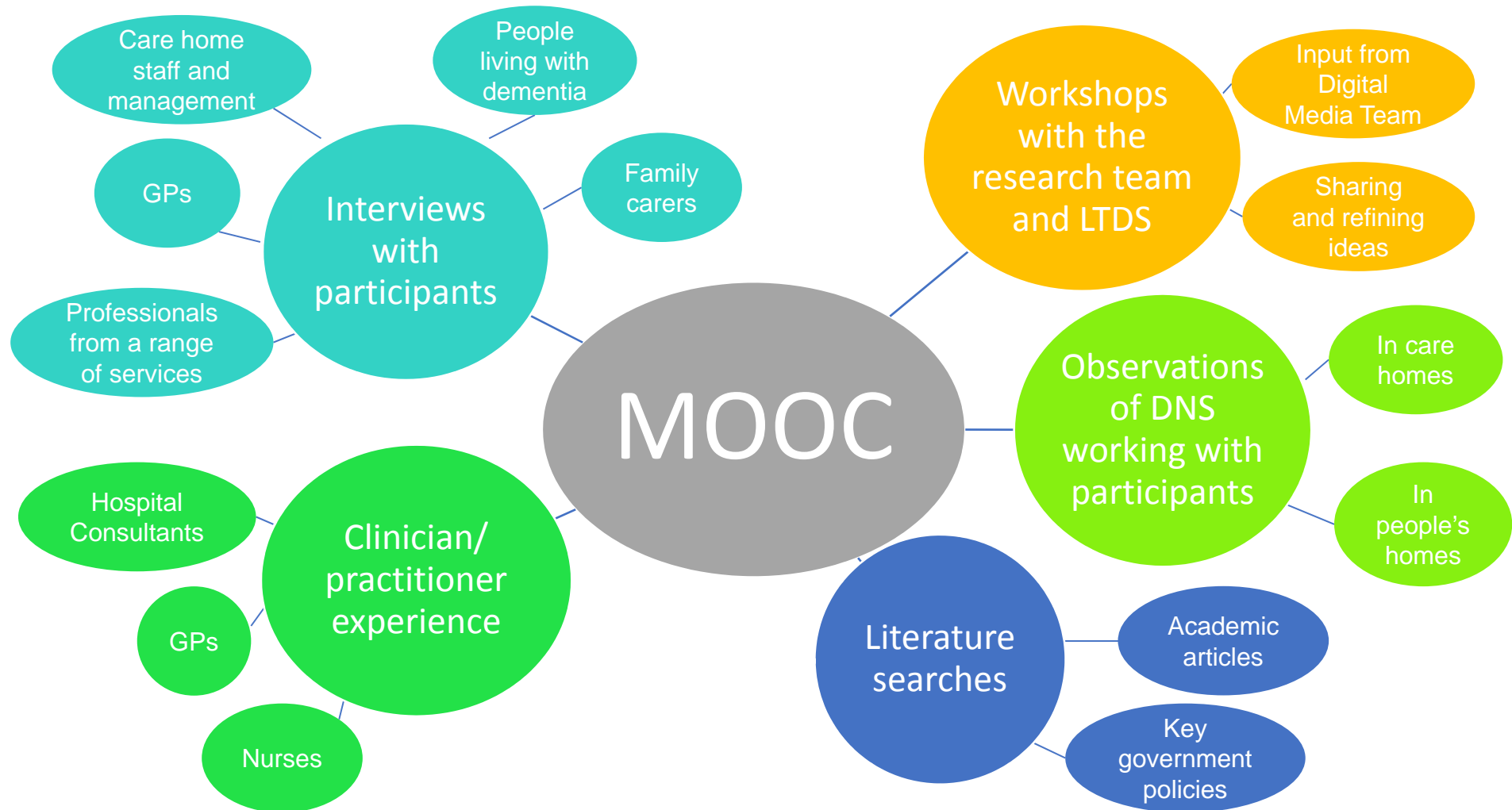


Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC



National Institute for
Health Research

Where the content comes from





Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

What are we presenting?

- Information and resources to help carers to understand and cope with changes in the person living with dementia as the condition progresses
 - Other people may also find the course useful e.g. care home staff, healthcare professionals, people living with dementia
- A variety of experiences, views and situations which may affect the person living with dementia and the person who supports them
- A space which encourages learners to interact with each other and the support team to share knowledge, experiences and views



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

How will we represent our ideas?

- Video clips (e.g. interviews)
- Animations
- Pictures/images
- Short articles
- Audio accounts
- Music
- Interactive participant areas (e.g. discussions, quizzes)
- Other ideas?



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Week 1 – Conversations around care and comfort

- Introduction – how to use FutureLearn, interactive forum for learners to introduce themselves
- Video exploring care and comfort in progressing dementia from the views of carers and a range of healthcare professionals and experts
- Dementia as a progressive illness – recognition of common symptoms and experiences, talking about disease progression and end of life
- Why planning is important – experiences of planning ahead, talking about the future, making plans, who to talk to
- Activity – participants encouraged to start completing ‘This is me’ documentation with person living with dementia



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Week 2 – Ensuring care and comfort

This week is based on a participant case study (Jack*, his daughter, Nurse Specialist, care home staff) and comfort care planning

- Physical wellbeing – managing common symptoms, managing pain, eating and drinking, hospitalisation, delirium
- Changes in memory and thinking – thought processes, communication
- Emotional wellbeing – identifying and meeting psychological and spiritual needs
- Comfort care planning – working together, meeting need, plans in action
- Making decisions – making the right decision at the right time, best interests, place of care
- Activity – write a comfort care plan



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC



Week 3 – Supporting carers, recognising me

- You as a carer – interactive experience cloud, carer stories from a range of perspectives
- Feeling supported – getting support, strategies, tools, technology
- Coping with grief – coping with loss, conflicting emotions, being prepared and supported
- Looking after yourself as a carer
- Reflections and recap



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Previous MOOC

- **Dementia Care: Staying Connected and Living Well**
- Key areas covered include:
 - Types and symptoms of dementia
 - Structure and functions of the brain
 - Communication
 - Caring role and experiences
 - Understanding challenging behaviour



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

ONLINE COURSE

Dementia Care: Staying Connected and Living Well

A course for carers, to help you stay connected to loved ones, manage stress at home and defuse difficult situations.



[Go to course](#)

[Overview](#) [Topics](#) [Start dates](#) [Requirements](#) [Educators](#)



<https://www.futurelearn.com/courses/dementia-care>



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Previous MOOC

- Course has run several times and has had a global reach
 - >7800 people worldwide actively participated
 - India: 69 learners
 - Malaysia: 43 learners
 - Tanzania: 1 learner





Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Global Reach

- The proposed MOOC:
 - Is UK-based (refers to UK healthcare structure and support options)
 - Requires internet to access
 - + Offers practical advice which could be beneficial to people in a wide range of locations and situations
 - + Will be freely accessible online



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Group Discussion

- Is this a resource we could adapt to be more relevant to other settings?
 - How could we make this more relevant?
 - Would this need to be translated? How many languages?
- Would people be able to access this online resource?
- How would we advertise this?



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

WS4 Overview

- Two core components:
 - WS4.1: Developing efficient, feasible and sustainable dementia care pathways
 - WS4.2: Building the workforce to deliver future dementia care



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Dementia Care Pathways

- Aim to explore the current healthcare pathway for people living with dementia in each country
- Use findings to co-produce dementia care guidelines for each country



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Qualitative Work

- Semi-structured interviews & focus group discussions
- Explore participants' views about dementia care and the healthcare system for older adults within the country in which they live or work



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Sample

- Healthcare professionals
- People living with dementia (PwD)
- Family members of people living with dementia
- Policy makers & commissioners
- Local government health officials
- Hospital/clinic managers and heads of community services and community leaders



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Sample

- 30-60 people from each country
- Approximately equal number of people from each group (healthcare professionals, policy makers and commissioners, PwD, family members, health officials, managers and leaders)



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Inclusion Criteria

- Able to communicate verbally
- Have capacity to consent to take part
- Comorbidity & multimorbidity acceptable
- Care experience in the last 3 years
- Healthcare professionals working in services providing care and support to PwD or older adults in general
- Policy makers and commissioners involved in decision-making regarding healthcare policies and services



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Exclusion Criteria

- Aged under 18
- Lack capacity to consent
- Unable to communicate views verbally



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Interviews/Focus Groups

- Consider participants' perspectives on:
 - The current healthcare system in the country
 - The dementia care pathway in the country
 - Factors influencing or affecting care received by people living with dementia in the country
 - The key priority areas to improve the situation for people living with dementia in the country



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
*National Institute for
Health Research*

Interviews/Focus Groups

- Interviews
 - Individual
 - Face-to-face
 - Quiet location
- Focus Groups
 - Accessible location (minimise travel difficulties)
- Audio recorded



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC

NHS
**National Institute for
Health Research**

Group Discussion

- Is this study feasible?
 - Is the proposed sample accessible?
 - How would this be run in each country?
 - What help/support can the UK team provide?
 - Training?
 - Researcher from the UK to collect the data?



Global Health Research
Group on Dementia
Prevention & Enhanced
Care: DePEC



Thank you