

# Right at the Start

DCAN Enquiry



**DEMENTIA  
CHANGE  
ACTION  
NETWORK**



Coalition for  
Personalised  
Care

**Dementia Change Action Network** is where that work comes together.

DCAN is a partnership between **NHS England & Improvement; Alzheimer's Society**, and the **Coalition for Personalised Care**.

Together we run our network dedicated to advancing personalised care and dementia.

Participation is open to anyone wanting to get personalised care working for people living with dementia.



# Our #DCAN Enquiries

Enquiry 1: Dementia Reframed

Enquiry 2: Right at the Start

Enquiry 3: Social Prescribing 360

Enquiry 4: What Matters Now?



# About the project

Improving pre-diagnosis support



# Background

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DCAN was approached by NHSE to support time limited activity to understand what the issues are and to develop ways to improve the experience of pre-diagnosis support.

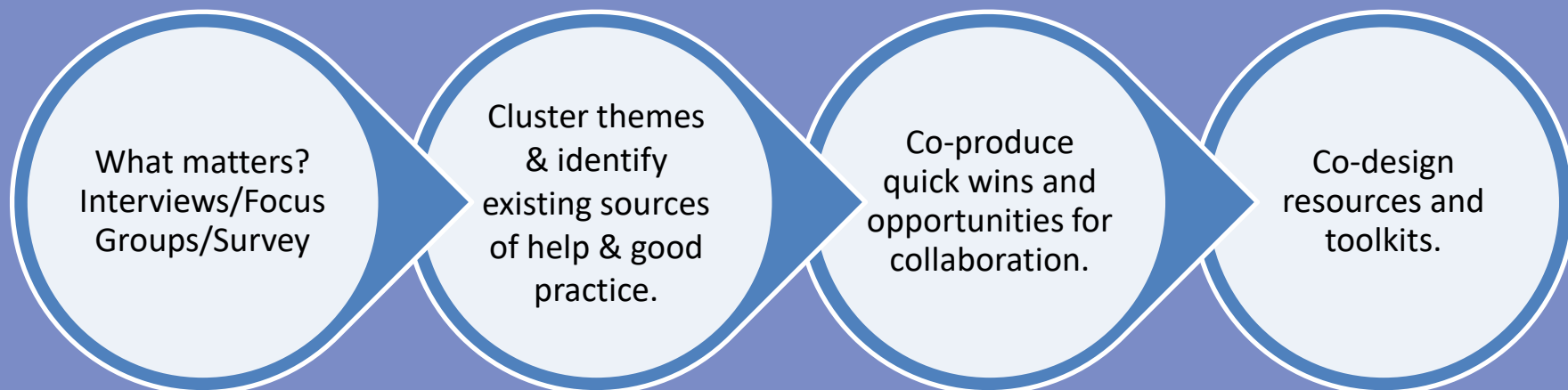
NHSE are aware of a fall in numbers of people receiving a diagnosis of dementia post Covid19.

People are experiencing longer than normal waiting times.

It's important to understand the impact of long delays on people worried about possible dementia in themselves, a relative or a friend and to identify what sources of support, advice and information could be available to people from across Health, Social Care and VCSE.

Whilst the longer delays associated with covid19 will have accentuated the situation, its likely that learning and outputs from this work will have longer term benefits.

# Right at the start | pre-diagnostic support



# In Summary

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- We are working with NHSE and others through the Dementia Change Action Network (DCAN) to make pre-diagnostic support as good as it can be.
- Our starting point is what is important to people in this position and we are holding focus groups, interviews and an online survey to capture this. We will present this in a briefing.
- We then want to understand what is currently available to people pre-diagnosis, working with Dementia Advisors, Admiral Nurses, Social Prescribing Link Workers, General Practice, Memory Assessment Services, and others to get as detailed an understanding of what support there is and how to access it.
- Where there are opportunities to highlight great practice, achieve quick wins or remove barriers we will.

# In Summary

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- Our focus will then be on improving **awareness** and **access** to existing support by bringing people and organisations together and co-producing resources for people and professionals.
- We will categorise support under the three categories of meeting **Clinical**, **Emotional**, **Practical** and **Social** needs pre-diagnosis.
- We expect opportunities for collaboration and innovation will emerge through this work and the conversations and learning it generates. We're therefore keeping the option open for a second phase of the work to seize on these.
- Though COVID-19 has been the driver for the project, we anticipate the project to identify and hopefully address long standing issues that will have a lasting positive impact.



# Learning so far...(very early days)

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What  
matters?

- This is needed!
- Not a blank page, can build on the good but significant challenges exist.
- Timing
- Deeper, richer awareness of dementia symptoms beyond memory loss
- Trust/Shared Decision Making
- Information
- Ease of referral via GP
- Environment -MAS assessment vs life at home felt v different .
- Peer support offers something different

# Phase 1

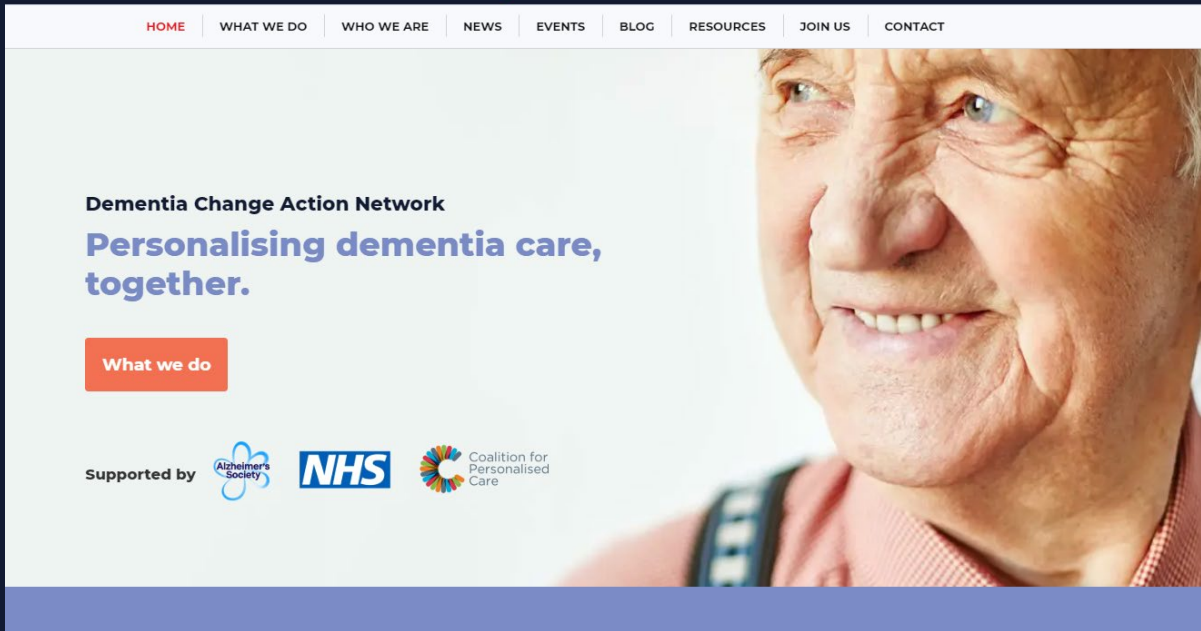
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Start Date: December 2020

- Launch project- via DCAN, Clinical Networks, Linkworkers
- Recruit participants – professionals and lived experience
- Engage with providers and identify leads to work with
- Gather feedback
- Produce discussion paper
- Capture offers and quick wins
- Co-design plan, materials and tools with target audiences
- Promote materials and roll out online, via GPs, support organisations, Link Workers and MAS.
- Review if Phase 2 required.

End Date: February 2021

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