Testing an evidence-based post-diagnostic dementia care model in primary care: preliminary learning from the PriDem feasibility and implementation study

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INTRODUCTION

Current models of dementia care are inequitable, unsustainable and unaffordable [1]. Locating post-diagnostic support within primary care has potential to improve service efficiency and patient/carer wellbeing. The UK PriDem research programme aims to develop and test primary care led models of post-diagnostic dementia care. An intervention development phase (workstreams 1-3) identified key components of post-diagnostic support [2-4] and a need to focus on three interlinked intervention strands: **developing systems, delivering tailored care & support, and building capacity and capability** within the workforce, to deliver improved post-diagnostic dementia support. An evidence-based, person-centred intervention was co-developed with key stakeholders. The three intervention strands are led by a **Clinical Dementia Lead (CDL)**, from a nursing/allied health background. The CDL is working with local stakeholders to support sustainable change through improving local systems and developing tailored resources e.g., to optimize annual dementia reviews and personalised care planning.
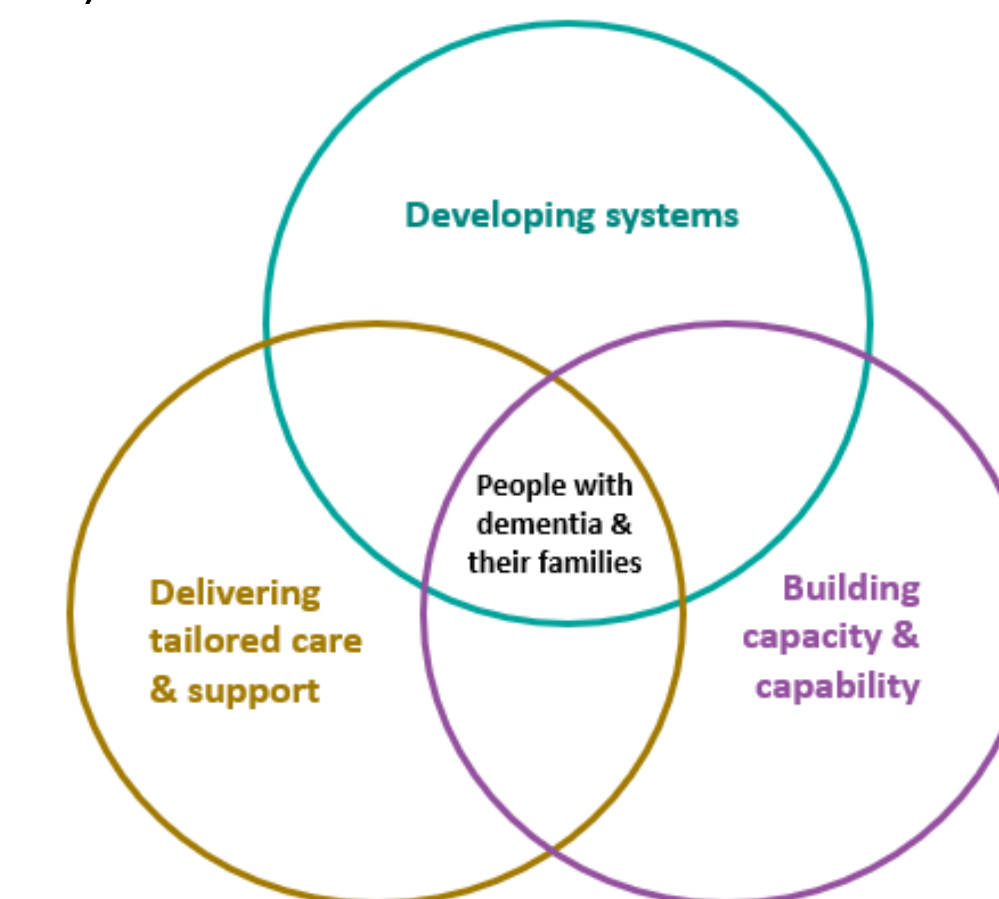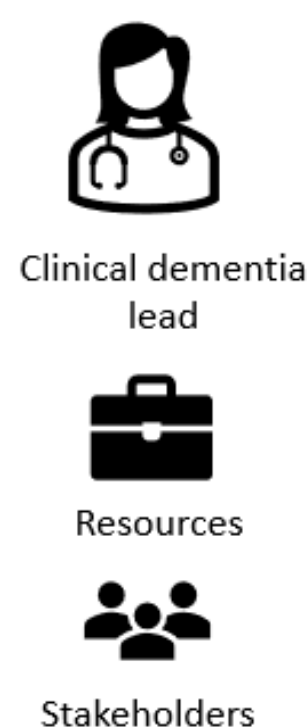
PRIDEM WORKSTREAM 4

12-month multi-site feasibility and implementation study, currently in recruitment phase (see timeline). CDLs are in post in the Southeast (SE) and Northeast (NE) of England and have undergone bespoke PriDem training. They are supervised by a dementia specialist nurse.
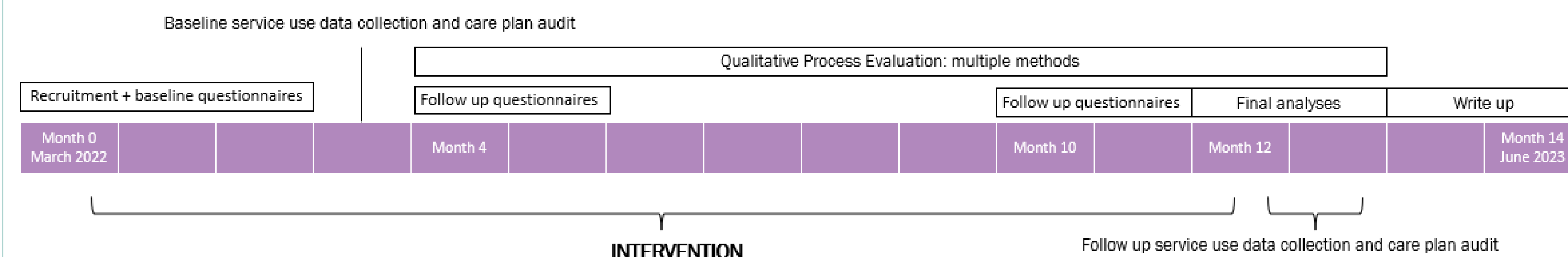
Study methods:

- Recruit up to 80 people living with dementia and 66 care partners across SE and NE England, from up to four Primary Care Networks (PCNs)
- Feasibility and acceptability outcomes (e.g., recruitment, retention, completion rates)
- Quality of life and wellbeing measures + service use data: baseline and two follow ups
- Electronic care records audit, for presence/absence and quality of personalised care plans. Audit includes patients on dementia registers of GP practices involved in the study. Baseline and follow up audits 12 month periods pre- and post-intervention.
- Multi-methods process evaluation (qualitative interviews, observations and reflections): describe factors influencing implementation of intervention in practice. Codebook thematic analysis [5].

EARLY STUDY SET-UP CHALLENGES	HOW WE OVERCAME THE CHALLENGES
Recruiting GP practices to the study	Building relationships over time/understanding unique pressures faced by practices
Enthusiasm about the research BUT…	Reducing burden on practices. obtained **NHS Confidentiality Advisory Group approval** for researchers to access medical records for recruitment activities and conduct care plan audit
COVID-19/vaccination programme response, NHS Recovery plan (focus on waiting lists/waiting times) and NHS staffing issues led to GP practice team concerns about capacity to take part	Highlighting benefits e.g., *'The CDL will provide mentorship alongside informal/formal bespoke training'*

Outcome: From initial meetings, to recruiting three GP practices (from one PCN) in the SE and five GP practices (across three PCNs) in the NE – **Duration = five months**

Recruiting Clinical Dementia Leads to deliver the intervention	Secondment and Job share opportunities highlighted in advert
Short term post + NHS staff shortage, exacerbated by COVID-19	Advertised widely nationally, and locally within NHS project localities
In SE, CDL employed by university - difficulty matching University/NHS salary grading	
In NE, CDL employed by PCN - advert could not go live until PCN participation agreed	
Once CDLs appointed, time also needed to set up secondment arrangements	

Outcome: From first advert to first CDL starting in post – **Duration = six months**

Operationalising personalised care plan audit	Informed by literature, existing care plan templates, national policy and key components of post-diagnostic care developed in PriDem Workstream 2 [e.g.,6-8], developed proforma for collecting audit data. Allows researchers to judge i) Is there a care plan? and ii) care plan quality criteria (e.g., these include *'Was the PLWD and/or carer invited to consider their priorities?'* *'Has the person living with dementia / carer been provided with a copy of the care plan?'*
How to judge presence and quality of a care plan	
Baseline year (04/2021- 03/2022) not typical for dementia reviews/care plans (Covid-19)	A Pre-COVID-19 year will be used as a 'more typical' baseline year - 04/2018 - 03/2019

IMPLICATION OF CHALLENGES: Workstream 4 original end date 30/09/2022. Project granted extension. New end date 30/06/2023

References