

*Improving post diagnostic dementia care – an evidence-based approach*

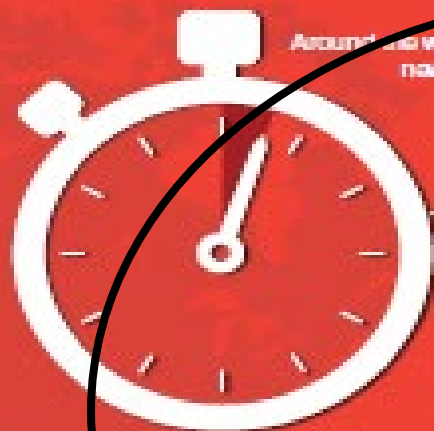
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From Newcastle. **For the world.**

INFOGRAPHIC

# The global impact of dementia

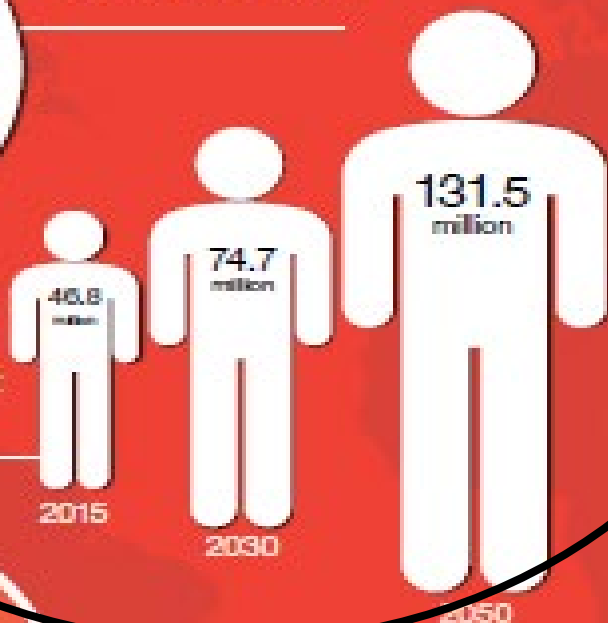


Around the world, there will be 9.9 million new cases of dementia in 2015,

**one every 3 seconds**

46.8 million people worldwide are living with dementia in 2015.

This number will almost double every 20 years.



Much of the increase will take place in low and middle income countries (LMICs): in 2015, 58% of all people with dementia live in LMICs, rising to 63% in 2030 and 68% in 2050.



The total estimated worldwide cost of dementia in 2015 is US\$ 818 billion. By 2030, dementia will become a trillion dollar disease, rising to **US\$ 2 trillion by 2030**

If global dementia care was a country, it would be the

**18th largest economy**

in the world exceeding the market values of companies such as Apple and Google



source: [www.alzdiscovery.org/news](http://www.alzdiscovery.org/news)



This map shows the estimated number of people living with dementia in each world region in 2015.

We must now involve more countries and regions in the global action on dementia.

INFOGRAPHIC

# The global impact of dementia

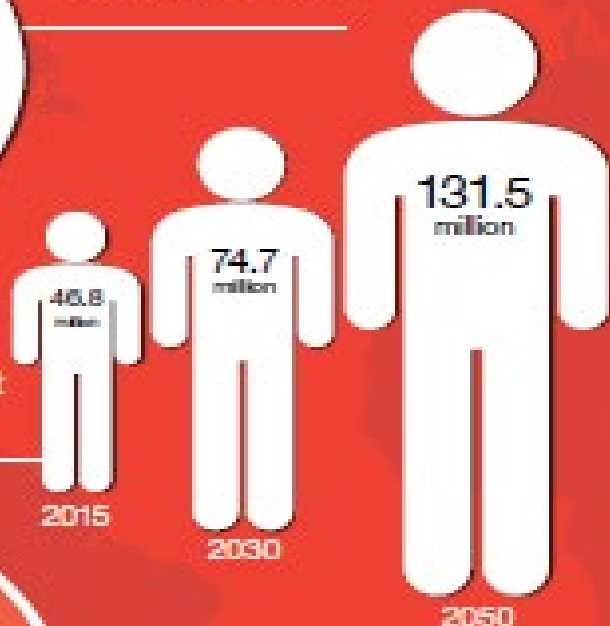


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source: world dementia report



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## 2006: UK NICE dementia guidance

- Specialist led care... 'memory clinic in every town'

## 2011: World Alzheimer Report

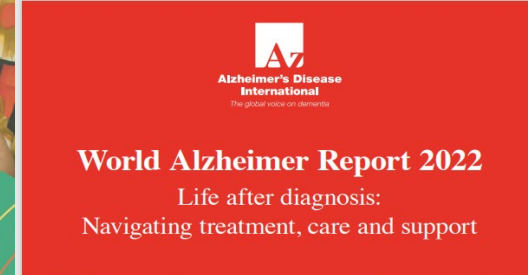
- Role of GP/primary care... 'under-used'

## 2016: World Alzheimer Report

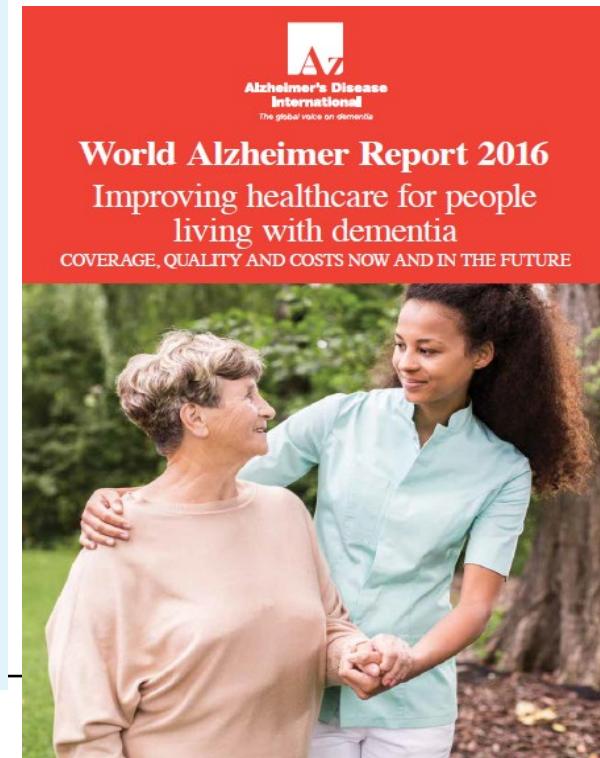
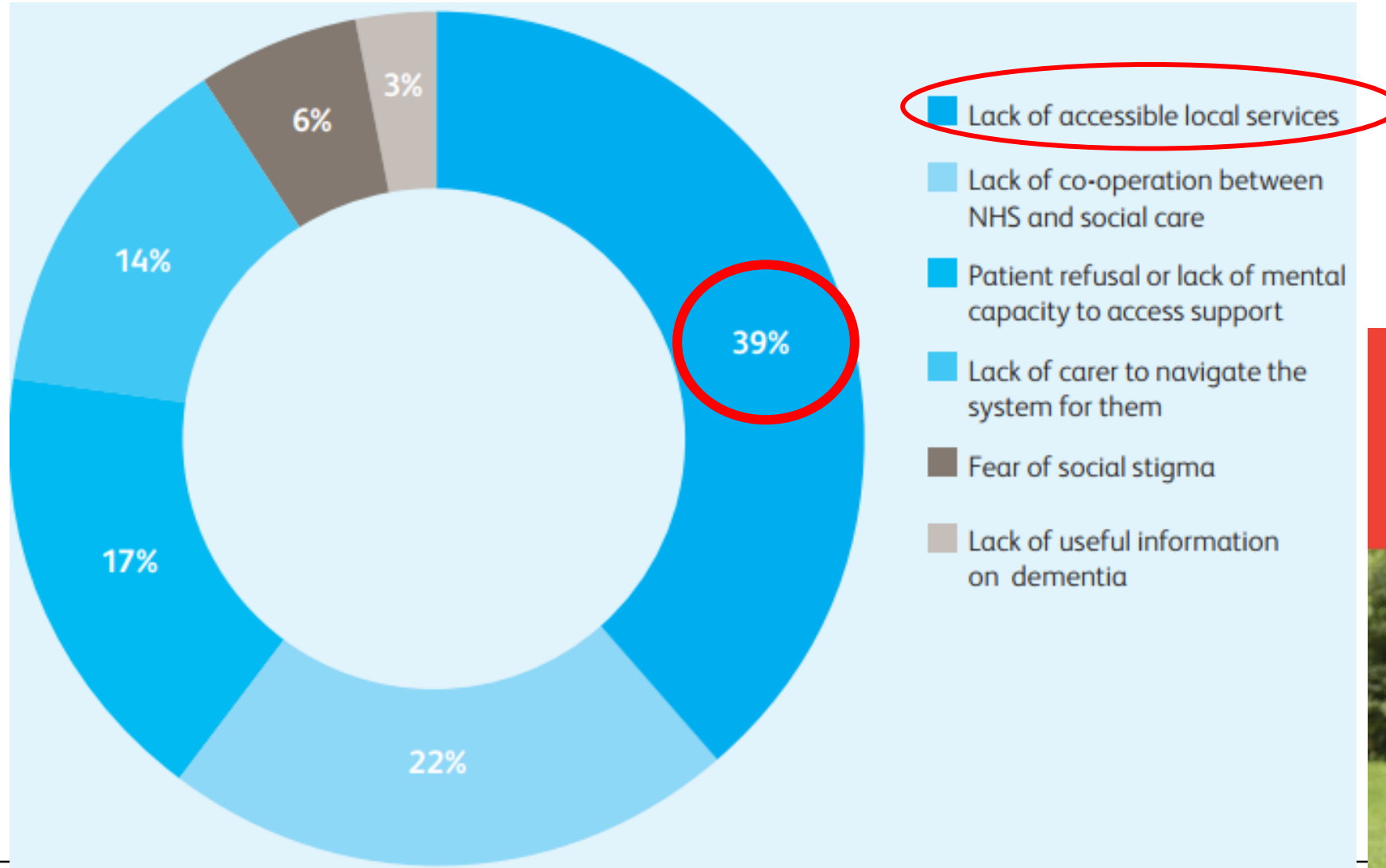
- Current care model unsustainable - *task-shifted*

## 2022: WAR/WHO 'research blueprint'

- Post diagnostic care: person centred, low cost, evidence based







5 year programme: £1.7million

## 6 work streams (WSs): Medical Research Council framework

1. Global evidence – systematic reviews
2. National practice: mapping + good practice case studies
3. 'Best practice' model development (data from 1+2 )
4. Testing in 'real world' primary care
5. Health economic evaluation
6. Translation into policy and practice

← **'Dementia Care Community'** →



## Research

Rachael Frost, Kate Walters, Su Aw, Greta Brunskill, Jane Wilcock, Louise Robinson, Martin Knapp, Karen Harrison Denning, Louise Allan, Jill Manthorpe and Greta Rait; on behalf of the PriDem Study project team

19 May 2020) of an abridged version published in print. Cite this version as: **Br J Gen Pract 2020; DOI: <https://doi.org/10.3399/bjgp20X710165>**

## Effectiveness of different post-diagnostic dementia care models delivered by primary care:

a systematic review

### WS1: evidence synthesis (3 reviews)

- **23 papers:** 5 RCTs (USA, Germany, Netherlands, Singapore)
- **4 types of Primary Care (PC) models**
  - PC provider led; PCP-led + specialist care; PCP case management; Integrated PC memory clinics

➔ **PCP case management model\* most promising**

impact on person with dementia and family carer, care costs  
(\*Specialist nurse: care-coordinator/lead professional)

# WS1 evidence synthesis...

- **Dementia expertise 'in PC'**
  - **Strong collaboration + specialists**
  - **Service providers: engagement + leadership**
  - **Care network: good links + social care/community services**
- 
- Patient/carer self management
  - SMART intervention outcomes
  - **Structured, formal collaboration**
    - **e.g. shared care pathway, shared care plan**



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## Implementing post diagnostic dementia care in primary care: a mixed-methods systematic review

Rachael Frost , Greta Rait , Su Aw , Greta Brunskill , Jane Wilcock , Louise Robinson , Martin Knapp , Nicole Hogan , Karen Harrison Denning , Louise Allan , Jill Manthorpe , Kate Walters & on behalf of the PriDem team

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REVIEW ARTICLE

Health and  
Social Care in the community

WILEY

## What works in managing complex conditions in older people in primary and community care? A state-of-the-art review

Rachael Frost PhD<sup>1</sup>  | Greta Rait MD<sup>1</sup> | Alison Wheatley PhD<sup>2</sup> | Jane Wilcock MSc<sup>1</sup>  | Louise Robinson MD<sup>2</sup> | Karen Harrison Denning PhD<sup>3</sup> | Louise Allan PhD<sup>4</sup> | Sube Banerjee MD<sup>5</sup> | Jill Manthorpe MA<sup>6</sup>  | Kate Walters PhD<sup>1</sup> on behalf of the PriDem Study project team



BMJ Open Task-shifted approaches to postdiagnostic dementia support: a qualitative study exploring professional views and experiences

Alison Wheatley <sup>1</sup>, Claire Bamford,<sup>1</sup> Greta Brunskill,<sup>1</sup> Karen Harrison Dening,<sup>2,3</sup> Louise Allan,<sup>4</sup> Greta Rait,<sup>5</sup> Louise Robinson <sup>1</sup>, The PriDem Study project team

## 2.1: England/Wales: key stakeholder views

N=61 Commissioners, providers, front line staff

**‘FRAGMENTATION & FRAGILITY’**

**‘INEQUALITY & INSTABILITY**

- Huge variability: especially NICE recommendations and access to specialist support
- Funding sources: major challenge to sustainability
- Lack of integration e.g. lack of shared care pathways; data sharing
- Primary care concerns: lack of capacity, skills and willingness

## 2.2: Good practice: 6 case studies

Specialist dementia nurse in GP

GPs + extended role (GPWERS)  
across a CCG

Third sector community memory  
support workers

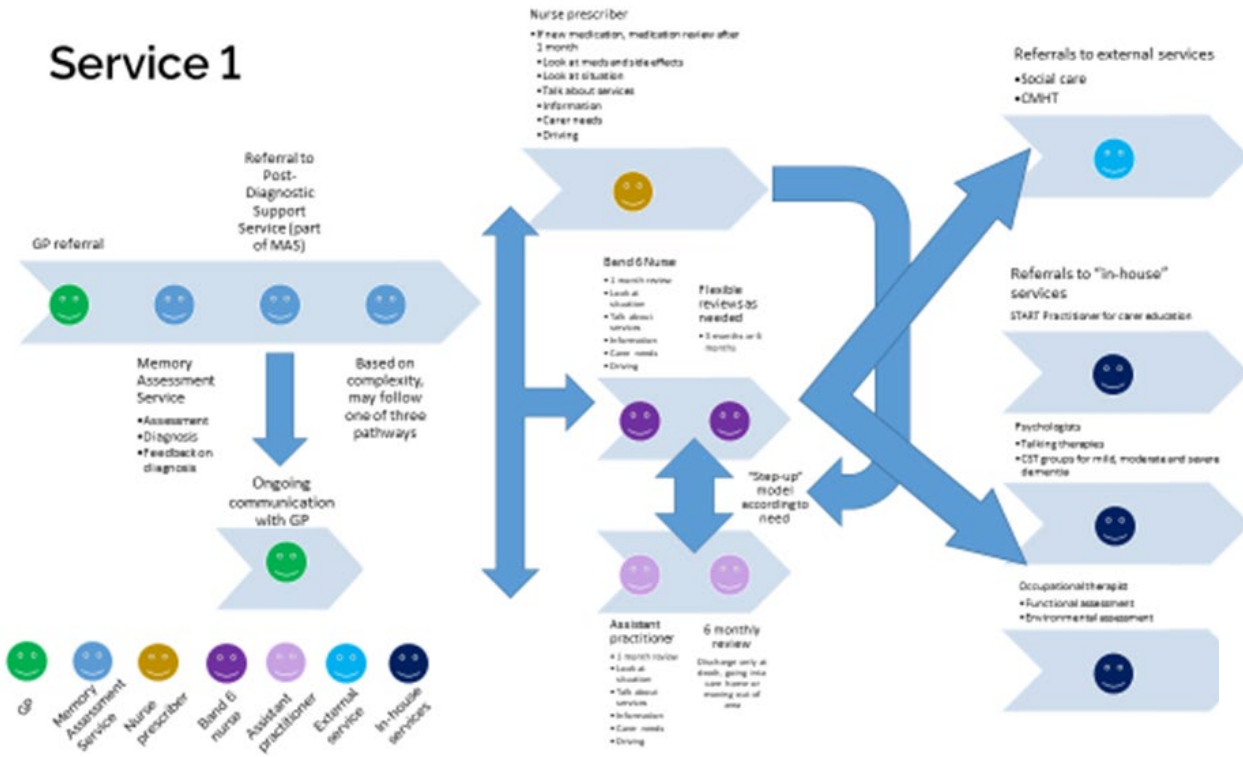
Secondary care enhanced memory  
assessment service

Secondary care step up/down  
models + GP practices (x2)

n= 17 people with dementia, 31 carers, 68  
service managers and 78 frontline staff.

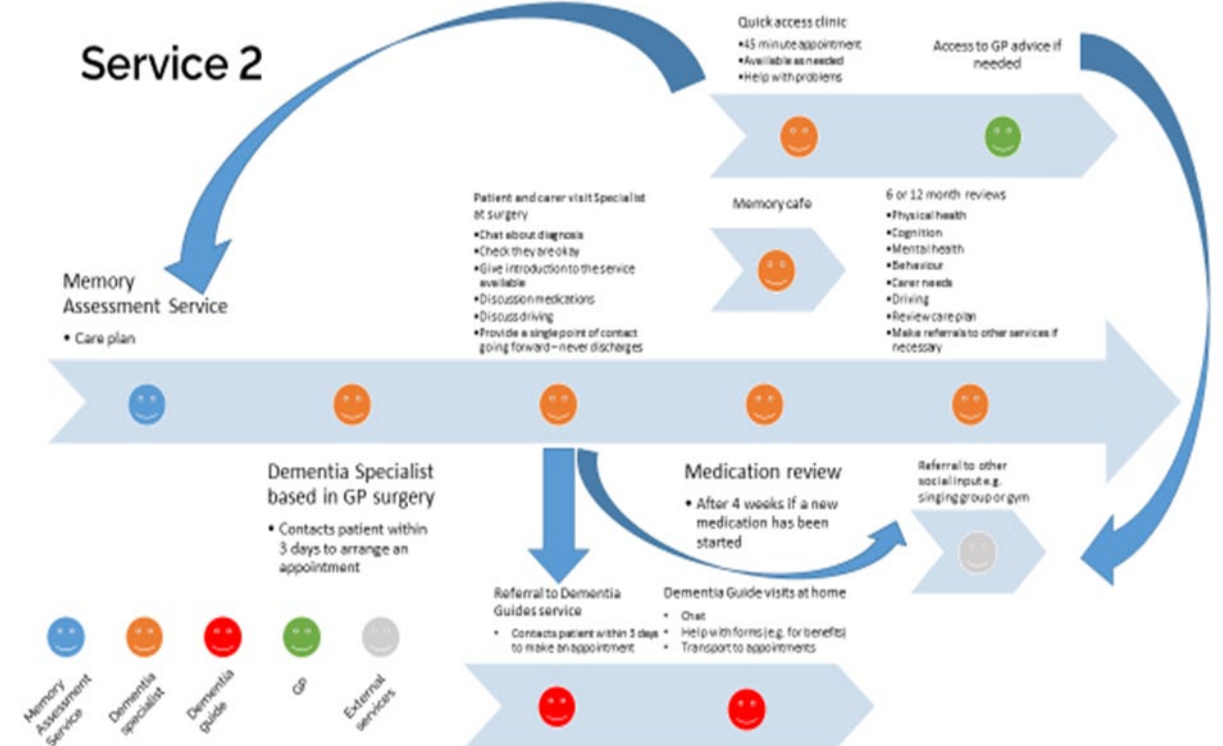


# Service 1



**No single perfect model**

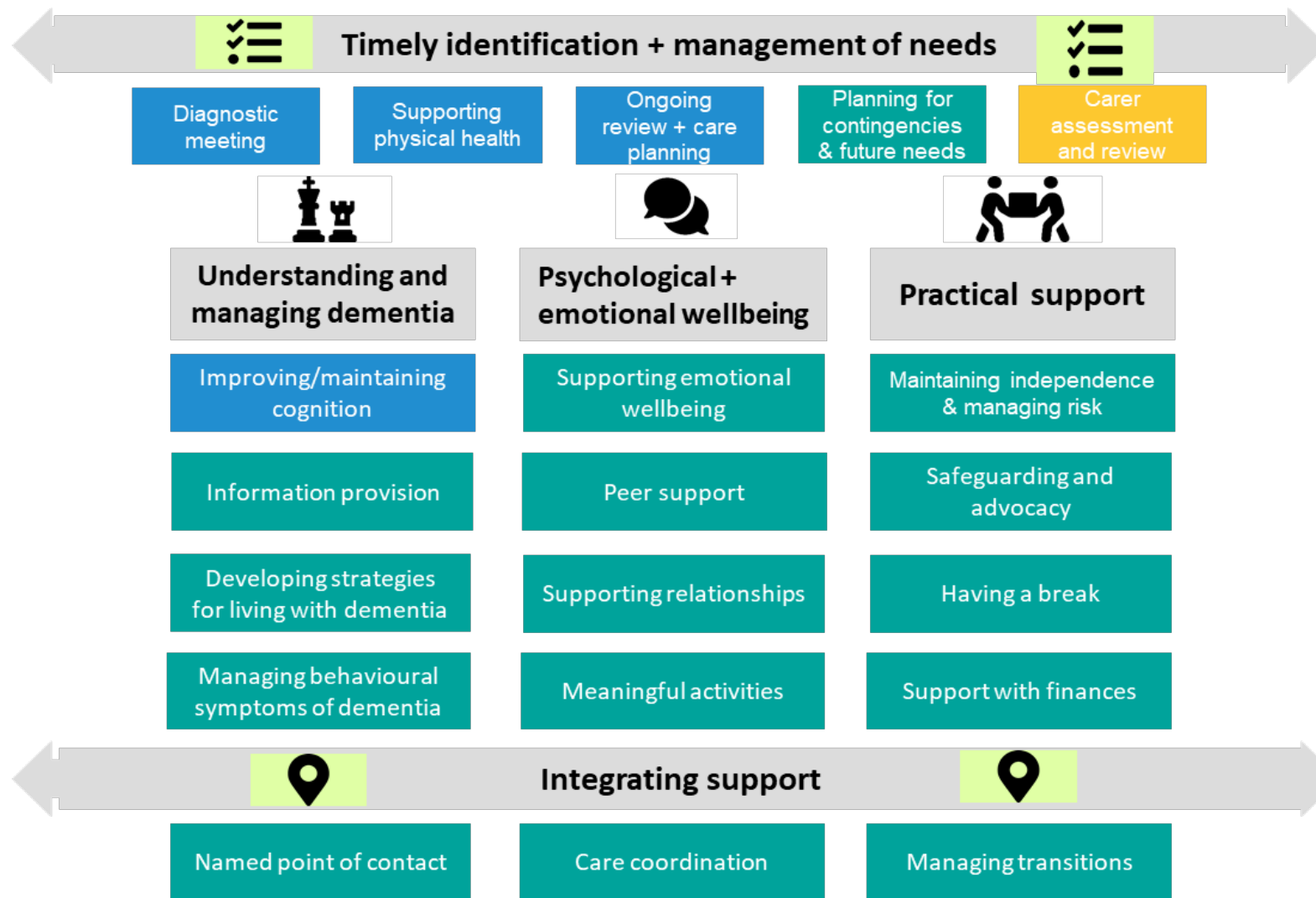
# Service 2



# PriDem: Core components of dementia care

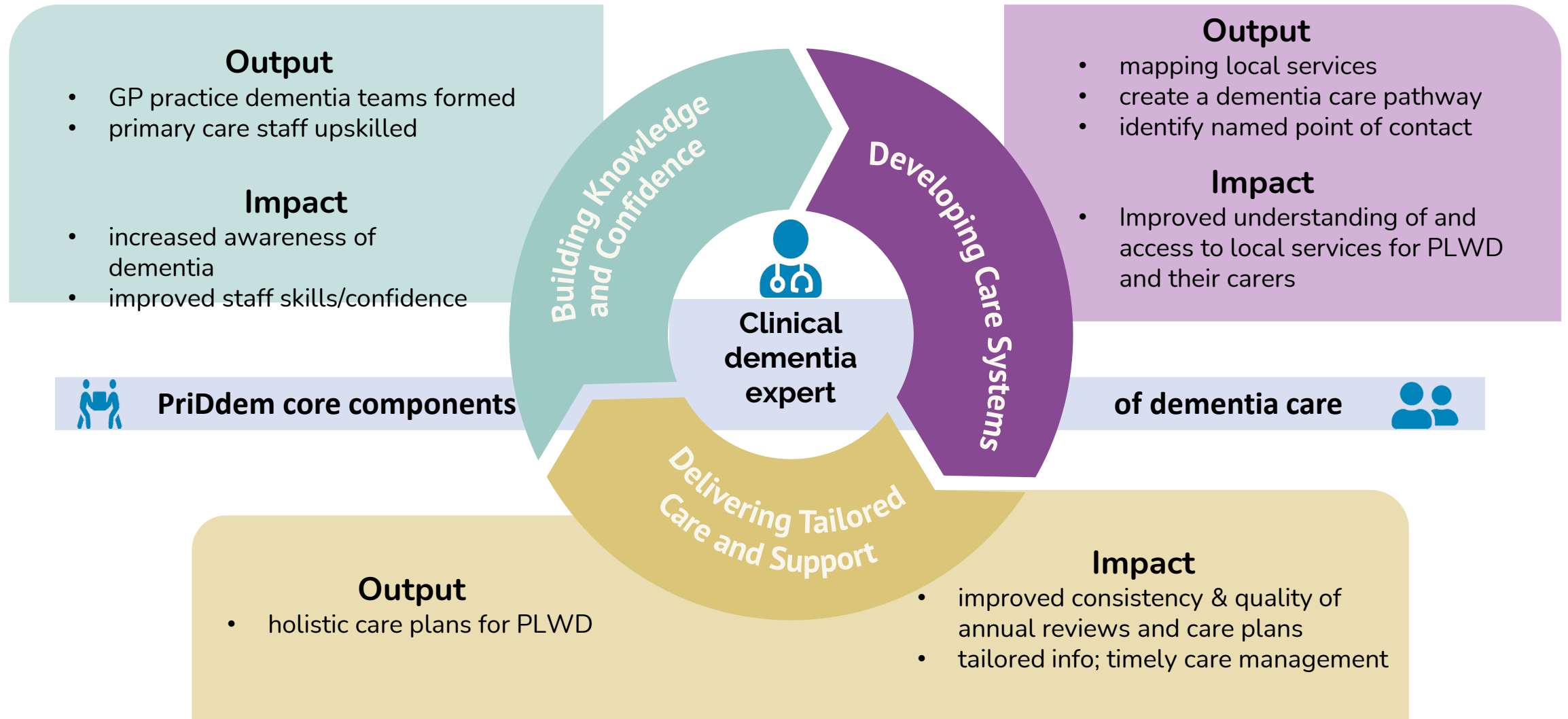
**Key**

- PLWD
- Carers
- PLWD or carers










# PriDem intervention and impact



# WS 4/5: pilot study + economic modelling

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BMJ Open Protocol for the feasibility and implementation study of a model of best practice in primary care led postdiagnostic dementia care: PriDem

Sarah Griffiths <sup>1</sup>, Emily Spencer,<sup>1</sup> Jane Wilcock,<sup>1</sup> Claire Bamford,<sup>2</sup> Alison Wheatley,<sup>2</sup> Greta Brunskill,<sup>2</sup> Federica D'Andrea,<sup>1</sup> Kate R Walters <sup>1</sup>, Natalia Lago,<sup>3</sup> Aidan O'Keeffe,<sup>4</sup> Rachael Hunter <sup>1</sup>, Remco Tuijt <sup>5</sup>, Karen Harrison Dening,<sup>6</sup> Sube Banerjee,<sup>7</sup> Jill Manthorpe,<sup>8</sup> Louise Allan,<sup>9</sup> Louise Robinson <sup>2</sup>, Greta Rait,<sup>1</sup> on behalf of the PriDem study team

**Mixed methods + process evaluation + health economics**

Quantitative data: baseline; 4 & 9 month follow up

**Outcome measures:**

**Primary: personalised care plan; secondary: quality of life; health and wellbeing; cognition**

**Setting: 7 general practices in 4 Primary Care Networks** in Northeast/Southeast England

**Intervention:** two **CDLs** delivered the intervention over **12 months**

**Sample:** eligibility: dementia diagnosis; living at home at beginning of audit period

**Recruitment: 60 PLWD (75% target) – 47 (13 withdrew)**

**51 carers (75% target) – 40 (11 withdrew)**

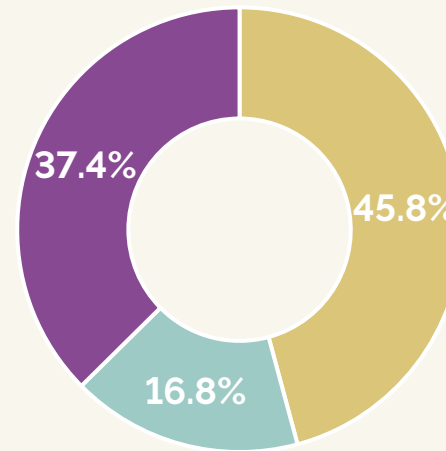
**Process evaluation** (1-1 interviews): 16 people with dementia; 14 family carers and 26 professionals

**Care plan audit:** 215 patients pre-intervention (2018-9) + during intervention year (2022-3)

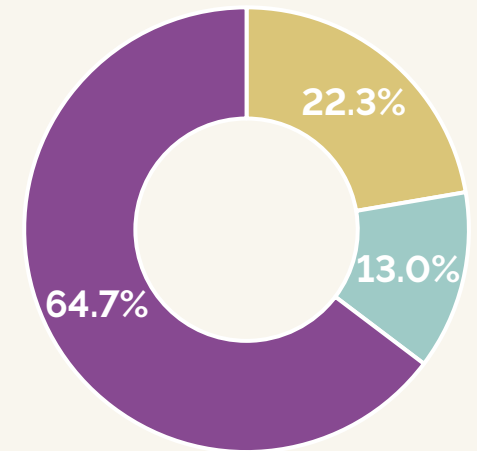
# Care plan audit results

Primary outcome: presence or absence of **personalised care plans**

Pre-intervention year, n=179



Intervention year, n=215



- personalised care plan
- care plan not personalised
- no evidence of care plan

QOF Year	Patients with personalised care plan	95% confidence interval	p-value
Pre-intervention (2018-9)	37.4%	[31.4%, 100%]	0.759
Intervention (2022-3)	64.7%	[59.1%, 100%]	< 0.0001



GP practices had varying **attitudes towards care planning at the start** - some considered this to be tick box exercise, which acted as a barrier to change.

*“One practice, it was a real struggle to get them to buy into why a dementia review was really important and why it was necessary, and the benefits to patients and families”.. (CDL)*

*“I had a phone call from the GP to say he was due for his annual dementia review. We’ve never had one before [laughs]. So that’s something new” (wife of person with dementia)*

**BUT for people with dementia, carers and professionals, the enhanced, holistic care planning process was mutually beneficial.**

*“ It was very enterprising I thought. Because it was pretty different from anything I’d had at [GP practice] before [...] I went away very, very well satisfied’*

*“ And the staff were wonderful.” (person with dementia and friend)*

*“a lot of patients have felt neglected and lost to general practice in the last two years.. these are our most vulnerable patients but they’re also the ones that we find most difficult to access because they’re not the loud ones that get the emergency appointments, they’re the ones that just, you know, things get worse and worse and they have crisis...so proactively reaching them and offering them such a comprehensive review has regained some of their trust in us. And so I think that’s been the overriding real benefit” (GP doctor).*

*“people with dementia their physical needs get neglected... oh, it's just dementia. So, it was really good to get their physical, mental health, as well as their social needs by using an MDT approach with the social prescriber, nurse and GP (CDL)*

# Engagement with intervention activities by GP practice

Intervention strand	Practice 01	Practice 02	Practice 03	Practice 11	Practice 12	Practice 13	Practice 14	Total per strand/35
Developing systems/5	3	4	1	4	5	4	1	22
Delivering tailored care & support/5	4	5	1	5	5	5	4	29
Building capacity & capability/5	4	4	4	5	4	4	4	29
<b>Totals</b>	<b>11/15</b>	<b>13/15</b>	<b>6/15</b>	<b>14/15</b>	<b>14/15</b>	<b>14/15</b>	<b>9/15</b>	<b>80/105</b>

- **Evidence based model of primary care based post diagnostic dementia care is feasible and acceptable; shows early signs of improving quality of care**
- **Co-ordinated by clinical dementia lead (specialist nurse) with focus on 3 areas:**
  - Direct patient care (complex cases)*
  - Supporting and training primary care staff*
  - Building systems: care pathway and personalised care planning*
- **Very similar to management of other long term conditions in UK (diabetes, cancer)**
- **More detailed findings on clinical effects and health economics analysis pending**

Acknowledgements: All participants and our research funders Alzheimer Society England.

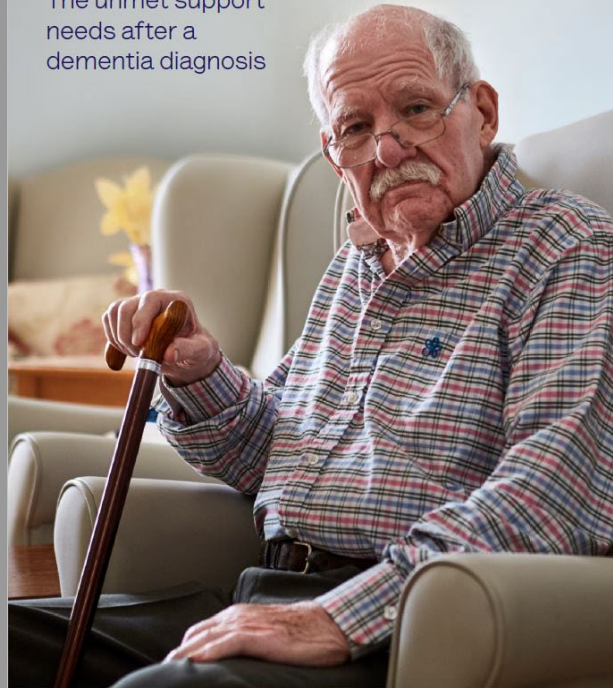
## From diagnosis to end of life:

The lived experiences of dementia care and support



## Left to Cope Alone

The unmet support needs after a dementia diagnosis



From Newcastle. For the world.



## From Plan to Impact V

WHO Global action plan:  
The time to act is now



ALZHEIMER'S DISEASE INTERNATIONAL | WORLD ALZHEIMER REPORT 2022

Expert essay

### An evidence-informed, primary care-based, task-shared approach to post-diagnostic dementia care: the PriDem programme

Louise Robinson

Newcastle University, United Kingdom

The 2016 World Alzheimer Report urgently recommended research into efficient, integrated, and holistic models of post-diagnostic dementia care and support. It concluded that the current specialist-led, healthcare model of dementia care was unsustainable, in view of our rapidly ageing populations, and urged a task-shared, task-shared approach, with greater involvement of primary care. Directly addressing this issue, our team in England developed the Primary care-based post-diagnostic Dementia Care (PriDem) programme. The aim of PriDem was to develop, implement, and evaluate evidence-based, person-centred, and sustainable models of post-diagnostic dementia care and support in primary care settings following national research recommendations. Our research would be unique in that it would be co-created with a patient, public, and professional stakeholder group, namely the Dementia Care Community (DCC). It comprised people living with dementia, their family carers, and health and social care providers as well as service commissioners[1].

#### Phase 1: Learning lessons from existing international research

We began by synthesising findings from previous research. In terms of effectiveness, a systematic review of research trials and economic evaluations of post-diagnostic dementia care interventions where primary care was substantially involved in care planning and decision-making included 23 papers [10 trials of nine interventions delivered in four countries][2]. A primary care case management model, usually specialist nurse-led, showed the most promise in terms of patient/carer outcomes and healthcare costs[2].

Next, we sought to identify key factors which facilitated the successful implementation of such primary care approaches. Our mixed methods systematic review included 49 service evaluations of a wide range of primary care models[3]. Key enabling factors included: having clinical dementia expertise within or easily accessible to primary care, primary care leadership, key stakeholder engagement and commitment,

and sufficient funding[3]. Finally, we questioned whether lessons could be learned from the primary care management of other long-term, complex conditions, such as Parkinson's disease, via an analysis of systematic reviews[4]. Having formal collaboration and service integration between key services – for example, a shared care pathway and/or shared review – was one of the important factors[4].

#### Phase 2: Learning from national examples of "good practice"

A decade after England's national dementia strategy was introduced, we mapped post diagnostic dementia care and support provision via an e-survey of dementia commissioners[5]. Findings from 82 service commissioners with representation from each region in England revealed: i) considerable geographical inequalities in services, with most focusing on information provision and support within the first two years after diagnosis and ii) fragile and fragmented services due to short-term funding sources. Despite an increasingly diverse population, few areas reported service provision for minority populations[5]. A follow-up interview study one year into the COVID-19 pandemic revealed potential worsening of such inequalities[6].

Building on our survey, we used qualitative approaches to further explore current dementia care provision in England and Wales in more depth[7,8]. Our sample included: 61 commissioners and service managers; 68 service providers (health, social care, and voluntary sector including frontline staff); and 48 service users (17 people living with dementia and 31 carers). Participants had varied views as to whether a primary care approach was appropriate, achievable, and/or desirable. Potential benefits of a task-shared approach were continuity and familiarity for both people living with dementia and staff and a more holistic approach to dementia care; challenges included the capacity, ability and inclination of primary care to deliver such services. Conceptual challenges included uncertainties around the nature and length of post-diagnostic support and identification of which tasks



## World Alzheimer Report 2022

Life after diagnosis:  
Navigating treatment, care and support





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