

Age-sensitive services for people affected by Young Onset Dementia (YOD)

WHERE TO FROM HERE?

CLAHRC funded study - Development Grant (12m)

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Disclaimer: The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or one of its programmes.

Background:

- Approximately 5% of people living with dementia have been diagnosed with Young Onset Dementia (YOD) (age at diagnosis <65); currently +/- 42 500 people in the UK

- Their post-diagnostic support needs differ considerably from those of people who are older
- Literature agrees that services should be
 - person centred
 - accommodate care needs along the disease trajectory
 - help to keep people at home for as long as possible
- BUT
- Lit was primarily needs-based
- There does not seem to be enough evidence in the literature to inform service design

RESEARCH QUESTIONS

- What does 'age appropriate' mean and do we really need such services?
 - If so, how do they need to differ from generic dementia services offered for much older populations?
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- What does current service provision look like?
 - Are there any care pathways for people living with YOD in England?
 - If so, what are the referral mechanisms involved, associated costs, and how is effectiveness evaluated?
 - What would a care pathway for people living with YOD need to include to provide appropriate post- diagnosis support?
 - Access to relevant services at home, in the workplace, and patient and carer engagement? [Q for service providers]

METHODS

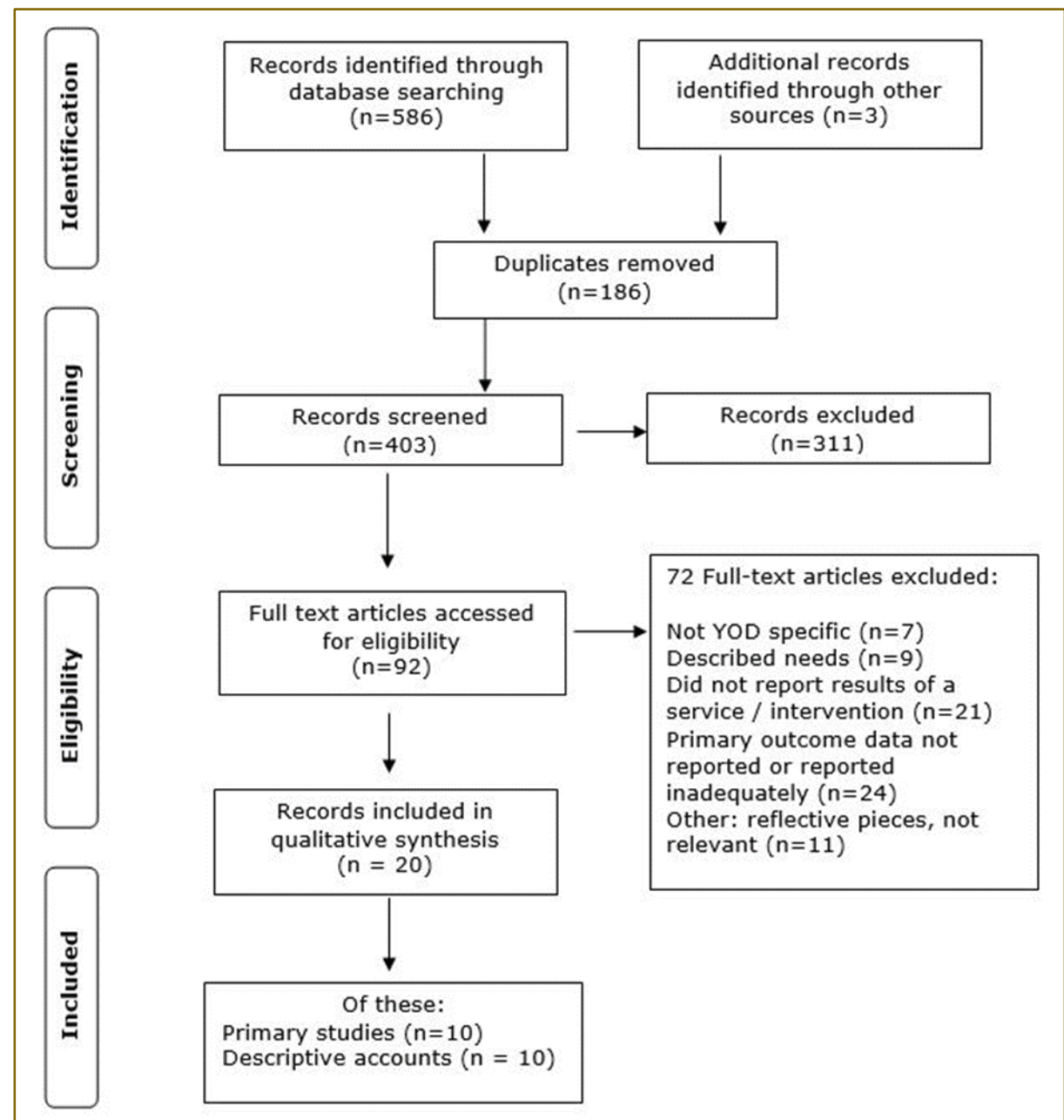
- 1) **COMPREHENSIVE SCOPING REVIEW:** To establish what is known about the range and perceived effectiveness of experience of post-diagnostic services
- 2) **A REVIEW OF GREY LITERATURE and ONLINE SEARCH** on service provision published by NHS organisations and charities that target people living with YOD
- 3) **PPI CONSULTATIONS** with people living with YOD and their carers (2 study sites)

The Scoping review, online searches and PPI consultations informed the focus of the systematic review

- 5) **A SYSTEMATIC REVIEW OF THE LITERATURE** of post-diagnostic interventions designed to support people living with YOD
- 6) **ECONOMIC REVIEW** to establish how costs associated with YOD are borne and how service provision is recorded
- 7) **INTERVIEWS WITH SERVICE PROVIDERS (2 study sites)**

Primary outcomes:

- Type of services
- Referral mechanisms
- User satisfaction / health and wellbeing, quality of life
- Barriers to accessing services



Accessing knowledge and information

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- ❖ In 26 years, only ten peer-reviewed papers discussing YOD specific services were produced, in contrast to the hundreds of papers that report on the need for age-appropriate services
 - ❖ Service provision is still very fragmented (literature, web-searches, PPI discussions)
 - ❖ **Yet, there is also another picture emerging (last year):**
 - ❖ *Current developments & activities – a bit more online, but little researched and published*
 - ❖ The launch of the Young Onset Dementia Network (Sept / Oct 2016)
BUT: the points made above still apply

Services that were perceived to be most useful

❖ **Memory clinics / Neurology services**

- ❖ If services were informative, educational in relation to the condition, addressed the person with YOD and their caregiver as a dyad, signposted to services that were appropriate to the illness trajectory

❖ **Community services:**

- ❖ Work-based programmes (gardening, zoo, hardware store) - conferred a sense of purpose, social connectedness and social interaction with people 'who understood'
- ❖ Activity –based programmes (playing football; men in sheds; women who lunch...)
- ❖ Day centres for PLW YOD
- ❖ Bespoke home-based care (remain at home for longer)
- ❖ Respite services for caregivers
- ❖ Support with legal and financial issues (NHS/Citizens' Advice Bureau)
- ❖ Services which support PLW YOD and their caregiver as a dyad
- ❖ Services which are cognisant of changing care needs along the disease trajectory
- ❖ Support to go out in the community

Yet, services are perceived to be lacking. Why?

1) Project-based commissioning

- Often for one year
- Legal requirements of tendering processes (3 to 5 years)
- Are not part of an integrated care pathway
- Lack continuity and sustainability
- Change of service providers
- Change of staff
- Discontinuity of care

2) Service providers do not appear to have population level data on YOD

3) Struggle to sustain specialist services that might be under-used, partly due to geographically dispersed populations and lack of an infrastructure of support

Recommendations from the literature

Key service design attributes identified in their reviews of the literature were that:

- ❑ Diagnostic services that signpost and streamline the pathway to post-diagnostic services need to be integrated at the systems level
- ❑ Services at the service level need to facilitate adjustment, enablement, and engagement
The management and care of the condition need to include people living with YOD and their caregivers routinely.
- ❑ Need for research on “service utilisation, costs for illness for YOD and social and informal care costs”.

Where to from here? Recommendations for researchers:

**To help create a joined-up care pathway
and increase the sustainability of post-diagnostic service provision for YOD
future research needs to make a contribution to:**

- Prevalence / incidence figures
- Service design that is informed by evidence of costs including family-borne costs related to age-appropriate interventions (cost of illness studies)
- Capture changing care needs along the disease trajectory (longitudinal)
- Investigating / facilitating legal/financial/welfare support
- Co-design of services that contribute to creating a care pathway
- Co-ordination of care might address the seemingly intractable challenges of sustainability, continuity and cost-effectiveness of service provision

Thank you

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