



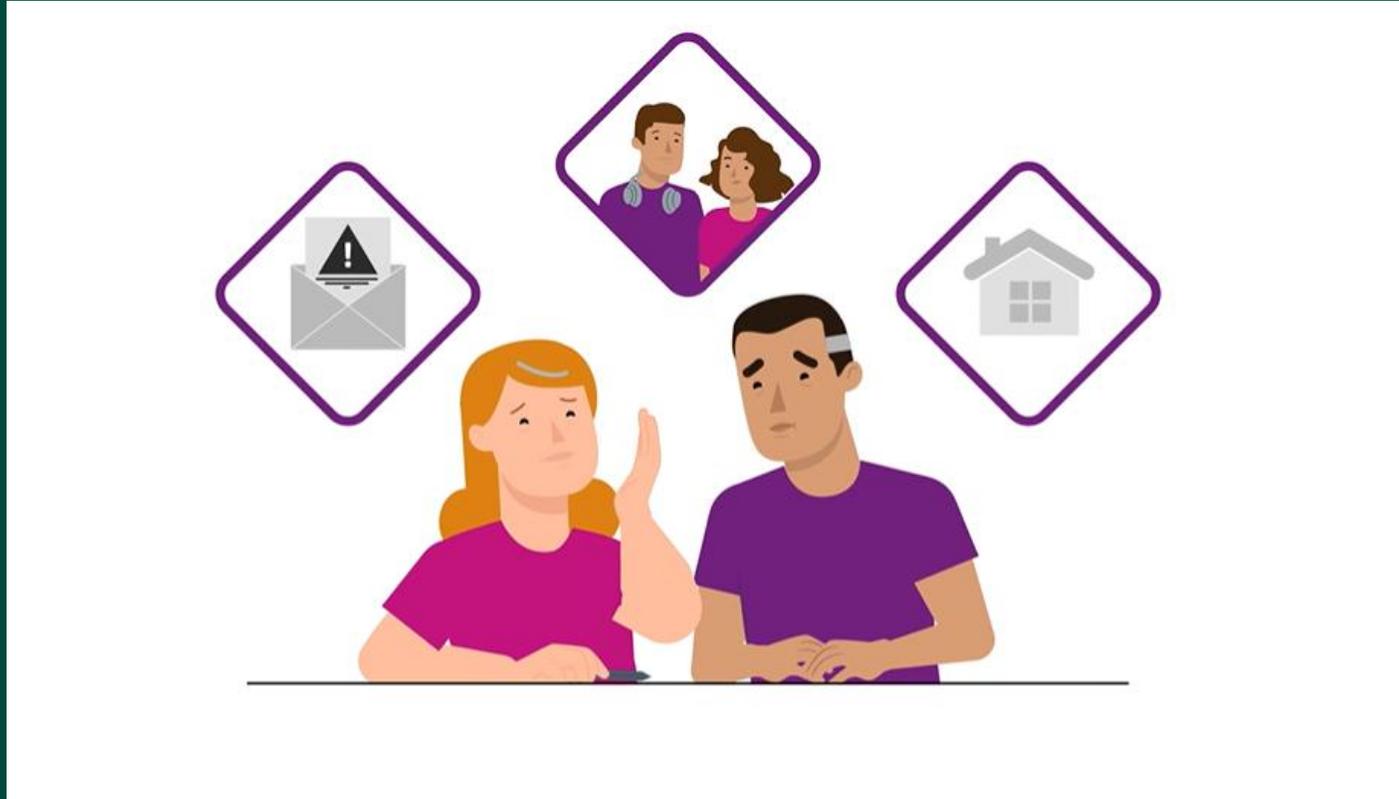
Social care for young onset dementia: The financial impact

Dr Catherine Quinn
c.quinn1@bradford.ac.uk



Social care for young onset dementia: The financial impact

- The DYNAMIC project
- Exploring the evidence base on the financial impact
- Developing the resources
- The resources



I don't think that you can really prepare you for the impact until you speak to someone

Living well

TABLE 1 Summary of responses to the question ‘What does living well mean to you’ by 1339 people with dementia in the IDEAL cohort

Category	Number of references coded
Engaged and active lifestyle	979
Positive relationships with others	636
Good living situation and environment	408
Having security	388
Getting on with life	318
Being able to get out and about	250
A positive outlook on life	236
Being able to cope	194
Having independence	155
Having a purpose	112
Unsure	25

Note: Numbers equate to number of references coded; some responses are coded under more than one category.

- “Having money and no financial problems
- “Money to pay mortgage, bills, buy food and be able to live comfortably and happily”
- “Having enough money to feed yourself, run your house & car”
- “Having money, not a lot but just enough to live comfortably. Have enough money in case of emergency”
- “We're very lucky in that we've got this house and no mortgage”
- “Not being in a position where I wasn't able to afford to lead the lifestyle we have now”

The DYNAMIC project

Social care for people with young onset dementia and their family supporters: Current practice and resources for improvement.

The DYNAMIC study is funded by the National Institute for Health and Care Research Programme through grant NIHR204266. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care

DYNAMIC project aims



Understand social care needs, experiences and preferences of people living with young onset dementia and their families



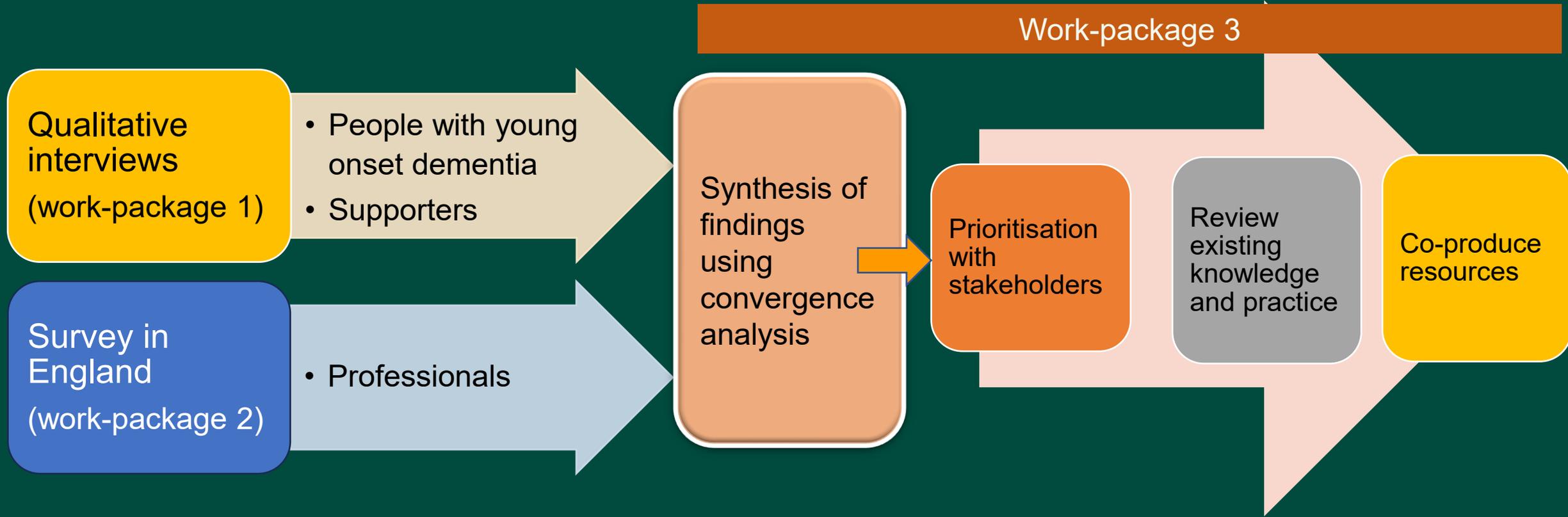
Establish levels of awareness, knowledge and practice among professionals regarding social care



Produce recommendations and resources to improve social care for people with young onset dementia and family members

Quinn, C. et al. (2024). Social care planning and provision for people with young onset dementia and their families: Protocol for the DYNAMIC study. *PLoS One*, 19(2), e0297747. <https://doi.org/10.1371/journal.pone.0297747>

DYNAMIC project overview



April 23

Nov 24

Oct 25

Work package 1: In-depth interviews with people with young onset dementia and their main supporters

25 interviews completed:

A flexible approach:

- 8 dyadic (person with dementia and supporter together)
- 17 individual (14 supporter alone, 3 person with dementia alone)

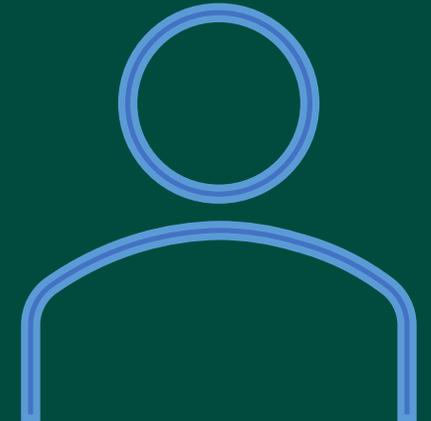
Choice of mode:

- 13 in-person
- 8 online
- 4 telephone

33 participants in total

11 people with young onset dementia

22 supporters



Person losing their job:

- *“But it's also monetary worries because he hasn't worked for at least 12 months before his diagnosis. He wasn't able to hold a job”*
- *“I've handed my retirement notice in because I can't cope with working and looking after [name of person with dementia] anymore. Didn't really want to, and I'm sad about that”*

Costs of care

- *“So, the only way to deal with that was to the, basically, financial ruination of paying for a live-in carer, and my attitude was, well, if I have to liquidate my whole pension and spend it on [name of person with dementia]’s care, so be it. Eventually... maybe the state will step in at that point”*

Additional costs

- *“All of this is it has a cost, especially the travel”*

Lack of support

- *“Dementia side, nobody talks about finances, about what you're entitled to or what you're not entitled to.... When I got diagnosed with cancer, the first thing they do is, we'll go through your finances and then it's, you should be on this. Dementia side, nobody mentions your finances”*

Survey on social care provision for YOD

- Created a short survey for staff with a role in or awareness of adult social care planning, provision, management, or commissioning in England.
- Aim was the better understand the provision.
- 139 people completed the survey.
- Respondents were commonly working in local authorities (34.5%), mental health trusts (25.9%), or third sector organisations (18.7%).



Quinn, C., Young, H., Stamou, V., Gridley, K., Mason, K., & Oyeboode, J. (2025). Professionals' Views on Social Care Planning and Provision for People With Young-Onset Dementia and Their Families in England: Findings From the DYNAMIC Study. *International Journal of Geriatric Psychiatry*: e70155. <https://doi.org/10.1002/gps.70155>.

What situations triggered referrals for a social care assessment for people with YOD or their families?

- Predominately responses indicated referrals were made in times of crisis/safeguarding
- Types of care needs triggering referrals- often due to concerns about the carer
- Financial issues were raised:
 - *“When finances are stretched and funding private support is no longer an option”*
 - *“If a person living with dementia has concerns about supporting the family / unable to work as long as planned prior to a diagnosis”*

How could access to social care for people with YOD be improved?

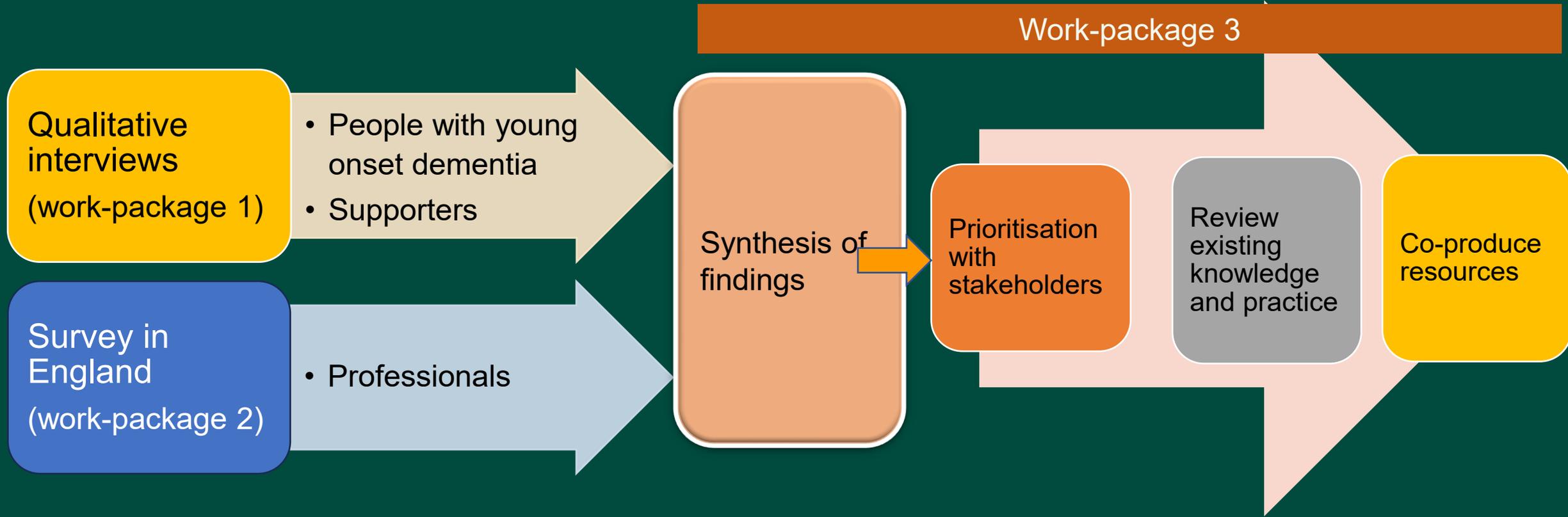
Better awareness of YOD and YOD services.

Better commissioning and care pathways for people with YOD and their families.

Better community support.

Better support for carers and the wider family.

DYNAMIC project overview



April 23 ----- Nov 24 ----- Oct 25

Financial issues as a key theme



30 stakeholders confirmed this as one of the two areas to focus on for the rest of the project at a workshop in September 2024.

Convergence analysis identified better awareness of young onset dementia by social care staff as 1 of 6 key areas for improving social care.

People with young onset dementia and family members told us about the financial issues they experienced.

Many people completing our survey highlighted financial issues as a concern for people with YOD and their families.

Co-producing the resources

Research into the impact of YOD on finances (80 articles)

- Impact on income of person with young-onset dementia e.g. loss of job
- Impact on income of carer e.g. reduce working hours or increase them
- Unexpected changes in household income
- Increased household costs
- Impact on children e.g. funding for education

Ways to help

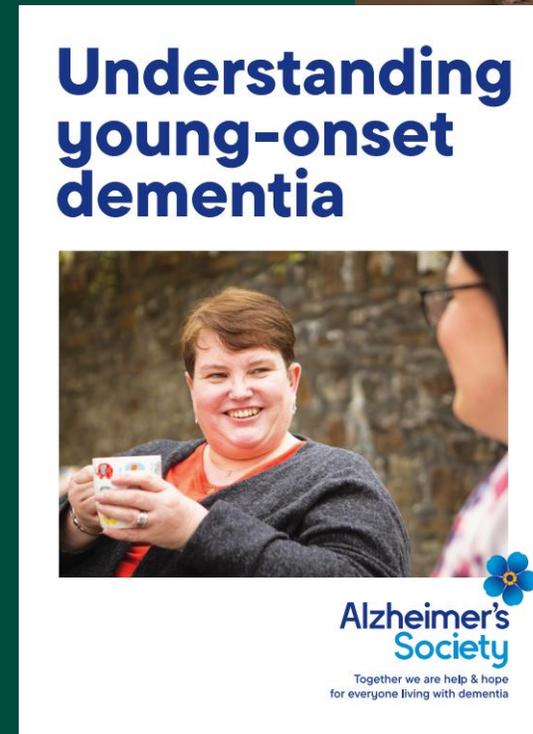
- Maintaining the person with young-onset dementia's income for longer
- Maintaining the carer's ability to stay in work e.g. home care, flexibility
- Signposting to age-appropriate financial support
- Advance planning e.g. power of attorney

Guidance and resources located via Internet searches – 20 sources

- A lot of guidance on maintaining and leaving employment
- Know your legal rights
- Tips on reducing costs
- Advice on advance planning regarding finances
- Encouraging people to seek help
- Where to get specialist advice



- Employment
- Pensions and early retirement
- Protecting your State Pension if you reduce your working hours or stop work
- Benefits and grants
- Day-to-day financial management
- Scams
- Legal matters
 - Lasting power of attorney
 - Deputyship under the Court of Protection
 - Making a Will
- Sources of support



Good practice to help person with YOD retain income

- advice on reasonable adjustments
- facilitating conversations with Occupational Health
- signposting to a range of offers from a connected team

Ideas for what could be provided

- intervene early
- link with big employers
- establish networks
- borrow from parallel/allied areas

Barriers

- the small window of time to support someone at work
- the lack of specialist knowledge
- lack of free advice when dementia is working age
- the lack of resources compounded by competing priorities
- systems problems
- “easier to retire”

Good practice: Learning through experience

“Over the years I've just gathered a wealth of information about the implications of certain financial situations, by doing the job, I always hold my hand up and say, you know, I'm not an independent financial advisor. I'm not the equivalent of going to your bank or building society or anything like that. I'm not Martin Lewis by any means...But I know a little bit which I believe is enough to guide that person to the right people or to make certain decisions which are to their advantage“

Good practice: Being aware things can change

“What I’m trying to install is things like finance...are reviewed regularly because just at the beginning when everything may be OK, doesn't mean to say that it's always going to remain OK. It needs to be reviewed and if issues start to develop and we catch them“

Good practice: Raising awareness

“The actual impact of being someone who has either had to stop working, reduce their hours and the impact that that has on the family unit, or if they were someone living alone. Financially, how does that impact when potentially there's mortgages involved?. Things like debts and arrears are more likely to be part of the mix, as well as having other responsibilities may be attached to dependents... it's information that I have gathered simply by working with people. You know, there's no amount of training, I don't think that can really prepare you for the impact until you speak to someone whereby they're talking about their house being on the line. How are they going to survive?”

Co-production groups

Where to focus

- Sustaining income of person with YOD
- Sustaining income of supporter
- Accessing entitlements and managing costs
- Advance planning for future outgoings
- All of the above

Who to target

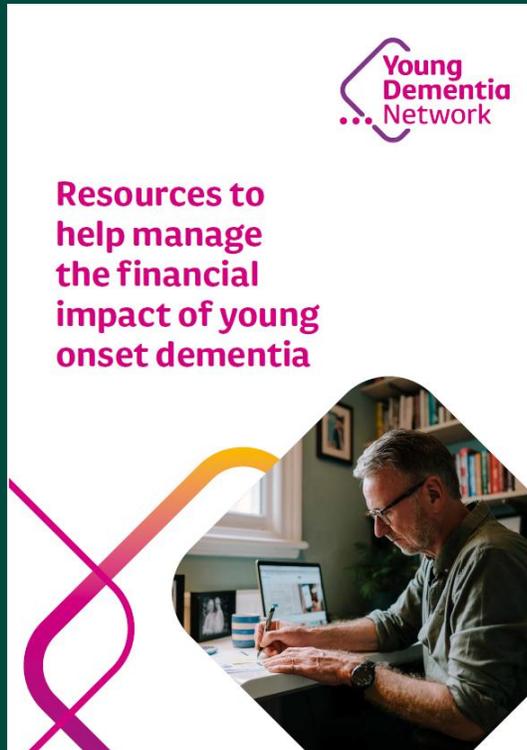
- People with a diagnosis/families
- Staff who deliver social care
- Senior managers
- Commissioners

Needed to be realistic - we had about 3 months and a small pot of funds.

Format to reach the target audience

- Video
- Online webinar
- Leaflet
- Briefing document
- Infographic
- Credit sized cards

Outputs: Information around the financial impact



A short booklet with information on key aspects of support for people with young onset dementia and their families to help manage the financial impact. It provides links to guidance on:

- Benefits and entitlements
- Managing the costs of care
- Managing money
- Employment
- Legal considerations

Further information on DYNAMIC

We have also developed resources around raising social care workers' awareness of young onset dementia.

Resources and publications will be available here:
<https://www.youngdementianetwork.org/dynamic/>

Raising social care workers' awareness of young onset dementia

Resources to raise awareness among social care staff about the social care needs of people with young onset dementia and their families.

Resource for social care workers

Download the DYNAMIC project's resource for social workers to raise awareness of young onset dementia.

Financial impact of young onset dementia

Resources to help manage the financial impact of living with young onset dementia.

Summary findings of the DYNAMIC project

Download an infographic showing summary findings of the DYNAMIC project.