An Evaluation of The Alzheimer Society of Ireland's **TeamUp for Dementia Research** Service

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THE Alzheimer
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Authorship and Acknowledgements

Authorship

Report written and prepared by a research team from University College Cork: Ms Lauren O'Mahony, Dr Siobhan Fox, Professor Suzanne Timmons and Dr Emma O'Shea.

With contributions from the Project Steering Committee (appendix 1) and PPI Expert Advisory Committee (appendix 2).

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This research is an external evaluation of the TeamUp for Dementia Research service, commissioned by The Alzheimer Society of Ireland (The ASI). The ASI supported recruitment, but had no role in data collection, storage, analysis or synthesis.

Foreword - Andy Heffernan, CEO, The Alzheimer Society of Ireland

I am very pleased to present this independent evaluation of TeamUp for Dementia Research.

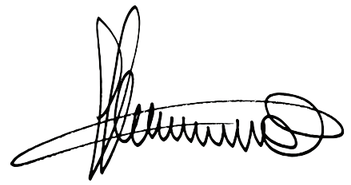
TeamUp for Dementia Research is The Alzheimer Society of Ireland's pioneering service that connects people affected by dementia with safe, supported opportunities to take part in ethically approved research.

Since its launch in 2021, TeamUp for Dementia Research (TUDR) has made a significant contribution to strengthening dementia research in Ireland. It has created a trusted bridge between researchers and the dementia community, ensuring that people living with dementia and their families can participate meaningfully in studies that will shape future care, treatment, and understanding.

This evaluation strongly affirms the value and impact of the service. It also highlights where continued focus is needed to ensure TUDR remains effective and responsive as research demand increases. A personalised and supported approach is central to the success of TUDR, and maintaining this standard will require ongoing attention to resourcing so we can capitalise on opportunities for more inclusive, diverse, and impactful research.

We are sincerely grateful to all who contributed to this evaluation. I would like to thank the authors - Dr Emma O'Shea, Dr Siobhán Fox, Ms Lauren O'Mahony, and Professor Suzanne Timmons - for their thorough and thoughtful work in conducting this evaluation. We also wish to acknowledge the dedicated team of PPI contributors - Ms Nuala Paley, Mr Raymond Cregan, and Mr John Crowley - who worked alongside the team. Above all, we are indebted to the members and users of TUDR, whose insights and experiences are at the heart of this service. Their voices will continue to guide us as we continue our work.

We are so glad that TUDR is playing an important role in a more inclusive and empowered research landscape in Ireland.



Andy Heffernan, CEO, The Alzheimer Society of Ireland

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Acronyms and Abbreviations

TUDR: TeamUp for Dementia Research
PPI: Patient and Public involvement
PSC: Project Steering Committee
HSE: Health Service Executive
The ASI: The Alzheimer Society of Ireland
DRNI: Dementia Research Network Ireland
DRAT: Dementia Research Advisory Team

Executive Summary

TeamUp for Dementia Research

The TeamUp for Dementia Research (TUDR) service, which is led by The Alzheimer Society of Ireland in collaboration with Dementia Research Network Ireland (DRNI), is a national initiative designed to connect people affected by dementia with opportunities to participate in research.

This independent evaluation was commissioned to assess the impact, accessibility, and strategic value of the TUDR service which is four years in operation. It highlights clear opportunities to enhance the service's reach, efficiency, and equity with direct implications for policy, funding, and infrastructure.

The recommendations outlined in this report support The Alzheimer Society of Ireland's goals around inclusive research, digital innovation, and equitable access to services. They also point to the need for targeted investment to ensure that TUDR can continue to grow, diversify its membership, and deliver meaningful impact for people living with dementia, their families, and the wider research community.

Methodology & Results:

A mixed method study was carried out using a survey and interviews with all TUDR members, and additional interviews with stakeholders which included researchers/academics with experience in using the service, ASI staff and health/advocacy professionals who have close links with dementia research and healthcare in Ireland.

- Of the 345 registered members, 19% are people living with dementia, 58% current family carers and 23% are former family carers.
- When asked about their motivation to join TUDR, 32% of survey participants said societal benefits, 26% said being affected by dementia directly or indirectly and 25% said personal benefit.
- 78% of participants rated their overall experience with TUDR as 'Excellent' or 'Good'.

Research participation was seen to offer a sense of hope for the future, with one member stating:

"When [Spouse] was diagnosed, he came from a scientific background and being part of research was really important to him because I think it gave some meaning to what he was going through … And then when he passed away, it was important to me to keep doing it. It's kind of a link to him still…"

Researchers and stakeholders also commented on how a more resourced service could enhance this service moving forward:

"To develop the service maybe they need at least two or three [TUDR staff members]. So that one person is doing administration, and one person is engaged in different activities like traveling for outreach purposes and reaching groups that are less privileged or able for technology".

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Key Findings and Recommendations:

Digital Infrastructure for Research Matching

Automating the matching process between TUDR members and research opportunities would reduce administrative burden and improve the experience for both participants and researchers. A multi-user online platform is recommended to:

- Empower members through accessible information on research participation.
- Enable members to manage their own data and preferences.
- Provide real-time access to open research opportunities.
- Facilitate feedback and learning about study outcomes.
- Support researchers with anonymized metrics and insights into member priorities.

Preserving Personalised Support

While digital tools are essential, the personalised and facilitated nature of TUDR must be retained. A named support person is vital to ensure equitable access, especially for those facing digital barriers.

Growing and Diversifying Membership

TUDR's reach can be expanded through:

- Increased signposting in community and clinical settings.
- Engagement with non-traditional dementia spaces.
- Inclusion in post-diagnostic support packages distributed by the National Dementia Service.

Enhancing Researcher Engagement

Promoting TUDR within Higher Education Institutions can raise awareness and diversify the research studies available to members.

Investment Required

To implement these recommendations and ensure sustainable growth, increased funding is essential. Investment is needed in digital infrastructure, personnel, and outreach to support a more inclusive and impactful research ecosystem.

Conclusion

This external evaluation of the TeamUp for Dementia Research (TUDR) service underscores its critical role in connecting people affected by dementia with research opportunities in Ireland. As dementia research continues to be a national priority – anchored in the National Dementia Strategy (2014) and further reinforced through the Model of Care for Dementia in Ireland – TUDR stands as critical infrastructure for public involvement in research. To ensure the service's sustainability and strategic growth, targeted investment is essential, which will enable the service to expand reach, improve operational efficiency and deliver measurable impact in the dementia research landscape for years to come.

Of the 345 registered members of TeamUp for Dementia Research

19%

ARE PEOPLE LIVING WITH DEMENTIA

58%

ARE CURRENT FAMILY CARERS

23%

ARE FORMER FAMILY CARERS





Members motivation to join TeamUp for Dementia Research

32%

SOCIETAL BENEFITS

26%

DIRECTLY AFFECTED BY DEMENTIA

25%

INDIRECTLY AFFECTED BY DEMENTIA

"We are so glad that TUDR is playing an important role in a more inclusive and empowered research landscape in Ireland."

Andy Heffernan, CEO, The Alzheimer Society of Ireland

Plain Language Summary

Prioritising research and innovation in dementia diagnosis, care, prevention and management is a national focus.

However, recruitment of individuals to take part in research can be challenging. Similarly, those seeking research participation opportunities are often not sure where to look.

Background

TeamUp for Dementia Research (TUDR) is an initiative led by The Alzheimer Society of Ireland (The ASI) in collaboration with the Dementia Research Network Ireland (DRNI), which connects people with dementia and their families with safe and supported research participation opportunities.

This report evaluates the TUDR service from the perspectives of service members (i.e., people with dementia and caregivers), academics/researchers, ASI staff and policymakers, and makes recommendations for TUDR service development.

How we evaluated the TUDR service:

We evaluated the TUDR service using a survey and interviews with TUDR members and additional interviews with other stakeholders. The research team had oversight from i) a Project Steering Committee (PSC) and ii) Patient and Public Involvement (PPI) advisors throughout the research process.

This research was commissioned by The ASI, who had no role in data analysis or synthesis.

What was found:

Across the survey and interviews, 59 TUDR members contributed data. Other contributing stakeholders included eight researchers, three ASI staff, and a national policy stakeholder. In this summary, we highlight six key recommendations for service development, based on the evaluation findings.

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Six Key Recommendations

1

TUDR may benefit from automating the process of matching eligible TUDR members with research opportunities. This would help reduce administrative burden and support key tasks, which members and researchers indicate could improve the matching experience and research relationship.

2

If processes are automated, retaining the personalised touch will be important to allow equal access to TUDR and growing a diverse and engaged membership. The importance of at least one named support person cannot be overstated, in particular for overcoming any digital divide in either recruitment or participation, and for member support navigating research processes.

3

TUDR could grow and diversify its membership through increased signposting within community and clinical services, and through groups/spaces that are not conventionally involved with dementia services.

4

Information about TUDR could be shared with people with dementia and their families shortly after diagnosis in the post-diagnostic support package of care distributed by National Dementia Services.

5

'Signposting' to TUDR within Higher Education Institutions may increase researcher awareness of the service nationally and help to grow the number and diversity of research studies available for TUDR member participation.

6

To facilitate recommendations 1-5, the service will require increased funding for investment in the necessary infrastructure and personnel.

1

Introduction

1.1 Introduction

It is estimated that over 57 million people are living with dementia globally.

Dementia is currently reported as the seventh leading cause of death worldwide (World Health Organisation, 2017).

In Ireland, there are approximately 64,000 people living with dementia, with this number expected to increase to 150,000 by 2045 (Begley et al., 2023).

The population aged over 65 years is rapidly ageing, with latest trends predicting that one in four people (26%) will be over the age of 65 by 2051 on the island of Ireland (Sheehan & O'Sullivan, 2020). While dementia is not a normal part of the ageing process, older age acts as a key risk factor for dementia, particularly for Alzheimer's disease and Lewy Body Dementia (Gale et al., 2018).

Dementia has a significant impact on a person's ability to maintain activities of daily living, and so prioritising research and innovation in dementia assessment, diagnosis, care, prevention and management is a high priority. This is clearly stated in the World Health Organisation (WHO) Global Action Plan on the Public Health Response to Dementia 2017–25 (World Health Organisation, 2017). The WHO report outlines that appropriate infrastructures must be available to assist with recruitment of people with dementia, their families and caregivers into research studies.

Action area 7: "promote equitable opportunities and access for people living with dementia and their caregivers to be part of clinical and social research that concerns them".

In Ireland, dementia research was recognised within the National Dementia Strategy (2014) as one of six Priority Action Areas: 'Research and Information Systems (Department of Health, 2014) and has been further cemented within the 2023 Model of Care for Dementia in Ireland (Begley et al., 2023). The latest report specifically outlines the importance of providing appropriate research opportunities for people with dementia and their families and caregivers. The TeamUp for Dementia Research (TUDR) service is recognised within the report for its actions in increasing awareness of the need for, and promoting willingness to participate in dementia research in Ireland.

Target 27: As part of care planning and early post-diagnostic support, 100% of people with dementia, irrespective of age or dementia subtype, and their supporters / family caregivers should be offered information about relevant and appropriate research opportunities. Similarly, 100% of people with MCI should be offered signposting to research participation.

Launched in 2021 as an initiative by The Alzheimer Society of Ireland (The ASI) in collaboration with the Dementia Research Network Ireland (DRNI), TUDR is a service which connects people with dementia and caregivers and families with safe and supported opportunities to take part in ethically approved dementia research. By acting as a bridge between research teams and potential participants, TUDR aims to make research opportunities more accessible, ensuring the voices of people with dementia and their families are heard, understood and appropriately valued.

To date, there has been no external evaluation of The ASI's TUDR service. This report is the output of an

external evaluation of the TUDR service, commissioned by The ASI in 2024. It explores the experience and value of TUDR from the perspectives of people with dementia and caregivers who are members of the service, and the perspectives of researchers, clinicians, and policymakers with a stake in this area.

This report also explores how TUDR fits into the overall dementia landscape in Ireland and explores opportunities for service development.

1.2 TeamUp for Dementia Research operations

TUDR operates by 'matching' people with dementia and family caregivers with opportunities to take part in dementia research.

TUDR collects standardised information from members upon sign-up, including basic demographics, as well as their dementia diagnosis, time since diagnosis, and what the person's research participation preferences include. For instance, some individuals may be interested in surveys, interviews and/or focus groups, while others may be keen to participate in randomised control trials, or other interventional research. Only researchers conducting ethically approved research may use TUDR to recruit participants.

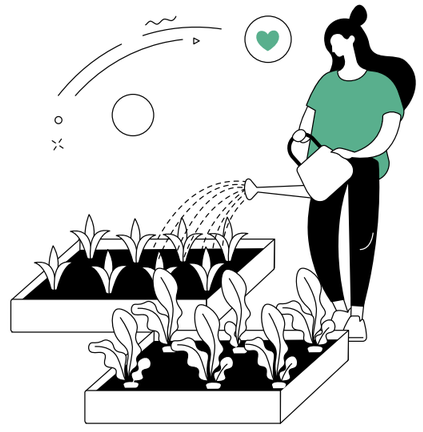
TUDR members opt-in to receive quarterly newsletters which provide a summary of recent research news and participation opportunities. When a TUDR member 'matches' with a particular study, they are issued an "Invite to Participate" which is an email detailing the project purpose, what is involved, the time commitment, among other details. The more types of research a member is interested in being involved in, the more they will hear from TUDR about opportunities.

1.3 Background and context to recruitment for dementia research

Despite the importance of expanding dementia research capacity, recruitment of participants for such studies can be challenging. Some of the challenges recognised in the recruitment of diverse and representative samples in dementia research can include fragmented and siloed health and social care services; the requirement for a study partner (e.g. family caregiver) for many observational and interventional studies, and the presence of multimorbidity, which can limit study eligibility (Bartlett et al., 2019; Grill, 2017; Watson et al., 2014). Recent literature has also pointed to key challenges for people with dementia in accessing information about and/or enrolling in research studies, e.g., 'self-silencing' by people with dementia owing to stigma experienced because of their dementia, the presence of risk-averse 'gatekeepers', not having a family member or other support person, and navigating complex research consent processes (Halonen et al., 2024).

In recent years, recruitment from memory clinics has been suggested as both a meaningful and useful method of enrolling participants into dementia research studies by people with dementia and care partners, researchers and clinicians (Lee et al., 2023, 2024). However, this can be limited in achieving sociodemographic and geographical diversity and often lacks standardised recruitment processes (Lee et al., 2024).

The value and feasibility of a dementia 'register' (record database) in Ireland was explored by Hopper and colleagues in 2021 (Hopper & Bowen, 2021). In 2025, the National Office of Clinical Audit (NOCA) announced the development of the first national Irish Dementia Registry, a clinically led development project which will record prospective data on people living with cognitive impairment and dementia in Ireland. The related press release indicated that the dementia register will "offer exciting opportunities for research on many aspects of dementia care" (Department of Health, 2025).



While the Irish Dementia Registry will provide population-level data that can be mined to improve future health and social care service planning, care quality and clinical outcomes for people with dementia, it will not facilitate recruitment into ongoing primary research studies or active research participation.

A 2017 systematic review identified 31 dementia registries operating on an international, national or local level between 1986 and 2016 (Krysinska et al., 2017). The review found that over half of the existing dementia registries aimed to conduct or facilitate research, while others solely collected epidemiological or quality of care data. Six of the identified registries (four in the United Kingdom, and two in the United States) specifically enrol volunteers for dementia studies. While TUDR is not a patient registry, it is a database that facilitates a systematic process of 'matching' prospective participants to research projects.

Join Dementia Research (JDR) is run by the National Institute for Health and Care Research (NIHR) in partnership with Alzheimer Scotland, Alzheimer's Research UK and The Alzheimer's Society. JDR allows people with dementia and caregivers to be matched to and self-select into ethically approved dementia research. 'Volunteers' give consent for researchers to have direct access to their contact information, for the purposes of assessing inclusion eligibility (Karagiannidou et al., 2022). As of July 2021, JDR has registered over 49,500 volunteers, had over 55,100 participants join research studies, and reported that over 500 studies have used the service as part of their recruitment strategies (Karagiannidou et al., 2022). Modelled on the UK's JDR, StepUp for Dementia Research was developed in 2019 with funding from the Australian Government Department of Health by the University of Sydney, in partnership with the University of Exeter and University College London. By July 2021, 1,070 volunteers had registered for the service. StepUp for Dementia Research uses a matching algorithm to link volunteers with relevant characteristics (location, age, health condition, etc.) with researchers. Similar to the UK-based JDR service, researchers can contact any 'matches' directly. The service has been described as a "'one stop shop', public engagement and dementia research participation platform" (Jeon et al., 2021). Both JDR and StepUp use an algorithm-supported online platform to facilitate matching.

The above-mentioned systematic review by Krysinska et al (2017, p. 1040) reported that 'volunteer registries' or 'matching services' can "raise community awareness of dementia research, care, and prevention, and provide an opportunity for members of the public and caregivers, to participate in studies and contribute to long-term knowledge translation resulting in improvement in dementia diagnosis, management, and care". However, the authors also acknowledge that matching services can present 'technical' and 'organisational' challenges in terms of their development and ongoing maintenance.

1.4 Research aims and objectives

The aim of this evaluation is to answer the following research questions:

Objective 1

What is the experience and value of the TUDR service to members?

Objective 2

What is the experience and value of TUDR to academic and research professionals who have used the service?

Objective 3

How does TUDR fit into the overall dementia research landscape?

Objective 4

What opportunities for development and improvement exist?

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2

Design and methodology

2.1 Research Design

A mixed-methods design was employed, comprising a survey of TUDR members' experiences/perspectives, and qualitative interviews with TUDR members and other stakeholders in dementia research.

2.2 Participants

Only TUDR members completed the online survey. Semi-structured interviews were conducted with participants across four different stakeholder groups:

- TUDR members (people with dementia, current/former family caregivers, family of people with dementia)
- Researchers/academics with experience of the service
- ASI staff with experience of the service
- Health/advocacy professionals who have close links with dementia research and healthcare in Ireland.

A brief interview was conducted with the TUDR service manager once all other data had been collected and synthesised. This provided some additional context, which helped us to better interpret and contextualise some of the findings.

2.3 Data Collection

Ethical approval was granted by the Social Research Ethics Committee at University College Cork. Data was collected from January-March 2025. Purposive sampling was employed.

Online Survey

An anonymous survey was designed by the UCC research team, modelled off a survey employed by Jeon et al. in their evaluation of StepUp for Dementia Research in Australia (Jeon et al., 2021). This survey was adapted to ensure relevance to the TUDR service and membership. The draft survey was presented to the Project Steering Committee (PSC) for feedback.

The PSC consisted of academics/researchers and policy-/decision-makers (Appendix 1). The tool was subsequently reviewed and piloted by the PPI advisory group, comprised of two family caregivers and one person with dementia (Appendix 2). The PPI advisory group met with the research team to provide detailed feedback. Adjustments to language/format were made accordingly.

The survey was distributed to all TUDR members (N=345) via the electronic mailing list on two separate dates during February and March 2025, from the TUDR email account.

Interviews

An invitation to participate in a one-to-one interview was also issued to all TUDR members. Members were invited to contact UCC researchers directly, or via the TUDR service manager.

All participants received a participant information leaflet and provided informed consent. Interviews were conducted via videocall or phone and were recorded and transcribed on MS Teams or by a UCC researcher. A semi-structured approach was used for all interviews, with separate topic guides developed for i) TUDR members and ii) other non-member stakeholders. Feedback was sought from the PPI advisory group and the PSC on the interview topic guides.

2.4 Data Analysis

Survey data were analysed using SPSS version 28. Interview data were organised, managed, and analysed in NVIVO version 14. Qualitative data were coded and analysed in accordance with Braun and Clarke's seven stages of thematic analysis (2019). A worked example of the coding process and thematic description is provided in Appendix 3.

3

Findings

3 Findings

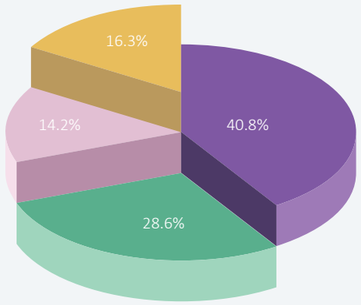
As of April 2025, TeamUp for Dementia Research has 345 registered members. Of those, 19% (n=65) are people with dementia, 58% (n=199) are current family caregivers, and 23% (n=81) are former family caregivers.

3.1 Survey

3.1.1. Participant Demographics

The survey was distributed to all TUDR members (n=345); 49 members submitted responses, i.e., a 14% response rate. The average survey completion time was 18 minutes. Please see Appendix 4 for an overview of survey respondent demographics. The breakdown of survey respondents' member status is depicted in Figure 1. Survey respondents' age and gender are outlined in Figures 2 and 3 below.

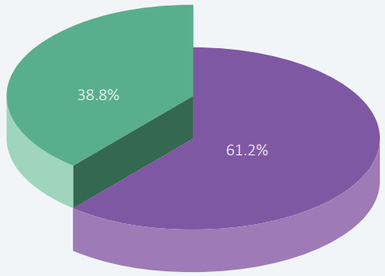
Most survey respondents lived in Leinster (57.1% n=28), followed by Munster (28.6% n=14), Connaught (10.2% n=6), and Ulster (4.1%). The breakdown of participants' area of residence is depicted in Figure 4, with most (approximately 39%) residing in a city or suburb (Figure 4).



TUDR Member Status (%)

- Person living with dementia - 40.8%
- Current carer of a person with dementia - 28.6%
- Not a formal carer, but family/friend of a person with dementia - 16.3%
- Former carer of a person with dementia - 14.2%

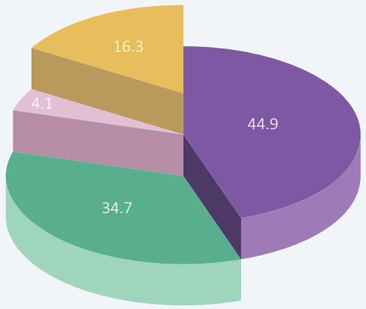
Figure 1 TeamUp for Dementia Research member status (n=49)



TUDR Member Gender %

- Female - 61.2%
- Male - 28.8%

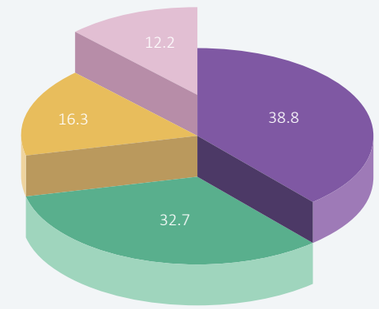
Figure 2 Participant gender (n=49)



TUDR Member Age %

- 50-64 years - 44.9%
- 31-49 years - 16.3%
- 65-79 years - 34.7%
- 80+ years - 4.1%

Figure 3 Participant age (n=49)



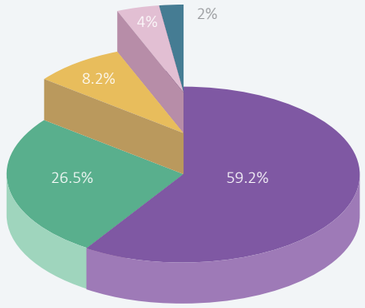
TUDR Area of Residence (%)

- City/suburbs - 38.8%
- Village/town - 16.3%
- Rural - 32.7%
- Large town - 12.2%

Figure 4 Participants' area of residence (n=49)

The majority were living with a partner or spouse or living with family. One person was living with others who are not family, and two described that they were living/staying with a person with dementia as a caregiver (Figure 5).

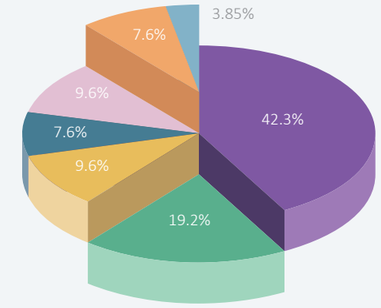
Most participants were employed full-time or retired. Other employment status is described in figure 6.



TUDR Living Situation (%)

- With a partner/spouse - 59.2%
- Living with family - 26.5%
- Living alone - 8.3%
- Staying with person with dementia as carer) - 4%
- Living with others (not family) - 2%

Figure 5 Participants' present living situation (n=49)



Employment status at present

- Retired 42.3%
- Employed full-time 19.2%
- Employed part-time 9.6%
- Home-duties/carer 9.6%
- Self-employed 7.6%
- Unemployed 7.6%
- Other 3.85%

Figure 6 Participant's employment status (n=52, multiple choice)

3.1 Survey Contd.

3.1.2. Member Introduction to TUDR

Participants heard about TUDR through various channels (Figure 7).

Most respondents indicated being a member of TUDR for '2+ years' or '1-2 years'. Others had been a member for under a year, or 6 months (Figure 8).

Where did you hear about TUDR (%)

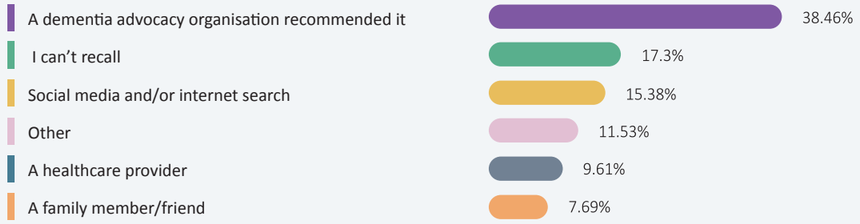


Figure 7 Hearing about TeamUp for Dementia Research (n=52, multiple choice question)

How long have you been a member of TUDR (%)

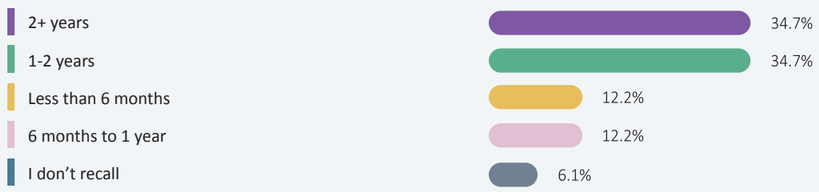


Figure 8 Duration of TeamUp for Dementia Research membership (n=49)

TUDR describes periodically *'checking-in'* with members via email and/or telephone to ensure ongoing consent for their details to be stored in the database, and for the service manager to continue matching them to appropriate studies. Participants were asked if they think this *'check-in'* is useful, to which almost all said *'yes'* (83.7%; n=41). Two said *'no'* (4.1%) and six said they were *'unsure'* (12.2%). From open text responses (n=36) the key reasons for this were that:

- Circumstances may change, a person is no longer caring
- It gives the opportunity to *'stand-back'* or *'re-engage'*
- Contact keeps people interested and acts as a prompt or reminder
- It helps to keep the member list *'active'* and *'accurate'.*

3.1.3. TeamUp for Dementia Research Webpage

Most participants reported visiting the TUDR webpage *'occasionally'* (46.9%; n=24) or *'only when registering'* (32.7%; n=16). One person said they visit *'frequently'* (2%), and the others said they have *'never'* visited the webpage (18.4%; n=9).

Participants were asked if it is easy to find information about TUDR on The ASI website (Figure 9), and were asked for feedback on the TUDR webpage:

"The user-experience [of website] on phone is not great. The visuals are small, and the quotes are long. It's very hidden on the website, I had to use the search tool".

Is it easy to find information about TUDR on The ASI website? (%)

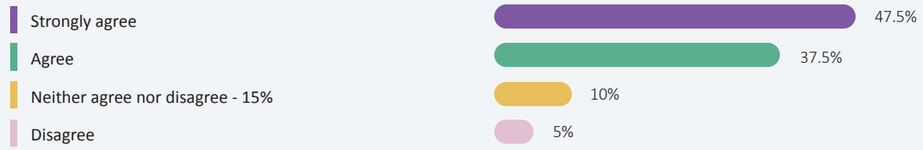


Figure 9 Finding information about TeamUp for Dementia Research on The ASI website (n=40)

The information on the TUDR webpage is clear and easy to understand (%)

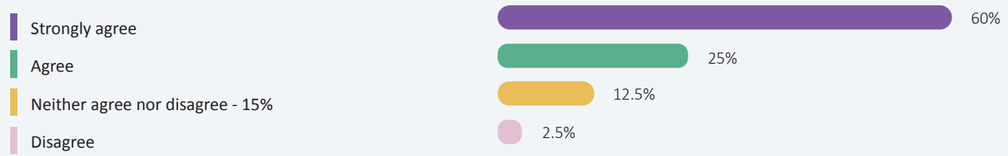


Figure 10 Clarity of information on the TeamUp for Dementia Research webpage (n=40)

3.1 Survey Contd.

3.1.4. Registering to become a member of TeamUp for Dementia Research

Most participants registered online on their own (59.2%), while others required some support to register (Figure 11).

Most respondents were satisfied with the overall experience of registration, while some *'neither agreed nor disagreed'* (15%) and one person was not satisfied (2.5%), but did not indicate a reason for their rating (Figure 12).

How did you register for TUDR? (%)

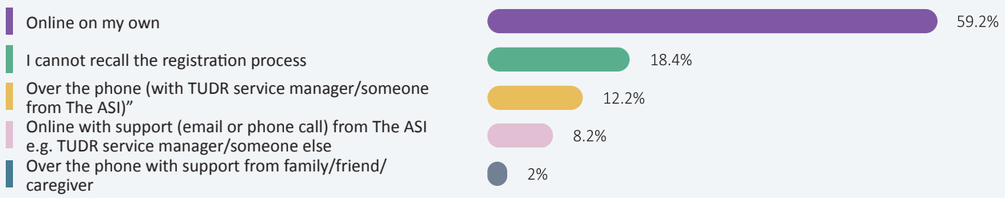
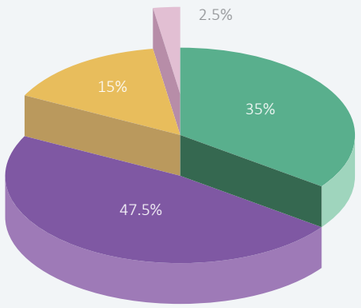


Figure 11 Registering membership with TeamUp for Dementia Research (n=49)

When asked for additional comments or feedback on the registration experience, participants described it as *"interesting and learned information", "helpful and understanding", "comprehensive and encouraging".*



I was pleased with the overall experience of registration (%)

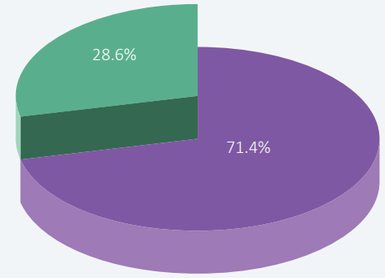
- Strongly agree - 35%
- Agree - 47.5%
- Neither agree nor disagree - 15%
- Disagree - 2.5%

Figure 12 Satisfaction with registration experience (n=40)

3.1.5. Matching with a research opportunity

Almost three-quarters of participants said that they have been offered the opportunity to participate in at least one research study (Figure 13). Of those who had been matched with research opportunities, 31% (n=11) said that they chose not to participate, for reasons including: *'I didn't have time'* (n=5), *'Personal circumstances were a barrier'* (n=3), *'Not related to my interests'* (n=1), *'I didn't qualify'* (n=1), and *'Not relevant caregiver'* (n=1).

Participants indicated how many studies they have been involved in (Figure 14).



I have been offered the opportunity to participate in/been matched to at least one study (%)

- Yes - 71.4%
- No - 28.6%

Figure 13 Research participation opportunity has been offered (n=49)

Approximately how many studies have you been involved in?

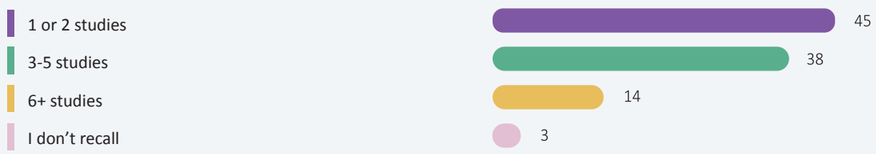


Figure 14 Number of research studies participant has been involved in (n=29)

3.1 Survey Contd.

3.1.6. Joining a research study

Participants 'strongly agreed' (54.2% n=13) and *'agreed'* (45.8% n=11) that the initial information given to them by TUDR about the research opportunity was easy to understand and made it clear what participation would involve. They felt that TUDR adequately supported them to join a research study (Figure 15).

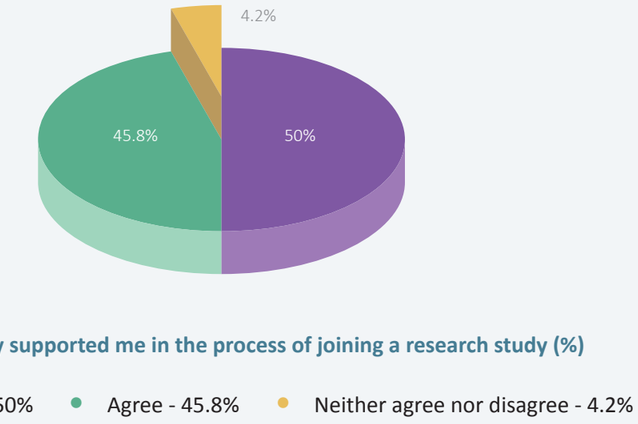
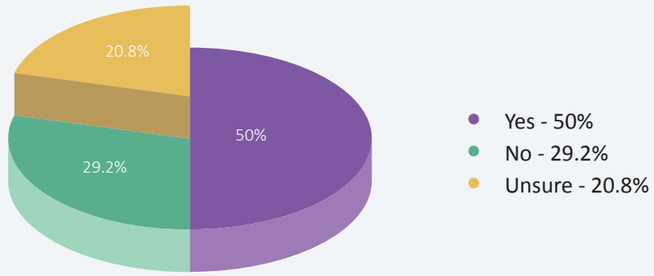


Figure 15 Support from TeamUp for Dementia Research in joining a research study (n=24)

When asked if they were satisfied with their interactions with the researchers upon joining a study via TUDR, participants *'strongly agreed'* (33% n=8), *'agreed'* (58.3% n=14) or *'neither agreed nor disagreed'* (8.3% n=2). In open-text responses (n=15) participants described their reasons for their ratings of external research being *"professional", "well-implemented", "I never felt like I was on my own", "there was no pressure".* However, others said that there was *"no clear message that participation was at an end"* and there was *"no follow up/thanks".*



Have you shared feedback of your experience of taking part in research with TUDR? (%)

Figure 16 Sharing feedback with TeamUp for Dementia Research following an experience of research participation (n=24)

Few indicated that they had shared feedback (positive or negative) about their experience of participating in a research study via TUDR (Figure 16).

3.1.7. Motivation to join TeamUp for Dementia Research and interest in dementia research

In a multiple-choice question, participants described their motivation to join TUDR (Figure 17).

Before registering with TUDR, approximately equal numbers of participants were aware as were unaware of any dementia research in Ireland (Figure 18). However, most had not previously participated in dementia research before registering with TUDR (Figure 19).

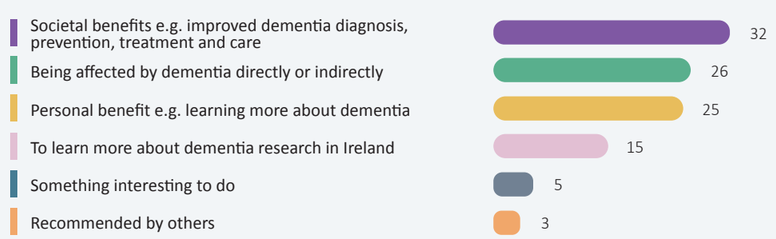


Figure 17 Motivation to join TUDR (n=106 multiple choice question)

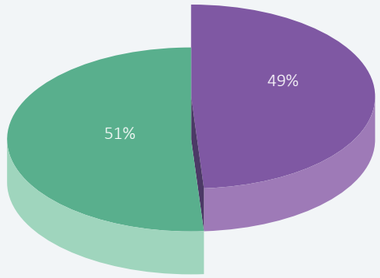


Figure 18 Awareness of dementia research in Ireland before joining TUDR (n=49)

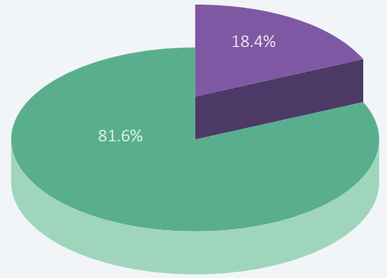


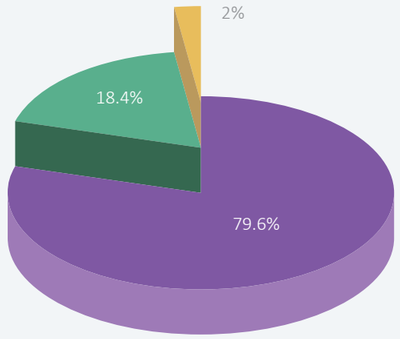
Figure 19 Previous experience of participation in dementia research before joining TUDR (n=49)

3.1 Survey Contd.

3.1.7. Motivation to join TeamUp for Dementia Research and interest in dementia research. Contd.

Most participants felt that participating in dementia research is a worthwhile thing to do (Figure 20). The key reasons given in the open-text box included:

- Contributing to and advancing dementia knowledge and research
- Learning more about dementia for personal benefit
- Developing better services, care and support and obtaining funding for dementia
- Informing researchers of the true lived experience and dispelling misinformation and assumptions about dementia.



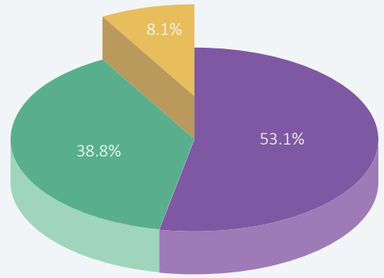
Participating in dementia research is a worthwhile thing to do (%)

Strongly agree - 79.6% Agree - 18.4% Neither agree nor disagree - 2%

Figure 20 Participating in dementia research is a worthwhile thing to do (n=49)

Participants *'strongly agreed'* (44.9% n=22) and *'agreed'* (40.8% n=20) that it is important to feel valued by the researchers when participating in a study. The others *'neither agreed nor disagreed'* (14.3% n=7).

Participants indicated it is important to be updated about study findings by the researchers once the study is complete (Figure 21). Qualitatively (n=34 open text responses), the key reasons included: Wanting to know the study outcomes; honouring participants' contributions and input; and fostering cooperation between researchers and participants.



It is important that researchers update me about study findings once the study is complete (%) worthwhile thing to do (%)

Strongly agree - 53.1% Agree - 38.8% Neither agree nor disagree - 8.1%

Figure 21 Importance of receiving follow up from researchers following participation (n=49)

3.1.8. Overall experience with TeamUp for Dementia Research

Most participants rated their overall experience with TUDR as *'good'* or '*excellent',* though some indicated it was *'modest*', and few indicated it was *'poor'* (Figure 22).

How would you rate your overall experience with TUDR (%)

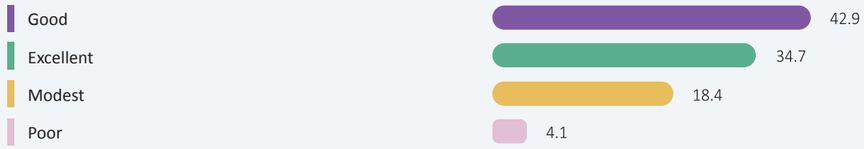


Figure 22 Participant's overall experience with TUDR (n=49)

Participants described the reason for their ratings, including how the service is *'positive', 'friendly' and 'well-run'* and that they felt there was an *'honouring of their contributions'.* The reasons given for modest or poor ratings related to not having participated in research since joining: *"I haven't interacted much", "I've not been part of anything yet",* and *"Nothing relevant came up for me"*

Participants were given the opportunity to share any final comments before submitting their survey responses. These are outlined in overleaf in Figure 23.

Diversify Participation Opportunities

"Consider more specific types of research into rare dementias and the supports that are available in Ireland to care for folks who might not have the typical presentation of memory loss and confusions. Dementia is so much more and the care required is so much more in depth than a lot of people realise."

"Its disappointing that my family, and others like us, have not been included in research to track decline because we come from a family scarred with dementia on all sides."

"My impression is that I could have participated more, but perhaps I am mistaken."

Keep up the good work and continue with feedback

"Nothing extra, thanks for asking. Keep up the good work, and make necessary tweaks to the process based on this type of periodic evaluation."

An Evaluation of The Alzheimer Society of Ireland's TeamUp for Dementia Research Service

"They're doing well and they've really helped me."

"Keep talking to us and providing for where we can learn."

""Keep doing what you are doing. It is great."

Advertise / Outreach / Introduce the Service

"I think anyone that is diagnosed with early onset in particular should be made immediately aware of this resource. I spent the first year or so heavily researching trials/ if there were peer groups/general services."

"They are getting better and better. More in-person events."

"More advertising. Tell people..."

3.2. Interview

In total, 21 interviews were conducted for this evaluation, with key stakeholders.

TUDR Members

One-to-one interviews were conducted with 10 TUDR members, five male and five female. Members were aged 50-64 (50%) and 65-69 (50%). One member was a person living with dementia, the others identified as either current caregivers (n=4) or former caregivers (n=5). See Table 1 for details.

No.	Code	Member Status
01	01	Person living with dementia
02	02	Former spousal caregiver (spouse deceased)
03	03	Spousal caregiver
04	04	Former caregiver / child of a parent with dementia
05	05	Former caregiver / child of a parent with dementia
06	06	Spousal caregiver
07	07	Spousal caregiver
08	08	Former caregiver / child of a parent with dementia
09	09	Former caregiver / child of a parent with dementia
10	10	Spousal caregiver

Non-Member Stakeholders

Interviews were conducted with 11 non-member stakeholders. These included 8 researchers who had used (n=7) or intended to use (n=1) TUDR for recruitment, ASI staff who do not work within TUDR (n=2), and a national policy stakeholder. There were 8 female and 3 male stakeholders, aged 31-49 (n=8); 18-30 (n=2) and 50-64 (n=1). The TUDR service manager was also interviewed for reflections on preliminary findings.

Seven common themes encompassing the findings of the evaluation, each with several sub-themes, were identified and are outlined in this section, with supporting quotes from the interviewees. The themes are listed in Table 2.

Hearing about TeamUp for Dementia Research

Theme	Subtheme
Sign up & communication processes	• Accessibility for members • Perceptions about eligibility • Updating member preferences
Challenges in recruitment	• Digital divide • Diversity, equity and inclusion in dementia research • Expanding the participant pool

Understanding of what TeamUp for Dementia Research and research participation involves

Theme	Subtheme
Navigating research relationships	• Format and timing of engaging with TUDR and research opportunities • Follow-up is important for research participants • Reimbursement and payment practices
Value of TeamUp for Dementia Research	• Knowledge development and contribution for members • Meaning and empowerment for members • Supporting capacity-building in research • Safeguarding members
Service development and future directions	• Capturing participant feedback and participation metrics • Member expectations and expanding opportunities • Improving and automating the matching process • Human and fiscal resourcing • Outreach and advertising

3.2. Interview Contd.

3.2.1. Hearing about TeamUp for Dementia Research

Members mostly discovered TUDR by searching online, frequently through The ASI website. Others discovered the service through their involvement in other ASI services, or through word of mouth.

Most researchers heard about TUDR via word of mouth, from clinical and academic colleagues, and/or through The ASI Dementia Advisors. One described finding TUDR after approaching The ASI for PPI support.

For one national policy stakeholder, there was a sense that TUDR is not as visible as it could be to relevant stakeholders:

> *"I'd heard of it, but it was kind of through the grapevine… It wasn't prominent… And then you have to look up on the (ASI) website and you can see it there" S1*

3.2.2. Sign up and communication processes

3.2.2.1. Accessibility for members

In line with the survey findings, members described completing an online form and then receiving email correspondence from TUDR upon sign up. Some were satisfied with email as the primary mode of communication regarding research opportunities, citing it as *'accessible', 'convenient' and 'professional'.*

Some members described that the emails were *'long' or 'text heavy',* that content could be clarified, or that emails could be *'more tailored'*. One member suggested that logos or photos of physical locations could assist in *'visualising*' the research. The interviews suggested that some members may see an email from TUDR arrive in their inbox but may not read it fully. One member described not noticing initially that a research opportunity was being offered.

> *"You're reading down the whole thing (email invite to participate) and then you're finding it at the end about the research … But sometimes people will just skip through things on there and then they miss the opportunity … Because I read it and I skipped it by, and it was [my daughter] who said to me "did you read that email? They're looking for you" …" M10*

3.2.2.2. Perceptions about eligibility

Some members perceived that the email invitations are non-targeted and that they don't always feel eligible for the opportunity in question.

> *"I think, 'I don't think it applies to me'. I don't think I'd be of any use…" M7*

One person suggested a targeted email would be useful to recruit participants more directly, but acknowledged that this may not be feasible, in terms of resourcing.

> *"If I got an e-mail saying '[Name], we really think this one is for you', then I'd definitely consider it…but that's a resource question" M4*

The service manager noted that while emails/texts are often a group email to all *'eligible'* members, they try to ensure that emails to people living with dementia are more personalised. The option to sign up over the phone is also available to all prospective TUDR members. The service manager spoke about the value of offering a text communication to overcome 'eligibility' concerns, but that this can considerably add to workload.

3.2.2.3. Updating member preferences

Upon sign-up, members are asked to indicate their preferences for the type of research they want to contribute to. Members described how it would be useful if they could view and update their research preferences, as several were unaware of what their present preferences were.

> *"It might be useful to see the options again … I don't really remember what I signed up for … or even what I didn't sign up for? … I guess they could change over time, so it might be nice to be refreshed on that" M2*

One person spoke about how it is important that preferences are *"checked up on more often "* (M5), as caregiver's circumstances tend to change over time.

> *"Being a caregiver and then no longer being a caregiver- things do change…" M5*

3.2.2.4. Accessibility for researchers

Researchers described the process of registering a research project with the TUDR service. Registration occurs via the TUDR website, with additional support provided by the service manager. The processes were described as timely, straightforward, and for one *"helped solidify and clarify what exactly it was that we were looking for"* R4D.

Researchers agreed that the participant data shared with them was secure and easy to access. One suggested that TUDR could collect more medical data to facilitate better inclusion/exclusion criteria matching.

In terms of the study invitation emails circulated to TUDR members, one researcher (R1C) suggested they don't know the format of how their study information was presented to the members. Another proposed that it would be useful for TUDR to share when/if they posted about the researcher's study via the TUDR social media platforms.

> *"It would be useful if they could have sent me something like, 'Look, we posted this on social media" R1C*

3.2.3. Challenges in recruitment

3.2.3.1. Digital divide

Both TUDR members and researchers described that technological abilities of the TUDR membership may vary, and that this should be considered in TUDR's communication channels.

> *"The profile of people with dementia is very often older … a lot of time, it's not, but the people that I've come across, like the dementia working group, they'd mostly be younger people… and typically they would be more ok with systems, computers and passwords" M2*

Some interviewees suggested that SMS texts or WhatsApp messages might be a more accessible and effective form of communication in this regard.

Most felt that face-to-face engagement is a great way to learn about research opportunities.

> *"… For this cohort, maybe TUDR could have more of an emphasis on in-person sign-up and engagement, rather than just online." R1C*

3.2.3.2. Diversity, equity and inclusion in dementia research

Researchers and other stakeholders spoke of the importance of and the challenges associated with service scale-up, in a way that maximises inclusion and diversity within the TUDR membership.

> *"Maybe there is a way of being targeted in efforts. To advertise and say 'The ASI are looking to meet with people who are living in rural Ireland, or who are from, you know, ethnic minority groups', or maybe migrants who have come from different countries" R2C*

3.2.3.3. Expanding the participant pool

Some individuals are more 'research active' than others, both within and outside TUDR. Interviewees discussed the potential implications of this, in the context of representation of the wider population of people living with dementia in Ireland.

> *"I was working at two different universities, and a familiar name came up the second time, so I worked with that dyad again in a different project" R4D*

A researcher indicated that TUDR is well-placed to support the avoidance of an 'extraction model' of research recruitment. Prior to TUDR existing, they noted that:

> *"We were constantly going to the same people all of the time, through the same gatekeepers, to get the same people into research projects…" R1B*

Expanding the participant pool is important so that active research participants do not feel "*overwhelmed*" by too many research opportunities: "One of the participants just said to me that (they're) overwhelmed with the research" R4L.

Separately, one TUDR member spoke of coming to realise that it isn't feasible to say 'yes' to every research opportunity, despite altruistic intentions.

"Maybe I feel a little bit obliged sometimes… I kind of feel I should say yes to everything. But now I'm beginning to see that that's not feasible" M3

Several researchers and other stakeholders noted that the onus for this is not just on TUDR; they spoke of the collective responsibility of those involved in research/ academia and care, to expand the participant pool.

3.2.4. Understanding of what TeamUp for Dementia Research and research participation involves

There is potential for TUDR to more clearly highlight its role and function to its membership, to further improve member engagement. This includes highlighting the differences in research participation, versus PPI involvement as 'co-researchers' (which The ASI also facilitate via the 'Dementia Research Advisory Team' (DRAT)).

Several members viewed TUDR as a service facilitating 'cooperation' between researchers and those with lived experience of dementia. For others, it was unclear what activities might constitute research participation:

"I think I fill out an online questionnaire. Would that be participation in research?" M7

"When you say 'taking part', what exactly would that involve? M9

In terms of the types of research offered through TUDR, some members felt this could be more clearly outlined on the website. Another suggested that TUDR could be better distinguished from other ASI services (e.g., the DRAT), and more clearly branded as a separate service, i.e., "its own identity" M10.

One ASI stakeholder felt that the unique function of TUDR could be better distinguished, and that TUDR member stories could be used to facilitate this:

"Maybe we need to showcase people who aren't involved in our [other] services because we're trying to show that it's a distinct service." ASI2

3.2.5. Navigating research relationships

3.2.5.1. Format and timing of engaging with TUDR and research opportunities

Perspectives varied as to the most appropriate format and timing of introducing research participation to people with dementia or their families. Some felt that the period immediately post diagnosis is not the right time. However, others suggested that learning about research opportunities and TUDR early in the post-diagnostic period would have been useful.

"The minute you go in. That's when you should be told. Then we would have known about it (TUDR) straight away, instead of a couple of years later" M10

One stakeholder separately supported the idea that research could be introduced to someone as a follow-up to their diagnosis through a TUDR leaflet within the "post diagnostic support package of care" (S1), distributed by National Dementia Services.

3.2.5.2. Follow-up is important for research participants

Several members spoke about how they would like to receive follow-up information after taking part in research, to see what became of their contribution. Open-text survey responses echoed this.

Members recognised that providing follow-up on the findings or impact of a research project might not be TUDR's responsibility, but that it would be useful if researchers could liaise with TUDR, to inform the membership of study outcomes. However, one person acknowledged that this may not be feasible, given TUDR's current resourcing.

"We probably don't hear enough about study results … But then you have to take into consideration, there's only one person running all this." M3

The service manager strongly agreed that there would be immense value to formalising a process whereby research findings are fed back to participating TUDR members, but that the administrative burden associated with this could be prohibitive.

3.2.5.3. Reimbursement and payment practices

Several researchers suggested that researchers should consider participant reimbursement in appealing to people to sign up for research opportunities, including via TUDR, especially for studies that might incur costs for the participant.

However, it was also recognised that this may be challenging to navigate, in practice. For example, one person noted that reimbursement could be a participation deterrent for some, if they felt that it might impact upon any social welfare schemes.

"… It's quite a stressor, actually, for family members and people living with dementia to go and try and navigate, whether their benefits are going to be taken away from them because they're participating in something." R1B

From the researcher point-of-view, another consideration is that introducing payment can have ethical implications or may influence who is willing to enrol in studies, potentially increasing the 'risk of bias' in the study.

One researcher suggested that TUDR could introduce a nominal fee for researchers to register their study using TUDR, as a way of promoting service sustainability. However, this may preclude certain researchers from registering their study, since not all dementia research conducted in Ireland is supported by funding.

3.2.6. Value of TeamUp for Dementia Research

3.2.6.1. Knowledge development and contribution for members

Participants suggested how taking part in research can offer a feeling of meaningful contribution to society, the opportunity to learn more about dementia and research, and reduce stigma.

"The more people that are involved in research, the sooner this disease is going to be tackled … Giving something back… It'll help other people coming up on the way … We need people now to be opening up, to stop hiding. It had a fair amount of stigma for a long time…" M10

Others described using TUDR to learn about ongoing research and about dementia for their own benefit.

"It straddles a very interesting line, between altruism and complete selfishness … You're doing it to be plugged in and you're doing it to keep an interest … After years of nothing, it feels like we're on the cusp of something, and for me it is reassuring to be part of that. And I can tell my family, I can tell my friends … about the little bits of good news that I pick up" M4

3.2.6.2. Meaning and empowerment for members

Researchers and other stakeholders spoke about how participating in research could offer a sense of meaning and empowerment to people with dementia and their families. This was echoed in open-text survey responses.

"The service is giving people with the lived experience and those affected by dementia the opportunity to have their lived experience expressed. This might be the first time that they've been able to talk about their journey… I think that there's a lot of intrinsic value to that - that sense of ownership." ASI1

Research participation was also seen to confer a sense of hope for the future.

"(Members) like to have a feeling of hope about the future, and hope about dementia research. It can make a real difference …A lot of them just want to pass on information, be a part of something to help the future generation" ASI2

Members spoke about the feelings that research participation can evoke, often making them feel that their experience of dementia 'wasn't all for nothing' (M3). This was echoed in open-text survey responses. One person described a "renewed sense of vigour" from their spouse's participation in research.

"When [Spouse] was diagnosed, he came from a scientific background and being part of research was really important to him because I think it gave some meaning to what he was going through … And then when he passed away, it was important to me to keep doing it. It's kind of a link to him still…" M2

One researcher spoke about the value of TUDR in ensuring that people with dementia feel they are not just "passive recipients".

"[TUDR] is actually helping to dispel that view of people with dementia as passive recipients of care. [They are] contributors to their communities and to their lives and the lives of other people" R1D

3.2.6.3. Supporting capacity-building in research

Researchers described their typical recruitment channels (e.g., memory clinics and support services, healthcare and social care professionals such as nurse specialists, Dementia Advisors, and social groups e.g., memory cafes, retirement groups) but highlighted how TUDR is hugely valuable in increasing reach.

"We used a few different [recruitment] avenues, but by far, TeamUp was the most efficient..." R4D

TUDR was noted as particularly valuable for early career researchers (e.g., Postdocs or PhD candidates), who may have less experience with recruiting participants.

One researcher noted that TUDR helped them to "link in" with other researchers and "research gatekeepers, like 'Dementia Advisors'" (R2G) for recruitment support, and helped them to grow their research networks.

3.2.6.4. Safeguarding members

Many researchers noted that the facilitated nature of TUDR is reassuring for them, in that it can minimise risk for vulnerable participants, maximise meaningful engagement, and promote safeguarding. This was echoed by members.

"[TUDR] is like a safeguard for us … if you go to them for a research project, they're going to check out the project, make sure it's validated" M1

"It was really like having a research gatekeeper, and a colleague as well, who was trying to ensure comfort and support the choices of the person." R2C

The requirement for researchers to provide evidence of ethical approval for their study before accessing TUDR members was also highly valued and viewed as a measure of security.

3.2.7. Service Development and Future Directions

3.2.7.1. Capturing participant feedback and participation metrics

Many interviewees suggested that TUDR could collect constructive feedback from both members and researchers, following each research project. Open-text survey responses echoed this finding. However, some members were conscious of the additional administrative workload this would incur. Several indicated that somehow automating this process would be useful.

"If that part of it was automated, then [service manager] could work through the list of people to just say 'just checking in with how your experience of TeamUp is going', because she'd have that that space" M2

It was suggested that capturing positive feedback from TUDR members could be a way to "showcase" experiences of positive and meaningful research participation, to be used in a way that might encourage more people to sign up for TUDR but noted that without appropriate resourcing this will not be feasible.

"We don't have the time or capacity for a more reflective look... How can we do more comms on the success stories and show the impact of the work? There's no time for that" ASI2

The service manager indicated, that from the TUDR service point-of-view, it would also be useful to capture recruitment rates from researchers to more accurately track participation metrics.

3.2.7.2. Member expectations and expanding opportunities

TUDR member experiences suggest there is scope for expanding research opportunities, particularly for former caregivers, and in relation to interventional research specifically. Some members were disappointed with the number of "relevant" opportunities which they felt were offered.

"I was expecting more when I signed up … I was disappointed that there wasn't more happening … I've had a sense of disappointment that I hadn't been used more" M7

Another family caregiver considered they would have useful knowledge to share, given the opportunity:

"… I know things about lived experiences as the caregiver, but I haven't been given the opportunity" M8

Several family caregivers and those with familial history of a dementia diagnosis were interested in studies which focus more generally on dementia prevention.

"I've tried [to take part in studies] …to put myself forward for a medical study. I was prepared to have brain scans done every other day and take all the DNA you want" M5

The service manager separately noted that while TUDR has untapped potential to facilitate more research opportunities for members, the TUDR service can't control what researchers are choosing to focus their investigations on.

"It's out of our hands, what the researchers are studying. We don't really get much clinical research, unfortunately … For some people, the right research project has not come through the service." SM

3.2.7.3. Improving and automating the matching process

Participants discussed the potential for improving and automating the sign up and matching processes involved in TUDR, to assist in managing volume, through technical support such as an online member log-in portal or software management systems. Interviewees considered that this could be done in an accessible way to maintain the personalised touch that TUDR currently employs.

The potential for an online log-in platform was considered in the context of updating member preferences and consent, and allowing members to check for available opportunities, at a time that is convenient for them, facilitating a sense of ownership over their TUDR membership.

"Sometimes you get an email, and you don't have time, or you're not in the humour. So, if I needed to, I could log in and see what I've signed up to. That might be useful, that people could take control of their own preferences" M2

Several suggested that the platform could display 'open' research opportunities and could also have a space for members and researchers to share information on project progression, provide feedback, and share project findings/outcomes.

"I would see it as a dedicated website that I either get a prompt from or that I go to. I could see all current projects, their start, middle and end." M8

Another researcher suggested that an online platform could additionally function as a space for researchers to learn about TUDR members' research priorities, and to plan future research funding applications that align with these.

"As well as putting the research studies that are ongoing on it, you could also have a space where people add suggestions for future research that they would like to participate in. To see people's priorities for research" R2C

The service manager offered reflections separately on how scale-up and growth of the service could be supported by a log-in based system.

"Similar I suppose to Join Dementia Research, that they (members) can see what opportunities are there, which again might take some of the pressure off whoever is responsible for the service" SM

Interviewees cautioned that if the service were to be automated, it would need to be done in a way that doesn't jeopardise what is perceived to be one of the main benefits of TUDR, i.e., the 'personal touch' of the membership.

"I think if you were to fully automate it and take away that personal touch, I think people are going to walk away from it because they're thinking, why would I want to engage with a computer?" ASI1

The importance of a named support person, a familiar and trustworthy face within the service, was also seen as important in overcoming any digital divide experienced by members who are not as confident with technology.

3.2.7.4. Human and fiscal resourcing

There was universal agreement across all stakeholder groups that, to grow the TUDR service and actualise its potential in line with stakeholder and member needs and preferences, more human and fiscal resources will be required to implement improvements.

TUDR members and researchers indicated a need for additional TUDR staff at this juncture: "It shouldn't be just one person. This needs a team" R2G. Presently, the service does not have one whole time staff member attached to it.

"It's not possible for me to grow the service with one hand while I'm managing [another ASI service] with the other hand… TeamUp membership recruitment has been paused, and we're not advertising it." SM

The potential for 'volunteers' to support the service was suggested by some members and one researcher.

3.2.7.5. Outreach and advertising

Participants recognised that outreach and advertising of TUDR will be essential for service growth. By reducing administrative workloads through streamlined online management systems and increased human & fiscal resourcing, the service manager or TUDR team could have more capacity for advertising and onboarding of new members.

Outreach and advertising to and from researchers / academics

Interviewees spoke of how many researchers may still be unaware of TUDR, especially early career researchers.

"I've talked to others who are doing dementia work. And I've said, have you contacted Alzheimer's Society? Did you know TeamUp exists? And oftentimes the answer was they were not familiar with it" R4D

'Signposting' to TUDR within Higher Education Institutions may increase researcher awareness of the service to diversify research opportunities and grow the TUDR membership.

"I think a lot of researchers rely on their own networks and communities, and so one of the best ways to provide information is by actually being in the university somehow. And maybe that's giving talks or, you know, coming along with a booth or something." R4D

One researcher described the potential for an in-person TUDR 'meet-up' to be hosted by The ASI, during which researchers and TUDR members could connect and converse: "… It could help us to find our peers and matches." R2G

The service manager considered that TUDR could benefit from undertaking something like a 'roadshow' outreach tour, to boost awareness nationally.

Outreach and advertising to and from healthcare, voluntary and community services

One stakeholder spoke of the importance of improving awareness of the value of TUDR, so that it would be more actively promoted post-diagnosis by, for example, Dementia Advisers, Regional Specialist Memory Clinics, Memory Assessment and Support Services, and Memory Technology Resources Rooms.

Both TUDR members and other stakeholders suggested that TUDR could be better 'signposted' via the range of other ASI services, and externally, through primary care services, nursing/care homes, social prescribers, and at national conferences.

Many researchers and stakeholders were conscious to advertise TUDR to groups who are not conventionally involved with dementia services, echoing earlier sentiments of promoting diversity, equity and inclusion within dementia research: "… approaching it at a much broader level to e.g., church groups, as opposed to going straight to dementia services." R1B

One TUDR member suggested that "places where people congregate" (M2) would be useful to house information leaflets about TUDR, to inform people about the service and research opportunities. However, this is not possible within current resources.

4

Conclusions and Recommendations

4. Conclusions and Recommendations

The experience of research participation for people with dementia and families and caregivers can be meaningful and empowering.

It can also contribute to knowledge development for both the individual and for the research community.

The value of the TUDR service and its potential to contribute to the landscape of dementia care/ support and research in Ireland has been highlighted through this evaluation, yet the full potential of TUDR simply cannot be realised within current resource constraints.

The development and expansion of TUDR would support advancement of the objective outlined in the Model of Care for Dementia in Ireland, to offer information about relevant and appropriate research opportunities to all people with dementia, their supporters and caregivers (Begley et al., 2023).

In light of the recent announcement of a National Dementia Registry in Ireland (Department of Health, 2025), it is worth noting that any such registry will likely facilitate the mining of routinely collected registry data for research purposes. However, a dementia registry will not facilitate participant recruitment to primary research studies. In this way, TUDR will remain the best-placed service nationally, to facilitate matching people with dementia and their caregivers to primary research studies.

To ensure all relevant stakeholders are aware of TUDR for this purpose, increased outreach and advertising of the TUDR service, to grow the membership, is essential. Our evaluation suggests that this could be achieved by reducing the TUDR staff administrative workload through i) supported and streamlined online systems and ii) increased resourcing.

Key recommendations for TUDR service development:

1. TUDR may benefit from automating the matching process, to reduce administrative burden and facilitate several key processes, which members and researchers indicate would improve the matching experience and research relationship.

A multi-user online platform could support the following for TUDR members, in a way that minimises administrative workload:

- Informing membership about what research participation is and involves, and the different types of research designs that exist. This would further empower the membership and facilitate decision-making about participation through improved literacy
- Managing their own TUDR membership consent, demographic and clinical data, and research participation preferences
- Viewing 'open' research opportunities, at a time that suits them
- Providing feedback on experiences of research participation Learning about study outcomes.

Such a platform could additionally support the following for researchers:

- Tracking anonymised eligibility and participation metrics for more transparent research reporting

- Learning about TUDR members' research priorities, to plan future research funding applications
- Receiving prompts to provide TUDR participants with information about study findings/outputs.

2. The personalised and facilitated nature of the service must not be lost, should any multi-user platform be introduced. The importance of at least one named support person cannot be overstated, particularly for overcoming any digital divide in either recruitment or participation, and for member support navigating research processes. Retaining the personalised touch will be vital for facilitating equitable access to TUDR and growing a diverse and engaged membership population.

3. TUDR could grow and diversify its membership through increased signposting within community and clinical services, and through groups/ spaces that are not conventionally involved with dementia services.

4. Information about TUDR could be shared with people with dementia and their families shortly after diagnosis in the post-diagnostic support package of care distributed by National Dementia Services

5. 'Signposting' to TUDR within Higher Education Institutions, may increase researcher awareness of the service nationally and help to grow the number and diversity of research studies available for TUDR member participation.

6. To facilitate recommendations 1-5, and grow and diversify the TUDR membership, the service will require increased funding, for investment in the necessary infrastructure and personnel.

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Appendices

Appendix 1

The Project Steering Committee (PSC) was convened to provide academic guidance to this evaluation.

Dr Laura O Philbín, The Alzheimer Society of Ireland

Ms Cíara O Reilly, The Alzheimer Society of Ireland

Mr Paul Maloney, National Dementia Services, Health Service Executive

Dr Louise Hopper, Dublin City University

Mr James Grassom, Join Dementia Research UK

Dr Emma O'Shea, University College Cork

Dr Siobhan Fox, University College Cork

Ms Lauren O'Mahony, University College Cork

Appendix 2

The PPI advisory committee were involved from the outset of this evaluation process to ensure that the lived experience of dementia was kept central to the project meaning. The PPI advisors met with the research team on four occasions over the course of the project.

PPI Advisory Committee members:

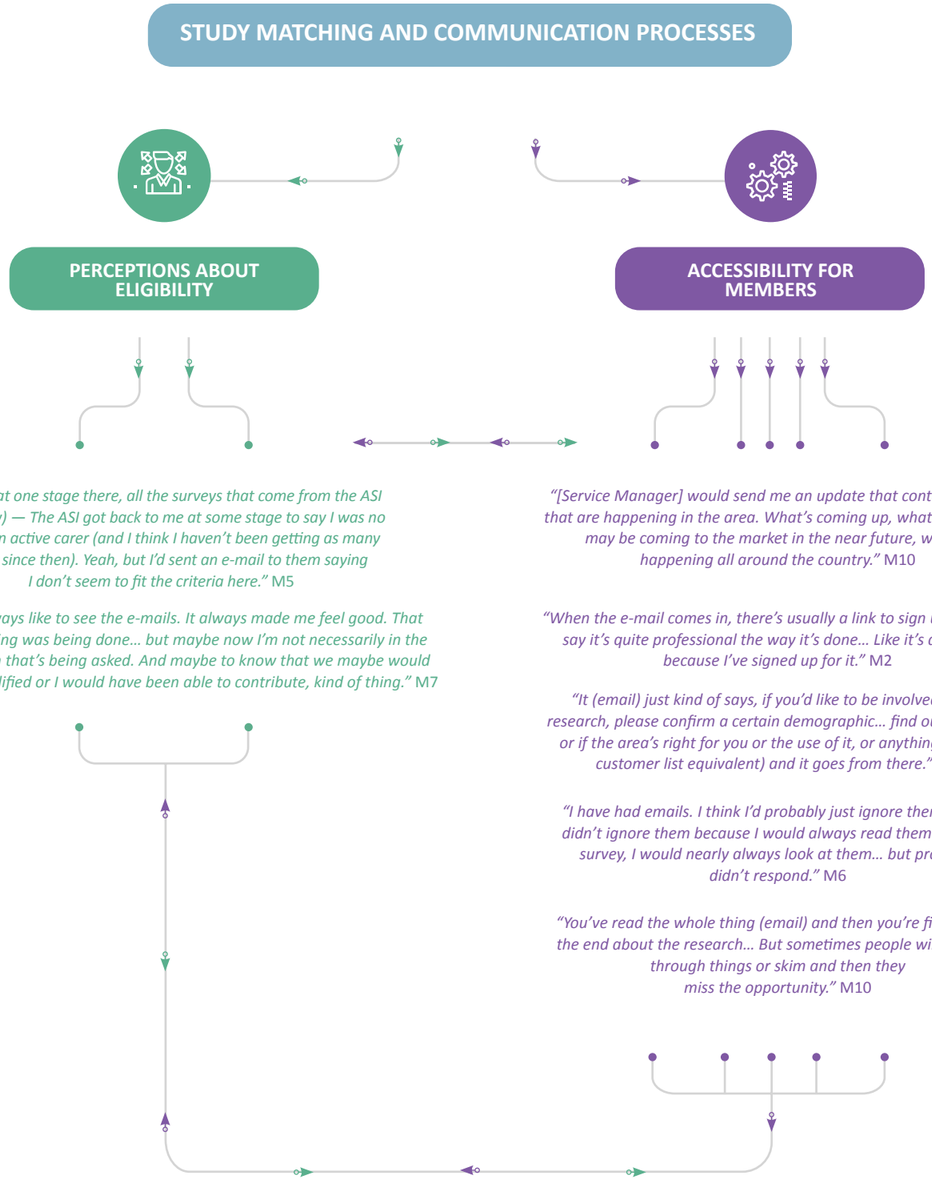
Mrs Nuala Paley

Mr Raymond Cregan

Mr John Crowley

Appendix 3

Worked example of thematic coding development for subthemes "Accessibility for members" within the theme Sign Up and Communication Processes, with worked example of how subthemes interconnect within the overarching theme.



"I know at one stage there, all the surveys that come from the ASI (probably) — The ASI got back to me at some stage to say I was no longer an active carer (and I think I haven't been getting as many emails since then). Yeah, but I'd sent an e-mail to them saying I don't seem to fit the criteria here." M5

"I'd always like to see the e-mails. It always made me feel good. That something was being done… but maybe now I'm not necessarily in the research that's being asked. And maybe to know that we maybe would have qualified or I would have been able to contribute, kind of thing." M7

"[Service Manager] would send me an update that contains things that are happening in the area. What's coming up, what new things may be coming to the market in the near future, what is happening all around the country." M10

"When the e-mail comes in, there's usually a link to sign up… I would say it's quite professional the way it's done… Like it's an e-mail because I've signed up for it." M2

"It (email) just kind of says, if you'd like to be involved in this research, please confirm a certain demographic… find out your age or if the area's right for you or the use of it, or anything… (like a customer list equivalent) and it goes from there." M4

"I have had emails. I think I'd probably just ignore them. Well, I didn't ignore them because I would always read them… If it's a survey, I would nearly always look at them… but probably didn't respond." M6

"You've read the whole thing (email) and then you're finished, at the end about the research… But sometimes people will just skip through things or skim and then they miss the opportunity." M10

Appendix 4. Survey participants' demographics

Characteristics		N%
Gender	Male	19 (38.8)
	Female	30 (61.2)
Age	31-49	8 (16.3)
	50-64	22 (44.9)
	65-79	17 (34.7)
	80+	2 (4.1)
Area Of Residence	City/suburbs	19 (38.8)
	Rural	16 (32.7)
	Village or small town	8 (16.3)
	Large Town	6 (12.2)
Province	Leinster	28 (57.1)
	Munster	14 (28.6)
	Connaught	5 (10.2)
	Ulster	2 (4.1)
Education	Junior Cert or Leaving Cert	7 (14.3)
	Undergraduate Studies	12 (24.4)
	Postgraduate Studies	26 (53.0)
	Other (diploma, cert)	4 (8.0)
Living situation	Living alone	4 (8.2)
	With a partner/spouse	29 (59.2)
	Living with family	13 (26.5)
	Living with others (not family)	1 (2.0)
	Other (staying with person with dementia as caregiver)	2 (4.0)
Employment at present*	Retired	22 (42.3)
	Employed full-time	10 (19.0)
	Employed part-time	5 (9.61)
	Home-duties or caregiver	4 (7.69)
	Self-employed	5 (9.61)
	Unemployed	4 (7.69)
TUDR member status	Person living with dementia	8 (16.3)
	Current caregiver of a person with dementia	20 (40.8)
	Former caregiver of a person with dementia	14 (28.6)
	Not a formal caregiver, but family/friend of a person with dementia	7 (14.2)

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