UK Data Service Study Number 854293

# Improving the experience of Dementia and Enhancing Active Life:

# The IDEAL Programme

## Waves 1 to 3

## User Guide

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# Important notes

## Note about participants removed from the archive datasets

The study consent forms allowed participants to take part in the study but refuse storage of their data in an archive. Table 1 shows PwD removed from the archive datasets by Wave, and Table 2 shows Carers removed from the Wave 1 archive dataset (no Carers were removed from Waves 2 or 3).

The numbers used in this User guide, and any other numbers relating to participants in archived documents, refer to the number consented to the study and not the number found in the archive datasets.

8 "blank" P_IDs with no associated data were included in the Wave 1 PwD and Carer datasets. These P_IDs were requested by the co-ordinating centre for continuity purposes at Wave 2 and are listed in 5.7 Combining datasets.

*Table 1: PwD removed from the archive datasets by Wave*

| PwD removed from Wave 1 archive dataset | PwD removed from Wave 2 archive dataset | PwD removed from Wave 3 archive dataset |
|---|---|---|
| 1000273 | 2236342 | 2854402 |
| 1103208 | 2854521 | |
| 1206134 | | |
| 2236333 | | |
| 2236352 | | |
| 2339303 | | |
| 2751502 | | |
| 3060703 | | |
| 3060811 | | |
| 3884417 | | |

*Table 2: Carers removed from the Wave 1 archive dataset*

| Carers removed from Wave 1 archive dataset |
|---|
| 1206124 |
| 1206125 |
| 1927108 |
| 2236338 |
| 2236364 |
| 2854515 |
| 2957232 |
| 3060703 |

## Note about variables removed from the archive datasets

Due to the sensitive nature of some information and the potential for re-identification of participants, variables were removed from the archive datasets. Table 3 shows the total number of PwD variables removed from the archive datasets by Wave, and Table 4 shows the total number of Carer variables removed from the archive datasets by Wave.

In some of the Data documents and Interview documents, for example the archived CRFs, all study variables are listed. This is for transparency and reference purposes only. The removed variables and their replacement derived variables are recorded in Data documents.

*Table 3: PwD variables removed from the archive datasets by Wave*

| PwD variables removed from Wave 1 archive dataset | PwD variables removed from Wave 2 archive dataset | PwD variables removed from Wave 3 archive dataset |
|---|---|---|
| 211 | 117 | 117 |

*Table 4: Carer variables removed from the archive datasets by Wave*

| Carer variables removed from Wave 1 archive dataset | Carer variables removed from Wave 2 archive dataset | Carer variables removed from Wave 3 archive dataset |
|---|---|---|
| 82 | 49 | 49 |

## Note about Wave nomenclature

The term “Wave” is used throughout this User guide to indicate specific times when interviews took place (explained in 3.1 Overview). Other study documents in the archive refer to these specific times as “Time points”. This is also how datasets and variables were labelled (t1, t2 or t3). For this reason, the terms Wave and Time point are interchangeable. Wave 1 may also be referred to as “baseline” in study documents.

**Note about archived CRFs**

Archived CRFs were altered from the versions used for interviews in order to include variable mapping. Mapped variables are identified by their labelling convention and red font, and are usually placed directly above the question being asked (see Figures 6 and 7 in 5.4 Variable values for examples).

The AAIQOL measure in the CRFs is preceded by a comment outlining the author, owner and copyright notice (see Table 5). This is in accordance with Section 2.02(b) of the user agreement's "special terms". In order to accommodate these details, the layout of either the AAIQOL questions or the questions preceding them may have been altered slightly by condensing their space on the page.

The EQ-5D measure and MMSE test form were removed from archived CRFs in line with their respective user agreements (see Table 5). An MMSE test showcard has also been removed. Comments on the CRFs and showcards identify where these measures have been removed.

No other changes were made to CRFs and the versioning on their cover pages is left unaltered to denote which versions were used during interviews.

*Table 5: Changes to measures in archived CRFs and publishers' details*

| Title of Measure | Publishers' Details |
|---|---|
| AAIQOL<br>(Activity and Affect Indicators of QOL) | AAIQOL © Steven M. Albert, 1996 - All rights reserved. Contact information and permission to use: Mapi Research Trust, Lyon, France.<br>E-mail: PROinformation@mapi-trust.org – Internet: www.proqolid.org |
| EQ-5D | EQ-5D™ is a trademark of the EuroQol Group. Without the prior written consent of the EuroQol Group Executive Office, it is not permitted to i.e. use, reproduce, alter, amend, convert, translate, publish or make available in whatever way (digital, hard-copy etc.) the EQ-5D and related proprietary materials. All copyrights in the EQ-5D, its (digital) representations, and its translations exclusively vest in the EuroQol Group Foundation. |
| UK English version of the Mini-Mental State Examination (MMSE) Test Form | Reproduced by special permission of the Publisher, Psychological Assessment Resources, Inc., 16204 North Florida Avenue, Lutz, Florida 33549, from the Mini Mental State Examination, by Marshal Folstein and Susan Folstein, Copyright 1975, 1998, 2001 by Mini Mental LLC, Inc. Published 2001 by Psychological Assessment Resources, Inc. Further reproduction is prohibited without permission of PAR, Inc. The MMSE can be purchased from PAR, Inc. by calling (800) 331-8378 or (813) 968-3003. |

**Note about archived Researcher's handbooks**

The Researcher's andbooks are the best resource to find information about the study design and implementation. As with the archived CRFs, the handbooks have had information pertaining to the MMSE test form removed, in line with the publisher's user agreement (see Table 5 in Note about archived CRFs). Comments in square parentheses and bold red font identify where information has been removed from the handbooks.

All appendices have been removed to prevent duplication of information, as the final versions of applicable study forms are included in the archive. However, references to appendices have been left in to show where researchers were prompted to refer to documentation. Links to external websites and contact details for study staff have also been left in for illustrative purposes only.

No other changes were made to the Researcher's handbooks and the versioning is left unaltered to denote which versions were used during the study.

**Note about documents that have not been archived**

Some study documents used in the compilation of this User guide are not being archived with the UK Data Service. These include training slides, guidelines for correction, and other study materials, as well as the funding application and original study protocol (version 4). Where directly quoted they have been added to 9. References with the prefix "Unpublished".

These documents and other study materials referred to in this User guide are archived at North Wales Organisation for Randomised Trials in Health (NWORTH) in accordance with the Standard Operating Procedure for archiving (NWORTH 3.10 Archiving v8).

**Document History**

| Version Number | Effective Date | Authorship | Summary of changes |
|---|---|---|---|
| 1 | 12/03/2020 | Greg Flynn | New document. |
| 2 | 02/06/2020 | Greg Flynn | Minor changes. Sect. 4.4 UK Data Service doi and citation for cohort study included. Sect. 6 citation updated. Sect 8 publications updated. |

# 1. Summary of documentation in the archive

The documentation in UK Data Service study number (SN) 854293 has been organised as follows:

**User guide**

- Overview of documentation in the archive.
- Study design and implementation.
- Data collection and data processing.
- Advice on dataset use and how to cite the data.
- Acknowledgements and study publications.

**Data documents**

- List of variables ordered into categories (best place to start for analysing data).
- List of derived variables including Stata syntax specification.
- Measures found in each Wave ordered into categories and their citations.
- Data dictionaries of variables in the order they appear in the datasets.

**Interview documents**

- Case Report Forms (CRFs) mapped to dataset variables.
- Showcards.
- Study consent forms.
- Data linkage consent forms.

**Supporting documents**

- Researcher's handbooks (best resource for information about the study design and implementation).
- Factsheet for clinic staff.
- Introduction to the study for participant, family friends, personal consultee.
- Invitation letter and reply slips.
- Participant information sheets.
- Demonstration of capacity checklist.
- Pre-screening and referral information form.
- Data linkage information pamphlets.
- Follow-up letter and reply slips.
- Summary of the study for follow-up.
- Contact details forms.
- Adverse event reporting form.
- IDEAL study protocol (open access).

## 2. Introduction to the IDEAL programme

The IDEAL programme is a 9-year longitudinal study of people with dementia (PwD) and primary carers (Carers) across Great Britain. This User guide and all other documentation in SN 854293 relates to the first part of the programme (Waves 1 to 3), which was jointly funded by ESRC and NIHR from 2014 – 2019. The second part of the programme is funded by Alzheimer's Society as a Centre of Excellence from 2018 – 2022. For the purposes of this set of documentation Waves 1 to 3 will henceforth be referred to as "the study".

The aim of the IDEAL programme is to identify what helps people to live well or makes it difficult to live well in the context of having dementia or caring for a person with dementia, and to understand what 'living well' means from the perspective of PwD and Carers. The findings are expected to lead to recommendations about what can be done by individuals, communities, health and social care practitioners, care providers and policy-makers to improve the likelihood of living well with dementia.[1]

The research questions that were central to the development of the study CRFs are as follows:

1. How do capitals, assets and resources, and adaptation in response to dementia-related and other challenges, influence the ability to live well for PwD and Carers, and what are the reciprocal influences between PwD and Carers factors?
2. How do changes over time in capitals, assets and resources, dementia-related and other challenges, and adaptation affect evaluations of living well for PwD and Carers?
3. What do PwD and Carers believe helps or hinders the possibility of living well, and what factors are particularly important to them as regards being able to live well with dementia?[2]

At Baseline (Wave 1), data from 1547 PwD and 1283 Carers were included in the study. Eligible participants were interviewed again at 12 months (Wave 2) and 24 months (Wave 3). Interviews were carried out in participants' own homes using paper CRFs. Researchers were NHS staff working from one of 29 research sites across Great Britain. Completed CRFs were returned to North Wales Organisation for Randomised Trials in Health (NWORTH) for electronic data entry, in order to ultimately produce the datasets.

The study was co-ordinated at the University of Exeter Centre for Research in Ageing and Cognitive Health (REACH). Professor Linda Clare is the Chief Investigator and developed the concept for the IDEAL programme while at Bangor University. Full acknowledgements are covered in 7. Acknowledgements.

More information about the study can be found in the IDEAL study protocol, which has been archived, and on the IDEAL programme website, which also contains comprehensive links to publications: http://www.idealproject.org.uk/

# 3. IDEAL study design

## 3.1 Overview

The study is a mixed-method, longitudinal cohort study of PwD and Carers. After identifying participants and assessing eligibility, interviews were conducted in participants' homes and occurred over three Waves: Baseline (Wave 1); 12-month follow-up (Wave 2); and 24-month follow-up (Wave 3). At the beginning of each Wave the PwD and Carer had to provide consent to take part (for Wave 1 this was informed consent), and at the end of each Wave a shopping voucher was given as a token of thanks for participating.

Researchers filled out paper CRFs face-to-face with the PwD with the aid of showcards, and Carers could fill out their CRFs at the same time, or complete and return their copies to the associated research site. For Wave 1, three separate CRFs were administered as interviews over the course of approximately six weeks. For Waves 2 and 3, two CRFs were administered approximately two weeks apart, although for some participants the time between interviews could be longer or shorter, depending on researcher or participant availability.

CRFs are composed of questions about demographic details, existing standardised measures and ratings, and new measures developed for the study. Some measures have been shortened or otherwise tailored for the IDEAL programme. A comprehensive list of measures, citations, and changes between Waves are found in the Data documents.

Completed CRFs were sent to NWORTH for electronic data entry. A database for each Wave was created in the MACRO Electronic Data Capture system to record information as it is presented in the CRFs. Quality control measures and data cleaning were continually implemented to ensure data integrity. After all CRFs for a given Wave had been entered, the database was locked and exported as SPSS files. These files were combined to form the datasets for each Wave. This process is covered in 4. Data collection.

Detailed information about the study design and implementation can be found in the IDEAL study protocol, and also at the start of the Researcher's handbooks, both in Supporting documents.

## 3.2 Timetable

A timetable was produced early in the study design and was documented in the study protocol, version 1 of which was finalised on 15/01/2013. Figure 1 shows the project timetable, taken from the Unpublished study protocol v4,[3] and gives a helpful overview of how the study was conducted.

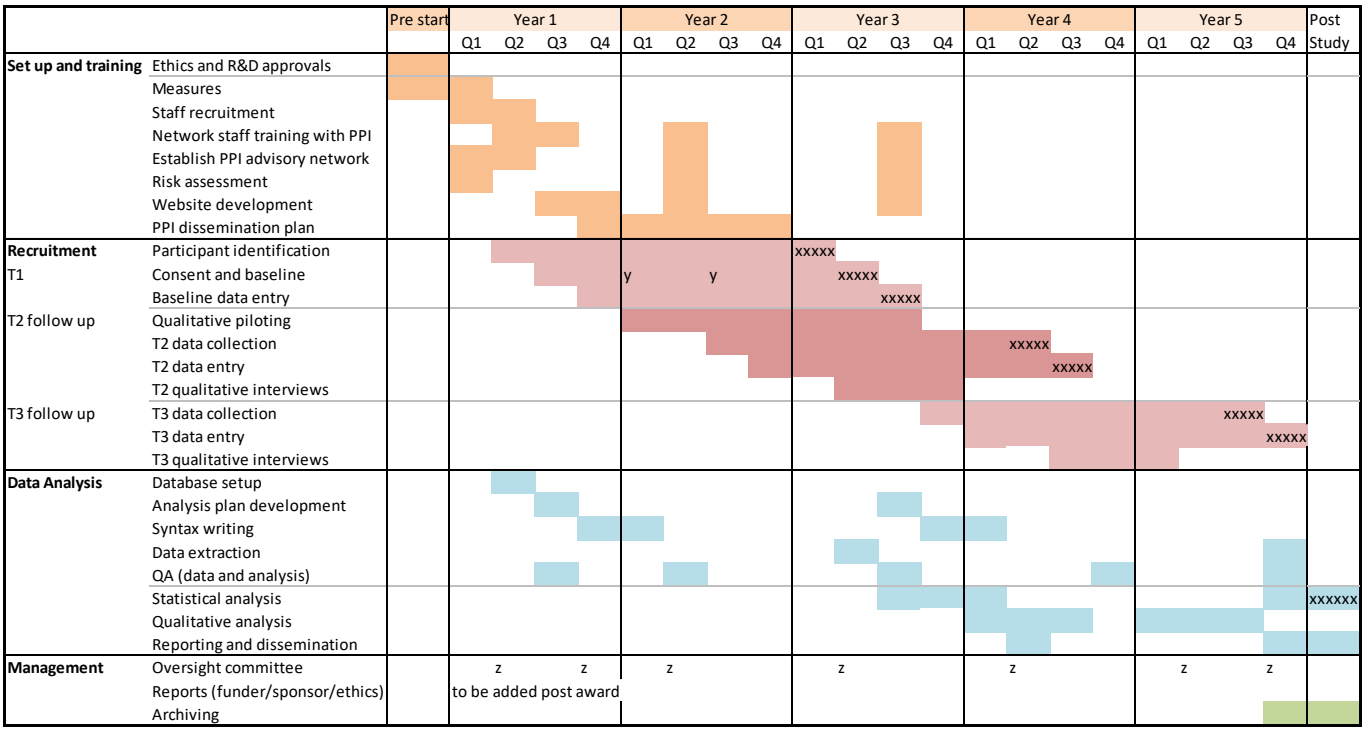



*Figure 1: Project timetable*

## 3.3 Sample design

Sample size was determined on the basis of the study team's prior experience with and findings from the MIDAS[4] and DADE[5] studies and on the nature of the proposed primary statistical analyses using structural equation modelling (SEM).[6] Based on previous experience,[7] it was anticipated that 70% of PwD would have a participating Carer, but participants were not excluded for not having a Carer. Inclusion criteria for the PwD were a clinical diagnosis of dementia (any sub-type) and an MMSE score of 15 or above. Exclusion criteria were co-morbid terminal illness in the PwD at Wave 1, inability to provide informed consent at Wave 1, and any known potential for home visits to pose a significant risk to researchers. Recruitment targeted people of any age and any type of dementia who had mild-to-moderate dementia on entry to the study, yielding a sample ranging from mild-to-severe dementia at follow up.[8]

The study's sampling strategy was informed by robust population estimates on the key parameters of dementia sub-type, age, gender, living situation and relationship with primary caregiver (see Table 6).[9] During the feasibility stage of the study, recruitment targets were agreed with research sites across Great Britain, reflecting the population covered by Clinical Research Networks (CRNs). Actual sample populations in the study are found in 3.6 Recruitment figures.

*Table 6: Population prevalence estimates and estimated Ns for sub-group analyses*

| **Dementia sub-type**[i] | Estimate % | Wave 1 N | Wave 3 N |
|---|---|---|---|
| Alzheimer's disease (AD) | 62.0% | 930 | 651 |
| Vascular | 17.0% | 255 | 178 |
| Mixed AD and vascular | 10.0% | 150 | 105 |
| Frontotemporal dementia | 2.0% | 30 | 21 |
| Dementia with Lewy Bodies | 4.0% | 60 | 42 |
| Parkinson's disease dementia | 2.0% | 30 | 21 |
| Other | 3.0% | 45 | 31 |

| **Age distribution**[i] | Estimate % | Wave 1 N | Wave 3 N |
|---|---|---|---|
| Young onset (< 65) | 2.2% | 33 | 23 |
| 65 – 79 | 12.8% | 192 | 134 |
| 80 – 89 | 68.0% | 1020 | 714 |
| 90+ | 17.0% | 450 | 315 |

| **Gender**[i] | Estimate % | Wave 1 N | Wave 3 N |
|---|---|---|---|
| Women | 66.5% | 998 | 699 |
| Men | 33.5% | 502 | 351 |

| **Living situation**[ii] | Estimate % | Wave 1 N | Wave 3 N |
|---|---|---|---|
| Living with others | 66.5% | 998 | 699 |
| Living alone | 33.5% | 502 | 351 |

| **Relationship with primary carer**[iii] | Estimate % | Wave 1 N | Wave 3 N |
|---|---|---|---|
| Spouse/partner | 63.0% | 683 | 478 |
| Adult child | 30.0% | 315 | 220 |
| Other relative | 5.0% | 53 | 37 |
| Friend | 2.0% | 21 | 15 |

[i] Dementia sub-type, Age distribution and Gender - Data from Dementia UK.
[ii] Living situation (living alone vs. living with others) - Estimate provided by Alzheimer's Society and supported by Miranda-Castillo et al (2010). Gould & Wiener (2010) reach a similar estimate based on studies in the US, Canada and several European countries.
[iii] Relationship with primary carer (expected carer N = 1050 at Wave 1) - Estimates based on studies from our group (MIDAS; Quinn PhD), NIHR Challenge Demcare study, and Miranda-Castillo et al. (2010).

## 3.4 Patient and Public Involvement (PPI)

PPI was led by Innovations in Dementia with support from Alzheimer's Society and utilised INVOLVE guidance. Issues identified as impacting on the ability to live well, which included loneliness, lack of understanding of dementia in their communities, losing contact with friends, isolation, fear of going out independently, and loss of control over aspects of one's life, contributed to the decision to focus on social, environmental and psychological factors in the study application.[10]

The ALWAYs ('Action on Living Well: Asking You') group was set up to provide PPI input to the IDEAL programme. ALWAYs is an involvement group of PwD and Carers. The ALWAYs group was formed in 2014 at the start of the IDEAL programme and members have advised on different aspects of the project, based on personal experiences, skills and expertise.

IDEAL programme researchers brought ideas, questions, materials and concerns to the ALWAYs group at regular intervals – ensuring that the role of the group was routinely linked to the study timetable. The involvement of PwD and Carers ensured that the study processes, materials and emerging outcomes were clear and relevant.

The ALWAYs group brought enormous benefits and made a very significant contribution to the development, implementation, analysis, interpretation and dissemination of the IDEAL project, summarised in Table 7.

*Table 7: PPI involvement throughout the study*[iv]

| **During 2014** |
|---|
| Inaugural meeting of the ALWAYs group. |
| Provided feedback that was used in the training of researchers who work on the study. |
| **During 2015** |
| Consulted on the questions we ask in the study questionnaires. |
| Advised the project on the introduction of data linkage to IDEAL. |
| Met with the photographer to discuss the linked project 'A Life More Ordinary'. |
| Helped by being involved in piloting of the IDEAL interviews. |
| **During 2016** |
| Reviewed study progress. |
| Members took part in piloting of the qualitative interview for IDEAL – this is now published. |
| Consulted about the research process and contributed to training. |
| Discussed a new measure to look at how people with dementia think about their condition. |
| Represented IDEAL at UK Dementia Congress 2016 in Brighton. |
| **During 2017** |
| Reviewed study progress. |
| Reviewed some of the findings for IDEAL T1 data. |
| Consulted about the continuation of IDEAL with the funding application for IDEAL-2 (which has now been funded). |
| Represented IDEAL at the British Gerontology Society Conference in Swansea, July 2017. |
| Contributed to an ESCR Festival of Social Science event in Exeter November 2017. |
| **During 2018** |
| Participated in a focus group discussion to reflect on the ALWAYs group. |
| Made a short film about the ALWAYs group. |
| Represented IDEAL at UK Dementia Congress 2018 in Brighton. |
| Represented IDEAL and co-presented a plenary talk at the Alzheimer's Disease International Conference in Chicago, July 2018. |
| Wrote a blog post for University of Exeter reflecting on contributions to IDEAL. |
| Helped develop a masterclass of good Patient and Public Involvement practice in research. |
| **During 2019** |
| Worked on concept of living well with dementia. |
| Gave reflections to build on the data from IDEAL. |
| Worked with Alzheimer's Society to help to shape the recommendations for commissioners using the IDEAL findings. |
| Gave reflections on Patient and Public Involvement presentation at Alzheimer's Society conference. |
| Provided feedback on new outputs. |

[iv] Table 7 was compiled and edited from programme records and from the publication below, which can also be found on the IDEAL programme website: Litherland, R., Burton, J., Cheeseman, M., Campbell, D., Hawkins, M., Hawkins, T., … Clare, L. (2018). *Reflections on PPI from the 'Action on Living Well: Asking You' advisory network of people with dementia and carers as part of the IDEAL study*. Dementia, 17(8), 1035–1044. https://doi.org/10.1177/1471301218789309

## 3.5 Recruitment process

Based on a feasibility assessment and subsequent discussions, 28 CRNs around Great Britain were identified to act as research sites, and 1 additional site was added shortly after recruitment began. Regional and local recruitment targets were set at the sample design stage. Each site assigned a lead researcher, who oversaw recruitment and was responsible for uploading progress data into the web-based data entry system MACRO Consort, which was chosen due to the large number of sites involved in the study.[11]

Participant Identification Centres (PICs) were established at each research site to ensure adequate numbers of people with different sub-types of dementia were invited to take part. PICs could be memory services, old age mental health services, or other services that specialise in other types of dementia. For example, people with Parkinson's disease dementia might be identified from movement disorders clinics. Where needed, PICs were checked to ensure they were covered by local approvals.[12]

From suitable PICs, researchers screened patient records, clinic files, and databases of people interested in taking part in research in order to identify eligible participants. Participants were also recruited by drawing on contacts with community mental health teams, social services, and voluntary sector groups. To help sites recruit participants, IDEAL made use of Join Dementia Research, a nationwide database of people willing to take part in dementia research. Study partners and other agencies promoted the IDEAL programme in relevant magazines, bi-annual newsletters, and through media and social media channels.[13]

PwD considered to meet inclusion criteria, along with a Carer if available, were contacted either by telephone, letter, or in person during clinic appointments in order to establish whether they were interested in participating. Non-responses to the initial contact was followed up by researchers to compensate for the possibility that letters and messages could be mislaid due to memory difficulties. Those who expressed interest were sent the participant information sheets and later visited at home, where consent was taken for the PwD and Carer if available.[14] Completed consent forms were kept securely at the research site and copies were returned to the co-ordinating centre in batches. Flow diagrams of the participant pathway through the study can be found in the Researcher's handbooks in Supporting documents.

A monitoring plan was put in place so that the project manager at the co-ordinating centre was able to evaluate recruitment rates and the relationship of these to population prevalence estimates. Each site's lead researcher uploaded recruitment data to the MACRO Consort database for monthly review (see Figures 2, 3 and 4). It was important that each site updated Consort in a timely fashion as the information had to be reported by the project manager to the study funders, sponsors and ethics committees.[15] MACRO Consort is covered in the Monitoring section of the Researcher's handbooks.

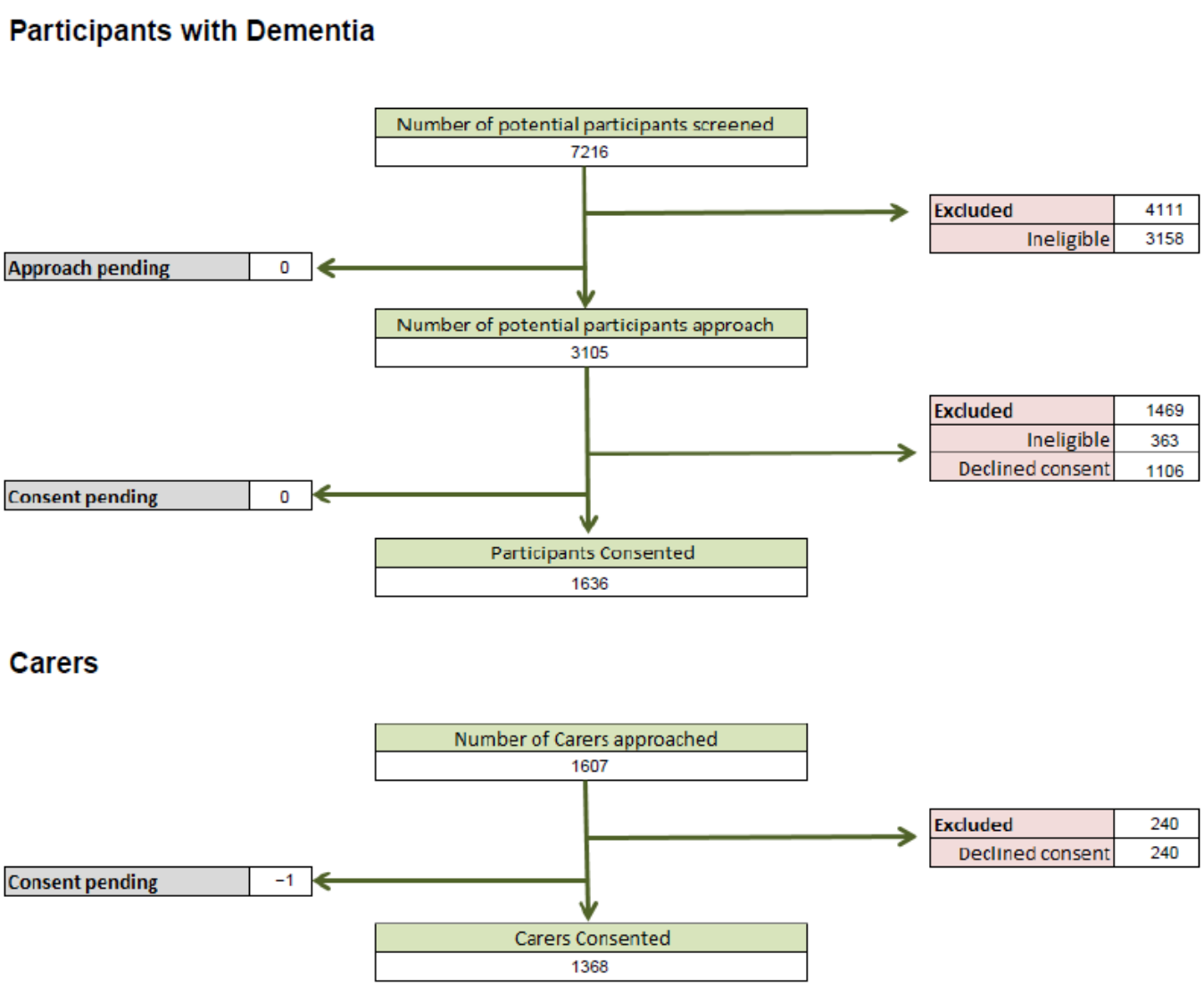



*Figure 2: MACRO Consort data of all participants screened and consented[16]. Note: the number of participants consented is greater than the number in the study, as the MACRO Consort data includes those who consented but later withdrew, or were withdrawn from the study before data could be collected.*

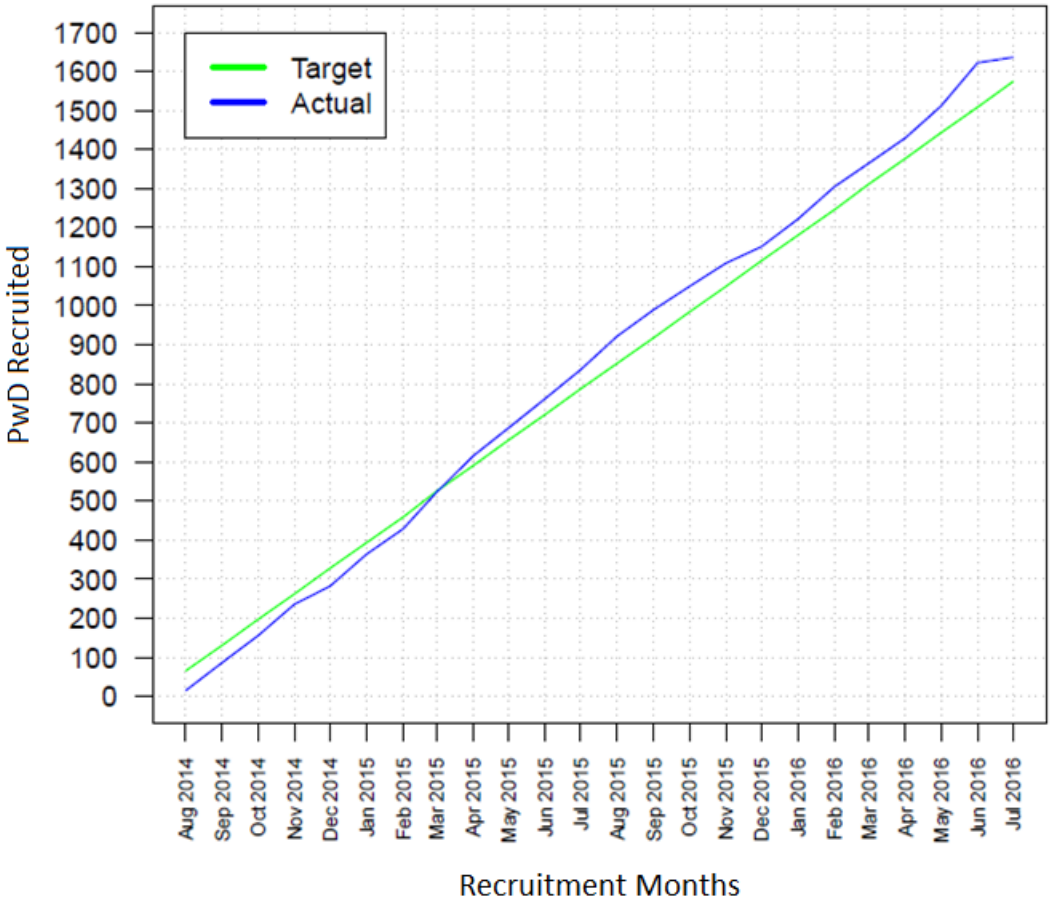



*Figure 3: PwD recruitment by month*[17]


*Figure 4: Carer recruitment by month*[18]

To keep track of recruitment and to assign Participant IDs, researchers used the IDEAL pre-screening and referral information form and contact details forms, which can be found in Supporting documents. At Wave 1, a spreadsheet was also issued to each site which automatically generated follow-up schedules for Wave 2 and 3 interviews. An acceptable window for follow-up was advised as no earlier than one month prior to scheduled follow-up date and no later than two months post the scheduled follow-up date for each Wave.[19] However, it was preferable that data were collected late rather than not at all, so in extenuating circumstances researchers could contact the co-ordinating centre for advice.

At Wave 2, PwD were asked to consent to data linkage. This gave the research team permission to get further information about the participants from records that the NHS and public organisations hold about them. Researchers were involved in gaining consent but not in the data linkage process.[20]

For PwD who moved into residential care and did not have a Carer taking part in the study, staff within the care home could be approached to provide some details and corroborating information about the PwD by completing a brief paid carer CRF. Information sheets and consent forms are in the Supporting documents. For Wave 2 there were two paid carers and for Wave 3 there was one paid carer; however to avoid potential re-identification of participants the paid carer datasets are not being archived with the UK Data Service. The paid carer CRFs are archived in Interview documents for illustrative purposes only.

An ALWAYS group member noted that "a year is a long time to wait". An important way of minimising dropouts between Waves was to ensure that participants' interest in the study was maintained between follow-up visits. Participants who consented for their contact details to be given to the co-ordinating centre were sent bi-annual study newsletters.[21] Participants could also find out about the progress of the study by accessing the IDEAL programme website where the newsletters were also available.

### 3.6 Recruitment figures

The data in Table 8 was compiled from the "Chief Investigator" datasets and does not include participants who initially consented but were later withdrawn.

*Table 8: Recruited PwD population prevalence Ns for sub-group analyses*

| **Revised Dementia sub-type**[v] | Actual at Wave 1 % | Wave 1 N = 1547 | Wave 3 N = 856 |
|---|---|---|---|
| Alzheimer's disease (AD) | 55.5% | 858 | 492 |
| Vascular | 11.1% | 171 | 82 |
| Mixed AD and vascular | 21.1% | 326 | 186 |
| Frontotemporal dementia | 3.5% | 54 | 32 |
| Dementia with Lewy Bodies | 3.4% | 53 | 27 |
| Parkinson's disease dementia | 2.8% | 44 | 17 |
| Other | 2.7% | 41 | 20 |

| **Revised Age**[vi] | Actual at Wave 1 % | Wave 1 N = 1547 | Wave 3 N = 856 |
|---|---|---|---|
| Young onset (< 65) | 8.8% | 136 | 68 |
| 65 – 79 | 52.2% | 807 | 404 |
| 80 – 89 | 35.1% | 543 | 332 |
| 90+ | 3.9% | 61 | 52 |

| **Gender** | Actual at Wave 1 % | Wave 1 N = 1547 | Wave 3 N = 856 |
|---|---|---|---|
| Women | 43.7% | 676 | 378 |
| Men | 56.3% | 871 | 478 |

| **Living situation** | Actual at Wave 1 % | Wave 1 N = 1547 | Wave 3 N = 856 |
|---|---|---|---|
| Living with others | 81.2% | 1256 | No data |
| Living alone | 18.4% | 285 | No data |
| Unclassifiable | 0.4% | 6 | No data |

| **Revised Relationship with primary carer**[vii] | Actual at Wave 1 % | Wave 1 N = 1283 | Wave 3 N = 760 |
|---|---|---|---|
| Spouse/partner | 81.0% | 1039 | 564 |
| Adult child | 14.6% | 187 | 98 |
| Adult step-child | 0.2% | 2 | 0 |
| Adult in-law | 0.8% | 10 | 2 |
| Adult grandchild | 0.1% | 1 | 0 |
| Other relative | 1.0% | 13 | 4 |
| Friend | 0.8% | 10 | 7 |
| Neighbour | 0.2% | 2 | 1 |
| Other | 0.1% | 1 | 0 |
| Not given | 1.4% | 18 | 84 |

[v] In raw data, researchers occasionally responded "Unspecified dementia/other", or it would be later found the diagnosis was given inaccurately. Revisions to the data were carried out by the co-ordinating centre.

[vi] In raw data, questions relating to age were sometimes given inaccurately; either due to the PwD not knowing; or the researcher leaving the question blank. Revisions to the data were carried out by the co-ordinating centre.

[vii] In raw data, the relationship with carer question was sometimes given inaccurately; either due to the PwD not having a Carer in the study but still filling in the question; the PwD having a Carer in the study but not filling in the question; or the given relationship not being correct. Revisions to the data were carried out by the co-ordinating centre, but sometimes no information could be inferred ("Not given").

## 3.7 CRF design and changes between Waves

The CRFs were designed to address each component of a hypothesised model of factors affecting the ability to live well with dementia. The questionnaires were derived from existing standardised measures, or from identification of sub-scales or single items with known psychometric properties from these measures.[22] Carer CRFs have measures for self-report and for reporting on the PwD to produce "informant ratings".

Alzheimer's Society was consulted over the acceptability of questions and appropriateness of the order of questions prior to a piloting phase with PwD and Carers in North Wales. The CRFs were piloted with PwD and Carers associated with the ALWAYS group to assess ease of completion and length of time for completion. This was done prior to Wave 1 and prior to Wave 2. The piloting phase at Wave 1 demonstrated that the CRFs were acceptable to PwD and Carers, and showed that the CRFs could be completed within the allocated time frames for assessment.[23] For Wave 2 CRFs were reformatted and shortened in consultation with the study team. Feedback about measures that were proving challenging to administer helped with the final selection of Wave 2 measures.[24]

It was recognised that over the course of the study PwD may become markedly more impaired than at Wave 1. For some measures, core questions were identified that could be solely administered in this situation, which are identified with a thick border line in the CRFs. In addition to this, for Waves 2 and 3, cognitive assessments were administered appropriate to the severity of dementia at the first interview: Either the ACE-III if PwD had an MMSE score of 10 or more; or the Test for Severe Impairment (TSI) if MMSE score was less than 10 at the first interview.[25]

Some measures were only intended to be asked at Wave 1 and others were newly added for Wave 2 or 3. Measures across Waves are found in Data documents.

# 4. Data collection

## 4.1 Overview

Researchers received study-specific training before going out in the field to conduct interviews with PwD in their own homes. The first interviews at Wave 1 were conducted in March 2014 as part of piloting, and the last interviews for Wave 3 took place in August 2018. Researchers filled out paper CRFs with the aid of showcards on behalf of PwD, and at the end of the interview researchers completed cognitive staging questions. Carers could fill out their CRFs at the same time, preferably in a different room,[26] or could complete and return their CRFs at a later date.[27]

At each research site the lead researcher would collect all completed CRFs from researchers and send batches by courier to NWORTH. The first batch was received in October 2014 and the last batch was received in September 2018. The schedule for returns was organised by the study co-ordinators. Research site PIs included a coversheet in each batch, which stated the contents of the delivery and reasons for any missing or late CRFs.

In total, data from 15,943 paper CRFs were entered into the electronic database at NWORTH.[viii] At Wave 1 this was a manual process, but for Waves 2 and 3 an automated process was designed and implemented, which transposed non-text data directly into the database.

During electronic data entry at NWORTH any inconsistencies or missing data found in CRFs could be queried with researchers by email. Data entry guidelines were produced to distribute information about commonly found errors, and relevant information was incorporated into the training for Waves 2 and 3 to improve future data collection accuracy. Researcher's handbooks were produced for each Wave, demonstrating how to conduct the interviews and score the cognitive assessments. These can be found in Supporting documents.

## 4.2 Researcher training

The co-ordinating centre ensured that researchers undertook study-specific training prior to going out into the field. Study-specific training days were conducted shortly before each Wave of data collection began and attendance was recorded and details stored in the Trial Master File. Researchers working on the study also completed courses in Good Clinical Practice (GCP), and copies of their certificates were stored in the Trial Master File. Researchers updated training records in the MACRO Consort database for each Wave once they received training and read that Wave's handbook.

[viii] 15,943 CRFs figure does not include cases at Wave 1 where only the part 1 CRF was returned, or CRFs which were initially input in the database but later removed if participant withdrew consent to use data.

The study-specific training days were designed to complement information found in the Researcher's handbooks and the study protocol, and to provide researchers with feedback and practical examples of data collection and monitoring.

### 4.2.1 Wave 1

Training days ran for 8 ½ hours and started with a general introduction to the study and team. The study aims, methods and timelines were explained, followed by a detailed refresher course on conducting research with PwD, including consent, capacity, and researcher safety. Then a general overview of the CRFs was provided, covering issues such as the nature of questions being asked, potential challenges, and tips for completing the CRFs. More detailed instructions were provided on administering parts of the CRF, such as the cognitive assessments and scoring, Representations and Adjustment Index (RADIX) and Client Service Receipt Inventory (CSRI) questionnaires. There was a practical session focused on administering and completing the CRFs. The final part of the training day addressed data management, progress monitoring and reporting procedures, followed by a brief summary and Q & A session.[28]

### 4.2.2 Wave 2

Training days ran for 7 hours and started with a progress update for Wave 1 and an introduction to conducting Wave 2 of the study, including instructions for contacting participants and what to do if they had moved area. Wave 2 progress monitoring, document management and reporting were explained in detail, followed by an outline of data linkage, why it was being used in the study at Wave 2 and the type of questions researchers might be asked. Wave 2 CRFs were described and the differences from Wave 1 explained, and refreshers were given on prompting participants for data quality purposes. There was then a practical session on administering the CRFs and a summary of the day.[29]

### 4.2.3 Wave 3

Training days ran for 6 ½ hours and started with a progress update for Waves 1 and 2. There was a brief outline of changes at Wave 3, and a discussion about conducting the interviews and how to conclude the final interview with participants. Wave 3 CRFs were described, new measures introduced, and wording changes to questions explained. There were practical exercises on CRF completion and supporting PwD. Feedback on previous completed CRFs was given to improve data quality. Wave 3 progress monitoring was explained in detail and researchers were thanked for their hard work. A new study whose aim was to develop a new Carer quality of life questionnaire – Scales measuring the Impact of DEmentia on CARers (SIDECAR) – was introduced and explained, as some IDEAL participants had been identified for recruitment.[30]

### 4.2.4 GCP, Data Protection Act and Mental Capacity Act

Some principles of GCP, data protection and mental capacity were disseminated in slideshow presentations during researcher training. These are listed below to give some context about how these important legislative issues were addressed during researcher training.

**Good Clinical Practice – some principles:**

- Each individual involved in conducting a trial should be qualified by education, training and experience to perform his or her respective tasks(s).
- The rights, safety and well-being of the Study participants shall prevail over the interests of science and society.
- The necessary procedures to secure the quality of every aspect of the Study shall be complied with.
- Clinical trials shall be conducted in accordance with the principles of the Declaration of Helsinki – which states that respect for the individual, their right to self-determination and the right to make an informed choice is the fundamental principle which must be upheld throughout the research on any subject.
- The rights of each subject to physical and mental integrity, to privacy and to protection of the data concerning him/her in accordance with Data Protection Act 1998 are safeguarded.[31]

**The Data Protection Act (1998) guidelines ensure information about the participant is:**

- Used fairly and lawfully.
- Used for limited, specifically stated purposes.
- Used in a way that is adequate, relevant and not excessive.
- Accurate.
- Kept for no longer than is absolutely necessary.
- Handled according to people's data protection rights.
- Kept safe and secure.
- Not transferred outside the UK without adequate protection.[32]

**Why conduct research involving adults lacking capacity?**

- "It is important that research involving people who lack capacity can be carried out, and that it is carried out properly. Without it, we would not improve our knowledge of what causes a person to lack or lose capacity, and the diagnosis, treatment, care and needs of people who lack capacity." Mental Capacity Act (2005) Code of Practice (2007).
- Capacity must be assessed in terms of a person's ability to make a decision at the point at which it is required.
- The Mental Capacity Act (2005) states that: "A person must be assumed to have capacity unless it is established that they lack capacity".[33]

### 4.2.5 Training verification

Training verification was a requirement to help improve data quality. At the beginning of a Wave, every researcher's first two completed CRFs were photocopied and sent to the co-ordinating centre to be checked for completeness and accuracy. This training verification process helped identify and resolve potential issues at the early stage of the study and ensured quality data was collected.[34]

## 4.3 Interviews

Wave 1 interviews were conducted from March 2014 until September 2016. Wave 2 interviews were conducted from March 2015 until September 2017. Wave 3 interviews were conducted from August 2016 until August 2018.

Interviews took place across Great Britain and were conducted in the participants' own homes. Researchers filled out paper CRFs with the aid of showcards on behalf of PwD, and Carers could fill out their CRFs at the same time, or complete and return their copies to the associated research site. After the Wave 1 interviews, researchers were able to give feedback to the co-ordinating centre about their experiences of administering the questionnaires. There were also open-ended questions for participants to give feedback on their experience. This feedback and the findings from piloting informed changes to the length and question structure of Wave 2 CRFs.

Common mistakes from the interviews, identified during data entry at NWORTH, were fed back to the co-ordinating centre. Further training was conducted prior to Wave 2 and a FAQ-type document produced to accompany the Researcher's handbook.

## 4.4 In-depth qualitative interviews

Two rounds of in-depth interviews with a small sub-set of IDEAL participants were conducted between October 2016 and March 2018, led by Dr Alexandra Hillman and Professor Ian Rees Jones, director of the Wales Institute of Social and Economic Research, Data and Methods (WISERD). The primary aim of the qualitative interviews was to understand the reasons why particular social and psychological factors shape people's experience of living with dementia, for better or worse. The interviews allowed PwD and Carers to describe what is important to them in relation to living well with dementia, in their own words and on their own terms.[35]

The first round of qualitative interviews included 20 PwD and 20 Carers, who were approached after completing Wave 2 of the study. Interviews varied in length from 30 minutes to over 2 hours, although some of the very long interviews were edited to shorter versions. The second round of qualitative interviews were conducted 10 to 14 months after the first round and saw 17 PwD and 17 Carers returning. Transcripts were created within weeks of the interviews being done.

The IDEAL programme aims to integrate the qualitative and quantitative research findings, first through the sampling process and second through the process of analysis and interpretation.[36]

The qualitative interview transcripts and study documents are archived with the UK Data Service ReShare under the following citation:

Clare, Linda and Jones, Ian Rees and Hillman, Alexandra and Henley, Josie (2020). *Improving the experience of dementia and enhancing active life: living well with dementia cohort study 2016-2018.* [Data Collection]. Colchester, Essex: UK Data Service. doi: 10.5255/UKDA-SN-854317

## 4.5 Data linkage

Data linkage aims to allow researchers access to participant information from NHS and other public organisation records to improve the quantity and quality of data available for longitudinal analysis, such as health service use and mortality. Data linkage is guided by strict Administrative Data Research Network (ADRN) procedures: only trained and accredited researchers working in a secure environment can access linked data; the data can only be used for academic, government or ADRN Board approved research; the data can only be used for a defined purpose, such as calculating the amount and costs of health and social care use, and results only presented in terms of totals or averages; and no information can be passed to external organisations.[37]

Consent for possible data linkage was sought at Wave 2. If a PwD or personal consultee did not consent to data linkage, it did not affect participation in the study. Consent could be withdrawn at any time without giving a reason[38]. Consent forms for data linkage and Information pamphlets and can be found in Interview documents and Supporting documents.

At the time of study completion, despite attempts to secure permission for data linkage extending over five years, due to administrative changes and procedural issues it had not been possible to link any data. Any future information from data linkage will not be archived with the UK Data Service.

## 4.6 Data processing and cleaning

### 4.6.1 Hardcopy processing

Blank CRFs, each with a unique barcode, were produced and printed at NWORTH. An external printing company later helped to meet the high printing demand. Blanks were distributed to the 29 research sites in batches according to their agreed recruitment targets and interviewing timetable. It was important that researchers used only the original CRFs, as photocopying blanks on site could lead to issues in barcode assignment and TeleForm scanning, outlined in 4.6.2 Data entry.

Completed CRFs were returned by courier to NWORTH. The timetable for returns was organised by the study co-ordinators. A paper trail of batches was kept at NWORTH for auditing purposes: For Wave 1 the first batch arrived on 16/10/2014 and the last batch arrived on 06/03/2017; for Wave 2 the first batch arrived on 15/10/2015 and the last batch arrived on 20/11/2017; and for Wave 3 the first batch arrived on 01/09/2016 and the last batch arrived on 25/09/2018.[ix]

Barcodes on the CRFs were used with an electronic management system to record the participant ID and date of tracking. The location, data entry status, archiving location, or destruction of a CRF – which only occurred in the event a participant withdrew consent for his/her data to be used in the study – would also be recorded, creating an audit log for the hardcopy data.

Figure 5 outlines the full data processing workflows carried out at NWORTH.[39]

[ix] Hardcopies of CRFs and the paper trail for returns are archived at NWORTH in accordance with the Standard Operating Procedure for archiving (NWORTH 3.10 Archiving v8).

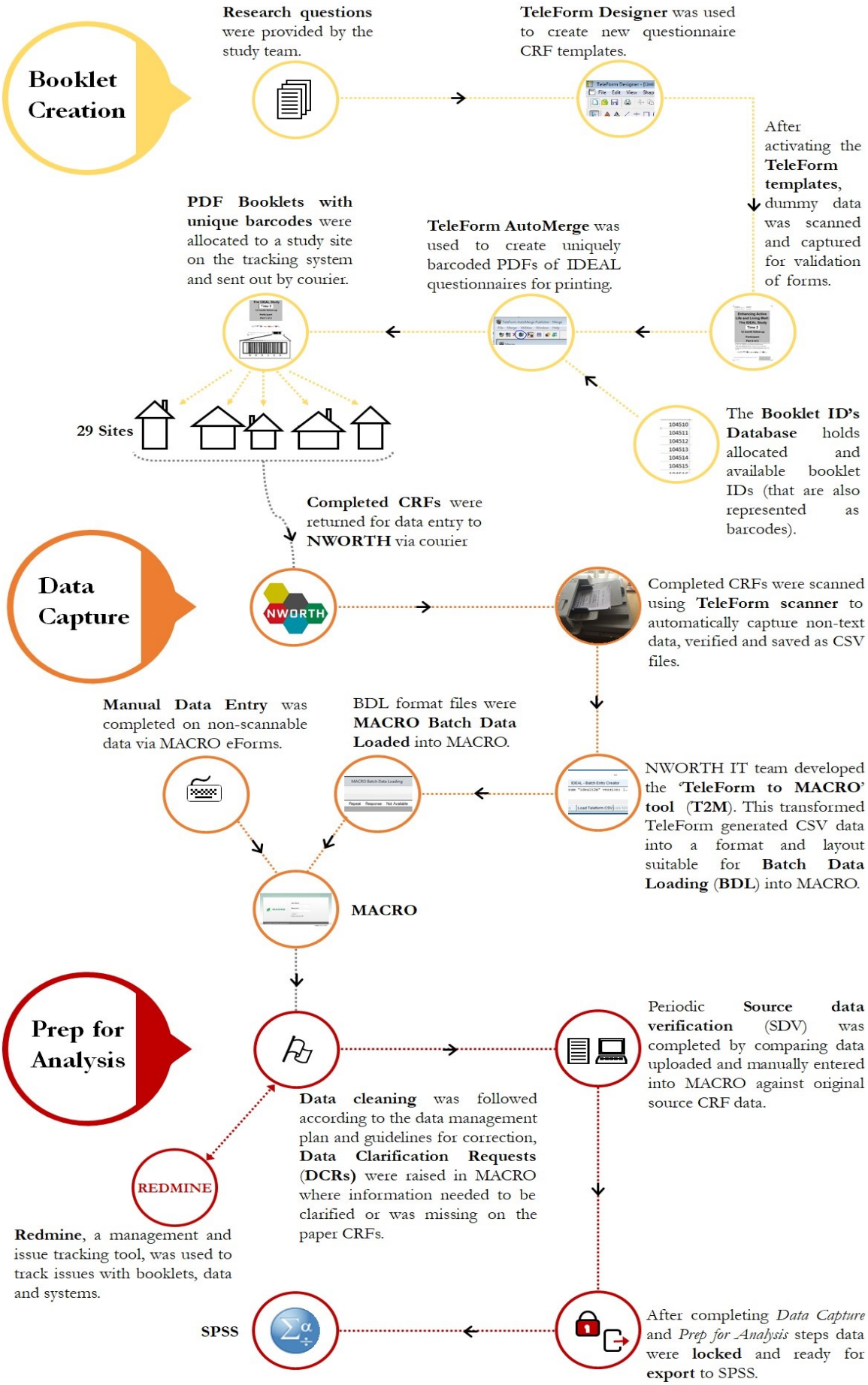



*Figure 5: Data processing workflows carried out at NWORTH*

### 4.6.2 Data entry

Electronic versions of study CRFs were designed and built in the MACRO Electronic Data Capture system. There is a MACRO database for each Wave. Data entry for Wave 1 was done manually. For Waves 2 and 3, the NWORTH data manager set up a scan station using TeleForm hardware, which could transpose non-text data directly into the database, increasing the speed with which CRFs could be entered into MACRO.

As CRF returns and data entry happened on a rolling basis while sites were conducting interviews, NWORTH could raise data queries with researchers, who could in turn check their research notes or, in rare circumstances, contact the participant for clarification. After all data for a Wave had been input and cleaned in MACRO, the Wave's database was locked to preserve data integrity.

### 4.6.3 Quality control

A data management plan and data entry guidelines ensured data entry clerks understood where quality issues were most likely to arise. MACRO databases were built with conditional variables, which could raise flags if data contradictions occurred, for example if a skip condition was ignored. Research sites were issued a document outlining frequently identified mistakes towards the end of Wave 1 and Wave 2 to improve future CRF completion.

During data entry for each Wave, 10% of the total number of participants were selected at random and their CRFs for that Wave were checked against the MACRO database entry. This quality control measure gave feedback to data entry clerks on input accuracy or CRF completion mistakes. After investigation, steps taken could include correcting the paper CRF, amending the data in MACRO, reporting the error to the research site PI, or adding to the guidelines for use in subsequent Waves. Findings and corrections were logged in an Excel spreadsheet.

At intervals during each Wave, the MACRO database was exported for distribution to the study project manager. The export format was a series of SPSS files as the sections appeared in MACRO. These "interim" datasets were used to monitor progress and data quality, to inform the creation of derived variables, and to allow the framework for the final dataset builds to be scripted.

### 4.6.4 Data cleaning for the archive

As the study is archived with the UK Data Service for re-use, extensive data cleaning was undertaken to ensure participants and any third parties could not be re-identified. The CRFs had many free-text fields where names, post codes, or other directly identifiable information were sometimes found. More commonly, indirect identifiers were sometimes found, such as age, workplace, occupation, etc. Data cleaning either completely removed or aggregated these identifiers into groups, such as "religious activity" for going to church. This was done jointly by the University of Exeter and NWORTH under the instruction of their respective University governance officers.

Removal of direct identifiers was conducted at NWORTH. SPSS files from the MACRO database were exported into Microsoft Excel to create correction log files. Every free-text response was manually checked for direct identifiers. A word search was then carried out for names and other identifiers to pick up any missed values. Corrections to the data were made in a separate cell, and all corrections to free-text values were re-uploaded into the MACRO database. The database was saved and exported to SPSS again. For each Wave a random 10% check on the corrected values was made, ensuring at least 1 value per affected question was checked. For all Waves there were 0 errors in this process.

Indirect identifiers were identified first at the University of Exeter and then further cleaning work was conducted at NWORTH. A second set of correction log files was produced at the University of Exeter, where the IDEAL data manager performed a similar manual check as described above. The corrections were then compiled at NWORTH and Stata syntax was used to overwrite original answers during dataset production.

A fictional example of the Stata syntax used:

replace P1_Q1_t1="Original response [aggregated response] original response" if P_ID==12345678

For each Wave a random 5% check on the corrected values was made, ensuring at least 1 value per affected question was checked. For all Waves there were 0 errors in this process.

For variables deemed high-risk for re-identification, for example date of birth, derived variables were produced. Derived variable specifications are provided in Data documents.

## 4.7 Attrition

### 4.7.1 Note about attrition calculations

Tracking participants over the course of the study sometimes does not follow on precisely between Waves. This is because for some participants, an accompanying Carer only joined the study at Wave 2 or Wave 3, or were not included at Wave 2 but re-joined at Wave 3. For PwD attrition calculations, participants are only counted if they were in the study at the previous Wave.

There are also instances where a Carer changes between Waves, but in this case the replacement Carer is not considered new to the study, as there was a Carer present already; e.g. if a PwD has a male Carer at Wave 1 but a female Carer at Wave 2, the Carer would be counted in attrition calculations.

The tracking spreadsheets referred to below contained more Participant IDs (PIDs) than are present in the study data. This is because the spreadsheets were working documents used to track participant consent dates and reasons for withdrawing. However, since data was either not collected, or not eligible for inclusion, the excess PIDs are not counted in the attrition calculations. Only PIDs who have data in the study are counted.

### 4.7.2 Overview

Attrition is to be expected in any study of PwD and occurs for various reasons. In order to track study participants over these first three Waves, the co-ordinating centre produced two spreadsheets to record consent dates and reasons for withdrawal for PwD and Carers respectively.[40]

The 3 most frequent explanations for both PwD and Carers being withdrawn from the study across all Waves were:

- Health reasons.
- Not interested.
- Unhappy with time commitment involved in taking part.

For PwD an approximate ratio for the above is 24:7:6 and taken together these account for almost 3/4 of all withdrawals. For Carers the approximate ratio is 16:5:7 and again these account for almost 3/4 of all withdrawals. However, there were many other withdrawal reasons recorded in the tracking spreadsheets.

### 4.7.3 PwD

- 1547 PwD were in the study at Wave 1.
- 1190 PwD were in the study at Wave 2. However, 8 of this number were not in the study at Wave 1 due to consent issues or research site issues. Therefore the attrition rate is 23.6% between Wave 1 and Wave 2 and there is an addition of 8 PwD not in the study at Wave 1.
- 856 PwD were in the study at Wave 3. However, 12 of this number were not in the study at Wave 2 due to being lost to follow up at that stage or withdrawn from that Wave for various reasons, or having Wave 2 consent issues.
- Therefore the attrition rate is 29.1% between Wave 2 and Wave 3 and there is an addition of 12 PwD not in the study at Wave 2.
- The overall attrition rate is 45.0% between Wave 1 and Wave 3.
- The overall attrition rate is calculated from 1555 total PwD at Wave 1 and Wave 2 (1547 at Wave 1 + 8 consented at Wave 1 but only included from Wave 2) to 856 remaining PwD at Wave 3.
- If we only count total PwD at Wave 1 (1547) to total PwD at Wave 3 (856) and disregard the PwD consented at Wave 1 but not included, the attrition rate is 44.7%.

### 4.7.4 Carers

- 1283 Carers were in the study at Wave 1.
- 992 Carers were in the study at Wave 2. However, 6 of this number were not in the study at Wave 1 due to consent issues or research site issues. A further 16 of the total were new to the study at this Wave.
- Therefore the attrition rate is 24.4% between Wave 1 and Wave 2 and there is an addition of 22 Carers not in the study at Wave 1.
- 9 of the Carers remaining in the study at Wave 2 were different to the Carers who had accompanied their PwD at Wave 1, but this is not taken into account for the attrition rate.
- 760 Carers were in the study at Wave 3. However, 18 of this number were not in the study at Wave 2 due to being lost to follow up at that Wave or withdrawn from that Wave for various reasons. A further 6 of the total were new to the study at this Wave.
- Therefore the attrition rate is 25.8% between Wave 2 and Wave 3 and an addition of 24 Carers not in the study at Wave 2.
- 5 of the Carers remaining in the study at Wave 3 were different to the Carers who had accompanied their PwD at Wave 2, but this is not taken into account for the attrition rate.
- The overall attrition rate is 42.4% between Wave 1 and Wave 3.
- This is calculated from 1289 total Carers at Wave 1 and Wave 2 (1283 at Wave 1 + 6 consented at Wave 1 but only included from Wave 2) to 743 remaining Carers at Wave 3 (760 at Wave 3 – 11 who joined at Wave 2 and remained at Wave 3 – 6 who joined at Wave 3).
- If we only count total Carers at Wave 1 (1283) to total Carers at Wave 3 (760) and disregard the fact new Carers joined at Wave 2 or Wave 3, or consented at Wave 1 but were not included, the rate is 40.8%.

### 4.7.5 Study dyads

PwD and Carer spreadsheets were combined in order to calculate whether at least one part of the study dyad (PwD + Carer) was included at each Wave. Unlike the attrition rate calculations for PwD or Carers, the calculations below do not take into account those who consented at Wave 1 but joined from Wave 2.

The study dyad attrition rate can be conceptualised in three different ways.

The first set of calculations include PwD who did not have an accompanying Carer or who were taking part in the study on their own, so the Wave 1 number is the same as for PwD (1547).

- There were 1547 participants at Wave 1. From these, there were 1206 cases where at least one individual (either PwD or Carer) remained at Wave 2, and 902 cases where at least one individual remained at Wave 3. The attrition rate is 22.0% between Wave 1 and Wave 2, and 25.2% between Wave 2 and Wave 3.
- The overall attrition rate is 41.7% between Wave 1 and Wave 3.

The second set of calculations include dyads where the PwD and Carer were both in the study at Wave 1, and at least one member of the study dyad remained at subsequent Waves. The Wave 1 number is the same as for Carers (1283).

- There were 1283 dyads at Wave 1. From these, there were 1020 cases where at least one member of the dyad remained at Wave 2, and 768 cases where at least one member of the dyad remained at Wave 3. The attrition rate is 20.5% between Wave 1 and Wave 2, and 24.7% between Wave 2 and Wave 3.
- The overall attrition rate is 40.1% between Wave 1 and Wave 3.

The third and final set of calculations include dyads where the PwD and Carer were both in the study at each Wave. Again the Wave 1 number is the same as for Carers (1283).

- There were 1283 dyads at Wave 1. From these, 946 dyads remained at Wave 2, and 663 dyads remained at Wave 3. The attrition rate is 26.3% between Wave 1 and Wave 2, and 29.9% between Wave 2 and Wave 3.
- The overall attrition rate is 48.3% between Wave 1 and Wave 3.

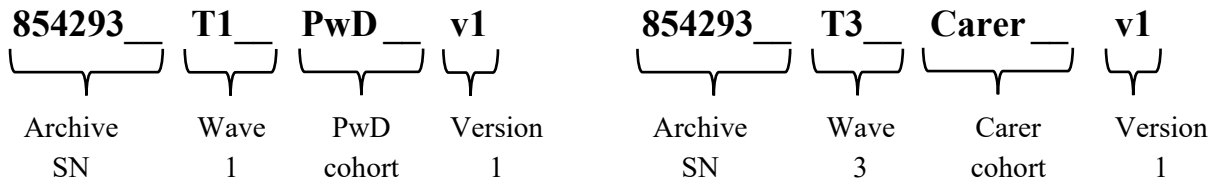
# 5. Using the data

## 5.1 Information about data files

SN 854293 release is comprised of multiple files in the SPSS (.sav) format, distributed by UK Data Service. Researchers without an SPSS licence should be able to use the open-source software programme R to access the datasets. However some variables and variable labels might get truncated.

Datasets for the two cohorts at each Wave are released in 6 separate files. The dataset filenames are composed of the following identifiers: UK Data Service study number; the study Wave; the cohort; and the version number.

Two examples:




## 5.2 Learning about the study variables

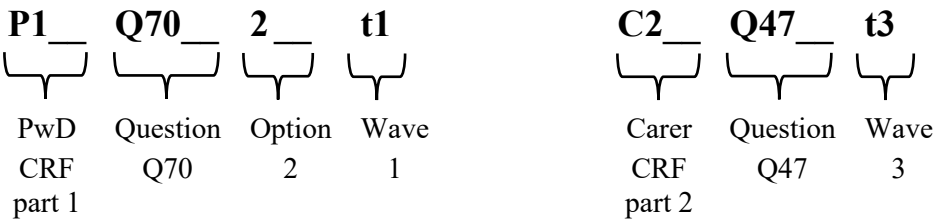
There are multiple documents that can be used with the study datasets to plan analyses and assist in finding which Waves contain desired measures. These include the archived CRFs in Interview documents; the measures across waves, variable lists, and data dictionaries in Data documents; and variable view in the archive dataset SPSS files themselves.

Many of the non-derived variables can be learned about directly from the CRFs, which present the full descriptive information of what was asked and where showcards were used to help the PwD answer. One way to do this is to search for the desired variable label in the CRF .pdf using the Find command. Two examples from CRFs can be seen in Figures 6 and 7 in 5.4 Variable values.

## 5.3 Variable naming and labelling conventions

Variable labels are generally composed of the following identifiers: the participant cohort and CRF part (where the question is found); the question number; the question option (if applicable); and the Wave. For some of the demographic questions in the PwD dataset, the question itself is used for the variable label, e.g. Sex_Prtcpnt_t1. For the MMSE, TSI and ACE-III questions, these are all prefixed with their namesake. Some of the questions asking to specify "other" information end "_oth".

Two examples:




To see how the above examples look in the CRFs, see Figures 6 and 7 in 5.4 Variable values.

Analysts are advised to carefully read the SPSS variable view description for desired variables to ensure the questions they are analysing are what they expect, as the question numbers or order they appear in the CRFs may not be the same at each Wave. Likewise, while the study team attempted to standardise all variable values, some values may not match up. For some values, recoding may be needed prior to longitudinal analysis. The data dictionaries can be used to identify these kinds of inconsistencies.

A fictional example of non-standardised variable values:

*(PwD and Carer asked at each Wave): How satisfied are you with support from your local community?*

*1=Very satisfied [up to] 6=Very unsatisfied for PwD Wave 1;*
*1=Very unsatisfied [up to] 6=Very satisfied for PwD Waves 2 and 3, and for Carer Waves 1 to 3.*

## 5.4 Variable values

The SPSS variable view gives a list of the value labels for each question. These can also be found in the data dictionaries. Standardisation for value labels, as with the variable question number, may not match up across Waves (see fictional example above).

It may appear that some variables have a lot of missing data. However, skip conditions were used to reduce the time taken to conduct interviews. The CRFs are the only means of checking where skip conditions are found. Figures 6 and 7 show skip conditions, taken from the archived PwD and Carer booklets.

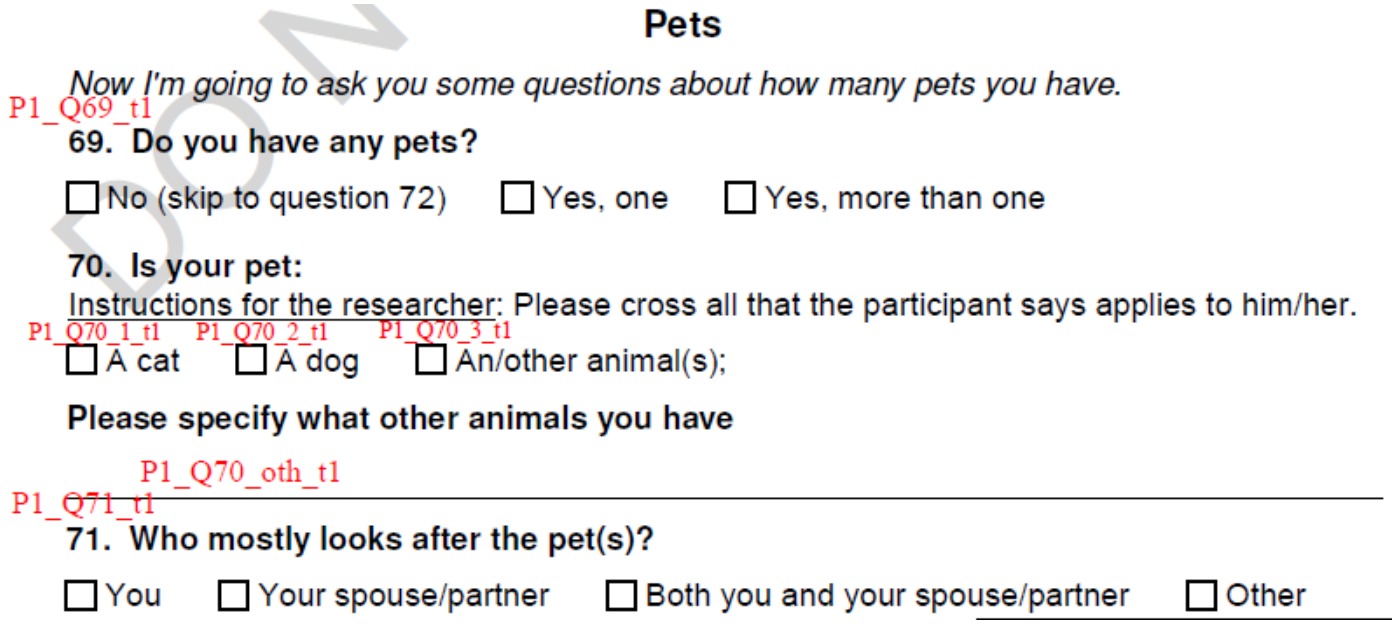



*Figure 6: Skip condition example 1; for P1_Q69_t1; where No is selected Q70 and Q71 should not be filled in.*

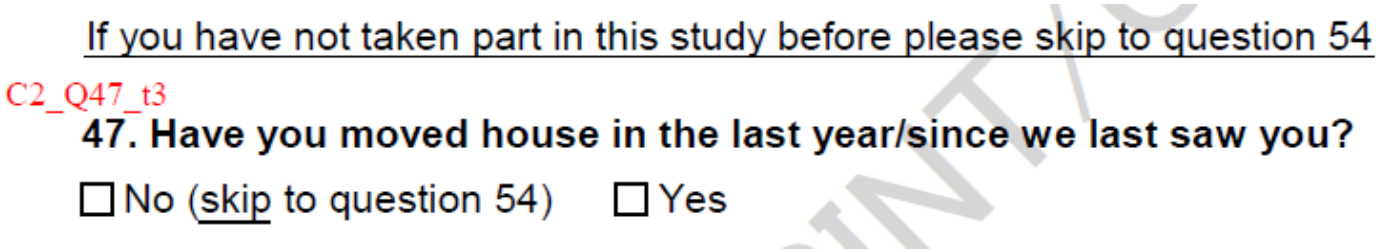



*Figure 7: Skip condition example 2; before and for C2_Q47_t3; where No is selected Q48 to Q54 should not be filled in.*

## 5.5 Derived variables

Derived variables are computed from one or more variables in a dataset, or were computed by the co-ordinating centre using third-party software. In the archive datasets all derived variables were created and computed post-field for the purpose of analysis. Some of the derived variables were created to reduce the risk of re-identification, such as the Age Groups and Nomenclature of Territorial Units for Statistics (NUTS) level 1 classification variables. Derived variables are grouped together at the end of the datasets to be easily identified by their position in the files. A full list of the derived variables and how they were computed is found in Data documents.

## 5.6 Different Carers between Waves

Some PwD at either Wave 2 or 3 are accompanied by a different Carer to the Carer from the previous Wave. Instances where a different Carer is involved can be found by searching the respective P_ID_CC string variable for a "B" or "C" suffix in the Wave 2 or 3 Carer datasets. The P_ID variable is numeric for the purposes of combining multiple datasets for longitudinal analyses. Table 9 describes all Carer changes between Waves. Please note the suffix is not used to identify Carers who joined the study at Wave 2 or 3 where no Carer had previously taken part.

*Table 9: Carer changes between Waves*

| P_ID | Wave 2 P_ID_CC_t2 | Wave 3 P_ID_CC_t3 | Description of difference |
|---|---|---|---|
| 1206104 | 1206104B | 1206104B | Carer changes at Wave 2 and remains in the study at Wave 3. |
| 1206133 | 1206133B | 1206133C | Carer changes at Wave 2. Carer changes again at Wave 3. |
| 1309261 | 1309261B | 1309261B | Carer changes at Wave 2 and remains in the study at Wave 3. |
| 1515152 | 1515152B | 1515152B | Carer changes at Wave 2 and remains in the study at Wave 3. |
| 1515223 | 1515223B | 1515223 | Carer changes at Wave 2. At Wave 3 the Carer from Wave 1 returns. |
| 1721103 | 1721103 | 1721103B | Carer changes at Wave 3. |
| 2030777 | 2030777B | 2030777B | Carer changes at Wave 2 and remains in the study at Wave 3. |
| 2133452 | 2133452B | | Carer changes at Wave 2 and does not take part at Wave 3. |
| 2648204 | 2648204B | 2648204B | Carer changes at Wave 2 and remains in the study at Wave 3. |
| 3678103 | 3678103B | 3678103C | Carer changes at Wave 2. Carer changes again at Wave 3. |
| 3884203 | 3884203 | 3884203B | Carer changes at Wave 3. |

## 5.7 Combining datasets

With the exception of P_ID, all variables include identifiers for the cohort (either P or C) and the Wave (_t1, _t2 or _t3). This allows simple identification of which dataset a variable is taken from when combining variables from multiple datasets.

P_IDs are unique identifiers attributed to a PwD at Wave 1 and kept throughout the study. In Carer datasets, the P_ID links the Carer with the corresponding PwD. When combining multiple datasets, the P_ID identifies a study dyad and remains constant across Waves. However, as mentioned in 5.6 Different Carers between Waves, it is possible a different Carer is in the study when comparing Waves. For this reason, it is advisable to note the P_ID_CC (Carer variable) when conducting longitudinal analyses involving Carers.

It is also possible that one part of the study dyad (either PwD or Carer) did not take part in a Wave when the other part of the study dyad did. This should be considered when conducting comparative analyses.

There are 8 P_IDs with no associated data in the Wave 1 PwD and Carer datasets. These represent participants who consented at Wave 1, but their data could not be included due to either consent issues or research site issues. Wave 2 data was included in the datasets, so for continuity purposes blank P_IDs were included in the Wave 1 datasets. Table 10 shows these 8 "blank" P_IDs, which have no associated data in Wave 1 datasets.

*Table 10: "Blank" P_IDs in Wave 1 datasets*

| "Blank" P_IDs in Wave 1 PwD and Carer datasets |
|---|
| 1824202 |
| 1824203 |
| 1824205 |
| 1824206 |
| 1824208 |
| 1824214 |
| 2030117 |
| 3266107 |

## 5.8 Requesting sensitive data

If you have a research objective that requires sensitive data please make a request to the IDEAL team by email: IDEAL@exeter.ac.uk.

## 5.9 Ethics

The IDEAL study was approved by the North Wales Research Ethics Committee - West (reference 13/WA/0405), the Scotland A Research Ethics Committee (reference 14/SS/0010) and the Ethics Committee of the School of Psychology, Bangor University (reference 2014 – 11684). The IDEAL study is registered with UKCRN, registration number 16593.

## 6. Citing the data

When publishing results from the study data, both protocol papers – as detailed in 8.1 IDEAL programme protocols – and the following citation must be included:

University of Exeter, REACH; L. Clare (CI), I.R. Jones, C. Victor, J.V. Hindle, R.W. Jones, M. Knapp, M. Kopelman, R. Litherland, A. Martyr, F.E. Matthews, R.G. Morris, S.M. Nelis, J. Pickett, C. Quinn, J. Rusted, J. Thom (2014-2019). *Improving the experience of Dementia and Enhancing Active Life: Living Well with Dementia*. [data collection]. UK Data Service. SN: 854293. doi: 10.5255/UKDA-SN-854293

## 7. Acknowledgements

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# 8. Publications

Comprehensive and regularly updated links to publications, presentations, blogs and media, and infographics can be found on the IDEAL programme website: http://www.idealproject.org.uk/

For the purposes of this User guide, a list of publications in chronological order taken from the website in June 2020 is as follows:

## 8.1 IDEAL programme protocols

Clare, L., Nelis, S.M., Quinn, C., Martyr, A., Henderson, C., Hindle, J.V., Jones, I.R., Jones, R.W., Knapp, M., Kopelman, M.D., Morris, R.G., Pickett, J.A., Rusted, J.M., Savitch, N.M., Thom, J.M., & Victor, C.R. (2014). Improving the experience of dementia and enhancing active life-living well with dementia: study protocol for the IDEAL study. Health and Quality of Life Outcomes, 12, 164. doi: 10.1186/s12955-014-0164-6 (open access)

Silarova, B., Nelis, S.M., Ashworth, R.M., Ballard, C., Bieńkiewicz, M., Henderson, C., Hillman, A., Hindle, J.V., Hughes, J.C., Lamont, R.A., Litherland, R., Jones, I.R., Jones, R.W., Knapp, M., Kotting, P., Martyr, A., Matthews, F.E., Morris, R.G., Quinn, C., Regan, J., Rusted, J.M., van den Heuvel, E.A., Victor, C.R., Wu, Y.-T., & Clare, L. (2018). Protocol for the IDEAL-2 longitudinal study: following the experiences of people with dementia and their primary carers to understand what contributes to living well with dementia and enhances active life. BMC Public Health, 18, 1214. doi: 10.1186/s12889-018-6129-7 (open access)

## 8.2 Published articles

Jones, I.R. (2017). Social class, dementia and the fourth age. Sociology of Health and Illness, 39(2), 303-317. doi: 10.1111/1467-9566.12520

Hillman, A., Jones, I.R., Quinn, C., Nelis, S.M., & Clare, L. (2018). Dualities of dementia illness narratives and their role in a narrative economy. Sociology of Health & Illness, 40, 874-891. doi: 10.1111/1467-9566.12729 (open access)

Litherland, R., Burton, J., Cheeseman, M., Campbell, D., Hawkins, M., Hawkins, T., Oliver, K., Scott, D., Ward, J., Nelis, S.M., Quinn, C., Victor, C., & Clare, L. (2018). Reflections on PPI from the 'Action on Living Well: Asking You' advisory network of people with dementia and carers as part of the IDEAL study. Dementia, 17, 1035-1044. doi: 10.1177/1471301218789309

Martyr, A., Nelis, S.M., Quinn, C., Wu, Y.-T., Lamont, R.A., Henderson, C., Clarke, R., Hindle, J.V., Thom, J.M., Jones, I.R., Morris, R.G., Rusted, J.M., Victor, C.R., & Clare, L. (2018). Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-

being, and life satisfaction in people with dementia. Psychological Medicine, 48, 2130-2139. doi: 10.1017/S0033291718000405 (open access)

Quinn, C., Morris, R.G., & Clare, L. (2018). Beliefs about dementia: development and validation of the representations and adjustment to dementia index (RADIX). The American Journal of Geriatric Psychiatry, 26, 680-689. doi: 10.1016/j.jagp.2018.02.004 (open access)

Silarova, B., Nelis, S.M., Ashworth, R.M., Ballard, C., Bieńkiewicz, M., Henderson, C., Hillman, A., Hindle, J.V., Hughes, J.C., Lamont, R.A., Litherland, R., Jones, I.R., Jones, R.W., Knapp, M., Kotting, P., Martyr, A., Matthews, F.E., Morris, R.G., Quinn, C., Regan, J., Rusted, J.M., van den Heuvel, E.A., Victor, C.R., Wu, Y.-T., & Clare, L. (2018). Protocol for the IDEAL-2 longitudinal study: following the experiences of people with dementia and their primary carers to understand what contributes to living well with dementia and enhances active life. BMC Public Health, 18, 1214. doi: 10.1186/s12889-018-6129-7 (open access)

Wu, Y.-T., Clare, L., Hindle, J.V., Nelis, S.M., Martyr, A., Matthews, F.E., & on behalf of the IDEAL study team. (2018). Dementia subtype and living well: results from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study. BMC Medicine, 16, 140. doi: 10.1186/s12916-018-1135-2 (open access)

Wu, Y.-T., Clare, L., Jones, I.R., Martyr, A., Nelis, S.M., Quinn, C., Victor, C.R., Lamont, R.A., Rippon, I., Matthews, F.E., on behalf of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study. (2018). Inequalities in living well with dementia – the impact of deprivation on wellbeing, quality of life and life satisfaction: results from the Improving the experience of Dementia and Enhancing Active Life study. International Journal of Geriatric Psychiatry, 33, 1736-1742. doi: 10.1002/gps.4998

Clare, L., Wu, Y.-T., Jones, I.R., Victor, C.R., Nelis, S.M., Martyr, A., Quinn, C., Litherland, R., Pickett, J.A., Hindle, J.V., Jones, R.W., Knapp, M., Kopelman, M.D., Morris, R.G., Rusted, J.M., Thom, J.M., Lamont, R.A., Henderson, C., Rippon, I., Hillman, A., Matthews, F.E., on behalf of the IDEAL study team. (2019). A comprehensive model of factors associated with subjective perceptions of "living well" with dementia: findings from the IDEAL study. Alzheimer Disease and Associated Disorders, 33, 36-41. doi: 10.1097/WAD.0000000000000286 (open access)

Clare, L., Wu, Y.-T., Quinn, C., Jones, I.R., Victor, C.R., Nelis, S.M., Martyr, A., Litherland, R., Pickett, J.A., Hindle, J.V., Jones, R.W., Knapp, M., Kopelman, M.D., Morris, R.G., Rusted, J.M., Thom, J.M., Lamont, R.A., Henderson, C., Rippon, I., Hillman, A., Matthews, F.E., on behalf of the IDEAL study team. (2019). A comprehensive model of factors associated with capability to "live well" for family caregivers of people living with mild-to-moderate dementia: findings from the IDEAL study. Alzheimer Disease and Associated Disorders, 33, 29-35. doi: 10.1097/WAD.0000000000000285 (open access)

Henderson, C., Knapp, M., Nelis, S.M., Quinn, C., Martyr, A., Wu, Y.-T., Jones, I.R., Victor, C.R., Pickett, J.A., Hindle, J.V., Jones, R.W., Kopelman, M.D., Matthews, F.E., Morris, R.G., Rusted, J., Thom, J.M., & Clare, L., on behalf of the IDEAL programme team. (2019). Use and costs of services and unpaid care for people with mild-to-moderate dementia: Wave 1 results from the IDEAL cohort study. Alzheimer's & Dementia: Translational Research & Clinical Interventions, 5, 685-696. doi: 10.1016/j.trci.2019.09.012 (open access)

Hillman, A., Jones, I.R., Quinn, C., Nelis, S.M., Lamont, R.A., & Clare, L. (2019). 'All the world's a stage': accounting for the dementia experience - insights from the IDEAL programme. Qualitative Research. Advance online publication. doi: 10.1177/1468794119893607

Lamont, R.A., Quinn, C., Nelis, S.M., Martyr, A., Rusted, J.M., Hindle, J.V., Longdon, B., & Clare, L. on behalf of the IDEAL study team. (2019). Self-esteem, self-efficacy and optimism as psychological resources among family caregivers of people with dementia: findings from the IDEAL study. International Psychogeriatrics, 31, 1259-1266. doi: 10.1017/S1041610219001236

Martyr, A., Nelis, S.M., Quinn, C., Rusted, J.M., Morris, R.G., Clare, L., & on behalf of the IDEAL programme. (2019). The relationship between perceived functional difficulties and the ability to live well with mild-to-moderate dementia: findings from the IDEAL programme. International Journal of Geriatric Psychiatry, 34, 1251-1261. doi: 10.1002/gps.5128 (open access)

Nelis, S.M., Wu, Y.-T., Matthews, F.E., Martyr, A., Quinn, C., Rippon, I., Rusted, J., Thom, J.M., Kopelman, M.D., Hindle, J.V., Jones, R.W., & Clare, L. (2019). The impact of comorbidity on the quality of life of people with dementia: findings from the IDEAL study. Age and Ageing, 48, 361-367. doi: 10.1093/ageing/afy155 (open access)

Quinn, C., Nelis, S.M., Martyr, A., Morris, R.G., Victor, C., & Clare, L. on behalf of the IDEAL study team. (2019). Caregiver influences on 'living well' for people with dementia: findings from the IDEAL study. Aging & Mental Health. Advance online publication. doi: 10.1080/13607863.2019.1602590 (open access)

Quinn, C., Jones, I.R., Martyr, A., Nelis, S.M., Morris, R.G., Clare, L., & on behalf of the IDEAL study team. (2019). Caregivers' beliefs about dementia: findings from the IDEAL study. Psychology and Health, 34, 1214-1230. doi: 10.1080/08870446.2019.1597098 (open access)

Quinn, C., Nelis, S.M., Martyr, A., Victor, C., Morris, R.G., & Clare, L., on behalf of the IDEAL study team. (2019). Influence of positive and negative dimensions of dementia caregiving on caregiver well-being and satisfaction with life: Findings from the IDEAL study. American Journal of Geriatric Psychiatry, 27, 838-848. doi: 10.1016/j.jagp.2019.02.005 (open access)

Rippon, I., Quinn, C., Martyr, A., Morris, R.G., Nelis, S.M., Jones, I.R., Victor, C.R., & Clare, L. on behalf of the IDEAL programme team. (2019). The impact of relationship quality on life satisfaction and well-being in dementia caregiving dyads: findings from the IDEAL study. Aging & Mental Health. Advance online publication. doi: 10.1080/13607863.2019.1617238 (open access)

Wu, Y.-T., Clare, L., & Matthews, F.E. on behalf of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study team (2019). Relationship between depressive symptoms and capability to live well in people with dementia and their carers: results from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) Programme. Aging & Mental Health. Advance online publication. doi: 10.1080/13607863.2019.1671316

Clarke, R., Farina, N., Chen, H.L., & Rusted, J.M. in collaboration with the IDEAL programme team. (2020). Quality of life and wellbeing of carers of people with dementia: Are there differences between working and non-working carers? Results from the IDEAL Programme. Journal of Applied Gerontology. Advance online publication. doi: 10.1177/0733464820917861

Lamont, R.A., Nelis, S.M., Quinn, C., Martyr, A., Rippon, I., Kopelman, M.D., Hindle, J.V., Jones, R.W., Litherland, R., Clare, L., & on behalf of the IDEAL study team. (2020). Psychological predictors of 'living well' with dementia: findings from the IDEAL study. Aging & Mental Health, 24, 956-964. doi: 10.1080/13607863.2019.1566811

Victor, C.R., Rippon, I., Quinn, C., Nelis, S.M., Martyr, A., Hart, N., Lamont, R., & Clare, L. on behalf of the IDEAL Programme team. (2020). The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. Aging & Mental Health. Advance online publication. doi: 10.1080/13607863.2020.1753014 (open access)

Victor, C.R., Rippon, I., Nelis, S.M., Martyr, A., Litherland, R., Pickett, J.A., Hart, N., Henley, J., Matthews, F.E., & Clare, L. on behalf of the IDEAL Programme team. (2020). Prevalence and determinants of loneliness in people living with dementia: findings from the IDEAL programme. International Journal of Geriatric Psychiatry. Advance online publication. doi: 10.1002/gps.5305 (open access)

Wu, Y.-T., Nelis, S.M., Quinn, C., Martyr, A., Jones, I.R., Victor, C.R., Knapp, M., Henderson, C., Hindle, J.V., Jones, R.W., Kopelman, M.D., Morris, R.G., Pickett, J.A., Rusted, J.M., Thom, J.M., Litherland, R., Matthews, F.E., & Clare, L. on behalf of the IDEAL Programme team. (2020). Factors associated with self- and informant ratings of quality of life, well-being and life satisfaction in people with mild-to-moderate dementia: results from the Improving the experience of Dementia and Enhancing Active Life programme. Age and Ageing, 49(3), 446-452. doi: 10.1093/ageing/afz177

## 8.3 Book chapters

Quinn, C. (2016). Positive Experiences in Dementia Caregiving. In C. Clarke & E. Wolverson (Eds.). Positive Psychology Approaches to Dementia, 232-252. London: Jessica Kingsley Publishers

Quinn, C. (2017). Conducting interviews with people with dementia and their caregivers. SAGE Research Methods Cases. doi: 10.4135/9781526404855

## 8.4 Published abstracts

Jones, I.R., Victor, C.R., & Clare, L. (2015). Capitals, assets and resources: a framework for understanding the lived experience of dementia. The Gerontologist, 55 (Suppl 2), 593-594. doi: 10.1093/geront/gnv306.05

Jones, I.R. (2015). Social class, dementia, and the social imaginary of the fourth age. The Gerontologist, 55(Suppl 2), 742. doi: 10.1093/geront/gnv377.04

Victor, C.R., & Clare, L. (2015). Living well with dementia: preliminary insights from the IDEAL study. The Gerontologist, 55 (Suppl 2), 592-593. doi: 10.1093/geront/gnv306.01

Victor, C.R., Pikhartova, J., & Woodbridge, R. (2015). Is loneliness a cause or consequence of dementia? The Gerontologist, 55 (Suppl 2), 593. doi: 10.1093/geront/gnv306.02

Clare, L. (2017). Improving the experience of Dementia and Enhancing Active Life: early findings from the IDEAL cohort. Innovation in Aging, 1, 1344. doi: 10.1093/geroni/igx004.4933

Clare, L., Nelis, S.M., Wu, Y.-T., Martyr, A., Knapp, M., Henderson, C., Lamont, R.A., & Matthews, F.E. (2017). Improving the experience of Dementia and Enhancing Active Life (the IDEAL study): cohort profile. Innovation in Aging, 1, 1344. doi: 10.1093/geroni/igx004.4934

Clarke, R., Chen, H.L., & Rusted, J.M. (2017). Exploring psychological well-being in working family carers. Alzheimer's & Dementia, 13, Supplement, P1164. doi: 10.1016/j.jalz.2017.06.1712

Hillman, A., Jones, I.R., Quinn, C., & Clare, L. (2017). Letting go of coherence: the challenges of representing dementia. Innovation in Aging, 1, 1345. doi: 10.1093/geroni/igx004.4937

Jones, I.R., Hillman, A., Quinn, C., & Clare, L. (2017). Dualities of dementia accounts: biographical reconstruction and narrative economies. Innovation in Aging, 1, 1344-1345. doi: 10.1093/geroni/igx004.4936

Martyr, A., Nelis, S.M., Quinn, C., Wu, Y.-T., Lamont, R.A., Henderson, C., Clarke, R., Hindle, J.V., Jones, I.R., Morris, R.G., Rusted, J.M., Thom, J.M., Victor, C.R., & Clare, L. (2017) Living well with dementia: a

systematic review and meta-analysis. Alzheimer's & Dementia, 13, Supplement, P1567–P1568. doi: 10.1016/j.jalz.2017.07.725

Martyr, A., Wu, Y., Morris, R., Hindle, J., Rusted, J., Thom, J., Clarke, R., & Clare, L. (2017). Factors associated with quality of life in dementia: a correlational meta-analysis. Innovation in Aging, 1, 1344. doi: 10.1093/geroni/igx004.4935

Clare, L., Wu, Y.-T., Jones, I.R., Victor, C.R., Nelis, S.M., Martyr, A., Quinn, C., Litherland, R., Pickett, J., Hindle, J.V., Jones, R.W., John Knapp, M.R., Kopelman, M., Morris, R.G., Rusted, J.M., Thom, J.M., Lamont, R.A., Henderson, C., Rippon, I., Hillman, A., & Matthews, F. (2018). A comprehensive model of factors associated with subjective perceptions of living well with dementia: findings from the IDEAL study. Alzheimer's & Dementia, 14, P1422-P1423. doi: 10.1016/j.jalz.2018.06.2954

Clare, L., Clare, L., Martyr, A., Quinn, C., Victor, C., & Matthews, F. (2019). Living alone with dementia: findings from the IDEAL cohort. Innovation in Aging, 3, S40. doi: 10.1093/geroni/igz038.155

Rippon, I., Quinn, C., Martyr, A., Victor, C., Mathews, F., & Clare, L. (2019). Prevalence of loneliness and isolation among people with dementia and their carers. Innovation in Aging, 3, S40-S40. doi: 10.1093/geroni/igz038.156

Victor, C., & Fauth, E.B. (2019). Loneliness, isolation, and living alone among people with dementia and their carers: insights from the IDEAL study. Innovation in Aging, 3, S39-S39. doi: 10.1093/geroni/igz038.153

Victor, C., Rippon, I., Martyr, A., Mathews, F., & Clare, L. (2019). How lonely and isolated are older people with dementia and their carers: a dyadic analysis. Innovation in Aging, 3, S39-S40. doi: 10.1093/geroni/igz038.154

**8.5 Newsletters and bulletins**

Clare, L. & Nelis, S. on behalf of the IDEAL study team. (2014). Improving the experience of Dementia and Enhancing Active Life: the IDEAL study. FPOP Newsletter, 128 (October), 11-13

Jones, R. (2014). Improving the experience of Dementia and Enhancing Active Life: living with dementia - the IDEAL study. RICE Newsletter, Autumn, 38, 2

Morris, R. G. (2014). The IDEAL project: Improving our understanding of dementia. The British Psychological Society, Division of Neuropsychology Newsletter, 13.3, 5

Improving the Experience of Dementia and Enhancing Active Life: The IDEAL Study (2014). NEURODEM Cymru Research Participant Register (Rpr) Newsletter, Vol. 1. Issue 5, 5

Article 'IDEAL: how to ‘live well', June 2015, Living with Dementia, The Magazine of the Alzheimer’s Society, 23

Clare, L. (2017). 'Living well with dementia has become a key focus of policy'. The Psychologist, 30, 66-69

Rippon, I (2017). Improving the experience of Dementia and Enhancing Active Life: living well with dementia - The IDEAL study. Ageing in Europe: The Newsletter of the Research Network on Ageing in Europe. 20, 4

# 9. References


[1] Clare, L., Nelis, S.M., Quinn, C., Martyr, A., Henderson, C., Hindle, J.V., Jones, I.R., Jones, R.W., Knapp, M., Kopelman, M.D., Morris, R.G., Pickett, J.A., Rusted, J.M., Savitch, N.M., Thom, J.M., & Victor, C.R. (2014). *Improving the experience of dementia and enhancing active life-living well with dementia: study protocol for the IDEAL study*. Health and Quality of Life Outcomes, 12, 164. doi: 10.1186/s12955-014-0164-6, p. 1.
[2] Clare (2014), p. 6.
[3] Unpublished study protocol v4, p. 35.
[4] Clare, L., Nelis, S.M., Martyr, A., Roberts, J.L., Whitaker, C.J., Marková, I.S., Roth, I., Woods, R.T., & Morris, R.G. (2012). *The influence of psychological, social and contextual factors on the expression and measurement of awareness in early-stage dementia: testing a biopsychosocial model*. International Journal of Geriatric Psychiatry, 27, 167-177. doi: 10.1002/gps.2705.
[5] Jones RW, Romeo R, Trigg R, Knapp M, Sato A, King D, Niecko T, Lacey L, for the DADE Investigator Group: *Dependence in Alzheimer's disease and service use costs, quality of life, and caregiver burden: The DADE study*. Alzheimers Dement 2014, doi: 10.1016/j.jalz.2014.03.001.
[6] Nunnally JC, Bernstein IH, Berge JMF. *Psychometric theory*. New York: McGraw-Hill; 1967.
[7] Clare L, Linden DEJ, Woods RT, et al. *Goal-oriented cognitive rehabilitation for people with early-stage Alzheimer disease: a single-blind randomized controlled trial of clinical efficacy*. American Journal of Geriatric Psychiatry. 2010;18:928-939.
[8] Clare (2014), p. 6.
[9] Unpublished study protocol v4, p. 8-9.
[10] Litherland, R., Burton, J., Cheeseman, M., Campbell, D., Hawkins, M., Hawkins, T., … Clare, L. (2018). *Reflections on PPI from the 'Action on Living Well: Asking You' advisory network of people with dementia and carers as part of the IDEAL study.* Dementia, 17(8), 1035–1044. https://doi.org/10.1177/1471301218789309.
[11] Archived T1 Researcher's handbook v1, p. 80.
[12] Archived T1 Researcher's handbook v1, p. 33.
[13] Unpublished study protocol v4, p. 7.
[14] Clare (2014), p. 8.
[15] Archived T1 Researcher's handbook v1, p. 81.
[16] Unpublished IDEAL Auto Report 16-10-2018, p. 2.
[17] Unpublished IDEAL Auto Report 16-10-2018, p. 455.
[18] Unpublished IDEAL Auto Report 16-10-2018, p. 459.
[19] Clare (2014), p. 8-9.
[20] Archived T2 Researcher's handbook v1, p. 11.
[21] Unpublished Time 1 Training 2014 training slides v2 230714, slide 179.
[22] Clare (2014), p. 7-8.
[23] Unpublished Time 1 Training 2014 training slides v2 230714, slide 55.
[24] Archived T2 Researcher's handbook v1, p. 56.
[25] Unpublished IDEAL Time 2 training slides 250615, slide 8.
[26] Archived T1 Researcher's handbook v1, p. 52, 63-64.
[27] Archived T1 Researcher's handbook v1, p. 67-68.
[28] Unpublished IDEAL training programme v1 290514; Time 1 Training 2014 training slides v2 230714.
[29] Unpublished IDEAL T2 training programme v1 180515; Time 2 training slides 250615.
[30] Unpublished IDEAL T3 training programme v1 240516; Time 3 training slides v1 170616.
[31] Unpublished Time 1 Training 2014 training slides v2 230714, slide 37.
[32] Unpublished Time 1 Training 2014 training slides v2 230714, slide 148.
[33] Unpublished Time 1 Training 2014 training slides v2 230714, slides 39,42.
[34] Archived T1 Researcher's handbook v1, p. 28.
[35] CARDIFF UNIVERSITY, *Blogs – Wales Institute of Social & Economic Research, Data & Methods (WISERD)* [online], 'The IDEAL study: finding strategies to live well with dementia' 25/01/2017, accessed 05/03/2020, URL https://blogs.cardiff.ac.uk/wiserd/2017/01/25/ideal-strategies-dementia/
[36] Clare (2014), p. 11.
[37] Archived T2 Researcher's handbook v1, p. 116-119.
[38] Archived T2 Data linkage information pamphlet Personal consultee v2.
[39] Rusiak, K., Woodrow, I., Flynn, G., Skelhorn, D., Ryan, J., Nelis, S.M., & Clare, L. (2019, October). *Managing the Paper Mountain: Systems and Processes for Tracing, Managing and Transforming High Volume Trial Data from Paper Sources*. Poster session presented at the 5th International Clinical Trials Methodology Conference, Brighton.
[40] Unpublished Attrition Report v1 09/12/2019.