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An independent evaluation of the Dementia Dwelling Grants pilot programme

Final report

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Summary

Headlines

- The Dementia Dwelling Grant (DDG) pilot programme was implemented across Worcestershire between April 2017 and March 2018, funded from The Better Care Fund by the six District Councils in Worcestershire. The pilot was independently evaluated by the Association for Dementia Studies at the University of Worcester.
- The aim of the pilot was to provide small-scale aids and home adaptations to improve the wellbeing of people living with dementia in Worcestershire, and in the hope that these might enable them to live at home for longer before they needed to consider moving into residential or long-term care.
- The DDG evaluation has demonstrated that relatively minor and inexpensive aids can improve quality of life for people living at home with dementia and their family carers.
- The concept behind the DDG is simple and easily understood by people affected by dementia and by all agencies. The grant is non means tested and aids and adaptations are available from stock within a few days to the majority of recipients.
- Outstanding, sustained leadership from Worcester City Council was needed to get a complex grants scheme off the ground and to keep it going
- The Dementia Dwelling Grant programme is based on a model of close multiagency partnership working and service integration that can be replicated in the future.
- The context created by the Better Care Fund, increases in the Disabled Facilities Grant, and the Care Act means that home adaptations can play a more central role in keeping people out of hospital and residential care.
- This evaluation of the Dementia Dwelling Grant pilot makes the case for flexible use of the Better Care Fund and shows the potential for similar schemes to have a positive part to play.

The Dementia Dwelling Grant pilot

This report describes an evaluation carried out by the Association for Dementia Studies at the University of Worcester of the Dementia Dwelling Grant (DDG) pilot programme that was implemented across Worcestershire between April 2017 and March 2018. The aim of the pilot was to provide small-scale aids and home adaptations to improve the wellbeing of people living with dementia in Worcestershire, and in the hope that these might enable them to live at home for longer before they needed to consider moving into residential or long-term care.

A provisional budget of £1,000 per customer was set, from which £250 was allocated to Age UK Hereford and Worcester in recognition of the additional input that would be required from the Dementia Advisors and the handyperson service. The grants took the form of aids and adaptations to the home rather than a monetary award and it was expected that 200 grants would be provided during the pilot period. The pilot programme was funded from The Better Care Fund by the six participating District Councils in Worcestershire: Bromsgrove, Malvern Hills, Redditch, Worcester, Wychavon and Wyre Forest.

The grants were not means-tested and were available to people with a clinical diagnosis of dementia who were living at home. Referrals were accepted from the Worcestershire Early Intervention Dementia Service, General Practitioners, the Community Older Adult Mental Health Team, and also via self-referral and family members. During the pilot, any person across Worcestershire diagnosed with dementia was expected to be referred to the Dementia Advice Service provided by Age UK Hereford and Worcester for support, and all referrals were assessed for inclusion in the DDG.

The Dementia Advisors from the Dementia Advice Service undertook initial assessments for the aids and adaptations available via the grant, co-ordinated their delivery with the help of the handyperson service, and carried out the follow-up assessments. An information and training day was held with the Dementia Advisors and members of the handyperson service to introduce the DDG; feedback received was used to inform the standard list of aids and adaptations to be offered via the DDG and the final data collection forms. It was possible for the Dementia Advisors to recommend other aids and adaptations be provided in addition to the standard list, thus giving the ability to personalise the DDG.

Evaluation

The aims of the evaluation were (i) to explore the experiences and impacts of the DDG for people living with dementia at home, and (2) to provide Worcester City Council with robust evidence of the overall impact of the pilot programme to inform its future planning.

Core evaluation data were collected by the Dementia Advisors at baseline, 3 months and 9 months. This included demographic information, indicators that are used nationally to measure quality of life[1], and a widely used wellbeing measure[2] Members of the research team carried out interviews with grant-recipients and key project stakeholders. They also collected feedback from the Dementia Advisors on their experiences of being involved in the pilot project.

Key Findings

Implementation of the pilot was successful and exceeded the target number of expected grant recipients. 510 people were assessed for the DDG by Dementia Advisors during the pilot programme, of whom 382 (75%) received a grant. The age range of those receiving a grant was 36 to 98 years with a mean of 80 years old. 55% were female and 97% were White British.

Following the pilot the DDG is continuing to be offered to people diagnosed with dementia who are living at home in Worcestershire.

101 grant recipients took part in the evaluation at the time of assessment, 73 at the 3-month follow up and 36 at the 9-month follow up. The majority of referrals (60%) came from the Early Intervention Dementia Service, with 14% unknown, and 13% from the Community Mental Health Team. The remainder were from families, self-referral and GPs.

Among the people consenting to be evaluation participants, Alzheimer's disease was the most common dementia diagnosis (40%) followed by vascular dementia (22%) and mixed dementia (21%). 54% reported having at least one other medical condition, with arthritis, diabetes, mobility issues, frailty and heart conditions being the most common. 95% had at least one carer, while 80% lived with their carer, who was most commonly a partner or spouse. 86% of the evaluation cohort were owner occupiers, with 64% living in a house and 23% in a bungalow.

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[1] www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/measuresofnationalwellbeingdashboard/2018-04-25

[2] https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/

The following items were rated as most beneficial by grant recipients:

- Freestanding dementia clock
- Notice board or white board
- Night light/automatic lights/light sensors
- Touch beside light
- Key safe

Customers required an average of 5 items, at a total core cost of £138 per customer (excluding other costs such as the additional time of a Dementia Advisor to undertake the assessment or the time of the handyperson to deliver and install items when required).

36% of evaluation participants had been given an OT assessment. 39% had received minor aids with grab/hand rails being the most common, followed by perching stools. Only 8% had received major aids, mainly wet rooms/bathroom adaptations.

Average levels of wellbeing at the time of assessment were similar to those for the wider UK population, a situation which was maintained at 3 and 9 months. Scores for participants' current situation based on their ratings for 'being able to look after yourself and others' and 'feeling safe' were an average of 4.2 out of a possible 5 at baseline. This increased to 4.5 at 3 months but decreased at 9 months.

Levels of satisfaction with general health and with their accommodation were higher for the evaluation participants than for the wider UK population. Satisfaction with general health remained stable between initial assessment and 3 months and again at 9 months. Levels of satisfaction with accommodation improved slightly between initial assessment and 3 months follow up and increased again at 9 months.

Levels of loneliness decreased between assessment and 3-month follow up, a change that was maintained at 9 months, although they remained higher than the wider UK population for this age group.

Levels of satisfaction with life, feeling worthwhile and being happy were all slightly below the UK average, while levels of anxiety were higher. All of these improved from baseline to 3 months. At 9 months there was a slight decrease in satisfaction with life, feeling worthwhile, being happy and anxiety levels.

The case study interviews indicated that the DDG was highly valued by people living with dementia. Sometimes the smallest of items which are inexpensive and readily available (such as the whiteboards, touch lamp and clock) were reported to have made a big difference to peoples' quality of life.

Key stakeholders from across the project partners highlighted benefits that had arisen across three main areas: promoting independence and quality of life for people with dementia and their family carers; increasing the skills and confidence of professionals involved in the project; and strengthening partnerships between the collaborating organisations. Three factors were thought to be key to the success of the pilot: the ability to personalise the aids and adaptations that were provided in response to an individual's need; the fact that the grants were not means-tested; and the incorporation of the scheme within the existing Dementia Advice Service.

Dementia Advisors involved in the DDG were largely positive about the pilot and the benefits it brought for people living with dementia, although they did express concerns about its impact on their workload and subsequent implications for the wider Dementia Advice Service. They made valuable suggestions for how the scheme could have been improved, particularly in terms of improved preparation and communication between partners, and providing more training about the aids/adaptations and the evaluation.

This evaluation did not include a full cost analysis. However, some of the data collected suggest that additional health and social care service use was relatively low for the grant recipients. For example, 14 people (19%) experienced a fall between assessment and the 3-month follow up. This compares with national estimates that 30 percent of people aged 65 and over will fall at least once a year, and 50 percent of those aged 80 and over[3]. In addition, after 3 months three participants had moved to long term care and a further two at 9 months. No comparator data has been found for this figure, but it is important to note that the average cost of private sector care homes is £806 a week for nursing care and £632 for residential care home[4].

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[3] www.nice.org.uk/guidance/cg161

[4] https://kar.kent.ac.uk/65559/

Learning Points

Organisational structures and relationships

- The success of this scheme was dependent on strong, strategic leadership by the City Council. Their role made it possible to get all the district councils to sign up and agree to fund the pilot.

- The DDG pilot could not have been successful without exceptional multi-agency support across diverse organisational boundaries. This included integrated working between health, social care and housing and required decisions to be made at a strategic and operational level.

- The pilot built on good existing partnerships and relationships between local stakeholders. For example, the City Council already had a contract in place with a local Care and Repair agency who subcontracted Age UK to provide the Dementia Advice Service and minor aids and adaptations Handyperson service. This provided an effective and efficient structure via which to deliver the DDG pilot.

- During any pilot programme it is crucial for management at all levels to engage with the professionals who are delivering the grant on the ground as early as possible and to continue this engagement on an ongoing basis, particularly during any changes in organisational management. This should include consulting professionals about their role within the scheme and providing appropriate levels of resource, training and support.

The assessment process

- The DDG assessments need to be undertaken by skilled individuals who understand the importance of enabling environments in supporting people to live well with dementia. The Dementia Advisors and the Handyperson service have been critical to the success of the DDG.

- It is important to ensure the person with dementia and their carer or family member are fully involved in selecting the items available from the standard list and that they understand how they work (e.g. how to change the 12 and 24 hour display options on the clocks).

- The value of future proofing should not be underestimated. There are many advantages to identifying items that could be useful in the future and which will help people retain their independence. This might include providing specific items that aren’t on the standard list but which grant recipients have identified as being useful.

- It is important to recognise and explain that some items may be useful for supporting the grant recipient rather than for use by the grant recipient, i.e. Key safe for use by family or friends.

- The scheme works most effectively with a relatively small list of ‘stock’ aids and adaptations. However, this can only be developed in response to feedback regarding what items are useful and popular.

- The assessment process works best when the person assessing the need for a grant has a catalogue that includes pictures of the items, and walks round the house with the person with dementia and/or a carer to identify difficulties and potential solutions, i.e. dark areas in the house which may be improved with LED motion sensitive lights. For the person with dementia, having ownership of these decisions will make it more likely that they will engage in the use of the items and understand their purpose.

- While the idea of the grant assessment being undertaken by the advisors during their initial home visit that was already taking place made sense, it is also important to recognise that they give out a great deal of information during the visit and the grant offer can be unclear within this. This and other issues could be ironed out through a pre-pilot to test assessment processes and data collection, which would provide the opportunity to review the competencies, workload and any additional training/support needs of the professionals involved.

- Because well over a third of the grant recipients in the evaluation pool had already been assessed by the Occupational Therapy service, with many receiving other aids and adaptations not available via the DDG, other approaches to the assessment should be explored, such as the use of Trusted Assessors.

Evaluation

- Despite the inherent challenges of undertaking an evaluation with this customer group, especially over a significant period of time in their illness, it is possible to do so sensitively and effectively.

- It proved more difficult than expected to recruit 100 grant recipients to the evaluation, which led to an extension of the evaluation period. There are indications that this may have been due to the impact of the pilot on the Dementia Advisors' workload and their levels of previous evaluation experience.

- Although the evaluation team were able to make some changes to the assessment and evaluation forms in response to feedback from the Dementia Advisors, a pre-pilot testing period would have been of benefit together with the continued direct engagement of operational management throughout the pilot programme.
- However the Dementia Advisors were supportive of the DDG and felt that items available had brought significant benefits to their customers. They welcomed the ability to flex the offering to ensure that it was person and family centred. From their point of view the DDG had also enhanced their role as it had enabled them to provide practical help rather than just advice and signposting.

The Dementia Dwelling Grants pilot programme

Introduction

The pilot of the Dementia Dwelling Grants programme was launched by Worcester City Council in April 2017 on behalf of the six District Councils in Worcestershire. It ran until March 2018, at which point it was agreed that the serviced should continue to be delivered across Worcestershire. The aim of the pilot programme was to provide small-scale aids and home adaptations in order to improve the wellbeing of people living with dementia in Worcestershire and enable them to live at home for longer before moving into residential or long-term care.

The Association for Dementia Studies (ADS), University of Worcester, was commissioned by the six District Councils to undertake an evaluation of the pilot programme. This final Evaluation Report covers the period from April 2017 to November 2018. It describes how the grant programme operated and the methods used for data collection, along with a summary of the findings. A detailed analysis of the data used for the evaluation is presented in Appendix 1.

The Dementia Dwelling Grants

The development of the Dementia Dwelling Grants (DDG) was led by Worcester City Council in response to the increasing number of people living with dementia in Worcestershire which is known to be proportionality higher than other areas of the country. The pilot programme was funded from The Better Care Fund (BCF) by the six participating District Councils in Worcestershire: Bromsgrove, Malvern Hills, Redditch, Worcester, Wychavon and Wyre Forest. This arrangement reflects encouragement given by Foundations, the national body for Home Improvement Agencies, for local authorities to use the BCF for innovative and creative purposes. A county wide multi-agency, multidisciplinary group was formed to develop the pilot and agreement reached on eligibility, referral pathways, assessment for the grant and the aids and adaptations to be offered. A Steering Group drawn from Worcester City Council, Age UK Hereford and Worcester, Care and Repair Worcestershire and the University oversaw the pilot programme.

At the time of the pilot, Age UK Herefordshire and Worcestershire were already commissioned to provide a Dementia Advice Service to people living with dementia in Worcestershire. As work on the setting up of the pilot DDG programme progressed, it was agreed that the data required for the assessment and evaluation forms would be collected by the Dementia Advisors as part of their routine visits and monitoring. It was hoped that this approach would minimise disruption and anxiety for the people living with dementia and their families.

During the pilot programme period Worcestershire County Council commissioned the Dementia Advice Service from Age UK Hereford and Worcester, who allocated a Dementia Advisor to support customers diagnosed with dementia. Age UK Hereford and Worcester also, via a sub contract from Care and Repair Worcestershire, ran the handyperson service across the county.

The DDG were not means-tested and were available to people with a clinical diagnosis of dementia who were living at home. Referrals to the service were accepted from the Worcestershire Early Intervention Dementia Service (EIDS), General Practitioners, the Community Older Adult Mental Health Team, and also via self-referral.

The DDG pilot did not provide a monetary grant but instead offered a range of small-scale aids and home adaptations that were believed to benefit people living with dementia, and that were not available through other grant programmes. The list of aids and adaptations was informed by research and best practice in dementia-friendly design. It included items for use around the home including key locators and clocks, and those for specific areas such as touch bedside lights and bath mats. It was agreed that in order to personalise the DDG additional items that were not on the standard list could be provided if required (see Appendix 4 for the DDG assessment form and standard list of aids and adaptions). The assessment form also gave information on equipment available via other grants, for example hand and stair rails, general advice about other improvements that could be made such as improving lighting and reducing glare and reflections. Each customer was given a copy of the Alzheimer's Society's *Making you home dementia friendly*[5].

A provisional budget of £1,000 per customer was set, from which £250 was allocated to Age UK Hereford and Worcester in recognition of the additional input that would be required from the Dementia Advisors and the handyperson service. It was anticipated that even if an individual required the majority of the available aids and adaptations the cost would not exceed £750. Provision was also made for additional bespoke items to be provided if required. 200 grants were expected to be provided during the 2017-2018 pilot period.

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[5] https://www.alzheimers.org.uk/get-support/making-your-home-dementia-friendly

The Evaluation

The aims of the evaluation were (i) to explore the experiences and impacts of the DDG for people living with dementia at home, and (2) to provide Worcester City Council with robust evidence of the overall impact of the pilot programme to inform its future planning. Information could then be disseminated to the District Councils and other interested parties. Research approval was obtained from Worcester City Council and ethical approval from the University of Worcester.

Evaluation Methods

Paper based forms were developed to capture information from at least 100 people living with dementia who consented to participate in the evaluation:

1. An assessment form, which included basic demographic data as well as information on the DDG. This form listed the aids and adaptations that were available via the DDG and via other grants and contained some general advice on how to make homes more dementia friendly. The Dementia Advisors completed this form as part of the baseline assessment, annotating the aids and adaptations required by customers.

2. An evaluation form including validated measures to assess aspects of the grant recipients' general health and wellbeing, which were taken from the Office for National Statistics 'People, Population and Community' survey[6] and the Short Warwick Edinburgh Mental Wellbeing Scale[7]. This form was completed as part of the baseline assessment and repeated after three and nine months to capture the impact of the DDG over time.

In addition, a purposeful sample of 15-20% of grant recipients who had completed their three-month evaluations were chosen as case studies. These case studies used semi-structured interviews conducted in a person's home to explore which aids and adaptations had been of most benefit, and if any additional aids or adaptations would be useful and might be made available and included in future grants.

An information and training day was held for the Dementia Advisors and members of the handyperson service to introduce the DDG and to gain feedback which informed the final standard list of aids and adaptations, the assessment form and data collection forms. A dedicated email address was set up to enable the Dementia Advisors to access ongoing advice from the evaluation team. Arrangements were made for the evaluation

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[6] https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing

[7] https://warwick.ac.uk/fac/sci/med/research/platform/wemwbs/

team to collect the completed data forms from the Age UK headquarters on a monthly basis.

Towards the end of the pilot, research interviews were carried out with key project stakeholders to discuss how the project was developed and implemented and to explore the main benefits, facilitators and barriers. In addition, a feedback session was held with a group of Dementia Advisors to capture their experiences of delivering the DDG.

Analysis

The information captured by the assessment form was analysed to provide descriptive statistics about the evaluation participants, while the validated measures in the evaluation form were analysed according to the relevant process for each individual measure. For the validated measures, UK comparator data was obtained from the Office of National Statistics to enable the DDG information to be viewed within the wider context.

Where possible, findings were also compared between baseline, 3-month follow up and 9-month follow up to investigate the experiences and impacts of the aids and adaptations for grant recipients.

Interviews with grant recipients and project stakeholders were transcribed and analysed for key themes. Feedback from the Dementia Advisors was noted and summarised.

Detailed findings from the Dementia Dwelling Grant pilot programme

Please see Appendix 1 for the full analysis.

Demographics

510 people were assessed for the DDG by the Dementia Advisors during the pilot programme. Of these, 382 (75%) received a DDG, with 101 (26%) of these consenting to be part of the full evaluation.

The majority of referrals (60%) came from the Early Intervention Dementia Service, with 14% unknown, and 13% from the Community Mental Health Team. The remainder were from families, self-referral and GPs.

The age range of those receiving a DDG was 36 to 98 years with an average (mean) of 80 years old. 55% were female and 97% were White British. Among the people consenting to be evaluation participants, Alzheimer's disease was the most common dementia diagnosis (40%) followed by vascular dementia (22%) and mixed dementia (21%). 54% had at least one other medical condition, with arthritis, diabetes, mobility issues, frailty and heart conditions being the most common. 95% had at least one carer, with 80% living with their carer. This person was most commonly a partner or spouse. 86% of the evaluation cohort were owner occupiers, with 64% living in a house and 23% in a bungalow.

DDG items requested

All individuals in the evaluation cohort requested at least one item from the DDG, with one person requiring 12 items. Nightlights, which had previously been available via Age UK, were added to the aids and adaptations list during the pilot, and including these the average number of items required by customers is 5 (4 different types of item) at a cost of £138. This cost does not include other costs such as the additional time of a Dementia Advisor to undertake the assessment or the time of the handyperson to deliver and install items when required.

The five most popular items requested were:

- Freestanding dementia clock
- Notice board or white board
- Touch beside light

- Key locators
- Memo minder

Participant wellbeing

People in the evaluation cohort reported feeling lonely more often than the wider UK population. However, they were more satisfied with their general health and accommodation than the UK comparator group. Overall, people in the evaluation cohort were positive about their lives.

Three month follow up assessments

Three-month assessments were carried out with 73 grant recipients. Satisfaction levels in relation to general health and accommodation had improved slightly overall since the baseline assessment. Levels of loneliness had decreased, although they remained higher than the wider UK population.

The most beneficial aids and adaptations as reported by individual grant recipients were:

- Freestanding dementia clock
- Night light/automatic lights/light sensors
- Notice board or white board
- Touch beside light
- Key safe

The least beneficial aids and adaptations were reported to be:

- Night light/automatic lights/light sensors
- Memo minder
- Key locators
- Notice board or white board
- Phone

Nine month follow up assessments

Nine-month assessments were carried out for 36 people. Overall there was a slight (non-significant) decline in terms of how people felt between the baseline and 9-month assessments. The decrease in loneliness that was seen at three months was maintained at 9 months, although levels remained higher than the wider UK population. Participants also reported greater satisfaction with their accommodation at nine months compared with baseline assessments.

When looking at the findings over time, it appears that while the DDG aids and adaptations had a short-term (3-month) positive impact in a number of areas, the longer-term (9-month and beyond) impact is less clear and more mixed. However, this should be seen in context of the decline in general wellbeing that is often seen for people living with dementia over a 9-month period.

At nine months the most beneficial aids and adaptations were the same as at three months:

- Freestanding dementia clock
- Notice board or white board
- Night light/automatic lights/light sensors
- Touch beside light
- Key safe

The least beneficial aids and adaptations showed a slight difference at nine months compared with three months:

- Notice board or white board
- Memo minder
- Night light/automatic lights/light sensors
- Key locators
- Key safe

Case studies

From the 101 Dementia Dwelling Grant recipients who took part in the evaluation, a sample of 13 agreed to be part of a case study. Participants were purposively chosen to represent a mix of age, dementia type, living arrangement and geographical location.

Ten of the case study participants lived with their spouse with three living alone either supported by carers or family members. They were between 55 to 92 years old.

Three items provided through the grant were particularly valued: whiteboards, touch lamps and clocks. For example, one woman with dementia said:

"The clock is a godsend", while another told us: "I've only got to touch my night light and it comes on. It's ever so useful by my bed. I could never find the switch when it was dark."

Another participant with dementia spoke about the whiteboard she was given through the grant:

"I write everything on there. I put everything that we are going to do through the week. I write it all down so that I don't have to keep saying 'what are we doing' all the time. When we have done something, I immediately rub it off because I know that's done. And it makes me think as well, I like that".

Overall, the case study interviews indicate that the DDG was highly valued by people living with dementia. Sometimes the smallest of items, which are inexpensive and readily available, appeared to make the biggest difference to peoples' quality of life. Our findings have informed a series of learning points, including the importance of introducing aids and adaptations as early as possible and the need to ensure that recipients are conversant with setting up specific items to work effectively.

Stakeholder Interviews

Four individuals from the partner organisations who played a key role in setting up, implementing and monitoring the project were interviewed towards the end of the pilot. The aim was to explore their experiences of the project, focusing on any benefits it delivered, what worked well, and what could be improved.

The stakeholders interviewed shared a strong belief that the pilot project had been successful and effective. They identified benefits across three main areas: promoting independence and quality of life for people with dementia and their family carers; increasing the skills and confidence of professionals involved in the project; and strengthening partnerships between the collaborating organisations.

Three factors were thought to be key to the success of the pilot: the ability to adjust what aids and adaptations were provided in response to individual need; the fact that the grants were not means-tested; and the incorporation of the scheme within the existing Dementia Advisor Service. However, the role of Dementia Advisors was also one of the main challenge to the programme, due to the concerns of staff regarding the additional workload that it brought. This theme followed through to the improvements to the project that were suggested, which included better engagement with and operational support for staff who were tasked with the assessments and delivering the DDG on the ground. Other suggestions focused on enhancing the grant by offering items based on assistive technology, emotional support and help with getting outdoors.

Feedback from the Dementia Advisors

Although the Dementia Advisors (DAs) spoke about the challenges that the DDG raised for them, they felt that it was a positive experience overall. They believed that people with dementia had really benefitted from the equipment provided, which helped to maintain their independence and autonomy. They felt that the DDG added value to their existing role as Dementia Advisors and enabled them to provide practical help in addition to talking and signposting.

Communication had not been as good as they would have liked, in several ways. For example, they would have liked more information about the project and their anticipated role in advance of the DDG pilot which might have allayed their concerns about the extra workload pressure the assessments and evaluation were likely to cause. During the DDG pilot their initial visits to customers were extended to 1.5–2 hours to allow for the assessments. They also said that they would have valued greater feedback during the pilot from operational management about how the DDG and the evaluation was progressing.

Finally in terms of communication, they felt that some publicity which mentioned the £750 as the cash value of the grant was unhelpful because it had led some customersto expect to receive the money themselves, or at least to be given items to that value via the DDG.

The DAs provided valuable feedback about the operation of the DDG scheme, which could inform its future development. This included the following points:

- While many of the aids and adaptations on the list were known to them already, some items were difficult to explain to customers. It would have been useful for the DAs to have had either the items themselves or a photograph of them to discuss before customers decided whether to have a particular item.

- It was sometimes difficult to assess people for the DDG during their initial visits when there was a great deal of other information to discuss. Some of the DAs felt that the assessments should be done separately or over a number of weeks to get the full picture.

- They welcomed the opportunity of personalising the DDG by adding items in addition to those on the standard for particular customers.

- Some customers initially declined aids but phoned later to ask if they are still able to get them. Others had offered to return items once they were no longer needed, which could help with long-term costs.

- There had been some delays in the delivery of the aids and adaptations during the pilot due to availability and staffing.

Various aspects of the DDG evaluation were also raised by the Dementia Advisors. Although the evaluation questions had been discussed during the training day it had not necessarily been clear that they had been taken from validated evaluation tools used in National surveys. However, they adapted way they asked the questions using prompts rather than asking the questions directly. For example ‘Do you work in the garden?’ enabled a conversation about an individual’s life was worthwhile.

The Dementia Advisors, as a result of their experience, suggested several items that could usefully be added to the standard list of aids and adaptations, including adaptive crockery/cutlery, cooker timers, pill dispensers and tracker devices. Overall they felt that the DDG offered them the opportunity of providing practical help to their customers in addition to the advice and signposting that they already provided. There was also a feeling that they enjoyed the evaluation process more as they became more experienced and started getting positive feedback which helped them feel like they had really made a difference to individual customers.

Conclusion

Implementation of the pilot was successful and exceeded the target for grant recipients. 510 people were assessed for the DDG by Dementia Advisors during the pilot programme, of whom 382 (75%) received a grant. 101 grant recipients took part in the evaluation at the time of assessment, 73 at the 3-month follow up and 36 at the 9-month follow up. The majority of referrals (60%) came from the Early Intervention Dementia Service, with 14% unknown, and 13% from the Community Mental Health Team. The remainder were from families, self-referral and GPs.

The age range of those receiving a grant was 36 to 98 years with a mean of 80 years old. 55% were female and 97% were White British. Among the people consenting to be evaluation participants, Alzheimer's disease was the most common dementia diagnosis (40%) followed by vascular dementia (22%) and mixed dementia (21%). 54% had at least one other medical condition, with arthritis, diabetes, mobility issues, frailty and heart conditions being the most common. 95% had at least one carer, while 80% lived with their carer, who was most commonly a partner or spouse. 86% of the evaluation cohort were owner occupiers, with 64% living in a house and 23% in a bungalow.

The following items were rated as most beneficial by grant recipients:

- Freestanding dementia clock
- Notice board or white board
- Night light/automatic lights/light sensors
- Touch beside light
- Key safe

Average levels of wellbeing were similar to those for the wider UK population, a situation which was maintained at 3 and 9 months. Scores for participants' current situation based on their ratings for 'being able to look after yourself and others' and 'feeling safe' were an average of 4.2 out of a possible 5 at baseline. This increased to 4.5 at 3 months but decreased at 9 months.

Levels of satisfaction with general health and with their accommodation were higher for our participants than for the wider UK population. Satisfaction with general health remained stable between initial assessment and 3 months and again at 9 months. Levels of satisfaction with accommodation improved slightly between initial assessment and 3 months follow up and increased again at 9 months.

Levels of loneliness decreased between assessment and 3-month follow up, a change that was maintained at 9 months, although they remained higher than the wider UK population for this age group.

Levels of satisfaction with life, feeling worthwhile and being happy were all slightly below the UK average, while levels of anxiety were higher. All of these improved from baseline to 3 months. At 9 months there was a slight decrease in satisfaction with life, feeling worthwhile, being happy and anxiety levels.

The case study interviews indicated that the DDG was highly valued by people living with dementia. Sometimes the smallest of items which are inexpensive and readily available (such as the whiteboards, touch lamp and clock) appeared to make a big difference to peoples' quality of life.

Key stakeholders from the project partners highlighted benefits that had emerged from the pilot across three main areas: promoting independence and quality of life for people with dementia and their family carers; increasing the skills and confidence of professionals involved in the project; and strengthening partnerships between the collaborating organisations. Three factors were thought to be key to the success of the pilot: the ability to adjust what aids and adaptations were provided in response to feedback; the fact that the grants were not means-tested; and the incorporation of the scheme within the existing Dementia Advice Service.

Dementia Advisors involved in the DDG were largely positive about the pilot and the benefits it brought for people living with dementia, although they did express concerns about its impact on their workload and subsequent implications for the wider Dementia Advice Service. They made valuable suggestions for how the scheme could have been improved, particularly in terms of improved preparation and communication between partners, and providing more training about the aids/adaptations and the evaluation.

This evaluation did not include a full cost analysis. However, some of the data that were collected suggest that service use was relatively for the grant recipients. For example, 14 people (19%) experienced a fall between assessment and the 3-month follow up. This compares with national estimates that 30 percent of people aged 65 and over will fall at least once a year, and 50 percent of those aged 80 and over[8]. In addition, after 3 months

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[8] www.nice.org.uk/guidance/cg161

three participants had moved to long term care and a further two at 9 months. No comparator data has been found for this figure.

Appendix One: Full findings from the DDG assessments

Total number of assessments

510 people were assessed by Dementia Advisors as part of the DDG pilot programme.

Of these, 382 (75%) received a DDG, with 101 (20%) consenting to be part of the full evaluation process.

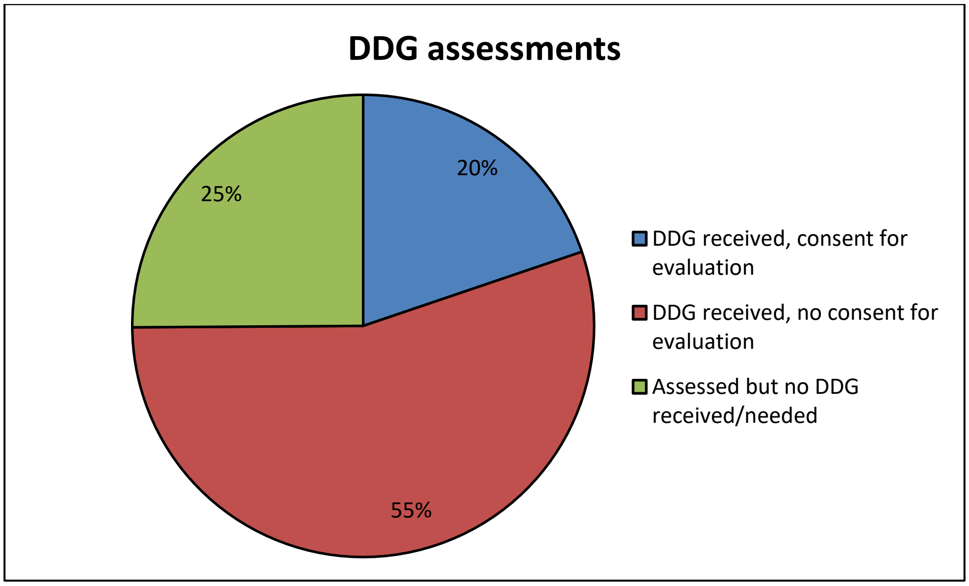

Figure 1: Summary of DDG assessments

Based on the assessments to date as shown in Figure 2, the Dementia Advisors collectively completed between 21 and 72 assessments per month at an average of 51 per month. A single assessment that was completed as part of the pilot during March has been excluded to avoid artificially skewing the figures.

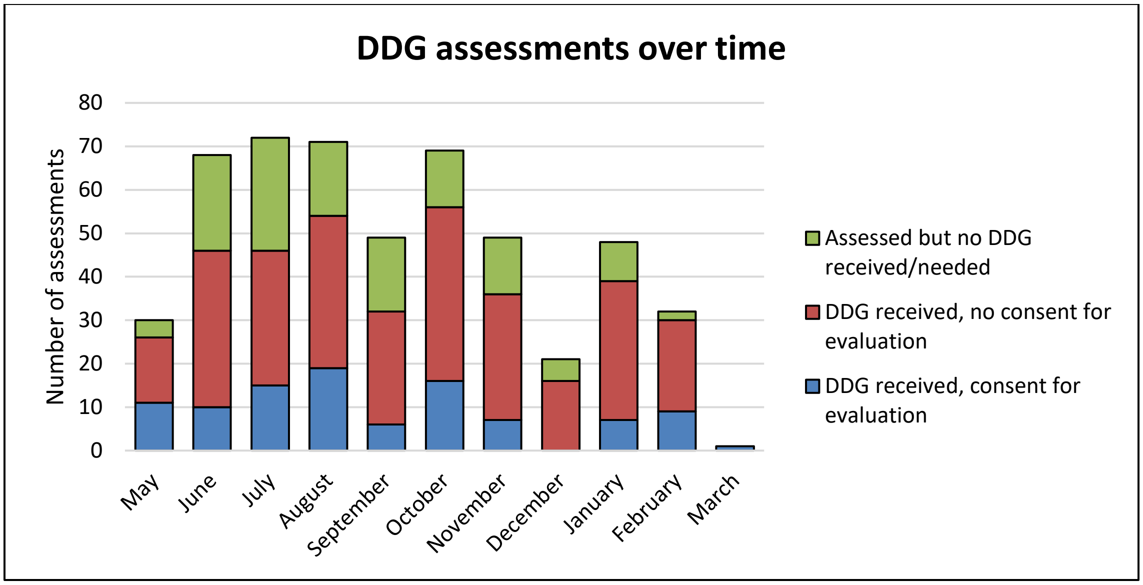

Figure 2: DDG assessments over time

As can be seen from Figure 3, there is considerable variation between the total number of assessments carried out in the different districts, ranging from 39 in Malvern Hills to 161 in Wyre Forest. In most districts there was a fairly even split between assessments resulting in no DDG being received, those resulting in a DDG being received but with the individual not consenting to be part of the full evaluation, and those resulting in a DDG being received and consent to be in the evaluation. Wychavon is the main district where this was not the case, with 83% of assessments resulting in a DDG being received but no consent given for the evaluation. Malvern Hills also had a slightly skewed split with only 5% of assessments resulting in a DDG being received and consent to be in the evaluation.

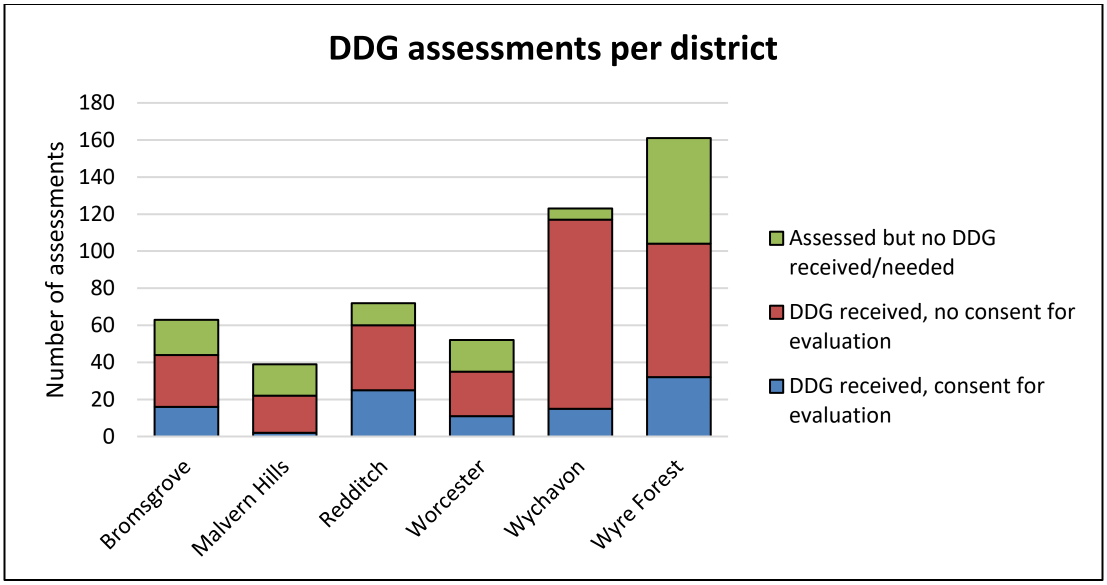

Figure 3: DDG assessments per district

People receiving a DDG

The information in this section is based on the demographic data provided on the **382** people who were assessed for and subsequently received aids and adaptations through the DDG. Of this group, 101 people consented to be part of the full evaluation.

Age

The ages of people receiving a DDG range from 36 to 98, with the average (mean) being 80.

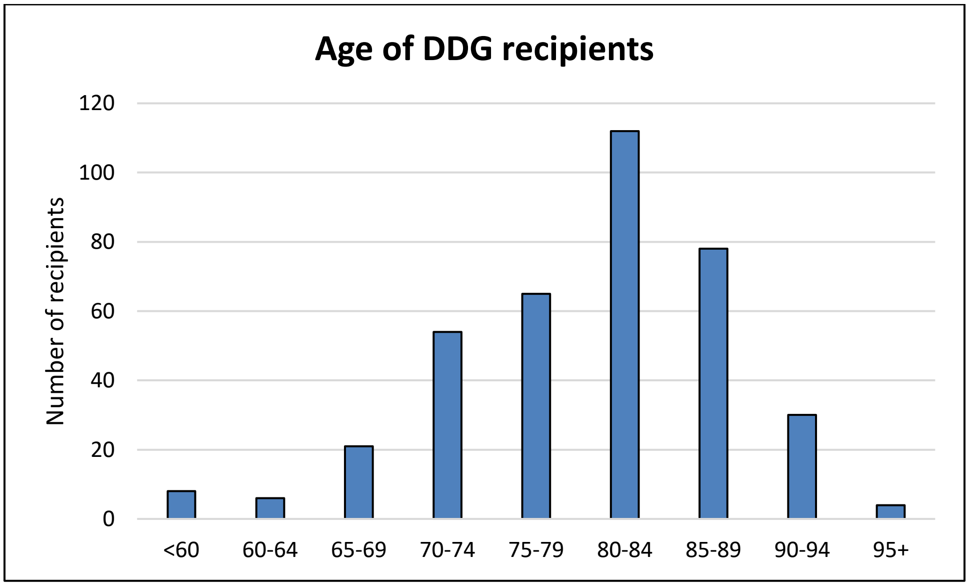

Figure 4: Age of DDG recipients

Gender

55% of the people receiving a DDG are female.

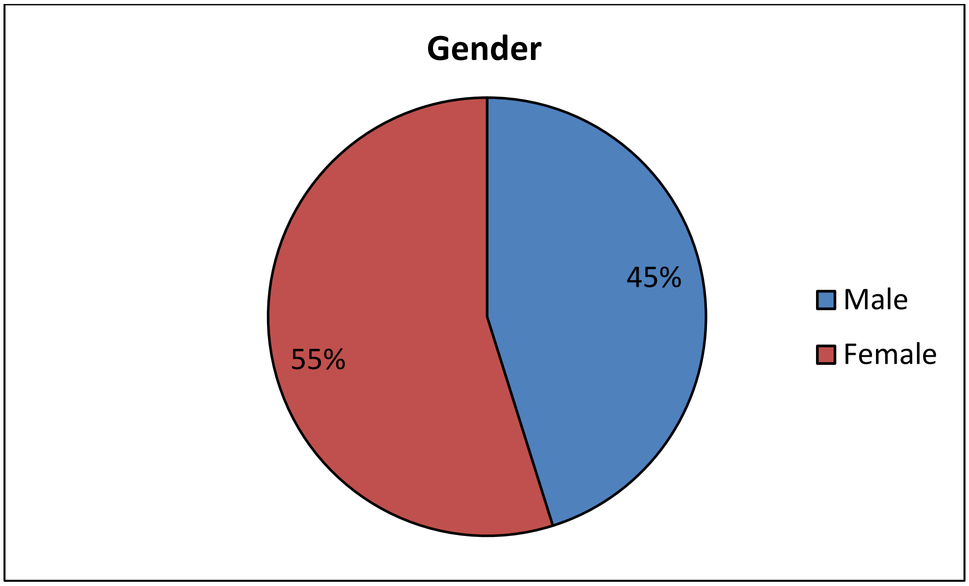

Figure 5: Gender of DDG recipients

Marital status

62% of DDG recipients are married, with the majority of the remainder being widowed.

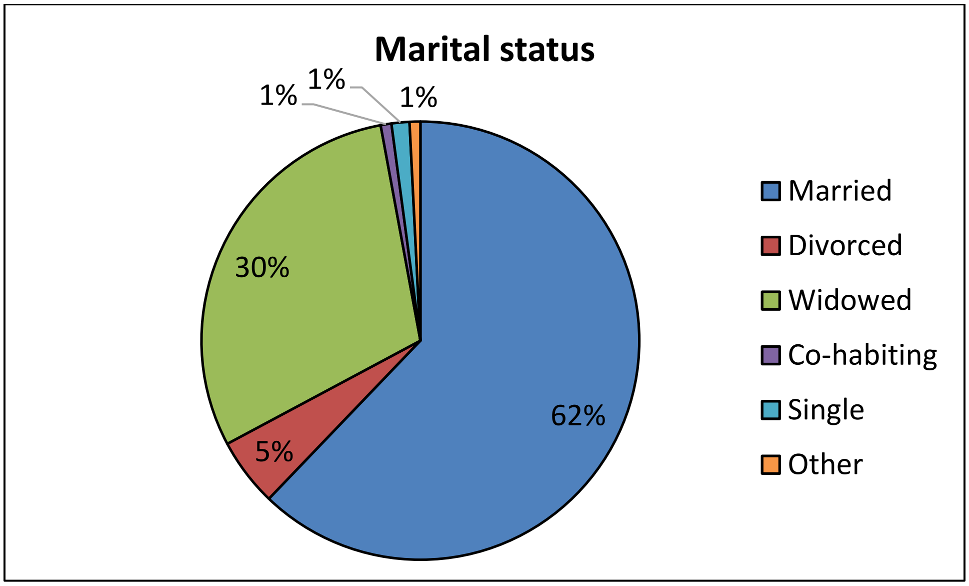

Figure 6: Marital status of DDG recipients

Ethnicity

The vast majority (96.8%) of people receiving a DDG are White British, with the rest being White Irish (1.6%), White & Black Caribbean (0.5%), White Other (0.5%), Indian (0.3%) and Pakistani (0.3%).

Referral route

The most common referral route is through the Early Intervention Dementia Service (EIDS) at 60%, followed by 'Other' organisations or an unknown source (14%) and the Community Mental Health Team (CMHT) at 13%.

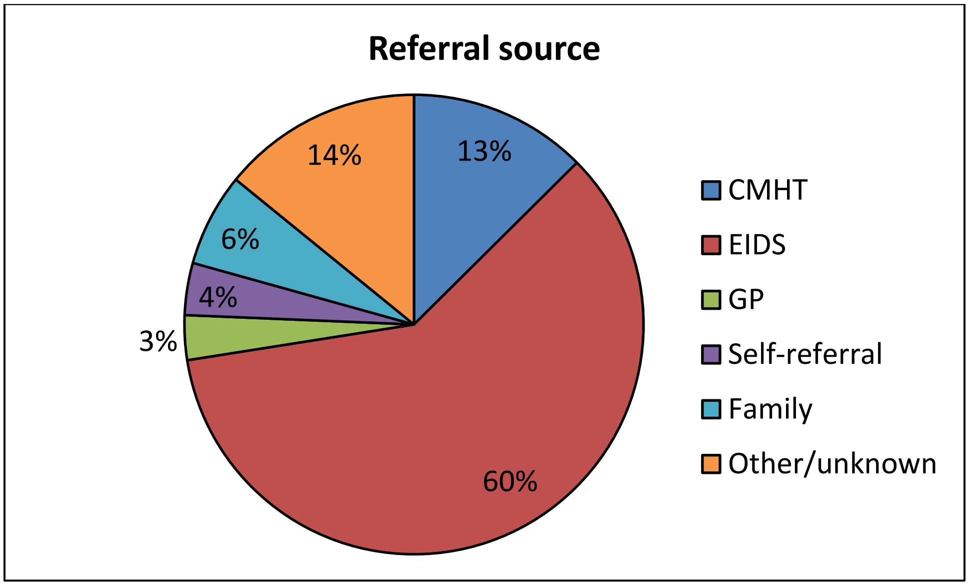

Figure 7: Referral route for DDG recipients

Although EIDS referrals dominate in each district, the breakdown of the remaining referrals does differ (see Figure 8). For example Bromsgrove and Redditch see more self-referrals than other districts, and Worcester and Wychavon see more family referrals. Wychavon also sees more GP referrals than other districts.

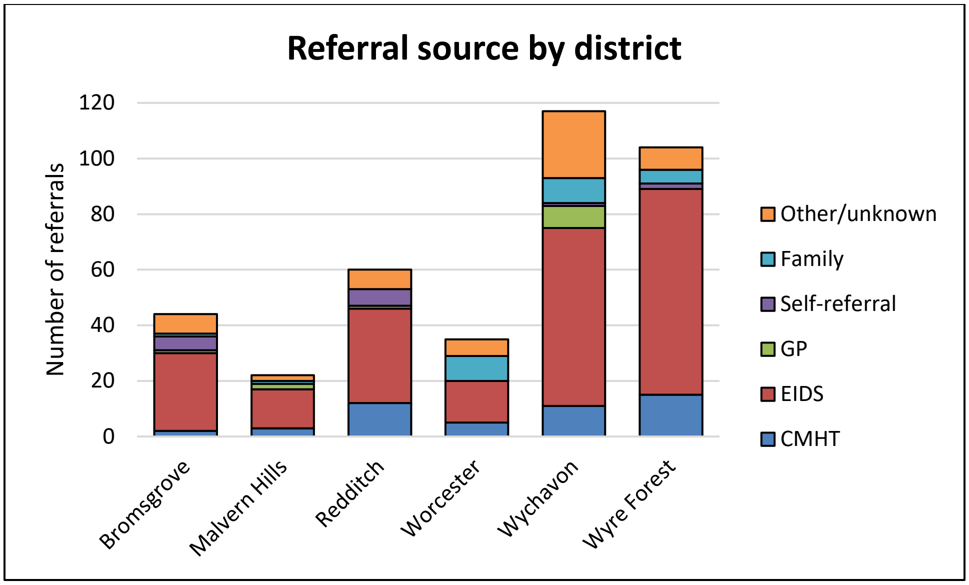

Figure 8: Referral routes in each district

People not consenting to be part of the evaluation

The information in this section is based on the **281** people who received a DDG but did not consent to be part of the full evaluation.

Although not specifically asked to, in many cases the Dementia Advisors gave an explanation of why someone had not provided consent, and these were grouped into a few key areas as shown in Figure 9. While 38% of people actively declined, for a further 43% the Dementia Advisors indicated that someone would be unable to consent to or participate in the full evaluation. For the remaining 19%, a reason may not have been provided or in many cases the participant’s anxiety was indicated as why the evaluation may be inappropriate for some people.

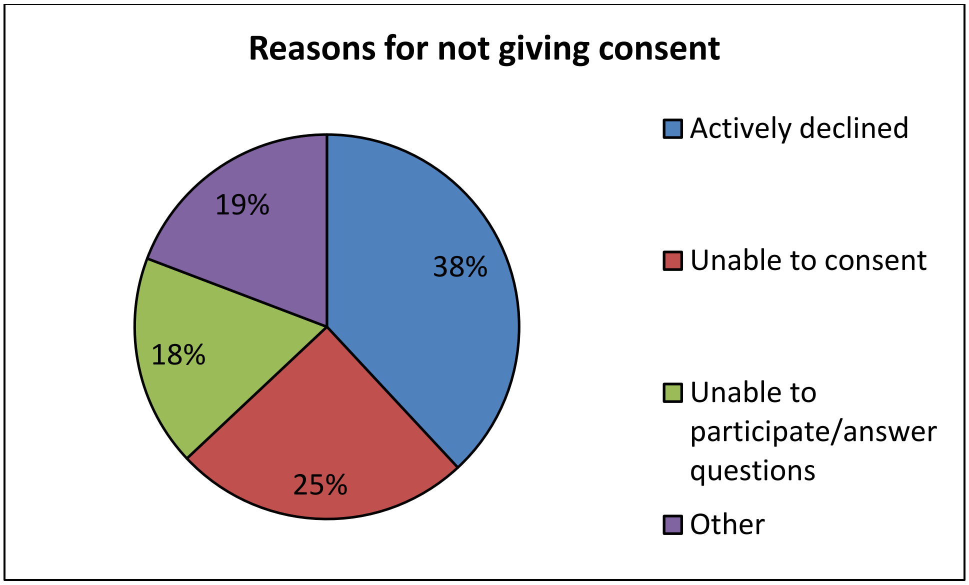

Figure 9: Reasons for DDG recipients not consenting to the evaluation

People receiving a DDG but not consenting to be part of the evaluation tended to be older than those who did consent (mean ages 81 and 78 respectively), with the difference in age being statistically significant (CI=0.05, $p<0.01$). This could suggest that age was a factor in the consent process, possibly because a person’s dementia was more advanced, or their general health was worse.

Evaluation participants

This section is based on the **101** participants who received a DDG and consented to be part of the full evaluation process.

Assessment details

Carers

The majority of the evaluation participants (95%) have at least one carer, with 11 participants having more than one carer. 80% of participants with a carer lived with them. For most participants their carer was a partner/spouse, followed by a son/daughter. ‘Other’ carers included agency carers, a sister and a secretary.

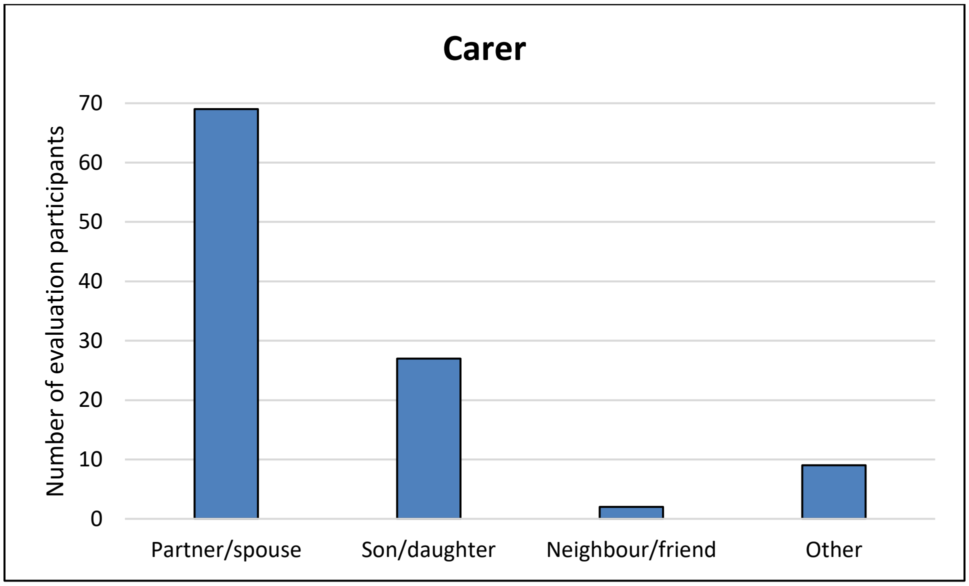

Figure 10: Person acting as carer

Due to the high number of family members involved, it is not surprising that for 86% of participants their carers were unpaid, with 5% having a paid carer and 8% having both paid and unpaid carers. When carers were paid for, they were almost twice as likely to be privately rather than publicly funded.

Health status

Alzheimer’s disease was the most common dementia diagnosis amongst the evaluation participants (40%), followed by vascular dementia (22%). 75% of the ‘Other’ diagnoses related to mixed dementia (21% of all cases). 84% of evaluation participants have received their diagnosis in 2014 or later.

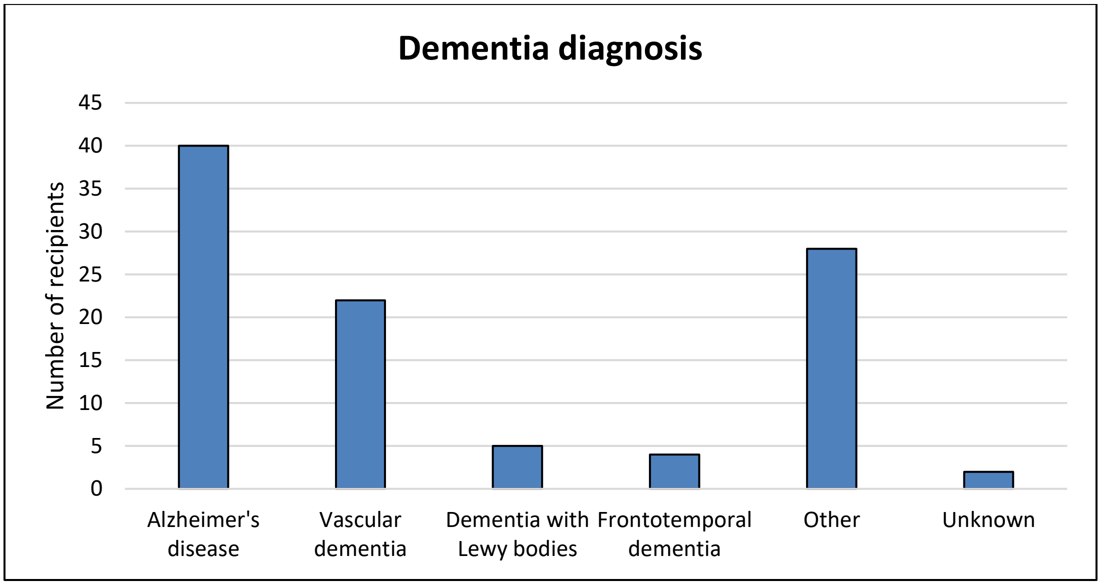

Figure 11: Dementia diagnosis of evaluation participants

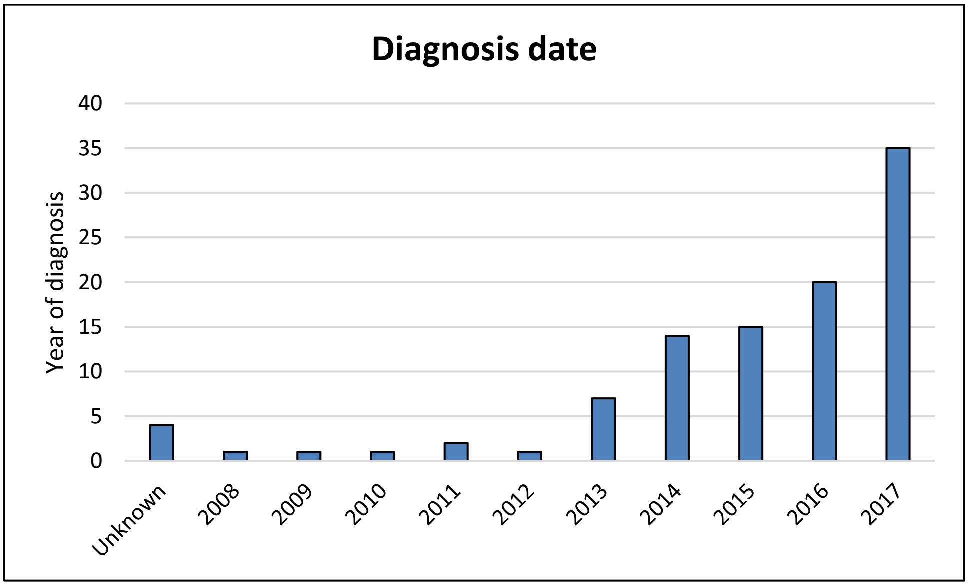

Figure 12: When received dementia diagnosis

54% of evaluation participants have a least one other medical condition, with arthritis, diabetes, mobility issues, frailty and heart conditions being mentioned frequently.

Housing situation

64% of evaluation participants live in a house, with a further 23% living in a bungalow. 86% are owner occupiers, and 68% live with a partner/spouse while 23% live alone.

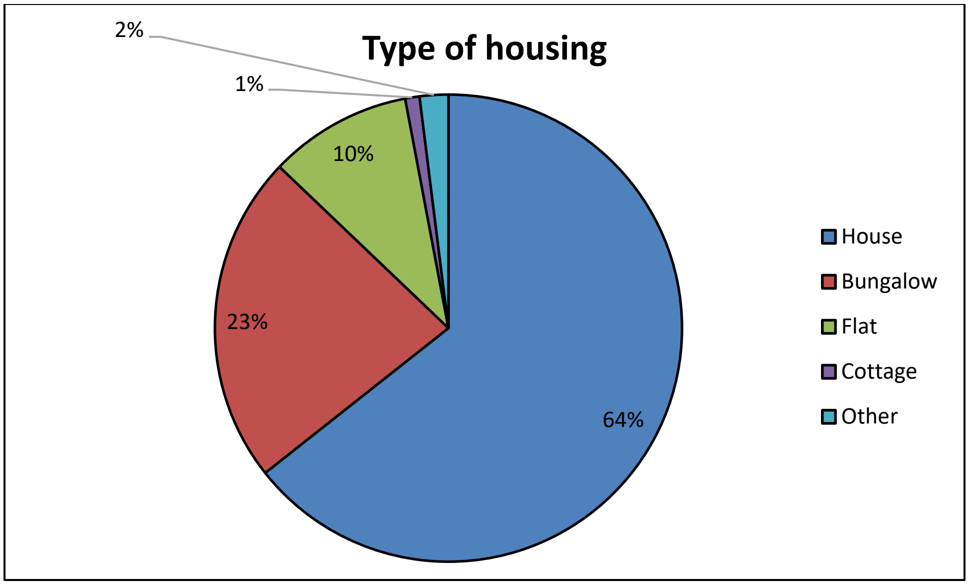

Figure 13: Type of housing

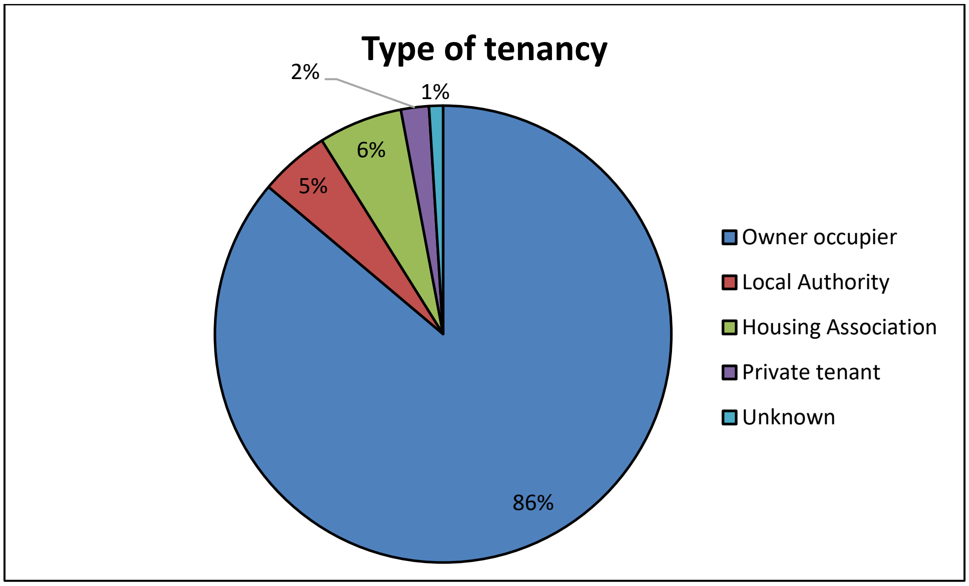

Figure 14: Type of tenancy

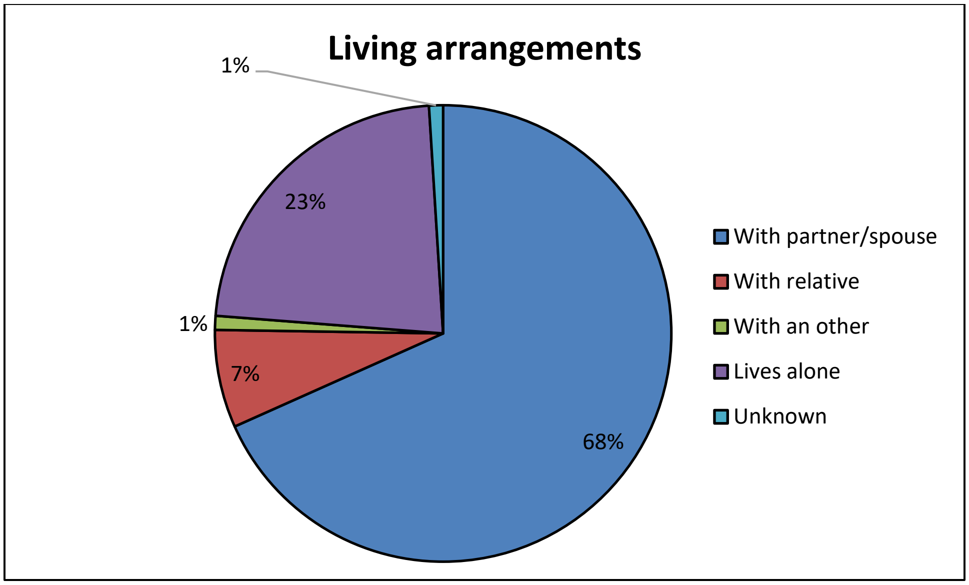

Figure 15: Living arrangements

Of the participants living in a house, 95% are owner occupiers, 66% live with a partner/spouse and 78% have 3-4 bedrooms.

Of the participants living in a bungalow, 78% are owner occupiers, 78% live with a partner/spouse and 70% have 2-3 bedrooms.

The participants living in a flat are a mix of owner occupiers, Council and Housing Association tenants, living alone or with their partner/spouse, and have 1-2 bedrooms.

Grants and benefits

63% of evaluation participants were in receipt of at least one other grant or benefit, with Attendance Allowance, Personal Independence Payment, Council Tax reduction and Disability Living Allowance being the most frequently mentioned.

36% of evaluation participants have been through an OT assessment. 39% had received minor aids with grab/hand rails being the most common, followed by perching stools. Only 8% had received major aids, mainly wet rooms/bathroom adaptations.

DDG items

The top 5 most common items requested from the DDG list are:

1. Dementia clock – free standing
2. Notice board or white board
3. Touch bedside light

4. Key locators
5. Memo minder

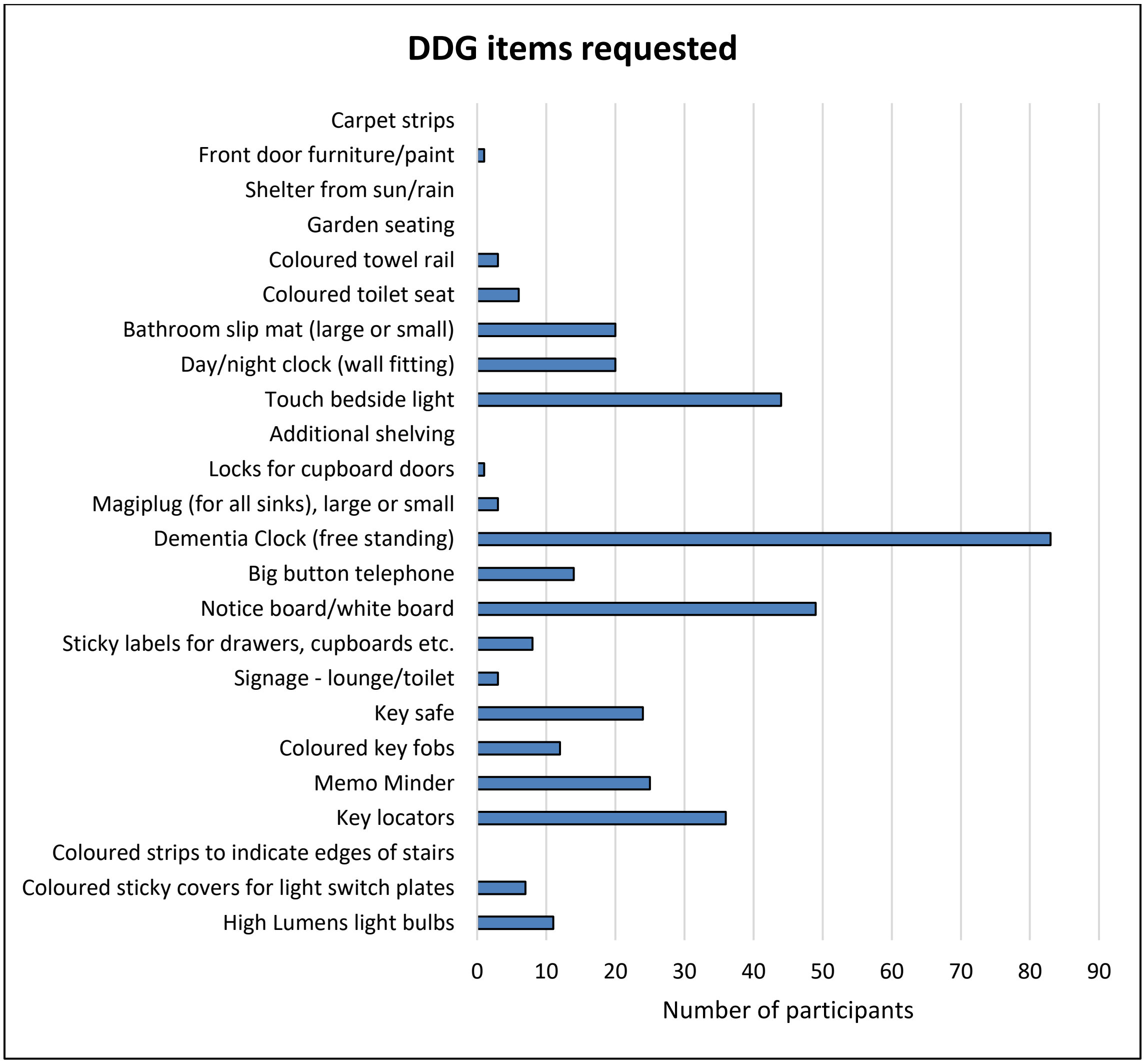

Figure 16: Requests for DDG items

Everyone in the group has required at least one item, and one person has required 12 different types of item. Most often, participants have required 2 different types of item, with the average (mean) being 3.7 different types of item.

Some participants have needed more than one of the same item, and one person needed a total of 19 items (12 different types). Most often, participants have only needed a total of 2 items with an average (mean) of 4.3 total items.

The total cost of the items requested per person has ranged from £11 to £434. These costs (and indeed all of those reported in this document) are purely based on the cost of the aids, and do not include any associated costs relating to assessment, fitting or a handyperson's time.

In summary, on average participants need 4 items in total (usually 4 different types) at a cost of £129. (These averages are rounded to the nearest item as it is not possible to have 3.7 items)

When night lights are included, these average summary figures change to participants needing 5 items in total (4 different types) at a cost of £138. The range of total costs just for the aids becomes £11 to £462.68.

	Excluding night lights		**Including night lights**	
	Different items	**Total items**	**Different items**	**Total items**
Range	1-12	1-19	1-13	1-21
Mode (most common number)	2	2	4	3*
Average (mean)	3.7	4.3	4.2	5.1
Range of costs of aids	£11 - £434		£11 - £462.68	
Average (mean) cost of aids	£129.17		£137.97	

* The 'total items' is less than the 'different items' as although one person was assessed as needing particular items, they declined some of them

Table 1: Numbers and costs of DDG items

On average, participants who live alone need more items than those living with someone else. The figures shown in Table 2 include night lights.

	Average (mean) number of different items requested	**Average (mean) number of total items requested**	**Average (mean) total cost of items**
Living alone	4.6	5.5	£150.16
Not living alone	4.0	4.9	£131.72

Table 2: Numbers and costs of DDG items depending on living situation (including night lights)

A participant's type of dementia did not appear to affect the mean number of items requested, apart from frontotemporal dementia which was associated with requiring fewer items. However, this was based on only four assessments where this diagnosis was given, so it is difficult to draw too many conclusions from this.

Although based on groups of different sizes, there does appear to be some difference between the number of items requested per person in different districts, with Malvern Hills being lower than the rest and Wychavon being higher. The reasons for this are not clear but could include individual Dementia Advisors having different approaches to promoting aids and adaptations or different situations in the districts. For example, if participants already have aids through self-purchase or other grants, they may not need additional aids from the DDG.

District (no. of assessments with consent)	Average (mean) number of different items requested	Average (mean) number of total items requested	Average (mean) total cost of items
Bromsgrove (n=16)	3.6	4.2	£118.92
Malvern Hills (n=2)	1.5	1.5	£19.57
Redditch (n=25)	3.8	4.0	£123.67
Worcester (n=11)	3.5	4.6	£139.70
Wychavon (n=15)	8.3	11.2	£288.15
Wyre Forest (n=32)	3.1	3.7	£90.76

Table 3: Numbers and costs of DDG items depending on district (including night lights)

Evaluation responses

Participant wellbeing

28% of participants did not respond to one or more of the baseline statements about their feelings for various reasons including not being able to remember, being unable to answer, and not being asked because the Dementia Advisor considered that the statements were inappropriate or could cause distress.

The participants’ responses that were captured are shown in Table 4. The arrows indicate the range of responses given, and the dots show the average (mean) response to each statement. The average scores indicate relatively positive responses, with high scores for the first three statements and a lower score for anxiety.

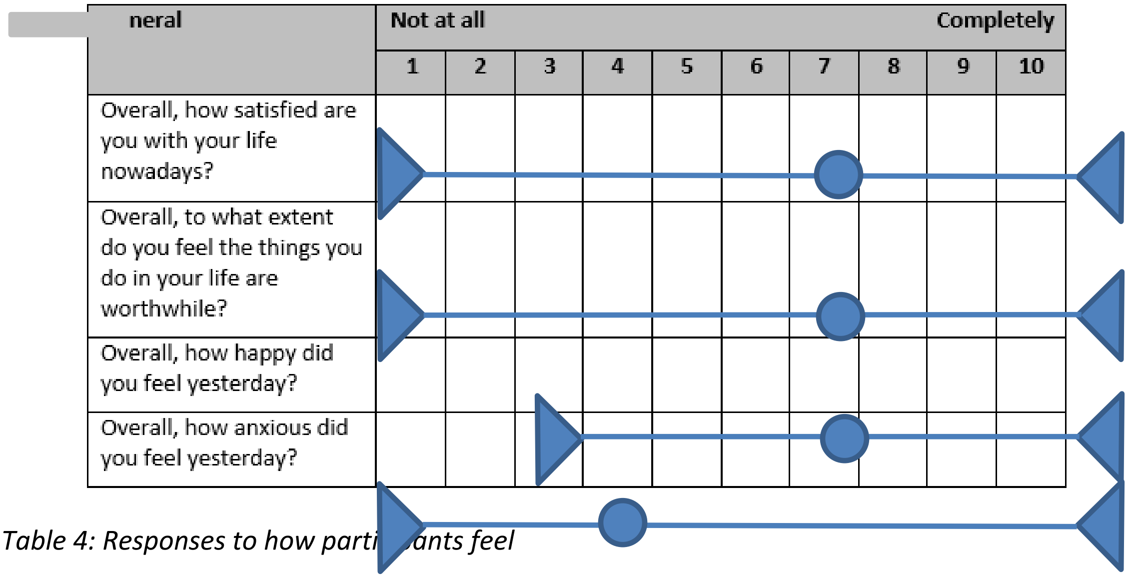

Table 4: Responses to how participants feel

The wide range of scores for the first and last statements are worthy of note, although it is possible that the high scores for anxiety could be due to the participant and/or the Dementia Advisor not realising that the scoring is reversed for this statement. Comparator data from the Office for National Statistics allows the responses from the DDG assessments to be viewed within the UK context. As the UK data is based on responses for the whole population, it is perhaps not surprising that the DDG data shows lower ratings for participants living with dementia. However, the difference between the results is not as large as might have been expected, especially in terms of the mean scores. As noted previously, the anxiety scores may be subject to confusion regarding the rating scale.

	DDG data		**UK comparator data**	
	%[9]	**Mean**	**%**[10]	**Mean**
Overall, how satisfied are you with your life nowadays?	25.00	7.07	30.16	7.69
Overall, to what extent do you feel the things you do in your life are worthwhile?	26.51	7.11	35.59	7.87
Overall, how happy did you feel yesterday?	27.50	7.19	34.92	7.52
Overall, how anxious did you feel yesterday?	32.50[11]	4.43	39.89[12]	2.92

Table 5: Responses to how participants feel – DDG v comparator data

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[9] % people responding 9 or 10

[10] % people responding 9 or 10 (Oct 2016 – Sept 2017)

[11] % people responding lowest two categories

[12] % people responding lowest two categories (Oct 2016 – Sept 2017)

Of the 101 evaluation participants 13 (13%) did not comment on loneliness, but amongst those who did there was a mixed picture. A large group of participants never felt lonely, while slightly more felt lonely at least 'occasionally' (Figure 17).

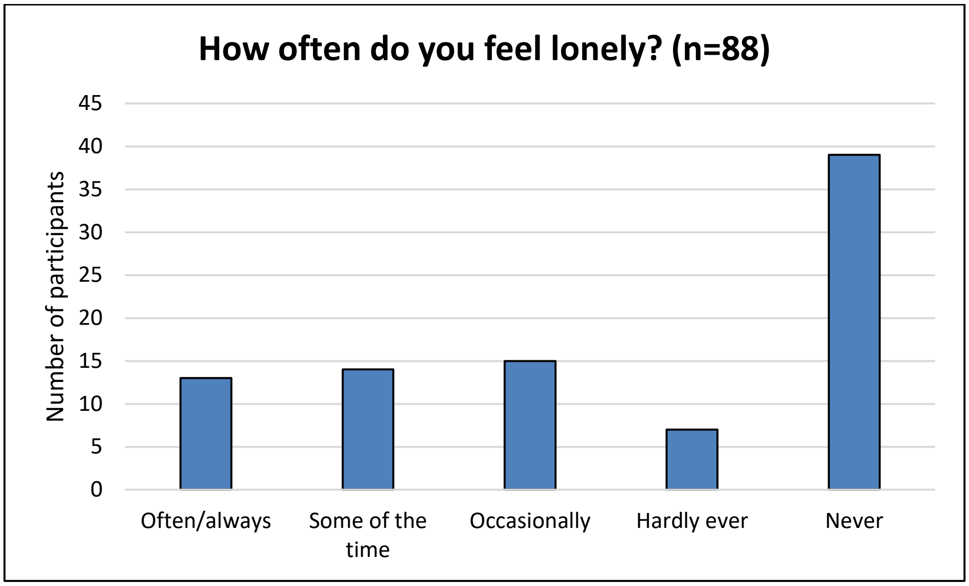

Figure 17: Loneliness

Perhaps unsurprisingly, participants living alone were likely to feel lonely more often than participants who lived with someone else (Figure 18).

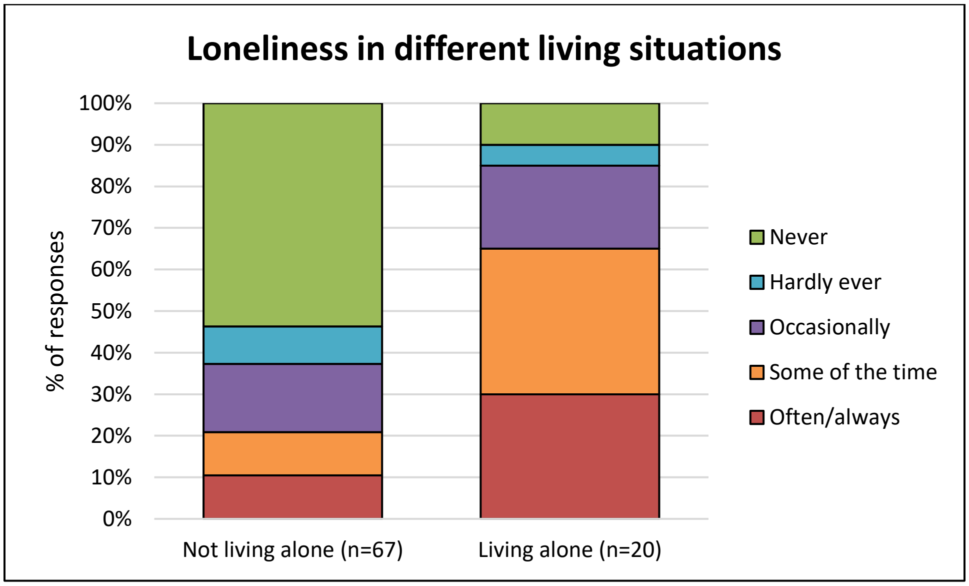

Figure 18: Loneliness based on living situation

Using the comparator data for the UK, it can be seen in Table 6 that the percentage of those reporting feeling lonely often/always is considerably higher amongst the DDG group.

	DDG data %[13]	UK comparator data %[14]
Feel lonely often/always	14.77	4.06

Table 6: Reported levels of loneliness – DDG v comparator data

Of the evaluation participants, 97% and 98% respectively commented on their levels of satisfaction with health and accommodation. As can be seen in Figure 19, most participants were quite positive about both, although health was more of a concern for some participants.

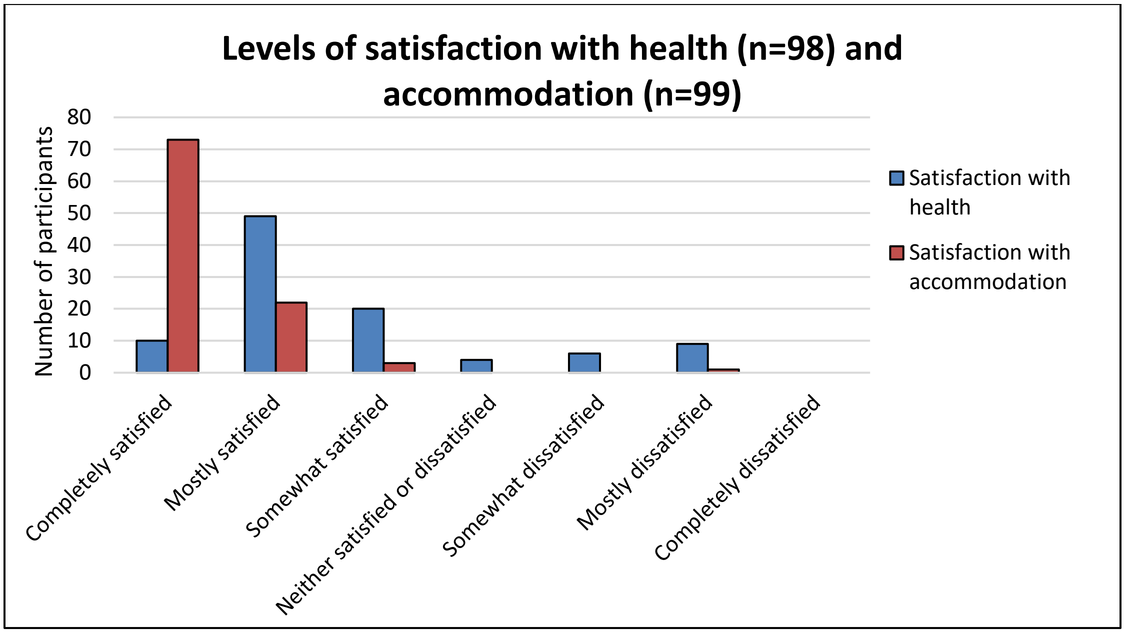

Figure 19: Satisfaction

Considering the situation facing the DDG group, it is perhaps surprising that they appear to be more satisfied with both their general health and accommodation than the wider UK population (Table 7).

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[13] % people responding 'Often/always'

[14] % people responding 'Often/always' (Oct 2015 – Sept 2016)

	DDG data %	UK comparator data %
How satisfied are you with your general health?	60.20[15]	49.60[16]
How satisfied are you with your accommodation?	98.99[17]	89.90[18]

Table 7: Responses to satisfaction – DDG v comparator data

Response rates to the statements about participant wellbeing varied (see values in x-axis titles in Figure 20), with 'Thinking clearly' being left blank half of the time. It is unclear whether this was because participants did not want to answer it, or whether it was omitted by the Dementia Advisor. Overall, responses were generally quite positive with 'some of the time' and 'often' being the most common responses for most statements.

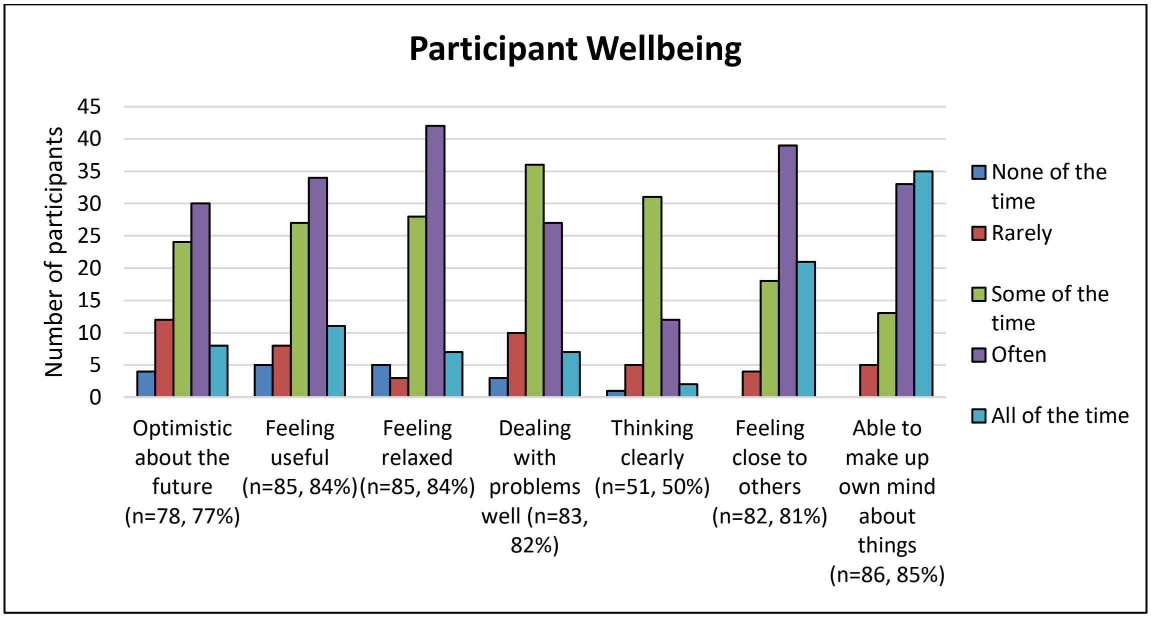

Figure 20: Participant wellbeing scores

77 participants responded to enough of the statements to generate an overall score. Possible scores are in the range 6-35, with higher scores indicating more positive

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[15] % people 'Completely satisfied' or 'Mostly satisfied'

[16] % people 'Completely satisfied' or 'Mostly satisfied' (2014-2015)

[17] % people responding with at least some satisfaction

[18] % people responding with at least some satisfaction (2014-2015)

feelings[19]. As indicated in Figure 21 most participants were towards the higher end of the scoring scale, with 23 being the most common actual score.

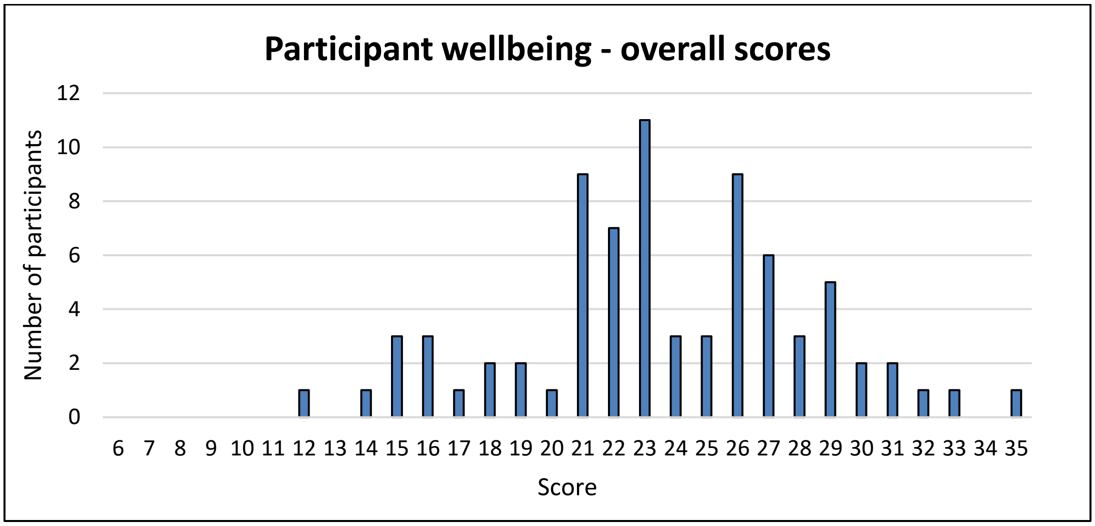

Figure 21: Participant wellbeing – overall scores

It was unclear if the comparator data reported the actual or adjusted mean score for this measure, so both values have been given for the DDG group. Regardless, it can be seen that the score was lower, i.e. less positive, for the DDG group than for the UK as a whole.

	DDG data Mean score (actual/adjusted)	**UK comparator data Mean score[20]**
Overall score out of 35	23.64/21.68	24.61

Table 8: Participant wellbeing – DDG v comparator data

Only a small selection of participants did not respond when asked to rate their current situation in terms of being able to look after themselves and others (12%) and whether they feel safe (7%). On a scale of 1-5 where 5 is positive, the average (mean and median) scores were high for both aspects, with safety being rated slightly higher.

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[19] This report uses the actual scores unless otherwise stated, as the scores can be adjusted (scaled) to allow comparison with results from other studies.

[20] Average score (2012-2013)

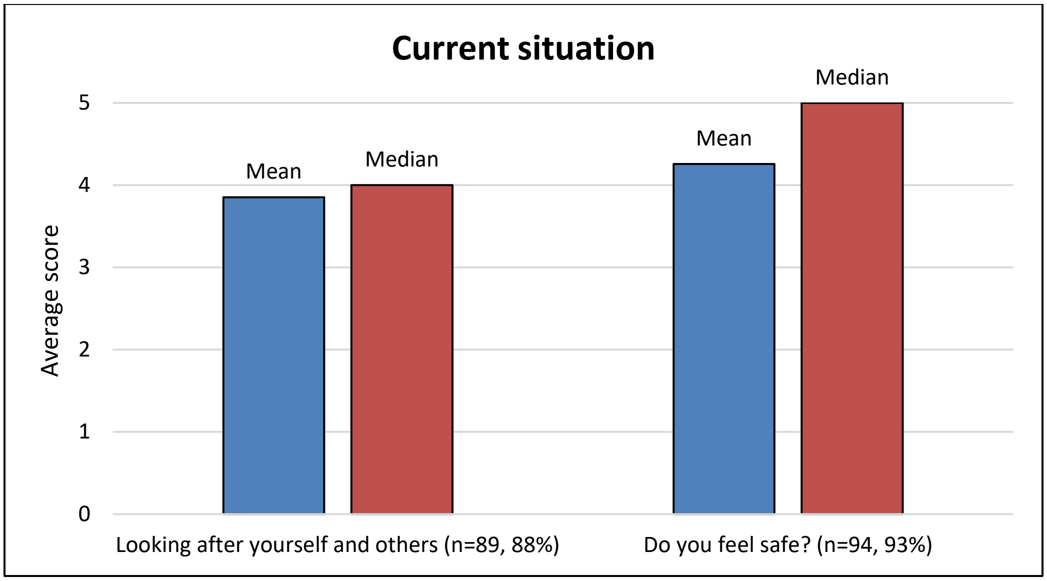

Figure 22: Current situation of participants

Taken together, the evaluation measures indicate that the participants are generally quite positive about their lives.

3-month assessments

3-month follow-up assessments were carried out for 80 of the 101 participants who consented to be part of the evaluation (79%). Of these, seven had left the study: three had moved into long-term care or required more substantial care; one was in hospital, one had passed away; one was no longer able to answer the questions; and one could not be contacted. The following analysis is based on the remaining 73 participants who completed a 3-month assessment.

Of these 73 participants, 14 (19%) had a fall since their baseline assessment. Ten of the falls took place at home, two of which were outdoors and one was due to low sugar levels related to the participant’s diabetes. Only two participants had been in hospital since their baseline assessment, due to a blockage in the chest and an infection.

Nine of the 73 participants (12%) withdrew from the remainder of the evaluation, with some indicating a deterioration in their condition as the reason for this. In some cases it was agreed with the carer that continuation with the evaluation would not be appropriate due to cognitive decline and/or anxiety.

Evaluation responses

How participants feel

Although 73 participants received a 3-month assessment, not everyone responded to all of the questions or statements at both the baseline assessment and 3-month assessment. To avoid potentially skewing the analysis, only those participants who responded at both time points (referred to as matched responses) are considered in Table 9. Higher scores are better for the first three questions, while lower scores are better for the final question. There was a slight improvement in the mean response for each individual question between baseline and 3 months. None of these improvements are statistically significant, but they are noteworthy nonetheless, given that people living with dementia might be expected to report reduced quality of life over time.

	Number of participants responding at both baseline and 3-month	**Mean (out of 10)**	
		Baseline	**3-month**
Overall, how satisfied are you with your life nowadays?	51	7.0	7.3
Overall, to what extent do you feel the things you do in your life are worthwhile?	41	7.2	7.5
Overall, how happy did you feel yesterday?	38	7.2	7.3
Overall, how anxious did you feel yesterday?	35	4.5	4.1

Table 9: How participants felt at baseline and after 3 months

When considering the matched baseline and 3-month data in relation to the comparator data, it can be seen that the DDG group had poorer responses in all cases (Table 10). Again this is not surprising given the cohorts involved, but it is interesting to note that although the mean scores for the DDG group had improved after 3 months, the % of participants giving the top two responses had actually decreased in most cases.

	DDG data – matched responses (Baseline/3-month)		UK comparator data	
	% *	Mean	% *	Mean
Overall, how satisfied are you with your life nowadays?	25.49 / 25.49	6.96 / 7.29	30.16	7.69
Overall, to what extent do you feel the things you do in your life are worthwhile?	31.71 / 26.83	7.22 / 7.46	35.59	7.87
Overall, how happy did you feel yesterday?	34.21 / 31.58	7.21 / 7.34	34.92	7.52
Overall, how anxious did you feel yesterday?	37.14 / 28.57	4.46 / 4.11	39.89	2.92

* % of participants giving a score of 9 or 10 out of 10 (or 1 or 2 for the final question)

Table 10: Responses to how participants feel – matched DDG responses v comparator data

Loneliness

Again looking at participants who responded at both time points, Figure 23 suggests that there has been a reduction in levels of loneliness. Fewer participants feel lonely ‘Often/always’, ‘Some of the time’ or ‘Occasionally’, and more participants responded ‘Hardly ever’ or ‘Never’.

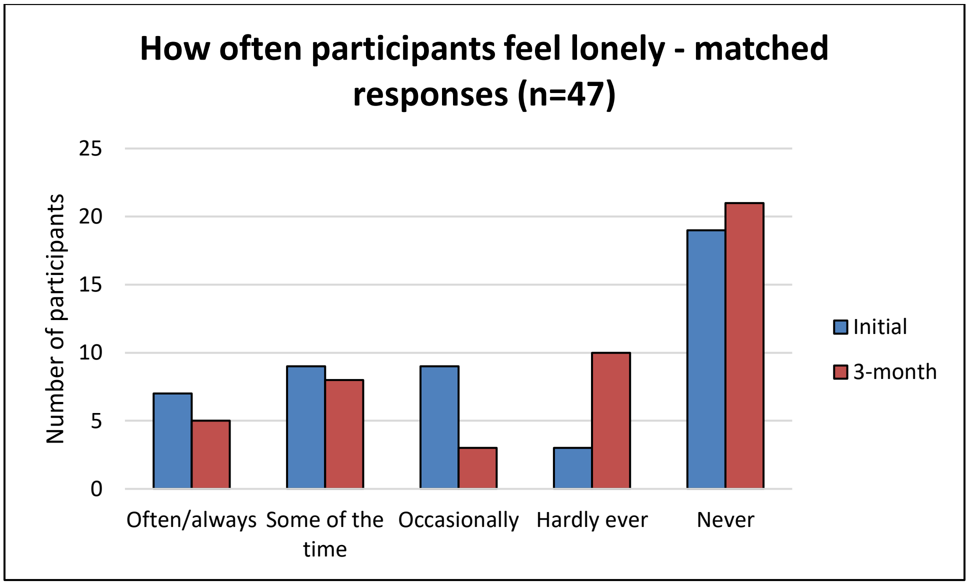

Figure 23: Matched responses for loneliness

Although the DDG matched data indicates considerably higher levels of loneliness than the UK comparator data at both the baseline and 3-month assessments, it is reassuring to confirm that the 3-month responses have indeed improved for the DDG participants.

	DDG data % responding Often/always (Baseline/3-month)	UK comparator data % responding Often/always
How often do you feel lonely?	14.89 / 10.64	4.06

Table 11: Responses to how lonely participants feel – matched DDG data v comparator data

Satisfaction

The matched responses in Figure 24 show that there has been little change in satisfaction with health during the 3-month evaluation period. However, there does appear to have been an improvement in terms of satisfaction with accommodation (Figure 25) with more participants being 'Completely satisfied'. Although the responses were already quite positive at the baseline assessment, the results raise the possibility that the aids and adaptations have impacted on accommodation experiences for some participants.

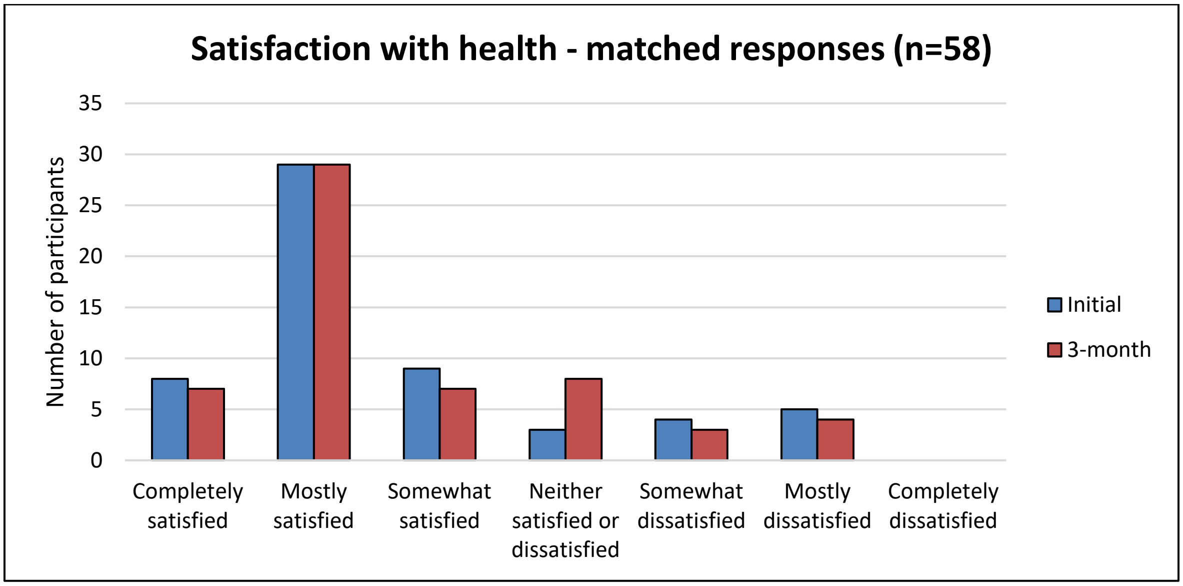

Figure 24: Matched responses for satisfaction with health

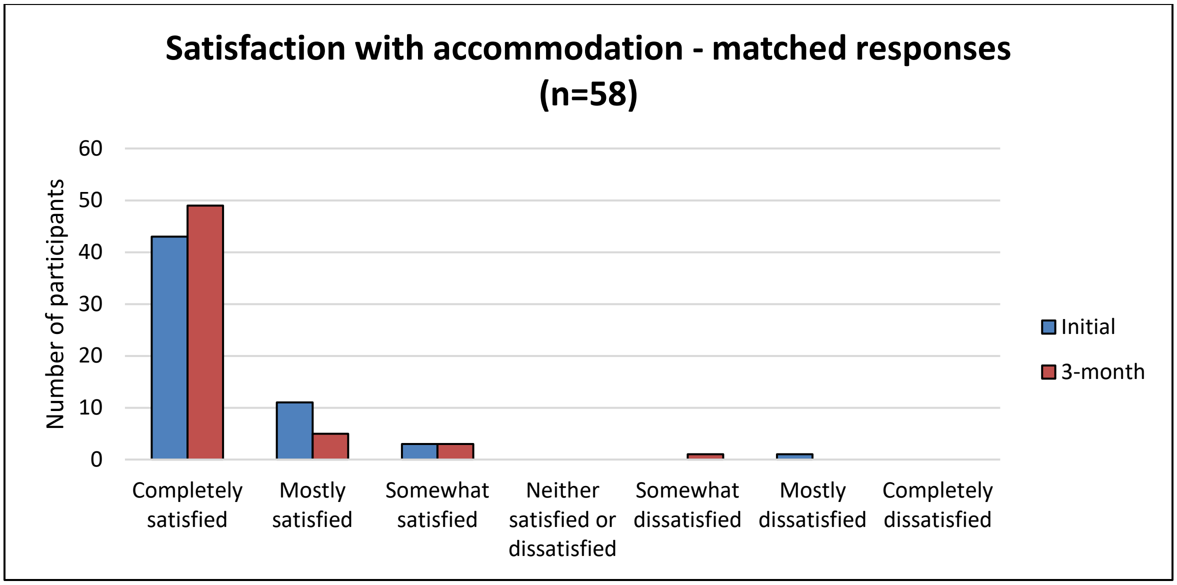

Figure 25: Matched responses for satisfaction with accommodation

The matched DDG data shows higher levels of satisfaction with health and accommodation than the UK comparator data at both the baseline and 3-month assessments, which is perhaps surprising given the nature of the DDG cohort.

	DDG data % * (Baseline/3-month)	**UK comparator data % ***
How satisfied are you with your general health?	63.79 / 62.07	49.60
How satisfied are you with your accommodation?	98.28 / 98.28	89.90

** % of participants saying completely or mostly satisfied with health, or any form of satisfaction with accommodation*

Table 12: Responses to satisfaction – matched DDG data v comparator data

Participant wellbeing

32 participants responded to enough statements about how they felt to generate overall scores at both their baseline and 3-month assessments. While there was no significant change in scores during the 3-month period, it is important to note that the reasonably positive scores seen at the baseline assessment have more or less been

maintained. However, these positive scores remain lower than the mean score obtained from the UK comparator data (Table 13).

	DDG data Mean score (actual/adjusted)		**UK comparator data Mean score**
	Baseline	**3-month**	
Overall score out of 35	23.75/21.88	22.84/21.04	24.61

Table 13: Participant wellbeing – matched DDG data v comparator data

Current situation

In terms of how participants rated looking after themselves and others, the data provided matched responses for 50 participants. Analysis showed an almost statistically significant improvement at the 3-month assessment (CI=0.05, p=0.06), with the mean response increasing from 4.2 to 4.5 (out of 5).

Matched responses for 51 participants relating to feeling safe also showed an almost statistically significant improvement (CI = 0.05, p=0.06), with the mean increasing from 4.6 to 4.8 (out of 5).

Reflecting on the aids and adaptations

The most beneficial aids were felt to include:

- Dementia clock (50 comments) – for orientation, *"just looking at it I know the date, day and time"*, use it several times a day
- Night light/automatic lights/light sensors (14 comments) - when the automatic light came on in the bathroom at night it was the first time in ages that someone had seen their partner smile
- Whiteboard/noticeboard (13 comments) – reduces anxiety about what is going on, helps with independence
- Bedside lamp (8 comments)
- Key safe (6 comments) – useful for carers, participant did not want it initially but thinks it is great because they have to carry their house keys when they go out
- Bath mat (5 comments) – helps participant feel safe
- Key locators (3 comments) – God send
- Memo minder (1 comment)
- Hand rail (1 comment)

Participants were pleased with how quickly they got the equipment and the advice and support provided.

The least beneficial aids were felt to include:

- Night light (9 comments) – participant kept wanting to turn it off, not very bright light, battery goes too quickly, not used it yet
- Memo minder (8 comments) – disorientating and frightening, gives out message every time someone walks past
- Key locators (8 comments) – not used yet/only used once, kept ticking even when not in use, thought it was a car key
- Whiteboard/noticeboard (4 comments) – not used it much
- Phone (4 comments) – not portable so could not get to it in time, stopped using it, returned it
- Clock (2 comments)
- Bedside lamp (2 comments) – confusing
- Key safe (1 comment)
- Light switch covers (1 comment) – not made any difference
- Plug (1 comment) – has a deep bath so not easy to remove the plug

Additionally, one participant received a toilet seat which was poor quality and had to be returned.

Further aids that participants suggested might be useful included a walking stick seat, a shower on/off indicator, a tablet dispenser, a pill cutter, a seat alarm, a doorbell light as they cannot hear it ring, a portable fan, and a wrist watch as well as a dementia clock.

9-month assessments

9-month follow-up assessments were carried out for 40 of the 101 participants who consented to be part of the evaluation (40%). Of these, four had left the study: two required more substantial care and two could not be contacted. The following analysis is based on the remaining 36 participants who completed a 9-month assessment.

Of these 36 participants, 9 (25%) had a fall since their 3-month assessment. Eight of the falls took place at home, one of which was outdoors. Only three participants had been in hospital since their 3-month assessment, two due to chest infections.

Evaluation responses

How participants feel

Although 36 participants received a 9-month assessment, not everyone responded to all of the questions or statements at the baseline, 3-month and 9-month assessments. To avoid potentially skewing the analysis, only those participants who responded at pairs of time points (i.e. at baseline and 9-month or at 3-month and 9-month, referred to as matched responses) are considered in Table 14. As before, higher scores are better for the first three questions, while lower scores are better for the final question. There was a slight decline in the mean response for the first two questions between baseline and 9 months, but a slight improvement for the final question. Although a decline in quality of life might be expected for people living with dementia over a period of nine months, none of the changes were statistically significant. Between the 3-month and 9-month assessments there was a slight decline for three of the four questions, but none of these changes were statistically significant either.

	Baseline v 9-month			**3-month v 9-month**		
	No. participants responding at both time points	**Mean (out of 10)**		**No. participants responding at both time points**	**Mean (out of 10)**	
		Baseline	**9-month**		**3-month**	**9-month**
Overall, how satisfied are you with your life nowadays?	28	7.0	6.4	24	7.2	6.6
Overall, to what extent do you feel the things you do in your life are worthwhile?	16	7.6	7.4	13	7.1	7.0
Overall, how happy did you feel yesterday?	18	6.8	6.8	11	6.5	6.9
Overall, how anxious did you feel yesterday?	16	5.6	5.4	7	4.0	5.3

Table 14: How participants felt at different time points

When considering the matched baseline/9-month and 3-month/9-month data in relation to the comparator data, it can be seen that the DDG group had poorer responses in almost all cases (Table 15). Additionally, the % of participants giving the top two responses had decreased in most cases. Again this is not surprising given the cohorts involved.

	DDG data – matched responses				UK comparator data	
	(Baseline/9-month)		(3-month/9-month)			
	% *	Mean	% *	Mean	% *	Mean
Overall, how satisfied are you with your life nowadays?	28.57 / 7.14	7.00 / 6.39	20.83 / 12.50	7.21 / 6.58	30.16	7.69
Overall, to what extent do you feel the things you do in your life are worthwhile?	43.75 / 18.75	7.63 / 7.44	23.08 / 23.08	7.08 / 7.00	35.59	7.87
Overall, how happy did you feel yesterday?	22.22 / 5.56	6.83 / 6.78	0.00 / 18.18	6.55 / 6.91	34.92	7.52
Overall, how anxious did you feel yesterday?	12.50 / 12.50	5.63 / 5.44	28.57 / 14.29	4.00 / 5.29	39.89	2.92

* % of participants giving a score of 9 or 10 out of 10 (or 1 or 2 for the final question)

Table 15: Responses to how participants feel at different time points – matched DDG responses v comparator data

Loneliness

Again looking at participants who responded at pairs of time points, Figure 26 suggests that there has been a reduction in levels of loneliness between the baseline and 9-month evaluations. Fewer participants feel lonely ‘Often/always’ or ‘Some of the time’ and more participants responded ‘Hardly ever’. There also appears to have been some level of improvement between the 3-month and 9-month assessments as again fewer participants feel lonely ‘Often/always’ or ‘Some of the time’ (Figure 27).

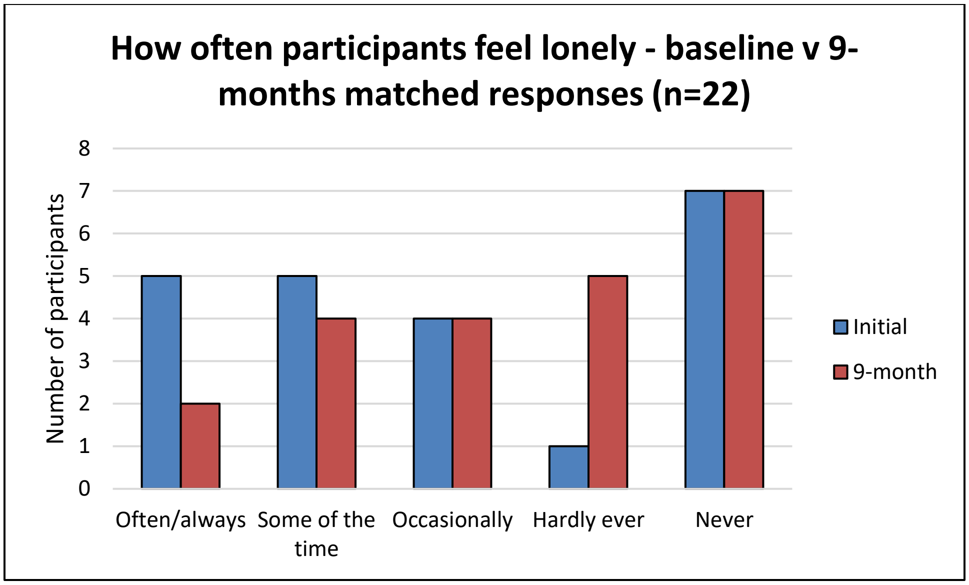

Figure 26: Matched responses for loneliness – baseline v 9-months

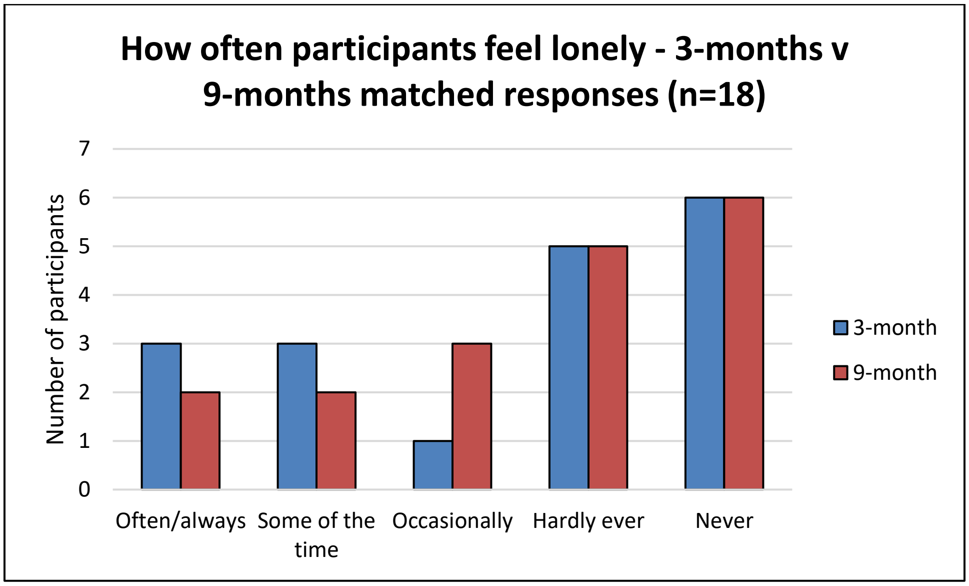

Figure 27: Matched responses for loneliness – 3-months v 9-months

Although the DDG matched data indicates considerably higher levels of loneliness than the UK comparator data, it is reassuring to confirm that the 9-month responses have indeed improved for the DDG participants when compared to both the baseline and 3-month responses.

	DDG data % responding Often/always		**UK comparator data % responding Often/always**
	(Baseline/9-month)	**(3-month/9-month)**	

How often do you feel lonely?	22.73 / 9.09	16.67 / 11.11	4.06

Table 16: Responses to how lonely participants feel at different time points – matched DDG data v comparator data

Satisfaction

The matched responses in Figure 28 and Figure 29 show that there has been little change in satisfaction with health by the end of the 9-month evaluation period when compared with either the baseline or 3-month matched responses. However, there does appear to have been an improvement in terms of satisfaction with accommodation between baseline and 9-months (Figure 30) with more participants being 'Completely satisfied'. Although the responses were already quite positive at the baseline assessment, the results raise the possibility that the aids and adaptations have impacted on accommodation experiences for some participants.

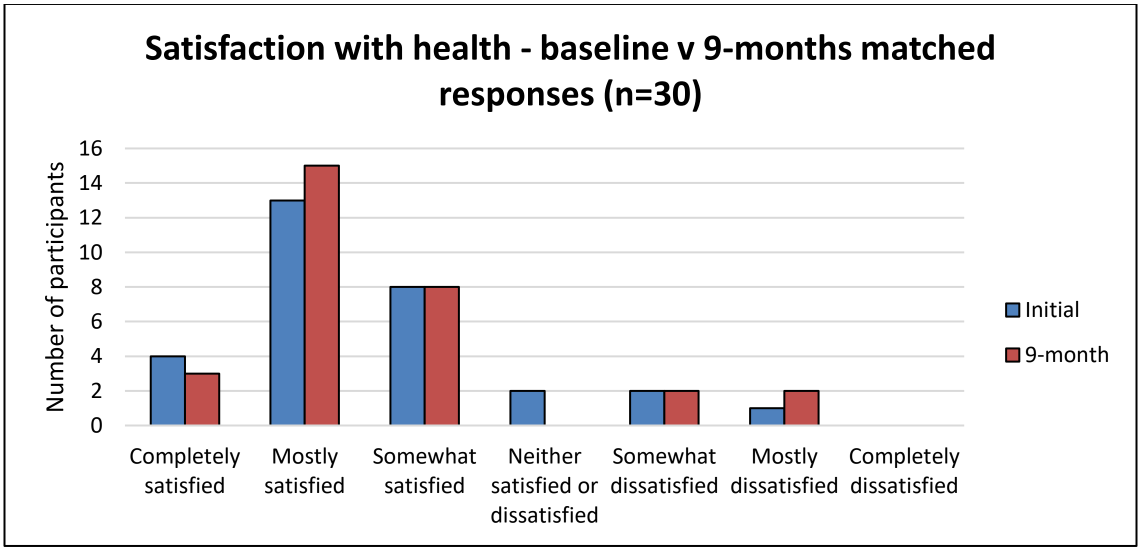

Figure 28: Matched responses for satisfaction with health – baseline v 9-months

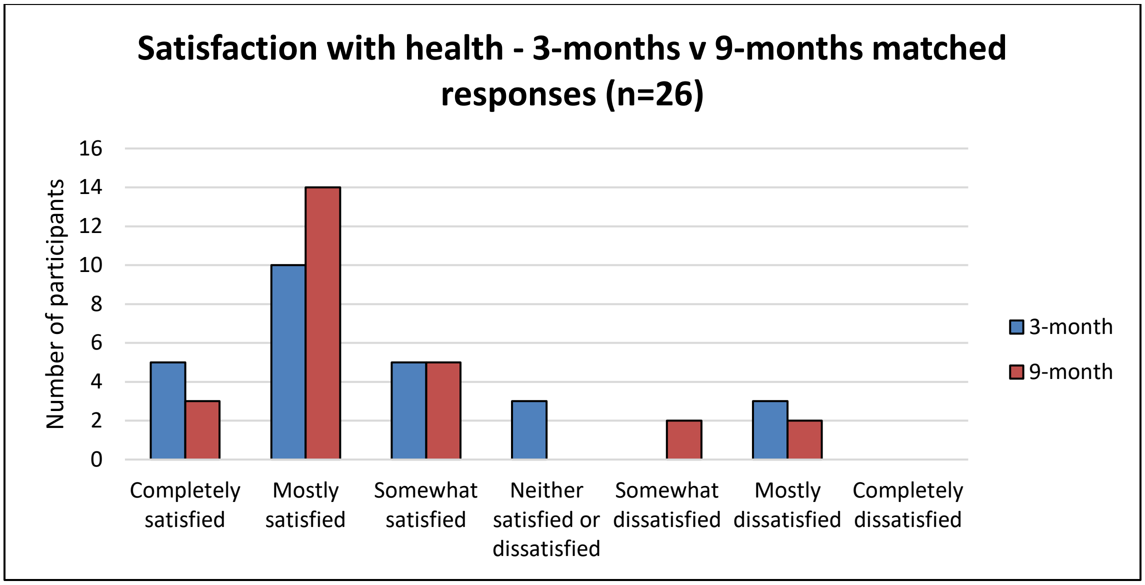

Figure 29: Matched responses for satisfaction with health – 3-months v 9-months

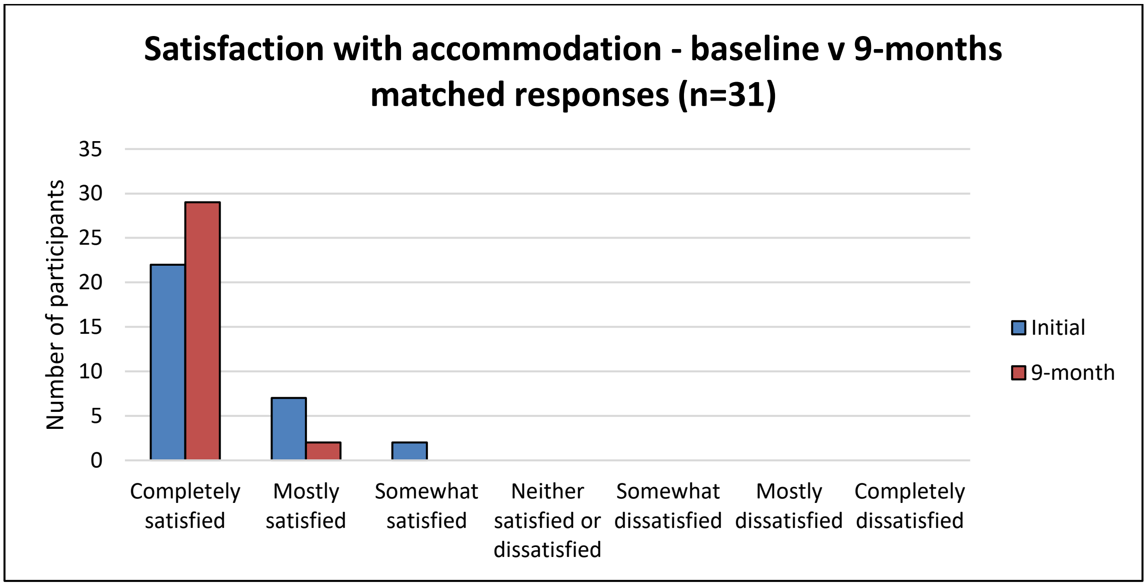

Figure 30: Matched responses for satisfaction with accommodation – baseline v 9-months

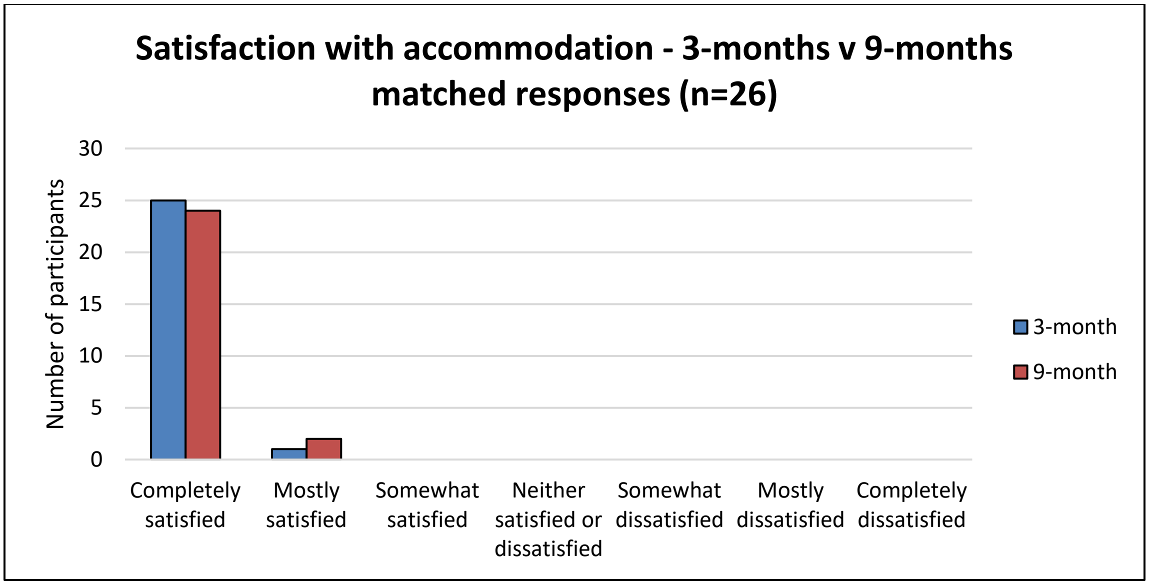

Figure 31: Matched responses for satisfaction with accommodation – 3-months v 9-months

The matched DDG data shows higher levels of satisfaction with health and accommodation than the UK comparator data for both time point comparisons, which is again perhaps surprising given the nature of the DDG cohort.

	DDG data % *		**UK comparator data % ***
	(Baseline/9-month)	**(3-month/9-month)**	
How satisfied are you with your general health?	56.67 / 60.00	57.69 / 65.38	49.60
How satisfied are you with your accommodation?	100.00 / 100.00	100.00 / 100.00	89.90

** % of participants saying completely or mostly satisfied with health, or any form of satisfaction with accommodation*

Table 17: Responses to satisfaction at different time points – matched DDG data v comparator data

Participant wellbeing

14 participants responded to enough statements about how they felt to generate overall scores at both their baseline and 9-month assessments. While there was no significant change in scores, it is important to note that the reasonably positive scores seen at the baseline assessment have more or less been maintained. These matched 'actual' scores are actually slightly higher than the mean score obtained from the UK

comparator data although the ‘adjusted’ versions are lower (Table 18). A similar pattern was seen for the 10 participants who generated overall scores at both their 3-month and 9-month assessments. It is unclear whether the UK comparator data uses the actual or adjusted scores, and it should also be acknowledged that the DDG results are based on relatively small sample sizes.

	DDG data Mean score (actual/adjusted)				UK comparator data Mean score
	Baseline	**9-month**	**3-month**	**9-month**	
Overall score out of 35	25.14/22.85	24.86/22.55	25.50/23.36	25.70/23.70	24.61

Table 18: Participant wellbeing at different time points – matched DDG data v comparator data

Current situation

In terms of how participants rated looking after themselves and others, the data provided matched responses for 25 participants for baseline v 9-months, and 24 matched responses for 3-months v 9-months. Analysis showed a statistically significant decline between the 3-month and 9-month assessments (CI=0.05, p=0.02), with the mean response decreasing from 4.6 to 4.0 (out of 5). Between the baseline and 9-month results there was no significant change with means of 4.0 and 4.1 respectively.

Matched responses relating to feeling safe were available for 26 participants for baseline v 9-months, and 24 matched responses for 3-months v 9-months. No statistically significant changes were seen in either case, although between the 3-month and 9-month assessments the mean decreased from 4.9 to 4.6 (out of 5). Between the baseline and 9-month results there was no change in means, staying at 4.5 in both cases.

As improvements were previously seen between baseline and the 3-month assessments, this suggests that while the DDGs may have a short-term impact in these areas, the longer-term impact is less apparent.

Reflecting on the aids and adaptations

The most beneficial aids were felt to include:

- Dementia clock (23 comments) – *“clearer than normal ones”*

- Whiteboard/noticeboard (9 comments)
- Night light/automatic lights/light sensors (6 comments)
- Bedside lamp (3 comments) – *"very useful, easily operated"*
- Key safe (2 comments)
- Bath mat (1 comments)
- Key locators (1 comments)

The least beneficial aids were felt to include:

- Whiteboard/noticeboard (5 comments) – don't like because people try to tell participant what to do by leaving messages
- Memo minder (4 comments) – frightening to hear a disembodied voice, more of a distraction so switched it off
- Night light (2 comments) – stopped working, keeps flashing
- Key locators (2 comments) – not work very well
- Key safe (1 comment)
- Bath mat (1 comment) – too small

One participant asked about a pendant alarm as they thought it would be an aid provided by the DDG scheme, while another expressed an interest in obtaining some bed rails.

Appendix Two: The case studies

From the 101 Dementia Dwelling Grant recipients who took part in the evaluation, a sample of 15 were invited to take part in a case study. Participants were purposively chosen to represent a mix of age, dementia type, living arrangement and geographical location.

Of the initial fifteen prospective participants contacted, one declined due to illness, one had lost capacity to consent, one told us his wife had passed away and one was unable to be contacted. Two further sets of details were obtained from Age UK who confirmed their wish to be involved, bringing the total to 13 participants. The demographics for the participants are as follows:

Dementia Dwelling Grant Case Study Participants		
Age range	55-92 years old	
Gender	Female	9
	Male	4
Type of dementia	Alzheimer's Disease	5
	Mixed Dementia	4
	Vascular Dementia	2
	Dementia with Lewy Bodies	1
	Fronto-temporal lobe dementia	1
Worcestershire locality	Wyre Forest	7
	Wychavon	3
	Worcester	3

Ten of the grant recipients live with their spouse with three recipients living alone either supported by carers or family. Of the participants living alone, all were female with an age range between 65-86 years of age. Most recipients were living in large towns or in the suburbs of a city with good access to local amenities. Three recipients were living in rural communities.

Of the six Worcestershire districts, Wyre Forest, Wychavon and Worcester were well represented. At the point of selecting case study participants, the remaining three districts (Bromsgrove, Malvern Hills and Redditch) had not completed 3 month assessments and had very few, if any, eligible participants.

Choosing aids and adaptations

Whilst participants were, on the whole, very pleased with the products they had received, they appeared to have had little involvement in choosing the products. Only 2 participants could clearly remember being shown a list. Most participants had products chosen for them either by the Dementia Advisor or by their son/daughter or spouse. However, this may be a piece of information which is not being correctly remembered by participants. For example, one participant said that the information about the aids and adaptations was given to her at the Town Hall. Whilst this may have been the case, it is difficult to check.

Method

Contact details for prospective participants were obtained from Age UK and initial contact was made by telephone to confirm involvement. Where recipients were willing to take part in a face to face follow up interview, mutually convenient arrangements were made to visit the person in their own home. Clarity was provided for the grant recipient that they did not have to participate in this further phase of the study and they could choose to have their family member, spouse or carer present.

In terms of the participant’s capability to engage in the interview process, there were a number of participants who were able to respond to questions to affirm that they found the items beneficial but were not able to engage in a detailed conversation. This applied to five of the thirteen participants. Three further participants were supported by their spouses who spoke on their behalf but when the participant had the opportunity to speak they were quite capable of responding. Two participants had their spouse with them but shared the responses in the form of a conversational dialogue. The remaining three participants were interviewed alone and were able to engage and respond.

An open interview schedule was devised to maximise opportunity for participants to comment on the items received from the DDG.

Findings

Some of the items on offer were reported as already having been purchased by participants prior to the grant being available. Additionally, some people remembered that they had items such as grab rails in the garden which had been provided through other funding sources. This sometimes added an element of ambiguity where the participant was not entirely sure that the items being discussed had actually been provided through the DDG.

Conversely, some items were not selected from those available as participants did not feel they were ready for that level of support. Others selected items not required immediately to ensure the house was ‘future-proofed’. This latter decision was met with mixed success.

The items reported as being of most use were whiteboards, lights and clocks.

Whiteboards

Whiteboards were generally fixed in the kitchen area and well used by all participants who received these. Some people had already bought their own whiteboards, particularly smaller more portable versions that could be kept by the armchair in the lounge, for example, to remind them of immediate tasks.

Case Study: Marjorie

Marjorie lives with her husband in a bungalow on the outskirts of a large town. She has mixed dementia. She is a bright, articulate lady who likes to maintain her independence. She said she was very pleased with the whiteboard and had put my name on there so that she knew I was visiting. She said:

“I write everything on there. I put everything that we are going to do through the week. I write it all down so that I don’t have to keep saying ‘what are we doing’ all the time. When we have done something, I immediately rub it off because I know that’s done. And it makes me think as well, I like that”.

Her husband said that initially she was writing everything on it haphazardly on the board and it became confusing for her. He divided the board into days of the week and found that this provided an excellent way to enable Marjorie to note, and anticipate, events for the forthcoming week.

Lights and touch lamps

Several grant recipients said they found the lights and touch lamps to be most beneficial. Some participants had chosen battery operated as opposed to plug in lights; some had chosen motion sensitive lights whereas others were able to be switched on and off. The lights appear to have helped with orientation, preventing injury and helped people to make sense of their environment:

> *"Getting up in the night and going to the loo. They've been tremendous" (15800 Male)*
>
> *"The best thing for me is the light, we've got it on top of the landing and it comes on by movement so in the middle of the night when either of us goes to the loo, it comes on. We sleep with our bedroom door open and I've only got to move my blanket and it comes on"*
>
> *"Before we had them, I meant to switch on the switch by the door, but I missed it and I cut my finger all down there because there was no light" (22119 Female)*
>
> *"I've only got to touch my night light and it comes on. It's ever so useful by my bed. I could never find the switch when it was dark" (36413 Female)*

One participant's spouse explained how having a touch lamp in the bedroom helps him to prepare for his bedtime routine: *"He goes in an gets his bed ready and puts his lamp on and he leaves his lamp on all night and he will even think about it and he will go and check" (wife of participant 35966)*

Clocks

Eight grant recipients had received either digital clocks (free standing or wall mounted) or day/night clocks.

Case Study: Florence
Florence lives with her husband in a bungalow on the outskirts of a small market town. She has mixed dementia. Florence received a day night clock, a digital clock, a whiteboard and a memo-minder Florence was not able to engage fully in verbal conversation but would respond well to specific questions. Her husband was able to demonstrate how they had used the

items to improve Florence’s quality of life. He said she found the large day/night clock very useful. This is fixed on the chimney breast in the lounge in front of where Florence sits. It is easily visible and, when asked if she finds it easier than her previous clock, she nodded and said *“yes, actually I can see it quite easily from here”*:

Day/night clock

Previous wooden clock

Her husband also says she uses the whiteboard a great deal and has found this useful for scheduling the week’s activities. He writes the week’s activities on the board and reminds her to look at it. He has also written her full name at the top of the whiteboard as she could not remember her surname.

A number of lights had been provided through the grant which had been placed in the bedroom and the bathroom to help Florence during the night. When asked if these helped, Florence replied emphatically; *“yes! I used to think there were big black things on……there…..but I don’t get that now!”* Previously, Florence had used a torch to help her find the bathroom.

Her husband told us that the memo-minder had been less successful. The device was fitted adjacent to the front door which plays a message to remind his wife to close the door properly or to take her keys if she leaves the house. He said the device is ‘too sensitive’ and had become a nuisance. To solve the problem he has switched the device off but then reports that he forgets to switch it back on when he goes out:

“I’ve recorded various messages. The one at the moment says ‘Florence, don’t forget to close the door properly’ because sometimes she doesn’t latch it properly and lock it,

'and if you go out, don't forget your key'. Now that's been on but it did get on our nerves a bit so what we've started to do is for me to only switch it on when I go out and I don't go out that often, just one night a week when I play squash, and I like to switch it on then but sometimes I forget and that's the disadvantage of that method….it's easy to go out and forget to switch it on. It could be useful but if you open the door to anyone it goes off".

Challenges with clocks: One grant recipient said he found it very difficult to understand the digital clock when it was set to 24 hour clock. His wife said

> *"He spends all day looking at that (TV magazine) and he's not always sure what time things are on in the evening" (wife of participant 38783).*

They had been unable to find out how to change the function and settings of the clock.

Future proofing

Sometimes recipient's families chose items as a way of future-proofing the home environment in anticipation of future needs. In some cases this worked and in others it presented challenges.

Case Study: Nancy

Nancy lives alone in a bungalow in a rural village. Her daughter lives locally and provides the majority of Nancy's care. Nancy was quite articulate and was able to respond to questions about the items with a few reminders from her daughter. Nancy's daughter had already introduced items to provide a better quality of life for her mother which included:

- A tracker which Nancy wears when she leaves the house. Her daughter has written her mother's name on it and her own phone number in case someone is worried about her mother. Nancy said "she puts it round my neck and I go for a walk, I like to go just up there, up a slight hill and then turn round and come back". The key locator is also attached to the tracker.
- A simple television remote. This has large buttons for volume and channel. Other buttons are available but hidden. This was purchased from Amazon.
- A simple radio with just one button to press to activate the radio. The tuner is hidden under a panel.

With the benefit of the grant, Nancy had been able to have signage for the lounge, a big button telephone, a digital clock, a memo-minder, a touch lamp, a white board, a red toilet seat and a key locator.

Nancy really liked the big button telephone which has capability for speed dial on large buttons at the top of the display which can accommodate photographs.

"We haven't put pictures on it….we have just put (son's name) press to call and (daughter's name) press to call. I think it's good to put 'press to call' rather than just a photograph because if it's just a face you don't know that's going to call".

Nancy, however, did not like the lounge sign at all and wanted to take it down:

"No, I don't like that…..because I don't need a blooming thing like that….I just go out of there and into there". Her daughter said she found the sign very 'institutional':

"I think that one (lounge sign) does look quite austere and I think the signs are all very good but it would be nice for them to be a bit more homely whereas that looks more institutionalised. I have a sticker on her bedroom door but it's a yellow post-it note because I haven't been able to find one that's pretty and I don't want to buy a chalk board one because that can easily be rubbed off but I don't think there was a bedroom option but that would be sensible, especially if you are getting out to go to the toilet in the night" (daughter of participant 40598).

She had brought her mother a pretty sign in a heart for the bathroom and reports that she prefers that type.

Nancy also felt that the red toilet seat did not perform any particular function. However, her daughter said that this was obtained to future proof the house.

The digital clock met with mixed success. Initially, Nancy thought this was her mother's clock. Her daughter said this had been particularly useful with the lighter summer mornings:

"Especially with the light changing, you know actually, it is only 4 in the morning, it's not 8 in the morning and it's still bedtime. Also we have a diary to say who's coming in and I will ask her what day it is and she will read off that (points to the clock) what the day is and the date, so I think they're brilliant". Her daughter also believes there is a function to be able to put a series of photographs on the clock to act as a kind of digital photo frame:

"I did want to get mum a frame so that where we take her out during the day she can read it in her diary that she's been out and then go 'oh yes, there is us' and that mum hasn't been sat down here on her own all day".

A memo-minder was also obtained via the grant but this has proven not to be effective at this stage. *"We thought it would be good because mum was going out quite a lot, but not shutting the door and leaving the door open, so you can record whatever you want on it 'remember to shut the door…..have you got your keys?', but because it is all quite sensitive and where we can put it, we haven't been able to use it.'*

Key safe

These have given a lot of reassurance both to people living with dementia and to their family. However, as the device requires a code to be inputted to release the key, the device has limited use for people with dementia.

> *"We don't use that really…I haven't shown him yet how to use it….I must get round to that but usually I'm with him anyway. If he forgets the key he's always got that key there but on the other hand…. with his dementia he perhaps wouldn't remember the number" (wife of participant 15800)*

Conclusion

Recipients of the grant are unanimous in their opinion that the DDG provides an excellent service to people living with a diagnosis of dementia. Sometimes the smallest of items, such as the self-adhesive LED lights, which are quite cheap and readily available, have made the biggest difference to the lives of people. Grant recipients were often unsure of what items are available on the market and the opportunity to try these has proven very beneficial. Whilst people earlier in their dementia journey have the opportunity to become more familiar with the items, this should not prevent people with advanced dementia from benefitting from the DDG, provided they have a carer or family member who can also become familiar with the items and their potential use.

The case studies suggest several recommendations going forward:

- Ensure the person with dementia and their carer or family member are involved in selecting the items available from the DDG. This may involve walking around the house (where possible) and identifying difficulties and potential solutions, i.e. dark areas in the house which may be improved with LED motion sensitive lights. For the person with dementia, having ownership of these decisions will make it more likely that they will engage in the use of the items and understand their purpose.
- Explain the importance of future proofing. Identify items which may be useful in the future and which will help people retain their independence.
- Expand the range of items available to incorporate those which grant recipients have identified as being useful i.e. large button remote control for the television.
- Ensure recipients and their carers are conversant with setting up devices such as changing 24 hour digital display clocks to a 12 hour setting.
- Explain that some items may be useful for *supporting* the grant recipient rather than for *use* by the grant recipient, i.e. Key safe for use by family or friends.
- Source alternative signage which looks more ‘homely’ and less institutional.

Appendix Three: Stakeholder Interviews

Stakeholders from the key partner organisations involved in the project were interviewed as part of the evaluation, towards the end of the pilot. Broad topics covered were the benefits of the DDG, the main challenges, what worked well, and what could be improved. Interviews were recorded and transcribed, and analysed for thematic content. Findings are presented by topic.

Benefits of the DDG

Interviewees identified a range of benefits arising from the DDG pilot. For the grant recipients, the items provided were thought to offer crucial support after a diagnosis of dementia, as well as a way to promote continued independence:

> *It's about realising that they have a future post diagnosis, and that we should be actually supporting that future actively, by providing whatever is necessary to keep that going.*
>
> *You've got to keep them using it, you've got to keep them stimulated. And some of this equipment does just that, they can tell their own time, they can tell what time of the day and night it is you know? They can see where they're going, they can look in a drawer, and know that it's the right one, because it's got a label on, okay it's got a label on, but so what? At least it means that they're not going into the wrong drawer, becoming frustrated, and then giving up.*

The benefits for family carers of someone living at home with dementia were also recognised:

> *'I think if we can benefit the carer, and make life better, easier for the carer as well, to be able to care for that person, and stay well themselves, then yeah, absolutely, I don't think we should distinguish between the two, as such.'*

Additional benefits were thought to arise from the highly collaborative nature of the pilot, putting the partners in a good position to deliver future initiatives:

> *Partnership working as well, has been really beneficial between obviously, the University, but also with Worcester City Council, and with Care and Repair, and our knowledge, as well, has increased in terms of what people need and want, to be able to manage their dementia, to be able to live at home as well.*

> *It inspires the team to go out and do these things, look at new projects, and then, if we decide what we want to do, my next point, it gives us that greater standing and competitive edge, so if we want to apply for funding for something else now, we can say, look what we've done, and we've done this.*

Finally, there were seen to be substantial benefits for some of the professionals involved in implementing the grant, in terms of their skills and confidence levels:

> *The more they (handyperson staff) went into people, they'd always visited people with dementia, 'cause they had mobility issues as well, but they actually hadn't thought about it from the dementia person's point of view, whereas actually fitting equipment and showing people how to work it, they got more of a feel for it, and their experience, and they became obviously more sensitive to the issues, and could also raise other issues that they were worried about.*

Challenges

Several challenges were reported in getting the pilot up and running successfully. One of these was addressing the concerns that the Dementia Advisors initially had about their role in the project:

> *'We had some teething issues to start off with, in terms of getting people on board with it. I think one of the initial issues, especially with the Dementia Advisors, was about, this is going to take loads and loads of work, and actually it was, we had to do quite a bit of selling the benefits, especially with the evaluation, and why that needed to happen, and that side of it.'*

Another challenge centred on the practicalities of dealing with a large number of grant applications in a timely manner.

> *'We had a staff issue, and we had a stock issue. And so, trying to resolve both of those was quite a…because if you haven't got the staff to resolve the stock, you're going nowhere. But, we literally, I literally sat there and got all of the DDG referrals in a big pile, and I said, these have got to be prioritised. And we actually cleared them quite quickly.'*

What worked well

Overall the DDG was judged to have been a great success, and the decision to extend the programme beyond the pilot period was unanimously welcomed. Three features of the pilot were seen as key to its success. First was the flexibility that it provided in terms of the list of aids and adaptations on offer. This allowed the original list to be amended in response to ongoing feedback from grant recipients, along with the characteristics of some items:

> *I mean, other things are still available, but these are the things we found that most people want. The whiteboards, the key safes, the clocks. We have got the day and night clock in again, because, although we found we had a lull when nobody wanted them, suddenly then we had a flurry where lots of people wanted them. So, we've reintroduced it, so we've got some…*
>
> *We sourced some better sized ones, which are actually, the combi boards we've got now, are a good A4 sized white, and an A4 sized notice, so actually they are better, I think, 'cause what happened with the combi boards before is that they were huge, and people couldn't fit them anywhere. And I'm finding that actually, now that we've thought about it, and sourced better ones, that, you know, and that's what we do, we continually look at what we're getting and see if we can get something better basically. So, you know, it's always an ongoing learning idea really.*

There was also flexibility to provide some items not on the list if the potential benefit justified it:

> *I think, as a regular list, this one is fine, then we just say to people, if there's something outside the box, you let us know, and we will review, and if it's kosher and okay, and comes from a reputable source, we'll probably buy it, to be honest with you.*

The fact the grants weren't means-tested was viewed by all stakeholders interviewed to be a key factor in the success of the pilot, largely due to the additional burden that means testing would place on people with dementia and their families:

> *And yes, it means that we get stuff to people quicker, and they benefit from it quicker as well. It doesn't matter whether you've got the money or not, if you haven't got the capacity, and you've got a carer who's stretched to the limit, they really aren't going to go out and source these things, and bother with them. So, they will go without them. And, at that point in time, that person then will deteriorate and lose their independence, and I think, for the small cost that it is, because it's not a massive amount of cost, means testing would be too much trouble, in reality.*

It was also suggested that means-testing would not be a fair approach to providing support in these circumstances:

> *Dementia is one of those things, that it's not based on how much income you've got, or anything like that.*

A third feature of the pilot thought to contribute towards its success was the organisational arrangements established for its delivery. These meant that the staff who assessed people for a grant and monitored its effectiveness were from the same organisation that provided the Handyperson service.

> *The idea that the one team need to decide, the dementia advisors, that dovetailed quite nicely in with the fact that we had our own handyperson team that would go and fit that. So, I think having a joined up service, enabled us to keep a good check and balance on the service. So, we've been able to see the start and finish of the process, and get the feedback on both sides of that, which has made it much more beneficial for us, and for the scheme, I think, that it's all in one place.*

It was also suggested that this arrangement brought advantages for grant recipients:

> *It's the amount of people you're having going in, because we can say we're all from one organisation. I think sometimes people get peace of mind from that. Whereas, if you say, right, I'm from here, but I'm going to be sending someone from there to come and fit your equipment, and they're going to need you to do this again, you're putting barriers up for people.*

This set up also made it easy for the process to be amended and made more efficient for items that didn't require specialist fitting expertise:

> *And I think in the beginning, everything was going to the handymen. And if we had to book a whole appointment to somebody in Kidderminster, just to take a night light, it wasn't effective really. So, what we did, was encourage the advice team, to actually take those things with them, and we wrote them out as a job sheet, so they effectively became handymen, if you like, so that we could then put it onto the system, that it had all been delivered. So, that speeded up the process quite considerably really, because we had more people doing it, and it worked for them, because they could just leave it there and then really, yeah.*

Suggested improvements

The pilot project provided the opportunity for considerable learning, and stakeholders identified several aspects of the project that they, or those setting up similar projects in future, might organise differently. One suggestion was to engage with the Dementia Advisors more fully and earlier in the process to explore any concerns about their role and workload in relation to the project and the evaluation:

> *I certainly think that was the main issue around this. The two things really, increased workload and not considering that, and also not involving the Dementia Advisors earlier on, in the scheme of things. And that's for us to learn, that's a learning curve for us, really.*
>
> *Having thought about it, I was like, yeah, why didn't we invite them to a couple of pre-meetings, this is what we're thinking, how do you think that's going to work for you on the ground, really?*

This could lead to the provision of any additional support that might be required, such as the Trusted Assessor Training. Another idea was to use a small number of specialist assessors, rather than add the task to the existing workload of the Dementia Advisors:

> *They could absolutely then, dovetail referrals into other support, like the Dementia Advice Service, or any other services that are needed. And that would be part of their remit to be able to do that true person centred assessment of need, and signpost and referral. So, they would also be able to, the minor equipment like the clocks and the lamps, they'd have those, and be able to fit those immediately, you know, be able to do that.*

Interviewees also offered ideas for how the DDG could be enhanced in future. These included adding some forms of assistive technology to the items on offer, and offering recipients other forms of support:

> *Yes, we've got the aids and adaptations, but sometimes the person or the family, or the carer, don't need a physical thing, they need some support or emotional support. And for me, that is, we take it for granted that we can go outside on a beautiful day like this, but there might be someone at home, with dementia, who would love to go out for a walk, but their wife or whoever, might be at work, might be looking after the children, probably exhausted, doesn't want to do it. If they had a support worker to meet them, and take them out for a walk, once or twice a week, they would probably reap huge benefits from that I think.*

Conclusion

The stakeholders interviewed shared a strong belief that the pilot project had been successful and effective. They identified benefits across three main areas: promoting independence and quality of life for people with dementia and their family carers; increasing the skills and confidence of professionals involved in the project; and strengthening partnerships between the collaborating organisations.

Three factors were thought to be key to the success of the pilot: the ability to change what aids and adaptations were provided, in response to individual’s requirements; the fact that the grants were not means-tested; and the incorporation of the scheme within the existing Dementia Advice Service. However, this was also the source of the main challenge to the programme, which centred on the concerns of staff regarding the additional workload that it brought. This theme followed through to the improvements to the project that were suggested, which included better engagement with and support for staff who were tasked with delivering the project on the ground. Other suggestions focused on enhancing the grant by offering items based on assistive technology, emotional support and help with getting outdoors.

Appendix Four: DDG Assessment form and aids/adaptations list

Client information - demographics

<table>
<tr>
<td>Date of birth</td>
<td>Gender
Male ☐
Female ☐</td>
<td colspan="2">Marital status
Married ☐ Single ☐ Divorced ☐
Widowed ☐ Co-habiting ☐ Other:</td>
</tr>
<tr>
<td colspan="2" rowspan="3">Ethnicity
White: British ☐ Irish ☐ Other ☐
Mixed: White & Black Caribbean ☐
White & Black African ☐
White & Asian ☐ Other ☐
Asian/Asian British: Indian ☐ Pakistani ☐
Bangladeshi ☐ Other ☐
Black/Black British: Caribbean ☐ African ☐
Other ☐
Chinese ☐ Gypsy/Romany ☐
Traveller ☐ Other ethnic background ☐
Prefer not to say ☐</td>
<td colspan="2">Employment status
Full-time ☐ Part-time ☐
Unemployed ☐ Retired ☐</td>
</tr>
<tr>
<td colspan="2">Current/previous occupation</td>
</tr>
<tr>
<td colspan="2">Geographical area/location</td>
</tr>
<tr>
<td colspan="2">Referral source
EIDS ☐ GP ☐
CMHT ☐ Other:</td>
<td>Referral date to Age UK</td>
<td>Assessment date</td>
</tr>
</table>

Dementia Dwelling Grant (DDG)

Was the DDG offered to the customer?	Yes ☐ No ☐	If it was not offered, please give a reason:
Did the customer accept the offer of the DDG?	Yes ☐ No ☐	If it was not accepted, please give a reason:

Consent to inclusion in the evaluation

Has the customer given their consent participate in the evaluation?	Yes ☐ No ☐

Care

Does the customer have a carer?	Yes ☐ No ☐	Partner/spouse ☐ Son/daughter ☐ Neighbour/friend ☐ Other:	
Do they live with the customer?	Yes ☐ No ☐	Was the carer present during the assessment?	Yes ☐ No ☐
Is the carer paid or unpaid? (If there is more than one carer, please tick all options that apply)	Paid ☐ Unpaid ☐	If the carer is paid, are they paid for by the statutory services or by the customer/family?	Statutory provision ☐ Private provision ☐
Please give details of provider and provision (e.g. number of hours/days per week) for each paid carer:			
Has the customer been assessed for eligibility under the Care Act?	Yes ☐ No ☐ Unknown ☐	If yes, please give date and outcome of the assessment (e.g. eligible or ineligible):	
Is the customer currently in receipt of publicly funded care and support from statutory services?	Yes ☐ No ☐	Details:	

Health status

Dementia diagnosis	Alzheimer's disease ☐ Vascular dementia ☐ Dementia with Lewy bodies ☐ Frontotemporal dementia ☐ Other:
Date of diagnosis	
Any other long term health conditions or disabilities	Details:

Housing situation

Property type House ☐ Flat ☐ Bungalow ☐ Cottage ☐ Other:	Number of bedrooms
Tenure Owner-occupier ☐ Private tenant ☐ Housing association ☐ Local authority ☐	Living arrangement Lives alone ☐ With partner/spouse ☐ With relative ☐ With an other ☐

Grants and benefits

In receipt of other grants and/or benefits (e.g. AA, Council Tax, SAFFA etc.)	Yes ☐ No ☐ Unknown ☐	Details:
Eligible for other grants and/or benefits	Yes ☐ No ☐ Unknown ☐	Details:

Previous grants, assessments and services

Has the customer previously had an OT assessment for	Yes ☐	Date:

minor DFG aids and adaptations?	No ☐ Unknown ☐	
Has the customer had any **minor** aids and adaptations (e.g. handrails)?	Yes ☐ No ☐ Unknown ☐	Details:
How were these paid for?	Statutory provision ☐ Private provision ☐	Details:
Has the customer had any **major** aids and adaptations (e.g. lift, additional bathroom)?	Yes ☐ No ☐ Unknown ☐	Details:
How were these paid for?	Statutory provision ☐ Private provision ☐	Details:

Assessment for Dementia Dwelling Grant – Requirements for aids and adaptations

DDG general aids and adaptations (from stock)

Around the home	Required Yes/No	Number required	Fitting required Yes/No	Date provided	Comments
High lumens light bulbs					
Coloured sticky covers for light switch plates					
Socket covers					
Coloured strips to indicate edges of stairs					
Key locators					
BIME Wander Reminder					
Coloured key fobs					
Key safe					
Signage					
Sticky labels for drawers, cupboards etc.					
Notice board/white board					
Big button telephone					
Dementia Clock					
Magiplug (for all sinks)					
Raised blue and red stickers for taps					

Child locks for cupboard doors					
Additional shelving					

Kitchen	**Required Yes/No**	**Number required**	**Fitting required Yes/No**	**Date provided**	**Comments**
Innohome Stove Alarm					
Bedroom					
Touch bedside light					
Day/night clock					
Bathroom					
Bathroom slip mat					
Red toilet seat					
Red towel rail					
External area					
Garden seating					
Shelter from sun/rain					
Front door furniture to aid with identification (or painting of front door)					
Bespoke items					
Carpet strips (need to match existing flooring)					

Available via minor aids and adaptations grants (via OT referral)

	Adaptations required Yes/No	Date referred to OT for assessment (if required)
Handrails and stair rails, raised toilet seat, red grab rail in bathroom, grab rails for front or back door, repairs to paths or front or back doors to ensure safety		

Available via Age UK winter grants

	Fitting required Yes/No	Date provided	Action taken and date referred
Automatic LED night lights (maximum 2)			

Items available from other sources

	Fitting required Yes/No	Action taken and date referred
Adapted furniture and fittings to assist with mobility		
Any medical aids e.g. medication aides or pill dispensers (refer to dispensing pharmacist)		
Smoke detectors (refer to fire service)		
SGN cooker valve (refer to supplier)		
External door locks (refer to community safety)		

Items not available via the DDG or other sources

Assessors to discuss need with customer/family member and give advice or refer to other agency where appropriate. In specific circumstances additional funding may be available	**Advice given Yes/No**	**Comments**
Additional task lighting		
Maximising natural light		
Reducing glare and reflections		
Darkening the bedroom at night		
Items to support family carers		
Clear, non-reflective, fronts for cupboards		
Covers for mirrors		
Kitchen		
Coloured crockery and glasses		
Clear containers for foodstuffs		
Plain, block coloured tablecloths and towels		
Bathroom		
Plain, block coloured towels and toilet rolls		
External areas		
Garden improvements e.g. raised beds, bird table (could refer to local gardening club if known)		

Any other information or additional notes – please continue on a separate sheet if necessary