



Resource allocation in dementia care: comparing the views of people with dementia, carers and health and social care professionals under constrained and unconstrained budget scenarios

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Case Type Development

Case types were developed using the approach adopted by (Challis et al., 2014). As is the case in many jurisdictions, there is no single data set available in Ireland with all the required variables to generate case types, so data from several sources were combined. The case types were developed mainly from an Irish data set of anonymised home care assessments of 277 people with dementia in an urban area (O'Brien et al., 2017). Four variables were used to generate the initial dementia case types: dependency measured by the Barthel Index, falls risk, living alone, communication difficulty (See Table 1). A set of dementia case types with all the possible combinations of the four variables was firstly generated, resulting in 24 case types. A sub-set of six case types, comprising 46 per cent of the dementia case types in the dataset was then selected for the study. The level of cognitive impairment for the case types was derived using a dataset of anonymised InterRai assessments (HSE, 2017) for 453 inpatients over 65 some of whom had been diagnosed with dementia. Further discriminating variables were sourced from the literature, specifically Behavioural and Psychological Symptoms of Dementia (BPSD) and Comorbidities. In previous balance of care studies, the attitudes to care mainly focused on attitudes to nursing home care (Tucker et al., 2016). However, in this study as the research question is more focused on the continuum of care, attitudes to care cover preferences in relation to spending, privacy, day-care attendance, carer preferences and attitudes to nursing home care.

Unit Costs

Unit costs for these services were calculated based on Irish Health Service Executive staff pay scales and the Irish literature on unit costs (O'Shea & Monaghan 2016). The full service cost, including voluntary, public and private funding, was used irrespective of the funding source, so that service prioritisation could be compared on a like for like basis. The full cost of a Psychiatry of Old Age referral and a carer education programme were included in the budget allocation for the hypothetical month, although in practice this cost may be spread over a longer period.

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Resource allocation in dementia care: comparing the views of people with dementia, carers and health and social care professionals under constrained and unconstrained budget scenarios

For Peer Review Only

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Background: People with dementia and their carers have a wide range of health and social care needs. People with dementia, carers and health and social care professionals (HSCPs) all have different perspectives on dementia care. Differences among these groups are important for commissioners of services and for front line HSCPs.

Objective: To compare the service recommendations of people with dementia and carers with those of HSCPs, under different budgetary conditions.

Methods: A mixed methods approach, which builds on the Balance of Care method, was used. Nine workshops were held with 41 participants from three groups: people with dementia, carers, and HSCPs. Participants were asked to make decisions on a set of services for case types of dementia under two scenarios: a no budget constraint (NBC) scenario and a budget constraint (BC) scenario.

Results: While each group allocated resources in broadly similar overall proportions, important differences in emphasis emerged: i) people with dementia and carers placed more emphasis on psychosocial supports than HSCPs; ii) carers put more emphasis on respite opportunities for carers; and iii) carers identified residential care as the most suitable setting for the person with dementia more frequently than health care professionals.

Conclusion: Our findings suggest that the importance of psychosocial interventions, including counselling and peer support programmes, are currently under-estimated by HSCPs. The provision of in-home respite is highly valued by carers. Even with unconstrained resources, some carers do not judge home care to be a viable option for dementia case types with high level care needs.

Keywords: Dementia, Balance of Care, Budget Experiment

Introduction

People with dementia and their carers have a wide range of health and social needs, including the need for help with personal care, home support, daytime activities and company (Van der Roest et al., 2009). Previous studies have identified that people with dementia, their informal carers and health and social care professionals (HSCPs) tend to emphasise different health and social needs (Cohen-Mansfield & Frank, 2008; Miranda-Castillo et al., 2013; Van der Roest et al., 2009). HSCPs tend to give more emphasis to clinical needs; carers focus more on support with daily activities; and people with dementia focus more on social isolation (Schulmann et al., 2017). Many people with dementia, and their carers, can identify their own objective and subjective needs (McCabe et al., 2016; von Kutzleben et al., 2012). In addition, health and social care professionals, through clinical experience and discipline expertise, may be well placed to identify the needs that their service can address.

In Ireland, as in many other countries, families provide the bulk of care for people with dementia, with public and private service providers playing a supporting role (O'Shea et al., 2017). The needs of people with dementia and their family carers can sometimes be difficult to disentangle (Keogh, Pierse, O'Shea, et al., 2020). Addressing the needs of the person with dementia will frequently also benefit their carer. Similarly, supporting the carer is likely to benefit the person with dementia (Thorpe et al., 2009). Therefore, the needs of both have to be considered separately and jointly to maximise benefits for both and ensure the most effective use of resources (Bunn et al., 2016; Quinn et al., 2013).

In Ireland, the processes through which resources are allocated for community services for people with dementia are complex, with separate administrations and separate budgets for key services (Keogh, Pierse, & O'Shea, 2020). HSCPs play an important role in the resource allocation process in a number of ways. HSCPs are central in the staffing and resourcing of services and in the prioritisation process. For example, public health nurses

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2
3 play a key role in the assessment of need for home support hours. In addition, front line
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5 HSCPs play an important role by referring clients to various services (e.g. day care,
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7 occupational therapy, physiotherapy, social prescribing) which generates a demand for those
8
9 services. Because of the central role of HSCPs in the resource allocation process, it is
10
11 important that managers and frontline HSCPs are prioritising needs and services in a way that
12
13 reflects the experiences and needs of people with dementia and carers. However, one of the
14
15 criticisms of current policy is that the system is primarily supply-driven, with most of the key
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17 decisions made by practitioners, with little or no input from people with dementia or family
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19 carers (O'Shea et al., 2017).
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24 The point when people with dementia move into residential care is a critical juncture,
25
26 both from a social and economic perspective (Wübker et al., 2014). Not surprisingly, there
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28 are different views among stakeholders on who should be admitted to residential care and at
29
30 what point along the dementia continuum (Saks et al., 2015; Tucker et al., 2016). Carers play
31
32 a critical role in the decision to access residential care; residential care placement is typically
33
34 initiated by families and moderated by access to public funding. In the absence of extensive
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36 support from a family carer, it is unlikely that a person with dementia with high care needs
37
38 can continue living at home (Keogh et al., 2018; McCabe et al., 2016).
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42 Budgets are an important consideration in comparing the resource allocation decision-
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44 making of people with dementia, carers and HSCPs. Decisions are likely to be different in the
45
46 presence and absence of budget constraints. Previous research has shown differences in
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48 service recommendations between carers of people with dementia and HSCPs when they
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50 have been asked to make decisions in the absence of any budget constraints (Giebel et al.,
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52 2016). Decision-making in the absence of budget constraints, highlights the potential latent
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54 demand for services that exist when people do not have to worry about costs or budgets
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56 (Keogh, Pierse, O'Shea, et al., 2020); participants have the scope to think about a wide
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3 variety of services, including psychosocial provision, that they may not have ever
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5 experienced due to their unavailability within local geographic areas. However, it is equally
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7 important to identify how services are prioritised by different stakeholders when there are
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9 budget constraints, because that is the reality, most of the time, in the vast majority of
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11 countries.
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15 In this study, we seek to identify differences among people with dementia, carers and
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17 HSCPs on what constitutes optimum care for a range of dementia case types in two scenarios:
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19 when there are no budget constraints (NBC); and when there are budget constraints (BC).
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21 The study also seeks to identify differences among the three groups on the most appropriate
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23 setting for people with dementia with different needs and with different levels of family
24
25 support. Differences in the needs that are identified, and how these are prioritised among
26
27 these three groups, are important to consider for various levels of decision making (Plochg &
28
29 Klazinga, 2002); so too is understanding variation in preferences for different kinds of
30
31 services to respond to those needs. At policy and organisational levels, differences among the
32
33 three groups may result in a misallocation of resources across dementia services - if HSCPs
34
35 underestimate the need for a particular service this may lead to the under resourcing of that
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37 service.
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43 This study builds on previous Balance of Care (BoC) studies in a number of ways
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45 (Tucker et al., 2013; Tucker et al., 2008). First, the notional budgeting exercise considered in
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47 this paper engages all key stakeholders in the decision-making process. Participants are asked
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49 to recommend a set of services with and without a budget constraint; this allows for priority
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51 services and needs to be identified under different fiscal constraints. Secondly, a mixed
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53 methods design is used to tease out the decision-making process; the quantitative element
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55 identifies the type and quantity of service that is prioritised while the qualitative element
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3 provides context and greater understanding as to why some services are prioritised over
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5 others.
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8 9 **Methods**

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11 An explanatory sequential design was used with qualitative phases following on from
12 quantitative phases as shown in Figure 1 (Fetters & Freshwater, 2015). A nominal group
13 method (NGM) was used within an overall BoC methodology to capture both quantitative
14 and qualitative data. The findings reported here are part of a larger study and further detail on
15 the qualitative methods and findings are available in Keogh, Pierse, O'Shea, et al. (2020).
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23 [Figure 1 about here]
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27 **Participants**

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29 There were three groups of study participants who each attended separate workshops:
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31 (i) people with dementia (n=4), (ii) current and former carers (n=13), and (iii) twenty four
32 HSCPs. These comprised of: public health nurses (n=6), social workers (n=3), occupational
33 therapists (OT) (n=2), physiotherapists (n=1), speech and language therapists (SLT) (n=1),
34 dieticians (n=1), psychologists (n=1), mental health nurses (n=2), home care coordinators
35 (n=4); and older person's service managers (n=3).
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43 The people with dementia and carers who participated in the study were recruited
44 though working groups organised by the Alzheimer Society of Ireland (ASI). Four members
45 of the ASI Irish Dementia Working Group, two men and two women, from different parts of
46 the country, at different stages of dementia, with a mix of younger and late onset dementia,
47 participated in the study. Given the complexity of the exercise we decided to hold two
48 workshops for dementia participants, with two people in each. Two groups of current and
49 former carers from the ASI Dementia Carers Campaign Network (DCCN) participated in
50 workshops in different parts of the country. HSCPs were recruited through senior managers
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3 who had responsibility for older persons services in four regional health organisations. The
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5 latter were asked to identify HSCPs from a range of disciplines who had direct experience of
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7 working with people with dementia or who had some role in the allocation of services and
8
9 supports to people with dementia living at home. Participants were recruited from different
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11 therapeutic backgrounds, experience and location to give as much variety to the decision-
12
13 making process as possible.
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16 17 18 *Case Type Development*

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21 The development of the dementia case types has been previously reported in (Keogh, Pierse,
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23 O'Shea, et al., 2020), for further details see the Supplementary Material file supplied with this
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25 paper. In summary, six case types were developed mainly from an Irish data set of home care
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27 assessments of 277 people with dementia (O'Brien et al., 2017). Four variables were used to
28
29 generate the initial dementia case types: dependency as measured by the Barthel Index; falls
30
31 risk; living alone; and communication difficulty (See Table 1). Additional variables for the
32
33 case types were derived using a dataset of InterRai assessments (HSE, 2017). Further
34
35 discriminating variables were sourced from the literature, specifically Behavioural and
36
37 Psychological Symptoms of Dementia (BPSD) and Comorbidities. Attitudes to care were
38
39 included to cover preferences in relation to spending, privacy, day-care attendance, carer
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41 preferences and attitudes to nursing home care. The case type vignettes were developed in
42
43 consultation with two people with dementia and two carers as part of public patient
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45 involvement (PPI) in the study. A person with dementia was also a member of the Oversight
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47 Group for this study.
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55 *Services*

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57 The service list provided to participants was informed by a mapping study of
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59 dementia-specific services in Ireland carried out in 2018 (ASI & NDO, 2017). There was
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3 also PPI involvement in the development and appraisal of the service list. In total, twenty
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5 community-based services and supports were included on the list presented to participants.
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7 Although all of the services are available in some parts of Ireland, many are not universally
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9 available. A concise description of the listed services was provided to participants to ensure
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11 that they were fully aware of their potential role in addressing need among the dementia case
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13 types developed for this study.
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16 17 18 *Vignettes presented to participants*

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20 The key characteristics of each case type were incorporated into vignettes to lend
21
22 realism to the study and to help participants consider the needs of each case type in allocating
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24 services (See Table 1). Six vignettes were presented to the HSCPs (case types 1-6). Three
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26 vignettes were presented to the carers (Case Types 2, 4 and 5). One vignette was presented to
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28 the people with dementia (Case Type 2). A smaller number of vignettes was presented to the
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30 groups of carers and people with dementia to reduce the complexity of the exercise for these
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32 stakeholders and to ensure that the exercise could be completed in a reasonable time to avoid
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34 over-burdening participants.
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39 [Table 1 about here]
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42 43 *HSCP Workshops*

44 Five resource allocation workshops were run with HSCPs. Each workshop participant
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46 was given a computer with a spread sheet workbook pre-loaded. The workbook showed the
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48 list of services that could be allocated for each vignette. Unit costs were embedded in the
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50 workbook, but were hidden initially. The first exercise was the no budget constraint (NBC)
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52 scenario. Participants were asked to read each vignette and allocate the amount of each
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54 service that would be of most benefit to the person with dementia and carer in each vignette.
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56 Each participant was then asked to discuss their decision-making in relation to one vignette;
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3 they were prompted to focus on the needs they were trying to address and the rationale for
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5 their choice of services to meet those needs.
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8 The second exercise involved decision-making under a budget constraint (BC)
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10 scenario. The cost of the services allocated for each case type was revealed and participants
11
12 were instructed to do the same exercise but to work within an overall budget for all six case
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14 types for one month of care. This exercise was followed by discussion on what services
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16 participants cut in order to meet the budget constraint, and why, with an emphasis on
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18 articulating their decision-making process.
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22 For the second exercise, participants were initially instructed to work within an
23
24 overall budget constraint of €7,000 to provide care for all six dementia case types for one
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26 month of care. This level was set with reference to the initial pilot and data from a recent
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28 national audit of services used by people with dementia in Ireland (Keogh, Pierse, & O'Shea,
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30 2020). Although participants in the first four HSCP workshops felt that this level of
31
32 expenditure approximately reflected the current availability of resources, many found it
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34 difficult to stay within this constraint and tended to 'overspend'. It was not feasible to enforce
35
36 the constraint rigidly in the first four HSCP workshops and the average budget expanded to
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38 €8,928, 28% above the initial constraint. For the final workshop, the budget was increased to
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40 €10,000 per month across the six dementia case types to explore whether a more relaxed
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42 constraint made the exercise easier for participants to complete.
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48 ***Carer Workshops***

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50 Two resource allocation workshops were run with carers. In both carer workshops,
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52 three case types (Case Types 2, 4 and 5) were presented for the NBC exercise and
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54 participants were asked to recommend a set of services. In the first carer workshop, carers
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56 were not asked to complete the spread sheet exercise in the BC scenario for any of the three
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58 case types. Instead, a discussion took place on service priorities and a consensus emerged on
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3 provision, but without formal consideration of a fixed budget value. However, it was noted
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5 by one participant that it was very difficult to prioritise services without addressing the
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7 question of costs and budget constraints in the deliberation process. Therefore, in the second
8
9 workshop, one case type (Case Type 2) was given a specific monthly budget constraint of
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11 €1,500, based on the allocation derived from HSCP's consideration of this case type under
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13 BC rules.
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17 [Box 1: Vignette 2 Here]
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20 21 *People with dementia workshops*

22 Two workshops were held with people with dementia, each with two participants and
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24 two researchers (TP and FK) and only one dementia case type was considered. In the first
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26 workshop, Case Type 2 was presented to the two participants along with the list of services.
27
28 Each service was discussed in terms of the participants own direct experience, or knowledge
29
30 of the service if they had not used it. The exercise was then completed for this vignette as per
31
32 the format above for HSCPs; each participant indicated a recommended set of services firstly
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34 with NBC and secondly with a BC of €1,500 for the case for one month. For the second
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36 group of participants with dementia, the vignette was found to be distracting for the
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38 participants and the format was changed to a one-to-one discussion with each researcher,
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40 focusing on the services in terms of what they found helpful and what they would prioritise.
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46 47 *Qualitative Data Analysis*

48 All recordings from the nine workshops (including two pilots with HSCPs) were
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50 transcribed and data was managed using NVIVO software (v.12). A thematic framework was
51
52 developed to summarise the themes and main categories and to show how these related to
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54 each other. In this article, qualitative findings are used to provide nuance and support or
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56 qualification to the qualitative results. A more detailed description of the qualitative methods
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3 and thematic analysis of the HSCP qualitative data are reported in Keogh, Pierse, O'Shea, et
4 al. (2020).
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9 ***Quantitative Data Analysis***

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11 The data from seven workshops was compiled from the spread sheet workbooks;
12 quantitative data from the **two pilots** was not included as the number of vignettes differed. In
13 total, quantitative data from 17 HSCPs, 13 carers and 3 people with dementia was included in
14 the analysis. The type and amount of services which were allocated for each case type for
15 both the NBC and the BC scenarios were compiled. For the BC scenario, all participant
16 information was included irrespective of whether the person achieved the target budget level.
17 In situations where an individual recommended nursing home placement, this observation
18 was not included as a denominator in the averaging of community service costs.
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31 **Results**

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33 Table 2 shows the average spending on each service by people with dementia and carers
34 relative to HSCPs in the NBC scenario. In Section A of Table 2 the service recommendations
35 of HSCPs are compared with the recommendations of carers and people with dementia.
36 These are shown for Case Type 2 only, as this is the case type that all three groups examined.
37 For this case type, with NBC, people with dementia and carers recommended spending 1.1
38 and 1.4 times more respectively than HSCPs. Both carers and people with dementia spent
39 more on counselling for carers, Alzheimer's cafés, dementia social clubs and dementia
40 friendly activities than HSCPs. The peer support, which can be provided in normal social
41 venues, was emphasised by the participants with dementia, particularly for people at an early
42 stage of dementia.
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3 *I see people's lives turn around in a heartbeat when they get to sit with somebody else*
4 *[with dementia]. And, you know, it's not all doom and gloom, you take the Michael*
5 *and you laugh as much as you can. We've got to keep reaching out to people who*
6 *have been diagnosed and being there for each other because, because we just need to.*

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12 **(Person with dementia, group D1)**
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16 The people with dementia did not recommend cognitive therapies for Case Type 2
17 due to the age of the case (79 years). Carers spent slightly less on home care and substantially
18 more on all forms of respite – day care, nursing home based respite and in home respite. The
19 qualitative discussion revealed their rationale:
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28 *“just to give them a break and the minimum you'd want is two hours, even if you just*
29 *want to go to the shop or go to the dentist or get your hair done or something like*
30 *that.” (Carer, group C2)*
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37 Case Type 2, shown in the box, contained information that the person with dementia
38 did not want to attend day care. Many participants were influenced by knowledge of this
39 preference and none of the people with dementia allocated this service. However, a small
40 number of HSCPs and carers did recommend the day care service for this case type. Some
41 carers were conflicted in their recommendations, based on their own experiences. One carer
42 described this situation as:
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52 *My mum dislikes day-care profoundly, but she will go one day a week because it gives*
53 *me a break and because there's a physio available there who is willing to work with*
54 *someone with advanced Parkinson's... But there is no stimulation, there's no chat,*
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3 *there's no engagement from the dementia side of things for her. She doesn't gain that*
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5 *there. (Carer, group C1)*
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10 Meals-on-wheels was recommended much more by carers and people with dementia
11 than HSCPs. A participant with dementia described how even the brief interaction as meals
12 are dropped off may be an important form of social engagement, particularly for those living
13 alone.
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18 All groups allocated a similar number of visits from community health professionals.
19 However, one participant pointed towards the importance of the quality of interaction with
20 people with dementia and the need to really engage with the person.
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27 *it screams out at me that nobody is listening to him. So whichever one of these people*
28 *has time to sit down and listen to him, whether it's the home help, the public nurse or*
29 *probably the dementia advisor. (Person with dementia. group D1)*
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36 A high volume of services may not be beneficial if they are not connecting with individual
37 needs.
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41 Section B of Table 2 shows the comparison of HSCPs and carers recommendations
42 for three case types (Case Types 2, 4 and 5). As the people with dementia reviewed only one
43 case type they are not included in this comparison. Overall, carers recommended spending
44 1.4 times more than HSCPs on these three cases under the NBC scenario. With the exception
45 of visits from HSCPs, carers recommended spending more on all of the service categories.
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47 Within the category of support in the home, carers recommended spending slightly less on
48 home care (0.9 times) and more on in-home respite (2.0 times).
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57 [Table 2 about here]
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3 The total and sub-totals in Table 3 shows the average expenditure by people with
4 dementia and carers on each service category for the BC scenario, relative to HSCPs. The
5 proportion of expenditure on each service or category is also shown to identify the scale of
6 each service. Overall, a similar proportion of resources were allocated for each category of
7 service by the three cohorts. For example, both groups spent between 53 and 60 per cent of
8 expenditure on the Supports in the Home category. The maximum difference between the
9 groups in the amount spent on any service category was 7 per cent.

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11
12 However, there are some important differences in emphasis between the three groups.
13 Relative to HSCPs, people with dementia and carers allocated a higher level of resources to
14 supports in the home. Within this category, the carers focused substantially more resources
15 on in-home-respite - 31 per cent of funding compared to 11 per cent and 4 per cent by HSCPs
16 and the people with dementia groups. The potential for substitution between home support
17 services in some situations is described by a carer:

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33 *I took away the home help and used the in-home respite and cut back on the dementia*
34 *advisors visits and the respite – the nursing home respite, brought it down to two*
35 *weeks – I'm still over budget. (Carer, group C1)*

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People with dementia and carers spent more on psychosocial supports (excluding
Dementia Cognitive Therapies). People with dementia and, in particular, carers, spent
substantially more on counselling services than HSCPs. However, it was noted by carers that
it could be difficult for carers to justify the time away from caring to go to counselling, which
links in with the need for in-home respite. The main area where people with dementia and
carers spent less than HSCPs was on cognitive therapies and Psychiatry of Old Age Services
respectively.

[Table 3 about here]

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3 Nursing home placement was included as an option for all case types. Table 4 shows
4 the choices that HSCPs and carers made under the NBC scenario. For all three case types,
5 carers more frequently identify long term care as the most suitable care setting, particularly
6 for Case Types 4 and 5. For Case Type 5, the case with the highest level of needs, 27 per cent
7 of HSCPs recommended nursing home placement compared to 62 per cent of carers. No
8 participants with dementia recommended nursing home placement for Case Type 2.
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21 Discussion

22 Our study compares how HSCPs, carers and people with dementia allocate resources in the
23 presence and absence of budget constraints. There are very few studies that have compared
24 the perspectives of all three of these groups in an integrated manner (Miranda-Castillo et al.,
25 2013). Moreover, including a budget constraint allows for the differences in priorities
26 between the different groups to be compared when difficult choices have to be made, thus
27 building on previous BoC studies which compared the recommendations of HSCPs and
28 carers in the absence of a budget constraint (Giebel et al., 2016). Our study also holds up a
29 mirror to the decision-making process, providing insight into how stakeholders think about
30 choosing one service over another and in what circumstances. Currently, health and social
31 care planners often make decisions about service provision without a transparent system for
32 allocating resources, especially one that takes explicit account of the views of key
33 stakeholders (Airoldi & Morton, 2011; Merlo et al., 2015).
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50 In Ireland, people with dementia and carers are not involved in decision making
51 around resource allocation and their priorities in relation to a broad menu of service types are
52 not typically sought (Donnelly et al., 2019). This exercise points to the potential and
53 implications of greater consultation with people with dementia and their carers in relation to
54 priority-setting in dementia care. Both groups demonstrated an appreciation of the merits of
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3 various services and supports in addressing specific dementia needs and an awareness of
4 budgets and budget constraints. The overall amount/proportion of resources allocated to
5 different services was broadly similar across the three decision-making cohorts - the
6 maximum difference among them in the amount spent on any service category was 7 per
7 cent. This is important new information indicating that the needs of people with dementia are
8 broadly interpreted correctly by HSCPs, but there are important differences in emphasis.
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17 One area where there are substantial differences is in the provision of in-home respite,
18 with carers putting more resources into this service than HSCPs or people with dementia. In
19 common with many other European countries, services to support carers, such as in-home
20 respite, are not well developed in Ireland (Keogh, Pierse, & O'Shea, 2020; Spasova et al.,
21 2018). While previous studies have shown that in-home respite for people with dementia is a
22 cost effective service (Vandepitte et al., 2020), this study reinforces the value placed on the
23 service by family carers. A recent systematic qualitative review on respite care reported
24 some divergence in stakeholder perspectives around the barriers to implementation of new
25 models of person-centred respite care (O'Shea et al., 2017). Organizational tension was
26 evident among frontline staff and management in respite services, hindering the cultural
27 change necessary to facilitate service development in line with the expressed needs and
28 preferences of people with dementia and their carers.
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45 Another area of difference among the three cohorts was the attention given to
46 psychosocial supports. While many studies have focused on normative (usually professional-
47 identified) needs (e.g. difficulties undertaking ADLs), our work suggests that more attention
48 should be given to incorporating clients' felt and experienced needs, including preferences
49 for social and psychological support (Clarkson et al., 2017). People with dementia and carers
50 highlighted the importance of psychosocial supports, allocating them more often than HSCPs.
51 In addition, Turjamaa et al. (2014) advocate that home care services must take greater
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3 account of the significance of the individual's psychosocial needs, such as social contact and
4 meaningful activities. Similarly, Hansen et al. (2017) highlight the importance of meeting the
5 psychosocial needs of people with dementia and carers living in the community, recognising
6 the existence of different perceptions and practices among providers.
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12 Peer to peer support for people with dementia at the early stages of dementia was
13 emphasised by participants, particularly the people with dementia themselves. This peer to
14 peer support can be provided in a range of ways, such as one-to-one or support groups and
15 has different functions, such as sharing coping mechanisms and reducing social isolation
16 (Keyes et al., 2016). Counselling services were also referenced more often by people with
17 dementia and carers than by HSCPs, a finding that reflects the international evidence on the
18 role and importance of psychological interventions, especially for the carers of people with
19 dementia (Elvish et al., 2013). These differences are also consistent with the heuristics
20 identified in the detailed qualitative analysis of the decision-making process, whereby HSCPs
21 reluctantly focused more on supporting the physical care needs of the person with dementia
22 and placed less emphasis on psychosocial supports in conditions of constrained resources
23 (Keogh, Pierse, O'Shea, et al., 2020).
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40 Day care was recommended more by carers than by HSCPs. The contribution of day
41 care to the well-being of carers may be under-appreciated (Orellana et al., 2018). In England,
42 the development of personal budgets for care has led to inadequate attention to congregate
43 services, such as day care, and a reduction in provision (ADASS, 2011; Needham, 2013).
44 There is sometimes a divergence between the needs and preferences of the carer and the
45 person with dementia in relation to day care. While a carer might need a break, people with
46 dementia are frequently reluctant to use the service (Rokstad et al., 2017). In such situations,
47 HSCPs often play a balancing role (Quinn et al., 2013), seeking to adjudicate on relative need
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3 and advocating for the needs of the person with dementia whose needs are not being fully
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8 Family carers play a critical role in supporting people with dementia to remain living
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10 at home in all European countries (Spasova et al., 2018). Many studies have shown that carer
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12 stress is associated with admission to residential care (Eska et al., 2013; Paulson &
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14 Lichtenberg, 2011). Previous BoC studies have shown that HSCPs are strongly influenced in
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16 long term care placement by the preferences of family carers (Tucker et al., 2016). Our study
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18 shows that even when extensive community-based support was provided, as under the NBC
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20 scenario, the majority of carer participants were of the view that the case type with the
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22 highest care needs (Case Type 5), should be in residential care. In this situation, the needs
23
24 and preferences of the person with dementia may sometimes diverge from the needs and
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26 preferences of their carer. Sometimes, the provision of additional resources to keep very
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28 dependent older people with dementia living at home may lead to high co-ordination and
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30 integration costs for care recipients and their families. The involvement of multiple health
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32 and social service providers can make coordinated communication challenging and costly
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34 (Tan et al., 2014).
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41 *Strengths and Limitations*

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43 In this study a framework is provided for identifying differences in service priorities
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45 among people with dementia, carers and HSCPs. Key strengths of this study are the
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47 involvement of key stakeholders, the provision of a wide array of services that participants
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49 could choose from, the inclusion of a realistic budget constraint and the mixed methods
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51 design. A limitation of the study is its exploratory nature and the relatively small number of
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53 participants, particularly people with dementia. While this limits the generalisability of our
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55 findings, our results point towards differences in emphasis among the groups in relation to
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57 resource allocation, including decision-making on residential care placement.
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Conclusion

People with dementia, carers and HSCPs all have an important role in influencing how dementia care is delivered, in both a positive and normative sense. In this paper, we have shown that the key stakeholders are able to grapple with complex decision-making in the presence and absence of budget constraints. The results highlight differences among the three groups in relation to service provision for different dementia case types, including placement decision-making. This allows us to identify elements of provision that may not be receiving sufficient attention from health and social care providers at the moment. Taking account the views of people with dementia and carers is of particular importance, given the very limited funding that is currently available for community services in Ireland. It is important that their voice is more prominent in resource allocation decision-making in the future.

For the commissioners of services and supports in the home, this study demonstrates that the provision of in-home respite and psychosocial care, such as social clubs and activities for people with dementia and counselling for carers, are important to people with dementia and carers. HSCPs should be more conscious of directing people with dementia and their carers towards peer and social supports in their day to day practice. This study also shows that increasing resources to the home care sector may not always be enough to allow people with dementia to remain living at home. If carers believe that it is not viable for them to continue to support the person with dementia living at home, then increasing resources may not always succeed in delaying admission to long term residential care.

Ethics

Ethical approval for the study was provided by the [removed for blind review]. Information sheets were given to all participants in advance of the workshops and again at the venue (the study was conducted pre-Covid), with opportunities to ask questions at all stages of the

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3 process. Signed consent was obtained from all participants.
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6 7 **Funding Details** 8

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10 [removed for blind review]
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13 14 **Disclosure statement** 15

16 The authors have no conflicts of interest.
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19 20 **Data availability statement** 21

22 The data that support the findings of this study are available from the corresponding author,
23 TP, upon reasonable request.
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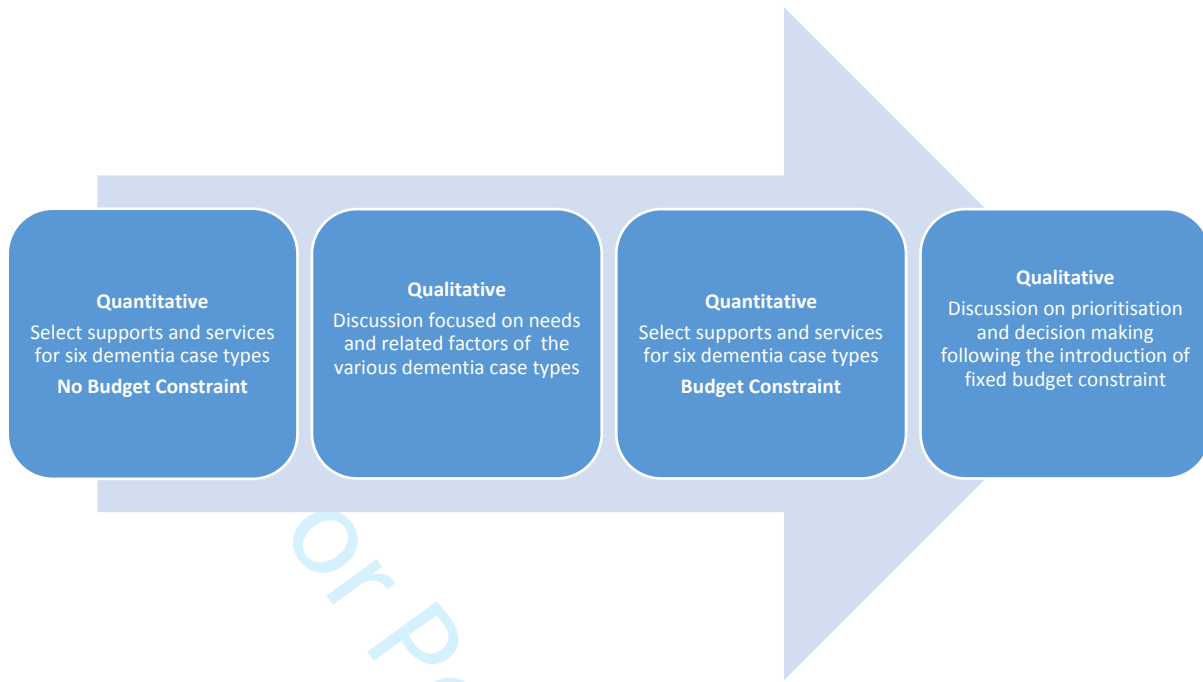


Fig. 1 Research Design

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Table 1: Variables and data sets used in the development of the case types

Assessments for home care service for people with dementia (N=277)								Single Assessment Tool data (N=453 inpatients) and literature			
Case Type	Dependency (Low, Medium, High)	Falls risk (Y/N)	Communication difficulty (Y/N)	Living alone (Y/N)	% of cases	Age	Sex (M/F)	Cognition (Mild, Moderate, Severe)	BPSD	Comorbidity	Amount of informal support (Low, Medium, High)
2	Medium	N	N	N	5.0	79	M	Mild	Depression and anxiety	Coronary Heart Disease	Medium
4	Medium	Y	N	Y	9.9	86	M	Moderate	Wandering and hallucinations	None	Low
5	Medium	Y	Y	Y	3.4	83	F	Severe	Apathy and sleeping problems	Stroke	Medium

Side box

Case Type 2

Home Situation: Mr Twomey is 79 years old and lives in the centre of a large town with his wife.

Activities of Daily Living: Mr Twomey struggles to bathe and needs to be reminded to wash and maintain personal hygiene. He has difficulty dressing himself and needs assistance both dressing and undressing.

Cognitive impairment: Mr Twomey's has been having mild problems with his short-term memory and concentration for about two years. He sometimes forgets to eat and often doesn't feel hungry.

Physical and mental health: Mr Twomey suffered a minor heart attack 12 months ago. Mr Twomey used to enjoy going to GAA matches but recently has lost interest and refuses to go. He frequently does not want to get out of bed. He gets very worried about small things and is preoccupied with things that might go wrong. He has been prescribed medication for depression but he sometimes refuses to take it.

Informal Support: Mr Twomey is supported by his wife, 73 and their daughter who live nearby. They are coping well but are worried about his low mood.

Care preferences: Mr Twomey has said that he does not want to go to dementia day care.

Table 2: Relative budget allocation between Health and Social Care Professionals (reference group), People with Dementia and Carers, No Budget Constraint (NBC) scenario

Service	Section A: Case Type 2 only				Section B: 3 Case types		
	HSCP (Ref Cost)	HSCP (Ref)	Carers	People with Dementia	HSCP (Ref Cost)	HSCP (Ref)	Carers
Support in the Home							
Home Care	€910	1.0x	0.8 x	1.6 x	€3,759	1.0x	0.9 x
In-home Respite/Sitting Service (eg visiting service)	€427	1.0x	1.8 x	1.2 x	€2,949	1.0x	2.0 x
Reablement / Dementia support worker	€44	1.0x	0.9 x	0.3 x	€133	1.0x	0.9 x
Sub-Total	€1,381	1.0x	1.1 x	1.4 x	€6,841	1.0x	1.3x
Day care	€161	1.0x	1.6 x	0.0 x	€2,033	1.0x	1.8 x
Psycho-social support							
Alzheimer's Café, Dementia Social Clubs, Dementia Friendly Activities , or other support group for people with dementia	€20	1.0x	2.4 x	2.1 x	€78	1.0x	1.6 x
Dementia Cognitive Therapies	€255	1.0x	1.4 x	0.0 x	€589	1.0x	1.2 x
Sub-Total	€275	1.0x	1.5 x	0.1 x	€666	1.0x	1.2 x
Visits from Health and Social Care Professionals	€136	1.0x	0.9 x	0.9 x	€675	1.0x	0.7 x

Carer Supports							
Caregiver Support Groups	€10	1.0x	1.9 x	1.2 x	€41	1.0x	1.0 x
Counselling for Family Carer	€11	1.0x	4.1 x	3.3 x	€57	1.0x	2.2 x
Carer Education Programme	€82	1.0x	1.0 x	0.9 x	€230	1.0x	1.1 x
Nursing home based respite	€78	1.0x	4.5 x	1.0 x	€740	1.0x	1.6 x
Sub-Total	€181	1.0x	2.7 x	1.1 x	€1,069	1.0x	1.5 x
Other Services							
Referral to Psychiatry of Old Age Team	€453	1.0x	1.0 x	0.8 x	€1,270	1.0x	1.0 x
Meals on Wheels	€17	1.0x	8.6 x	12.1 x	€375	1.0x	1.9 x
Transport		No	Yes	No	€402	1.0x	1.9 x
Sub-total	€469	1.0x	1.2 x	1.2 x	€2,046	1.0x	1.4 x
Total	€2,604	1.0x	1.4 x	1.1 x	€13,330	1.0x	1.4 x

Table 3: Relative service allocation by for Case Type 2: Health and Social Care professionals, People with Dementia and Carers. Budget Constraint (BC) scenario

	Section A: Case Type 2						
Service	HSCPs (Ref Cost)	HSCPs (Ref)	Carers	People with Dementia	% Funding (HSCPs)	% Funding (Carers)	% Funding (People with Dementia)
Support in the Home							
Home Help	€593	1.0x	0.6 x	1.5 x	40%	24%	56%
In-home Respite/Sitting Service (eg visiting service)	€157	1.0x	3.1 x	0.4 x	11%	31%	4%
Reablement / Dementia support worker	€26	1.0x	1.9 x	0.0 x	2%	3%	0%
Sub-Total	€776	1.0x	1.2 x	1.2 x	53%	58%	60%
Day care	€0	0.0 x	0.0 x	0.0 x	0%	0%	0%
Psycho-social support							
Alzheimer's Café, Dementia Social Clubs, Dementia Friendly Activities , or other support group for people with dementia	€11	1.0x	2.1 x	2.3 x	1%	1%	2%
Dementia Cognitive Therapies	€107	1.0x	1.0 x	0.0 x	7%	7%	0%
Sub-Total	€118	1.0x	1.1 x	0.2 x	8%	8%	2%
Visits from Health and Social Care Professionals	€84	1.0x	1.2 x	1.5 x	6%	7%	8%
Carer Supports							

Caregiver Support Groups	€9	1.0x	1.5 x	1.2 x	1%	1%	1%
Counselling for Family Carer	€2	1.0x	10.7 x	3.3 x	0%	1%	0%
Carer Education Programme	€72	1.0x	0.8 x	1.0 x	5%	3%	5%
Nursing home based respite	€50	1.0x	1.4 x	1.6 x	3%	4%	5%
Sub-Total	€133	1.0x	1.2 x	1.3 x	9%	10%	11%
Other							
Referral to Psychiatry of Old Age Team	€309	1.0x	0.7 x	0.9 x	21%	13%	19%
Meals on Wheels	€26	1.0x	0.9 x	0.0 x	2%	1%	0%
Transport	€19	1.0x	2.1 x	0.0 x	1%	2%	0%
Sub-Total	€353	1.0x	0.8 x	0.8 x	24%	17%	19%
Total	€1,465	1.0x	1.1 x	1.0 x	100%	100%	100%

Table 4: Nursing home placement, No Budget Constraint.

Cohort	Case Type 2	Case Type 4	Case Type 5
HSCP	0% (0 of 15)	7% (1 of 15)	27% (4 of 15)
Carer	8% (1 of 13)	31% (4 of 13)	62% (8 of 13)