



THE ALZHEIMER
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An Economic Analysis of *Home-Care Services* for People with Dementia

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The Health Service Executive will consider how best to configure resources currently invested in home care packages and respite care so as to facilitate people with dementia to continue living in their own homes and communities for as long as possible and to improve the supports available for carers.

The Irish National Dementia Strategy (DoH 2014, p.15)

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Introduction

The economic impact of dementia has been estimated to equate to 1% of global GDP (Wimo, Jönsson, et al. 2013), remaining one of the foremost health and economic challenges facing society today. It has become imperative that policy explicitly considers *optimal* arrangement of the limited societal resources to mitigate the impact on people with dementia, their families, health and social systems and wider society. Sustaining people with dementia at *homes* is a generally agreed preference and makes rational economic sense. In community settings, research finds that increasing demands for care are often borne by family and friends, however formal provisions are often required to augment care and any provision must be cost-effective (Quentin et al. 2010).

Activities of Daily Living (ADL) are '*daily self-care activities within an individual's place of residence*' (Krapp 2002) and can be quantifiably shown to deteriorate as the dementia progresses through stages, thus increasing demand for care (Trépel 2011b). Deterioration may be termed as a loss of '*ADL independence*' and for people with dementia (at risk of institutionalisation), losing independence is correlated with the highest change in demand for home care (Wübker et al. 2014). This progressive loss ultimately leads to complete dependency on others (Jönsson et al. 2006).

Progressive disability in dementia increases demands for formal and informal care (Hallberg et al. 2013; Hallberg et al. 2014). Formal care is most often provided by health and social care (Gannon & Davin 2010), although households may also enlist formal care through private channels. Informal care relies on the contributions of family or friends (Connolly et al. 2014), is most often unpaid and tends to be from

individuals living in close proximity (Bonsang 2009). However, who exactly will provide home care varies in each individual case and often lacks co-ordination. In the absence of a structured care plan, responses to the changing demands for care may be *ad hoc* and may be provided by a variety of individuals. Figure 1 summarises a European mapping system of the range of agents identified as providing home care throughout the trajectory of dementia.

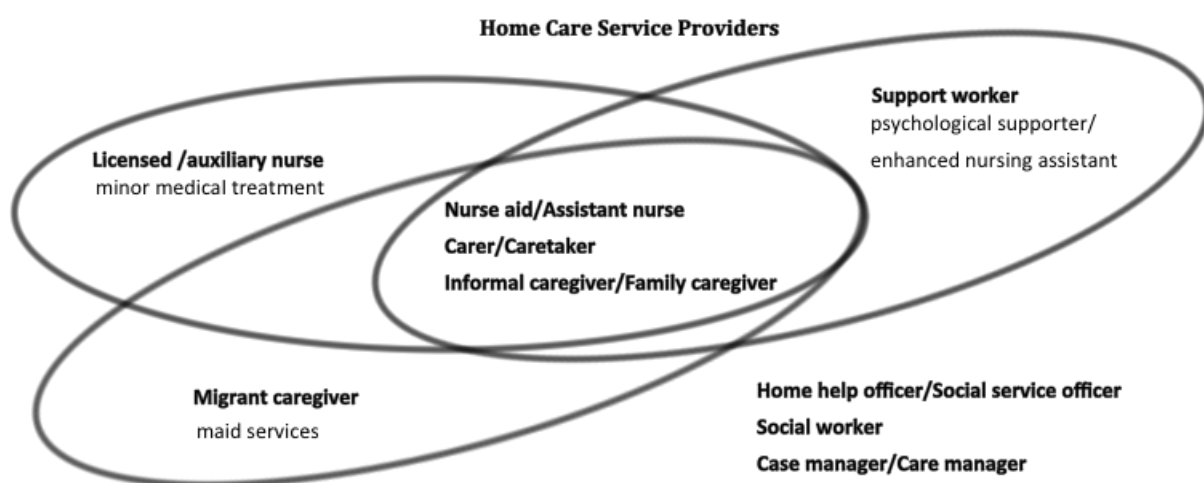


Figure 1: Individual providers of home care Source: *Professional care providers in dementia care in eight European countries; their training and involvement in early dementia stage and in home care.* (Hallberg et al. 2014, p.6)

Three potential types of agents exist to deliver home care. Firstly, there is a group for whom their sole role is the *hands-on* care in the home; this may be formal (nurse aids or carers) or informal (e.g. family members). Secondly, those who jointly provide home care in addition to other tasks; this may be licenced nurses (in addition to other medical treatments), support workers or private caregivers (who may also provide maid services). Finally, those who *co-ordinate* deployment of home care services but might not act as hands-on carers (e.g. home help officers, social workers or case managers). Professionals involved in care vary over the spectrum of dementia care,

and research is required to establish the quality and cost of how professionals are complementing informal carers (Hallberg et al. 2014).

The variety of potential agents contributing to dementia care, compounded by continuously changing demands and variations in competencies of carers increases the likelihood of inefficient and inequitable arrangements of care. The goal for people with dementia and for wider society is to provide an *optimal* arrangement of care - that is, maximising overall welfare given scarce available resources.

This report will firstly examine consensus on definitions for 'home care services', then present a conceptual framework of home care and concludes with a discussion on efficient design of dementia home care services.

Defining 'Home care' services'

It is commonly agreed that people with dementia should remain living in the community for as long as possible (Department of Health, 2014; NICE, 2006; NICE, 2010). Whilst substantial benefits exist by remaining in one's own homes (versus long-term institutional settings), *community care* is less structured and may require focused effort to organise. *Home care services* are therefore associated with uncertainties in their deployment and outcomes (Zabalegui et al. 2014).

In Ireland, whilst higher levels of dependence is associated with increasing levels of informal care, formal services are not found to respond where demand for care increases (Gillespie et al. 2014). To quantify the economic burden of care provided by family members, UK estimates suggest this informal care saves public expenditure £8 billion a year (Iliffe, Robinson, et al. 2014).

Decreasing the overreliance on family members requires a consensus on *home care services*. Such a consensus should stipulate parameters on realistic expectations from informal care, and identify the proposed criteria for formal services to ensure good quality, effective, and cost-effective dementia care at home (Jones 2014).

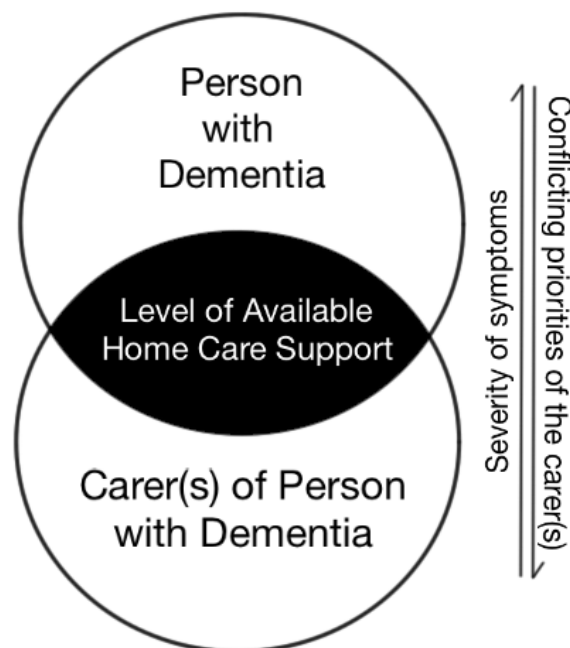
A selection of policy documents are identified which partially providing the criteria of *home care services*. O'Shea and colleagues (2007) suggest the levels of disability associated with dementia creates a need for personal care, social support and domestic assistance. In operational terms, the Health Service Executive (HSE) identifies ADLs as washing, taking a shower, assistance with changing position, oral hygiene, or help at mealtime, and on essential domestic duties (like lighting a fire or bringing in fuel if there is no alternative heating source, or basic essential cleaning of the person's personal space) (HSE 2015). The Health Act (1970, sec.61) stipulates the state's legal obligations to provide care and the *Citizen Information Board* (2013) states that professional home help should 'not extend into services such as provide nursing or medical care' (recognising other health care professionals limited time to provide this additional level of assistance).

These national definitions of *home care services* importantly set the context for the duty of care in dementia; however definitive *service-level* obligations remain unclear. A consensus should extend to *explicitly* set out situations when care would be supplied in dementia, the professional who will be involved across varying stages (i.e. mild, moderate, late and end of life) and how their performance would be monitored.

With varying intensity of care required as dementia progresses, *assessment*, *coordination* and *monitoring* are imperative. Appropriate delivery must be Specific, Measurable, Attainable, Relevant and Time-framed - underpinned by SMART objectives (Trépel 2012). Such objectives should explicitly plan *assessment*, *coordination* and *monitoring* activities and these should be tailored for each individual's situation.

At the household level, *assessment* of need should also consider the person with dementia and how they have formed *dyads* with available carer(s). Figure 2 adapts 'examples of experiences of care' presented by NICE-SCIE (2007, pp.72–75), illustrating the importance of assessing needs in *dyads*; to inform objectives, services should identify the *specific*, *measurable* and *relevant* considerations within dyads when organising care.

Figure 2: Carer-Person with Dementia dyad illustrating forces resulting in variation in 'levels of available home care support'



With increasing severity of symptoms, mounting responsibility to provide home care is transferred onto carers within these dyads. However, any carer (either formal or informal) within a *dyad* will only have a finite amount of time that they can/should supply to care and *conflicting priorities* will exert forces to limit available care; this makes *coordination* of efforts imperative.

To portray the implications of *competing priorities* in a real-world context, analysis of an Irish survey of informal caregivers reveals how informal care varies. This is contingent on where an informal carer lives and their employment status (see Table 1).

Table 1: Mean (s.d.) daily hours of informal care dependent on cohabitation and employment status.
Source: *Informal Cost of Dementia Care – A Proxy-Good Valuation in Ireland* (Trépel 2011b, p.492)

| <i>Live Apart</i> | <i>Daily Informal Care by Employment Status</i> | | | |
|-------------------|---|------------------|-----------------|-----------------|
| | <i>Full-time</i> | <i>Part-time</i> | <i>Retired</i> | <i>Resigned</i> |
| Yes | 3.76 (2.54) | 6.38 (3.46) | 13.56 (3.21) | 17.48 (4.17) |
| No | 12.76 (4.64) | 17.85 (4.37) | 17.13 (3.82) | 19.41 (3.56) |
| Total Hours | 8.67 (5.91) | 11.34 (6.91) | 16.77 (3.90) | 19.14 (3.68) |

Firstly, carers have competing demands for their time that affect the level of care provided (e.g. their employment reduces supply of care). Secondly, closer proximity (e.g. co-habitation) increases the reported number of hours of care. Finally, carers who state they are *retired* or have *resigned* may have impaired capacity to provide care themselves. Importantly, this demonstrates how information regarding one dyad of care might inform formal service provision (albeit only with two variables potentially limiting supply of informal care).

As the *dyad* cannot be assumed to stay constant over time and must be continuously *monitored*. SMART objectives within a care plan must become SMARTER - that is objectives must be Evaluated and Re-evaluated. To achieve SMARTER objectives of care, a framework for evaluating home care is required. The following section discusses a potential framework to monitor *configuration of resources* with the objective of optimising overall welfare.

Conceptual frameworks of home care

With scarcity of resources for society to meet demands for home care balanced against requirements that individuals remain productive elsewhere in society, a conceptual framework is required to consider the opportunity cost of time spent caring against other *competing priorities*.

To define a set of potential agents involved in care for people with dementia, consider three identifiable potential agents - *Health Care* (H), *Social Care* (S), *Informal Care* (I) - and one more ambiguous group – defined here as *Others* (O). The sum contributions to care by all *Agents* (A) is defined as

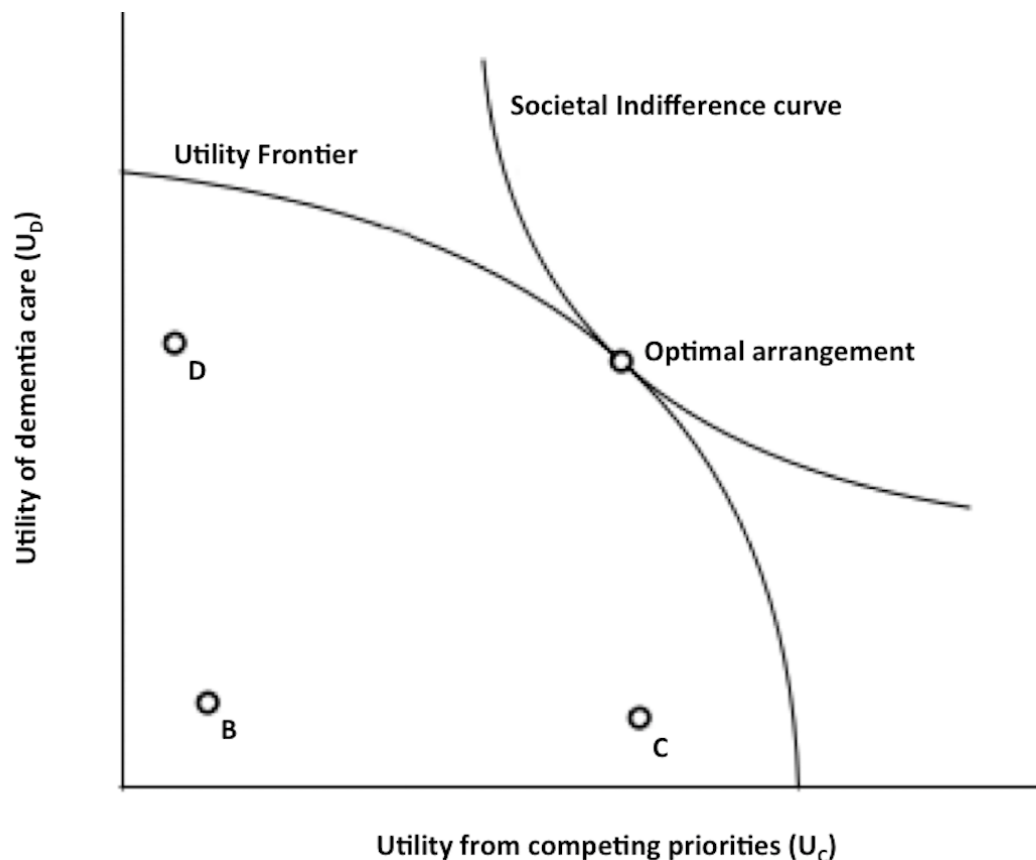
$$A = (H, S, I, O).$$

Societies primary object should be to maximise overall societal welfare and using welfare measures of agents' input into the person with dementia, one might consider the cardinal utility gained for the person with dementia (U_D) given a *dyad* of care (i) as

$$U_D = \frac{1}{n} \sum_{i=1}^n A_i.$$

To solely focus on maximising utility gained by the person with dementia (U_D) would overlook total societal welfare (W). By considering all agents forming dyads (A_i) as having competing priorities (C_i) and assuming efforts applied to competing priorities creates an alternative cardinal utility (U_C). Figure 3 portrays this dynamic relationship between providing care for the person with dementia with balancing competing priorities elsewhere in society.

Figure 3: Relationship between caring for person with dementia and competing priorities elsewhere in society



Firstly, the scheme presents the concept of a **societal indifference curve** which represents sets of arrangements between dementia care and competing priorities where society would be indifferent in terms of overall utility gained (Geanakoplos 2004). Secondly the concept of a **utility frontier** considers all arrangements of

activities which can be considered efficient (Pareto 1927). In theory, an *optimal arrangement* exists where *the societal indifference curve* intersects the *utility frontier* and for this balance of dementia care and competing priorities (which will be specific to each agent) social welfare would be maximized.

An efficient balance of the dementia care and competing priorities may not always occur without some form of intervention. In this scheme, three points provide potential examples of arrangements where overall utility may be less than optimal:

Point D (Dementia): This point illustrates a carer who prioritises care for the person with *dementia* forsaking competing priorities; in this state, the disutility of neglecting their other priorities (related to U_C) will exert rightward force towards the utility frontier in order to rectify neglecting priorities elsewhere in society.

Point C (Competing): Carers' efforts may have increased likelihood of being directed at *competing priorities* over care for the person with dementia; in this state the person with dementia utility state (U_D) is lower relative to what it might be with greater care. Examples could be carers who are a significant distance from the person with dementia, or a caregiver constrained by their available time (Trépel 2012, pp.155–156). One might expect poor outcomes (health or otherwise) of the person with dementia.

Point B (Burnout): This final point depicts an extreme state where carer's exhibit diminished productivity in terms of care and competing priorities. Examples can be where the primary carer is an elderly spouse also with impaired health (Argimon et al. 2004) or situations where the act of providing

care causes burnout (Trépel 2011a) or where a publically funded system (health and/or social) experience impaired information to regulate service providers (HIQA 2009; Dawson et al. 2005). In this state, intervention is likely to be required by both the person with dementia and their carer.

All three examples of care are inefficient and may in fact have a greater cost to society (although net monetary value may not be immediately evident).

The set of *Agents* (A) contributing to care can be assumed (to a greater or lesser extent) to act independently and with limited awareness of the actions of other agents. This *asymmetry of information* is a fundamental source of inefficiency with regards to health care markets (Arrow 1963).

To remedy this, one might consider a minimum set of information transferred between all agents in the set A and increasing levels of *coordination*. Specific forms of information can be obtained through routine *assessment* and *monitoring* outcomes. Specific examples include:

1. **Generic health outcomes:** To a healthcare decision-maker who must make decisions on the allocations of healthcare resources, generic measures of health provide a means to compare investment in terms of cost versus health outcomes for a given service. This allows a health system to ensure that all competing disease states receive resources equitably. Common metric used included quality-adjusted life years or QALY (Williams et al. 1987), which are ascertained at the individual level using questionnaire such as the EQ-5D (Ankri et al. 2003; Coucill et al. 2001), SF6D (Brazier & Roberts 2004) or DEMQOL (Rowen et al. 2012).

2. **Condition-specific health outcomes:** To a healthcare provider who works with patients, these provide a measure of the relative severity of the disease and may indicate the level of care required. Stage of dementia is commonly measured using the clinical measures of dementia (e.g. Standardized Mini Mental State Examination (Folstein et al. 1975) or a Neuropsychiatric Inventory (Kaufer et al. 2000)). In addition, specific tools address relative needs for care, one might be assessed by measuring Katz Index of Independence in Activities of Daily Living (Katz 1963). Levels of depression have been identified to increase demand for care (Trépel 2012) and it may also be suggested such symptoms are assessed using the *Cornell Scale for Depression in Dementia* questionnaire (Alexopoulos et al. 1988).
3. **Non-health outcomes:** The arrangement of care (e.g. home care services) may not significantly alter or improve health state (e.g. the severity of dementia) and therefore when evaluating potential arrangements of care, these may not be good measures of efficiency or productivity of various arrangements of the agents of care. To dementia care, this may represent an important realisation in terms of informing policy decisions on home care. ASCOT questionnaire has constructed validity to measure *social care-related quality of life* with older people (compared to EQ5D) and is significantly sensitive to outcomes related to use of home care services (Forder & Caiels 2011; Malley et al. 2012).
4. **General Quality of Life:** Beerens and colleagues (2014) examined European-level impacts of Quality of Care for People With Dementia and their carers using the *Quality of Life-Alzheimer's Disease scale* (Logsdon &

Gibbons 1999). Their results showed no significant difference between quality of life for those in Institutional care 32.5 (6.3) versus Home Care 33.5 (5.9), however they did show depressive symptoms to be consistently associated with lower quality of life. General quality of life measures would not specifically speak to any explicit healthcare guidelines (HIQA 2010; NICE 2013), however they may still serve to indicate general failure at a broader societal level.

5. **Resource use and cost:** Many outcomes can be quantified in terms of the relative use of society's limited resources (e.g. hospitalisation, nursing home placement, informal care & lost productivity). Specific resource utilisation questionnaires for dementia have been developed in an attempt to inform European policy (Wimo, Gustavsson, et al. 2013). European analysis of average costs in dementia deduced that *institutional long-term care* costs €4,491 per month compared to €2,491 for aggregate costs from *home care*; in relative terms suggesting a 1.8 (min-max: 1.4 - 2.4^{*}) difference across all countries (Wübker et al. 2014). Measurement of resource implications (and estimating associated costs) is critical to monitor implications of dementia and to ensure sustainability.

When considering the above information to public systems which must improve their efficient use of scarce resources, Arrow (1963) states that *health states* may be characterised by extreme uncertainty causing information to become a commodity, however consumers (e.g. a people with dementia) ability to acquire information is limited and thus this increases the value of information (Haas-Wilson 2001).

* Incremental differences varied between countries from 1.4 in the United Kingdom to 2.4 in Sweden; in the absence of data for Ireland, the range may provide a means to estimate the potential variance in other countries.

Applying notions of uncertainty and the value of information in *dementia home care services*, raises three questions: 1) *who is best placed to organise the supply of care*; 2) *how best to monitor whether required care is being provided*, and; 3) *how is this valuable information captured and shared?* The next section provides a provisional review of evidence to inform optimal arrangements of dementia home care services.

Efficient design of *dementia home care services*

Estimates suggest that a quarter of UK hospital beds are occupied by people with dementia (Alzheimer's Society, 2012) and emerging evidence implies that similar situations exist in Ireland (Department of Health 2015). This paper has shown evidence to suggest home care versus long-term institutional care results in comparable quality of life but home care is approximately half the cost. This section examines the evidence on the most effective approach to maintain individuals within their home.

O'Shea et al. (2007) defines home care services as '*a need for personal care, social support and domestic assistance*' associated with the person with dementia '*levels of disability*'. Considering *home care services* as a commodity, essentially carers substitute for functions the person with dementia can no longer perform. Short-term outcomes are evident (i.e. people eat, stay clean or keep warm) however a lack of care over time may result in avoidable suffering and diminished health. To ascertain an efficient arrangement of care, one must therefore ask *who is best placed to organise the supply of care?*

A recently completed Cochrane review determined current knowledge on the effectiveness of case management approaches to home support for people with dementia (Reilly et al. 2015). The review identified randomised control (all with very similar designs) and analysis of this evidence suggests that case management reduces likelihood of institutionalisation by 18% (OR: 0.82, $p=0.02$, 95% CI 0.69 to 0.98) at 6-month follow-up. Evidence was uncertain whether the effect was sustained longer-term (10 - 12 months: OR 0.95, 95% CI 0.83 to 1.08; and 24 months: OR 1.03, 95% CI 0.52 to 2.03, $I^2 = 0\%$, $P = 0.94$, respectively). The research also interestingly finds evidence that suggests that case management may have a small but significant effect on improving symptoms of depression in caregivers.

Having strong evidence to suggest that case management is effective to organise care for people with dementia at home, the next question is *how best to monitor whether required care is being provided?*

Recent research funded by the National Institute for Health Research[†] (NIHR) explores the feasibility (and effectiveness) of collaborative care for people with memory problems in primary care (Iliffe, Waugh, et al. 2014). Using case managers, collaborative care aims for a structured management plan which systematically schedules patient follow-ups and plans enhanced communication and supervision. Specifically, Iliffe and colleagues explored four main questions (which should be considered equally relevant in informing changes to dementia services in Ireland):

1. What skills are needed to be a dementia case manager working in primary care and who might be suited to this role?

[†] <http://www.journalslibrary.nihr.ac.uk/collections/dementia>

2. Is case management acceptable and beneficial to people with dementia and their families?
3. Is case management of people with dementia feasible in UK general practice?
4. What resources are needed to deliver case management to people with dementia in UK primary care?

Whilst only one potential goal of collaborative care might be *home care services*, this research provides a good template on how healthcare systems might plan, organise and evaluate potential models of care for people with dementia living at home.

Building on the example of case management in collaborative care, the system must now realise and make use of *valuable information* being produced. To benefit both the person with dementia and also to make best use of limited resources, the final question is *how should valuable information be captured and shared?*

One pertinent example of case management collaborative care underpinned by appropriate information systems can be drawn from the CASPER study (Overend et al. 2014). In this model of collaborative care, an academically developed information system was used to monitor the delivery of a well-organised package of care and implement evidence-based practice. Specifically, case managers were trained to deliver a specific protocol of objectives to clients over a defined period. To monitor appropriate delivery, case managers received weekly supervision meetings from a designated supervisor in which each case contact was reviewed (approximately 5 minutes per case discussed). To ensure wider movement of information, protocol also defined how case managers directly feedback to GPs and engage (where required) other agencies (e.g. social care). All case manager service and associated

information was centralised using the *PC-MIS*[‡] (*Patient Case Management Information System*) providing a fully audible system to track care individuals received.

Whilst the above examples digress from core actions of *home care*, the challenge presented here is to develop frameworks to co-ordinate and ensure that all available agents providing care are accounted for. Lines of accountability (underpinned by SMART objectives) with the ultimate goal of maximising societal welfare requires an enhanced model of care, making best use of value of information to identify inefficiencies. Further research is required to better understand which agents should provide what care (Hallberg et al. 2013), which specific intervention should be recommended (Zabalegui et al. 2014) and to translate policy recommendations into clearly visible changes in practice.

[‡] PC-IMS was developed at the University of York – for further information, see <http://www.york.ac.uk/healthsciences/pc-mis/>

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