Models of Reablement: a mixed methods evaluation of a complex intervention The MoRe project

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Abstract

Background

Reablement is an intensive, time-limited intervention for people at risk of needing social care or increased intensity of care. Differing from homecare, it seeks to restore functioning and self-care skills. In England, it as a core element of intermediate care. The existing evidence base is limited.

Aims

- Describe reablement services in England and develop a service model typology;
- Conduct a mixed method comparative evaluation of service models investigating outcomes, factors impacting outcomes, costs and cost-effectiveness, and user and practitioner experiences;
- Investigate specialist reablement services/practices for people with dementia.

Methods

Work package 1 (WP1), taking place in 2015, surveyed reablement services in England. Data were collected on organisational characteristics, service delivery and practice, and service costs and caseload.

Work package 2 (WP2) was an observational study of three reablement services, each representing a different service model. Data collected included: health- (EQ-5D-5L) and social care-related (ASCOT SCT-4) quality of life, practitioner (Barthel Index) and self-reported (NEADL scale) functioning, individual and service characteristics, and resource use. It was collected on entry into reablement (n=186), at discharge (n=128) and, for those reaching the timepoint within the study timeline, six months post-discharge (n=64). Interviews with staff and service users explored experiences of delivering or receiving reablement and its perceived impacts.

Work package 3 (WP3) interviewed staff in eight reablement services to investigate experiences of reabling people with dementia.

Results

201 services, located in 139 Local Authorities took part in the survey. Services varied in their organisational base, relationship with other intermediate care services, use of out-sourced providers, skill mix, and scope of reablement input. These characteristics influenced aspects of service delivery and practice. Average cost per case was £1,728.

Lower than expected sample sizes meant a comparison of service models in WP2 was not possible. Findings are preliminary. At T1, significant improvements in mean score on outcome measures except self-reported functioning were observed. Further improvements were observed at T2, but only significant for self-reported functioning. There was some evidence that individual (e.g. engagement, mental health) and service (e.g. service structure) characteristics were associated with T1 outcomes and resource use. Staff views on factors affecting outcomes typically aligned with, or offered possible explanations for, these associations. However, it was not possible to establish the significance of these findings in terms of practice or commissioning decisions. Service users expressed satisfaction with reablement and identified two core impacts: regained independence and, during reablement, companionship. Staff participating in WP3 believed people with dementia can benefit from reablement, but objectives may differ and expectations for regained independence inappropriate. Furthermore, practice (e.g. duration of home visits) should be adjusted and staff adequately trained.

Conclusions

The study contributes to our understanding of reablement, and what impacts on outcomes and costs. Staff believe reablement can be appropriate for people with dementia. Findings will be of interest to commissioners and service managers. Future research should further investigate factors impacting on outcomes, and reabling people with dementia.

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List of Abbreviations

ADL: Activities of Daily Living

ASCOT: Adult Social Care Outcomes Toolkit

CCG: Clinical Commissioning Groups

ERPC: Experiences of Reablement Practice Checklist

GHQ: General Health Questionnaire

HRERS: Hopkins Rehabilitation Engagement Rating Scale

HRERS-RV: Hopkins Rehabilitation Engagment Rating Scale - Reablement Version

HS&DR: Health Services and Development Programme

IC: Intermediate Care

LA: Local Authority

LASSD: Local Authority Social Services Department

LSA: Local Study Administrator

LSO: Local Study Officer

NAIC: National Audit of Intermediate Care

NEADL: Nottingham Extended Activities of Daily Living Scale

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

NIHR: National Institute for Health Research

NSF: National Service Framework

OT: Occupational Therapist

QoL: Quality of Life

RSM: Report Supplementary Material

SCPQ: Services and Care Pathway Questionnaire

Plain English Summary

When people grow old they sometimes begin to lose everyday living skills and struggle to look after themselves. This happens after they have been in hospital or it can just happen over time. In England, councils and local NHS services try to help people so they can continue living independently. They do this through a service called reablement. After a careful assessment, workers visit people once or twice a day for around six weeks. During these visits they gradually help people to do everyday living tasks for themselves again. Reablement is an important part of the way we look after older people in England, but there is very little research about it.

This study looked at the sorts of reablement services which exist in England, what impact reablement has on people's lives, and whether having reablement means that people use other services more or less. It also talked to reablement staff about working with people with dementia.

We found that reablement services in England vary enormously. They are different in how they are staffed and the sorts of work they will do. Whilst we cannot draw firm conclusions, it seems how services are organised and run may affect how well reablement works. People's own characteristics (e.g. motivation to regain independence; whether they live alone) may also impact on whether reablement makes a difference. The type of reablement service and individual characteristics also seems to influence how many other services people need to use. Finally, staff believe reablement can help people with dementia, but staff may need to work differently and proper training is very important.

Some of our findings are new and others support the results of other studies. We think it would be valuable to do another study like this one so we understand even more about reablement.

(299 words)

Scientific Summary

Background

Reablement is restorative, goals-focused intervention comprising intensive, time-limited (up to 6 weeks) assessment and therapeutic work delivered in the usual place of residence. Its purpose is to restore/regain self-care and daily living skills for individuals at risk of needing social care support to continue living in their own homes, or an increase in its intensity. It contrasts markedly with traditional homecare. Despite significant government investment and policy directives over the past decade, research on reablement is limited.

This study arose from a commissioned call from NIHR's Health Services and Delivery Research (HS&DR) programme. The call asked for research which, for the first time, would identify the service models and/or service characteristics which support positive outcomes, and investigate the impact of user engagement and other individual factors on outcomes. HS&DR also wanted to commission research on reabling people with specialist needs (e.g. dementia).

Objectives

Work package 1 (WP1): To map services and develop a typology of service models.

Work package 2 (WP2): To evaluate up to four service models, as identified in WP1, investigating outcomes, predictors of outcomes, costs, cost-effectiveness and the reablement process.

Work package 3 (WP3): To investigate current practices regarding reabling people with dementia.

Methods

Work package 1

A national survey of reablement services in England. The survey, completed by service leads, covered service organisation and structure, staffing, objectives, domains of reablement input, referral and assessment processes, policies regarding people with specialist needs, outcomes assessment, and service costs.

Work package 2

A mixed method observational study of three reablement services each representing a different service model.

The outcomes evaluation: Outcomes, socio-demographic and health data were collected on referral (T0), at discharge (T1), and six month post-discharge (T2). Intervention fidelity and engagement with reablement were assessed at T1 using measures developed by the study (the Hopkins Rehabilitation Engagement Rating Scale-Reablement Version and the Experiences of Reablement Practice Checklist). Outcomes assessed were: health-related (EQ-5D-5L) and social care related (ASCOT SCT-4) quality of life, practitioner-reported functional status (Barthel Index), self-reported functional status (NEADL scale) and mental health (GHQ-12).

The economic evaluation: Data on service and resource use, out-of-pocket costs and use of informal care was collected using an instrument (the Services and Care Pathway Questionnaire (SCPQ)) developed by the research team and administered at T0, T1 and T2.

The process evaluation: individual interviews or focus groups were used with service users, family members, commissioners, service managers, reablement assessors and reablement workers. They explored views on impacts of reablement, factors supporting or hindering outcomes, and service receipt/delivery.

Work package 3

WP1 data identified reablement services which reported working with people with dementia. Semi-structured interviews with service leads, reablement assessors and front-line staff from nine services were conducted.

Quantitative data included descriptive and regression statistics. Thematic analysis of verbatim transcripts were used to analyse qualitative data.

Results

Work package 1

Just over 200 services were identified and data collected from 143 (71% response rate) services. Their organisational base was either Local Authority (53%), NHS (4%), integrated services (15%), or an out-sourced provider (14%). Most (52%) were stand-alone services. Two-thirds of services were wholly in-house; where out-sourcing did occur, this was typically for delivery of reablement home visits. Services clustered around two further characteristics: the scope of reablement input and skill-mix. The great majority of services either provided functional reablement (35%) (restoring functional abilities associated with activities of daily living) or comprehensive reablement (65%), which extends input to include getting out and about outside the home and social engagement. Comprehensive reablement corresponds to policy and NICE definitions of reablement. Under one in five respondents (17%) described the skill mix of their service as including occupational therapists as well as reablement workers. Another set of services (29%) had reablement workers but no occupational therapists. A small minority (14%) included occupational and physio-therapists and, sometimes, other health care professionals. Around a third of services (29%) reported having homecare workers, suggesting the service delivered both homecare and reablement. These service characteristics were associated with a number of aspects of service delivery and practice; such as whether the service was open referral or selective, typical duration of reablement, assessment and review processes, and destination following discharge.

Response rates to questions on the costs was poor and some responses appeared implausible, raising questions about generalisability and data accuracy. Based on available data, the cost of reablement per case was calculated to be ~£1,700.

Work package 2

Outcomes evaluation

Difficulties with study set-up and slow throughput in some research sites meant the desired sample size was not achieved. As a result, we could not compare research sites in terms of effectiveness, costs and cost-effectiveness. It also limited the complexity of modelling work used to explore the impact of individual and service characteristics on outcomes. Findings should therefore be treated as preliminary.

186 individuals were recruited to the study, with 129 retained at T1 and 64 at T2. Improvements on all outcomes (health-related (EQ-5D 5L) and social care-related quality of life (ASCOT SCT-4), practitioner-reported functioning (Barthel Index), self-reported functioning (NEADL scale)) were observed at T1. For those where data was available at T0 and T1, improvements in health- and social care-related quality of life and practitioner-reported functioning were significant. Outcomes had further improved at T2. Improvements on quality of life measures were not statistically significant. However, and in contrast with T1, the change (improvement) in mean score in self-reported functioning (NEADL scale) was significant.

Regression analyses explored the association between individual (age, gender, living situation, referral reason, sufficient, co-morbidities, intervention engagement, mental health, informal carer involvement, T0 outcomes) and service (intervention duration, single vs split/multi team arrangement, n-house vs out-sourced provision, intervention fidelity) characteristics on T1 outcomes. Having sufficient money was associated with both quality of life outcomes and practitioner-reported functioning at T1. In terms of age, there was weak evidence of an association with just one outcome (self-reported functioning). There was some evidence of an association between referral reason and social care-related quality of life only. There was consistent evidence of an association between user engagement with reablement and all outcomes. Individual and service/worker characteristics are likely to

both contribute to intervention engagement. There was some initial evidence, and lacking the strength and consistency across outcomes, that duration of intervention, service structure (single team vs separate assessor and reablement worker teams; in-house vs out-sourced reablement workers) (as opposed to from an out-sourced provider) may be associated with outcomes achieved at the point of discharge from reablement. Small sample size meant it was not possible to use multiple regression to further test these associations, nor to conduct this analysis was not conducted on T2 data. Furthermore, it was not possible to establish the 'clinical significance' of these findings.

Process evaluation

Findings from the process evaluation aligned with, and typically offered explanations for, the patterns of association between individual and service characteristics and outcomes at T1 described above. For example, staff frequently reported service users and family members had a poor understanding of reablement and this acted as a barrier to engagement, at least in the early stages. Our interviews with service users also revealed some confusion about reablement, and its difference to homecare. Or, in terms of a possible association between a single vs separate assessor and worker teams, assessors working in a separate team model reported concerns or inadequacies with monitoring/review processes and supervision of reablement workers.

A number of other issues were raised by staff. First, the impact of the Care Act 2014, and also NHS discharge-to-assess policies, on the characteristics of their caseloads. Reabling to full independence was no longer the predominant outcome. The merging of reablement and assessment functions, and lack of other in-house social care provision for older people, had resulted in increased caseload volume for assessors and a slowing throughput due to difficulties in transferring on those with on-going care needs.

There was a strong and consistent belief among staff of the superiority of reablement over traditional homecare. Staff skills and knowledge of reablement principles were regarded as key to successful reablement. In addition, staff believed the social contact occurring during home visits served to re-connect, and re-kindle, interest in everyday life.

In addition to engagement, service user characteristics which staff believed impacted on outcomes included personality, problem-solving skills, mental health, cognitive impairment, the presence of a partner/spouse. Housing tenure was a potential barrier, with installation of aids or minor modifications difficult if the property was rented, particularly from a private landlord.

In addition to the issue of separate assessor and reablement worker teams mentioned earlier, staff believed other aspects of service delivery and practice impacted on outcomes. The importance of flexibility in timing and duration of visits, and an expectation this would reduce over the course reablement, was noted. Some believed this was not sufficiently specified, or incentivised, in contracts without-sourced providers. Views were mixed about the optimum number of workers assigned to a case: advantages to having one or two or, alternatively, multiple workers were both articulated. Timely access to specialist expertise, particularly physiotherapy and mental health, was regarded as important but difficult, if not impossible, to achieve.

Overall, service users reported very positive experiences of reablement. The majority believed positive outcomes had been achieved through the skills and input of the reablement workers. Six factors were articulated as impacting on outcomes: the service user-worker relationship, workers' reablement skills, service user's confidence in the worker, duration of home visits, willingness, to accept support, and being able to review progress. Continuity of workers was not identified as important to achieving positive outcomes.

Economic evaluation

The planned duration of reablement was on average 6 weeks, with 1 to 2 home visits per day. Actual duration was, on average, 4 weeks. Services most used prior to receiving reablement and up to 6 months post-discharge were hospital, community health care and social care. A downward trend in resource use from the period prior to reablement to 6-month post-discharge was observed.

Public sector costs, falling on health and social care, were the largest cost category. Of these, hospitalisations with overnight stays were the largest cost item at all time points.

Out-of-pocket costs were generally small. With respect to other costs, the major cost item was informal care. Receiving reablement from out-sourced providers was associated with higher hospital costs and smaller social care costs compared to those who received in-reablement from an in-house service. Referrals to reablement due to a musculoskeletal problem or a fall, or due to an infection, were associated with lower costs of community health care during reablement. Type of health co-morbidity appeared to affect levels of cost, with arthritis and chronic respiratory conditions associated with higher costs, and cardiovascular conditions lower costs. Increasing age was associated with higher costs of community health care. Sample size limited the tests that could be undertaken and the inferences that can be drawn from the economic evaluation.

Work package 3

Staff believed reablement has the potential to offer benefits to people with dementia, though achievement of full independence from social care may not be possible. Seeking to restore functioning in activities of daily living alongside, where required, a comprehensive needs assessment was regarded as an effective approach to supporting people with dementia where concerns regarding their ability to manage to home had been raised. Interviews believed these differences in emphasis should be better recognised by commissioners. Interviewees reported practice often needed to be adapted, and extended, to secure good outcomes. Thus work to restore routines, practising of tasks, using visual communication tools, and working on social networks and carer support made reabling people with dementia different and, often, more complex. Staff observed that resources allocated to reabling people with dementia and/or commissioning arrangements should be modified to allow for, for example, extended visits, extending the duration of reablement, or reducing the number of reablement workers involved. Concerns were expressed, particularly by reablement workers, about levels of training. Generic dementia training was regarded as insufficient and that training on the implications of a dementia diagnosis on providing reablement should be developed and mandatory.

Conclusions

The on-going implementation of the 2014 Care Act means the structure and organisation of reablement provision in England is likely to have changed since our survey was carried out in 2015. However, the heterogeneity of service and practice characteristics observed in the survey may well remain. Indeed, the three services acting as research sites for WP2, all of whom reported changes to their services in response to the 2014 Care Act, demonstrate the alternative ways reablement is now being delivered.

Firm implications for health and social care practice cannot be drawn from the outcomes and economic evaluations: our data is not sufficiently robust. Overall, findings on outcomes align with previous research (though heterogeneity of measures and outcome time points limit close comparison). They also provide important new evidence on the range of outcome domains which reablement may impact, and trajectories to impact. The process evaluation corroborated initial findings regarding associations between outcomes and individual and service characteristics, something not explored by previous studies. Importantly, some characteristics (e.g. user engagement, mental health, single team vs separate teams, intervention integrity, in-house vs out-sourced providers) are amenable to change. Findings from the economic evaluation should also be treated with caution. They do point to the importance of future research investigating the way individual and service characteristics explored in this study may impact on costs.

Finally, there was strong support among staff working in reablement for its benefit to at least some people with dementia. This may not be the position adopted by commissioners. Given the multiple ways in which staff reported adjusting aspects of practice and service delivery, it is clear that evidence-informed guidance for commissioners and service leads/practitioners on reabling people with dementia are required.

Research recommendations

- A large scale, multi-site mixed method outcomes and economic evaluation of reablement to investigate outcomes, the impacts of service, intervention and individual characteristics on outcomes and costs.

- The development and evaluation of an intervention to improve service users' and family members' understanding of reablement.
- To support future research on improving engagement with reablement, a systematic review on strategies and practices which support engagement with reablement and other relevant interventions.

A systematic review of practices/technologies which support understanding or remembering of instructions, or stages of executing tasks/activities relevant to reablement, among people with dementia.

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Chapter 1. Introduction

1.1. Background

Increased life-expectancy – brought about mainly by improvements in health care – presents a number of health and care policy challenges. Increased rates of hospital admissions due to long-term health problems or frailty, subsequent delays in discharge from hospital, and growing demands for social care caused by heightened rates and levels of dependency have placed significant demands on services.

The 1990's saw the development of models of care to address these challenges which, collectively, came to be designated as 'intermediate care'.[1, 2] This concept became formally recognised and defined in the National Service Framework (NSF) for Older People[3] published in 2001: '...a new layer of care, between primary and specialist services…to help prevent unnecessary hospital admission, support early discharge and reduce or delay the need for long-term residential care' (p.13). In response to the NSF, and supported by £900m investment by government, new models of care, or practices, emerged.

The health care sector saw the development of admission avoidance and supported early discharge schemes – typically described, or defined, as intermediate care. Importantly, some – but not all – supported early discharge schemes specifically sought to restore an individual's ability to manage to look after themselves, perhaps independently, in their own homes.

Similarly, local authorities (LAs) began to develop interventions for individuals who presented concerns in terms of their ability to continue to stay well and live independently or, at least remain in their homes with low levels of support.[4] Importantly, these latter developments were informed by a challenge issued by the Department of Health and directed at LAs to develop approaches to care which reduced dependency on services and supported individuals to 'make most use of their own capacity and potential'.[5] These twin levers saw the emergence of services across the country which shared similar features: short-term and intensive support delivered in the home with a focus on regaining, or preventing, the decline of daily living skills and social participation. By the early 2000's this

approach had gained considerable traction and government support.[6, 7] The term 'reablement' was used to describe the approach and significant levels of investment made in the development of such provision. In other countries a similar shift in approach to providing social care support was also taking place; some also referred to this new approach as 'reablement'. Others, for example the USA, Australia and New Zealand, used the term 'restorative care'.[8]

1.2. The challenge of defining reablement

The past fifteen or so years have seen changing and inconsistent use of the terms 'intermediate care' and 'reablement' both within policy[9] and as applied to specific health and social care provision. In terms of the latter, the criteria, or 'labels', applied to different government funding initiatives – typically directed via health to encourage integrated planning – go some way to account for this.

Within the context of this study, it is not useful or necessary to recount these changes in great detail. However, this lack of a shared definition was something which had to be explicitly addressed in developing the bid for funding and the study protocol. Indeed, the lack of an agreed description of reablement using a standard intervention framework[10] continues to present a significant challenges to those seeking to review existing evidence and those conducting primary research.[11]

1.3. Defining reablement for the purposes of the study

This study was commissioned in mid-2014, and arose from a commissioning call issued by NIHR in early 2013. From the outset, it was essential that a clear definition of reablement was established which was relevant and meaningful in terms of current policy and practice, and carried reference to the concepts of intermediate care and rehabilitation. An analysis of recent evaluative literature[12, 13] and current policy and practice guidance documents[8, 14] was therefore carried out. It was clear from this exercise that two key characteristics distinguish intermediate care and reablement from other health and care services:

1. the objectives of intermediate care/ reablement; this is: acute admission avoidance at the point of clinical need for acute care; early supported discharge after acute admission; longer-term avoidance of unplanned hospital admission; reduction in the use of home care services; avoidance of admission to long-term care;
2. the time-limited nature of the service offered (usually up to a maximum of six weeks). This is the key defining characteristic that distinguishes intermediate care or reablement from, say, generic rehabilitation services.

A further characteristic emerged as distinguishing reablement from intermediate care; this is its restorative, self-care approach. In other words, a reablement service is about enabling people to regain or retain self-care function for themselves, rather than providing input that *replaces* that function (for example, reablement teaches people how to cook for themselves again, rather than providing meals on wheels). Table 1 sets out these distinctions, and overlaps, between reablement and intermediate care.

Table 1: Distinguishing between intermediate care and reablement

INTERVENTION CHARACTERISTICS			TYPE OF INTERVENTION
Objective	*Time-limited?*	*Restoring self-care abilities?*	*Intermediate care or reablement?*
Acute admission avoidance at the point of clinical need for acute care	Yes	Not usually	Intermediate care
Early supported discharge after acute admission	Yes	Sometimes	Reablement if it includes a restorative element, otherwise intermediate care
Longer-term avoidance of unplanned hospital admission	Yes	Yes	Reablement
Reduction in the use of home care services	Yes	Yes	Reablement
Avoidance of admission to long-term care	Yes	Yes	Reablement

1.4. The study's definition of reablement

Drawing on the work referred to above, the following definition of reablement was used:

- Intervention objective:
    - to support people to regain or maintain independence in their daily lives.
- Intervention approach:
    - to restore previous self-care skills and abilities (or re-learn them in new ways) which enable people to be as independent as possible in the everyday activities which make up their daily lives for example, cleaning the house, shopping or bathing and dressing themselves, rather than having someone (such as an informal or formal carer) do things 'to' them or 'for' them.[8, 9] The provision of equipment may be used to support this.
    - individualised and goals-focused
- Population:
    - individuals returning home from hospital or other in-patient care setting following an acute episode;
    - individuals where there is evidence of declining independence or ability to cope with everyday living.
- Nature of intervention delivery:
    - intensive;
    - time-limited (up to 6 weeks);
    - goals-focused;
    - delivered in the usual place of residence.

This definition aligns with current policy and practice guidance.[15, 16]

1.5. Subsequent developments in policy and definitions of reablement

During the period the study was underway the 2014 Care Act[16] – heralded as the most significant reform to social care in over sixty years – became law. Full implementation of the

Act is on-going, but Phase 1 implementation had significant implications in terms of the perceived role of reablement within the wider portfolio of social care provision.

First, reablement was presented as one of the core interventions which can delay, or reduce, demands for care services and keep individuals living independently in their own homes. To this end, LAs are now required to consider providing reablement before, or alongside, carrying out a needs assessment. Further, this approach should be considered both for individuals not previously known to adult social care and existing users. Second, reablement was presented as an intervention falling under the umbrella term of 'intermediate care', and was specifically identified as having the function of helping individuals leave hospital in a timely way and regain their independence. The need for integrated working with health services to deliver this was made explicit.

Together, these elements of the Care Act – and the continued growing and significant concerns within the National Health Service (NHS) about delayed discharge of older patients[17] - have seen the emergence, and adoption, of 'Discharge to Assess' pathways, with these pathways including discharge to social care for assessment and reablement[18].

The recently published 2017 NICE guidance (Intermediate Care Including Reablement)[15] makes clear that, as an intervention, reablement is regarded as one of the four core elements of 'intermediate care', the other three elements being (health) crisis response, and bed- and home-based intermediate (health) care. It is important to note that the guidance continues to represent reablement as being distinctive in its restorative approach and focus on supporting independence in self-care and everyday life skills, and with social care leading on its delivery. The guidance also stresses the need for integrated working within the context of providing intermediate care.

These significant changes in health and social care policy and guidance had two important implications for this study. First, it meant that changes to services and service developments were happening during the study period (2014-2017), and are on-going. Second, it signals that, as an intervention, reablement is highly topical and likely to remain a core aspect of meeting the health and social care needs of older people. As a result, the findings from this study are highly relevant and timely.

1.6. Existing evidence on reablement

The recently published NICE guideline (Intermediate care including reablement)[15] offers a useful review of existing evidence.

It concludes that the quality of existing evidence on the effectiveness of reablement is not as high as for other forms of intermediate care (for example, home-based or bed-based intermediate care). To date, there have been just three comparative evaluations, of variable quality, which have used randomisation,[12, 13, 19] none of which are UK-based. Among a further four non-randomised comparative evaluations,[20-23] two were carried out in England: both these studies reported in 2010.[20, 21] On the basis of this set of evidence, the following conclusion was drawn: "There is a moderate amount of moderate quality evidence that reablement is more effective when compared with conventional home care" (p.137). [15] It was noted that the evidence was most consistent and positive with respect to care needs or impact on service use. Similarly, overall, findings related to quality of life and ability to carry out activities of daily living suggest reablement is an effective intervention, though this was not found in a low quality trial.[12, 13] NICE also report they did not find any evidence on cost-effectiveness which was relevant to the UK.

A separate set of evidence concerns issues of the design of reablement services. Here low to moderate quality evidence indicates that access to particular specialisms (for example, physiotherapy, occupational therapy) may influence the effectiveness of reablement.[20, 24, 25] In addition, there is reasonable evidence to suggest that the skills of reablement workers may impact on outcomes.[25, 26] For example, judging the timing and degree of support to offer a service user when carrying out a task, increasing service users' confidence and motivation. Two studies conclude that reablement services should include the ability to respond to users' goals which concern their social or leisure lives, which for some users will be a high priority or have the greatest impact on their lives.[26, 27] Finally, there is some indication that service models should incorporate the ability to be flexible and responsive to user needs and progress.[25] However, this may have implications for service users' views and experiences of the service.[24, 25]

Some existing studies have investigated issues related to the characteristics of the service user. There is reasonable evidence that individual motivation may impact on the effectiveness of reablement.[25, 26] More specifically, there is weak to moderate quality evidence – primarily based on practitioner views – that individuals with end of life care needs or complex needs should not be referred to reablement services.[20, 21, 28] No studies have investigated the effectiveness of reablement in people living with dementia.

Finally, in terms of service users' and family members' views and experiences, the key issue identified by existing research is the potential lack of understanding of the objectives of reablement, and the fundamental difference of approach compared to home care.[24, 25, 27, 28]

A number of other systematic reviews of reablement have been published recently.[11, 29-31] Their inclusion criteria (in terms of study design and quality) vary and, as a result, the conclusions drawn differ somewhat. However, all note the pressing need for further research due to the core place given to reablement within health and social care policy, particularly with respect to older people and the investment in services delivering this intervention.

1.7. Evidence gaps

Studies into the effectiveness of reablement *per se* are beginning to be reported though, as noted above, more are required. A further gap in evidence concerns the way to deliver reablement. [15] Since the early days of 'reablement' in the late 1990's different localities and sectors have developed different service models by which to deliver this intervention.[8, 15, 32] Thus, in addition to evaluating the impact of reablement with a no-intervention comparator group, a complementary stream of research is required which looks at different approaches – or service models – to providing reablement. In addition, whilst there is some evidence on factors which may impact on intervention outcomes (for example, service user characteristics such as motivation/engagement, reason for referral to reablement, co-morbidities, and living circumstances), clearly, further work in this area is required and particularly with respect to factors which are amenable to intervention. Finally, and also highlighted in the recently published NICE guidance[33], increasing the evidence-base on costs

and cost-effectiveness of reablement, and providing reablement to people with dementia are both important priorities.

1.8. Study aims and objectives

This study was funded by NIHR in response to a commissioned call which sought research proposals addresing the following over-arching questions: How effective are reablement services in enhancing self-care and independence in the population they are designed to cover; and how are they best delivered?

In responding to this call, we chose to focus on some of the specific evidence gaps discussed in the previous section. Table 2 sets out the study aims and associated objectives.

Table 2: Study aims and objectives

Aim	**Objective**
To establish the characteristics of generic and specialist reablement services in England.	Undertake a national (England) survey to map different models of reablement services that currently exist. (Work package 1 (WP1))
To establish the impact of different models of reablement on service-level and service user outcomes	Using an observational cohort study design, to carry out outcomes and economic evaluations of different generic reablement models. Follow-up timepoints are to be at discharge from reablement and six months later. In addition, to carry out a nested process evaluation to understand the views and experiences of all relevant stakeholder groups. (Work package 2 (WP2))
To establish the impact of different models of reablement on different groups of service users.	
To establish the indicative costs for the health and social care system of different models of reablement.	
To establish how local context influences the ability of reablement services to achieve their goals.	
To establish how specialist practice/services has developed for individuals with complex needs or 'atypical' populations who would benefit from reablement.	To carry out a qualitative study of specialist reablement practice and service models. (Work Package 3 (WP3))

Thus the focus of the study was not the effectiveness per se of reablement. Rather its aim was to evaluate and compare existing reablement service models and to also conduct a smaller, parallel piece of work focused on reablement for groups where adjustments to a generic model of provision may be required (e.g. young adults, people with dementia).

1.9. Structure of the report

The report comprises ten chapters. Chapter 2 provides a high level overview of the study and reports deviations to the original protocol. Chapter 3 reports on Work Package 1 (WP1), the national survey of reablement services, and the reablement service models derived from that work. Chapter 4 describes the selection and recruitment of research sites for Work Package 2 (WP2) and provides a description of the characteristics of each site. In Chapter 5 we report the outcomes evaluation (WP2a). Chapter 6 describes one element of the process evaluation (WP2b), namely the interviews with reablement staff. In Chapter 7, we report second element of WP2b: the user perspective. The economic evaluation (WP2c) is reported in Chapter 8. Chapter 9 turns to WP3, the qualitative study of practitioner views and experiences regarding reabling people with dementia. Chapter 10 discusses the implications of the study findings for health and social care, and recommendations for future research.

Chapter 2. Overview of study design and methods

2.1. Introduction

This chapter provides a broad overview of the design of the study and any deviations from the protocol. A detailed description of objectives, design and methods are described in the chapters reporting the various aspects of the study. The original protocol for the study has been published.[1] However, deviations from this protocol were required all of which were discussed with the project's Study Steering Committee and approved by NIHR.

2.2. Study design and structure

The study comprised three work packages:

- **Work package 1 (WP1):** Mapping reablement services and the development of a typology of reablement service models.
- **Work package 2 (WP2):** A mixed-method comparative evaluation of up to four reablement service models, as identified in WP1, investigating outcomes, costs, cost-effectiveness and service user and practitioner experiences.
- **Work package 3 (WP3):** An investigation into specialist reablement services/practice approaches, and the rationale for adjustment made to generic provision.

A survey was used to map reablement services (WP1). An observational study design was used to generate quantitative and qualitative evidence regarding the outcomes, effectiveness and cost-effectiveness of different reablement service models and the factors affecting individual outcomes (WP2). Qualitative methods elucidated descriptions of practice and practitioners' views regarding the provision of reablement to people with dementia. WP1 preceeded WP2 and WP3. WP2 and WP3 ran concurrently. The study was carried about between October 2014 and November 2017.

2.3. Ethical considerations

WP 1 was defined as a service audit by the Health Research Authority and did not require ethical approval. For WPs 2 and 3 ethical approval was obtained from the North East York Research Ethics Committee (REC), UK (REC reference 15/NE/0299). Substantial amendments (arising from deviations to the original protocol) were approved by this REC.

2.4. Public and service user involvement

We worked with public and service user representatives throughout the project. During the project design phase, we consulted our research unit's long-standing Adults, Older People and Carers Consultation Group about the proposal we were developing. We also sought advice from professionals who represent voluntary sector organisations supporting people who use reablement services. These discussions highlighted several issues which informed our decision-making:

a. The need to track the use of health/community/social services and not just hospital services.
b. The belief that in-house and out-sourced services may be different, with in-house teams regarded as 'care driven' and contracted out services perceived as 'profit driven'.
c. To compare, if possible, NHS and LA provision.
d. The importance of exploring the ethos/philosophy used by service managers.
e. The importance of examining how multiple impairments impact on outcomes and how they are addressed by reablement services.

Throughout the project we updated, and sought feedback from, this group. This helped us to be certain that the aims of project remained important to the public, as well as service commissioners and providers, and that outcome measures were relevant to service users.

The Study Steering Committee (SSC) included service users who had experience of reablement services and representatives of voluntary sector organisations supporting people who use reablement services. Throughout the project, the SSC provided advice on

methods, research materials and project management. The service user and public representatives were contacted between meetings for feedback on recruitment and data collection materials. The SSC also provided a forum for the research team to discuss initial research findings and consider their implications. Members were kept up-to-date between meetings with a 3-monthly newsletter.

2.5. Work Package 1 (WP1): Mapping reablement services and developing a typology of reablement service models

The aims of WP1 were to generate 'stand-alone' evidence on reablement services in England and to develop a typology of reablement service models. This typology was then used to identify and select (up to) four service models for evaluation in WP2. It was also used to provide preliminary evidence, and inform sampling decisions, for WP3. Survey methodology, comprising a three-stage process, was used:

i. identification of all reablement services in England;
ii. identification of a key informant(s) in each reablement service;
iii. data collection from these key informants.

2.5.1. Deviations from the protocol

There were no deviations from the original protocol.

2.6. Work Package 2 (WP2): An evaluation of different models of providing a generic reablement service

The purpose of Work Package 2 (WP2) was to evaluate different reablement service models in terms of service user outcomes, the experiences of delivering and receiving reablement, and the relative costs and cost effectiveness of the models. It comprised three elements:

- WP2a: outcomes evaluation.
- WP2b: process evaluation
- WP2c: economic evaluation

Samples for WP2b weres drawn from the WP2a sample (service users) and WP2a research sites (staff). Service user-reported data for WP2c was collected within WP2a data collection processes.

We encountered significant issues with this work package with respect to:

i. recruiting research sites;
ii. study set-up in the research sites;
iii. with some research sites, much lower than expected throughput which significantly affected recruitment.

The first two issues caused considerable slippage in the project timetable. Given this, and coupled with very slow rates of recruitment in two research sites, the decision was made not to extend the study until sample size requirements had been achieved across all research sites. As a result, the study closed early in three sites, and recruitment was not started in the final site. Deviations from the protocol are detailed later in this section.

2.6.1. WP2a: The outcomes evaluation

The original objectives of the outcomes evaluation were as follows:

- to conduct a quantitative, comparative evaluation of the effectiveness of the four reablement service models identified by WP1 in terms of service user outcomes at discharge and 6 months post-discharge;
- to explore and test the impact of service (for example, in-house vs contracted-out provider; skill mix on the team) and user characteristics (for example, reason for referral, co-morbidities, engagement with the intervention) on outcomes.

The evaluation design was an observational study of a cohort of service users receiving reablement from one of four reablement services across England - each identified as typical of one of the service models identified in WP1 – in which outcomes were tracked from entry to the service (T0), at discharge (T1), and at six months post discharge (T2). Self- and

practitioner-reported outcome measures were used. Data collection from service users was via home visits.

Difficulties with under-recruitment within the study timeline required the following changes to the objectives and design of WP2:

- significant under-recruitment in two sites meant comparisons between service models was not possible;
- delays in the study and the decision not to extend to accommodate these delays meant it was necessary to move the primary outcome time-point from T2 (6 months post-dischage) to T1 (discharge from intervention);
- the small sample size meant that exploration of the impact of user and service characteristics on intervention outcomes at T1 was only exploratory;
- only initial and exploratory analysis of T2 data would be possible.

The **revised objectives** – agreed with the Study Steering Committee and NIHR - were as follows:

- to provide a descriptive, exploratory description of changes in outcomes between entry to (T0) and discharge from (T1) a reablement intervention;
- to provide a descriptive, exploratory analysis of outcomes at 6 months post-discharge (T2), compared to outcomes at entry into (T0) and discharge from the intervention (T1);
- to explore whether outcomes at discharge from reablement are associated with:
    - individual characteristics
    - intervention delivery characteristics
    - service characteristics;
- to contribute to study design and methodological knowledge related to the evaluation of reablement interventions.

Deviations from the original protocol

Revised design and study objectives are reported above (section 2.6.1). Other deviations are reported here.

Number of service models represented in WP2

Due to significant delays in study set-up, one of the service models identified in WP1 was not represented in WP2.

Mode of data collection at 6 month (T2) follow-up in WP2

Due to early closure of the study and consequent loss of local study teams, some T2 data was collected via postal administration rather than home visit. Whilst a necessary deviation from the original protocol, this did allow us to collect some useful data on the impact of mode of administration on study retention.

The use of routinely collected service audit data

The original protocol included collecting 12 months service audit data from research sites (for example, 'destination' after discharge). However, it became apparent in WP1, and confirmed when approaching services to act as research sites for WP2, that this information was not routinely recorded by services. We therefore did not attempt to collect this data.

2.7. WP2b: The process evaluation

The overall aim of the process evaluation was to generate rich data – from the key stakeholders - on the delivery of reablement, the impacts of reablement, and how and why these effects may vary between individuals and different service contexts. The objectives of this element of the evaluation were therefore to develop an understanding of:

- the immediate and wider context in which reablement service models exist,
- the experiences of providing and delivering reablement, and what impacts on the process of service delivery,
- the different effects reablement can have on service users
- how, and why, these effects vary between recipients and different service models.

A qualitative descriptive case study approach was used, with the unit of analysis being the delivery and receipt of reablement. We sought the perspectives of service users and family members, service leads, reablement assessors, reablement workers, and commissioners. Individual interviews and focus groups were used to collect data.

Deviations from the protocol

There are two deviations to report. First, we had planned to identify and recruit reablement workers via service users participating in the process evaluation. The reason for this was to allow to explore different perspectives with respect to the same delivery of reablement. However, the use of multiple reablement workers with a single case in some research sites meant this was not appropriate. Second, we had planned to use individual interviews with reablement workers. We revised this to using focus groups, believing this would generate a richer set of data since we were no longer seeking different perspectives with respect to specific instances of delivering/receiving reablement.

2.7.1. WP2c: The economic evaluation

The original objective of the economic evaluation was to evaluate the cost-effectiveness of four reablement service models. This objective was revised in response to under-recruitment and early closure of sites. The revised objectives were:

- (As per the original protocol), to review the economic evaluation methods used to evaluate reablement, and use this to inform data collection for WP2c. This has been published.[2]
- (As per the original protocol), to develop a new instrument to collect data on resource use and costs from service users (the Services and Care Pathway Questionnaire SCPQ) and to explore the feasibility of using the SCPQ in terms of data quality (e.g. amount of missing data).
- To describe the costs of providing reablement using data collected during WP1 and WP2.
- To describe and compare resource use and costs for reablement at T0, T1 and T2.
- To explore whether the costs during receipt of reablement and in the 6 month period following reablement can be predicted in terms of service user and service characteristics.

Deviations from the protocol

For WP2c, a site-specific questionnaire collecting detailed information on case-load and costs of providing reablement was developed. Unfortunately, research sites did not answer the questionnaire. As a result, we were only able to calculate an estimate of the cost of providing reablement based on the information collected in WP1.

2.8. Work Package 3 (WP3): An investigation into specialist reablement services/practice approaches

The aim of WP3 was to investigate the organisation and delivery of reablement services to people with specialist needs.

Findings from WP1 indicated that the majority of specialist provision or practice concerned people with dementia. With support from the Study Steering Committee, and with agreement from NIHR, WP3 therefore focused exclusively on this population.

This work package comprised:

- a case study of 'adapted or extended practice' within generic reablement services and of specialist provision across ten case sites,
- an investigation into the costs of such provision in each site.

Qualitative interviews with service leads and reablement workers were used to investigate the approaches, service structures, practices and experiences of providing reablement to people with dementia. Data on service costs was collected via a structured questionnaire administered during the interview with service leads. Data was collected during January to July 2016.

2.8.1. Deviations from the protocol

There were no deviations from the original protocol.

Chapter 3. WP1: A National Survey of Reablement Providers

3.1. Introduction

The main purpose of WP1 was to provide a current picture of reablement provision in England. This included describing the organisational, structural and skill-mix features of reablement services and the scope of reablement being delivered, and then looking at how these features affect intervention objectives, operating practices, referral routes, assessment tools and processes, outcome measurement and destination following discharge. It also sought to establish the costs of reablement.

Findings informed a number of elements of the evaluation work package (WP2) including: selection of sites, decisions regarding the selection of explanatory variables within the outcomes analyses, and the topics covered in the process evaluation. WP1 data were also used to identify the focus of, and thereby potential services to approach, for WP3.

3.2. Methods

3.2.1. Identification of reablement services

All local authorities (LA) (n=152) in England were contacted for the details of individuals commissioning reablement in that locality. Thirteen LAs declined to provide this information (n=8) or did not respond (n=5). Clinical commissioning groups (CCGs) in these localities were therefore contacted; however, this did not identify any reablement services.

Introductory emails, followed up with telephone reminders, were used to contact the commissioners identified, inviting them to complete a brief screening survey which was administered via a structured telephone interview (see Report Supplementary Material (RSM) 1). This established whether the individual was commissioning any services that potentially fulfilled our definition of reablement (see Box 1). Where a service was identified, the commissioner was asked for the name of the service and contact details.

Box 1: Overview of study intervention's inclusion criteria

- **Intervention objective**: to support people to regain or maintain independence in their daily lives.
- **Intervention approach**: to restore previous self-care skills and abilities (or re-learn in them new ways) using a goals-focused approach.
- **Population**: individuals returning home from hospital or other in-patient care setting following an acute episode; individuals where there is evidence of declining independence or ability to cope with everyday living.
- **Nature of intervention delivery**: intensive; time-limited (up to 6 weeks); delivered in the usual place of residence.

3.2.2. Confirmation service fulfils inclusion criteria and identification of 'key informant'

Service managers/service leads of services identified by commissioners were contacted the research team via telephone or email to check t the service fulfilled study inclusion criteria. In localities where commissioners had reported more than one service, we also clarified whether these were separate as opposed to being a locality team, or out-sourced provider, within a wider service. The algorithm used to screen services into the survey sample was as follows:

Service helps people to leave hospital more quickly than they would otherwise
AND/OR
Service helps to prevent admission to long-term care when people are at risk of it
AND/OR
Service helps to reduce people's need for home care (social care)
AND/OR
Service helps prevent longer term avoidance of unplanned hospital admission
AND
Service helps people to regain everyday living skills
AND
Service is provided in person's usual place of care
AND
Service is time limited (usually six weeks but may be some flexibility round this)
AND
Service users are not charged for the service

Service managers/service leads were then asked to confirm they were the most appropriate individual to act as 'key informant' with respect to the service (that is, most able to provide detailed information about the service).

3.2.3. Survey of key informants

Across the 139 LA's where commissioners had provided information to the research team, 181 reablement services were identified. In the majority of LAs (n=106; 76%) one reablement service was identified. In 28 LAs (20%) two separate services were identified, and a further 5 LAs (4%) reported three or more separate reablement services. Outside of this process, the research team was notified about, or became aware of, additional services which potentially fulfilled the study inclusion criteria. The same process was used to screen these services: two were out of scope and one LA declined to provide the information required. In total, therefore, key informants of 201 reablement services were invited to take part in the survey.

The survey was administered via email and completed electronically using Qualtrics© survey software (Qualtrics, Provo, UT). The survey questionnaire (see Appendix 1) collected information about service delivery and organisational characteristics previously identified as important in terms of process and intervention outcomes in these types of services.[2-4] It also collected information on service costs and funding.

Email reminders and telephone calls were used in cases of non-response. Email and telephone calls were also used when responses were unclear. After excluding surveys which were minimally completed, a response rate of 71% was achieved (n=143/201).

3.2.4. Plan of analysis

We used five variables to describe the core characteristics of the reablement services represented in the survey. Three were derived directly from survey questions: **organisational base**, **organisational structure** and **contractual arrangements**. Two were derived from cluster analysis of survey data with respect to **staffing** and **reablement input provided**. These core characteristics provided the framework for subsequent analyses which explored the way reablement was being implemented and delivered.

3.3. Findings

Survey findings are reported in three sections:

- the core characteristics of reablement services
- service provision and delivery
- the costs of reablement

Data not presented in the text are provided in Appendix 2.

3.3.1. The core characteristics of reablement services

Organisational base

Survey respondents were the individuals identified as the person able to provide most information about individual services. The organisational base of over half (53%) respondents was a LA social services departments (SSDs). Fifteen per cent were based in an integrated NHS and LA organisation and 4% in the NHS. Of the remainder, 14% were based in a private (for profit) organisation or the voluntary (not for profit) sector (7%). A very small proportion were based in a social enterprise (n=4) and or LA trading company (n=3).

Organisational structure

Just over half of services (52%) were a separate, or stand-alone, service. The remainder were located within a wider organisation; 18% were reported to be part of intermediate care (IC) provision, 13% part of home care provision, and 4% part of an early intervention/rapid response service. One service was described as part of 'other intermediate community' provision and two part of an independent living service. Finally, three were described as being part of mental health service provision.

NHS-based services were more likely, and those based in LASSDs less likely, to be part of IC provision within a locality. In addition, LASSDs were more likely, and NHS organisations less likely, to be providing a reablement service that was separate from other IC provision in the locality ($\chi 2=29.94$, df=16, p=0.018).

Contractual arrangements

Two thirds of services (66%) were described as being wholly 'in-house' to their organisational base. A fifth had both 'in-house' and 'contracted out' elements and 7% were wholly contracted out to another organisation. A small minority described other arrangements. Contractual arrangements were not related to a service's organisational base or structure.

When some aspect of a service was 'contracted out' (38/143 services) this was most often the delivery of reablement support (n=20/38), as opposed to assessment of eligibility for the service (3/38) or the reablement assessment itself (4/38).

Staffing and skill mix

Cluster analysis was used to understand the different patterns of staffing and skill mix in the teams. There was sufficient data on 129/143 services (90%) for them to be assigned to a cluster. Four distinct patterns of staffing were identified (Appendix 2, Tables 20 -22):

- Cluster 1: *Reablement with occupational therapy* (OT) (n=24)
    - These services were very likely to have OT and social work involvement but, unlike the multi-disciplinary teams in Cluster 3 (below), it was unusual for them to have a registered nurse or health support worker.
- Cluster 2: *Home care reablement* (n=42)
    - All services in this cluster reported having home care workers and were also likely to report home care organisers and reablement workers. They did not typically have an occupational therapist.
- Cluster 3: *Multi-disciplinary reablement* (n=20)
    - All services in this cluster had OTs and physiotherapists. They were also highly likely to have registered nurses and more likely than any other type of team to include health support workers, although this was not typical.
- Cluster 4: *Reablement workers* (n=43)

  None of these services had home care workers but were highly likely to have reablement support workers and unlikely to have any of the other staff listed.

Bi-variate analyses explored patterns of association between staffing and organisational characteristics. Key findings are reported below, further data are available in Appendix 2, Tables 22 - .

Staffing and organisational base

'Reablement with OT' teams were most likely to be found in LASSDs (28% compared with 19% of all teams), while services based in the NHS or integrated health/social care services were most likely to have 'multi-disciplinary' teams (39% and 67% respectively, compared to 16% of all teams). Third sector services were more likely to be 'home care reablement' teams (54% compared with 32% of all services). These differences were statistically significant ($\chi 2=44.97$, df=12, $p<0.001$).

Staffing and organisational structure

Over two thirds (68%) of reablement services being provided within wider home care provision had 'home care reablement' teams (68% compared to 30% of all teams). By contrast, half of services that were part of wider IC provision had 'multi-disciplinary reablement' teams (50% compared to 16% of all teams). These differences were statistically significant ($\chi 2=51.40$, df=12, $p<0.001$).

Type of reablement input

Respondents were asked about the scope of reablement provided; that is, the domains of an individual's life which they sought to 're-enable' and which domain was the focus of the majority of the service's input. (It was stressed that respondents should only report what they *enabled* service users, as opposed to *what they did for them*.) The domains were:

- personal care
- domestic tasks
- safety (including preventing falls and providing aids and equipment)
- information and signposting to other services or support
- getting around in the home
- getting out and about outside the home
- re-engaging with social activities and friends
- managing health-related needs

- specific activities to help rebuild confidence and improve well-being.

Personal care re-enabling was the predominant activity, and the one that made up the majority of services' work. Helping people to get out and about again outside the home and to re-engage with social activities were least commonly reported. Bivariate analysis suggested that patterns of reablement input varied systematically in terms of the organisational characteristics (organisational base, organisational structure, contractual arrangements) of the services (see Appendix 2, Table 23 - 26).

Data reduction, again using cluster analysis, produced three stable and fairly distinct clusters of type of reablement input for 136/143 of the services:

- Cluster 1: *'Functional' reablement* (n=40)
    - These services reported that they re-enabled personal care, domestic skills, safety, information, helping people to move about inside, health-related needs and confidence building.
- Cluster 2: *Comprehensive reablement* (n=87)
    - These services said that they re-enabled in all the domains. Thus they were similar to services delivering 'functional' reablement, but *also* helped with people getting out and about and with social activities.
- Cluster 3: *Social reablement* (n=9)
    - These services reported that they re-enabled in the areas of safety, information, getting out and about, social activities and confidence building.

Type of reablement input and staffing

Multi-disciplinary teams were more likely than expected, and 'reablement worker' teams less likely, to be providing comprehensive reablement (see Appendix 2, Table 27). Indeed, 'reablement worker' teams were the only ones associated with providing social reablement.

3.3.2. Service provision and delivery

The final stage of analysis examined the way reablement was being provided and delivered in terms of the following:

- Service objectives
- Operating practices (referral pathways, eligibility criteria, reabling individuals with specialist needs, duration of reablement and charging policy, assessment and monitoring of outcomes)
- Destinations following discharge from reablement

We also explored whether the core service characteristics described in the previous section (3.3.1) were associated the provision and delivery of reablement. Constraints of space mean that we are limited in the level of detail reported.

Service objectives

Respondents were presented with a list of service objectives and asked to select all that were part of the purpose of their service, and to identify the main objective. The objectives, drawn from policy and existing literature on the reablement and/or IC were:

- help people regain everyday living skills
- reduce the need for ongoing (social) home care
- prevent longer than necessary stays in hospital
- prevent admission to long-term care when at risk
- prevent hospital admission during acute illness

The majority of respondents selected most of these objectives, but one ('prevent hospital admission during acute illness') divided the services almost equally (Appendix 2, Table 28). NHS-based services were significantly more likely to report this as an objective than were other services ($\chi2=12.49$, df=4, $p=0.014$). The most often reported main service objective was to 'help people regain everyday living skills' (58% of services), with LASSD based services more likely to report this than others ($\chi2=56.38$, df=24, $p<0.001$). Only two services

reported ‘preventing hospital admission during acute illness’ as their main objective and, as might be expected, both of these were based in the NHS.

Services staffed by a multi-disciplinary team were more likely to report ‘preventing hospital admission during acute illness’ as a service objective (40% compared to 16% of all services). This was the only difference in objectives found across the different staffing models.

Operating practices

Referral pathways

Existing literature and our own preliminary work indicated that referrals to reablement services occurred in one of two main ways. Either everyone referred for home care or domiciliary support was first referred to the reablement service, *or* referral was selective (for example, for those being discharged from hospital, those felt to be at risk of admission to long-term care, or those whom another professional felt might benefit from reablement). Survey respondents were asked to choose which of these two models best represented their service.

Just over half of respondents (52%) reported that access to their service was selective, 24% non-selective, and 15% described other models, often incorporating some element of triaging. Over a third of LASSD services (38%) reported that reablement was provided to all referrals for home care. Few services (27%) reported accepting self-referrals.

Not unexpectedly, a greater proportion of referrals to NHS based services and/or those operating within wider IC provision were from primary care, compared to services with different organisational bases or relationships to wider IC within their locality (see Appendix 2, Table 29).

Eligiblity criteria

The majority of services (88%) represented in the survey accepted adults aged 18 years and above, imposing no upper age limit. However, social reablement was strongly associated with providing services to adults aged 18 to 65 only ($\chi 2=39.41$, df=6, $p<0.001$).

The majority of services (86%) reported meeting the needs of a wide range of people, we defined these as ‘generic services’. We asked such services whether individuals who might

have specialist needs –people with dementia, younger disabled adults (to the age of 65), people with learning disabilities, people with brain injury, and people with sensory impairments - were eligible for their service. The great majority reported they accepted referrals of individuals with these needs, see Table 3.

Half of respondents stated that their service applied other exclusion criteria, assessed either at referral or following assessment and some provided information about this. The most frequently reported criterion was that the person was at the end of life and/or needed palliative care. This was followed by the person not having reablement 'potential' (29%), the presence of cognitive impairment or dementia (28%), identified risks to care staff (19%), the client having longer-term care needs (17%), and evidence of a lack of engagement with the reablement process (13%). Over a third reported other exclusion criteria

Reabling individuals with specialist needs by generic reablement services

Services reporting they provided reablement to individuals who, potentially, might have specialist needs were asked whether the service had specialist pathways and/or protocols for such individuals. Few reported having specific pathways or protocols in place (see Table 3).

Table 3: Specialist needs accepted & the presence of specialist pathways or protocols

Specialist group	**Services accepting individuals with specialist need (%)**	**Services that accept and have specialist pathway/protocol (%)**
People with dementia	87	24
Younger disabled adults (<65)	89	8
People with learning disabilities	81	20
People with brain injury	80	12
People with sensory impairments	89	20
Total N	123	123
Missing	20	20

Duration of reablement and charging policy after-six weeks

An intervention period of a maximum of six weeks has been a key feature of reablement in the UK since its inception in the early 1990s. In England it remains as the period of time during which service users cannot be charged. After this, LA and integrated NHS/LA

providers have the option to charge for the service, in the same means-tested way that home care services are charged for.

Respondents were asked about the typical duration of reablement. Four out of five respondents reported it was between four and six weeks, and 13 per cent as fewer than 4 weeks (see Appendix 2, Table 30). An intervention period of less than four weeks was significantly associated with services defined as providing 'functional reablement', as opposed to 'comprehensive reablement' ($\chi 2=27.21$, df=6, $p< 0.001$).

The majority of services (85%) reported that the intervention period could be extended beyond six weeks in certain circumstances. The reason for extension was typically due to difficulties with onward referrals or finalising care packages (83%), rather than there being an expectation that extending the intervention would result in further improvement (22%). Of the services reporting that the duration of intervention could extend for more than six weeks, almost two-thirds (61%) said there was no limit on this time period. In the remaining services, the duration of extension ranged from seven to 21 days.

Fewer than a third of respondents (28%) reported that service users were charged after the first six weeks. However, charging policies varied in terms of the organisational characteristics of services. LASSD based services were much more likely than those based in the NHS or in integrated NHS and LA organisations to report charging after six weeks ($\chi 2=19.47$, df=8, $p=0.013$). Similarly, services that were part of wider home care provision were also more likely to report charging after six weeks ($\chi 2=16.75$, df=8, $p=0.033$) compared to those with other organisational structures. Wholly contracted out services were more likely (75%), and those comprising both in-house and contracted out elements less likely (14%), to report charging after six weeks ($\chi 2=12.84$, df=6, $p=0.046$).

Approaches to assessing and monitoring outcomes

Respondents were asked about the types of assessment carried out once an individual had been accepted by their service. Assessment, and tracking progress, may be informed by setting and reviewing personalised goals, using standardised measures, or other methods.

Most (73%) reported that assessment processes were multi-faceted covering: planning how reablement could meet the person's needs (85%), setting specific goals for reablement

(79%), conducting a wider, full needs assessment (70%), and assessing any other needs (64%). Four respondents reported their service followed a reablement programme set by another service. Just one respondent referred to carrying out 'baseline' assessments for outcome measurement purposes.

Goal setting

Of the services using personalised goals (n=118), 92% said that they always set the goals in partnership with the user, and this was done before reablement started (49%) or soon after (42%). Most services (83%) said that they used staff's professional judgement regarding achievement of personalised goals to monitor service users' progress.

OTs were the professionals most often involved in goal setting (56% of services), followed by reablement care workers (42%), physiotherapists (36%), social workers (35%), and nurses (12%). Almost half (45%) referred to a wide range of other people involved in goal-setting, including 'assessors' not otherwise described, care managers, reablement managers or co-ordinators, and care co-ordinators.

Staff involved in goal-setting varied according to some service characteristics (see Appendix 2, Table 31). OTs and nurses were more likely to be involved when the services were 'multi-disciplinary' and/or when the service ran as part of or alongside an IC service. They were less likely to be involved in where the reablement service was 'standalone' as opposed to being situated within a wider service/provision. This was also the case for physiotherapists, but they were also more likely to be involved with NHS-run services. Nurses were also more likely to be involved when the service was based in the NHS, and less likely to be involved in LA-based services. In terms of the impact of type of reablement input on the staff involved with goal-setting, OTs were less likely to be involved in goal setting in social reablement.

Use of standard approaches for assessment and review

Of the 33 services that said they used 'standard measures' to assess progress towards reablement goals, almost all assessed mobility, quality of life, physical health and activities of daily living (ADL). Fewer, but still the majority, assessed mental health and social and personal outcomes.

However, very few services reported using *standardised* measures. Just five reported using a standardised measure to assess mobility and quality of life, three used them for physical health outcomes, four for mental health outcomes, three ADLs, and two social and personal outcomes.

'Multi-disciplinary' teams were more likely to use standardised measures of ADLs (50% compared to 10% of all services, $\chi 2=16.98$, df=9, p 0.049), and/or NHS teams (20% compared to 10% of all services, $\chi 2=16.91$, df=9, p=0.05). Small sample and sub-sample sizes mean that interpretation must be cautious, but these patterns do suggest different approaches that echo other differences between services reported.

Use of assessment tools other than personalised goals to review progress

Just a quarter of services recorded outcomes (using an assessment tool other than personalised goals) at entry to the service *and* at some point later on. Thus, 30% of respondents reported assessment tools were only used at one point during reablement. Of those who reported that they assessed before the service started (33% of all services, n = 47), six then also assessed during the service, six towards the end of the service and 36 after the service episode was over. Some services indicated that follow-up extended well beyond discharge, with five mentioning reviews at six weeks and three months.

'Multidisciplinary services' were more likely than other services to record outcomes (using an assessment tool over than personalised goals) at entry into the service and later (55% compared with 36%), this difference was not statistically significant. Services situated within wider home care provision were very unlikely to assess outcomes before and at some later stage (5% compared to 33% of all services). No other service characteristics were related to whether services recorded outcomes (using an assessment tool over than personalised goals) on entry to the service or at some later timepoint.

Destination following discharge

Respondents were asked to indicate the most common 'destination' for service users at the end of reablement. Almost two-thirds (62%) reported that service users were most often discharged without an on-going care package. Eight percent said that people were most

usually referred on for assessment of their eligibility for other social care, five per cent said that services users most often moved into long-term care.

One in ten gave other answers, most suggesting that outcomes were split relatively evenly between independent living (albeit with possibility of involvement of informal carers) and ongoing requirements for care. Some said that while service users required further care, this was at a lower level than had previously been the case. Fourteen per cent either said that they did not know the answer to this question, or did not answer it.

Services run from LASSDs were more likely than others to say that the most common outcome for service users was discharge without any on-going involvement of care services (71% compared to 63% of all services). Services run jointly between health and social services were most likely not to know or not provide an answer to this question (50% compared to 12% of all services). Services in the 'other' organisational category were more likely to say that the most common outcome was transfer into long-term care (29% compared to 5% of all services). These differences were statistically significant ($\chi 2=26.39$, df=12, p=0.009) although many cell sizes were small.

Services providing 'functional' reablement were least likely to report users were discharged without on-going support (53% compared to 66% of all services), and were most likely to report transfer into long-term care (15% compared to 5% of all services). By contrast, 'comprehensive' reablement services were more likely to report discharge without other services being in place (74% compared to 66%), and least likely to report transfers into long-term care (1% compared to 5%). These differences were statistically significant ($\chi 2=14.79$, df=6, p= 0.022).

3.3.3. The costs of reablement

Questions on service budgets and caseload were used to gather data on the costs of providing reablement. It was outside the scope of the survey to collect information on regional variances in workforce costs, size of the population, their demographics and the local organisation of services. Therefore, the results presented here are descriptive. No inferences about reasons for differences in service costs, or the association between costs and effectiveness, can be drawn from these data.

Data collection and analysis took the perspective of the NHS and Personal Social Services (PSS). Therefore, the relevant costs were those falling on the budgets of the CCG (representing the NHS) and/or LA (representing PSS). Ideally, the costs reported by survey respondents represent the full economic cost to the commissioner of providing the service, including direct, indirect costs, and overheads. However, given it was not possible to corroborate the data provided by respondents, we cannot be certain of this. Further, the information provided may not necessarily reflect the full economic cost of providing the service. For example, if the provider is a private contractor, the cost of providing the service to the commissioner may be smaller than the cost charged to the commissioner to allow for profit; conversely, it may be larger if the service is provided at a loss.

The data collected

Respondents were asked to report for the 2014-2015 financial year. Different commissioning and contracting arrangements meant data had to be collected in different forms. Thus, expenditure (or 'spend') on the reablement service was collected as either:

- total expenditure for wholly 'in-house' services
- total expenditure for in-house and contracted out services where the service included both elements
- value of the reablement contract if the service was fully contracted out.
- where respondents did not know the answer to the question but the service was run from a LASSD, the NHS, or an integrated service, we asked for the cost of the service as a proportion of the budget for all older people's services.

The survey also asked about the number of reablement 'cases'. 'Cases' refers to the number of individuals who received the service, recognising that some individuals may use a service more than once.

The analytical approach

Data was summarised in terms of mean, standard deviation, minimum and maximum. Analyses were conducted only if the minimum cell count was greater than ten. Additional data are presented in Appendix 2 (Table 32).

Where respondents reported the total budget for older people's services and the percentage dedicated to reablement, expenditure on reablement was calculated by multiplying the two values. The typical number of cases to whom the service was provided was converted to cases per year. The average cost per case calculated by dividing the total expenditure in reablement in 2014-15 by the number of cases per year. The average cost per type of reablement service was explored using the core service characteristics described earlier (see Section 3.3.2) and by commissioner.

Findings

Expenditure on reablement

Around a third of respondents (42/143; 29%) provided information on expenditure. Most answers referred to direct expenditure on the reablement service (n=31; 22%). On average, expenditure was £2.6 million. Some respondents reported expenditure in terms of the expenditure on in-house (n=8; 6%) and on contracted out elements (n=7; 5%). Here expenditure on average was £1.5 million and £0.9 million respectively. Seven services reported expenditure as the proportion of the budget for older people's services devoted to reablement; their average expenditure was £1.7 million. Two services reported the total value of the reablement contract (£1.2 million and £0.2 million respectively). Overall, the average expenditure on reablement was £2.4 million. However, there was wide variation (range = £5,000 to £8.5 million).

Caseload

One hundred respondents (70%) provided information on annual caseload (n=81; 57%) or on the typical number of cases per month (n=19; 13%). On average, the caseload was 1,383 (range = 10 to 9,500).

Cost per case

It was possible to calculate the cost per case for 37 (26%) services. The average cost of per case was £1,445 (range = £20 to £2,235). Clearly, the value of £20 per case is implausible. (This value was derived from the respondent stating that their budget for older people's services was £1.5 million, the percentage spent on reablement was 1.33% (hence £19,950) and the reablement service saw 1,015 cases per year). Data provided by a further five

respondents yielded costs per case of below £500. Again, these are highly atypical. Excluding these six respondents increased the average cost per case from to £1,728.

Cost per case per type of reablement input

Of the services providing 'functional reablement' which reported costs (n=10), their average cost per case was £1,577 (range £533-£2,235). Of the services providing 'comprehensive reablement' which reported costs (n=24), the average cost was £1,512 (range=£20 to £3,333). Only six services providing 'social reablement' reported costs; we therefore did not carry out a calculation with respect to this type of reablement input

3.4. Summary

Reablement services varied in terms of their organisational base (LA vs NHS vs integrated service); over a half were LA services. Just over half were 'standalone' services, as opposed to integrated within wider IC provision in the locality. The latter was more likely to be observed if the service was based in the NHS. Most services were delivered by in-house teams. Where aspects of the service were outsourced, it was most likely to be with regards the hands-on delivery of the intervention, as opposed to assessment processes.

Services could be grouped according to the types of staff working in the service. Not all services had occupational therapists, LA-based services were most likely to have them. NHS or integrated services presented the most multi-disciplinary profile. It appeared that workers in some services have both home-care and reablement clients. The scope of reablement input varied between services. Some did not work on aspects of functioning external to the home environment: we labelled this functional reablement. Comprehensive reablement, which included reabling with respect to getting out and about outside the home and re-engaging with social activities and friends – was, however, the more common approach. The primary objective of services, and particularly among LA services, was to restore everyday living skills. Multi-disciplinary teams, which tend to be based in the NHS, were most likely to report preventing hospital admission as an objective.

Services varied in terms of the clients they worked with. Over a third offered reablement to all referrals for home care received by their LA. Just over a quarter accepted self-referrals.

The majority of services reported they accepted a wide range of people. The most commonly reported exclusion criteria were individuals requiring end of life care and where there was no evidence of reablement potential. Over a quarter of services reported cognitive impairment or dementia could be a reason to refuse a referral.

The typical duration of reablement reported was four to six weeks. Services delivering comprehensive reablement were more likely to report a longer duration than those delivering functional reablement. Most services reported they were able to extend the period an individual remained in the service, but this was predominantly attributed to delays in arrangements for longer-term care. Charging policies for extended involvement varied. LA based services were most likely to charge.

A small minority of services used standardised outcome measures. Professional judgement with respect to achievement of reablement goals appeared to be the predominant approach to assessing progress. Almost two thirds of services reported that, on discharge from reablement, only a minority were transferred to homecare services. Services providing functional reablement were least likely to report this as the typical outcome at discharge.

The section of the survey on costs was poorly completed. Where sufficient data was available, the average cost of reablement per case was calculated at £1,728. There was relatively little difference in cost between services providing functional versus comprehensive reablement.

Chapter 4. WP2: identification and description of research sites

4.1. Introduction

This chapter reports the selection and recruitment of services to WP2, each representing one of the service models identified by WP1. Each service is then described in comparison to the others. These descriptions are based on data collected during WP1, information gathered at meetings with services during site recruitment and study set-up, documentary material, and interviews with staff and commissioners within the process evaluation (WP2c).

4.2. Identification and recruitment of the case sites

WP2 was a mixed methods evaluation of up to four reablement services – each representing a different model of delivering reablement – using an observational study design. Identification of these service models was a key output of the national survey of reablement services (WP1) as reported in the previous chapter. Two concepts emerged from our analysis of the survey data which best served to distinguish reablement services: the type of reablement input, and staffing (see Chapter 3, section 3.3.1).

In terms of the type of reablement input, the survey identified three types: 'functional', 'comprehensive' or 'social' reablement. (The latter was very unusual and not relevant to WP2 as it is restricted to mental health settings.) The majority of services (60.8%) represented in our survey reported that they delivered 'comprehensive reablement'. 'Comprehensive reablement' fully adhered to what, at the time of the study, was understood to properly constitute a reablement intervention,[15, 16] and this remains the case[8]. Thus, for the evaluation phase, we only sought to recruit services delivering 'comprehensive reablement'.

The second concept which best differentiated services was staffing. Here, four 'types' emerged:

- ‘reablement with occupational therapy’
- ‘home care reablement’
- ‘multi-disciplinary reablement’
- ‘reablement workers’

For the evaluation, we therefore sought represent services delivering comprehensive reablement but which differed in terms of staffing.

Outputs of the WP1 cluster analysis of staffing typologies were used to identify services to approach regarding participation in WP2. Services closest to the centre of each cluster – in other words, best representing each staffing typology – were approached first regarding their participation in the evaluation. If the invitation was declined we moved on to the next ‘closest’ service. This continued until the involvement of a service was secured. Forthwith, we refer to these services as our research sites.

Unfortunately, significant delays experienced by the project led to the decision to close, rather than extend, the study. This meant that recruitment did not open in the research site which would have represented the ‘reablement worker’ typology.

4.2.1. Alignment of research sites to the designated service model

By the time recruitment of service users to WP2a commenced, the three research sites had undergone significant changes. Two key factors contributed to this. First, the continued implementation of the ‘Transforming Care’ agenda and the 2014 Care Act resulted in changes in relation to wider intermediate care provision, integrated working with the NHS, and Local Authority social care intake and assessment processes. Second, resource constraints had impacted on commissioning decisions. Examples of observed changes include: changes in private providers; the introduction of joint working arrangements with other services; reorganisation of intermediate care provision within the locality; and reversal of joint working arrangements between the local authority and NHS.

However, as this chapter reports, the research sites did represent differences according to a wide range of service characteristics which are highly relevant to policy makers, commissioners and service providers. It is also the case that different models of provision

were operating within a research site. It is the impact of these factors and characteristics which our evaluation was able to explore and test in terms of service users' outcomes and experiences, and the experiences of providing and delivering reablement.

4.3. The WP2 research sites

The checklist of features for describing complex interventions developed by Dorling et al (2014)[54] was used to determine the range of information on research sites reported. This information is presented in the following sections. We note that level of detail is constrained by the need to ensure anonymity of research sites. The information presented is correct for the time when recruitment to WP2 was open and the intervention was being delivered to study participants.

4.3.1. Overview of research sites

Information about the overall setting, location, and a high level description of the service and the wider service context are set out in Table 4. Sites differed in terms of their organisational context and socio-geographical characteristics. The core function of all sites was the delivery of social care assessment and reablement. All delivered reablement to individuals returning home from hospital and those living in the community at risk of significant increased demands on social care. Sites varied in the extent to which they were co-located within the wider IC offer in the locality. In two sites there was some degree of joint-working/integration of NHS and LA-funded IC provision. In the two sites using private providers for at least part of their reablement provision, private provider involvement in the study was limited in some way.

Table 4: Setting and summary description of research sites

	Site A	Site B	Site C
Service setting	Local authority.	Social enterprise commissioned to provide a range of community health and social care services.	Local authority
Commissioner	Local authority	Local authority	Local authority
Location	Small metropolitan borough geographical area in the northern half of England. Comprises rural, urban and industrial areas. Two main conurbations, occupying around a third of the land and where around two-thirds of the population lives. The remainder is predominantly rural. Population: > 300,000; higher than national average proportion aged 65+ years. Relatively deprived, with many areas of significant deprivation. Over 95% of the population are White British.	Small London borough. Population: < 200,000; lower than national average proportion of the population aged 65+ years. Overall deprivation rate is low, but a few areas of high deprivation rates. Almost two thirds of population are White British; no large representations of specific minority groups.	A large county in the southern half of England. Predominantly rural, it also has several large towns with sizeable populations. Population: > 1 million; higher than national average proportion of the population is aged 65+ years. Overall deprivation rate is low, but there are pockets of high levels of deprivation. The majority of the population (over 90%) are White British.

Service function	Assessment and reablement of individuals being discharged from hospital and those living in the community. Delivery achieved through an in-house assessment team and two private providers.	Assessment and reablement of individuals being discharged from hospital and those living in the community. Delivery achieved through in-house teams (separate assessment and reablement worker teams). Private providers used to deliver homecare when service operating a waiting list.	Assessment and reablement for individuals being discharged from hospital and those living in the community. Delivery achieved through in-house teams comprising assessment and reablement workers, and five private providers.
Essence of service's 'operational definition' of reablement	Not all/many clients – this proportion varied between services - will achieve significant functional improvements/independence, but any gains are worth trying to achieve and, aside from end of life care should be sought before moving to homecare.		
Wider intermediate care context	Separate referral routes into community and hospital 'assessment and reablement' services and a 'rapid response' service. Implementing a single referral point, with triage decisions taken by reablement assessor, social worker and nurse. Phone call with referrer used to inform triage process. The joint-funded NHS/LA 'rapid response' service responds within 4 hours and provides 72 hour intensive case	An integrated community health and social care team receives referrals for 'intermediate care', 'assessment and reablement', 'community nursing' and 'rapid response' services. Assessors working across 'reablement and assessment' and 'intermediate care' assess referrals and allocate to 'intermediate care' or 'reablement' care pathway. The 'Intermediate care' service is funded by the CCG. It provides short-	All other intermediate care provision delivered by NHS services.

	management. Service is for individuals at risk of being admitted or whose discharge requires intensive support.	term bed-based or home-based care and rehabilitation for individuals with temporary problems (eg. falls, fractures), no functional concerns and few co-morbidities.	
Participation of private providers inWP2a?	Declined participation in terms of staff completing measure of service user engagement at discharge.	n/a	Three private providers declined participation and this precluded service users allocated to them being included in the study.

4.3.2. Core service features

Table 5 presents the core service features of the research sites. Geographical size and population density determined whether there was a single, co-located assessment team, or locality/regional teams. The user profile in Site B is of greater functional impairment with many already known to social care. In this site, the pathway for 'non-complex' referrals – typically recovery from falls or fractures - is to an NHS funded intermediate care service for short-term input.

All sites used private providers for the 'reablement worker' workforce, though one site also had an in-house team of reablement workers. There were different models of working with private providers – and this occurred within and between sites - particularly in terms of whether assessment and review responsibilities were also out-sourced. All the services were LA commissioned and funded. Referral routes were similar though in one site different teams handled hospital discharge and social care referrals. This involved a joint working arrangement with the local hospital.

The degree to which assessors worked autonomously varied between services, reflecting level of qualification. In one site, the assessment team comprised occupational therapists (OT). In the other sites, no occupational therapists were core members of the team. However, in one of these sites, *all* referrals were jointly reviewed by the assessment and reablement team and the community OT team with, if appropriate, joint-working initiated. These two teams were co-located. For the services without OT within the core team, access to OT input was on a case-by-case basis. In terms of access to community health care services, in all sites this was on a case-by-case basis but expedited in Site B which was located within an integrated community health and social care organisation. Ad hoc advice from community health practitioners was also easier to access in this site compared to Sites A and C.

Table 5: Core features of reablement services

	Site A	Site B	Site C
Organisation of reablement assessment staff	Three locality teams and a single, hospital-based team.	A single co-located team.	Four regional teams.
User profile	Wide range of severity of functional impairment. Around half are re-abled to independence with the remainder moving on to package of care.	Severe functional impairment. Many already known to social care.	Wide range of severity of functional impairment.
Integrated working	Joint working arrangements with NHS with respect to referral processes for those being discharged from hospital.	Service is sited in an integrated health and social care organisation; however, no posts in the service are funded by the NHS.	No integrated working with NHS
Service delivery	Two models: ○ In-house staff assess, and review; private provider delivers 'hands-on' reablement and monitor. ○ In-house staff assess; private providers deliver hands-on reablement, monitor and also review.	One model: ○ In-house team assess, monitor and review ○ Separate in-house team delivers 'hands on' reablement.	Three models: ○ In-house staff assess, monitor and review and deliver 'hands-on'. ○ In-house staff assess and review; private provider delivers 'hands-on' reablement and monitor. ○ Assessment and review also carried out by private provider.
Occupational therapy within service?	No-one within the service is OT qualified. OT input secured on a case by case basis.	All assessors are OT-qualified.	No-one within the service is OT qualified. OT input secured on a case by case basis.
Access to community health services	Referral on a case-by- case basis	In same organisation and co-located with, dementia, continence, district nursing services. Easy to source advice and	Referral on a case-by-case basis.

		describe close-working‘ & ‘liaise’ with relevant services on a case by case service.	
Roles in assessment and review process	Team lead: accepts referrals, allocates cases, reviews complex referrals, oversees work of assessors. Assessors: carry out assessment and review processes.	Team lead: accepts referrals, allocates cases. Assessors: carry out assessment, monitoring and review processes.	Team lead: accepts referral, allocates cases, signs-off all assessments and reviews. Assessors: support assessment and review processes, monitor intervention delivery.
Referral routes	Hospital-based assessment team receive referrals from hospital discharge teams. Community-based assessment teams receive referrals from local authority’s ‘central advice and duty team’ (includes self-referrals.	Hospital discharge teams and locality’s community health and social care provider’s ‘central advice and duty team’ (includes self-referrals)	Hospital discharge teams and local authority’s ‘central advice and duty team’ (includes self-referrals)

Explanation of terms:
Assess*: refers to the work associated with assessing an individual in order to develop a personalised, goals-focused reablement plan.*
Monito*r refers to the work associated with monitoring progress against the reablement plan*
Review*: refers to the work associated with decision-making around the timing of discharge from reablement.*
Team lead*: services used different terms for this role, we have used this generic term is used to ensure anonymity. The role of team leads varied between services.*
Assessors*: as for team leads, we have used this generic term is used to ensure anonymity.*
Reablement workers*: again, we have used this generic term is used to ensure anonymity. Reablement workers refers to the staff doing the ‘hands-on’ work of delivering the intervention through home visits.*

4.3.3. Service processes and practices

Finally, in Table 6 we present some additional, more specific comparisons between the research sites in terms of the processes and practices of the service. We focus particularly here on those characteristics which, drawing both on existing evidence, guidance, and findings from the study's process evaluation, are viewed as having the potential to impact on reablement outcomes.

The assessment and reviewing process in Site C presents as having a higher level of surveillance and involvement by senior staff on the team, with team leads signing off reablement assessments via a home visit, and leading the decision on discharge. In one site, assessment of referrals being discharged from hospital was carried out whilst the individual was still an in-patient.

Reablement workers based in out-sourced services had mixed caseloads of reablement and home care clients. This was not the case for reablement workers based in in-house reablement worker teams. Finally, sites differed in terms of the policy regarding the number of workers involved in delivering reablement to an individual. In one site (B), the practice was to assign two workers (with back-up sickness/holiday cover). In the other sites, multiple workers were used; in Site C this was the case for their in-house and out-sourced provision.

Table 6: Further service characteristics

CHARACTERISTIC	SITE A	SITE B	SITE C
Waiting list?	No	Yes. Referrals referred on to private provider to deliver care package as an interim measure.	No
Assessment and reviewing process	Single tier	Single tier	In-house service only: team leads involved in assessment process; and decide re discharge.
Return home clients: location of assessment	Hospital	Home	Home
Decision-making re discharge involves home visit by assessor/team lead	No	No	Yes (for both in-house and out-sourced clients)
Policy re number of reablement workers assigned/case	Two	Multiple	Multiple
Reablement workers have mixed case-load: reablement & home care	Yes	No	In-house: No Out-sourced: Yes

4.4. Summary

This chapter describes the services which acted as research sites for the evaluation Work package (WP2). It demonstrates the range of service and practice characteristics about which services may differ, many of which were explored in the outcomes and economic evaluation (WP2a and 2c). It also reveals that different service models may operate within a single commissioning locality. These findings highlight the importance of understanding a wide range of service and practice characteristics when conducting evaluations of complex interventions. Finally, we note that all these services had changed in some way between the national survey and WP2 commencing (a period of around less than a year) reflecting, we believe, changes associated with the implementation of the 2014 Care Act.

Chapter 5. WP2a: the outcomes evaluation

5.1. Introduction

This chapter reports the outcomes evaluation (WP2a). The difficulties encountered during the execution of WP2 (see Chapter 2, section 2.6), and its impact on sample sizes achieved across research sites, mean the findings should be considered as indicative. However, they are important given the dearth of existing evidence – particularly in terms of the exploration of the impact on service user, intervention and service characteristics on outcomes, and findings regarding the different outcomes assessed.

5.2. Objectives and study design

The objectives of WP2a, revised in response to lower than expected sample sizes in research sites, were:

- to describe changes in outcomes between entry to and discharge from reablement;
- to describe outcomes at 6 months post-discharge, compared to outcomes at discharge;
- to explore whether outcomes at discharge are associated with individual and/or service/intervention delivery characteristics.

5.3. Study design

An observational study of a cohort of individuals receiving reablement from one of three reablement services across England in which outcomes were tracked from entry to the service, at discharge, and at six months post discharge.

5.4. Methods

5.4.1. Setting

The setting was three reablement services (referred to as research sites) located in different regions of England. All fulfilled the study criteria of delivering comprehensive reablement. Chapter 4 reports selection and characteristics of research sites (sections 4.2 and 4.3).

5.4.2. The local study team

Research sites had a local study team comprising a Local Study Administrator (LSA) and Local Study Officer (LSO). These teams were responsible for: liaising with sites to ensure all new referrals were approached regarding study participation, recruitment and consent processes, administration of research questionnaires to service users and service staff, and facilitating recruitment to the process evaluation (WP2c). They were located within the same building as the research site. Site-specific systems and processes were jointly developed to ensure smooth and efficient communication of relevant information between the site and local study team. Teams were fully trained and closely supervised and supported by the York research team via telephone, email and face to face meetings.

5.4.3. Study participants

Inclusion criteria were:

- offered and accepted reablement delivered by one of the research sites;
- able to give informed consent as judged by the practitioner carrying out the reablement assessment.

5.4.4. Variables: outcomes

A suite of outcome measures were used (Table 7). Outcomes were captured within the first week of referral to the reablement service (T0); within a week of discharge from the reablement service (T1); and 6 months post-discharge (T2=T1 + 6 months).

Table 7: Outcomes and data sources

Variable	Measure /data source	Respondent	Data collection time-point		
			T0	T1	T2
Health-related quality of life	EQ-5D-5L	Service user	*	*	*
Social care related quality of life	ASCOT SCT-4	Service user	*	*	*
Mental health	General Health Questionnaire (GHQ-12)	Service user	*	*	*
Functional status	BARTHEL Index	Reablement practitioner	*	*	
	Nottingham Extended Activities of Daily Living (NEADL) scale	Service user	*	*	*

EQ-5D-5L

EQ-5D-5L[5, 6] is a standardised measure of health status providing a descriptive profile of health-related quality of life with respect to five domains (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) and a single index value of health status. It is a self-report measure comprising five items and visual analogue scale (EQ VAS). Respondents report difficulty with each domain in terms of one of five levels: no problems, some problems, moderate problems, severe problems, extreme problems (coded 1 to 5 respectively). The five digit figure generated is then converted into a single weighted index score. The EQ VAS records self-rated health on a vertical scale (1-100) from 'Worst imaginable health state' to 'Best imaginable health state'.

The Adult Social Care Outcomes Toolkit (ASCOT SCT-4)

The ASCOT SCT-4[7, 8] was designed to measure outcomes that may be affected by using social care. It captures nine social care-related domains of quality of life: control over daily life; personal cleanliness and comfort; food and drink; personal safety; social participation and involvement; occupation; accommodation; cleanliness and comfort; dignity. Four response

levels are offered: ideal state, no needs, some needs, or high needs. It provides a descriptive profile of social-care related quality of life with respect to these domains. The single index score is calculated from these responses. The ASCOT tools are used routinely by local authorities and government and were used in a previous national evaluation of reablement services in England.[2]

General Health Questionnaire (GHQ-12)

The GHQ-12[9] was used to measure mental health. It focuses on two major areas – the inability to carry out normal functions and the appearance of new and distressing experiences. It comprises 12 items, with each item is rated on a four-point scale (less than usual, no more than usual, rather more than usual, much more than usual). T0 scores were also used as a predictor.

The measures of functional status

A measure of functional status was proposed in the original protocol, but not specified as it was, to some extent, dependent on whether the research sites were routinely using such a measure. This was not the case and two measures were selected - the practitioner-completed Barthel Index (only available for T0 and T1) and the user-completed Nottingham Extended Activities of Daily Living (NEADL). T0 scores were also used as predictors.

Barthel Index of Activities of Daily Living

The Barthel Index[10] measures patients' functional status as assessed by health professionals based on observation. It assesses functional status across ten domains: presence/absence of faecal incontinence, presence/absence of urinary incontinence, personal care (cleaning teeth, shaving), using the toilet, feeding, transfers (e.g. from chair to bed), walking, dressing, climbing stairs and bathing (or showering). Scoring of individual domains range between 0-15 (at 5 point intervals); domains vary in the number of intervals offered. The total score is used which ranges from 0 (no functioning) to 100 (independent functioning).

Nottingham Extended Activities of Daily Living (NEADL) Scale

The NEADL Scale[11] is a self-report measure of functional ability, or independence, with respect to a wide range of activities of daily living. It comprises 22 items which are grouped into four areas of activities of daily living: 'mobility' (six items), 'kitchen' (five items),

'domestic' (five items) and 'leisure' (six items) activities. Each item is scored on the response to four options: No (0 points), With help (0 points), On my own with difficulty (1 point), On my own (1 point). The maximum score is 22, with higher scores indicating greater independence.

5.4.5. Variables: predictors

Data was also collected on a number of predictors; that is variables which we hypothesised may be associated with outcomes. They included characteristics identified in the research commissioning brief, findings from existing studies and findings emerging from our own process evaluation (WP2b). They comprised characteristics of the service user (see Table 8), the intervention received and service level characteristics (see Table 9).

Table 8: Service user characteristics

Variable	Data source and measurement
Age (years)	Socio-demographic and health status questionnaire completed by the service user.
Gender	Socio-demographic and health status questionnaire completed by the service user.
T0 assessor-rated functioning	Barthel Index: total score
T0 self-rated functioning	NEADL: total score
T0 mental health	General Health Questionnaire (GHQ-12): total score
Engagement with reablement	Hopkins Rehabilitation Engagement Rating Scale – Reablement Version (see below): total score
Reason for referral to reablement	Participant classified by reablement service as: Remain at Home versus Return Home. Classification shared with research team.
Key physical health comorbidities	Derived from question on socio-demographic and health status questionnaire completed by the service user. Question: *Do you have any health problems in addition to any associated with the need for reablement*. Responses were categorised as: 'none', 'one' or 'two or more' comorbidities.
Living situation	Derived from socio-demographic and health status questionnaire. Question: *Who do you usually live with*? Response options: 'alone', 'with partner', 'with family' or 'other'.
Perceived financial situation	Derived from socio-demographic and health status questionnaire. Question: *Do you feel you have enough money to live on*. Response options: 'yes', 'no'
Informal carer involvement	Derived from socio-demographic and health status questionnaire: Question: *Have you received help from friends and family in the past two weeks* Response options: 'yes', 'no'

Table 9: Intervention- and service-level characteristics

Variable	Data source and measurement
Duration of intervention (weeks)	Derived from the administrative data held by the service.
Intervention Fidelity	Experience of Reablement Practice Checklist (ERPC) (see below). All five items reported to have been present = complete implementation. Binary variable: 'complete' vs 'incomplete' implementation created
Reablement received from in-house vs outsourced reablement workers	Information collected from service leads by the research team. Binary variable: 'in-house' vs 'out-sourced'
Single vs multi-team model (assessors and reablement workers in same team)	Binary variable: 'single' vs 'multi-team'
OT integral to team, or not	WP1 Process evaluation
Service located within integrated health & social care organisation vs single agency	WP1 Process evaluation
Policy re number of reablement workers allocated/case	WP1 Process evaluation

The measures of user engagement (HRERS-RV) and intervention fidelity (ERPC) were created for the purposes of the study and are described below.

Hopkins Rehabilitation Engagement Rating Scale-Reablement Version (HRERS-RV)

As no measure of user engagement in reablement existed, we adapted the Hopkins Rehabilitation Engagement Rating Scale (HRERS)[12] (see Appendix 3).

The Hopkins Rehabilitation Engagement Rating Scale – Reablement Version (HRERS-RV) comprises five statements which capture the following domains of engagement: prepared for intervention; attitude towards intervention; acceptance of need for intervention;

participation in intervention; and impairments affecting participation. A six point rating scale is used by the practitioners to indicate the degree to which each statement was observed in the target individual during the intervention period (never, rarely, some of the time, most of the time, nearly always, always). It was completed by a reablement practitioner immediately post-discharge.

It was not possible to administer this measure in one of the research sites (Site A) because the out-sourced provider did not agree to including completion of the HRERS-RV within reablement workers' usual roles and responsibilities.

Experiences of Reablement Practice Checklist (ERPC)

In the absence of an existing measure of intervention fidelity, a 5 item checklist comprising statements which describe the domains of reablement practice was developed for the purposes of the study (see Appendix 4). The checklist comprised statements with respect to: understanding of the reablement approach; experience of a goals-focused approach; user involvement identifying goals; working towards achieving independence potential; and reviewing progress. Completed by the service user at T1, ERPC asks respondents to report on their overall experience of reablement by answering 'yes' or 'no' to each statement.

5.4.6. Piloting the research instrument

The suite of questionnaires administered to service users was piloted to test overall respondent burden, comprehension of items and response formats for the socio-demographic and health status questionnaire, and the data collection instrument developed for the economics evaluation (WP2c): the Services and Care Pathway Questionnaire (SCPQ). It also explored preferences with respect to mode of administering study questionnaires: self-completion or via a structured interview.

Findings indicated the importance of offering choice in how participants completed the study questionnaires. Pilot respondents typically preferred completing the SCPQ via a structured interview. Items on all questionnaires which raised queries were noted, and particular instructions regarding how to respond to such queries was included in LSO training. In terms of respondent burden, mixed mode of administration, pacing, and the

benefit of company seemed, together, to mean that pilot respondents did not find the battery of questionnaires too burdensome.

5.4.7. Data collection

T0 and T1 measures completed by service users were administered via a home visit by the LSO. Study participants chose whether to complete questionnaires themselves or through a structured interview.

T2 measures completed by service users were administered via home visit or post. Postal administration was used when the LSO was no longer in post due to closure of the study (see Chapter 2, section 2.6.1).

Administration of practitioner-completed questionnaires (Barthel Index (T0, T1); HRERS-RV (T1)) was also carried out by the local study team. In addition, the local study team requested data from the service with respect to study participants' reasons for referral and intervention duration.

5.4.8. Study recruitment and retention

Recruitment, taking place over a six month period (between Autumn 2016 – late Spring 2017) was a three stage process.

i. **Assessor seeks consent to contact:**
   During assessment of a new referral carried out within 1-3 days of referral, the assessor briefly introduced the study, handed over the Study Information Sheet and requested permission for the LSO to make contact via telephone to discuss participation ('consent to contact'). Research sites were instructed that 'consent to contact' should be sought from all eligible referrals. The outcome of that discussion was recorded on a pro-forma and, for those not agreeing to 'consent to contact', the reason for this decision recorded.
ii. **LSO contacts service user:**

Service users agreeing to contact by the research team were contacted by telephone by the LSO. During the call, further explanation was given regarding study participation and, if agreed, arrangements made for a home visit.

iii. Home visit by the LSO

During the home visit, consent was taken and T0 data collection undertaken.

Figure 1 provides an overview of the recruitment process and outcomes. Recruitment materials are available (RSM 2). A discussion of our experiences of recruitment and retention to the study, and their implications, can be found in Appendix 5.

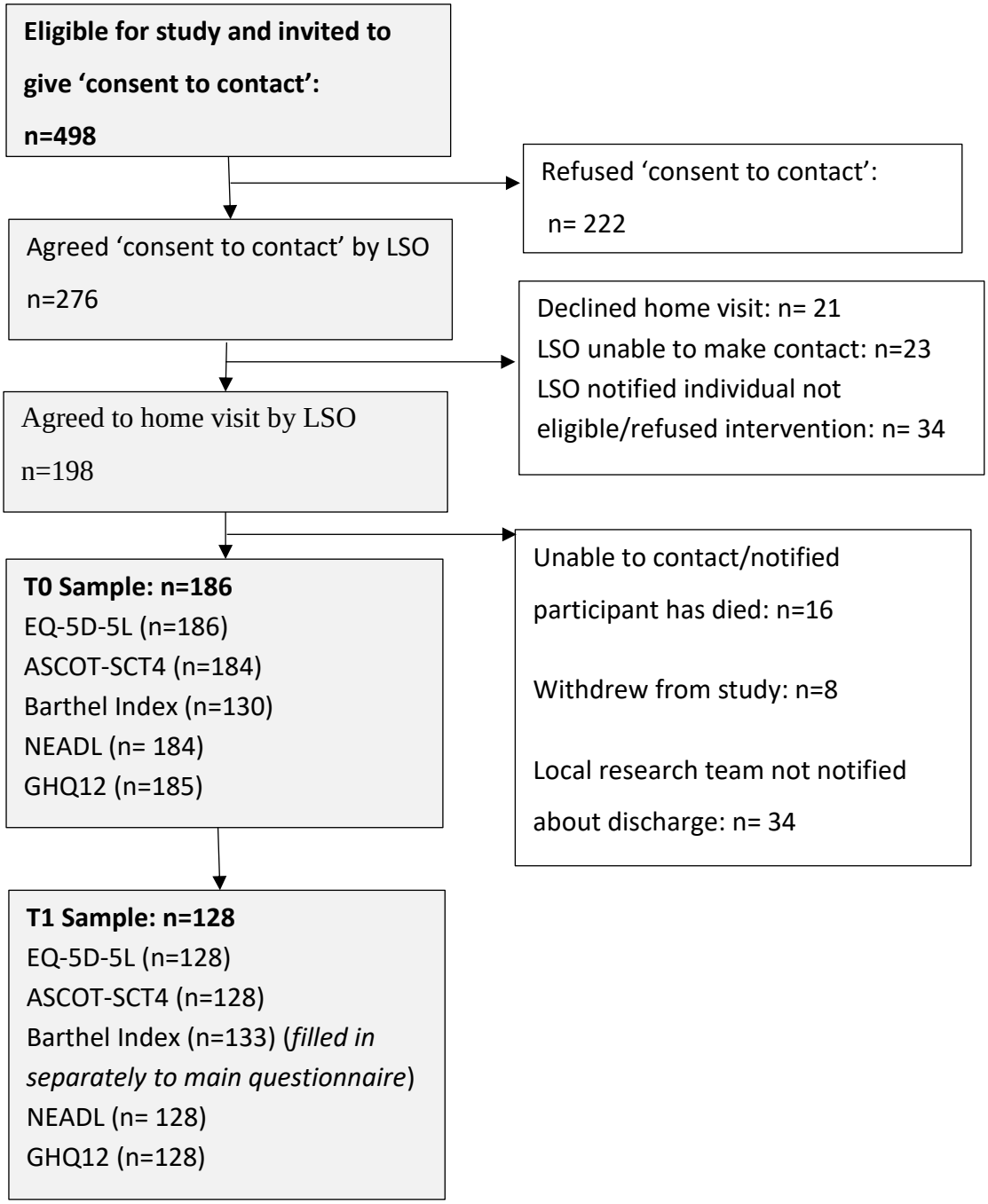

Figure 1: Recruitment process and retention: T0 to T1

Recruitment

Just under 500 individuals (n=498) across the three research sites were invited to give 'consent to contact'. Over half (n=276, 55.3%) agreed. Of these, 198 (71.7%) agreed to a home visit once contacted by the LSO. A total of 186 individuals (representing 67.4% of

those who gave consent-to-contact, and 37.3% of those invited to give 'consent to contact'), were recruited to the study and baseline data collection completed.

Retention at T1

The reablement service notified the local study team when a study participant was being discharged. This triggered the LSO to re-contact the study participant to request a home visit to conduct T1 data collection. Unfortunately, in two research sites, on 34 occasions the service failed to notify the local study team about a discharge (18.3% of the T0 sample). These individuals were retained for T2. For the remaining study participants, retention at T1 was good (84.2%). Thus T1 data collection was achieved for 128/186 study participants. Figure 2 provides an overview of attrition and retention between discharge and T2.

Retention at T2

162 individuals were retained for follow-up 6 months after discharge from the reablement service. Unfortunately, 46 individuals could not be followed up due to closure of the study. However, we attempted T2 data collection with the remaining 116 study participants. In the original study protocol we had planned to use home visits again to collect T2 data. In two sites, due to study closure, local study teams were no longer in place. As a result, we administered the research instruments via post. In the third site (Site C), for those recruited early in the study timeline, it was possible for the LSO to attempt to collect T2 data via a home visits (n=21). A T2 sample size of 64/116 was achieved (55.2%). Retention was higher when home visits were used to collect data compared to postal administration (91% vs 51.8%). In total, the number of study participants for whom we had complete T0, T1 and T2 data was 52/186.

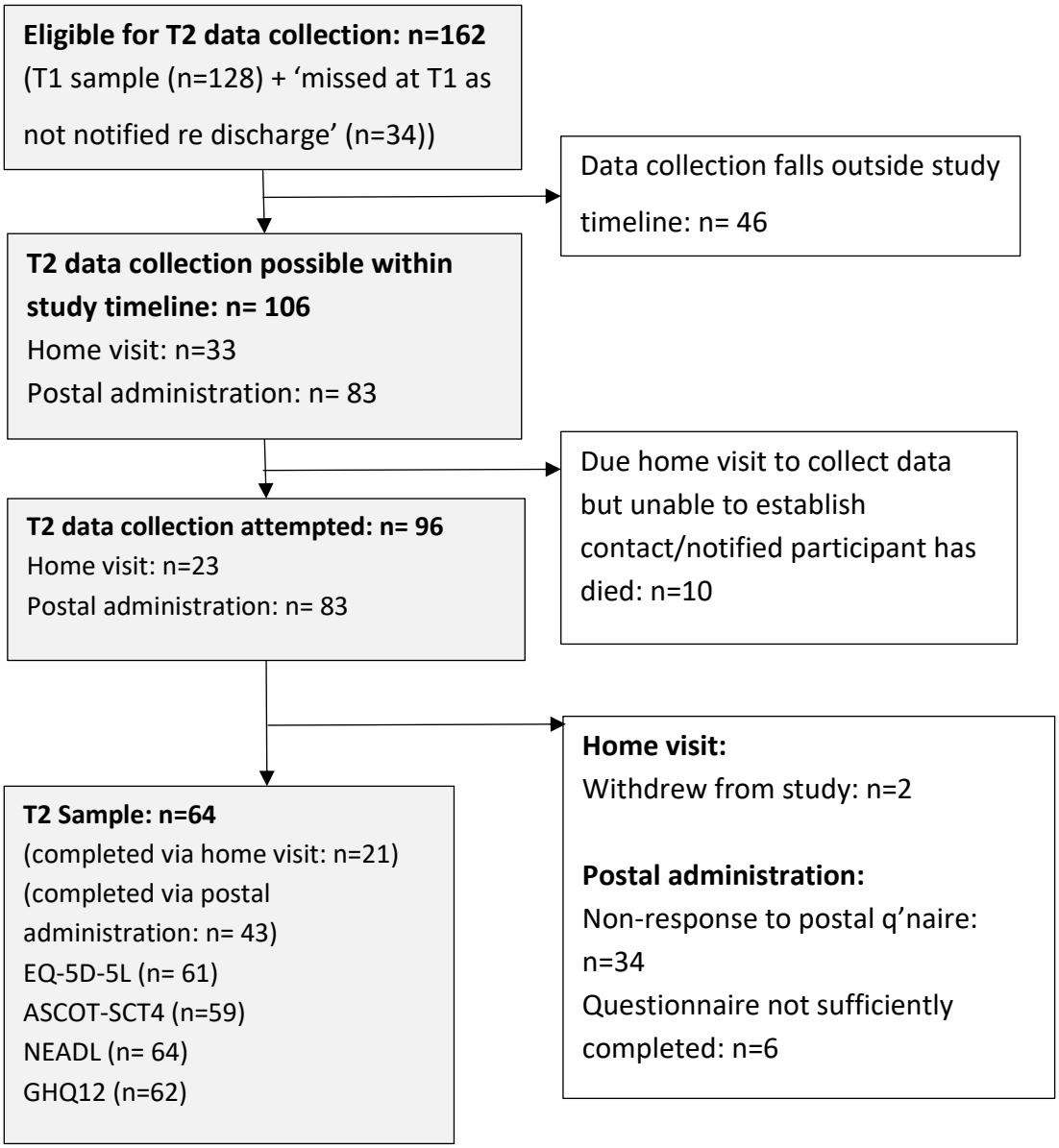

Figure 2: Retention: T1-T2

Loss to study through death or permanent move to residential care

According to the information available to us, very few participants were lost to the study due to death (n=10) or permanent move to residential care (n=1). We would note, however, that these may also be the reasons why we failed to re-establish contact with some study participants at T1 and T2.

5.5. Analytical plan

The statistical software STATA 14.2 was used.

5.5.1. Sample characteristics

Descriptive statistics explored the socio-demographic characteristics of study participants. For continuous variables means, standard deviations, minimum and maximum values and medians were used. Categorical data was calculated as counts and percentages. The characteristics of study participants retained to the study, and those lost to follow-up were compared. Comparisons between sites were also made.

5.5.2. Outcomes

Scores on outcome measures were explored by examining their mean, standard deviation, median, minimum and maximum values at T0, T1 and T2. We also examined changes in scores between time points (T0 to T1, T1 to T2). Overlaid histograms were used to visually present the score distributions. Analysis of EQ-5D index scores used the 2017 tariff, with the 2016 tariff used for a sensitivity analysis. We also conducted an ancillary analysis of EQ-VAS scores. Finally, we examined the number/percentage of respondents reporting deteriorating/maintained/improved outcomes at each time point.

5.5.3. Associations between predictors and outcomes at discharge.

Linear regression techniques were utilised to investigate associations between predictor variables and outcomes at T1, taking account of clustering of data. These analyses were then repeated controlling for site. Sample size limited our ability to control for explanatory variables simultaneously, hence only baseline characteristics and one other single predictor

was added to each regression model. In addition to estimates, we report associated 95% confidence intervals and P-values.

5.6. Results

5.6.1. Sample characteristics

Socio-demographic characteristics

Characteristics of the sample, also stratified by site, are presented in Table 10.

The mean age of study participants was 80.8 years (range = 51- 102 years). The median age (total sample = 82 years) varied between sites, with a lower median age in Site A (75 years) compared to Sites B (83.5 years) and C (82 years).

The majority of participants were female (n=119). The proportion of males varied between sites. Over half the sample (58%) lived on their own, this varied a little between sites. The majority of study participants (83%) reported having sufficient money to live on. In Sites A and C, the majority of participants (60%) had been referred to the service because of concerns about their ability to continue living independently at home (classified as 'remain at home'). This figure was much lower in Site B 36% (n=5), where the majority had been referred to the service following discharge from hospital (classified as 'return home'). Around 90% study participants in Sites B and C reported receiving regular help from friends and family (classified as 'informal carer involved'); this proportion was smaller in Site A. A third of the sample (36%) reported no key health comorbidities, 42% reported one key comorbidity, and nearly one in five two or more key comorbidities.

Table 10: Characteristics of study participants

		Number (%)			
		Site A	**Site B**	**Site C**	**Total**
Total recruited		33	14	139	186
Variable					
Age	Mean	77.3	83.0	81.5	80.8
	SD	9.13	8.33	9.06	9.13
	Median	75	83.5	82	82
	Range	51 – 89	70-95	52-102	51-102
Gender	Female	23 (70)	12 (86)	84 (60)	119 (64)
	Male	10 (30)	2 (14)	55 (40)	67 (36)
Living alone	No	16 (48)	7 (50)	56 (40)	79 (42)
	Yes	17 (52)	7 (50)	83 (60)	107 (58)
Sufficient money	No	4 (13)	2 (18)	25 (18)	31 (17)
	Yes	28 (88)	9 (82)	112 (82)	149 (83)
Referral reason	Return home	12 (36)	9 (64)	54 (61)	75 (40)
	Remain at home	21 (64)	5 (36)	85 (61)	111 (60)
Informal carer involved	No	9 (29)	1 (7)	10 (7)	20 (11)
	Yes	22 (71)	13 (93)	129 (93)	164 (90)
Number of health comorbidities	None	19 (58)	8 (57)	40 (29)	67 (36)
	1	8 (24)	4 (29)	67 (48)	79 (42)
	2 or more	6 (18)	2 (14)	32 (23)	40 (22)

Engagement with reablement

HRERS-RV scores were only collected in Sites B and C. On average, study participants in Site C scored higher compared to Site B (average score Site C= 26.2 (SD: 4.64) (maximum score 30) vs Site B=25.4 (SD: 4.24).

Intervention and service level characteristics

The nature of the sample in terms of intervention and service level characteristics are set out in Table 11. (Note: more than one model of service delivery was represented in Site C (see Chapter 4, Section 4.3.2)).

Table 11: Intervention and service characteristics

		n (%)			
		Site A	**Site B**	**Site C**	**Total**
Duration of reablement (weeks)	Mean	3.87	3.52	3.93	3.89
	SD	1.55	1.47	1.62	1.59
	Median	4.0	3.71	4.07	4.0
Multi vs single team model	multi team	32 (100)	14 (100)	29 (21)	75 (41)
	single team	n/a	n/a	110 (79)	110 (59)
In-house vs outsourced reablement workers	in-house	n/a	14 (100)	104 (75)	118 (64)
	outsourced	32 (100)	n/a	35 (25)	67 (36)
Intervention fidelity (ERPC) (T1 sample)	Partial	10 (53)	8 (57)	26 (27)	44 (34)
	Complete	9 (47)	6 (43)	69 (73)	84 (66)

The mean duration of reablement was similar across sites. Median duration was slightly lower in Site B (3.71 weeks) compared to Sites A (4.0 weeks) and C (4.07 weeks). Across the total sample, just over 40% had received reablement via a multi-team service model (that is, assessors and reablement workers based in separate teams). In terms of the organisational base of the workers who delivered the reablement, just under two thirds of the sample received reablement via an in-house team of reablement workers. Finally, intervention fidelity, as reported by study participants using the Experiences of Reablement Practice Checklist (EPRC), varied between sites. The majority (73%) of the Site C sample reported complete intervention fidelity, compared to less than half in Site A (47%) and Site B (43%).

The sample retained at T1

There were no significant differences between T0 and T1 samples with respect to socio-demographic characteristics and scores on outcome measures at T0 (see Appendix 6, Table 40).

5.6.2. Health-related quality of life (EQ-5D-5L)

Index and VAS score descriptives: T0, T1 and T2.

Scores derived using the 2016 and 2017 tariffs were highly correlated at T0 and T1 (see Appendix 7, Tables 44, 45 & Figures 10-13). The 2017 tariff only is therefore reported.

A comparison of total samples found a mean increase (represents improvement) in EQ-5D-5L index score from T0 to T1 of 0.16, and a mean increase of EQ VAS score of 11.7 points (Table 12). At T2, the mean EQ-5D-5L index score was slightly improved compared to T1 and there was a mean 5 point increase in VAS score at T2. At T1 the minimum VAS score was 1, whilst at T2, the minimum score was 20. Histograms presenting changes in distributions of EQ-5D scores are presented in Appendix 7 (Figures 14-16).

Table 12: EQ-5D-5L index & VAS scores: T0, T1 and T2 (total samples)

Time	N	mean	SD	median	min	max
EQ-5D index						
T0	186	0.51	0.23	0.52	-0.09	0.92
T1	128	0.67	0.24	0.75	-0.09	1.00
T2	61	0.69	0.26	0.78	-0.01	1.00
EQ-5D VAS						
T0	185	51.83	20.23	50	5	95
T1	128	63.52	20.45	69	1	100
T2	61	68.77	20.55	75	20	100

Change in index and VAS scores: T0 to T1, T1 to T2

There was a statistically significant improvement in EQ-5D-5L index and EQ-5D VAS scores between T0 and T1 among participants who completed the measure at both time points (n=128). The mean improvement in index score 0.15 (95% CI: 0.18 to 0.11) and for the VAS, the mean improvement was 11 (95% CI: 15.5 to 8.1). Scores at T1 were positively, linearly correlated to those at baseline. For the great majority (84%), an improved health-related quality of life was observed at T1 (Appendix 7, Table 46). However, a deterioration was observed in over one in ten (13%) participants.

For study participants for whom we have T1 and T2 data (n=49), the difference in mean EQ-5D-5L index scores between these two time points (diff=0.023, 95% CI: -0.0386, 0.085) was not statistically significant (p=0.451). The majority of respondents (57%) had maintained or

improved EQ-5D-5L index scores at T2 compared to T1 (Appendix 7, Table 46). For the EQ-5D 5L VAS, the mean difference in T1 and T2 scores was not statistically significant difference (diff=3.22, 95% CI: -9.923, 3.492, p=0.34, n=51). Over 60% had maintained or improved T1 EQ 5D-5L scores at T2.

Domain scores: T0 to T1

Reported level of impairment (5 point scale: extreme, severe, moderate, slight, no impairment) at T0 and T1 (total samples) with respect to the five domains of health-related quality of life (mobility, self-care, pain or discomfort, usual activities, anxiety or depression) are available (RSM 3).

For participants who completed the EQ-5D-5L at T0 and T1, the majority reported improved **mobility** (52%), **self-care** (71%), and **performance of usual activities** (55%) at T1 (Appendix 7, Table 47). For the **pain or discomfort** and **anxiety or depression** dimensions, the level of impairment remained the same for the majority of study participants (49% and 48%, respectively). However, for almost a fifth (19%) of the sample, level of impairment had deteriorated in one domain at T1 compared to T0. A further 5% reported deterioration in two domains and just under 2% in more than two domains. The proportion of study participants experiencing deterioration were small for **mobility** (9%), **self-care** (2%), and **usual activities** (7%), but higher for **pain or discomfort** (14%), and **anxiety or depression** (17%).

5.6.3. Social care related quality of life (ASCOT-SCT4)

Index score descriptives: T0, T1 and T2

The mean ASCOT-SCT 4 index score at T1 had improved by 0.11 compared to T0 (Table 13). At T2, the mean score had decreased slightly, by 0.02.

Table 13: ASCOT SCT4 scores at T0 and T1 (total samples)

Time	N	mean	SD	median	min	max
T0	184	0.71	0.17	0.73	-0.04	1.00
T1	128	0.82	0.15	0.86	0.06	1.00
T2	59	0.80	0.17	0.84	0.05	1.00

Histograms presenting changes in distributions of ASCOT-SCT 4 index scores across timepoints are presented in Appendix 8 (Figures 17, 18).

Change in index scores: T0 to T1, T1 to T2

There was a statistically significant improvement in ASCOT-SCT4 index score between T0 and T1 for the 128 participants who completed this measure at both time points. The mean improvement was 0.09 (95% CI: 0.06 to 0.11). Scores between baseline and discharge were positively correlated (correlation coefficient=0.62). For study participants where data was available at T0 and T1 (n=128), the great majority (73%) reported improved health-related quality of life at discharge (Appendix 8, Table 48). However, nearly a quarter (24%) reported a deterioration in health-related quality of life.

For study participants where we have T1 and T2 data (n=46), the between the mean ASCOT-SCT4 index scores at T1 compared to T2 was not statistically significant (difference=0.0018, p=928). Over half (55%) maintained or improved ASCOT scores (Appendix 8, Table 48).

Domain scores: T0 to T1

The distribution of scores at T0 and T1 (total samples) for the nine social care-related quality of life domains captured by ASCOT-SCT4 are available (RSM 3).

For participants who completed the ASCOT SCT-4 at T0 and T1 (n=128) (Appendix 8, Table 49), the domains were greatest proportions reported improvements were **feeling clean and presentable** (46%), **control over daily life** (43%), **spending time doing things which value or enjoy** (42%), **social contact** (38%), **having food and drink when want it** (35%). Over a quarter of study participants reported improved outcomes with respect to their home feeling clean and comfortable (**accommodation**) (29%) and **feelings about having help** (26%). The two domains where there were smallest increases in proportion reporting improvements were feeling **safe** (17%) and how **being helped** made them feel about themselves (17%). Typically, the proportions of study participants reporting deteriorations were small, ten per cent or less. However, at discharge, almost one in five reported a deterioration in **social contact** (19%), 15% felt less **safe**, and 13% reported a deterioration in the **way they spent their time.**

5.6.4. Practitioner-rated functioning (Barthel Index of Activities of Daily Living)

Completion of the Barthel Index

Reablement assessors completed the Barthel Index at the referral assessment visit (T0) and on discharge from the service (T1). Unfortunately, not all assessors adhered to instructions regarding its completion. The most common issues were that respondents had not used the (up to 4 point) categorical scoring system (0, 5, 10, 15) but inserted a 'score' such as 2 or 8, or items were missed or noted as 'not applicable'. This issue was observed across all sites, but appeared to be less of a problem in the site where reablement assessors were occupational therapists.

Total score descriptives: T0 and T1

A comparison of Barthel Index scores between T0 and T1 samples revealed a mean increase of 9.2 (Table 14). It was not possible to administer the Barthel Index to staff at T2.

Table 14: Barthel Index scores at T0 and T1 (total samples)

Time	N	mean	SD	median	min	max
T0	130	71.692	17.022	75	10	100
T1	133	80.451	20.277	90	5	100

Histograms presenting changes in distribution of Barthel Index scores at T0 and T1 are presented in Appendix 9 (Figure 19).

Change in total score: T0 to T1

For the study participants where a Barthel Index score was available at T0 and T1 (n=105), there was a statistically significant improvement in score at T1 (mean score change=8.4 (95%CI: 11.8 to 5.0). Barthel Index scores at T1 were positively linearly correlated to those at T0 with a correlation coefficient of 0.53. Over two thirds of participants were assessed as having improved functioning at T1, whilst one in five were assessed as having deteriorated (Appendix 9, Table 50).

Domain scores: T0 to T1

The distribution of item scores at T0 and T1 (total samples) for the ten domains of activities of daily living assessed by the Barthel Index are available (RSM 3).

For participants where this data was available at T0 and T1 (n=96), domains where the largest number of study participants improved functioning were **dressing** (53% improved functioning at T1), **bathing** (49%), **personal grooming** (35%), **transfers** (25%) and **managing stairs** (21%) (Appendix 9, Table 51). The proportion of study participants assessed as having deteriorated in functioning with respect to an activity of daily living was never greater than the proportion assessed as having improved. Domains where the largest proportions of deterioration in functioning were observed at T1 compared to TO were: **mobility** (17%), **managing stairs** (15%), **using the toilet** (13%), and **transfers** (13%).

5.6.5. Self-rated functioning (NEADL scale)

Total score descriptives: T0, T1 and T2

There was a small (0.75 point) increase in mean NEADL score at T1 compared to T0 (Table 15). At T2, there was an almost 3 point increase in mean NEADL score compared to T1 mean score. Histograms presenting changes in distribution of NEADL scores are presented in Appendix 10, Figure 20).

Table 15: NEADL scores at T0 and T1 (total samples)

Time	N	mean	SD	median	min	max
T0	184	9.65	5.48	8.5	0	22
T1	128	10.40	4.46	10.0	3	22
T2	64	13.22	6.27	13.5	0	22

Change in total score: T0 to T1, T1 to T2

The change in mean NEADL scores (0.73; 95%CI: 1.51 to 0.06) between T0 and T1 participants who completed the NEADL questionnaire at both time points (n=128) was not significant (p=0.07). NEADL scores at T0 and T1 were significantly correlated (r=0.625, p<0.001). For over half of study participants, NEADL scores had improved at T1 compared to T0 whilst less than a third reported a deterioration in functioning (Appendix 10, Table 52).

For participants where we have data at T1 and T2 (n=52), the mean self-reported functional status score was 1.79 higher at T2 than T1, this is a statistically significant difference (95% CI: 3.03, 0.55, p<0.01). The majority (73%) of respondents a maintained or improved NEADL score. Two thirds of NEADL scores had improved between T1 and T2, whilst scores for just over a quarter of the sample had deteriorated.

Domain scores: T0 to T1

The distribution of item scores at T0 and T1 (total samples) with respect to the four domains of (extended) activities of daily living (mobility, kitchen, domestic, leisure) assessed by the NEADL are available (RSM 3).

For participants who completed the NEADL at T0 and T1, similar proportions had improved or deteriorated with respect to **mobility** (walking, climbing stars, getting in and out of car, and walking on uneven surfaces) (Appendix 10, Table 53). For majority (67% - 83%), level of functioning remained the same at T1 compared to T0. However, greater proportions had deteriorated, as opposed to improved) in functioning with respect to crossing roads and managing public transport at T1 compared to T0. Again, for the majority (77% - 85%) level of functioning was unchanged.

With respect to the items comprising the **kitchen domain**, a deterioration in level of functioning was extremely rare. Over one in ten study participants had improved in functioning with respect to making a hot drink (12%), carrying a hot drink (16%), washing up (15%), and making a snack (13%). As with the mobility domain, for the majority (80% - 94%), level of functioning was unchanged.

For the **domestic domain**, around one in five study participants had improved in functioning with respect to laundry tasks (handwashing small items (20%), full clothes wash (17%), and almost one in ten had improved their functional ability to go shopping (9%). However, around one in ten had deteriorated with respect to being able to go shopping (9%) and do a full clothes wash (13%). This latter item was therefore were fewest (70%) maintained the same level of functioning at T1 compared to T0.

Finally, in terms of the **leisure domain**, for the great majority, level of functioning with respect to constituent items was the same at T0 and T1 (84% - 97%). However, greater proportions reported deteriorating abilities to socialise (9%), garden (7%) and drive (9%), than improved functioning in this areas (&%, 3% and 3% respectively). The item where the largest proportion of study participants reported improved functioning at T1 compared to T0 was writing letters (16%).

5.6.6. Mental health: GHQ-12

Finally, we conducted a preliminary exploration of changes in scores on the GHQ 12 across the outcome timepoints.

Total score descriptives: T0, T1 and T2

The mean GHQ-12 score was lower (improved) at T1 compared to T2, and had further decreased at T2, though the change, see Table 16. Histograms presenting changes in distribution of score are presented in Appendix 11 (Figures 21).

Table 16: GHQ-12 scores at T1 and T2 (total samples)

Time	N	mean		SD	median	min	max
T0	185	4.14		2.85	4		
T1	128	2.42		2.60	2	0	12
T2	62	2.10		2.65	1	0	12

Change in total score: T0 to T1, T1 to T2

For study participants where GHQ-12 scores were available at T0 and T1 (n=128), over two thirds (69.5%) had improved scores at T1 compared to T0. For around a fifth (18%), scores had deteriorated (Appendix 11, Table 54).

In terms of change in GHQ-12 scores between T1 and T2 (n=50), scores were on average 0.56 point higher at T2 than T1 (95%CI: -10.157, 1.277). This difference was not statistically significant (p=0.123). A deterioration in score was observed in just under a quarter of study participants (24%). However, scores had further improvement for a half of participants and for the remainder (26%), no change in score was observed.

5.6.7. Association between predictors and T1 outcomes

Regression analysis was used to carry out an initial exploration of whether identified individual and service/intervention characteristics (see Section 5.4.5) were associated with T1 outcomes. It was not possible to do this analysis with respect to three identified service-level characteristics because these features were all unique to the research site where only 14 service users were recruited to the study. These were: OT integral to team, or not; service located within integrated health & social care organisation vs single agency; and policy regarding number of reablement workers allocated/case.

Sample sizes were small, and multiple regression was not possible. Scrutiny of outputs from both regression analyses (both accounted for clustering by site, one also used site as an explanatory variable) in terms of statistical significance, regression coefficients and 95% confidence intervals were used to allocate characteristics to one of three categories:

- strong evidence found of an association between the characteristic and the outcome measure ($p<0.01$);
- some evidence found of an association between the characteristic and the outcome measure ($p<0.05$);
- insufficient evidence found of an association between the characteristic and the outcome measure.

Full analytical outputs are provided in Appendix 12 (Tables 55 – 58). We would remind readers that these analyses should be regarded as preliminary as insufficient total sample size and small sample sizes in two sites means more complex analyses were not possible. Thus, it was not possible to control for other predictors when testing the association between a particular characteristic and an outcome. Equally, it was not possible to explore the relative contribution of different predictors on outcomes. Finally, we would stress that evidence of an association cannot be taken to infer that the impact of a particular individual or service/intervention characteristic on an outcome is 'clinically significant' – that is, it is

meaningful or of practical relevance to service users or service providers. The findings reported in this section should, therefore, be regarded as preliminary evidence which can be used to inform future research.

Associations between predictors and T1 health-related quality of life (EQ-5D-5L)

Service user characteristics

Strong evidence was found of a positive association between the following variables and improved health-related quality of life (EQ-5D-5L index score) at T1: having sufficient money (compared to feeling not having insufficient money); greater engagement in reablement; being male; and living with partner/family (compared to living alone).

Some evidence was found of an association between better mental health at entry into reablement and self-reported functional ability and greater improvement in EQ-5D-5L score at T1.

Service/intervention characteristics

There were no service/intervention characteristics where strong evidence of an association with T1 EQ-5D scores was found. Some evidence was found that receiving reablement from a worker based in an out-sourced provider was associated more negative outcomes than when reablement is provided by an in-house team. Also there was some evidence of an association between being reabled by a service comprises a single team (as opposed separate assessor and reablement worker teams) and greater improvements in EQ-5D-5L index score.

Associations between predictors and T1 social-care related quality of life (ASCOT SCT4)

Service user characteristics

Strong evidence of a positive association between improved social care-related quality of life (ASCOT SCT4 index score) at T1 and the following service user characteristics was found: having sufficient money (compared to feeling not having insufficient money); better mental health at T0 and greater engagement with reablement.

There was also some evidence that referral to reablement in order to remain at home (compared to those referred to support a return home from hospital) and greater age were associated with greater improvements in social-care related quality of life at T1.

Service/intervention characteristics

There was strong evidence of an association between greater improvements in T1 ASCOT scores and longer duration of reablement. In addition, there was some evidence of a positive association between greater gains in ASCOT scores at T1 and intervention fidelity and receiving reablement from in-house (as opposed to out-sourced) providers.

Associations between predictors and T1 practitioner-rated functioning (Barthel Index)

We note that sample size for Barthel Index scores was lower than for other analyses (n=105/128) due to inaccurate completion of the measure (see section 5.6.2).

Service user characteristics

Strong evidence was found of an association between greater improvements in practitioner-reported functioning (Barthel Index score) at T1 and the majority of service user characteristics: having sufficient money (as opposed to reporting insufficient money); better self-reported functional status at T0; greater engagement with the reablement intervention; greater age; having no physical health comorbidities; better mental health at T0; no informal carer involvement and being female.

Service/intervention characteristics:

There were no service/intervention characteristics where strong evidence of an association with practitioner-rated functioning scores at T1 was found. There was some evidence that receiving reablement from a single team (compared to separate teams assessing and delivering reablement) was associated with greater improvements with practitioner-rated functioning at T1.

Associations between predictors and T1 self-rated functioning (NEADL)

Service user characteristics

Strong evidence was found of an association between self-rated functioning at T1 and the following service user characteristics: greater engagement with the reablement and

assessor-reported functioning at T0. Some evidence was found of a positive association between this outcome and the following service user characteristics: younger age, those referred to support remaining at home (compared to those referred to support a return home from hospital); having sufficient money (compared to those reporting insufficient money).

Service/intervention characteristics

Some evidence of association was found between greater improvements in self-rated functioning at T1 and two service characteristics: receiving reablement from a single team (compared to separate teams assessing and delivering reablement); and receiving reablement from in-house (as opposed to out-sourced) providers.

5.7. Summary

Smaller than expected sample size, particularly in two research sites mean the data presented should be considered as exploratory.

Improvements on all outcomes – health-related quality of life (EQ-5D 5L), social care-related quality of life (ASCOT SCT-4), practitioner-reported functioning (Barthel Index) and self-reported functioning (NEADL scale) were observed at discharge from reablement (T1) compared with entry into the service (T0). For the sub-sample for whom data was collected at both time points, improvements in health-related quality of life, social care-related quality of life and practitioner-reported functioning were statistically significant.

Outcomes had further improved at 6 months post-discharge. However, improvements in health-related and social care-related quality of life were not statistically significant. However, the improvement in self-reported functioning was statistically significant, a contrast with degree of improvement at discharge which was not significant. Barthel Index scores were not available at this time point. Using the GHQ-12, we also looked at mental health outcomes at 6 months follow-up. A (non-significant) improvement in mean GHQ score was observed between T1 and T2.

A set of regression analyses explored, in a preliminary way, the association between service and individual level characteristics on outcomes at discharge from reablement. There was some evidence of a positive association between intervention engagement, better mental health and having sufficient money and health-related quality of life at discharge. There was weaker evidence of a positive association between this outcome and sharing the home with others and self-reported functioning at entry into reablement. There was also weak evidence of an association with two service characteristics: receiving reablement from a single (vs multi) team and from in-house (as opposed to outsourced) reablement workers.

In terms of social care-related quality of life, there was some evidence of association between this outcome at discharge and a number of individual (sufficient money, referral reason, mental health at entry, engagement with reablement) and service characteristics (intervention fidelity, duration of reablement). A weak association between this outcome and informal carer involvement and in-house vs out-sourced was also found.

With respect to practitioner-reported functioning at discharge, there was some evidence that following individual characteristics were associated with more positive outcomes: having sufficient money, referral for reablement was to support return home from hospital (as opposed to support remaining at home), and engagement with reablement. There was also some evidence of a positive association between self-reported functioning at discharge and health-related quality of life at entry into the service and practitioner-reported functioning. There was also some evidence that informal carer involvement was negatively associated with this outcome. In addition, there was weak evidence that living alone and better mental health at entry into the service was associated with better practitioner-reported functioning at discharge. In terms of service characteristics, there was some evidence that practitioner-reported functioning at discharge was positively associated with receiving reablement from a single team. There was also weak evidence that receiving reablement from in-house, as opposed to out-sourced, reablement workers was positively associated with practitioner-reported functioning at discharge.

Finally, in terms of self-reported functioning at discharge, there was some evidence of a positive association with engagement with reablement. There were a number of other individual characteristics for which there was weak evidence of a positive association with

self-functioning at discharge. These were: health-related quality of life and practitioner-reported functioning at entry into the service, living alone, having sufficient money, referral reason is to support return home from hospital and a younger age. There was some evidence of an association between self-functioning at discharge and two service characteristics: the reablement service being formed of a single team and having in-house reablement workers.

Chapter 6. WP2b: Delivering Reablement: Practitioner Views

6.1. Introduction

This chapter concerns the experiences of staff directly involved delivering reablement, both staff in reablement assessment teams and those who do the hands-on reablement work with service users. Investigating staff views comprised one element of the process evaluation (WP2b), the other being research with service users and family members. Its purpose of this aspect was to understand both the experience of providing and delivering reablement and elicit views regarding the outcomes of reablement and the factors which impact on outcomes.

6.2. Methods

Focus groups were held with assessors in each site, and with reablement workers in two sites (the third site – an out-sourced service - declined to participate). Data collection took place between April – July 2017.

6.2.1. Recruitment

Local study teams facilitated recruitment and liaised with service/team leads regarding the time and venue for focus groups. They distributed an invitation and study information sheet (hard copy or via email) to all staff within assessment and reablement worker teams based within the research site, including any out-sourced services. Staff were invited to respond if they were interested in taking part. Consent to participate was secured at the start of the focus group. Recruitment materials are available (RSM 4).

6.2.2. Data collection

Focus groups were held at the organisational base of each research site and explored the following topics:

- views and experiences regarding the processes involved in delivering reablement by their service, including the factors that inhibit and facilitate that process and the outcomes achieved
- views regarding the intervention itself, its appropriateness and perceived effectiveness
- views regarding the active ingredients of reablement and mechanisms for change.

Topic guides and visual tools/activities used to facilitate discussions are available (RSM 5).

6.2.3. Data analysis

Data was analysed thematically.[13] The Framework approach[14, 15] was used to ensure systematic data management and audit trails of the data management process. Data from assessor and worker focus groups were analysed together. Participant group and research site were key variables used to test and explore similarities and differences in views and experiences. Data analysis particularly focused on issues which were not context-specific, such as a particular local sticking point in terms of service delivery.

There are four stages to the analytical process. First, researchers familiarise themselves with the data, and identify themes and key issues (both a priori and emergent). An index of themes is then constructed (the thematic framework). Data are then indexed according to the theme(s) in the analytical framework they relate to. Finally, the indexed data from each case (e.g. participant, focus group) are summarised onto a series of thematic matrices (or charts). Each chart is divided into columns, allowing relevant data to be organised according to sub-themes/issues. A single row on each chart holds one participant's data. Thus reading along a row provides an overview of everything an individual spoke about in terms of a specific issue. Reading down the chart (or down a column) allows comparison between participants'. The final stage of analysis involves 'reading' of the charts, composing 'analytical notes' which describe the data, and developing interpretation and hypotheses which are then tested against the charts and raw data. The thematic framework can be found in Appendix 16.

6.2.4. Sample

Across the three research sites, four focus groups with assessment team staff and two focus groups with reablement workers were achieved. Staff working in in-house and out-sourced providers were represented. A total of 20 reablement assessors (n=4 focus groups) and 12 reablement workers (n=2 focus groups) were carried out. A breakdown of the sample by site (including highlighting any missing staff groups) is set out below:

- Site A:
    - Assessment team (in-house): 5 participants
    - Reablement workers (out-sourced providers): not achieved; providers declined to participate.
- Site B:
    - Focus group with assessment team (in-house): 6 participants
    - Focus group with reablement workers (out-sourced provider): 6 participants
- Site C:
    - In-house assessment team: 7 participants
    - Out-sourced provider assessment team (other out-sourced providers in locality do not conduct assessments): 2 participants
    - In-house reablement workers: 6 participants
    - Out-sourced providers' reablement workers: not achieved. Failed to recruit via one provider. Other providers declined to participate in study.

6.3. Findings

We report the findings under five key themes:

- Impact of the 2014 Care Act on reablement services and practice
- The impact, and suitability, of reablement as an intervention
- User and family understandings of reablement
- Individual and contextual factors impacting on reablement outcomes
- Practice and delivery issues

6.3.1. Impact of the 2014 Care Act on services and practice

Most interviewees regarded the shift in approach to offering reablement to all relevant referrals to adult social care – as introduced by the 2014 Care Act - as sensible and appropriate. Interviewees expressed the value of assessing an individual's capacity for independence within the setting of their own homes *and* whilst monitoring the extent to which systematic efforts to restore independence in activities of daily living were having an impact.

> When they're in hospital you might think "Oh yeah, they're going to need a lot of help"; and then when they get home they actually somehow just sort of slot into doing it naturally. Put them in front of their own bathroom sink, and they know and just get on with it...

At the same time, it was noted that expectations for reablement necessarily had to be broader and working towards the achievement of full independence could no longer be the default position.

> …then it was pure reablement; now it's a lot different because we're an assessment team now, so we have different things coming through…..
>
> At the beginning, we saw people really achieve their goals. They were coming, they were with us for six weeks, and all of a sudden they didn't need it any longer. It was like that constantly. But now, I don't see it.

In addition, across all services, there was a belief that the capacity of reablement services had been compromised by these changes. The fact that assessment and reablement services may be the only 'in-house' provision within a local authority meant that services were required to accept referrals which had no, or very minimal, reablement potential but which had been turned down by external care providers and/or there were not sufficient external care providers in the locality. As a result throughput, and capacity to accept new referrals, had been affected.

> Lately, we were getting a lot of long-term care packages handed back to us because of the agencies going down. So it's not really, it wasn't really reablement.

> We seem to be spending less time with our clients that we can reable.

> There is a lot of cases when it [*reablement*] does work, but it's the odd few that we've been referred, but they're not reablement. They're the ones it doesn't work with.

6.3.2. The impact, and suitability, of reablement

We asked staff if they believed reablement 'worked', was it effective and was it the best approach to use for people experiencing a decline in independence or recovering from an acute medical event which threatened their independence? There was strong and consistent support for reablement.

> It definitely helps people to become independent, without a doubt.

> [*A service user said to me*]… "I've got my life back, dear." People often to say that they never dreamed they'd come on so far as when they first come as to when they finish with us. Sometimes they're even further than when they went in in the first place.

Many had experience of traditional homecare, which does not seek to restore the skills of independent living, and there was a great confidence among interviewees of the far more superior outcomes achieved by the reablement approach.

> It's much better than dishing out packages of care.

Thus, whilst suggestions were made as to how local service structures and processes could be changed or improved, support for reablement *as an intervention* was unwavering and no suggestions were made as to how the intervention *per se* could, or should, be improved. Perhaps as a consequence of this staff generally reported finding their work very satisfying and, aside from staff working for a private provider, no reference was made to changing jobs.

> It's very rewarding watching someone get better and they stay at home where they want to be which is nice. I like that. Love my job. You actually get a sense of achievement because we're helping people. We're trying to do our best for them.

> It's a fantastic buzz for us because you've seen a vast improvement and they're getting back to doing their own thing.

The 'active ingredients' of reablement

Within this discussion about its effectiveness as an intervention, we asked interviewees for their views on the 'active ingredients' of reablement. A number of distinct components were consistently identified.

Workers' knowledge

Two distinct domains of worker knowledge were identified. First, practical knowledge and expertise with respect to finding solutions, or alternative ways, to carrying out activities of daily living.

> So it's giving them little skills and tips. Sometimes just showing them a different way of doing something. And working with them to do things. [*For example*]…if you can't do buttons up, but you've got several tops that you can just pull over your head.

> It's making a way for someone to do it, instead of saying "You can't". So there's always a way that you can do something

These solutions may include identifying and securing appropriate aids and equipment; or recommending to families where they can readily purchase aids and equipment which do not require specialist assessment or fitting.

> I tell them to go down to [*national DIY chain*]

The second area of knowledge is with respect to local services, and particularly voluntary sector organisations offering social and daytime activities.

> We signpost them …to charities, organisations providing companionship.

Workers' skills

Overall, an understanding of the differences between reablement and homecarea and having the skills to work with individuals using a re-abling approach were regarded as core to the achievement of positive outcomes. Perceived threats to this were either where reablement workers had previously worked in home care and had not received adequate re-training and on-going supervision, or workers had a mixed caseload of reablement and home care clients.

Across all focus groups, staff clearly articulated the inter-personal skills required to develop an effective therapeutic relationship in which the service user trusts the worker(s), accepts their need for support, and feels confident and motivated to work on their reablement goals.

> The [*reablement workers*] are really good because they have all sorts of ways from laughing and joking and being a little but firm and every bit of their experience to try and get these people to engage.
>
> And the client has to really like you. There's got to be a good relationship there.
>
> ….you need to coax them into being able to be a bit more independence.
>
> It's trying to get people's trust and to accept your assistance, as one would say, without forcing them. You're there trying to help them and [*sometimes*] they don't think they need our help.

Staff also highlighted the importance of the somewhat intangible skill of knowing at what level to 'pitch' the demands they place on a service user and to observe and respond to progress, or deterioration.

> There's a little bit of divide and conquer! So they still feel supported but they're given autonomy and control to take the lead with certain tasks until they feel able to take more on.
>
> It's understanding when to step back and when to move in.

Social contact and reconnecting

Finally, staff believed that the delivery of reablement via home visits provided a source of company and served to re-establish routines and reconnect with everyday life.

> They don't see anyone else all that day, just sitting down, or even if you work alongside them, just having a chat. If they've got concerns or something, you can put their minds at ease. Just like a conversation.

These outcomes in themselves were regarded as improving mental well-being and confidence which, in turn, placed the individual in a better position to engage with achieving their reablement goals.

6.3.3. Users' and family members' understanding- of reablement

The lack of understanding of reablement as an intervention – on the part of both service users and family members - and the impact this had on expectations of the reablement service was a dominant theme.

> Some of them [*service users*] have their own concept of caring. So, they're expecting a domestic to come and do everything for them.

> They just can't get round the whole reablement process, they're still back with the old dom care days.

> They [*family members*] say, "Well aren't *you* supposed to making their cup of tea?"!

Typically, family members were presented as an unhelpful influence, urging the service user to adopt a passive role and being risk averse. This could jeopardise the therapeutic relationship and managing family members diverted staff's time away from their work.

> We've had things like, "Oh my daughter's told me not to do anything cos otherwise I won't get any help".

> How many times have we heard family say: "Don't go out *[to]* the kitchen because it's dangerous!"?!

Inaccurate representation of reablement on the part of referring agencies was viewed as an important contributor to these mis-understandings.

> I think they've got mis-understandings of what the service is. There is misinformation at the time when patients are initially having contact [*with professional managing hospital discharge*] …that leads to these unfounded expectations from the patient. We've tried to educate the referrers but it doesn't seem to be sticking.

However, users' and families' more general understanding about social care, particularly an awareness that statutory social care usually comes with charge, led to confrontation when family members' perceived workers as "not doing what they should be doing" and disgruntlement when the intervention finished "before the full six weeks".

> Families are often harder to deal with. Trying to get the relatives to understand what reablement and intermediate care is about.
>
> "We've been told we'll get six weeks of this" is the classic line!

Interestingly, this sense of entitlement to care was regarded as generational issue, not observed among very old clients.

> …the seventy year olds, there is this expectation: "I'm entitled to this…". I see it more now than I ever have before: this expectation…even if the need isn't there.

Overall, reablement staff described overcoming and changing these perceptions to be very challenging.

6.3.4. Individual and contextual factors impacting on reablement outcomes

The previous section (6.3.3) reported staff's views on the way that individual and family members' **understandings and expectations** of reablement might impact on engagement with reablement and reablement outcomes. In this section we report on other individual and contextual factors which staff identified as impacting on the effectiveness of reablement. There was a remarkable level of consistency in the issues raised across all focus groups.

Personality

First, staff spoke of service users' inherent qualities, such as temperament or personality. Here their discussions referred to concepts such as motivation, positive attitude, realism, adaptability (that is, a willingness to try different things), and a sense of self-responsibility for themselves and their health.

> Yeah, willing to give it a go. It's not just motivation, but it's just being like: "I'll give it go! It sounds like a really different way of doing things but I'll give it a try". It's beyond motivation, not just the talk of motivation, it's the physical action of putting into practice as well.

Problem-solving skills

Second, staff described how users varied in their problem-solving skills or willingness to actively seek to manage the difficulties they were facing. It was noted that, and particularly for those where an acute medical crisis had led to their referral to the service, a previous experience of overcoming a significant challenge or set-back was often helpful. This was for two reasons. The individual may have acquired relevant problem-solving skills during that previous episode. In addition, they had learnt, and experienced, recovery is possible. Typically, staff believed these qualities were more usually observed among the older service users.

> It's the one hundred year olds, they literally just get on with it. They're just like "Oh don't worry dear, I'll do it this way"…and then they do it. They have a stoic nature, they're good problem solvers. They've lived so long that they naturally have to problem solve …they have a really good skill set already.

Mental health and cognitive impairment

Low mood and mental health difficulties such as anxiety and depression were regarded as negatively affecting reablement outcomes. Co-morbidites such as alcoholism, hoarding and dementia were also flagged as a challenging to manage.

> The most challenging are the ones who have the drug and alcohol problems. When they get back home to their own environment [*with*] the factors that make them

> drink or make them use…they're not interesting in helping themselves anymore; they're just interested in that…
>
> It's people with depressions and things like that. I would imagine if you're suffering from depression, one thing and another, you don't want to do anything. You might be able to, but you just don't want to. And they have to get past that.

There was widespread support for better access by the reablement service to mental health and other specialist input and/or rapid referral pathways.

Housing

The issue of housing was raised a number of times.

> [*Housing*] can have an impact on what sort of equipment there is or whether people get outside. You have to work with it.

In particular, staff described delays in securing agreement, or experiencing outright refusal, to install aids and equipment when users living in rented housing. Private landlords could be very difficult, even impossible, to contact which meant that equipment to support, for example, mobility, personal or self-care, could not be installed.

> Private landlords…it's just impossible. Say if you've got to put in a gragb rail. You've got to have written consent, and trying to get through to a private landlord is nigh on impossible. I mean some aren't even in the country. For anything permanent, I find it impossible to progress it forward.

Reabling within a relationship

Managing reablement within the context of a marriage/partnership was also raised, with the belief it could both support, and hinder, reablement. Changes in health or functioning may have upset the equilibrium of previously established roles, with partners being required, if only temporarily, to assign new roles: something which may need negotiation and management and which reablement workers can support.

> Cos they're co-dependent, so the way they're functioning when they're both well works. But whatever reason, if one does off-balance, they both off-balance, and then it's trying to rectify that.

6.3.5. Practice and delivery issues

In this final section we briefly report opinions regarding other practice and delivery issues which previous research, or practice guidance, have identified as being associated with intervention effectiveness or service user experience.

Flexibility in timing and duration of visits

There was a consistent view that flexibility in timing and duration of visits – and a gradual reduction in intensity - was essential to the reablement approach and allowed staff to be responsive to the needs of individual users. Some noted that this approach may be more difficult to secure with outsourced providers where contractual arrangements require a specification of the number and duration of visits. There may also be disincentives to reduce intervention intensity.

> They'll sometimes see eight patients in a morning. Imagine the pressure: "I've got to let her do everything" "I've got to get to my next visit".

Staff also identified an additional positive impact of flexible visit times with service users sometimes choosing to manage a reablement task independently than waiting for when the reablement worker arrived. Successfully achieving this could boost confidence and progress.

Monitoring and supervision of reablement workers

Adequate monitoring and supervision of reablement workers was viewed by assessors as very important and our study included a range in terms of the extent to which this was possible. A separation of assessors and reablement worker teams inevitably created a barrier which, potentially, was more evident when reablement workers were out-sourced.

> Once it's passed over to the agency, it's out of our hands, we have no control over it. We visit if we can, but that depends on caseloads….I suppose really we just try and oversee it as best we can. They're still our responsibility...

Number of workers assigned to cases

One research site had a policy of assigning just two reablement workers to each case (with holiday and sickness cover as required). In the other sites each service user could be visited by multiple reablement workers. The benefits of both approaches were identified. Multiple worker involvement was regarded as positive in terms of allowing a range of different ideas or approaches to be brought to supporting the reablement of a particular individual. It was also regarded as increasing the likelihood of a service user finding a worker they liked and "connected with" which, in turn, supported the development of a positive therapeutic relationship. On the other hands, workers from the service where cases were assigned to two principal reablement workers believed this approach offered important benefits in terms of continuity of care.

Access to specialist expertise

Finally, across all three sites additional core posts – or timely and easy access – to further professional expertise was flagged. Staff in all services highlighted the importance of physiotherapy, addictions, and mental health input.

> R1: I find people are waiting on a physio…then they're sitting around also losing body muscle and it delays us doing our job.
>
> R2: It can almost become disenablement, can't it?

For services without occupational therapy, this was equally, if not more, important. No issues were, however, reported with respect to timely and efficient access to community equipment provision.

6.4. Summary

This chapter has reported on findings from focus groups with staff working in the reablement services acting as research sites for the study's evaluation work package (WP2). Interviewees included those with an assessment and review role and reablement workers. Staff based in in-house and out-sourced teams were represented. The interviews explored experiences of delivering reablement from a number of the perspectives.

Both assessment staff and reablement workers discussed the impact of the Care Act 2014, and also NHS discharge-to-assess policies on their characteristics of their caseloads with reabling to full independence was no longer the predominant outcome. At the same time, reablement was still regarded as a relevant and effective intervention for individuals with support needs associated with staying in their own homes, or returning home following an inpatient episode.

A key impact of merging assessment and reablement services was the significant increase in volume of referrals which some services were struggling to manage. This appeared to be exacerbated by a lack of sufficient home care provision (typically out-sourced) or a refusal by providers to accept referrals for onward transfer of individuals needing on-going support. This had the impact of a slowing service throughput.

There was a strong and consistent belief of the superiority of reablement over “traditional homecare”. The skills and knowledge of staff to adopt a reabling approach was regarded as vital to the success of the intervention. In addition, staff believed the frequent social contact resulting from home visits by reablement workers served to re-connect, and re-kindle, interest in everyday life.

The issue of user and family understanding of reablement was an issue raised across all focus groups. A lack of understanding of the difference between reablement and homecare was regarded as a barrier to the effectiveness of reablement and distracted staff time away from delivering the intervention. Staff reported that they had been unsuccessful in finding ways to address this issue.

Aside from the issue of user, or family, understanding of the intervention, a number of other factors were identified as impacting on reablement outcomes. These included service user characteristics (personality, problem-solving skills, mental health, cognitive impairment, the presence of a partner/spouse). Housing was also identified as a potential barrier to success, installation of aids or minor modifications to the home could be difficult to achieve if the individual rented their home.

A number of aspects of service delivery and practice were also identified on impacting on the effectiveness of reablement. Flexibility in timing and duration of visits, and an

expectation this would reduce over the course reablement, was noted. However, some staff believed that this was not sufficiently incentivised in contracts without-sourced providers. Adequate monitoring of an individual's progress and supervision of reablement workers was regarded as critical and more difficult to achieve in services where assessors and workers were based in different teams. There were mixed views about the optimum number of workers which should be assigned to a case: advantages to having one or two or, alternatively, multiple workers were both articulated. Finally, access to specialist expertise – particularly physiotherapy and mental health –was regarded as important but difficult, if not impossible, to access in a timely way.

Chapter 7. WP2b: user and family members' views and experiences

7.1. Introduction

This chapter reports the second element WP2b, the study's process evaluation of reablement, which involved interviews with service users and family members.

7.2. Methods

7.2.1. Identification and recruitment: service user sample

Interviewees were recruited from the outcomes evaluation (WP2a) sample. At the time of joining the study individuals indicated whether or not they would be willing to take part in an interview about their experiences of reablement. We aimed to recruit 10-12 service users from each research site using a purposive sampling frame in order to represent a range of outcomes at T1, service user characteristics (age, gender, lives alone/with partner or family), and the reason for referral for reablement ('remain at home' vs 'return home'). In Site C, we also sought to recruit participants from across the three services delivering reablement in that locality and taking part in the study. Sampling information was drawn from data collected for the purposes of the outcomes evaluation (WP2a).

In each research site, the research team passed details of the target sample to the Local Study Officers. The LSO contacted potential interviewees by telephone to ascertain interest in taking part in the study and, if agreed, to make arrangements for an interview. An information sheet was sent with a covering letter confirming data and time of the interview. On the agreed date and time, a member of the research team visited the participant at their home and obtained their written informed consent to take part in the study before the start of the interview. Copies of recruitment materials are available (RSM 4).

7.2.2. The sample: service users

Thirty-one participants were recruited from across the three research sites. An overview of the characteristics of the service users who took part in an interview are set out in Table 17.

Table 17: Characteristics of service users taking part in interviews

Sample size	Weeks since discharge	Age (years)	Gender		Living situation			Reason for referral	
			Male	Female	Alone	With spouse/ partner	With other family member	Remain at home	Return from hospital
Site A									
11	mean=12 range=2-21	mean=79 range=67-89	2	9	4	6	1	8	3
Site B									
6	mean=17 range=7-22	mean=85 range=75-95	2	4	2	2	2	0	6
Site C: out-sourced provider (n=2)									
8	mean=15 range=11-18	mean=83 range=68-96	3	5	5	2	1	6	2
Site C: in-house service									
6	mean=10 range=3-17	mean=78 range=55-90	2	4	6	0	0	2	4
Total sample									
31	mean=13 range=2-22	mean=81 range=65-96	9	22	17	10	4	16	15

7.2.3. Recruitment: family members

At the end of the service user interviews, respondents were asked if they had a family member supporting them who might be willing to take part in a short telephone interview about their views of, and involvement in, the reablement process. If they did, the research team sent the service user a 'Relative's Information Pack' to pass on to this individual. The pack included a response form (and reply paid envelope) to return to the research team if they were interested in taking part. A researcher then contacted the family member who to discuss participating in the study and, if agreeable, to arrange an interview. Informed consent was collected in writing in advance of the interview or audio recorded at the beginning of the interview. Copies of recruitment materials are available (RSM 4).

7.2.4. Sample: family members

Just two family members responded to the invitation to take part in an interview. Both agreed to be interviewed by telephone. One who lived with the relative they cared for and provided care in excess of 50 hours a week. Another who lived separately from their relative and provided up to 19 hours of care a week.

7.2.5. Data collection

Topic guides (RSM 6) were informed by findings from previous research and in discussion with members of the Study Steering Committee. Interviews with service users focused on the experience of receiving reablement, understandings and expectations of the service, perceived outcomes and views on aspects of the intervention which supported achievement of those outcomes, their feelings and reflections when the service ended, and longer-term outcomes. Interviews with family members covered the same topics but also explored the family member's relationship with the reablement team and their role or involvement in supporting reablement. Data collection was carried out by SC and RM; they and BB met regularly during the fieldwork period to review interviews and ensure consistency in use of the topic guide.

With permission, interviews were audio-recorded. The duration of interviews was very variable, ranging from around 20 to 60 minutes. Fieldwork with service users took place between April and June 2017. Interviews with family members took place in September 2017.

7.2.6. Data analysis

Service user and family member interviews were analysed separately. The overall approach to the data analysis was a thematic analysis.[13] The Framework approach[14, 15] was used to facilitate systematic data management and data interpretation and ensure audit trails of the data management process. SC led the data analysis and writing.

There are four stages to this process. First, the researchers (SC, BB) involved in data analysis familiarised themselves with the data independently with a view to identifying topics and issues emerging from the interviews. They then met on a number of occasions to review

their impressions and to identify themes – a priori and emergent – present in the dataset. This led to an index of themes being constructed (the thematic framework) (see Appendix 13). The framework was then tested by attempting to use it to index a sub-sample of interviews. The outcome of this was reviewed by the research team and led to refinements in the thematic framework. Once the team were satisfied with the framework, all the transcripts were indexed according to which theme(s) in the analytical framework they relate to. Next, the indexed data from interview were summarised onto a series of matrices (or charts) which are organised and labelled according to the thematic framework. Each chart is divided into columns, allowing relevant data to be organised according to sub-themes/issues or themes to be grouped analytically. A single row on each chart holds one participant's data. Thus reading along a row provides an overview of everything an individual spoke about in terms of a specific issue. Reading down the chart (or down a column) allows comparison between participants. The final stage of analysis involved a process 'reading' of the charts and composing 'analytical notes' to describe observations and findings. These notes included verbatim quotes each of which include a note of their specific locations in a transcript. Analytical notes were shared and discussed among the research team, and interpretation and writing developed and refined in an iterative process.

7.3. Findings

We present the findings from the interviews with service users using a 'chronological' framework – presenting views and experiences encountered during an individual's journey through reablement, and life since being discharged. While we tested and looked for discernible differences in respondents' accounts between services and sites, none were apparent. Thus findings are presented generically and concern experiences of five different reablement services – one each from Sites A and B, and three from Site C. Findings from the interviews with a family member are situated towards the end of this account.

7.3.1. Being referred to, and anticipating receiving, reablement

There was a confused picture, both from those who received reablement following discharge from hospital and those referred to the service to prevent (increased) reliance on

home care, as to the history of their referral. This is not unsurprising given that this will have occurred when they may have been recovering from an acute or on-going health issue or had been struggling with everyday life.

Among those being discharged from hospital, several described themselves as keen to return home and saw their referral to the reablement service as a means of doing so. What was not apparent, however, was whether they had properly understood the objective of the intervention – something we return to in the following section.

> .. in the end I just had to agree, cos I just wanted to get home, that's all I wanted to do was to get home [X1].

Others reported they had been unaware of the referral to the service until a reablement worker arrived at their home.

> The carers just came of their own accord, as far as I know [W1].

> So they didn't tell me that they were going to put someone in so I was quite surprised when it all happened and I was pleased [S1].

Among those who recalled anticipating receiving reablement, most described being pleased and relieved. They recognised they needed help to manage to living at home. They reported being pleasantly surprised such support was available.

> So I was relieved, yeah, cos I knew they'd ... somebody would arrive each day and that's, that was enough [D1].

For some this relief centred on the fact it meant they did not have to rely on family members.

> It gave me, yeah, it, it gave me some confidence ... well just knowing that somebody was coming in ... every morning, that somebody would come in and I'd be able to talk to somebody rather than me picking up the phone, bothering my daughter or somebody [A2].

While most interviewees recalled recognising that they needed support, some spoke of a tension between receiving help and a desire to (continue to) manage by themselves. Being independent was very important to many interviewees, and some perceived receiving support as relinquishing this. It is possible that a lack of understanding of the objectives of reablement may have contributed to these feelings.

> I was absolutely shocked. And I laid there one night and I thought [*to myself*] what's happening, why is all this happening, why have I gotta have carers, why can't I do it? And it just frustrates you and that's the only word I could use [X1].

> I didn't like it at first cos it was losing my independence, but I knew it was necessary - and I knew I couldn't cope by myself - until such times as I could cope by myself [N1].

Finally, a few believed they had been referred to the service needlessly. They felt they were managing on their own from the outset and did not want to deprive others, needier than themselves, of valuable resources.

> I, I felt it was a waste of their time when other people are more needy than, than me, you know [C1].

7.4. Understanding of the reablement approach

We asked interviewees about their understandings of the ethos and objectives of reablement. Views and understandings were mixed. Some, particularly those who had received reablement support previously, were clear that the overall objective of the service was to enable individuals rather than to do things for people as in conventional home care.

> Well the reablement people ... their aim is to make you do it yourself, you know, they're, they're not there to do it for you, they're there to encourage you to ... do everything yourself if you can [T1].

The responses of others implied, rather than explicitly demonstrated, an understanding of the reablement approach in that they referred to how their reablement workers had

supported and encouraged them to do things for themselves. Among other interviewees, however, it seemed they had not fully grasped the difference between reablement and home care. There was evidence that, sometimes, reablement workers perpetuated this understanding and allowed a service user to assume a very passive role.

> Whatever I asked them to do, you know, they, they would do it for you, so. Nothing was any trouble to them, no [E1].

Thus, these interviewees talked about their understanding and expectations of the service in terms of someone coming in to do 'whatever needs to be done' [F1] or simply 'to help' [I1]. Some explained that they had understood reablement was free care for up to six weeks after which time it would be charged, suggesting that they were expecting to require support after that period.

There was evidence that a lack of understanding of the reablement approach had caused confusion as to the role and remit of the reablement workers who visited them.

> At first I didn't understand it until, as time went on and I realised what they could do for me and what they couldn't do for me [N1].

Indeed, a couple of interviewees reported feeling concerned that they were not taking full advantage of the reablement service. The fact that there was some variability in the help and support provided by different reablement workers did not help with this. This lack of clarity led to some instances of awkwardness and embarrassment when reablement workers refused to assist with a task which the user had felt was reasonable to request (e.g. to buy a morning newspaper; to wash their hair).

7.5. Experiences of reablement practice and service delivery

7.5.1. The goals-focused approach

Only a minority of interviewees recalled a visit, or telephone call, at the beginning of reablement in which what they wanted and needed from the reablement service was discussed.

> Well I suppose they did ask us what I wanted doing and, or rather suggested what, things that they could do and what did I want [H1].

There was also little evidence in interviewees' accounts of an awareness of joint goal setting between themselves and reablement staff – something which is meant to be a core characteristic of the intervention.

> They may have had goals I don't know, but I don't remember talking to them about them [D1].

> I think, to be honest, I was pretty much told what they were going to do [Q1].

A few reported that it was decided in hospital what tasks and activities the reablement workers would support them with. It was not clear from their accounts, however, whether they were at the centre of this decision-making process. In contrast, some interviewees did describe ongoing discussions with the reablement workers about the tasks and activities they wanted support with as reablement proceeded and their health, confidence and/or mobility improved.

7.5.2. Aspects of everyday life where support provided

Unsurprisingly, the aspects of everyday life with which service users described receiving support and assistance varied according to individual needs and, on occasion, between workers. Interviewees commonly described input and assistance with regards to managing personal care, and mobility linked to these activities, such as getting in and out of bed or the shower or bath, on and off the toilet, or up and down stairs. While a few service users described being helped by workers to prepare basic meals by, for example, getting the foodstuffs out of the cupboards or demonstrating how to heat up a meal in a microwave, around a third of interviewees reported having hot drinks made for them (particularly in the early days of reablement) for which they were very appreciative. Similarly, there were reports from around half the interviewees of workers doing domestic tasks or health-related tasks for them. Examples given included washing dishes, making the bed or taking out the rubbish and prompting to take medication, applying creams and ointments and help with putting on and taking off compression stockings. While most people did not receive support

outside the home (or ask for this type of assistance), two interviewees receiving reablement from the same service said they were supported by their reablement workers to go for a walk in their garden or immediate vicinity.

Some interviewees complained that reablement workers did not support them with aspects of everyday life that they prioritised or placed importance on, such as having a bath (although inadequate facilities often accounted for this). Some also expressed disappointment that they did not get more help with domestic tasks like shopping, cooking a fresh meal and general housework. Again, this is evidence that some interviewees believed they were receiving homecare support and lacked an understanding of the objectives of reablement.

7.6. Timing and time keeping

One of the most frequently expressed criticisms of the service concerned the unpredictability of visits by reablement workers. However, this was not a universal complaint and the majority of respondents were sympathetic towards workers in light of their busy schedules. They also felt they could not complain about what they regarded as a "free" service.

> Well yeah, they've gotta lot on their books and there's a lotta people worse than me [U1].

> Well it's just, you know, it's one of those things you have to cope with because the care was there and it was free and you, you, you, you're grateful for anything really [R1].

Another key source of dissatisfaction was the timing of visits. First, for visits to help with washing and dressing, interviewees disliked it when these took place late morning, feeling it held up their day. When visits were scheduled for later in the morning, or workers were running late, a few respondents described trying to get washed and dressed themselves or (if available to them) getting others in the household to help them. Whilst, in a sense, this

may serendipitously support the achievement of the objectives of reablement, it was not seen this way by the service users we interviewed.

> I mean when they, they used to come I, and I was up, washed, dressed... hair done and everything, had me breakfast, washed up, tidied up and sitting down [C2].

Interviewees also disliked it when visits to help them with getting ready for bed were too early. Indeed, some interviewees had asked for these visits to cease: they had not enjoyed going to bed at a time earlier than usual.

> In fact I didn't have them in the evening, purely because they wanted to get me ready for bed at five o'clock in the afternoon [M1]

A few respondents reported other difficulties associated with the timing of workers' visits. For example, one woman was anxious that if workers arrived too early to help her to shower the bathroom might be in use by others in the household getting ready for work. Finally, some interviewees found the reablement visits restrictive or disruptive in terms of not being able to make other arrangements or participate in activities in and outside of the home. For these individuals, it was often a relief when reablement ended.

> Sometimes it's a bloody nuisance, excuse my language...especially if you're doing something, you know [L1].

7.6.1. Duration of visits

The majority of interviewees said they found they were given the time they needed by the reablement workers. However, there were some reports of hurried visits with workers being described as rushing through their duties in order to get to their next client. In one interview, unpleasant experiences of brusque care were directly attributed to workers' lack of time.

7.6.2. Workers' gender

Reflecting the wider care workforce, the majority of reablement workers who had visited our interviewees were women. Some, but not all, of the men we interviewed specifically

noted that they particularly enjoyed sessions with a male reablement worker. They described feeling they had more in common with someone of their own gender which made for easy conversation.

> And he was a, a male carer that came,… [*we'd*] have a good old chat about the good old days [U1].

While some interviewees recalled feelings of discomfort around nudity in general, no interviewee specified this discomfort - or greater discomfort – in relation to workers of a different gender supporting them with personal care.

> I felt comfortable with all of them. I mean I, I know that I needed them and they had a job to do and it didn't worry me, me whether it was male or female, cos I, you know, when I first came out, I mean .. I feel as one would put it, felt very exhausted, etc, you know, and .. this was helping me to get back to normal [J1].

> I wasn't really expecting a man (*laughs*). But never mind. It all went well. It worked fine [V1].

We would note that these reflections were being made after having received support, rather than in anticipation of having help with personal care from workers of a different gender for the first time.

7.7. Perceived outcomes and views on 'active ingredients'

7.7.1. Reported outcomes

The great majority of interviewees were satisfied with the help, care and support they received from the reablement service they had used. They reported positive outcomes in terms of the core objective of reablement, namely regained independence. Within this notion of regained independence was the relief and pleasure of not feeling (further) reliant on family members. This could relate both to an awareness of their families' lack of capacity to support them, and/or maintaining valued boundaries within their relationships.

> ... you know, I was able to, to get dressed or undressed without their help ... you know, it's not easy for a daughter to see her dad naked (*laughs*) [R1].
>
> Well they help you to get back your independence... and I, I mean you can't rely on your, your family all the time [E1].

A few, nevertheless, reported no notable changes resulting from their time with a reablement service. These were all interviewees with chronic poor health who were unconvinced that a return to independent living had ever been a real possibility. Nevertheless, they still reported gains from reablement.

> Yes, that was very helpful. Well when you compare that with having nothing, you know, I mean it's like a little miracle (laughs) [T1].
>
> I was just glad they were there [Y1].

Typically, it was these interviewees who, by the time of the interview, had moved on to a package of homecare once reablement came to an end, or were receiving extensive support from informal carers.

A second outcome – companionship - was frequently experienced whilst receiving the intervention but not sustained afterwards. In the next section we report interviewees' views about how reablement supports regaining, or maximising, independence. The following section (7.7.3) considers the issue of companionship.

7.7.2. Views on how reablement 'works'

Interviewees identified three aspects of the presence or activities of reablement workers which supported, or enabled, positive progress towards re-gained/maximised independence:

- personalised and enabling assistance
- advice and information
- emotional support.

Interviewees described that, through the visits and input from reablement workers, they had regained the confidence and practical skills which enabled them to manage everyday life independent of any formal support.

Personalised and enabling assistance

Interviewees described being assisted with personal care, transfers and moving around (for those whose movements were limited by fractures and other injuries, acute and chronic illness or general frailty). Importantly, the majority described how this assistance was gradually reduced with responsibility for doing tasks, or managing independently, being passed to themselves. This was recognised by most as being an important element of the way the intervention was delivered.

> …where previously they did it [*dressing*] all, I could then start tugging things, you know, pulling me pants up and me trousers up and things. Yes, it just, it was just a gradual process [J1].

It was clear from interviewees' accounts that having workers "stand by" and observe whilst they attempted tasks, and knowing they would "step in" if things went awry, was very important to regaining confidence. The sense of safety and security offered by the presence of a reablement worker was particularly mentioned in relation to a fear of falling. Interviewees reported they were more inclined to try to do things for themselves knowing that workers were standing by to help them if they got into difficulties.

> It, it made you feel more confident, shall I say, cos you knew that if .. as soon as they see you sort of wobble they would, they would come to you straightaway; well they're only just a shake away sort of thing [B1].

Furthermore, this sense of safety extended beyond the times the reablement worker was present. Those that lived alone described being reassured that, were they to fall and be unable to summon help, their workers would soon be calling. This gave them the confidence to begin to re-assume tasks and activities when they were on their own.

> .. it's just the fact that another human being comes to see you that makes you feel better and gives you the bit of confidence, oh well I'll do that myself [D1].

Advice and information

Interviewees also spoke about, and appreciated, the advice and information they had received from their reablement workers. This included hints and tips on, for instance, how to wash, shower or dress themselves when their mobility was limited, safe ways to get in and out of bed, and removing and replacing a catheter bag. Respondents valued the time workers took to explain what they were doing and why.

> Yes, yeah, little things ... like putting your socks on, doing up your laces, you know, it's easier if you've got slip-on shoes and things like that, all, all practical useful tips [R1].

> it's just somebody to say do you think, do you think I should do this, do you think I should do that; it's just that little bit of backup or support to say yes, go on, I think you should do that, yeah [D1].

Emotional support

It was clear from interviewees' accounts that the encouragement, reassurance and acknowledgement of achievements received from reablement workers was an important aspect of the intervention, increasing interviewees' motivation, self-confidence and satisfaction with reablement.

> ... and to know how much they'd help me get on and do things for myself, I think that made... quite a lot of difference to me, and to know that they could turn round and say to me 'You're really doing well *XXX*, just keep it up' [X1].

In addition, and a quite different aspect of emotional support, some interviewees referred to the consolation, or comfort, of knowing someone was aware of them and would be visiting them in the near future. There was a sense in some interviewees' accounts that this knowledge made them more settled and comfortable and, for those being discharged from hospital, helped with adjusting to being back home.

> Yeah, it was, I felt safe, you know, I was just so, at the beginning, I was so scared of falling again [E2].

> Knowing that somebody's gonna come and, you know, if I pass out or anything, they'd come and they'd find me. Otherwise, who knows? [U1].

The physical benefit of this – in terms of better sleep - was also noted.

> ... you just feel more secure in your bed for some reason [..] it's just the fact that somebody comes in in the morning makes you feel so much better and you sleep better, yeah [D1].

Some interviewees also noted that their families had found the schedule of regular visits reassuring following their relatives' discharge from hospital.

> I think they were relieved to know that there was somebody coming in and that if any, if there was anything wrong ... they could ... obviously phone [my sons] to say this, this or whatever [X1].

7.7.3. Companionship

Overwhelmingly, people reported increased positive emotions and social connectedness from the companionship that reablement workers provided. Social isolation and loneliness were common and, for some, the daily visits from reablement workers had, temporarily, addressed a significant area of unmet need.

> Well you, one of the things you need is, especially when you're in this bloody condition, is you need people to talk to and you don't get anybody to talk to cos they haven't got long enough to listen to yer [F1].

Typically, interviewees reported that their reablement workers took a friendly interest in their lives. Unsurprisingly, therefore, some service users explained they had become quite attached to their workers. The conversations and "laughs" they had with their workers were viewed by some as both the most enjoyable and the most important aspect of reablement.

> ... because at the time ... I wasn't able to get out anyway and I know ... yes I did have visitors, but, you know, you, you do feel, you feel very strange coming out of hospital

> even into your own home, you know. So it was nice to have someone to chat [with], you know [B1].
>
> ... it was just that little bit of contact, human contact. Cos some days I can go, I don't speak to anybody [A2].

7.8. Key factors impacting outcomes

Key factors perceived as impacting on outcomes were:

- the client-worker relationship
- workers' reablement skills
- users' confidence in the worker,
- duration of visits
- a reluctance to accept help
- records of progress.

7.8.1. The client-reablement worker relationship

Two, connected, aspects of the client-reablement worker relationship emerged from users' accounts which appeared to be associated with the extent to which they engaged with reablement – either generally or during a specific visit by a reablement worker. First, whether or not they liked a reablement worker; and, second, whether or not they liked the way that worker worked with them. Here, this related particularly to the way in which the worker instructed or encouraged the service user and how personal care was managed.

Overall, interviewees typically said they liked their reablement workers and enjoyed their visits.

> They were absolutely marvellous, I can't tell you how, you know, they were always cheerful and helpful and wonderful [B2].

Inevitably people had 'favourites' and got on better with some than others. Generally – but not always – interviewees said they preferred workers who were friendly, and interested in

them, but maintained professional boundaries in terms of what they shared about their own lives.

> I prefer them to be friendly; I don't, I don't want them falling over me or anything like that, but to be able to turn round and say something to them and have a laugh [K1].

However, interviewees also occasionally reported they had not liked, or got on with, one of their reablement workers. Sometimes this was simply attributed to a difference in personality or they simply did not "connect". At other times, it appeared that the interviewee had not liked the worker's approach to instructing and encouraging them as they worked on their reablement goals, or had felt they were being over-stretched.

> Well they, on the whole they, they were treating you as if you'd no intelligence and couldn't do anything, to be honest [C1].

> Trying to get me to do things on me own but I couldn't do 'em, which I didn't like [U1].

With respect to this, a range of preferences were certainly expressed. Some, for example, appreciated workers taking control and making decisions for them, while others preferred a softer, more gentle, approach.

Another issue which could engender, or threaten, a positive relationship was how reablement workers managed issues of dignity and discretion in relation to personal care. Again, preferences varied: some liked it better when workers were discrete while others said they would rather it was dealt with in a matter-of-fact way.

> …. rather than sit on the bed and watch me and embarrass both of ourselves, they used to go out in the kitchen and find out what wanted doing [D2].

> And... and then when they used to ... do the lower part of me they said "Stop worrying about it, *XXX*, just relax". That's all the word I can use. They used to say to me: "Relax, you've got nothing to worry about the, we do this every day of our lives." [X1].

7.8.2. Workers' reablement skills

Achieving the right balance between providing care and supporting reablement was identified as an important skill by several interviewees. It was felt that some workers were better at judging when to step in to provide assistance than others. This was the case for one woman in chronic pain with a progressive health condition who struggled to dress herself. She explained that some workers recognised when she needed help while others did not.

> Some of them were more helpful to you than others (…). Some, some knew when to step in and, and others were more intent on you doing it yourself (laughs) [T1].

7.8.3. Confidence in the worker

Experiencing competent care and support engendered users' confidence and, in consequence, their willingness and/or confidence to engage in reablement tasks and activities. Judgements about competence were made on the basis of the skills shown in the way a worker managed the balance between care and enabling practice. For some, these judgements were made with particular respect to managing new medical devices or procedures (for example, changing a catheter or putting on and taking off compression stockings).

> ...they were very good, I mean they, they knew exactly what they were doing, exactly [P1].

7.8.4. Duration of visits

It was clear from interviewees' accounts that a key factor regarded as contributing to poor outcomes was reablement workers having insufficient time for a visit. This resulted in reablement principles being abandoned and workers adopting a homecare role. Thus interviewees reported that when workers were in a rush, they were more likely to take over tasks rather than supporting the user to do it for themselves. Some were content to go along with this.

> [*Some workers*] well needed to get on with things; cos they've such a tight schedule that they were quite happy to do most of it all the time and I'm afraid I was quite happy to sit back and accept it [J1].

7.8.5. Records of progress

In all research sites, reablement workers recorded details of their visits, including accounts of their client's progress, in a folder kept in each service user's home. A couple of users described how reading these notes acted as a strong motivator in making further progress. It was not clear from the interviews whether notes were reviewed with a reablement worker, or alone.

> … each time I progressed they would note it down on their paperwork and it would give me the incentive to get to the next bit where I could do a bit more for myself [N1].

The usefulness of these folders as a communication aid between families of service users and their relative's workers, was also noted by a family carer as reported in a later section.

7.8.6. Service delivery and practice issues

Two service delivery and practice issues, whilst not attributed to impacting on outcomes, were explored in interviews with service users.

Continuity of workers

Research sites varied as to whether users were typically allocated a couple of reablement workers (one site), or whether any worker within the team can be allocated to visit a service user. Thus, some interviewees described a core team of two or more reablement workers who worked on rotation. These interviewees described how they had got to know these regular workers over a period time and felt at ease with them.

> Well it, it is, it is nice to have familiarity, I suppose, you know, with the same, same person rather than different, different people every day [L1].

Interviewees from our other two case sites, however, were supported by a number of workers with a few reporting a different worker visited most days. Perhaps unexpectedly, complaints about this lack of continuity were rare. Overall, compared to the case site above, interviewees were no less positive in their views about service they had received.

> I mean there was a lot of carers in, in the time I was, six weeks and... they were all good, I've got nothing but praise for them really [R1].

Family involvement

During our interviews we explored whether service users were aware of any work with family members being done by their reablement workers; for example, instructing them as to how they could best support their relative's reablement. Whilst, as reported earlier, interviewees spoke of the way the intervention removed a possible pressure or burden on families, almost no reference was made to instances where they had observed a worker upskilling a family member in terms of supporting reablement. The only exception was a situation where a husband was carefully instructed by reablement workers on how to put on and remove a splinting equipment.

7.9. Family members' accounts of the reablement intervention

In this section we present two case studies of reablement from the perspectives of a family member; first, a daughter and, second, a husband.

7.9.1. Family member case study 1

Our first family interviewee was a daughter who cared for her father who lived alone. He was receiving reablement following a fall and broken hip.

The daughter described making sure she attended the reablement workers' first visit to "back up" what her father said and make sure he got the care and support she felt he needed. She noted that she, and the wider family, had been very reassured by the arrangements made for her father following his discharge from hospital, both the fact he was receiving twice-daily visits and support and that they would be contacted if there were

any problems. She valued being able to view the progress record kept in her father's home and also used this record to communicate with the reablement workers herself. She found this "two-way thing" very helpful and was satisfied with her overall involvement in the reablement process.

> .. Dad couldn't remember everything that had happened. It was always good to read it from the people that were actually there. Each time they came in, the notes they left were very comprehensive, exactly what they'd done and exactly how Dad was, physically and also in his mental health as well, because obviously he had down days when he's stuck in there not being able to see and being on his own.

This interviewee was very pleased with the outcomes of the reablement her father received. She believed the combination of physical support and encouragement to move around and carry out basic personal care and domestic tasks at home had led to him regaining his confidence to live independently. In addition, she believed that his recovery was, in no short measure, due to the company the reablement workers also provided which, his daughter said, "kept his spirits up and gave him a purpose" at a vulnerable time.

> Yes, otherwise I think he would have just sat and festered in the chair and become a bit of a recluse.

7.9.2. Family member case study 2

Our second family member interviewee was a husband. Due to his wife's degenerative physical illness, he also identified himself as her carer. We interviewed this gentleman after his wife received reablement following a period in hospital due to a number of falls. His understanding of the purpose of reablement was that it would help his wife to become as independent as possible in terms of getting up, washed and dressed.

This interviewee did not believe reablement had achieved the desired objectives and identified reasons for this. First and foremost, he felt the duration of the visits was inadequate for the pace at which his wife could manage her own personal care. Consequently, workers, pushed for time, did things for her rather than helped her to do

things for herself. That said, our interviewee was grateful for this support as his own physical strength and mobility was compromised.

> ... they had a slotted time of about half an hour and they couldn't stand there and wait for [his wife] to do things herself otherwise it would have taken forever; so they had to make sure that they dressed her and washed her and did everything else. [...] It saved me having to do it and perhaps have an accident falling over where the leg wasn't strong enough.

Another issue for this couple was that while reablement visits usually took place between eight and nine thirty in the morning, and sometimes workers were considerably delayed. This unpredictability meant they were unable to plan their mornings. The husband also believed that it meant that workers often had "nothing to do" when they did arrive because, by this time, his wife had managed to get washed and dressed. He did note, however, that one or two workers would, instead, spend time supporting her with her mobility and strengthening exercises, which again was helpful to them both.

The service ended a week earlier than expected but this carer was "quite glad" when it did finish because it was no longer necessary to plan the day around visits by reablement workers. However, given the nature of his wife's illness, our interviewee did not think the reablement service had helped to restore his wife's independent functioning or reduce her need for ongoing support.

> I don't think there was anything to do with [*reablement*], no. I think confidence comes from being able to do things on your own and unfortunately, with [*my wife's*] condition, it's not there.

7.10. The end of the intervention

The majority of interviewees described themselves as feeling ready for reablement to end; some even reported asking for it to stop as soon as they felt they were managing independently. Here, however, some were encouraged to remain in the service in order to take full advantage of the "free" support being offered. However, a few interviewees

reported that reablement had ended unexpectedly with little or no notice. Typically this was bound up in their understanding that the intervention was of a fixed duration of six weeks: suggesting an incomplete understanding of reablement as an intervention seeking to support recovery of skills, with discharge being linked to this.

Some interviewees had moved on to home care packages following discharge from reablement. For those eligible for statutory support, this had been a seamless transfer with the same agency now providing home care. Others had had to source and fund their continuing care. Interviewees reported that the reablement service had provided them with information about local care agencies, but a few people had experienced difficulties finding an agency with the capacity to take on their care.

Feelings were mixed when reablement came to an end. Those that were able to function independently again were pleased that they no longer had to plan their day around workers' visits.

> It became more of a nuisance to me cos I have things to do here [S1].

> Oh thank goodness, to be honest, yeah, I can get on with me life now (laughs) because I was invited out and I thought I, I can't go out cos those carers are coming [C1].

Those that still needed help with washing and dressing or preparing a meal, were thankful when ongoing care was found.

On the other hand, many of those who had enjoyed the company of the reablement workers and grown close to their workers, described feelings of sadness and loss that they would not be seeing them again.

> Oh well I was sorry to see them go, not because I didn't feel better,... you get to know people a little bit and I thought oh they won't be coming in, you know [A1].

> I looked forward to them coming and I missed them when they went because they'd been very... friendly... you know, they, they didn't stay long, obviously, cos they've

> got other people to go and see to, but they always did make five minutes time for chat [N1].

For some their feelings were tempered by a gratitude that reablement had been made available to them and a desire not to divert valuable resources away from those in greater need.

> I didn't want to be that person that was stopping someone else coming out of hospital, I wasn't that bad [M1].

> ...I wanted them to go because I felt that there was other people needing it more than me (laughs) type of thing, you know [P1].

7.11. Interviewees' current situations

At the time of interview (between 2 and 21 weeks post discharge) most interviewees were managing without home care support. Specialist equipment (e.g.: dressing aids, walking sticks/frames, wheeled trolleys and grab rails) – most of which had been brought in during reablement – played an important role in this. As noted above, a few had moved on to long-term care packages.

Many, however, described relying on family, friends and neighbours for help with shopping, cooking and other household tasks and for providing regular social contact and emotional support. A few also paid privately for help with housework, gardening or for meals-on-wheels services.

7.12. Views about service improvements

Interviewees were generally very positive about the reablement service they had received. Not unexpectedly, therefore, suggestions about ways in which to improve the service were few. They can be organised into three themes:

- workforce issues
- information at the start of the intervention

- scope of reablement.

The majority of suggestions centred on the number of workers within a service and the need to bolster the pool of reablement workers. More workers, it was felt, would help to address the issue of the unpredictable nature of the timing of visits and visits that were rushed due to pressures of work. In terms of the pool of workers, it was suggested more should be done to recruit men into the workforce. Indeed, a third of male interviewees said they preferred the company and attention of male reablement workers to female ones.

In a few instances, there was some evidence of confusion about when the reablement service would start following discharge from hospital. For example, a few reported that they had expected a reablement worker to call the day they were discharged from hospital and had felt let down that they did not arrive until the following day or later.

The final suggested area of service improvement centred on a desire for the intervention to be used with respect to activities outside the home, for example, going for a walk, catching the bus to the local shops and services. Some interviewees believed that help with these activities was just as necessary in enabling people to remain living independently in their own homes. Interviewees expressing these opinions said it would be helpful if reablement services could be tailored to their individual needs and priorities.

7.13. Summary

This chapter reported the experiences of individuals who had received reablement. The experiences of the two family members – a spouse and daughter – we were able to recruit to the project are also described.

The majority of interviewees, at least at the start of reablement, did fully not understand the nature of this intervention regarding it, instead, as homecare. The exception to this was individuals who had received reablement in the past. Some aspects of dissatisfaction with the service they had received can be attributed to this mis-understanding. Aside from this,

the main source of dissatisfaction concerned unpredictable visit times and 'bedtime' visits happening too early in the evening.

Overall the great majority of interviews reported positive outcomes in term of the core objective of reablement, namely independence. Those not reporting these gains all had chronically poor health. That said, they had valued the support they had received. Four (connected) aspects of practice were identified as having supported reablement outcomes. First, the provision of personalised and enabling assistance. Second, advice on alternative ways to carry out tasks and activities. Third, building confidence. Finally, interviewees spoke of the comfort of knowing someone was aware of them and their situation and would be visiting them. It is important to note that few could recall goal-setting and it was not clear from service users' accounts of whether they were involved in identifying intervention objectives. An additional outcome experienced during the intervention was companionship. For some, this was described as the most valued outcome.

Six factors were identified as impacting on outcomes. These were: the service user-worker relationship, workers' reablement skills, service user's confidence in the worker, duration of home visits, willingness, or reluctance, to accept support, and being able to review records of progress. Continuity of workers was not identified by interviewees as being important to the outcomes achieved. Furthermore, those being supported by a number of reablement staff did not usually report this as a problem or source of dissatisfaction with the service.

Chapter 8. WP2c: providing reablement: costs and impacts on resource use

8.1. Overview

This chapter reports WP2c which examined the resource use and costs associated with the package of care used by individuals receiving reablement. In addition to the reablement service, it considers the resource use and costs falling on the health care, social care and voluntary sectors, as well as users' out-of-pocket costs and any use of informal care.

8.1.1. Perspective: costs falling on public and non-public budgets

We chose a broad perspective of costs falling on public and non-public budgets, consistent with the NICE methods guide on social care guidance.[16] We focused on costs falling on the health and social care sector because reablement is funded by the NHS and/or LAs through their social care budgets.[17] We included costs falling on non-public sector budgets, namely the voluntary or charitable sector, private out of-pocket costs, and the use of any informal unpaid care. Here the rationale was use of reablement may impact on service users' use of voluntary services, their out-of-pocket expenditure, and the level of informal care required. Out-of-pocket costs were included because service users may have to contribute towards the cost of social care and voluntary services, and may privately fund additional services, house modifications or equipment. Informal care time was included because services users may be supported to live in the community with the help of family and friends.

8.2. Methods

8.2.1. The costs of providing reablement

Assessment of the direct cost of providing reablement was carried out in WP1 (see Chapter 3, section 3.3.3). For WP2c we intended to examine the cost to LAs and CCGs for each of research site. To do this sites were asked to complete a questionnaire, specific to their service, which asked for information on costs, resources, caseload and number of sessions

(see RSM 7). However, the sites did not respond to our requests for information within the duration of the study.

8.2.2. Resource use

We developed a new questionnaire, the Services and Care Pathway Questionnaire (SCPQ), to collect information from study participants on their resource use (see Appendix 14 for details). It involved five steps:

1. Identification of the resource use items to be collected given the objectives of reablement and the perspective of the evaluation.
2. Review of other questionnaires published in the economic evaluation literature.
3. Drafting of the initial version of the questionnaire.
4. Piloting of the questionnaire
5. Development of the final version

The Services and Care Pathway Questionnaire (SCPQ)

The SCPQ included questions on resource use as follows.

- Hospital overnight stays, including planned admissions, unplanned admissions, stays post-transfers, and other hospital overnight stays.
- Hospital visits without an overnight stay, including outpatient appointments, day case visits, visits to the A&E, and calls to emergency numbers.
- Community health care, including GP, nurse, nurse specialist, and therapist appointments..
- Care services, including home care and day care.
- Other social care services, including meals-on-wheels, social services appointments, sitting services, transport services and use of other services.
- Voluntary services, such as befriending, shopping, advice services, or other services provided by voluntary organisations or charities.
- Informal care, referring to unpaid help from family and friends.
- Private out-of-pocket costs, referring to whether individuals had paid anything for each service and to report their expenditure.

Period of recall

The period of recall varied according to the type of service or resource. This was because pilot work indicated that people found it easier to recall hospital appointments, having house modifications and equipment but more difficult to remember use of community services. Thus, a recall period of 2 months was used for hospital services, home adaptations and equipment at T0 and T2. For T1 this was specified as the period during which the individual was receiving reablement. At all time points, a 2 week recall period was used for community health care services, social care services, and voluntary services. The recall period was 7 days for informal care, asked in terms of help from family and friends.

8.2.3. Duration and intensity of reablement

Information about the duration and intensity of reablement was obtained by the local study team from case notes. We used descriptive analysis to summarise the duration of reablement, as number of weeks between assessment at entry to the service discharge, and intensity of reablement as the total number of contact hours.

8.2.4. Costing resource use

We calculated costs by multiplying the number of times each resource was used by its unit cost (see Appendix 15, Table 59).[18, 19] Informal care time was valued using the opportunity cost method,[20] as the average hourly wage rate in England in 2016 at £15.72 per hour.[21] All costs are expressed in pounds sterling for 2015-16. Supplementary material details the assumptions used to clean and prepare the SCPQ data to estimate resource use and costs (RSM 8). We did not annuitise the cost of home adaptations given that the objective was descriptive rather than comparing costs between services.

8.2.5. Description and comparison of resource use and costs

We described resource use and costs as the average service use per individual at entry to the service, at discharge, and 6 months after discharge. We described informal care as the average hours of care per individual. We grouped resource use into categories: hospital overnight stay, hospital visit without overnight stay, community health care, social care services (including care services and other social care services), voluntary services, major

house modifications, minor house modifications, equipment, and informal care time cost as explained in Section 8.1.2.

We grouped costs in sectors according to the budget. We considered public sector costs, i.e. those costs that fell on the public budget, and included hospital overnight stays, hospital visits without overnight stay, community health care, care services and other social care services. Out-of-pocket costs comprised private costs to the individual, including community health care (namely therapists), care services, other social care services, financial contributions towards voluntary services, major and minor house modifications, and equipment. Other costs were the costs of resources which may or may not be funded by the public sector, namely voluntary services, major and minor home adaptations, equipment, and informal care time, costed as if these services were provided by the public sector (i.e. using unit costs based on national public sector average costs).

Resource use and costs were scaled to one week to allow for comparisons between follow-up periods points.

8.2.6. Determinants of costs

Regression analysis investigated the predictors of costs during reablement and 6-months after discharge given the information available at baseline. The methods are presented in detail in RSM 9. In summary, we used stepwise regression at a critical alpha of 20% to select characteristics of study participants and the services that were associated with costs. We rescaled the costs before reablement to correspond to the same time period as the costs during reablement, based on the actual duration of reablement. The analysis aimed to predict i) hospital costs, ii) community health care costs, and iii) social care costs at discharge. The analytic sample consisted of study participants with complete data. Sensitivity analysis was conducted by re-estimating the regression on data from site C. The rationale was to explore whether there were systematic differences between the participants in site C and sites A and B that were reflected in the predictors of costs, given site C's greater recruitment and retention rates.

8.3. Results

8.3.1. Duration and intensity of reablement

Figure 3 shows the duration and intensity of reablement.

Planned duration and intensity of reablement

Information on the planned duration of reablement was available for 184/186 (99%) study participants. For the majority of participants reablement was planned to last 6 weeks (n=170; 91%). The number of planned reablement sessions was recorded for all study participants but one. Most study participants had 2 sessions per day, which is equivalent to 14 sessions per week (N=83; 45%). Over a third had 1 session per day, equivalent to 7 sessions per week (N=66; 35%). Some study participants had a more irregular pattern with 1-6 sessions per week (N=12; 6%); a similar number of participants had 3 sessions per day (N=12; 6%). Eight study participants (8%) had more than 3 sessions per day.

Actual duration of reablement.

Information on the actual duration of reablement was available for 175 (94%) study participants, and was calculated as the time period between baseline and discharge. The median duration of reablement was 4 weeks (mean 3.9; min=0.6; max=6.4 weeks). Information on the actual number of sessions was not recorded.

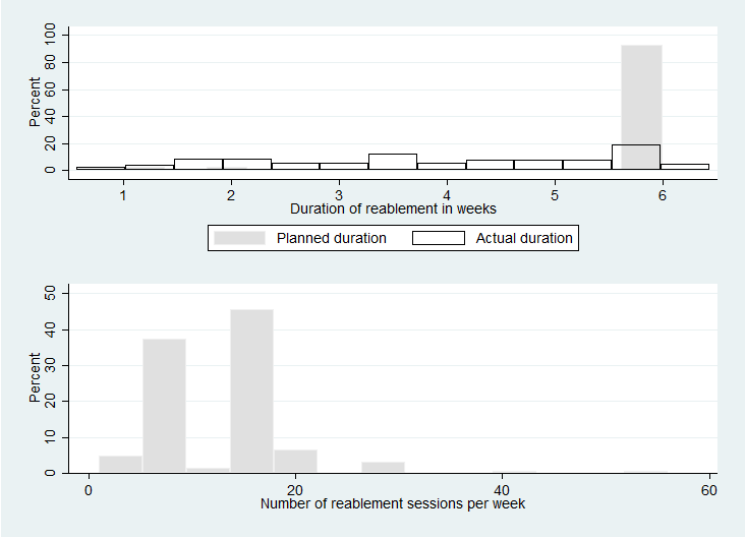

Figure 3: Intensity and duration of reablement

8.3.2. Resource use and costs

Responses and missing data

The proportion of missing data is shown in Appendix 15 (Figures 22-24). At T0, all study participants apart from one completed the SCPQ. At T1 and T2, all study participants who remained in the study answered the SCPQ. The response rate for all questions was above 90%. The lowest response rate (91%) was for the question on whether any transfers had occurred to other hospitals from unplanned hospitalisations.

8.3.3. Resource use

Table 18 summarises the use of services, rescaled to use per week given the different recall periods for each follow-up questionnaire (see RSM 10 for details).

Hospital overnight stays. In the 2 months prior to reablement, 72% (132/185) of study participants had unplanned hospitalisations. The average length of hospital stay per week was 2.32 nights (SD=2.34). During the period of reablement, 6% (8/128) reported having unplanned hospitalisations. In the 6-months following discharge from reablement, hospitalisations slightly increased. This was driven by unplanned admissions with an overnight stay, which were reported by 23% (15/66) of study participants with a returned questionnaire.

Hospital visits without overnight stay. Hospital visits without an overnight stay were less frequent than nights in hospital at, on average, less than one per week. Most of the hospital visits without an overnight stay were visits to A&E and emergency calls in the period prior to reablement. In the 6-months following discharge from reablement, the average number of hospital visits was 0.18 per week; these were generally for outpatient appointments.

Community health services. On average, study participants used community health services twice per week in the period prior to reablement; and around once per week during reablement and in the 6-month follow-up.

Care services. The use of care services was on average 3 hours per week in the period prior to reablement, 2 hours per week in the period during reablement and 30 minutes per week in the 6-month follow-up.

Other social care services. Study participants reported using other social services once per week on average in the periods prior to and during reablement. The use of social services at the 6-months follow-up was slightly less frequent at 0.7 times on average per week.

Voluntary services. Few study participants reported using voluntary services during the study.

House adaptations. Few reablement users had major and minor adaptions during the study period.

Equipment. The receipt of equipment was similar on a weekly basis in the period pre- and during reablement at 0.24 items per week. It was less frequent in the 6-month follow-up at 0.06 items per week.

Informal care. On average, study participants received 24 hours of informal care in the week prior to entry into reablement, and 20 hours in the week prior to discharge. In the 7 days prior to the 6-months follow-up, service users had on average 11 hours of help from family and friends.

Table 18: Weekly use of services

Resource	T0			T1			T2		
	N	Mean	SD	N	Mean	SD	N	Mean	SD
Hospital length of stay, number of nights	158	2.32	2.34	124	0.04	0.27	50	0.16	0.42
Hospital visit without overnight stay, number of visits	174	0.31	0.21	127	0.24	0.34	65	0.18	0.21
Community health care, number of visits	180	2.08	2.35	128	1.19	1.61	62	0.90	1.36
Care services, number of hours	182	3.09	2.51	127	2.10	2.71	65	0.50	1.65
Other social care services, number of times service was used	180	0.92	1.29	123	1.00	1.63	61	0.72	2.77
Voluntary or charity service, number of times service was used	183	0.04	0.16	127	0.02	0.12	64	0.07	0.22
Major home adaptations, number of adaptations	185	0.01	0.03	128	0.01	0.05	66	0.00	0.01
Minor home adaptations, number of adaptations	185	0.04	0.09	128	0.09	0.32	66	0.02	0.04
Equipment, number of equipment items	185	0.24	0.23	128	0.21	0.30	66	0.06	0.09
Informal care, hours	177	23.77	35.76	123	20.03	37.23	56	11.21	27.68

N is the number of non-missing observations. Use of services was rescaled to use per week. Supplementary material X shows the use of services for each resource use item without rescaling.

8.3.4. Costs

Table 19 summarises the package of service costs, rescaled to one week (see RSM 10 for details).

Public sector costs

Prior to reablement, hospital overnight stays were the main public sector cost driver. During reablement, the public sector costs consisted mostly of community health and social care, and hospital overnight stays were the smallest component. At 6-months follow-up, hospital overnight stays were the main component of public sector costs.

Out-of-pocket costs

Out-of-pocket costs involved study participant privately paid costs. Out-of-pocket costs were small during the study. The exception were major home adaptations prior to reablement, which although rare, involved large upfront costs of, on average, £13 per week per study participant. However, the costs would be considerably smaller had they been annuitised to reflect the useful life of the adaptation.

Other costs

Other costs are the costs of services, house adaptations and equipment costed according to the cost had they been provided by the public sector. It also includes informal care time costed using the average wage rate, which assumes that the cost of providing informal care corresponds to the average wage rate in the UK for all population in 2016. Informal care time is the major cost component, representing an input valued at £374 per week before reablement, £315 per week during reablement and £176 at the 6-months follow-up. The cost of house adaptations and equipment would be a considerable cost to the public sector if funded by the public sector.

Table 19: Weekly costs by sector

Sector	T0			T1			T2		
	N	Mean	SD	N	Mean	SD	N	Mean	SD
Costs falling on the public sector									
Hospital overnight stays	158	£719	£722	124	£11	£81	50	£52	£138
Hospital visits	174	£31	£31	127	£29	£46	65	£26	£33
Community health care	180	£27	£28	180	£21	£22	62	£16	£22
Social care	179	£44	£33	126	£32	£36	61	£10	£27
Out of pocket costs									
Community health care	184	£0	£1	128	£0	£0	51	£2	£6
Social care	182	£2	£5	127	£3	£8	59	£2	£9
Voluntary sector	184	£0	£1	127	£0	£0	65	£0	£0
Major home adaptations	181	£13	£67	127	£0	£0	62	£3	£22
Minor home adaptations	180	£0	£1	128	£0	£1	53	£0	£1
Equipment	172	£1	£5	123	£0	£2	58	£0	£1
Other costs									
Voluntary sector	183	£1	£4	127	£0	£2	£1	£1	£3
Major home adaptations	182	£32	£145	127	£24	£268	£228	£9	£43
Minor home adaptations	182	£1	£4	128	£2	£9	£13	£1	£2
Equipment	180	£23	£45	111	£13	£39	£139	£6	£16
Informal care	177	£374	£562	123	£315	£585	£176	£176	£435

N is the number of non-missing observations. Use of services was rescaled to use per week. Supplementary material (RSM 10) shows the costs for each item without rescaling.

8.3.5. Determinants of costs

The analysis sample comprised data on study participants for whom there was complete data for T0 and T1 (n=86). There were 27 study participants for whom there was complete data for T0, T1 and T2. There were 33 study participants for whom there was complete data for T0 and T2. The limited analysis sample for T0 and T2 precluded an analysis of the determinants of costs at 6months post-discharge. The reasons are two-fold. First, it would be difficult to run regressions on such a small sample; second, any results would be unreliable and might not be generalisable to the full population of study participants.

Comparison analysis sample vs. full sample

In general, participant and service characteristics were distributed similarly for the total sample recruited to the study and the analysis sample (RSM 10). Note that the hospital costs in the period before reablement were adjusted to reflect the same time period as the questionnaire at discharge, i.e. the duration of reablement.

Predicting hospital costs during reablement

We summarise the statistically significant coefficients for the most comprehensive model since this was the model with the greatest explanatory power. We focus on those characteristics that seem to affect costs in a meaningful way and do not report differences in magnitude smaller than £1. Data tables are available (RSM 9)

Costs of Hospital. Hospital costs during reablement were poorly predicted by any of the regression models examined. Given that hospital costs are typically highly variable and that the analysis sample was small, the performance of the prediction model was likely to be poor.

Significance level=0.1%. No predictors at this level.

Significance level=1%. No predictors at this level.

Significance level=5%. Study participants who received reablement from outsourced providers were associated with higher hospital costs during reablement compared to in-house services (£255 (95%CI 12.6; 498.0)).

Costs of community health care. The regression models explained less than half the variation in community health care costs in the 2 weeks prior to discharge from reablement.

Significance level=0.1%. Study participants who received reablement due to an infection had lower costs of community health care, controlling for other characteristics (£32 (95%CI -34.95; -28.99) lower costs). Study participants with worse mental health had slightly higher community health care costs (£2 (95%CI 2.19; 2.58) increase during reablement per point increase in GHQ-12).

Significance level=1%. Study participants who had other comorbidities were associated with higher costs (£9 (95%CI 6.9; 10.9) higher costs). Study participants who were referred for reablement to support return to home from hospital were associated with lower community care costs of £9 (95%CI -11.4; -7.2). This may reflect the recovery of individuals following a period of acute ill health that required hospitalisation.

Significance level=5%. Those who reported having enough money to live on, and those who were older were associated with higher costs ((£38 (95%CI 14.0; 61.9)) (£6 (95%CI 2.9; 8.5) per additional year, respectively). Male study participants had £19 (95%CI -34.5; -2.6) lower costs. Study participants for whom the problem leading to reablement was musculoskeletal or a fall were associated with £36 (95%CI -59.8;-11.2) lower costs.

Costs of social care. The regression models predicting the costs of social care during reablement explain around 64% of the variation in the sample.

Significance level=0.1%. Study participants who received reablement from an outsourced provider had, on average,£42 (95%CI -43.6; 39.8) lower costs.

Significance level=1%. No statistically significant predictors.

Significance level=5%. Study participants who rent privately had £28 (95%CI 5.1; 50.0) higher costs compared to owning their own home. Study participants who had greater health-related quality of life had higher costs, but the association was small £2.5 (95%CI 0.6; 4.3) higher costs per 0.1 increase in EQ-5D-5L). Comorbidities showed an inconsistent association with social care costs: there were higher costs for arthritis and COPD/asthma, and lower costs for cardiovascular disease.

Sensitivity analysis. We re-estimated the most comprehensive model using the data collected in site C (N=61), and excluding sites A and B (see RSM 9). Consistent with the base-case results, outsourced providers were associated with greater hospital costs and smaller costs of social care, and older age was associated with higher costs of community health care. These results should not be interpreted as causal effects, but instead as associations that warrant future research.

8.4. Summary

The analysis presented in this chapter is the first to explore the feasibility of collecting and using a broad set of costs and outcomes data within the context of reablement services in England. We undertook comprehensive descriptive analysis, and exploratory analysis using regression analysis to investigate the determinants of costs during reablement given the information available at baseline. This was informed by the ever first systematic review of the methods applied for the economic evaluation of reablement.[22]

The tool developed to collect information on resource use and costs falling on health care, social care, voluntary services, private (out-of-pocket), and informal care time (SCPQ) appears to have performed well with response rates (overall questionnaire and per question) generally high. We would note that study participants could chose to have the questionnaire administered by the Local Study Officer as a structured interview, or could self-complete with support from the LSO. Thus self-completion without support and/or no choice over mode of administration has not been tested.

The planned duration of reablement was on average 6 weeks and the actual duration of reablement was 4 weeks. Most study participants were planned to have 1 to 2 reablement sessions per day.

Services most used prior to receiving reablement and up to 6 months after discharge were hospital, community health care and social care. Few major house adaptations, mostly in the period prior to reablement, were reported. Some minor house adaptations and equipment items were reported. Most study participants received help from family and

friends. A downward trend in resource use from the period prior to reablement to 6-month post-discharge was observed.

Public sector costs, falling on health and social care, were the largest cost category. Of the public sector costs, costs of hospitalisations with overnight stays were the largest cost item at all time points. Out-of-pocket costs were generally small, at a maximum of £3 per week on average. In the other costs category, the major cost item was informal care, followed by major house adaptations and equipment. From a public sector perspective, the key cost items were hospital overnight stays and social care.

Study participants who received reablement from out-sourced providers were associated with higher hospital costs and smaller social care costs compared to those who received in-reablement from an in-house service.

Referrals to reablement due to a musculoskeletal problem or a fall, or due to an infection, were associated with lower costs of community health care during reablement. Furthermore, study participants with arthritis and chronic respiratory conditions were associated with higher costs whereas cardiovascular conditions were associated with lower costs.

In terms of demographic characteristics, older study participants were associated with higher costs of community health care; in contrast, males were associated with lower costs. Study participants who rented their home were associated with higher costs of social care. Finally, study participants who reported having sufficient money to live on were associated with higher costs of community health care.

Finally, unit costs were sourced from national reference materials.[18, 19] We were unable to find unit costs from some services, and had to generalise from similar services. We were explicit about the unit costs we used and our costing assumptions. Our extensive reporting of the use of services allows future studies, such as modelling studies, to use these data and apply other unit costs. However, sample size limited the tests that could be undertaken, and the inferences that it is possible to draw. Specifically, we were unable to evaluate the cost-effectiveness of service models or to make robust inferences about which characteristics and factors are predictors of costs.

Chapter 9. WP3: Reabling People with Dementia

9.1. Introduction

There is a growing population of people with needs for reablement which may challenge generic services and/or practice. In particular, the number of people in the UK living with dementia is expected to double in the next 30 years,[23] . Evidence from previous UK studies indicates that people with complex needs (e.g. dementia, sight loss, learning disabilities) may be ineligible for support from generic reablement services, or may not experience the same level of benefit as 'typical' users.[2] Indeed our own survey of services (WP1) (see Chapter 3, section 3.3.2) found that over a quarter of services (28%) specifically reported excluding people with dementia. Furthermore, people with dementia may also be more likely to be susceptible to commonly reported exclusion criteria including: not having reablement potential (29%), having longer-term care needs (17%) and lack of engagement (see Chapter 3, section 3.3.2).

However, there is a growing interest in reablement for people with dementia.[24] The recent NICE guideline [17] notes that people with dementia may be excluded from reablement services because they are *perceived* as being unlikely to benefit from the intervention. Its position, however, is that people with dementia should not be excluded from reablement on the basis of their diagnosis, stating: "Consider reablement for people living with dementia, to support them to maintain and improve their independence and wellbeing" (p.9). The guideline also draws attention to the virtual absence of any evidence on the effectiveness and cost-effectiveness of reablement for people with dementia, and the views and experiences of people with dementia, their families and professionals (managers and front-line practitioners) in terms of service delivery, practice and outcomes. Indeed, with respect to the latter topic of views and experience, no studies were identified by NICE in the evidence synthesis work carried out to support and inform guideline development. Addressing these evidence gaps is presented as one of the research recommendations arising from the development of the guideline.

Our research questions, originally formulated in 2013, address some of these gaps in evidence and were as follows:

- How are generic reablement services adapting their service model or practice to accommodate the needs of 'specialist' groups? What is the rationale for these adjustments?
- What has been their learning as they have developed this provision?
- What are the barriers to the delivery of reablement and achievement of positive outcomes for these groups within the context of generic reablement services?
- How do specialist services approach and deliver reablement? How does it differ from generic provision?
- What are the barriers to the delivery of reablement and achievement of positive outcomes for groups with specialist needs within specialist services? Do these differ from people with low level needs using generic services?
- What do specialist reablement approaches or services cost?
- What specific ingredients of service and support arrangements might best support the quality of life and independence of people with specialist needs?
- What outcomes might be appropriate to assess the success of these services in future evaluation?

This workstream was led by P.R. She conducted all data collection and led on qualitative data analysis. All members of the research team were involved in development of data collection tools, data analysis and interpretation. WP3 was conducted during the period January 2016 – July 2016.

9.2. Study design and methods

WP3 comprised a case study of adapted or extended practice within generic reablement services for people with dementia and dementia-specific provision. In terms of the generic services, we sought to include services reporting to have a 'dementia protocol', and those without such a protocol. Here our assumption was that having a protocol might indicate more specialist or systematised approaches to providing reablement to service users with dementia. Data was gathered from service leads and reablement workers. We also sought to collect data on the costs of dementia-specific provision or practices. Qualitative and quantitative (costs only) methods were used.

Inclusion criteria were:

- the service /practice had existed in their present form for at least a year, thus ensuring the sample would comprise practitioners who had some degree of experience of working with people with dementia and where practice was reasonably well established

- the service had a relatively large proportion of people with dementia within their caseload – again, the rationale for this was that interviewees would have a depth of cumulative experience.

9.2.1. Identification and recruitment of case study sites

Case study sites were drawn from services which participated in WP1. Of the 143 reablement services responding to the survey, 107 services stated they accepted referrals of people with dementia. Of these, three identified themselves as a specialist service, 30 (28%) as generic services with dementia specialist protocol, and 74 (69%) as generic services with no specialist protocol.

We attempted contact on at least two occasions with services leads of all these services (n=107) via email or telephone. The purpose was to confirm the survey data remained correct, to secure an indication of the proportion of service users with diagnosis of dementia, and to ascertain their willingness to be involved in the study. We sought to

recruit ten services and efforts to establish contact with services were maintained until sufficient sites had been recruited.

No contact was achieved for 51/107 services. Where contact was established, 16 services had been in existence in their current for less than 12 months and were therefore excluded. None of the services where contact was established were able to supply information on the proportion of service users with dementia.

Agreement to participate in WP3 was secured from nine of the forty remaining services, one specialist dementia service and 8 generic reablement services. Of these 3 reported using a dementia protocol. However, it emerged that these were restricted to generic and widely available guidance on working with people with dementia. We therefore treated all the generic services as a single analytical entity. We had hoped to recruit ten services but this did not prove possible within the WP3 timeline. In each service we sought to recruit the service lead and two reablement workers.

9.2.2. Recruitment of interviewees

Service leads were approached via email and telephone regarding eligibility for inclusion in WP3 (see section 9.2.2.) and, if eligible, to participate in an interview. Service leads were also asked to nominate two reablement workers within their service who had good experience of working with people with dementia. Study recruitment packs were sent to these workers via the service leads. Workers willing to participate returned a consent form direct to the research team. A summary of the topics to be covered in the interview was sent in advance to all interviewees.

9.2.3. Data collection

Topic guides – one for service lead interviews and one for interviews with reablement workers – were developed by the research team, informed by existing literature and findings from WP1 (RSM 11). The Study Steering Committee commented on a draft version. Topic guides comprised structured and open questions. Each topic guide was piloted on one occasion which highlighted the need for very minor revisions. No further pilot work was conducted.

Interviews with service leads covered: the aims and objectives of the service; eligibility criteria; the professional skills within the team; the content and delivery of the reablement service to people with dementia; assessment, monitoring and discharge arrangements; and views on factors promoting and hindering successful outcomes of reablement for people with dementia.

Interviews with reablement workers covered: the ways in which workers approached/adapted their practice to accommodate the needs of people with dementia; goal setting, monitoring and discharge arrangements; and views on what outcomes might be appropriate to assess the success of reablement for this group, and factors helping and constraining the benefit of reablement for people with dementia. These interviews also covered issues explored in interviews with service leads.

Consent was secured before the start of the interview. The duration of interviews ranged from 60 to 75 minutes. All interviews were audio-recorded, with the participant's consent, and subsequently transcribed.

Data on costs was collected via during the interview with service leads (n=9). Where the service lead could not provide that information immediately, this was followed up by email correspondence. Five out of nine service leads provided some data, though it was extremely limited and lacking in detail. After careful review of the data by the researchers leading on the economic work, the decision was taken not to analyse this material.

9.2.4. Sample

Service leads in eight of the nine case study sites were interviewed. The manager in the remaining service was unavailable due to long-term sickness absence. With the individual's consent, the pilot interview was also included as study data.

Sixteen of the 18 reablement workers approached (2 per service) agreed to participate in the study. The remainder did not respond to the invitation to participate despite email and telephone reminders. All services were represented by at least one reablement worker.

9.2.5. Data analysis

Data was analysed data thematically[47]. The Framework approach[48, 49] was used to support systematic data management, allow audit trails of the data management process, and analysis and interpretation of the data. Service lead and reablement worker data was analysed together but participant group and nature of service (specialist vs generic) were key variables used to test and explore differences in experiences and beliefs. There are five stages to the analytical process. It was led by PR with other members of the team involved in discussions at all stages.

First, researchers familiarise themselves with the data, and identify themes and key issues. Based on identified themes (comprising a priori and emergent issues), an index of themes is constructed (the thematic framework, see Appendix 16). Data are then indexed according to which theme(s) in the analytical framework they relate to. Next, the indexed data from each case (e.g. participant, focus group) are summarised onto a series of thematic matrices (or charts). Each chart is divided into columns, allowing relevant data to be organised according to sub-themes/issues. A single row on each chart holds one participant's data. Thus reading along a row provides an overview of everything an individual spoke about in terms of a specific issue. Reading down the chart (or down a column) allows comparison between participants'. The final stage of analysis examining the charts, composing 'analytical notes' which describe the data, and developing interpretations and hypotheses which are then tested against the charts and raw data.

9.3. A dementia reablement service

One of the services recruited to this work package was a service describing itself as a 'dementia reablement service'. During interviews with staff, it became clear the service was outside the remit of this study. We do, however, offer a brief report on this service because, it is an interesting example of implementing the reablement approach for a different purpose, as is also the case for reablement for people with mental health difficulties.

9.3.1. Client group and referral route

This service was described as being specifically for individuals who have been diagnosed with mild or moderate dementia within the past 12 months, and their families. The majority of referrals were from the local memory clinic.

9.3.2. Service objectives

The core objectives of this service were described as:

- enabling and supporting the individual to access to social activities,
- accepting and adjusting to the diagnosis of dementia,
- providing information relevant to future planning and empowering individuals, and family members, to (start to) plan for the future.

The area reported as being where most work was typically done concerned supporting people to remain active or become engaged in social activities. The service did not address many of the domains covered by generic reablement provision. Indeed, if needs related to independent living were identified this service either signposted to other services or made a referral for a social care assessment. Thus it was clear that this service, whilst sharing the same overall objective with the generic services participating in this research (that is, maximising independence), it served a different population – those newly diagnosed - and had different functions.

9.3.3. Comment

This service clearly has some commonalities with post-diagnostic support services for people with dementia. However, the type and intensity of support provided appears to be different from that typically offered. Thus, in addition to offering information, advice, and signposting, this service provided a degree of sustained and direct support; for example helping service users to access social groups by organising transport for them, accompanying them to a few sessions until they felt comfortable to attend independently.

It is certainly interesting to observe this model of care and support for people recently diagnosed with dementia and their families and, particularly, the services' identification

with the notion of reablement. Further work investigating this service would appear to be worthwhile. However, this service fell out of the scope of this study and we do not report any further data on this service.

9.4. Generic reablement services and people with dementia

The remainder of this chapter reports our findings with respect to the experiences and practices of generic reablement services in relation to working with service users with dementia, and how they have responded to any additional needs and challenges.

9.4.1. Overview of the case study sites

Within our eight case study sites, six services were based in adult social services and only delivered reablement. The other two services were independent providers of reablement and home care. Two were jointly commissioned by the NHS and LA and were part of a wider initiative within their respective localities to improve both the integration of health and social care for older people and, more specifically, service provision for people living with dementia. All services accepted referrals of people with dementia where a potential benefit to receiving reablement was indicated, a criteria applied to all referrals.

We report our findings in terms of the following themes:

- reablement objectives
- the relevance of reablement for people with dementia
- the opportunity for meaningful assessment
- additional areas of reablement work
- measuring success
- commissioners' and other services' understanding of reablement for people with dementia
- issues with referral information
- adaptations to practice
- staff training and access to dementia expertise
- onward referral at discharge.

9.4.2. Reablement objectives

Interviewees regarded the overall objective of reablement for people with dementia – restoration of functioning with respect to everyday life – as no different to the wider population using the service. However, as we later report, the approaches taken to reach this outcome, could differ and the duration of that outcome may be more time-limited.

A second service objective - to carry out a depth assessment of the individual which would enable and support planning and decision-making with regard to longer-term support – was addressed simultaneously and the two objectives regarded as inter-connected and informing each other. Interviewees believed that this objective typically carried greater emphasis – and was of great value – for people with dementia compared to service users without this diagnosis.

9.4.3. The relevance of reablement for people with dementia

All interviewees believed reablement could have positive impacts on the lives of people with dementia. Staff believed that people with dementia could learn to do everyday living tasks differently, with greatest successes likely to be seen in people in the earlier stages of dementia.

Whilst major improvements in the functional ability may be an unreasonable expectation for a person with dementia, most interviewees believed that reablement could lead to regained skills related to independent living. The positive impacts these gains had on users' sense of self-worth and quality of life were noted. Interviewees did, however, remark that such gains may be short-lived. Equally, there was a consensus that the severity of dementia affected the impact of reablement on functioning.

Reablement was also regarded as being relevant and effective in terms of achieving positive social outcomes, such as connecting people into local sources of support and social networks. For example, some interviewees described successes in establishing regular use of day centres. Social outcomes are a core domain of comprehensive reablement but may receive less emphasis among other user groups. Typically, however, interviewees

emphasised this aspect of reablement when discussing the relevance of this intervention for people with dementia.

> *… If they [family members] know that they can … respond to what they need … it can take the pressure off them so much and they can continue to support that person in the community, but if they don't have any means to respite or additional support in the community, it'll break down quickly. [Manager]*

9.4.4. The opportunity for meaningful assessment

Most interviewees reported that, compared to other service users, their expectations in terms of outcomes were centred less on regaining 'full' independence (though this may be possible, at least in the short-term) and more on using the intervention period to achieve an in-depth assessment and knowledge of the individual. This enabled appropriate levels of care and support to be put in place which enabled individuals to live at home safely and as independently and for as long as possible. One worker described her role as preparing "the stepping stone… [to] build up a better picture for the next agency that goes in". This six week period of intense contact, and observation of the extent of an individual's skills and abilities, was believed to be extremely valuable in decision-making about packages of care. A further outcome was that the individual was used to and/or accepted the involvement of external agencies in their lives.

A lack of complete information from referring agencies and/or there being no family members to contribute to a wider life story of the service user were reported as making the assessment process more challenging and could mean the assessment took longer to complete.

9.4.5. Additional areas of reablement work

A number of additional areas of work were reported by interviewees as, potentially, needing to be incorporated into the process of reabling someone with dementia. We describe these in turn below.

Fostering engagement

An issue identified as particularly salient for people with dementia concerned the individual's acceptance that they needed help and/or may need it in the future. This concerned both the reablement intervention and community and statutory services more generally. This issue was often spoken about as being bound up with an individual's lack of insight into their dementia, believing themselves to be "just a bit forgetful". Addressing this was regarded as essential to the individual's engagement with reablement.

One of our case study sites – which was part of wider integrated provision for people with dementia – had responded to this issue by offering a two week extended assessment to period for those were not accepting the involvement of statutory support. This was used, prior to making the referral to the reablement service, to assess whether an individual was ready, or able, to engage with this intervention. The two specialist outreach workers within the LA social work team had been appointed to this role. It was clear this was a carefully paced process of initiating a relationship and establishing trust before moving on to assess whether reablement was an appropriate option for the individual. This is illustrated by one worker's account which is transcribed in Box 2.

Box 2: The process of an extended assessment of reablement potential

… my first visit is just … showing my face and introducing myself; invariably I don't get invited in and we just have a conversation on the doorstep; and that's as far as it goes … sometimes you don't even get that. But once ... you do it time and time again and eventually it is the client that invites you in and once they invite you in then you can start slowly building up the trust between two of you and eventually you can work towards the goals … I'll wait until the opportunity arises when I can see that I can ... go forward… when the person asks me, would you like a drink or anything … cup of tea, coffee or, or water … that is a sign for me to, to feel that I'm beginning to break through, because we go into the kitchen together... and then I can start ... seeing whether the client can actually make the tea herself… or whether just me being there and prompting her, she would be able to do it…invariably you get people putting the milk into the kettle instead of the water. So the first time I leave it in, just observe, but the second time I'm there then I, … just prompt a little bit; and it's almost like a training for them again, what they have forgotten … it's got to be coming from them… to be able to sort of move forward…

Re-orientation to the home environment

For people with dementia being discharged from hospital, interviewees described the necessity of re-orientating individuals back to their home environment before embarking on the usual work of reablement. Workers described giving additional levels of encouragement and reassurance and prompting service users to re-engage with tasks and activities around their home, and return to old routines.

Re-establishing routines

Even among those who had not been hospitalised, the need to re-establish everyday routines was also sometimes a pre-requisite to starting reablement.

Connecting in to local support services

Staff also reported that connecting individuals with local services – both voluntary sector and statutory (commissioned) provision – during the period of reablement featured more strongly in the work they did compared to other users who greater potential to regain full independence.

Re-establishing relationships

As would be expected, workers reported that they often had to reintroduce themselves on each visit and, in a sense, re-establish an enabling relationship.

Corroborating accounts

Workers also reported that they could not, necessarily, rely on the individual's accounts of whether they had, for example, had a shower, taken their medication etc... Thus, at each visit, it may be necessary to establish what, and what not, an individual had done. Finding physical evidence of such activities (e.g. a wet bath towel) was therefore sometimes part of the visit. Not unsurprisingly, this was a particular issue when the individual lived alone and/or family members were not in touch with the reablement service.

Work with family members

Several workers also highlighted the work they did with family members with caring responsibilities. Again, it appeared that this work was more likely, or more intense, with families of people with dementia. The sorts of support included information and signposting to carer support networks and advice on how to manage and provide care to their loved one.

> *… when we're going in with people with dementia… family members are, you know, sort of tearing their hair out … they don't realise… that it's them who needs, the family that needs the support to, you know, get through the day with their loved ones. [Manager]*

Thus, interviewees believed reablement could have a positive impact on family members – removing the pressure off their caring responsibilities by connecting the service users into local support networks and activities, and enabling them in their role of informal carer.

9.4.6. Measuring success

Interviewees believed it was incorrect to assume that outcome or performance indicators used to measure the success of reablement services for people without dementia could be used with people with this condition. Instead, an approach was required which took account of the way the objectives, and range of work done, may be different for a person with dementia. Thus, whilst regained independent living skills may be appropriate, the expectation - or indicator of success - should not be independent living *per se*. Furthermore, the long-term benefits (and savings) yielded by a meaningful and detailed assessment – in terms of appropriate levels and types of care, and how to best work with and support an individual – needed to be recognised. Thus, interviewees believed that requiring ongoing care after the period of reablement should not be considered as evidence that reablement does not 'work' for people with dementia: a stance reported to be taken by some commissioners. Other reablement outcomes – unique to, or certainly more typical of, people with dementia – were also identified. These included: willingness to engage with services and receive care and support, use of local (social) support networks and organisations, and the well-being, or quality of life, of informal carers.

9.4.7. Commissioners' and other services' understanding of reablement for people with dementia

Some service leads believed of that, across both health and social care, wrong assumptions were being made as to the appropriateness of referring a person with dementia to reablement. They spoke of two mis-perceptions which meant that people with dementia may not be offered this intervention: first, reablement should only be provided if an individual can be 'fully' reabled; and, second, if people have dementia they cannot learn new ways of doing things.

9.4.8. Issues with referral information

The amount of information that the reablement services received about new referrals was said to be largely dependent on where the referral had come from, and whether the person had a formal diagnosis of dementia. In general, it appeared that services received more detailed information from hospital referrals than community referrals, and that dementia or

other cognitive impairments were more reliably flagged up. When such information was not provided, reablement workers – who typically visit prior to the reablement assessment being carried out – felt unprepared. Interviewees also called for referrers to provide wider 'life story' information which may not be easy to access directly from the service user. Such information would, they believed, assist them when seeking to establish rapport and engage the individual in the intervention.

9.4.9. Adaptations to practice and service delivery by generic reablement services

In this section we report the adaptations to practice and service delivery which generic reablement services had implemented, or believed would be valuable if implementation was possible.

'Dementia protocols'

In sampling services for this study, we had sought to include services which identified themselves as having a 'dementia protocol'. We had expected the content of such protocols to include permitted adaptations to usual service delivery – such as extended visits and a longer duration of reablement. However, this was not the case. Whilst, as we report below some of those adaptations were being implemented for people with dementia – these were not presented as being a service's protocol for delivering reablement to this population. The content of any 'dementia protocols' was instead limited to non-specific information for workers about communicating with people living with dementia and guidance on safety and quality of care.

Adjusting instructions and the way they are delivered

All interviewees highlighted the importance of straight-forward language to convey simple instructions, and the need for repetition of these instructions over, perhaps, a number of visits. Workers also spoke of the need to repeat tasks and processes, sometimes many times. Signs and labels were sometimes used to help people to remember where things were, and the order in which tasks were expected to be carried out.

Duration of visits

There was a general consensus that greater time was required for reablement visits to people with dementia. As noted in the previous section, a worker may need to re-establish a rapport with an individual, and identify what has been happening since the last visit. In addition, workers described how visits could include an extended period of encouragement or negotiation in order to support someone with dementia to, for example, eat, to change clothes or take medication. Furthermore, there was the extra time required to allow the individual to repeat, perhaps a number of times, the steps in a process. Workers in two case study sites – both integrated services - reported they were able to extend the duration of their visits where the individual had dementia. However, for most, and in particular those working in contracted-out services, this was not the case. They either reported that that people with dementia on their caseload could/did not always receive a longer visit because they had a fixed number of visits to make; and/or they understood that the duration of visit was fixed, determined by the service agreement between the agency and local authority.

Duration of the intervention

Interviewees also agreed that it took longer to reable a person with dementia. Three out of eight services (including the two services that were in partnership with the NHS) represented in this study had the facility to extend the duration of reablement support for people with dementia for up to 12 weeks.

Number of workers assigned to case

All interviewees believed there was benefit in having a small number of staff working with people with dementia. However only two of the eight services represented – and both integrated provision - operated a policy where a reduced number of staff, usually a couple, worked with service users with dementia. Managers of the other services reported that their rota system did not allow them to specifically reduce the number of workers visiting service users with dementia. As a result, the number of workers involved was typically 4 to 8 and, potentially, higher.

The role of assistive technology

The use of assistive technology when working with people with dementia was highlighted by workers across all services. Medication carousels or a dosette box to prompt people to take

their medication, and fire alarms and heat and door sensors to support safety within the home were the pieces of equipment most often mentioned by workers.

9.4.10. Onward referral at discharge

Several managers noted that identifying an agency to provide on-going care for a person with dementia could be a protracted process, taking a few weeks or even months. This was particularly the case if a substantial package of care was required. For in-house providers, this could lead to slow throughput through the service and, potentially, to an inability to accept new referrals. In these instances, new referrals were assigned to a homecare agency to provide interim care.

The importance of ensuring a smooth transition into ongoing care and support was emphasised by interviewees. In most services, the hand-over was a longer process for people with dementia, taking one or two days – sometimes longer - compared to the usual couple of hours.

9.4.11. Staff training and access to dementia expertise

A common feature of all services was that the same workers supported people with and without dementia. As reported in previous sections (in particular, sections 9.4.5 and 9.4.9), they needed to and/or were expected to adapt the way they worked to accommodate the specific needs of people with dementia. While all managers highlighted the value and importance of dementia training and for a service to have access to dementia expertise, there were differences between services in the extent to which this was realised, and the reach of this training across all staff in the service.

None of the reablement workers interviewed said they had received training *specific to reabling* an individual with dementia. Whilst all the workers reported they had attended a basic dementia training session as part of a wider in-house training programme, this level of training was felt to be inadequate. It also appeared it was not necessarily compulsory.

… they do have the basic video on dementia ... but it's not enough for, we need specific training on reablement with dementia…. cos if you don't understand dementia then you're not gonna know what to do…. to reable them…

It's a case of you go out there and … do it as best you can.

It should be noted that two services did report they had recently accessed additional funding to provide advanced dementia training for all their staff.

Many of the workers we interviewed reported drawing on experiences of working with people with dementia from previous roles or their cumulative experiences to date within the reablement service. Concerns were expressed about the skills and competences of staff who do not have that experience to draw on. It appeared that staff working in 'contracted-out' services were particularly concerned about the inadequacy of dementia training within their agency.

Dementia can be a very complex... problem and to sort of try to squeeze it into a two hour session after lunch on a Friday type thing isn't really enough, cos there's so much more to dementia than somebody being a little bit confused.

Access to more advanced levels of training on dementia were reported by managers of the two integrated reablement services, though this was not specific to delivering reablement to this population. In one service, all workers were reported as receiving advanced dementia training, whilst in the other this training had be made available to senior workers. These services also reported that accessing dementia-specific advice was relatively easy given the expertise and remit of other services within their organisation, and reported liaising regularly with a community dementia nurse and specialist outreach workers.

9.5. Summary

Interviews with service leads and front-line practitioners drawn from eight generic reablement services and with extended experience of reabling people with dementia yielded rich data on reabling people with dementia.

Interviewees agreed that reablement is an appropriate intervention for people with dementia. However, the stage of the dementia will influence the focus of reabling work and intervention objectives. In addition, the expectation that reablement will eliminate the need for on-going service involvement may not be appropriate, particularly in terms of expectations around long-term outcomes. Service leads did not always feel that commissioners understood the argument for this. Interviewees also believed that adopting a reablement approach within an extended assessment of social care needs was an effective approach and supported acceptance of involvement of services should this be required.

Front-line practitioners offered detailed descriptions of the way that reabling people with dementia may involve additional areas of work, or increase time and attention needed in these areas. These included: fostering engagement, supported re-orientation to the home environment, re-establishing routines, connecting in to local support services, work with family members and, at each visit, needing to re-establish the therapeutic relationship and finding a means to corroborate that self-care or other activities had been undertaken.

Interviews explored whether service policies and practices were adjusted to accommodate the additional or unique needs of people with dementia who are being reabled. None had formal processes or protocols related to the delivery of reablement to people with dementia. Whilst all interviewees agreed that longer home visits were typically required, only two services did this. Similarly, only a minority of services routinely provided reablement for longer than the usual 6 week period, or restricted the number of reablement workers assigned to a case.

Whilst access to generic training on working with people with dementia, none of the reablement workers reported they had received training on reabling people with dementia. Staff working in out-sourced services were most concerned about the lack of training they had received.

Finally, in selecting case sites for this Work package a specialist dementia reablement service was identified that worked with people soon after diagnosis. Its remit excluded it from our study, but a short description of the service was included in this chapter as an illustration of applying a reablement approach in a different context.

Chapter 10. Discussion

10.1. Introduction

This chapter considers the strength and limitations of this study before moving on to discuss the study findings, placing them in the context – where possible – of existing evidence.

10.2. Strengths and limitations

The national survey of reablement services (WP1) generated the most comprehensive and detailed snap-shot of reablement services ever conducted. It demonstrated that organisational and practice characteristics differentiate services and also generated another source of evidence on the costs of providing reablement. The detailed descriptions of the organisation and practice of the services acting as research sites in the second Work package are a rich case study of the variability of the way reablement services are organised and delivered.

The evaluation Work package (WP2) encountered a number of challenges. Recruitment of research sites and study set-up took much longer than anticipated, and severely affected progress of the study according to the original timeline. A second key issue was the rate of referrals and/or throughput of two research sites significantly affected levels of recruitment to the study. As a result, the decision was taken to close the study rather than extend and/or add additional research sites, which would have been required to achieve all the study objectives. The implications of this is that our dataset for the outcomes and economic evaluation was much reduced. Furthermore, it was not possible to collect Time 2 (6 month follow-up) data from all study participants. Thus, it is appropriate to conceive the outcomes and economic evaluations as both pilot and feasibility studies, rather than the full and robust study that was intended. Despite these difficulties, however, recruitment rate (>37%) was good given the nature of the population and that the study design. Retention to the study was good (>80% at T1; >90-% at T2 where, as per the protocol, home visits were used to collect data). In addition, for the first time, the association between a wide range of

individual and service characteristics –some of which are amenable to change - have been subject to an initial exploration.

The process evaluation (WP2b) was less affected by these difficulties. Service users across all three research sites were recruited, though recruitment of family members to interview about their experiences proved extremely difficult. Rich data was generated from interviews with service users and staff – both make a significant contribution to a rather limited existing evidence base.

Our investigation into staff's views about reabling people with dementia (WP3) recruited one less service than was planned and we did not achieve total samples of service leads and frontline staff. However, again, the data generated was rich and, we believe, is an important addition to the very limited evidence base on this topic.

The limitations of the outcomes and economic evaluations places considerable restraint on the extent to which implications for policy and practice can be drawn. That said, we do believe the study has strengths and makes an important and valuable contribution to the existing evidence base. They lie in the following areas: understanding of current service design, structures and practices with respect to the delivery of reablement; research design and research methods (including implementing research in non-NHS settings); and informing the future research agenda. Whilst unable to draw firm implications for health and social care practice from our findings, some comments - based on both our qualitative and quantitative findings – are possible. Chapter 11 sets out these contributions and reflections regarding service organisation, delivery and practice.

10.3. The organisation and practice of reablement in England

The first work package of this project (WP1) (see Chapter 3) comprised a national survey of reablement services in England carried out mid 2015. Surveys of services are, by definition, snap shots of provision at a particular moment. Findings have, therefore, to be read in that light.

Our findings also have to be understood in relation to the decisions we made while determining our sampling framework and selecting services to approach. Most important of these was the focus on services that aimed to help people regain everyday living skills, in their usual place of residence, for a defined period of around six weeks, and for which no charge was made. This definition is close to the original conception of 'social' reablement as envisaged by its originators in the Department of Health.[25, 26] It is also close to the definition of reablement used since 2013 in the annual national audits of intermediate care (NAIC). The 2014/2015 NAIC (which covers the period of our survey) received responses from only 44 reablement services.[27] To the best of our knowledge, then, our survey provides the first, large-scale, detailed and comprehensive picture of reablement services in England.

At the time of the survey, the organisational base of over half of services was the LA. Such services were less likely to be part of any wider intermediate care provision within the locality and were typically presented as a separate, or standalone, service. A small minority of reablement services were based in the NHS, although there were others that were based in integrated NHS/LA organisations, or organisations jointly funded by the NHS and LA. In both cases, these services were more likely to be part of wider intermediate care provision.

The majority of reablement services did not contract out any aspect of the provision to another agency. If they did, it was most likely to be the delivery of reablement support: that is, the 'hands-on' work of delivering the intervention through home visits.

Overall, reablement services shared the common objectives of helping people regain everyday skills, reduce the need for on-going home (social) care and preventing longer than necessary stays in hospital. Preventing admission to residential long-term care was less often reported (by around half) and closely associated with certain types of organisational base and structure. In terms of services' primary objectives, most identified this to be either help with regaining everyday skills or reducing the need for on-going home (social) care. Two services – both of which were NHS-based - identified preventing hospital admission during acute illness as the primary objective of their service.

Around two thirds of reablement services reported they worked to reable individuals across a wide range of domains of everyday living activities that allow people to live as

independently as possible. We defined these types of service as 'comprehensive reablement'. However, a third of services were more restricted in the way they implemented the reablement approach and we labelled this as 'functional reablement'. An additional distinct cluster of reablement input was also identified which we referred to as 'social reablement'. It differed considerably from 'functional' and 'comprehensive' reablement in its service characteristics and aspects of service provision and delivery. Both our survey and other literature suggest that social reablement is most likely to be being delivered by mental health services.[28, 29]

How services assessed service users and measured progress towards reablement varied with most apparently reliant on non-standardised measures or professional judgement to assess their effectiveness. A surprisingly high proportion of respondents were not able to report the usual outcome of service users after discharge. Nonetheless, where this information was provided, the usual outcome most often reported was discharge without involvement of care services. This is broadly in line with results from the 2015 NAIC.

Overall, therefore, this survey of reablement services revealed a common objective of restoring, as much as possible, an individual's functioning and ability to live independently. There was, however, heterogeneity in terms of where services were located, the degree to which reablement was integrated into wider intermediate care provision, the staffing of services and the extent to which services were being outsourced. In addition, not all services reported delivering comprehensive reablement, and focusing instead only on functioning with respect to activities of daily living. Finally, it was clear that routine use of standardised measures to assess and monitor outcomes was rare.

This broad understanding of reablement services is supplemented by the much more detailed picture of the three reablement services which comprised the research sites for the evaluation Work package (WP2). Chapter 4 described and compared these services and it reinforced the notion of diversity which exists in reablement service models. Thus, even within just three services, varying approaches, or models, to providing reablement is captured both in terms of organisational and service characteristics and practice. It also highlighted that, within a single site, a number of different delivery models may be operating. Importantly, no consistent patterns of association of service characteristics were

observed, something sometimes also found in the analysis of the national survey. Indeed, it was a recognition of this variety in terms of service delivery and practice that stimulated NIHR's commissioned research call on this topic, and the questions posed.

10.4. The costs of providing reablement

The national survey of reablement services (WP1) also collected data on the costs of reablement and service caseload. The average cost of reablement was £1,455. However, 61% of services did not provide information on costs, and in those who did, there was wide variation in the answers from £20 to £3,333 per case. When services with a cost per case of under £500 were excluded, the average cost per case rose to £1,728. Both these figures are within the ranges reported in the literature. Using data from a previous evaluation of reablement,[2] the 2015 Unit Costs of Health and Social Care[18] report a cost per case of £2.096. The 2015 National Audit of Intermediate Care[29] reported a cost per case of £1,484. This provides some reassurance that most of survey respondents provided accurate information.

However, collecting providing information on costs did present issues, both in terms of non-response or apparently implausible answers. We can hypothesise that respondents found the questions difficult to understand or answer, or they did not have access to the required information. Furthermore, some answers yielded such small costs being calculated (e.g. £20 per case) that errors in survey completion may have also occurred. Overall, our experiences suggest that future attempts to collect data on the costs of reablement services should consider targeting at least some questions to finance departments, which are more likely to understand the nature of the information required and have relevant information at hand. Furthermore, to highlight errors to the respondent, electronic surveys could be designed so the implied cost per case is calculated automatically and made visible to the respondent.

10.5. The outcomes of reablement

The outcomes evaluation was reported in Chapter 5. Given issues with sample size, particularly in two research sites, it was not possible to compare outcomes between sites and descriptive analyses of the total sample were therefore only reported.

Improvements on all outcomes – health-related quality of life (EQ-5D 5L), social care-related quality of life (ASCOT SCT-4), practitioner-reported functioning (Barthel Index) and self-reported functioning (NEADL scale) were observed. For the sub-sample for whom data was collected at both time points, improvements in health-related quality of life (index score and VAS), social care-related quality of life and practitioner-reported functioning were statistically significant.

Outcomes (excluding Barthel Index which was not collected at this time point) had further improved at 6 months post-discharge. Compared to the mean improvement in EQ-5D 5L and ASCOT index scores between T0 and T1, the difference between T1 and T2 scores was smaller and not statistically significant. However, for the NEADL scale, size of improvement in mean score was greater between T1 and T2 than T0 and T1 and, unlike T0 to T1, was statistically significant. Using the GHQ-12, we also looked at mental health outcomes at 6 months follow-up. A (non-significant) improvement in mean GHQ score was observed between T1 and T2.

One of the objectives of the study was to compare outcomes between research sites – each representing a different model of providing reablement. This was not possible due to inadequate sample sizes. However, our findings still make a useful and important contribution. First, they suggest that a number of outcome measures should be used in order to capture the impacts of reablement. Second, the inclusion of a measure of mental well-being – an outcome not usually included in evaluations of reablement - should be considered. This is particularly pertinent given concerns about mental well-being, social isolation and ageing.[30] Third, they indicate the validity and value of capturing longer-term outcomes. Fourth, and related to the previous point, they suggest that the chronology of impact of reablement may vary between outcomes.

10.6. Factors associated with outcomes of reablement

Reablement is a complex intervention[31] there is no fixed protocol, rather its core approach is to tailor and individualise the intervention to each individual whilst remaining within the overall paradigm of a restorative, intensive, time-limited intervention.[32] In addition, a number of external and person-centred factors are likely to moderate or mediate intervention effectiveness.[32] These issues were clearly reflected in NIHR's commissioning brief for this study.[33] Emphasis was given to the need for evidence on service, intervention and individual characteristics which impact on intervention effectiveness.

A core objective of the study was, therefore to explore the impact of a range of characteristics on reablement outcomes. We used regression analysis to conduct initial, exploratory analyses, sample size limited the complexity of modelling work. However, we would argue findings are highly useful given existing evidence is extremely limited.[17] We now consider the findings (described in Chapter 5) with regard to each characteristic placing, where possible, in the context of existing evidence.

Overall, our findings support the notion that reablement should be offered to individuals regardless of **age** and **gender**. We have not identified any studies which offer counter evidence. We used the question 'Do you feel that you have enough money to live on' as a proxy indicator of **perceived financial situation**. The conclusion from our analysis is that having sufficient money may affect reablement outcomes. However, the nature of this association is likely to be complex with a number of different issues at play including, for example, housing quality and suitability[34] and general physical health. An additional explanation has begun to be explored[35] with rehabilitation is the potential impact of service user socio-economic status on therapist attitudes and decision-making.

We found evidence that <u>not</u> having family or friends as **informal carers** was associated with greater improvement in some outcomes (ASCOT SCT-4, Barthel Index). Similarly, there was weak evidence that **living alone** was associated with a greater improvement in professional and self-reported functioning (Barthel Index and NEADL scale respectively). However, in terms of health-related quality of life, living alone was negatively associated with positive outcomes. Overall, these findings accord with an RCT of reablement vs usual care[36] in which

having a carer was related to receiving on-going care at three and twelve months post-intervention in both arms of the study. The wider literature offers support the notion that living alone *may* impact aspects of health status in a positive way. For example, a recently published systematic review of adherence to exercise programmes for older people found that living alone is associated with higher rates of adherence.[37]

Our analysis indicated the association between **referral reason** and outcomes may vary according to type of outcome. In terms of social care-related quality of life, there was some evidence that 'return home' referrals do better than 'remain at home' referrals. However, the opposite was observed with respect to self-reported functioning (NEADL). Findings such as these reiterate the importance of using assessing a number of outcome, as the concepts captured differs.

We found that **functional ability at referral** into the service *may* impact on quality of life outcomes and functional outcomes at discharge. This aligns with findings from an RCT of reablement.[36] We note, however, that even small reductions in dependency can impact on levels of need for on-going care. Related to this, and equally important, is the evidence that maintaining some degree of independence something is highly valued by older people.[38] In terms of **physical co-morbidities**, we found no evidence of an association between this variable and health and social care quality of life at discharge from reablement, and some evidence of possible association with functional outcomes. It is useful here to refer to evidence from previous studies that on-going health issues may impact reablement outcomes as any gains in functioning and independence may be regarded as likely to be short-lived. [17]

Two previous studies [39, 40] report practitioners' and/or service users' beliefs that service users' motivation is an important factor in successful reablement. Another[41] describes service users saying they wanted to feel they were 'working with' their reablement worker, which gives a sense of active, collaborative involvement. These studies, and practice guidance, identify motivating and increasing the confidence of service users to be key aspects of the reablement worker role.[17, 24, 39-41] We have not identified any previous evaluative research exploring this concept – the lack of a measure may account for this. This study has generated, in an initial and exploratory way, some evidence – and across all

outcomes – of the association between **engagement** and outcomes. A recent conceptual review concluded that engagement is multi-dimensional construct comprising both a co-constructed process and a patient state.[42] The authors argue this highlights the practitioner's role in supporting engagement, and note that work to support engagement is likely to require an individualised approach by sufficiently skilled practitioners.

Our analyses also indicate that **mental health** at entry into reablement was associated with health and social-care quality of life at discharge and also, though a weaker association was found, functioning. We have not identified any previous evaluative studies which have explored the association between mental health and reablement outcomes. Insufficient sample size means we have not been able to run any multiple regression analyses: this will have allowed us to explore, for example, the relationship between mental health and intervention engagement. Intuitively this would seem an important relationship to understand. Certainly, as reported in Chapter 6, practitioners believed mental health impact on the effectiveness of reablement. For this reason, staff identified the need for access to mental health expertise and input within reablement provision.

We were also able to test, in a preliminary and exploratory way, the association between some service or intervention-specific characteristics and reablement outcomes. Aside from some relevant qualitative evidence of user and practitioner views on the importance of access to physiotherapy and occupational therapy, and 'joined up' provision with the service, and between other services,[39, 43, 44] to our knowledge this is the first time such work has been carried out.

The characteristics we tested were:

- duration of the intervention,
- reablement workers' adherence to reablement principles,
- whether the service comprised as single team or separate teams of assessment and reablement worker staff,
- whether reablement workers were located 'in-house' or out-sourced from a private provider.

In terms of functional outcomes, there was some evidence to indicate that **being looked after by a single team** was associated with better outcomes. There was also weak evidence that a single team model is associated with better health-related quality of life at discharge.

In addition, there was some evidence that **intervention fidelity** and **duration of reablement** are associated with outcomes – but only with respect to social care-related quality of life.

Finally, there was some or weak evidence from the regression analyses that **in-house** reablement workers, as opposed to workers from an out-sourced team, are associated with more positive outcomes at discharge across all outcome measures.

The wider literature on out-sourcing of adult social care has raised questions about the quality of care (for example, Hudson, 2016)[45]. Our interviews with staff offer some further reflections (see Chapter 6, section 6.3.5). They noted that out-sourced providers may not be incentivised, nor is it in their 'business' interests, to seek to reduce levels of input with a service user. This is contrary to practice within in-house teams where this as a clear objective. Second are issues of training and skills – a number of interviewees believed there is greater 'churn' within care agencies compared to in-house workers, thus the cumulative experience and skills of delivering reablement may be less evident. Third, out-sourcing arrangements may place any on-going monitoring and review by the assessment team – and supervision and support to reablement workers – at, at best, arms' length. That said, this may also be the case where separate in-house services deliver assessment and 'hands-on' reablement.

Again, we note we can only hypothesise about possible mechanisms at play, and the connections between some of these service characteristics, some of which may have become clearer had we been able to conduct multiple regression analyses.

Finally, we remind readers that other service characteristics could not be explored by regression analysis due to small sample size: OT integral to team, or not; located within integrated health & social care organisation vs single agency; and policy re number of reablement workers allocated/case. Based on our interviews with service users and professionals working in reablement (reported in Chapters 6 and & respectively), and the wider literature on issues such as continuity of care and skill mix/access to skills within the

reablement service,[17, 39, 43, 44] we would argue for the importance of including these characteristics in a future research as well as those where we have been able to conduct some initial exploratory analysis.

10.7. The impact of reablement on resource use

A economic evaluation (WP2c), running in parallel to the outcomes evaluation (WP2a) and reported in Chapter 8, explored the impacts of reablement on resource use and costs. The findings from this aspect of the study are limited in a similar way to the outcomes evaluation, and therefore conclusions should be circumspect.

To support the economic evaluation, early in this project, a systematic review of the methods applied for the economic evaluation of reablement interventions was undertaken.[22] We identified five areas of methods uncertainty common to some if not all of the studies. There was a lack of clarity, about which outcome measure/s it was appropriate to use, as reported in four studies.[2, 46-48] There was uncertainty in the cost savings achieved from reduced hospital stays.[48, 49] Six studies discussed the uncertainty around the impact on carers.[2, 47, 50-55] Six studies discussed the potential benefits of subgroup analysis to determine how the individual's characteristics affect the costs and outcomes and to tailor reablement to the individual's needs.[2, 48, 50, 51, 56, 57] Two studies suggested that more research is required on the cost-effectiveness of different service models.[2, 48] The findings from this review supported the objectives and design of the economic evaluation. It also provided useful information regarding methods and scope of data collection.

Overall, findings from the economic evaluation suggest a downward trend in resource use from the period prior to reablement to 6-month post-discharge. This may reflect the study participants' recovery after a period of ill health. However, it may be confounded by the losses to follow-up if the study participants who did not take part in the follow-up were those with the greater use of services. The frequent use of informal care suggests that this was an important source of support for study participants.

From a public sector perspective, the key cost items were hospital overnight stays and social care. Given the magnitude of the cost of hospital overnight stays, future studies should aim

to collect this information in detail in order to cost it accurately. In addition, costs of major home adaptations and equipment should also be collected if funded by the NHS or the local authority, given their magnitude. From a wider perspective, informal care time should be considered.

It is difficult to place our findings on the costs of reablement in context given the paucity of previous research on reablement. Only one previous UK study reports this.[2] Here, the health care costs during reablement were mostly driven by hospitalisations. In contrast, in our study, hospitalisations during reablement were rare. The differences may be related to the different characteristics of the two study populations and the different study methodologies. Specifically, the study sample in Glendinning et al was much larger (N=697), had worse health-related quality of life at baseline, a greater proportion of study participants were categorised as “return home”, and greater proportion were living alone. The duration of reablement was also longer at 8 weeks (vs. 4 weeks in our study).

10.8. Factors affecting the costs of reablement

Type of provider, the reason for referral to the reablement service, co-morbidities and the demographic and economic characteristics of service users were associated with higher costs.

Thus, study participants who received reablement from outsourced providers were associated with higher hospital costs and smaller social care costs compared to those who received in-reablement from an in-house service.

In addition, study participants who were referred to reablement due to a musculoskeletal problem or a fall, or due to an infection, were associated with lower costs of community health care during reablement. Furthermore, study participants with arthritis and chronic respiratory conditions were associated with higher costs whereas cardiovascular conditions were associated with lower costs.

In terms of demographic characteristics, older study participants were associated with higher costs of community health care; in contrast, males were associated with lower costs.

Study participants who rented their home were associated with higher costs of social care. Finally, study participants who reported having sufficient money to live on were associated with higher costs of community health care.

This analysis was conducted on a subset of the study sample (N=86) for which there was complete data on all variables of interest and, therefore, its predictive power should be interpreted with caution. Large sample sizes are usually required to predict health care costs, given the high variability of costs.[58] We cannot exclude the possibility that these associations are spurious, given the limitations of the analysis, which we highlight below.

The results suggest that the type of provider (outsourced vs. in-house) may have an effect on costs associated with the use of health and social care services. Both in the main analysis and in the sensitivity analysis, outsourced providers were associated with higher hospital costs and lower social care costs, controlling for other characteristics. This may reflect differences in the case-mix that out-sourced providers tend to receive that we were unable to control for, or differences in the way that reablement is delivered and its implications for service use.

The results also suggest that there may be some income inequality in the provision of hospital and community health care services. These costs were greater for study participants who resided in more affluent areas or who perceived they were in a better financial situation. Income inequality in the provision of health care services in the UK has been reported in the literature.[59] In contrast, costs of social care were greater for those renting privately compared to those who own their home. This is consistent with previous research[2].

At the individual level, we found that variation in costs was mostly related to the health of study participants, either reflected in their EQ-5D-5L score, health problems leading to reablement or co-morbidities. Therefore, we suggest that this information is collected, not only in future research but also as part of routine data collection by reablement services.

10.9. The experience of delivering reablement

To date there have been very few studies of practitioners' views and experiences of delivering reablement, particularly in terms of intervention effectiveness and factors which support, or act as barriers to this. Thus, some findings reported in Chapter 6 of this report (which form part of the project's process evaluation (WP2b)) concern issues or topics not previously explored or identified.

Views on the importance of service user motivation – and the need, sometimes, for skilled workers to achieve this – consistently expressed by staff taking part in WP2b has been previously described.[25] Staff participating in this study emphasised the importance of flexibility in the timing and duration of visits, the difficulties – and negative impacts - of working with 'resistant families'. This and another study[28] also both report views on the importance of access to specialist knowledge and expertise, with occupational therapy and physiotherapy – as well as community nursing teams – being variously mentioned. Finally, these two previous studies also report reablement workers' accounts of finding their work very satisfying.[25, 28]

The issue of a lack of awareness and understanding of the reablement approach – among service users and family members – was a dominant issue across interviews and something observed in previous research with staff.[25] It was perceived as affecting intervention effectiveness because of its impact on engagement with reablement and the therapeutic relationship.

The findings from our initial and exploratory modelling analyses of the impact of individual and service/intervention characteristics on outcomes (Chapter 5, section 5.6.3), and our tentative interpretations of them, certainly chime with the themes and issues which emerged from our interviews with reablement staff which serve to offer further explanatory value.

10.10. The service user experience

Prior to this study, there has been relatively little research on the perspectives of service users and family carers on reablement services. It was a topic area which the recent NICE guidance[15] noted as needing to be incorporated into future research.

Some of the issues related to the practicalities of service delivery that interviewees describes have been previously reported, for example, dissatisfaction with unpredictable timings of reablement workers' visits and experiences of rushed visits by reablement workers which may undermine reablement objectives[24]. Interestingly, previous studies report service users' preferences for consistency in the reablement workers visiting them[24, 64, 66] – something we did not find and, as reported in Chapter 6 (section 6.3.5), it was not something that all staff agreed was helpful.

Despite some areas of dissatisfaction with the practicalities of service delivery, as has been reported in previous studies, our interviewees were typically extremely positive about their experience of receiving reablement and the outcomes it achieved.[21, 27, 28] Furthermore, the role of reablement workers in motivating, encouraging to take responsibility, and giving confidence to service users – and its impact on reablement outcomes – is something that other qualitative studies with service users have also reported.[26, 67]

Perhaps one of the most important issues emerging from these data is a lack of complete understanding about the approach and objectives of reablement. It resulted in individuals feeling dissatisfied and/or confused about the support they were receiving and for a minority this remained their dominant view of the service. In addition, there was evidence that this mis-understanding of the role of the reablement worker, and their own role in the intervention, impacted on the extent to which they engaged with the intervention. Another indicator of this issue is that there was inconsistency between interviewees as to whether they had understood, and co-developed, the objectives of their reablement. This issue has been reported by previous studies,[24, 27] though another[28] describes service users in their study as having a good understanding of reablement and its objectives. This is potentially significant in that it shows it is possible for service users, and family members, to have a good understanding of the intervention.

Finally, we highlight the relational element to reablement which emerged from these data. Regular home visits by, typically, a positive and friendly workforce were often enjoyable times, something that previous research has also reported.[64] For some they addressed an issue of loneliness and social isolation. Importantly, our data reveals that the nature, or quality, of relationships with their reablement workers was identified as impacting on engagement with the intervention. This accords with other work which argues that the worker/therapist – user/patient relationship plays a significant role in securing engagement with an intervention.[42]

10.11. Reabling people with dementia

Existing research evidence on reabling people with dementia is extremely limited. At the same time, there is concern that people with dementia may be excluded from reablement.[17, 24] Given the growing proportion of older people with dementia - and the implications, or associated risks, of the diagnosis in terms of need for support from health and social care services - it is not surprising that the NICE guidance includes within its research recommendations a call for evaluations of the effectiveness and cost-effectiveness of reablement for people with dementia and research to secure the views and experiences of key stakeholders. A standalone work package (WP3), reported in Chapter 9, comprising interviews with service leads and frontline staff explored views and experiences of providing reablement to people with dementia.

Interviewees were in agreement that the dual objectives of 'assessment and reablement' services – which form the new 'location' for the delivery of reablement since the 2014 Care Act – worked well for people with dementia. It was regarded as a positive and effective approach to needs assessment. People with dementia were also consistently viewed as having potential to be reabled – particularly those with mild or moderate dementia. However, expectations with respect to the extent to which everyday living skills/independence was restored, and the period of time over which it will be sustained, needed to differ to those without this diagnosis. There was strong consensus that a diagnosis of dementia should not, on its own, preclude offering reablement to a person with dementia.

Another difference between reabling people with and without dementia identified by interviewees was that a greater emphasis was likely placed on working on, and supporting positive changes in, social outcomes (for example, social networks, activities) both for the person with dementia and family members.

It was for all these reasons that interviewees were clear that adjustment should be made regarding perceived objectives, and indicators of success, of reablement for people with dementia. This position accords with that set out in a recently published 'concept paper' on reablement in dementia which drew both on the existing evidence base and the views of strategic/service leads, practitioners and academics.[60]

In terms of the practice of reablement, some distinctions and issues were highlighted by interviewees. Interviewees noted that greater investment had to be made in 'pre-reablement' work – or getting the individual 'ready' for reablement. This included fostering engagement, re-establishing daily living routines and, for those returning home from hospital, settling and re-orienting to the home environment. In terms of on-going adjustments to practice, practitioners spoke about, potentially, a need to re-establish their relationship with the user at each visit. When working with service users who lived alone, it may not be possible to reliably establish what tasks/activities had and had not been done (for example, having meals, taking medication). Finally, work with family members was often presented as part of the intervention – though, as is reported in Chapter 6, family members' input was not always helpful or supportive of reablement objectives.

Interviewees also described the adaptations to their usual practice which may be needed. First, adjustments to communication were likely to be required, or helpful. This included simplifying language, repeating instructions and the use of visual cues. Second, there was agreement that is was likely that the duration and intensity (i.e. length of visits) of the intervention should, ideally, be extended, and that the number of reablement workers assigned to a case restricted. These adjustments were only being formally implemented in a minority of services represented in this study (though we would note this gives no indication of wider adoption of such approaches).

A final area of findings concerned staff training. Interviewees – and specifically those who were reablement workers – felt that the training they had on dementia was inadequate.

Desiring to place these findings in some sort of context, and given the lack of existing evidence on staff's views and experiences of reabling people with dementia, we have looked at existing evidence regarding the *physical rehabilitation* of people with dementia following hip fracture. There are certainly parallels in terms of findings. For example, a systematic review of the effectiveness of hip-fracture rehabilitation in people with dementia concluded that, for people with mild or moderate dementia, they may make similar gains in function and mobility as those without dementia.[61] A recently published systematic review of "current best practice" for rehabilitation interventions of older individuals with cognitive impairment post-hip fracture[62] concludes that implementing rehabilitation interventions with this population is feasible. It also notes that innovative approaches to support engagement with the intervention may be required. Finally, an Australian-based qualitative study of health professionals[63] reported strong consensus among interviewees that access to rehabilitation should be determined by an individual's ability, or willingness, to engage with the intervention and not assessed solely on cognitive impairment. Linked to this, interviewees in this study reported that some professionals assumed people with dementia have limited capability to benefit from rehabilitation.

Chapter 11. Conclusions

11.1. Contribution to understanding reablement services in England

The timing of this study within a changing policy landscape – in particular, the 2014 Care Act and its subsequent implementation – had both positive and negative impacts. It meant the study was being carried out at a time of enormous change within social care for older people and intermediate care provision. Specifically, the notion that all (new) referrals for home care/support should undergo reablement alongside a comprehensive assessment process led to considerable changes in the organisation of services and the perceived role, or objectives, of reablement.

Whilst these changes – being implemented as we were seeking to recruit services to the study and during study set-up - created difficulties for us, it does mean the study has generated early and detailed evidence in three localities on the ways in which local authorities have responded to the Care Act and wider work on integrating intermediate care provision. Importantly, our research sites were quite diverse – with a range of differences in terms of their characteristics. We have been able, though sometimes only in a preliminary way, to explore the impacts of these characteristics on outcomes, user experience, and practitioner experience.

In addition, this study makes a significant contribution to our understanding of the way that reablement services are responding to people with dementia. The findings from our national survey indicate that some reablement services may still exclude people with dementia. Our qualitative research with reablement staff has generated rich evidence on the way services are responding and, where possible, the development of practices and strategies to support engagement and positive outcomes. However, we also report concerns about the lack of training and a perceived lack of recognition on the part of commissioners to the value of reablement for this population and also, within commissioning arrangements, the adaptations which may be required to maximise its impact.

11.2. Contribution to research design and methods

In meeting the health and social care needs of the elderly population - specifically those at risk of (increased) use of social care or unsuccessful discharge from hospital following an acute episode - reablement continues to be key to the policy and practice response in this country and elsewhere. Given the paucity of existing evidence, evaluative research on reablement is, and will continue to be, needed. The findings from this study are an important and useful resource for such research both in terms of issues of feasibility and study implementation.

First and foremost, the findings from this study – both in terms of the complexity of reablement provision and our (early) findings on the individual-, intervention- and service-level factors which may affect intervention effectiveness – point strongly to the value of observational studies within any body of work evaluating reablement.

Second, the findings offer insight into the individual, service and intervention-level characteristics which should be considered in future evaluative research.

Third, it provides evidence – based on practitioner views - on the outcome dimensions that evaluations of the effectiveness of reablement for people with dementia should consider.

Fourth, when regarded as a feasibility study, it offers the following:

- data on the performance of, and effect sizes for, four outcome measures – two quality of life measures, and two measures of functional ability – at discharge and 6 months post-discharge;
- preliminary data on mental health outcomes;
- data on recruitment, retention and attrition rates;
- approaches to embedding research staff within local authority services to support recruitment and timely data collection;
- information – of relevance research teams and research funders - which may help to pre-empt the difficulties and challenges of implementing a complex study local authority settings;

- initial data on the effectiveness of alternative modes of administering research instruments;

Finally, the study has contributed in terms of the development of three new research instruments which we believe are highly relevant to future evaluations of reablement.

First, two new measures were created: the Hopkins Rehabilitation Engagement Rating Scale-Reablement Version and the Experience of Reablement Practice Checklist. No equivalent measures exist. We have noted that both would be improved by additional work; but even in their current state they offer a means by which user engagement in reablement and intervention adherence can be captured. Our initial findings suggest these are, potentially, important variables in terms of their impact on user outcomes. Crucially, these are both variables which are amenable to intervention by reablement services. Second, a questionnaire (the Services and Care Pathway Questionnaire) to assess resource use was developed and performed well.

11.3. Informing health and social care practice – some considerations

Whilst noting the time (and policy changes) which have occurred since the survey of reablement services (WP1) was carried out, it is valid and important to particularly highlight some findings. First, the evidence of 'two tiers' of reablement provision – comprehensive versus functional – is of concern. Also concerning is that, based on evidence from our process evaluation, services which report to provide comprehensive reablement are not necessarily doing so. Comprehensive reablement – which adheres to the original concept of reablement and pays attention to an holistic restoration of everyday living beyond simply basic functional skills – demands more from service providers including having a knowledge of, for example, local social groups and daytime activities and being able to work with service users outside of their home (should that be required). Our process evaluation suggests this is an important issue. The lack of a more holistic approach was one of the few areas of improvement raised by service users we interviewed. Furthermore, a failure to do this meant service users' priorities were not necessarily attended to. From the interviews

with professionals working in reablement services, workers' knowledge of local social/activity provision was regarded as an active ingredient of reablement and this was also stressed by staff who participated in WP3 where we explored the issue of reabling people with dementia. These findings certainly align with wider evidence that attending to individuals' social capital is a core aspect of preventing physical and mental health problems (REF). This is, perhaps, particularly pertinent for older people who are at increased risk of social isolation and loneliness (REF).

A second issue to particularly highlight from our survey of reablement services is that monitoring of outcomes through the use of a standardised measure is extremely unusual. Our experiences of using the Barthel Index is that, with training, it is feasible to integrate this into the assessment and review process. In addition, we encountered no difficulties using the NEADL scale – a self-report measure of (extended) activities of daily living functioning.

The difficulties and challenges which this study encountered meant that an insufficient sample size was recruited for the evaluation work package. As a result, the findings from the outcomes and economic evaluation should be treated with caution. Indeed, with respect to these elements of the study we would suggest regarding these as initial, exploratory evidence. It is therefore not appropriate to use these findings to draw implications for health and social care practice.

However, we do note that in our exploratory analyses of factors which may moderate or mediate the effectiveness of reablement – or explain differences in reablement outcomes between research sites – are user, service and intervention characteristics which are amenable to change in terms of service structure and practices.

In terms of individual characteristics, these include mental health and informal carer involvement. There are no indications that characteristics such as age or presence of co-morbidities effects intervention outcomes. Engagement with reablement was the factor with the strongest and most consistent evidence regarding impact on outcomes. Whilst we have classified it as an individual characteristic, recent thinking stresses the role of the professional in engendering and maintaining engagement. Findings from our process

evaluation fully align with that position. This also revealed that service user and family member (mis-)understandings of reablement could be a barrier to engagement and that staff skills vary. We would suggest that these are two areas which service providers and commissioners may want to explore.

This study is the first to explore the possible impact of organisation and delivery factors on outcomes. Findings are tentative and uncertain. However, intervention fidelity, duration of reablement, service structure (single vs separate assessment and delivery teams), and in-house versus out-sourced reablement worker teams were found to have some degree of (statistical) association with at least one outcome. Findings from the process evaluation – particularly the interviews with staff working in reablement services – both support and offer explanations for these findings. However, the significance of these associations in terms of practice or commissioning decisions could not be established.

Furthermore, this study incorporated collecting qualitative evidence from a range of stakeholders. Whilst this evidence is limited to three reablement services, and data is incomplete in terms of full representation of all stakeholder groups across all research sites, our qualitative evidence consistently supports, and offers some degree of explanation, for our exploratory quantitative analyses.

Thus, whilst not able to draw practice implications from our study findings, we strongly advocate for the need for further research to ensure commissioning, strategic and practice decision-making is evidence informed. Until that evidence becomes available, we should be aware that current decision-making is not evidence-informed and may, potentially, have (significant) impacts on service user outcomes and service efficiencies.

Finally, we draw attention to the findings from the final Work package which looked at reabling people with dementia. There was strong and consistent support from participants in this qualitative study that a diagnosis of dementia *per se* should not preclude someone from being offered reablement. However, interviewees consistently agreed that aspects of service delivery and practices may need adjusting or adapting. Within this, interviewees agreed that all staff working within the reablement pathway should be adequately trained on dementia. Whilst there is not necessarily yet the evidence to offer detailed guidance on

practice, it should be possible to devise training which considers the implications of a dementia diagnosis on delivering reablement.

11.4. Recommendations for future research

The findings from this study indicate securing robust evidence with regard to the following topic areas would be highly relevant and useful to commissioners, managers, front-line staff and policy makers.

1. A large scale, multi-site mixed method outcomes and economic evaluation of reablement. We would suggest an observational study design which allows a robust and thorough investigation of the impacts of service, intervention and individual characteristics on reablement outcomes, *and* includes people with dementia.
    - We recommend that such a study involves larger number of services than were used for the current study.
    - We also note the importance of sufficient resources being made available to services acting as research sites.
    - Nesting a local study team within the service appears to work well. The success of the study in terms of retention and data quality indicates the value of using home visits for data collection.

    Further, in order to properly execute such a study, the following additional and preliminary pieces of work are recommended:
    - Identification of service and intervention characteristics deemed important and relevant to commissioners, strategic leads and service managers. These should then be represented in the research sites.
    - Further psychometric evaluation, and if required development, of the Hopkins Rehabilitation Engagement Rating Scale – Reablement Version and the Experience of Reablement Practice Checklist is recommended.
    - Through consultant with stakeholders, a systematic review and, if necessary, primary research, the identification and testing of a relevant set of reablement outcome indicators for people with dementia.

- Exploration of using routinely collected data on service use (e.g. Hospital Episode Statistics) as part of the outcomes and resource use dataset.

2. The development/identification and evaluation of feasible interventions – delivered prior to/on point of entry into reablement - to improve understanding and expectations of reablement, both on the part of potential service users and family members.

3. The identification and evaluation of strategies and practices to support engagement with reablement. We would suggest a systematic review to start, which seeks to synthesise evidence across a wider scope of interventions including rehabilitation. Such a review, and any on-going work, should include people with dementia.

4. A systematic review, again synthesising evidence from reablement and also other relevant interventions, of practices and technologies which support understanding, assimilation and remembering of instructions, or stages, of executing tasks, routines and daily activities among people with dementia.

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Faria, R, Weatherly, HLA, Kiss, N, Manca, A, Parker, GM, Beresford, BA, Pilkington, G, Laver Fawcett, AJ, Kanaan, M, Rabiee, P, Mann, RC & Aspinal, FJ (2015) 'The challenges in evaluating the cost-effectiveness of complex interventions' *Value in Health*, vol 18, no. 7, pp. A727-A728. DOI: 10.1016/j.jval.2015.09.2770

Faria, R, Kiss, N, Aspinal, FJ, Harden, M & Weatherly, HLA (2015) 'Economic Evaluation of Social Care Interventions: Lessons Drawn from a Systematic Review of the Methods Used to Evaluate Reablement' *Health Economics & Outcome Research*: Open Access. https://www.omicsonline.org/open-access/economic-evaluation-of-social-care-

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Contributions of authors

Fiona Aspinal (Senior Research Fellow, health and social care services research): lead applicant and Principal Investigator (October 2014 – May 2017). Oversaw delivery of the project until May 2017 and contributed to all work packages. Supervised junior staff and local study teams. Led on delivering WP1.

Bryony Beresford (Professor, Health and Care Services Research): co-applicant and Principal Investigator (May 2017- November 2017). Oversaw final stages of project and the outcomes and process evaluations within WP2. Contributed to all work packages and led writing, or contributed to chapters for, of final project report.

Rachel Mann (Research Fellow): involved in WP1 data collection and analysis. Supported/led study set-up and day to day management of research sites and data collection for WP2. Supported/led supervision of Local Study Teams. Contributed to process evaluation (WP2b) data collection and analysis, and analysis of service characteristics, and report writing. Supported collection of costs data. Contributed to all other aspects of the project.

Gillian Parker (Professor, Social Policy Research): co-applicant. Oversaw WP1 data collection and the analysis and reporting of this element of the project. Contributed to all other elements of the project.

Mona Kanaan (Senior Research Fellow, Statistics): co-applicant. Provided statistical expertise to the project and led on the outcomes data analysis and reporting (WP2a) and supervised other staff involved.

Rita Faria (Senior Research Fellow, Health Economics): co-applicant. Worked on the costs aspects of the WP1 survey and the economics evaluation (WP2c), leading on data analysis, writing and the systematic review. Also led analysis and reporting of ASCOT outcomes data (WP2a).

Parvaneh Rabiee (Senior Research Fellow, health and social care services research): co-applicant. Led WP3, collected all data and conducted data analysis and report writing. Contributed to data collection for WPb (process evaluation): staff focus groups.

Helen Weatherly (Senior Research Fellow, Health Economics): co-applicant. Oversaw the economics evaluation (WP2c) and supervised junior health economists working on the project.

Susan Clarke (Research Fellow): conducted data collection and data analysis for service user and family member interviews within WP2b, also supported focus groups with staff within this Work package. Assisted and supported production of the final report.

Emese Mayhew (Research Fellow): led on data management and cleaning of outcomes data (WP2a); conducted data analysis for the outcomes evaluation and report writing, and the psychometric testing of the Hopkins Rehabilitation Engagement Rating Scale – Reablement Version and the Experience of Practice Checklist. Assisted and supported production of the final report.

Ana Duarte (Research Fellow): contributed to the health economics evaluation (WP2c) in terms of data management and cleaning, analysis and writing.

Alison Laver-Fawcett (Senior Lecturer, Occupational Therapy): provided occupational therapy expertise and advice to all aspects of the project, directly involved in the development of the Hopkins Rehabilitation Engagement Rating Scale – Reablement Version and the Experience of Practice Checklist used in WP2a.

Data sharing statement

Available data have been included in appendices and supplementary material. Any queries or data requests should be submitted to the corresponding author for consideration. Access to available anonymised data may be granted following review

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Appendix 1.

Appendix 1. WP1: National Survey of Reablement Services in England

This survey was administered electronically using Qualtrics software. It is a complex instrument with considerable amounts of routing. For this reason we offer a link to a copy of the questionnaire.

https://york.qualtrics.com/jfe/form/SV_0cWUhIULIMocT0F

This link will remain active until 31st December 2019.

Appendix 2. WP1: Data tables

Table 20: Distance between final cluster centres

Cluster number	1	2	3	4
1	-	1.616	1.384	1.359
2	1.616	-	1.960	1.130
3	1.384	1.960	-	1.943
4	1.259	1.130	1.943	-

Table 21: Staff in core teams by cluster

	% teams reporting type of staff as core member				Total	Sig.
Staff in core team	Cluster 1	Cluster 2	Cluster 3	Cluster 4		
Reablement worker	54	57	85	81	69	*
Social work assistants	58	7	60	5	24	***
Senior social workers	96	19	60	12	37	***
Care manager	58	43	40	42	45	NS
Home care workers	4	100	35	0	39	***
Home care organiser	21	69	40	26	41	***
Other social care staff	27	28	16	33	27	NS
OT assistants	50	7	70	7	25	***
OTs	92	29	100	21	49	***
Physio assistants	0	0	65	0	10	***
Physios	29	12	100	0	25	***
Other therapists	8	0	0	2	2	NS
Health support workers	8	5	30	12	12	*
Registered nurses	8	0	85	5	16	***
Other health care staff	4	0	0	0	1	NS

Table 22: Access to OT input by type of service

OT access in team and/or from elsewhere	%				
	1: Reablement with OT (%)	2: Home care reablement (%)	3: Multi-disciplinary reablement (%)	4: Reablement worker teams (%)	Total (%)
Yes	92	57	100	44	66
No	8	43	0	56	34
Total (n)	24	42	20	43	100

Table 23: Different types of reablement input, main type reported

Type of reablement input	**Services reporting this type of reablement input (%)**	**Services reporting this type of input makes up the majority of their work (%)**
Personal care	89	73
Domestic tasks	88	1
Safety issues	90	3
Information and signposting	87	<1
Getting around inside the home	90	2
Getting out and about	71	1
Re-engaging with social activities	68	<1
Managing health related needs	83	2
Confidence building	84	11
Total (N)	143	142
Missing cases	-	1

Table 24: Type of reablement input by organisational base

	Services reporting this type of reablement input (%)								
Organisational base	Personal care	Domestic tasks	Safety issues	Information and signposting	Getting around inside	Getting out and about	Re-engaging with social activities	Managing health-related needs	Confidence building
LA SSD	97	97	92	96	99	78	77	89	93
Health service	100	100	100	100	100	67	67	100	100
Joint health & SSD	81	76	91	95	90	75	85	90	91
Private provider	100	90	100	74	100	90	61	100	80
Voluntary provider	57	86	100	100	71	86	100	71	100
Social enterprise	100	100	75	100	75	100	100	75	100
Other	100	100	100	86	100	86	50	86	83
All	93	93	93	92	96	81	77	89	91
Missing cases	9	9	8	11	10	19	19	12	13
	X^2=23.93, df=6, p=.001	X^2=12.21, df=6, p=.057	X^2=5.59, df=6, p=.471	X^2=12.53, df=6, p=.051	X^2=17.76, df=6, p=.007	X^2=3.184, df=6, p=.785	X^2=9.403, df=6, p=.152	X^2=6.102, df=6, p=.412	X^2=4.914, df=6, p=.555

Table 25: Type of reablement input by contractual arrangements and service structure

	Services reporting this type of reablement input (%)								
Contractual arrangements	Personal care	Domestic tasks	Safety issues	Information and signposting	Getting around inside	Getting out and about	Re-engaging with social activities	Managing health-related needs	Confidence building
Wholly in house	93	93	94	92	97	79	75	90	91
In house and contracted out	92	92	92	92	92	83	88	87	96
Wholly contracted out	100	100	88	100	100	100	88	88	100
Other	93	86	93	92	93	75	58	93	77
All	93	93	93	93	96	81	77	89	91
Missing cases	8	8	7	10	9	18	18	11	12
	X^2=.651, df=3, p=.885	X^2=1.66, df=3, p=.645	X^2=.675, df=3, p=.879	X^2=.694, df=3, p=.875	X^2=.1.548, df=3, p=.671	X^2=2.147, df=3, p=.542	X^2=4.454, df=3, p=.216	X^2=.358, df=3, p=.949	X^2=4.639, df=3, p=.200

Table 26: Type of reablement input by organisational structure

	Services report this type of reablement input (%)								
Organisational structure	Personal care	Domestic tasks	Safety issues	Information and signposting	Getting around inside	Getting out and about	Re-engaging with social activities	Managing health-related needs	Confidence building
Separate service	97	97	93	86	96	76	68	85	93
Part of intermediate care service	92	89	96	100	96	77	85	96	89
Part of home care service	100	90	100	84	100	68	58	100	74
Part of crisis/rapid response service	100	100	100	100	100	80	80	60	100
Other	29	57	71	100	43	86	86	43	86
All	93	92	94	90	94	76	71	86	89
Missing cases	14	14	14	14	14	14	14	14	14
	$\chi^2 = 48.48$ df =4 $p < 0.001$	$\chi^2 = 15.70$ df = 4 $p = 0.003$	$\chi^2 = 7.93$ df = 4 $p = 0.094$	$\chi^2 = 6.10$ df = 4 $p = 0.192$	$\chi^2 = 33.55$ df = 4 $p < 0.001$	$\chi^2 = 1.02$ df = 4 $p = 0.902$	$\chi^2 = 5.19$ df = 4 $p = 0.268$	$\chi^2 = 19.10$ df = 4 $p = 0.001$	$\chi^2 = 6.54$ df = 4 $p = 0.162$

Table 27: Type of reablement input by type of team (missing data n=16)

	Reablement input delivered by team (%)				
Type of reablement input	**Reablement with OT**	**Home care reablement**	**Multi-disciplinary reablement**	**Reablement only**	Total (%)
'Functional'	26	37	15	30	29
Comprehensive	74	63	85	51	65
Social	0	0	0	19	6
N (100%)	23	41	20	43	127

Chi-square = 20.68, df = 6, p=0.002.

Table 28: Reported objectives and main objective of reablement services

Objective	**Services reporting this as an objective of their service (%)**	**Services reporting this as the main objective of their service (%)**
Help people regain everyday living skills	95	58
Reduce need for ongoing (social) home care	90	24
Prevent admission to long-term care when at risk	80	1
Prevent longer than necessary stay in hospital	88	7
Prevent hospital admission during acute illness	49	1
Other	9	6
N (100%)	138	137
Missing	5	6

Table 29: Source of referrals to reablement services and relationship to service delivery, organisation and type of reablement

Source of referral	Services taking referrals from this source (%)	Service delivery and organisational variables significantly associated with this source of referral	Statistical significance	Type of reablement input significantly associated with this source of referral	Statistical significance
Acute hospital	60	-		-	
Early discharge team	61	-		-	
Emergency department	48	-		-	
Primary care	45	Services based in health service more likely to take referrals	χ^2 = 9,88, df = 4, p = 0.043	'Functional' reablement less likely to take referrals	χ^2 = 8.93, df = 2, p = 0.011
		Services run as part of or alongside IC more likely to take referrals. Services run as separate reablement service less likely to take referrals.	χ^2 = 12.01, df = 4, p = 0.017	-	
Primary care out of hours service	36	Services run as separate reablement services less likely to take referrals	χ^2 = 9.09, df = 4, p = 0.059	'Functional' reablement less likely to take referrals	χ^2 = 7.52, df = 2, p = 0.023
Social services emergency duty team	62	-		-	
Social services intake team	75	Service in 'reablement only' staffing cluster more likely to take referrals	χ^2 = 7.39, df = 3, p = 0.06	-	
Intermediate care bed-based unit	50	Services run as part of or alongside IC more likely to take referrals	χ^2 = 8.80, df = 4, p = 0.07	-	

Intermediate care home based service	43	-		-	
Service user	27	Services run as separate reablement service less likely to take referrals Services run as part of crisis/rapid response service and 'other' services more likely to take referrals.	$\chi^2 = 15.32$, df = 4, p = 0.004	'Functional' reablement less likely to take referrals. 'Social' reablement more likely to take referrals	$\chi^2 = 18.57$, df = 2, p < 0.001
Voluntary sector	27	Services run as 'other' more likely to take referrals.	$\chi^2 = 13.16$, df = 4, p = 0.01.	'Functional' reablement less likely to take referrals. 'Social' reablement more likely to take referrals	$\chi^2 = 20.75$, df = 2, p = 0.001
Other	13	Services with 'other' contractual arrangements more likely to take referrals	$\chi^2 = 9.97$, df = 3, p = 0.019	-	
N (100%)	143				

Table 30: Typical duration of intervention

Typical duration	**% services**
Less than four weeks	13
4-5 weeks	30
6 weeks	50
7 or more weeks	7
N (100%)	132
Missing	11

Table 31: Type of staff setting personalised goals and relationship to service delivery, organisation and type of reablement

Staff who usually set goal	Service delivery and organisational variables significantly associated with these staff setting goals	Statistical significance	Type of reablement significantly associated with this source of referrals	Statistical significance
Occupational therapists			Less likely to set goals in 'social' reablement	$\chi^2 = 6.30$, df = 2, p = 0.043
	More likely to set goals in multidisciplinary reablement services	$\chi^2 = 13.41$, df = 3, p = 0.004	-	
	Less likely to set goals when service is separate reablement service More likely to set goals when service is part of or alongside an IC service	$\chi^2 = 12.99$, df = 4, p = 0.011	-	
Physiotherapists	More likely to set goals in multidisciplinary reablement services	$\chi^2 = 16.31$, df = 3 , p = 0.001	-	
	More likely to set goals in services run from health service	$\chi^2 = 10.06$, df = 4, p = 0.039	-	
	Less likely to set goals when service is separate reablement service. More likely to set goals when service is part of or alongside IC service	$\chi^2 = 14.36$, df = 4, p = 0.006	-	
Nurse	More likely to set goals in multidisciplinary reablement services	$\chi^2 = 18.23$, df = 3, p = <0.001	-	
	Less likely to set goals in service run from LASSD. More likely to set goals in services run from health service.	$\chi^2 = 23.29$, df = 4, p< 0.001	-	
	Less likely to set goals when service is separate reablement service. More likely to set goals when service is part of or alongside IC service	$\chi^2 = 24.36$, df = 4, p< 0.001	-	

Table 32: Annual expenditure based on different types of data provided, number of cases and costs/case

	Number answered (%)	Mean	Standard deviation	Min	Max
Expenditure on reablement service as reported by the services					
Total expenditure on reablement service	31 (22%)	2,558,007	2,196,177	5,000	7,092,570
Expenditure on in-house reablement	8 (6%)	1,537,428	2,083,990	300,000	6,500,000
Expenditure on contracted out elements	7 (5%)	865,123	642,622	269,678	2,000,000
Total value of the reablement contract	2 (1%)	£200,000; £1,200,000			
Total budget for older people's services	10 (7%)	16,800,000	16,700,000	1,013,000	50,400,000
Percentage expenditure on reablement	8 (6%)	24	34%	0	100%
Total expenditure on reablement based on estimates provided by services					
Total using expenditure if expenditure and percentage budget were answered	42 (29%)	2,366,626	2,245,076	5,000	8,500,000
Total using percentage of older people's budget if expenditure and percentage budget were answered	42 (29%)	2,359,779	2,204,305	5,000	8,500,000
Number of cases					
Number of cases that the service provided reablement to in 2014-15	81 (57%)	1419	1596	10	9500
Typical number of cases per month	19 (13%)	103	91	8	275
Calculated overall number of cases per year	100 (70%)	1383	1510	10	9500

	Number answered (%)	Mean	Standard deviation	Min	Max
Cost per case					
Total using total expenditure if total expenditure and percentage budget were answered	37 (26%)	1445	830	20	333

Appendix 3.
Appendix 3. WP2a: Adaptation of the Hopkins Rehabilitation Engagement Rating Scale

A 3.1. Background

The Hopkins Rehabilitation Engagement Rating Scale (HRERS)[12] was developed in the United States to measure engagement in with physical/functional rehabilitation interventions. It is a five-item, practitioner completed scale and has good psychometric properties. In developing the measure, and based on reviews of existing research into patients' participation in rehabilitation interventions, the scale authors defined the construct of 'engagement' as being comprised of five dimensions; attendance; ability to participate affected by cognitive impairments or low mood, positive attitude, acknowledgement/acceptance of need, active participation. HRERS comprises five items – each representing a different dimension, see Table 33.

Table 33: Hopkins Reablement Engagement Rating Scale (HRERS): items and concepts

Item	**Concept (see Kortte et al., 2007)**
The patient regularly attended my therapy/rehabilitation activity.	Attendance
The patient required verbal or physical prompts to actively participate in my therapy/ rehabilitation activity. (Reverse score)	Ability to participate / engage affected by cognitive impairments or low mood
The patient expressed a positive attitude towards my therapy/rehabilitation activity.	Positive attitude
The patient acknowledged a need for rehabilitation services and the benefits of therapy exercises or rehabilitation activities.	Acknowledgement/ acceptance of need
The patient actively participated in his/her rehabilitation therapy/activity.	Active participation

A six-point response format (Never, Seldom, Some of the time, most of the time, nearly always, always) is used by clinicians to report the frequency, or consistency, at which they observed each dimension.

A 3.1.1. The item adaptation process

Permission was sought from the scale authors (corresponding author K. Kortte) to adapt the measure for use in reablement services. Permission was granted. The main adaptation requirement was changing references in the items from rehabilitation to reablement. Adaptation of item 2 was more challenging. Verbal/physical prompts/directions are used in rehabilitation when cognitive/memory impairments or low mood affect a patient's engagement. In contrast, verbal/physical prompts are a core element of reablement; for example, providing instructions, or offering advice, about how to do a task; supporting mobility or a particular posture, and encouraging and building confidence through the spoken word. As a result, substantive changes to this item were required.

Two members of the research team (BB, AL-F) – both with prior experience of scale development and one also a qualified occupational therapist – examine the HRERS items and constructs. Each item was reviewed in turn as follows: does it need any adaptation with regards to its use in reablement services and in the UK. If an item identified as needing adaptation, then an adapted version was created through discussion.

This first draft of the adapted version was then re-considered on an individual basis by BB and A-LF and further adaptations agreed. This second complete draft was shared with the remainder of the research team and the study's Study Steering Committee. Further revisions were made in light of these comments. This yielded a first version of the Hopkins Rehabilitation Engagement Rating Scale - Reablement Version (HRERS-RV). In addition to the scale items, we inserted a separate, standalone questionnaire regarding changes in levels of engagement over time. This was included on the advice of the Study Steering Committee to allow scope for a wider exploration of the concept of engagement in relation to receiving reablement, see Box 3. These were then tested and evaluated using cognitive interviewing techniques.

Box 3: First version of HRERS-RV taken forward for cognitive interview

Reablement Engagement Scale

Please rate this client's participation in the reablement visits you made to their home. This rating is a summary of his/her participation during the entire course of your visits.

1. **When I made my visits, the person was ready for me.**

Never	Seldom	Some of the time	Most of the time	Nearly always	Always
❑	❑	❑	❑	❑	❑

2. **Learning or memory difficulties, or low mood, affected participation in reablement activities.**

Never	Seldom	Some of the time	Most of the time	Nearly always	Always
❑	❑	❑	❑	❑	❑

3. **The person expressed a positive attitude towards the reablement activities we worked on together.**

Never	Seldom	Some of the time	Most of the time	Nearly always	Always
❑	❑	❑	❑	❑	❑

4. **The person questioned their need to regain or improve their independence and/or ability to manage activities of daily living.**

Never	Seldom	Some of the time	Most of the time	Nearly always	Always
❑	❑	❑	❑	❑	❑

5. **The person actively participated in my reablement sessions/visits.**

Never	Seldom	Some of the time	Most of the time	Nearly always	Always
❑	❑	❑	❑	❑	❑

****

To what extent did the client's engagement with reablement change across the period of time you worked with them?

- ❑ Deteriorated
- ❑ Remained at around the same level throughout
- ❑ Fluctuated
- ❑ Improved

A 3.1.2. The cognitive interviews and further adaptations

Cognitive interviews[64] with reablement workers were used to evaluate their understanding or interpretation of the items and experiences of completing the questionnaire. Two approaches were used. First, the 'think aloud' technique, in which an individual verbalises their thoughts as they complete the draft questionnaire, was used to identify ambiguities or difficulties in the wording of items, instructions and/or the response format. Second, post-completion, respondents were asked about their experiences of completing the draft tools and suggestions regarding modifications to the layout and response format.

A 3.2. Methods

Cognitive interviews were undertaken with 10 reablement workers based in two services. All except one completed this process with respect to two service users: this allowed us to explore whether the statements and response options were distinct enough to show differences between service users. A staged process was used, with revisions being made to the HRERS-RV during the process. Thus, a set of interviews were conducted and findings shared and discussed within the research team and modifications agreed. It was then subject to further cognitive interviews and so on.

A 3.2.1. Issues raised during cognitive interview & revisions of the HRERS-RV

Three practitioners were presented with the first adaptation of HRERS-RV, see Box 3. They suggested inclusion of some additional statements:

- Does the client accept their need for reablement?
- Did the client have the potential (physically and cognitively) to be reabled?
- The degree to which the client's goals were met?

We were surprised by the first of these comments as this concept was already included in HRERS-RV (Item 4). However, their response indicated that the wording of this statement was unclear. As a result this item was re-worded. We did not regard the other two suggested questions as relevant to the concept of 'intervention engagement'. However, we decided to include two further supplementary questions captured these two concepts, but not to treat them as part of the HRERS-RV. They were as follows:

- Do you think that the client achieved their goals?
- Did the client make the progress you expected with achieving their goals?

A second version of the HRERS-RV was then taken forward for further cognitive interviews. Findings and resulting adaptations to each item are reported below.

Item 1: When I made my visits, the person was ready for me.

Five practitioners did not raise any issues about this item and interpreted it as we expected. However, the remaining five felt that this statement could be interpreted in several ways and they each gave at least two different interpretations. The range of interpretations are outlined below:

- That the client is prepared to start the reablement session – for example, chosen clothes to wear
- That the client is aware of when the practitioner is due to arrive
- That the client understands what reablement is about
- That the client is ready to accept the reablement process

In particular, they were concerned the item might be interpreted as asking if the person was out of bed, washed and dressed; however, these activities could well be reablement objectives. In response, we revised the wording to clarify the meaning.

Item 2: Learning or memory difficulties, or low mood, affected participation in reablement activities.

As with first statement, half of the respondents understood the statement and had no difficulty responding to it but half identified some challenges with the statement. Two people felt that the wording was unclear and that this resulted in the purpose of the statement being unclear. Three people hesitated when responding to this statement. When asked about this, these practitioners said that thought they understood the statement, but that summing up clients' fluctuating mood and memory/cognitive difficulties over a six-week period, into a single response option took time. In response, we reordered the clauses in the statement to make it easier to understand and, after further cognitive interviews,

revised the wording again. After these changes, practitioners taking part in the final phase of cognitive interviewing found it easier to complete this item.

Item 3: The person expressed a positive attitude towards the reablement activities we worked on together

All of the participants understood this item and were clear about how to choose appropriate response options.

Item 4: The person questioned their need to regain or improve their independence and/or ability to manage activities of daily living

In the early phase of cognitive interviewing, three people found the wording of this item too long and were unclear of its meaning. In response, we simplified the item. Once this change had been made, no practitioners appeared to have, nor reported, difficulties with this statement.

Item 5: The person actively participated in my reablement sessions/visits.

All of the participants understood this item and were clear about how to choose appropriate response options.

Supplementary question 1: To what extent did the client's engagement with reablement change across the period of time you worked with them?

All but one of the practitioners understood what this question was asking but one thought it was about the clients' confidence. To minimise the risk of other practitioners misinterpreting the focus of the statement, we simplified it.

Supplementary question 2: Do you think that the client achieved their goals?
Supplementary question 3: Did the client make the progress you expected with achieving their goals?

Practitioners had no difficulties with understanding and interpreting these questions.

Response format

Some practitioners did not know what 'seldom' meant. We discussed its meaning and practitioners suggested 'seldom' was replaced with 'rarely'. This change was implemented.

Layout

Practitioners preferred the response option statements placed below the related tick figures. The scale was formatted accordingly. Overall, however, practitioners thought that the format was clear.

Instructions for completion

Some of the practitioners felt that the instructions could be written more clearly. Based on their comments, we identified key changes that could improve understanding and adapted the instructions accordingly.

Ability to distinguish between service users

Among those practitioners who completed the HRERS-RV with respect to two service users, there was good evidence that the scale was distinguishing between service users.

A 3.2.2. The final version of the (HRERS)-Reablement Version

The final version of the Rehabilitation Engagement Rating Scale (HRERS)-Reablement Version (HRERS-RV) administered as part of data collection for the outcomes evaluation (Work package 2) is set out in Box 4. Supplementary questions are presented in Box 5. The HRERS-RV was completed with respect to 126 study participants across two of our research sites. Psychometric evaluation of the scale was conducted using the data collected; this decided whether or not we would use the measure within our analyses. We present the findings of our psychometric evaluation in the following section.

Box 4: Hopkins Rehabilitation Engagement Rating Scale – Reablement Version

Hopkins Rehabilitation Engagement Rating Scale – Reablement Version (HRERS-RV)

Name of client: ……..

For each statement, please report your experience of working with this client over the entire course of your visit by ticking the relevant Figure (☑).

When I made my visits, the person was ready to start their reablement session.

❑	❑	❑	❑	❑	❑
Never	Rarely	Some of the time	Most of the time	Nearly always	Always

The person's ability to take part in the reablement sessions/visits was affected by memory difficulties and/or low mood.

❑	❑	❑	❑	❑	❑
Never	Rarely	Some of the time	Most of the time	Nearly always	Always

The person expressed a positive attitude towards the reablement activities we worked on together.

❑	❑	❑	❑	❑	❑
Never	Rarely	Some of the time	Most of the time	Nearly always	Always

The client accepted that they needed to be reabled.

❑	❑	❑	❑	❑	❑
Never	Rarely	Some of the time	Most of the time	Nearly always	Always

The person actively participated in my reablement sessions/visits.

❑	❑	❑	❑	❑	❑
Never	Rarely	Some of the time	Most of the time	Nearly always	Always

Box 5: Supplementary questions administered with the HRERS-RV

Did the client's level of engagement with reablement change across the period of time you worked with them?

❑ Reduced ❑ Remained the same ❑ Varied ❑ Increased

Do you think that the client achieved their goals?

❑ All goals achieved ❑ Some goals achieved ❑ No goals achieved

Did the client make the progress you expected with achieving their goals?

❑ Much less than expected ❑ Less than expected ❑ As expected ❑ More than expected ❑ Much more than expected

A 3.3. Testing the psychometric properties of HRERS-RV

A 3.3.1. Analytical methods

We examined the distributions of scores on each of the five items and that of the total score. Construct validity was tested using factor analysis using the principal-factor method. The principal-factor method uses the estimates of shared variance in the initial correlation matrix to calculate the communality and uniqueness value for each variable. Communality is the amount of variance that a variable has in common with all the other variables in the correlation matrix. Uniqueness is the amount of variance that is unique to the individual variable, hence it is variance that is not captured by the factor. This approach was used

because we wanted to estimate the degree of covariance across the five dimensions.[65] Scale reliability was measured using Cronbach α. Finally, given that the degree to which an individual engages with an intervention is thought to impact on intervention outcomes, we assessed predictive validity by testing the association between HRERS-RV summary score and scores on outcome measures at T1: EQ-5D-5L summary score, Barthel summary score and the ASCOT index score.

A 3.3.2. Total scores and distribution of scores across items

A total score was calculated by summing up the scores on each of the five items (maximum range 0-30). A higher score represents greater engagement with the intervention. Figure 26 presents HRERS-RV total scores for the sample. The distribution is skewed to the left, demonstrating a ceiling effect. The majority of the participants (<74%) scored highly on the instrument (total score=25 or over).

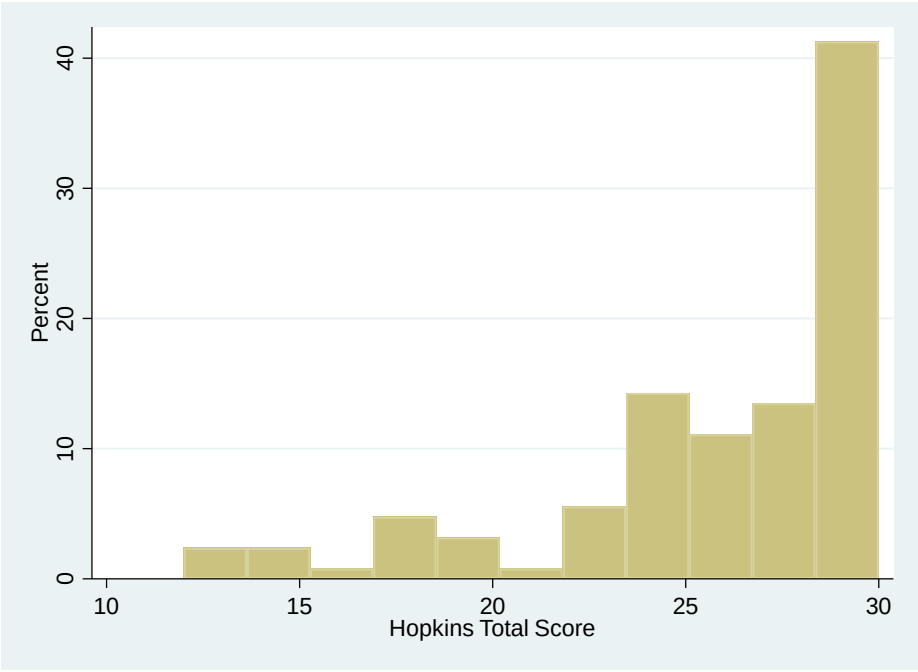

Figure 4: HRERS-RV: distribution of total scores

Looking at scores on an item by item basis, there was a pattern of high scores across all the dimensions regarded as contributing to the construct of engagement (Figure 5).

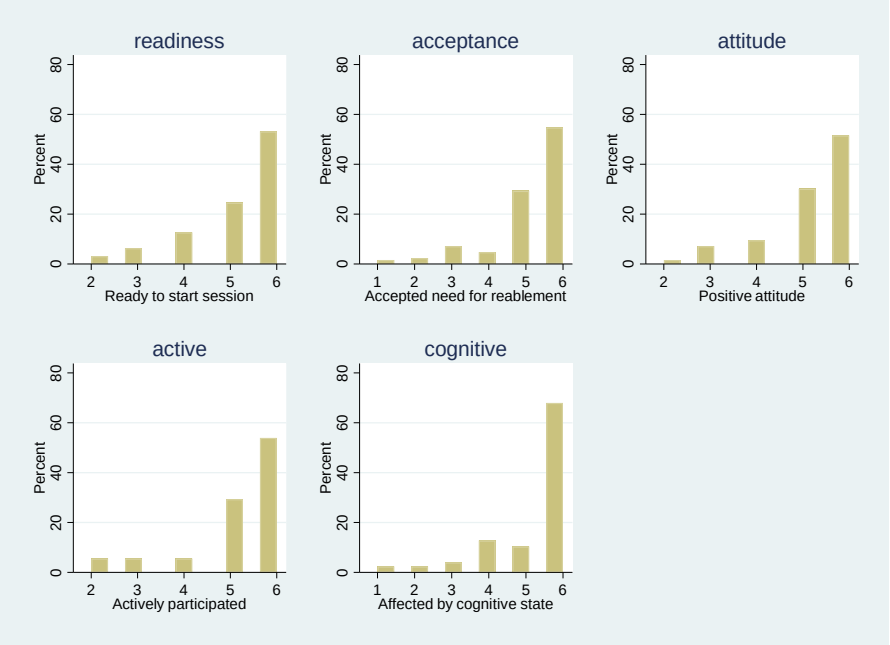

Figure 5: Distribution of responses across the five dimensions of the HRERS-RV

A 3.3.3. Construct validity

Factor analysis was performed to establish the construct validity of the HRERS-RV. An initial correlation matrix across the HRERS-reablement variables confirmed that there was significant amount of correlation between the five dimensions (Table 34).

Table 34: Correlation matrix across HRERS-RV

	readiness	attitude	acceptance	active	cognitive
readiness	1.0000				
attitude	0.7973*	1.0000			
acceptance	0.7022*	0.8098*	1.0000		
active	0.7961*	0.8988*	0.7104*	1.0000	

Bartlett's test showed that the correlations between the five components were overall significantly different from zero (p<0.001, N=126). The determinant (det) of the correlation matrix[1] indicated that there was no extreme multicollinearity across the variables, whilst they were not completely unrelated either (det=0.018). Iterated principal-factor method was conducted using orthogonal varimax rotation. The Kaiser-Meyer-Olkin Measure verified the sampling adequacy for the analysis (KMO=0.82).

There was only one factor with an eigenvalue over 1 (eigenvalue=3.38, after rotation=2.89), explaining over 80% of the total variance. The (rotated) factor loadings ranged from 0.36 to 0.94. The scree plot (Figure 6) showed a clear inflexion after the first factor, justifying keeping one single factor in the analysis.

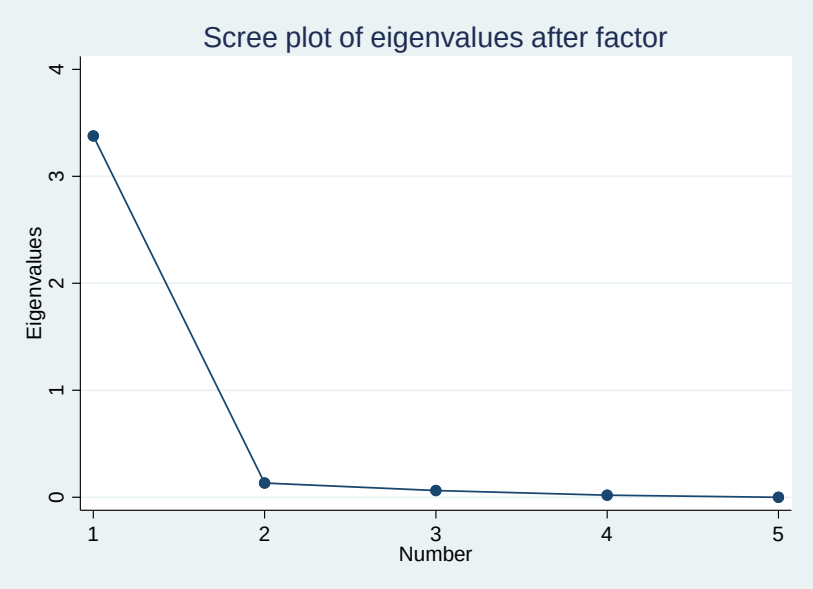

Figure 6: Scree plot – HRERS-RV

Table 35 shows the factor loadings for all 5 dimensions. Factor loadings show the degree to which a dimension is correlated to the underlying factor: 'engagement with reablement practice'. Positive attitude and active participation in reablement have the highest factor loadings. Cognitive ability to take part in reablement has a factor loading of 0.36 which is below the threshold of 0.4 of significance.[66, 67] Communalities represent the amount of

[1] The determinant (det) of the correlation matrix is a measure of collinearity. In case of perfect correlation (singularity), the determinant is 0, and if all variables are completely unrelated, the determinant is 1. In order to be able to perform factor analysis, the determinant of the correlation matrix needs to be greater than 0.00001.

variance in each variable that can be explained by the factor, whilst uniqueness shows the amount of variance that is not shared with other variables.

Table 35: HRERS-RV: factor analysis output

HRERS- reablement dimension	Rotated factor loading	Uniqueness	Communality
Ready to start session	0.76*	0.25	0.75
Cognitive ability to take part	0.36	0.81	0.18
Positive attitude	0.92*	0.03	0.98
Acceptance for the need for reablement	0.67*	0.25	0.75
Active participation in reablement	0.94*	0.07	0.93

*loadings above 0.4 are considered significant.

A 3.3.4. Reliability

We performed a Cronbach's Alpha reliability test which indicated that this uni-dimensional scale had a high reliability α=0.89 (95%CI: 0.85-0.93).

A 3.3.5. Predictive validity

Finally, we explored associations between the HRERS-RV total score and the main outcome measures at Time 1: the EQ-5D summary score, Barthel summary score and the ASCOT index score (see Figure 7).

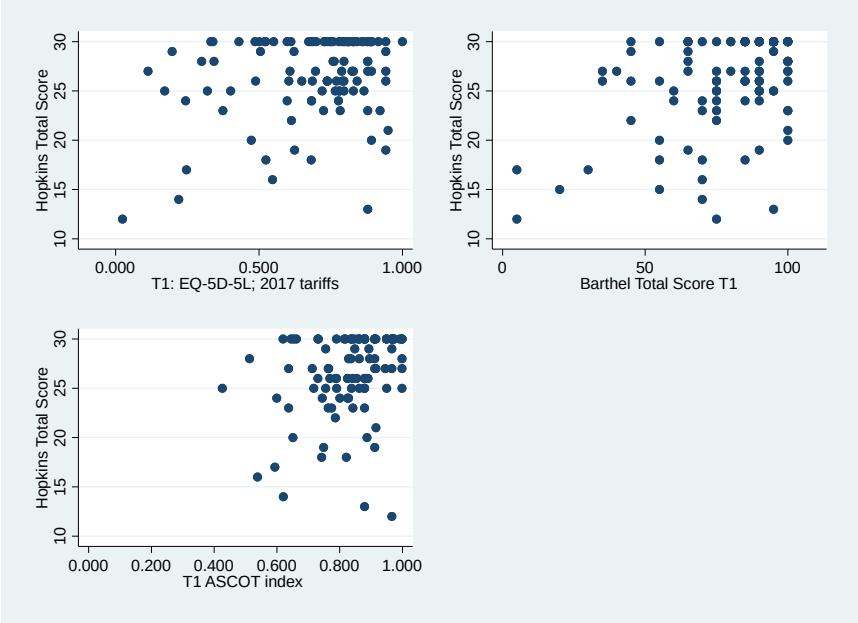

Figure 7: Associations between HRERS-RV score and main study outcomes

HRERS-RV correlated weakly with the EQ-5D score (r=0.263, p<0.01) and the ASCOT score (r=0.306, p<0.01). It correlated more strongly with the Barthel measure of functional status (r=0.454, p<0.001).

A 3.4. Conclusions

The findings from our psychometric evaluation of the HRERS-RV raise some concerns but are, overall, positive. The relatively small sample size means any interpretation should be cautious.

We would note the ceiling effect and question whether revisions to the response format may address this. Adding further items would mean a departure from the conceptual basis of this scale and its 'parent version' (HRERS). The tests of construct validity yielded good results, though we query whether Item 2 should be retained or re-worded. This was the most problematic item to adapt in terms of retaining a conceptual meaning true to the 'parent version'. Finally, tests of predictive validity were in the direction expected, with strongest associations with functional ability outcomes at discharge from reablement.

On the basis of these result we included the HRERS-RV within our suite of predictor variables. We refer the reader to Chapter 5 which reports that engagement in

reablement, as measured by HRERS-RV, was found to be a significant predictor of health and functional outcomes. This supports the argument for including a measure of intervention engagement when evaluating reablement.

Further work to test, and perhaps further refine, the HRERS-RV would appear to be worthwhile and important.

Appendix 4. WP2a: Development of the Experience of Reablement Practice Checklist

The purpose of creating the Experience of Reablement Practice Checklist was to allow us to assess, using a simple, user-completed tool, the extent to which reablement practitioners adhered to a reablement approach. That is, an intervention which seeks the re-gaining, or restoration, of daily living skills. This contrasts sharply with the traditional homecare approach in which care is 'done' to the recipient. No equivalent measure already existed. The components of reablement practice which we sought capture in this checklist were as follows:

- the service user understands the objective of reablement;
- the service user understands the intervention is working towards specific goals;
- the service user believes they were involved in setting those goals;
- the reablement worker motivates the service user to work towards achieving those goals;
- during the intervention, the service user and reablement worker/assessor review progress towards those goals.

The intention was that the checklist would be administered at discharge from the service.

A 4.1. Development of the experience of Reablement Practice Checklist

Two members of the research team (BB, A-LF) – both with experience of questionnaire development and one also a senior occupational therapist with experience of delivering reablement – met to discuss and develop a set of five items which described the core components of the reablement approach. Each item was presented as a statement, with the respondent asked to report whether or not they agreed with a statement by answering 'yes' or 'no'. After meeting, the items were then reviewed individually by the two researchers after which a first full draft of the Experience of Reablement Checklist was agreed. This was then shared with the wider research team for comment. No further revisions were made at that stage. The draft version (see Box 6) was then taken forward for testing via cognitive

interview with 10 respondents, all of whom had recently used a reablement service, who were taking part in a wider pilot of the study's research instruments.

Box 6: Draft version of Experience of Reablement Practice Checklist.

The Experience of Reablement Practice

This questionnaire is about the visits you have had from a worker(s) from the reablement service. We would like to know about your **overall experience** of these visits.

Use the rating scale to show how much you agree or disagree with each statement:

The worker(s) helped me understand that the reablement service helps people to become as independent as possible in doing daily living tasks *(eg. cooking, bathing, going to the toilet, moving about my home etc..)* **and/or getting out and about.**	Strongly agree ❑	Agree ❑	Disagree ❑	Strongly disagree ❑
The worker and I decided together how I was going to work towards becoming more independent in doing daily living tasks and/or getting out and about.	Strongly agree ❑	Agree ❑	Disagree ❑	Strongly disagree ❑
Visits from the worker motivated me to try to become more independent in managing daily living tasks and/or getting out and about.	Strongly agree ❑	Agree ❑	Disagree ❑	Strongly disagree ❑
The worker helped me to work towards doing daily living tasks by myself rather than doing them for me.	Strongly agree ❑	Agree ❑	Disagree ❑	Strongly disagree ❑
Every now and again the worker and I checked back over how I was	Strongly agree	Agree	Disagree	Strongly disagree

Cognitive interviews with two respondents prompted some early revisions to the draft checklist. First, it was clear that they were struggling to know how to respond to the items which, at that stage, were presented as statements. They were heard re-constructing the statements into questions. It was also clear that they were not sure which 'workers' the checklist was referring to. It was also suggested that instructions about completion should be more detailed. Finally, in terms of layout, it was suggested that the checklist should be presented in portrait, rather than landscape orientation, with response options underneath.

Aside from retaining the items as statements, changes to the checklist were made in response to these observations and suggestions. Five further cognitive interviews indicated we should re-word the items into questions. We made this amendment and administered it, with a cognitive interview, to a further three respondents. We concluded from these cognitive interviews that respondents found it easy to complete. They had no suggestions about further improvements to the checklist. This version therefore became the final version of the Experience of Reablement Practice Checklist (ERPC), see Box 7 overleaf.

Box 7: The Experience of Reablement Practice Checklist: final version

Experience of Reablement Questionnaire

We would like to know about your **overall experience** of the visits you have had from your reablement worker(s). Please read each question and **tick the appropriate box (☑)**.

1. Did you understand that the reablement sessions were aiming to help you become as independent as possible?

Yes ❑ No ❑

2. During your reablement, did you know you had specific goals that you were working towards?

Yes ❑ No ❑

3. Were you involved in setting the goals to help you become as independent as possible?

Yes ❑ No ❑

4. Did the reablement workers motivate you to work towards being as independent as possible?

Yes ❑ No ❑

5. Every now and again, did the reablement workers review your progress with you?

Yes ❑ No ❑

6. Did you look forward to your reablement worker's visits?

Yes ❑ No ❑

A 4.2. Psychometric properties

A 4.2.1. Methods

We ran descriptive statistics to summarise respondents' experience of reablement across sites and across the sample as a whole. We explored the internal structure of the checklist by looking at response patterns across all five questions. We conducted exploratory factor analysis to determine whether the ERPC measured a single underlying construct. We performed chi-square tests to explore associations between partial/complete adherence to the reablement approach and the site and type of service provision.

A 4.2.2. Results

Descriptives

Table 36 summarises the descriptive statistics for the five items comprising ERPC. The majority of respondents were aware of the overall purpose of reablement (92-100% across sites). There are slight variations across sites regarding participants being aware of having specific goals (71% (B) to 82% (C)) and being involved in goal setting (ranging from 63% (A) to 80% (C)). There are relatively lower percentages of people who reported to be motivated to be independent in Sites B (57%) and A (79%), compared to Site C (93%). Chi-square and the Fisher's exact test statistics results suggest that this difference is mildly significant, ($\chi_{(2)}$=14.51, p=0.001, Fisher's exact=0.001). Significantly smaller proportions of participants report that they received feedback on progress in Sites A (57%) and B (71%) compared to Site C (96%); ($\chi_{(2)}$=33.456, p<0.001, Fisher's exact<0.001). One must interpret these results with caution because of low sample sizes, especially in Site B.

Table 36: ERPC: Numbers answering 'yes' / component

ERPC Item	Site A N=19 (%)	Site B N=14 (%)	Site C N=95 (%)	Total N=128
Overall purpose	17 (98.47)	14 (100)	88 (92.63)	119 (92.97)
specific goals	14 (73.69)	10 (71.43)	78 (82.11)	102 (79.69)
own goal setting	12 (63.16)	9 (64.29)	76 (80.00)	97 (75.78)
motivation	16 (78.95)	8 (57.14)	88 (92.63)	111 (86.72)
feedback	9 (47.37)	10 (71.43)	91 (95.79)	110 (85.94)

Answer patterns across the five components of reablement practice

We explored the internal structure of the ERPC by looking at the frequency of specific types of response patterns across the sample (see Table 37), where all the 'yes' answers were coded as 1 and all the 'no' answers coded as 0 for each element of the reablement experience. The answer patterns of those reporting incomplete adherence to reablement practice, seem to be evenly distributed across the sample; there is/are no item(s) of which were consistently under, or not, reported. The most commonly occurring pattern (n=8/129, 6.2%) is a negative response to the items 'being aware of specific goals' and 'involved in all goal setting', whilst affirming the remainder aspects of reablement practice. Because of the low cell numbers, it is hard to draw any conclusions from this finding. In addition, it was not possible to explore associations between patterns of response and sites because of the low sample sizes.

Table 37: Response patterns to items comprising ERPC

pattern	Freq.	Percent	Cum.
missing	1	0.78	0.78
00000	2	1.55	2.33
00001	2	1.55	3.88
00011	2	1.55	5.43
00110	1	0.78	6.20
01010	1	0.78	6.98
01111	1	0.78	7.75
10000	4	3.10	10.85
10001	2	1.55	12.40
10010	3	2.33	14.73
10011	8	6.20	20.93
10111	2	1.55	22.48
11001	1	0.78	23.26
11010	2	1.55	24.81
11011	4	3.10	27.91
11100	2	1.55	29.46
11101	4	3.10	32.56
11110	3	2.33	34.88

A 4.2.3. Factor Analysis

The dichotomous nature of the response option meant that a polychoric correlation matrix was used to explore associations across the items comprising the checklist. We found significant associations across all five components. Effect sizes were largest between the components: 'aware of the overall purpose of reablement' and 'involved in setting goals' (r=0.943, p<0.001, CI: 1.09, 0.878); and between 'aware of the overall purpose' and 'having specific goals to work towards' (0.726, p<0.001, CI: 0.975, 0.477). Exploratory factor analysis found one underlying factor with an eigenvalue of 2.549 (after orthogonal varimax rotation), explaining over 75% of the variance across the five components. The variables with the highest loadings on the factor are being aware of overall purpose (0.92) and being involved in own goal setting (0.89) (Table 38).

Table 38: ERPC: results of factor analysis (n=128)

Experience of reablement component	Rotated factor loading	Uniqueness	Communality
overall purpose	0.65	0.45	0.55
specific goals	0.92	0.06	0.94
own goal setting	0.89	0.08	0.92
motivation	0.49	0.44	0.56
feedback	0.48	0.41	0.59

Note: Factor loadings over 0.4 are considered significant.

A scree plot and factor loadings matrix (see Figure 8 and 9) suggest that there is an additional underlying factor, although weaker, and with an eigenvalue less than 1.

'Being motivated to be independent' and 'receiving feedback' load slightly higher on this second factor (0.56 and 0.59 respectively). On the basis of this exploratory analysis we can conclude that there seems to be a dominant factor explaining most of the variance across five checklist items and this seems to represent the "practical" aspects of reablement: 'being aware of the overall purpose', 'setting specific goals' and 'involvement in goal setting'. There is a secondary factor representing the "psychological" component of reablement: encouraging independence by motivating the client and providing feedback on progress. However, these hypotheses need further testing with a larger sample.

For the purpose of this study, therefore, we chose to use the ERPC as a categorical variable, taking two values: (1) ‘complete intervention adherence’ or (0) ‘partial intervention adherence’.

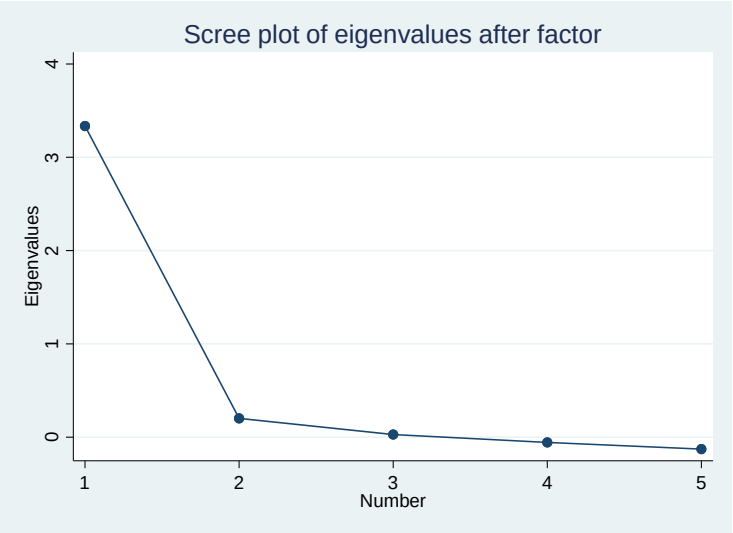

Figure 8: EPRC factor analysis: scree plot

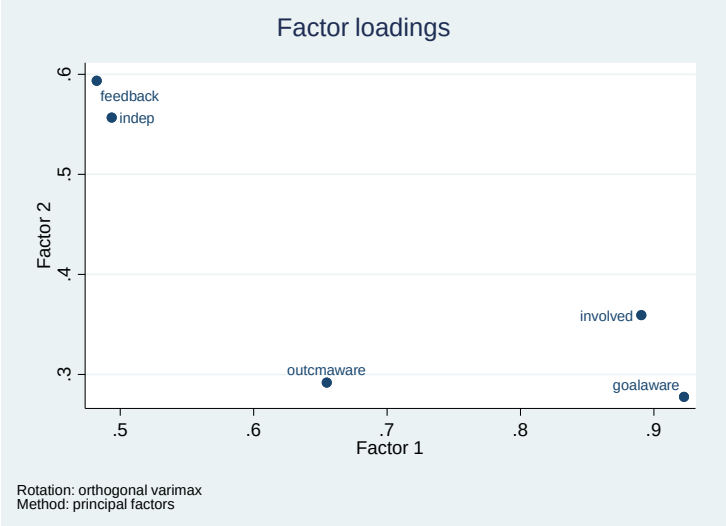

Figure 9: ERPC factor analysis: factor loadings plot

A 4.2.4. Associations between EPRC scores & service characteristics & user outcomes

Based on existing evidence about the delivery of reablement, we hypothesised that EPRC scores would be associated with service characteristics, particularly whether reablement workers were based in 'in-house' teams within the local authority, or working for an out-sourced provider.

A slightly higher percentage of those receiving reablement from a single-team provider report 'complete' reablement experience (N=58, 73.42%) than those who received reablement from a mixed-team (N=25, 52.08%). Because of the skewness of the data and limited sample size, it is hard to establish whether this difference is significant ($\chi_{(1)}$=6.00, p=0.014). These tentative results suggest that better outcomes may be expected from in-house providers, compared to out-sourced providers.

A 4.3. Conclusions

We attempted to create a simple checklist, completed by service users at discharge from reablement, which would capture the extent to which the intervention they had received adhered to the ethos and approach of reablement. In other words, a user-report measure of intervention adherence. Our testing of the checklist's psychometric properties suggests that additional items and/or revisions to the response format should be considered and tested. Specifically, based on ERPC scores, two thirds of study participants received reablement which adhered to the five components of reablement practice represented in the checklist. In addition, it should be considered whether further items should be created and tested which further distinguish the so-called "practical" and "psychological" aspects of reablement detected in our analyses.

However, for this purposes of this study, we were comfortable taking the Experience of Reablement Practice Checklist forward as a predicator in our outcomes evaluation, using not a score but treating the score as a categorical variable: complete vs partial adherence.

Appendix 5.
Appendix 5. WP2a: Doing research in Local Authorities: experiences and implications

A 5.1. Introduction

The commissioners of this research (NIHR HS&DR Programme) requested that the research team record its experiences of delivering the study, and reflect on implications for future research. This appendix reports this and consider the following in turn:

- research readiness and Local Authorities
- working in a fluid service landscape
- the involvement of private providers in research
- ambiguity regarding eligibility of NIHR Clinical Research Network support

A 5.2. Research readiness and Local Authorities

A 5.2.1. The capacity of services to engage with the study

Four services were recruited as research sites. Securing the participation of these services involved approaching a total of twenty-seven services. Often some initial discussions were held and, for a few, discussions had reached an advance stage when the service withdrew. A lack of capacity was one of the reasons for declining participation. This was presented in two ways:

- a lack of capacity within the service to accommodate the research within usual their processes; specifically, assessment staff having an initial conversation with new referrals about the study and seeking 'consent to contact';
- a lack of capacity in managers and senior management to oversee the research set-up process.

A 5.2.2. Barriers to setting up the study in the research sites

In each research site, a significant period of time elapsed between informal confirmation of participation in the study and recruitment opening. Table 39 details this, and the timings allocated in the original project timetable.

Table 39: Duration of phases of site recruitment and study set-up

	Months elapsed approaching other services*	Initial contact with site to informal confirmation (months)	Informal confirmation to contract signed (months)	Contract signed to recruitment opening (months)	Total (months)
Site A	3	4	2	2	11
Site B	4	4	2	2	12
Site C	0	3	4	3	10
Site D	1	2	8	5	16
Timings as per project timetable	4			2	6

* *Potential research sites were approached in a staged process, starting with those which best represented the service model and so on.*

The delays encountered illustrate key issues in terms of the research capacity and research infrastructure within local authorities. This, in turn, reflects the extent to which research is regarded as a core activity of an organization and, as a result, the priority given to it.

A separate example of a lack of 'research readiness' within local authorities was the withdrawal of a potential research site because they were unable to identify staff to second to the local study team posts. At that stage, they had to withdraw their involvement in the study as only people employed by the LA were allowed to work in or out of their premises. Whilst this is also a requirement for the NHS, the system of research passports addresses this.

Thus, a lack of capacity within the services (and organizational settings) recruited to the study affected the pace and progress of study set-up in terms of decision-making about the specifics of implementing study processes within the service. Service managers' time and capacity to chase study set-up issues being dealt with at a higher level in the local authority was highly constrained. Whilst very keen to be involved in the study, participating in or supporting research was not a specific role within their job descriptions. Similarly, dealings with more senior managers indicated a lack of existing processes, role and responsibilities with regard to taking part in externally funded research. Research governance processes

were highly variable and some of the issues raised suggested a certain degree of research naivety. The process of drawing up a research contract with a university was a new situation for all the sites.

A 5.2.3. Commentary

Prior to this study, the research team had extensive collective experience of carrying out research in non-NHS settings and were aware of the challenges. Some of the difficulties encountered were not unfamiliar. However, the scale and complexity of the project and the requirements it placed on LA's revealed the extent of the limitations of their research readiness. This can be observed at strategic and operational levels as follows:

- a lack of an existing research infrastructure in terms of policies and procedures, and defined roles and responsibilities.
- there was a lack of capacity among senior staff to engage with and work on setting up and implementing a complex study within their organization;
- supporting or taking part in research was not with service leads and managers' job descriptions and therefore they could not prioritise planning for and implementing the study;
- the recruitment process necessarily required service staff have capacity to seek 'consent to contact';
- no pre-existing systems and practices were in place to facilitate arrangements regarding the Local Study Teams being located within an organisation's premises in order to fulfill recruitment and data collection duties;

A 5.3. Working in a fluid service landscape

This study commenced just after one of the most significant reforms in social care policy in recent times. As described in Chapter 1, this stimulated changes in the approach to managing individuals referred to adult social care who potentially may need long-term packages or care – at home or in a residential settting. Specifically, a parallel process of assessment and reablement was advocated. Furthermore, reablement was clearly positioned as part of a locality's intermediate care provision, with the expectation of an integrated approach to delivery. The NICE 2017 'Intermediate care and reablement' guidance reiterated and fleshed out policy guidance associated with the Care Act and also

the move within the NHS to a model of 'discharge to assess'. As a result, the service landscape at the time the study was seeking to recruit research sites was quite fluid. This impacted on the study in two ways.

First, services keen and interested to take part were not able to because they anticipated a period of service reorganization.

Second, the work carried out as part of the Workpackge 1 survey which assign each reablement service to a particular type of service model was not necessarily accurate – either at the time of approaching services to take part in the evaluation (Work package 2), or by the time recruitment began. This, indeed was our experience.

A 5.3.1. Commentary

Generally speaking, within health services and care research it is important for researchers to have strategies in place with respect to responding to changes in the services they are investigating, and to incorporate this eventuality into the study design. Our experiences also point to the importance of having a clear understanding of the services in terms of their specific characteristics and ways of working, and particularly those thought to impact on service delivery and/or outcomes.

In terms of this study, we were careful to ensure we were kept up-to-date with any changes or developments in services during study set up and once recruitment was open. Good relationships with service leads in our research sites and the presence of local study staff proved useful in this regard. However, a naivety on the part of service staff in terms of the implications of service re-design for the research meant such changes were not sufficiently communicated. However, the scope of the process evaluation included an exploration of any changes and a close examination of the features, or characteristics, of the service. In addition, the proposed design – in which service models would be compared and also, through a within-group analysis, the impact of service characteristics on outcomes investigated – accommodated the fact that service models may not be as enduring or distinct as is conceived at the stage of designing the study.

Our experience also reiterates the importance of research teams being aware of the wider policy landscape in which their research is situated. In the case of this project, these changes – whilst substantially affecting one of our research sites – have reiterated the core role of reablement within intermediate care, thus re-confirming the importance and timeliness of this commissioned study.

A 5.4. Participation of private providers in the study

All sites outsourced at least some of their reablement provision to private providers. In two sites we encountered difficulties securing their involvement in the research. As a result, in one site we were not able to collect, at discharge from reablement, reablement workers' reports of user engagement in the intervention. In a second site, only two of the five private providers agreed that the study could recruit individuals using their service. In all instances, non-involvement was attributed to the fact that involvement in research was not specified in the contract the provider had with the local authority. We would note this issue was also encountered at the survey stage (Work package 1) some private providers declining to participate.

In addition, whilst not directly impacting on the study, it also useful to report that changes in private providers was observed during study set-up and recruitment – both in terms of providers losing or choosing to close contracts and/or new providers being commissioned.

A 5.4.1. Commentary

We encountered mixed attitudes to participating in research from private providers. Certainly, and not surprisingly, participating in or supporting research was not part of the commissioning arrangements. As a result, private providers were not obliged to co-operate. This is an issue which may need to be considered when designing research and is also something which, potentially, needs to be considered as part of service commissioning arrangements.

A 5.4.2. Eligibility of NIHR Clinical Research Network support

Finally, the study applied to be adopted by NIHR's Clinical Research Network Portfolio but this was not successful. The reason was none of the research sites were NHS services, rather they were local authorities or a social enterprise funded by a Clinical Commissioning Group (CCG) and Local Authority (LA).

Access to Clinical Research Network (CRN) support may have eased some study set-up issues and, when the challenges with recruitment reported above began to emerge, may have also offered the potential of alternative recruitment pathways, certainly for individuals being discharged home and those referred to reablement by GPs or other NHS services.

A 5.4.3. Commentary

We have not been in a position to check if this decision, and the rationale behind it, would be the same today. If that were the case, it indicates that current NHS research support structures need to consider their 'reach' into social care. Furthermore, should investment be made in research infrastructure within local authorities, it is important that any structures or resources do not, in themselves, create new barriers to research into integrated care and services and/or the care of, or services being used by, NHS patients.

A 5.5. Concluding comments

Integration, or joint-working, between health and social care is regarded as an essential core feature of ensuring older and disabled people live healthy lives and are as independent as possible. This means that research on these populations has, and will continue to, cut across the two sectors. This will, perhaps increasingly, require the active involvement of Local Authorities in what might be regarded as health services research. The experiences of this study, and also reported by others, point to substantive differences in research awareness, capacity and infrastructure within local authorities compared to the NHS. This has significant implications in terms of the efficiency of research and the ability to deliver, in a robust way, large and complex projects. It is for these reasons that the research team was encouraged by the funder to provide an account and commentary of the issues and challenges encountered in this study. The purpose of preparing this account is to support an

awareness among the health and social care research community and research funders of the issues which may be encountered when engaging in social care research. It also raises the question of whether strategic investment in research capacity and infrastructure within local authorities, as has been seen in the NHS, is required.

Appendix 6. WP2a: Sample Characteristics: T0, T1 & T2

Table 40: Descriptives – categorical variables: T0, T1, T2 (total samples)

Variable		T0	T1	T2
N		186 (100)	129 (100)	64 (100)
Individual Characteristics				
Gender (ref: Female)	Male	67 (36.02)	41 (31.78)	20 (31.25)
Living alone (ref: No)	Yes	107 (57.53)	78 (60.47)	37 (57.81)
Sufficient money (ref: No)	Yes	149 (82.78)	104 (83.20)	48 (81.36)
Referral reason (ref: Return to home)	Remain at home	111 (59.68)	76 (58.91)	42 (65.63)
Help from friends and family (ref: No)	Yes	164 (89.13)	116 (89.92)	57 (89.06)
Number of comorbidities	None	67 (36.02)	46 (35.66)	28 (43.75)
	1	79 (42.47)	56 (43.41)	25 (39.06)
	2 or more	40 (21.51)	27 (20.93)	11 (17.19)
Service/intervention characteristics				
Provider type (ref: in-house)	Outsourced	67 (36.22)	39 (30.47)	30 (47.62)
Practitioners' adherence (ref: partial) At T1	Complete	-	84 (65.63)	-
Single Team Model (ref: mixed team)	Single Team	110 (59.46)	80 (62.50)	29 (46.03)

Table 41: Descriptives – continuous variables: T0, T1, T2 (total samples)

	Time	N	mean	SD	median	min	max
Individual Characteristics							
Age (years)							
	T0	186	80.849	9.127	82	51	102
	T1	129	80.822	9.200	82	51	102
	T2	64	81.047	8.806	83	51	98
NEADL (T0)							
	T0	184	9.652	5.480	8.5	0	22
	T1	129	9.651	5.633	8	0	22
	T2	64	11.578	6.312	11	0	22
GHQ-12 (T0)							
	T0	185	4.135	2.849	4	0	12
	T1	129	3.930	2.878	3	0	12
	T2	64	3.844	2.835	3	0	12
HRERS-RV							
	T1	126	26.103	4.59	27	12	30
Intervention Characteristics							
Reablement duration (weeks)							
	T1	175	3.889	1.596	4	0.571	6.429

Table 42: Descriptives – categorical variables: T0, T1, T2 (by site)

		Site A			Site B			Site C		
Variable		**T0**	**T1**	**T2**	**T0**	**T1**	**T2**	**T0**	**T1**	**T2**
N		33	19	14	14	14	9	139	96	41
Individual Characteristics										
Gender (ref: Female)	Male	10 (30.3)	5 (26.32)	3 (21.43)	2 (14.29)	2 (14.29)	1 (11.11)	55 (39.57)	34 (35.42)	16 (39.02)
Living alone (ref: No)	Yes	17 (51.52)	7 (36.84)	7 (50.00)	7 (50)	7 (50)	3 (33.33)	83 (59.71)	64 (66.67)	27 (65.85)
Sufficient money (ref: No)	Yes	28 (87.5)	17 (89.47)	11 (84.62)	9 (81.82)	9 (81.82)	6 (85.71)	112 (81.75)	78 (82.11)	31 (79.49)
Referral reason (ref: Return to home)	Remain at home	21 (63.64)	14 (73.68)	2 (14.29)	5 (35.71)	5 (35.71)	5 (55.56)	85 (61.15)	57 (59.38)	15 (36.59)
Help from friends and family (ref: No)	Yes	22 (70.97)	15 (78.95)	12 (85.71)	13 (92.86)	13 (92.86)	9 (100)	129 (92.81)	88 (91.67)	36 (87.80)
Number of comorbidities	None	19 (57.58)	10 (52.63)	9 (64.29)	8 (57.14)	8 (57.14)	4 (44.44)	40 (28.78)	28 (29.17)	15 (36.59)
	1	8 (24.24)	5 (26.32)	2 (14.29)	4 (28.57)	4 (28.57)	3 (33.33)	67 (48.2)	47 (48.96)	20 (48.78)
	2 or more	6 (18.18)	4 (21.05)	3 (21.43)	2 (14.29)	2 (14.29)	2 (22.22)	32 (23.02)	21 (21.88)	6 (14.63)
Service/intervention characteristics										
Provider type (ref: in-house)	Outsourced	32 (100)	18 (100)	13 (100)	14 (100)	14 (100)	9 (100)	35 (25.18)	21 (21.88)	17 (41.46)

Practitioners' adherence (ref: partial) (T1)	Complete	-	9 (47.37)	6 (54.55)	-	6 (42.86)	5 (55.56)	-	69 (72.63)	23 (71.88)
Single Team Model (T1) (ref: mixed team)	Single Team	0	0	0	0	0	0	110 (79.14)	80 (83.33)	29 (70.73)

Table 43: Descriptives – continuous variables: T0, T1, T2 (by site)

		N			mean			SD			median			min			max		
	Site	T0	T1	T2	T0	T1	T2	T0	T1	T2	T0	T1	T2	T0	T1	T2	T0	T1	T2
Individual characteristics																			
Age (years)																			
	A	33	19	14	77.3	76	76.2	9.1	10	9.9	75	75	75	51	51	51	89	89	89
	B	14	14	9	83	83	81.7	8.3	8.3	6.63	83.5	83.5	83	70	70	72	95	95	92
	C	139	96	41	81.5	81.5	82.6	9.1	9.1	8.4	82	82	84	52	52	62	102	102	98
NEADL T0																			
	A	31	19	14	10.9	9.9	9.9	5.8	4.1	4.7	11	8	9	1	1	2	22	22	18
	B	14	14	9	7.6	7.6	9	3.4	3.4	3.2	8	8	10	3	3	3	13	13	13
	C	139	96	41	9.6	9.9	12	5.5	5.7	6.5	8	8.5	12	0	0	0	22	22	22
GHQ-12 T0																			
	A	32	19	14	4.8	5.4	4.5	3.5	3.7	3.7	4	5	3.5	0	0	0	12	12	12
	B	14	14	9	4.9	4.9	4.3	2.9	2.9	3.0	4.5	4.5	4.0	0	0	0	10	10	8
	C	139	96	41	3.9	3.5	3.5	2.7	2.6	2.5	3	3	3	0	0	0	11	11	9
HRERS-RV																			
	A	0	0	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
	B	14	14	9	25.4	25.4	25.9	4.2	4.2	4.5	25.5	25.5	27	17	17	17	30	30	30
	C	112	95	35	26.2	26.7	27.2	4.6	4.1	2.9	27	28	28	12	12	20	30	30	30
Intervention /service characteristics																			
Duration																			
	A	27	19	14	3.9	3.9	3.9	1.6	1.7	1.4	4	4.1	3.9	1.3	1.3	1.9	6.4	6.4	6.0
	B	14	14	9	3.5	3.5	3.6	1.5	1.5	1.6	3.7	3.7	4.1	1.7	1.7	1.7	6.3	6.3	6.3
	C	134	96	40	3.9	4.3	4.1	1.6	1.6	1.5	4.1	4.9	4.3	0.6	0.6	1.0	6.1	6.1	6.1

Appendix 7. WP2a: EQ-5D-5L: additional data

2016 vs 2017 EQ-5D-5L tariffs: index and VAS scores

Table 44: Correlation coefficients: EQ-5D-5L index & VAS scores - T0 & T1 (total sample)

	Correlation coffieicent
2017	0.71
2016	0.70
VAS	0.46

Scores for the two tariffs were highly correlated both at baseline and at discharge with a correlation coefficient of 0.9988 and 0.9995, respectively. The mean difference between the two tariffs was approximately 0.014. The ICC estimate for the EQ-5D-5L 2017 tariff at discharge was 0.114 (SE: 0 .116; 95% CI: 0.0085, 0.4898); using the 2016 tariff gave similar results 0.116 (SE: 0.117; 95% CI: 0.0090, 0.4914). Table 45 provides further summary statistics of the difference between the two tariffs at baseline and discharge.

Table 45: EQ 5D-5L: difference between 2016 and 2017 tariffs: T0 and T1

	N	Mean	SD	Min	Max
Difference at T0	186	-0.013	0.012	-0.035	0.017
Difference at T1	128	-0.014	0.008	-0.032	0.008

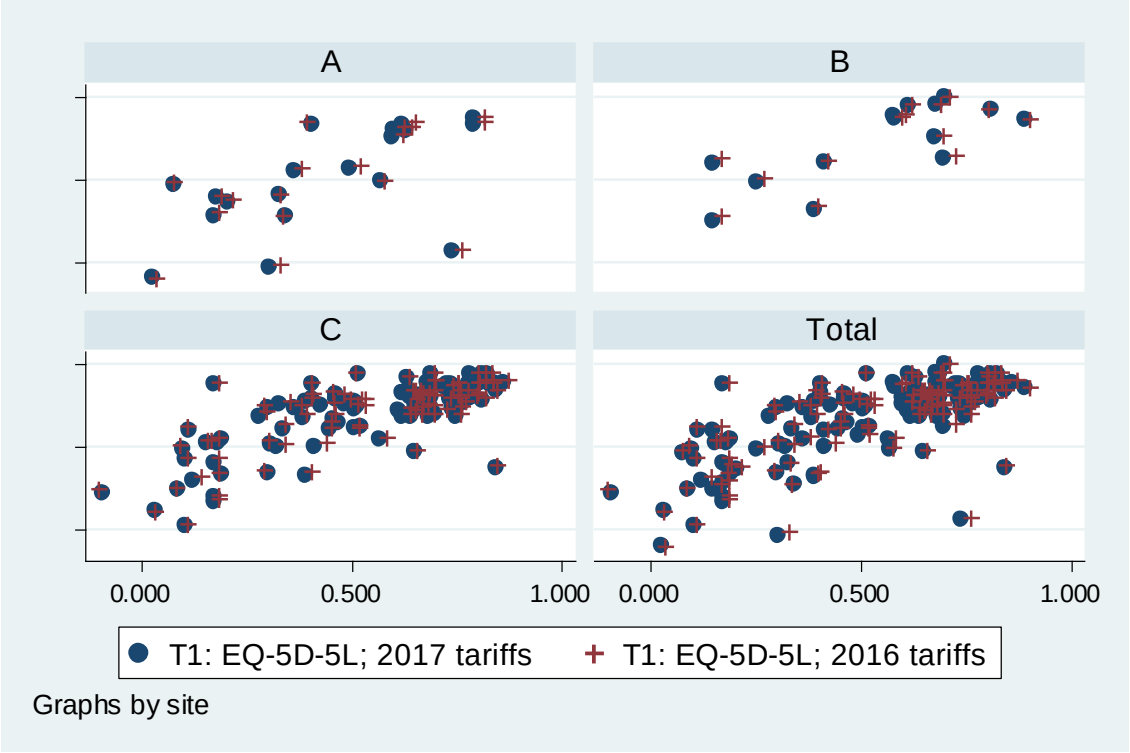

Figure 10: T0 EQ-5D-5L index scores – 2016 & 2017 tariffs (Site A)

Figure 11: T0 EQ-5D-5L index scores – 2016 & 2017 tariffs (Site B)

Figure 12: T0 EQ-5D-5L index scores – 2016 & 2017 tariffs (Site C)

Figure 13: T0 EQ-5D-5L index scores – 2016 & 2017 tariffs (total sample)

Outcomes data

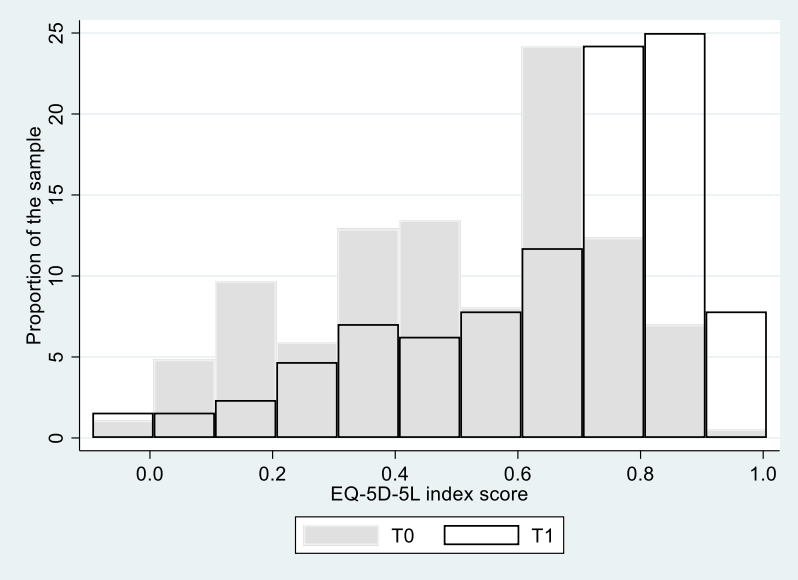

Figure 14: EQ-5D-5L index scores: distributions at T0 and T1 (total samples)

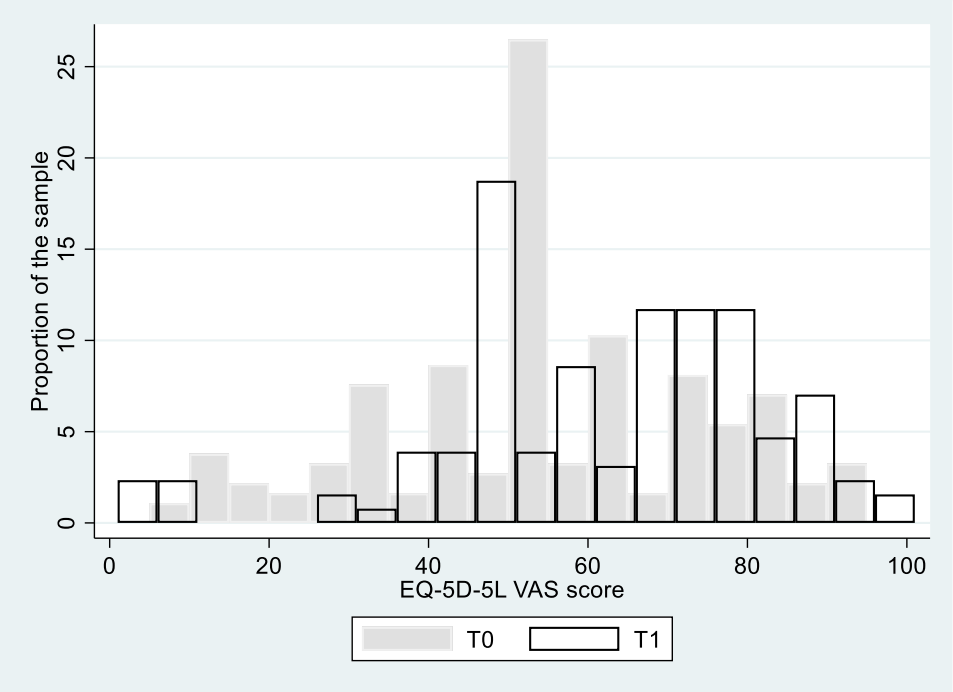

Figure 15: EQ-5D VAS scores: distributions at T0 and T1 (total samples)

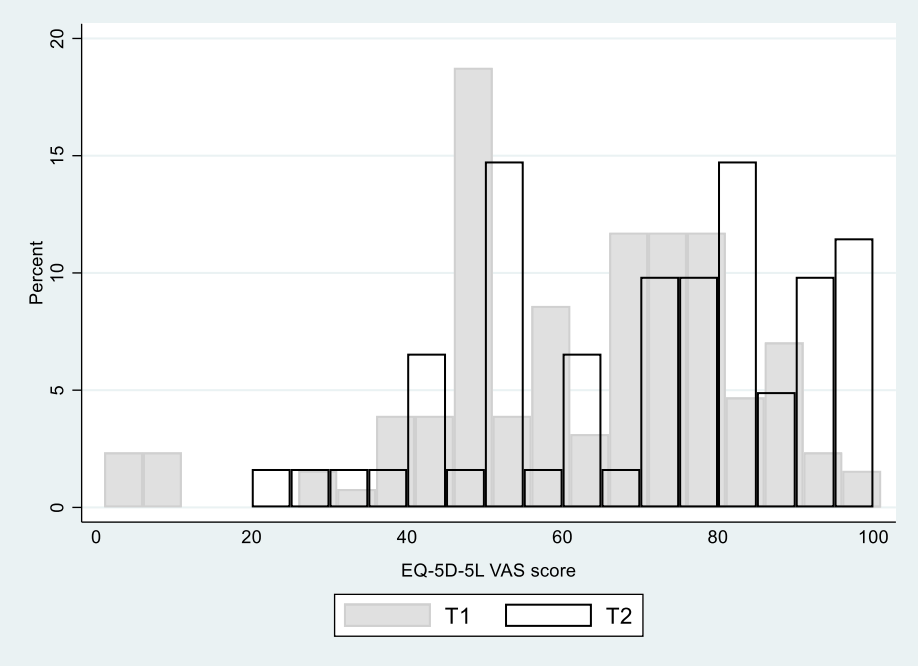

Figure 16: Distribution of EQ-5D VAS scores: T1 and T2 (total sample)

Table 46: Direction of change in EQ-5D-5L scores: T0 to T1, T1 to T2

EQ-5D-5L Index				
	T0 to T1		**T1 to T2**	
Change	***n***	***%***	***n***	***%***
Deteriorated	16	13	21	43
Maintained	4	3	3	6
Improved	108	84	25	51
Total	*128*	*100*	*49*	*100*
EQ-5D-5L VAS				
Change			**n**	**%**
Declined	17	13	20	39
Maintained	4	3	10	20
Improved	107	84	21	41
Total	*128*	*100*	*51*	*100*

Table 47: Direction of change: EQ-5D-5L domain scores between T0 and T1

	EQ 5D-5L domains									
	Mobility		**Self-care**		**Usual Activities**		**Pain/Discomfort**		**Anxiety/Depression**	
	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %
Declined	12	9%	3	2%	9	7%	18	14%	22	17%
Maintained	50	39%	34	27%	48	38%	63	49%	61	48%
Improved	66	52%	91	71%	71	55%	47	37%	45	35%
Total	128	100%	128	100%	128	100%	128	100%	128	100%

Appendix 8. WP2a: ASCOT-SCT4 data: figures and tables

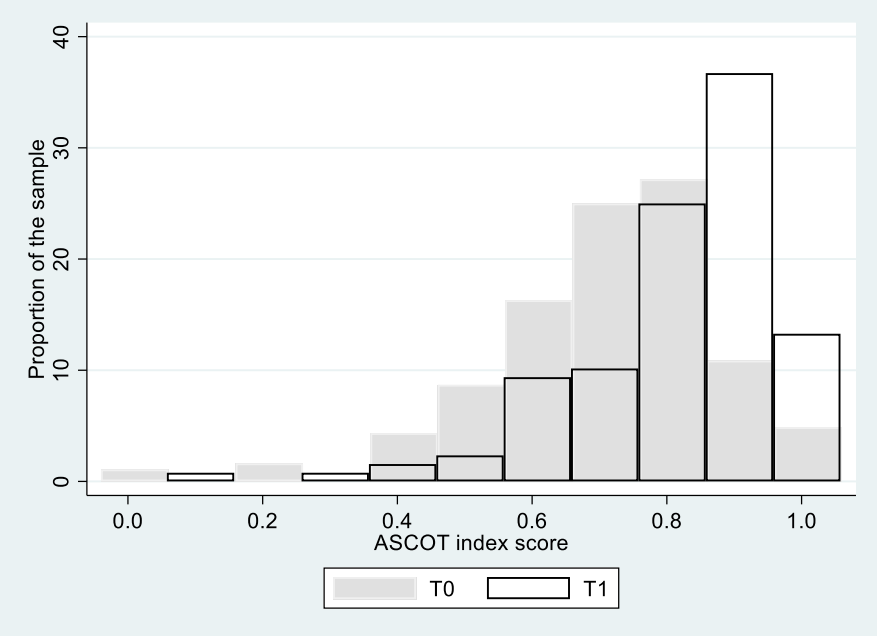

Figure 17: ASCOT-SCT4 index scores: distributions at T0 and T1 (total samples)

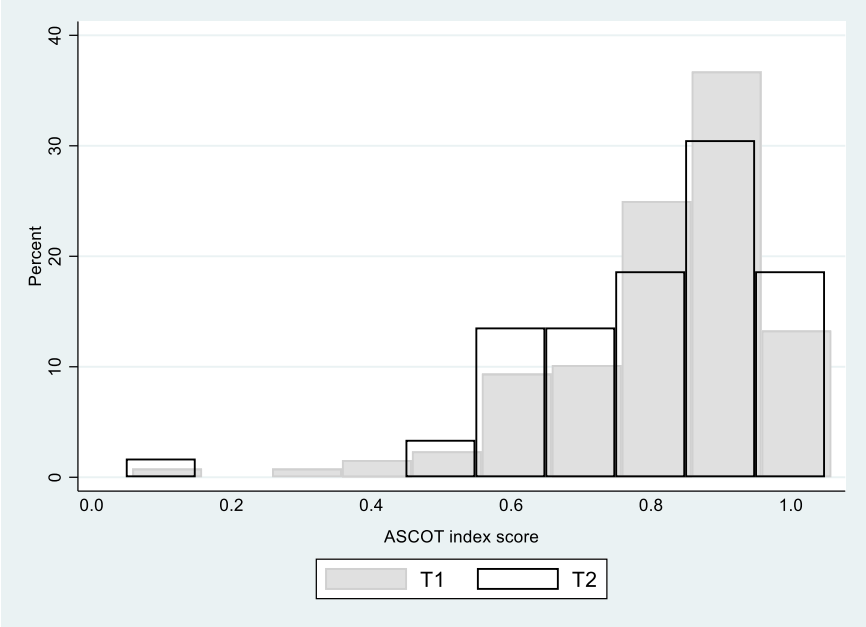

Figure 18: ASCOT-SCT4 index scores: distributions at T1 and T2 (total samples)

Table 48: Direction of change in ASCOT-SCT4 index score: T0 to T1, T1 to T2

	T0 to T1		T1 to T2	
	n	***%***	***n***	***%***
Declined	31	24	21	45
Maintained	4	3	3	6
Improved	93	73	23	49
Total	*128*	*100*	*47*	*100*

Table 49: Direction of change: ASCOT SCT4 domains and index score between T0 and T1

	ASCOT SCT-4 domains																	
	Control		**Personal appearance**		**Food & Drink**		**Safety**		**Social contact**		**Time**		**Accommodation**		**Feeling about having help**		**Feeling about help**	
	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %
Declined	13	10%	7	5%	5	4%	19	15%	24	19%	16	13%	11	9%	7	5%	13	10%
Maintained	60	47%	62	48%	78	61%	87	68%	55	43%	58	45%	80	63%	88	69%	93	73%
Improved	55	43%	59	46%	45	35%	22	17%	49	38%	54	42%	37	29%	33	26%	22	17%
Total	128	100%	128	100%	128	100%	128	100%	128	100%	128	100%	128	100%	128	100%	128	100%

Appendix 9: WP2a: Barthel Index Descriptive data: figures and tables

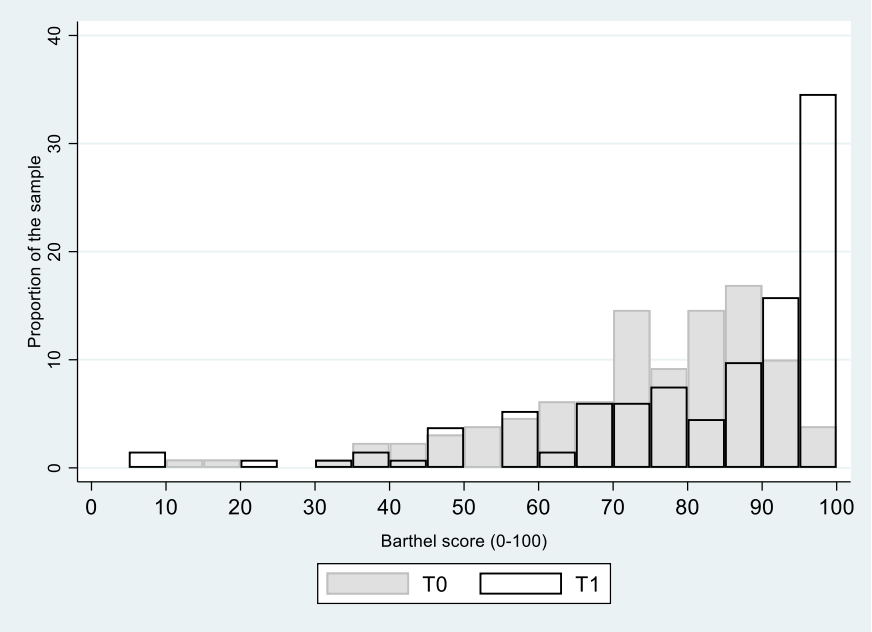

Figure 19: Barthel Index scores: distributions at T0 and T1 (total samples)

Table 50: Direction of change in Barthel Index score: T0 to T1

Type of change	n	%
Deterioration	22	23%
Maintenance	11	11%
Improvement	63	66%
Total	96	100%

Table 51: Direction of change: Barthel Index domain scores & total score: T0 to T1

	Barthel Index domains																					
	Feeding		Bathing		Grooming		Dressing		Bowels		Bladder		Toilet use		Transfers		Mobility		Stairs		Total score	
	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %
Declined	5	5%	8	8%	9	9%	7	7%	10	10%	7	7%	13	14%	14	15%	18	19%	15	16%	22	23%
Maintained	72	75%	43	45%	53	55%	38	40%	76	79%	73	76%	70	73%	58	60%	67	70%	61	64%	11	11%
Improved	19	20%	45	47%	34	35%	51	53%	10	10%	16	17%	13	14%	24	25%	11	11%	20	21%	63	66%
Total	96	100%	96	100%	96	100%	96	100%	96	100%	96	100%	96	100%	96	100%	96	100%	96	100%	96	100%

Appendix 10: WP2a: NEADL scale data: figures and tables

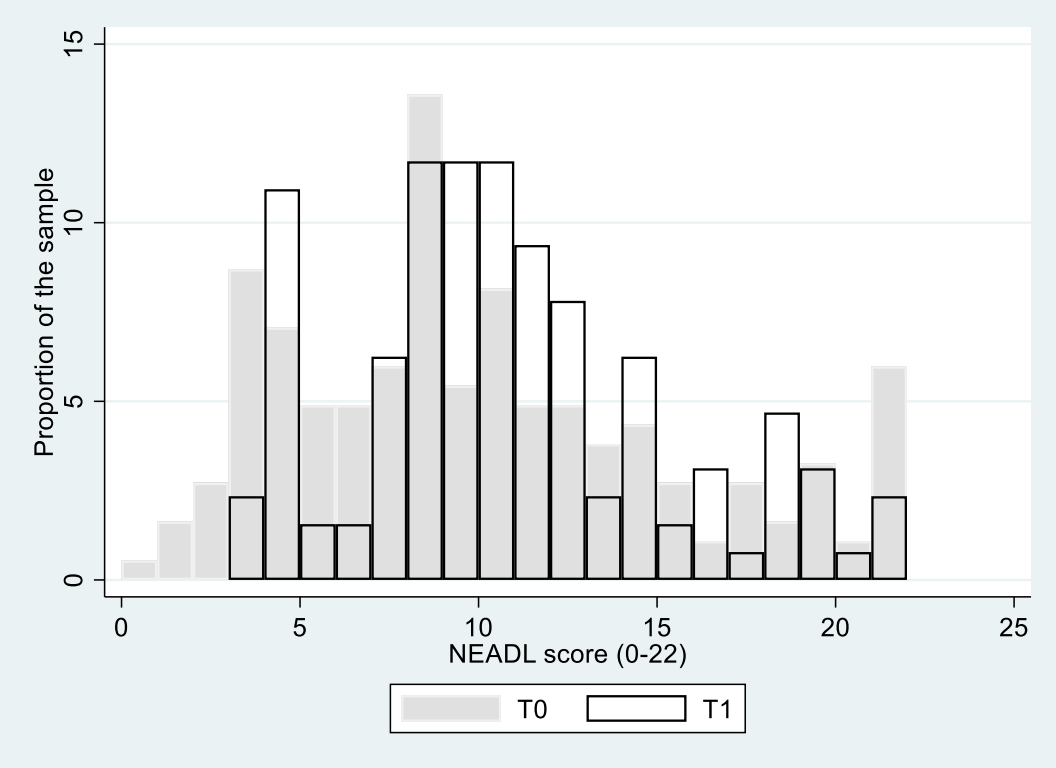

Figure 20: NEADL total scores: distributions at T0 and T1 (total samples)

Table 52: Direction of change in NEADL score: T0 to T1, T1 to T2

	T0 to T1		T1 to T2	
Change	**n**	**%**	**n**	**%**
Declined	39	30.5	14	26.9
Maintained	18	14.1	4	7.7
Improved	71	55.5	34	65.4
Total	*128*	*100*	*52*	*100*

Table 53: Direction of change: NEADL domain scores and total score between T0 to T1

	Mobility Domain												Kitchen Domain									
	walk		climb		in/out car		uneven		cross roads		transport		feed oneself		make drink		carry drink		wash up		make snack	
	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %
Declined	21	17%	9	7%	22	17%	18	14%	17	13%	13	10%	1	1%	3	2%	4	3%	1	1%	3	2%
Maintained	87	69%	106	83%	85	67%	90	71%	98	77%	108	85%	120	94%	110	86%	103	80%	108	84%	108	84%
Improved	19	15%	12	9%	20	16%	19	15%	12	9%	6	5%	7	5%	15	12%	21	16%	19	15%	17	13%
Total	*127*	*100%*	*127*	*100%*	*127*	*100%*	*127*	*100%*	*127*	*100%*	*127*	*100%*	*128*	*100%*	*128*	*100%*	*128*	*100%*	*128*	*100%*	*128*	*100%*

	Domestic Domain										Leisure Domain													
	money		small wash		housework		shopping		clothes wash		read		use phone		write letters		socialise		gardening		drive		Total score	
	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %	No.	Col %
Declined	17	13%	3	2%	10	8%	11	9%	17	13%	3	2%	0	0%	0	0%	11	9%	9	7%	11	9%	39	30%
Maintained	95	74%	100	78%	111	87%	106	83%	89	70%	116	91%	124	97%	108	84%	108	84%	115	90%	113	88%	18	14%
Improved	16	13%	25	20%	7	5%	11	9%	21	17%	9	7%	4	3%	20	16%	9	7%	4	3%	4	3%	71	55%
Total	*128*	*100%*	*128*	*100%*	*128*	*100%*	*128*	*100%*	*127*	*100%*	*128*	*100%*	*128*	*100%*	*128*	*100%*	*128*	*100%*	*128*	*100%*	*128*	*100%*	*128*	*100%*

Appendix 11: WP2a: General Health Questionnaire (GHQ 12): figures and tables

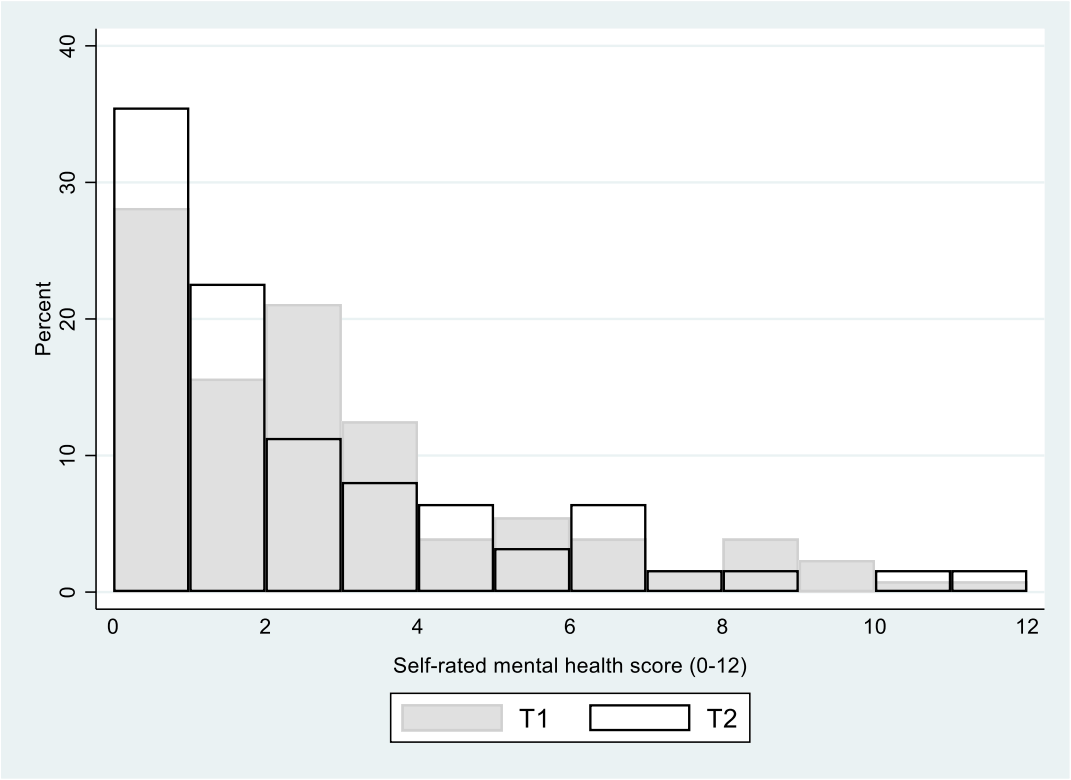

Figure 21: Distribution of GHQ-12 scores: T1 and T2 (total samples)

Table 54: Direction of change in GHQ-12 score: T0 to T1, T1 to T2

	T0 to T1		T1 to T2	
Type of change	**n**	**%**	**n**	**%**
Deterioration	23	18.0%	12	24.0%
Maintenance	16	12.5%	13	26.0%
Improvement	89	69.5%	25	50.0%
Total	*128*	*100%*	*50*	*100%*

Appendix 12: WP2a: Factors associated with T1 outcomes: regression models

Table 55: Regression models: T1 EQ 5D-5L scores and predictor variables

Outcome:	**Version A***					**Version B****				
Health-related quality of life at discharge.	**Coef.**	**P-value**	**95% CI**	**llik**	**BIC**	**Coef.**	**P-value**	**95% CI**	**llik**	**BIC**
Explanatory Variables:										
Model 1: 128										
Health-related quality of life at baseline	0.707	<0.001	(0.573, 0.84)	47.9	-607.8	0.677	<0.001	(0.603, 0.752)	53.2	-612.9
Individual level Characteristics										
Model 2: 128										
Health-related quality of life at baseline	0.705	<0.001	(0.569, 0.842)	48.06	-607.8	0.676	<0.001	(0.6, 0.753)	53.4	-608.1
Gender (ref: Female vs Male)	0.018	0.009	(0.004, 0.031)			0.015	0.233	(-0.01, 0.039)		
Model 3: 128										
Health-related quality of life at baseline	0.719	<0.001	(0.591, 0.847)	48.2	-607.8	0.696	<0.001	(0.623, 0.77)	54.2	-608.1
Living alone (ref: No vs Yes)	-0.024	<0.001	(-0.03, -0.019)			-0.042	0.033	(-0.08, -0.003)		
Model 4: 124										
Health-related quality of life at baseline	0.671	<0.001	(0.519, 0.823)	48.4	-584.8	0.62	<0.001	(0.582, 0.657)	55.2	-585.1
Sufficient money (ref: No vs Yes)	0.081	<0.001	(0.063, 0.098)			0.102	<0.001	(0.049, 0.155)		
Model 5: 128										
Health-related quality of life at baseline	0.713	<0.001	(0.582, 0.844)	49.1	-607.9	0.683	<0.001	(0.606, 0.76)	53.8	-608.1
Referral Reason (ref: Return to home vs Remain at home)	0.046	0.313	(-0.043, 0.134)			0.032	0.313	(-0.03, 0.094)		
Model 6: 128										
Health-related quality of life at baseline	0.702	<0.001	(0.55, 0.854)	48.1	-607.8	0.667	<0.001	(0.58, 0.754)	54.1	-608.1
Informal carer involved (ref: No vs Yes)	-0.033	0.653	(-0.179, 0.112)			-0.062	0.221	(-0.161, 0.037)		
Model 7: 128										
Health-related quality of life at baseline	0.713	<0.001	(0.576, 0.849)	48.74	-607.8	0.678	<0.001	(0.612, 0.73)	53.5	-608.1
Physical health key co-morbidities (ref: none vs one)	0.025	0.514	(-0.049, 0.098)			0.007	0.832	(-0.057, 0.071)		
None vs two or more	-0.025	0.602	(-0.118, 0.068)			-0.034	0.545	(-0.145, 0.077)		

Model 8: 128										
Health-related quality of life at baseline	0.659	<0.001	(0.615, 0.703)	50.1	-607.9	0.645	<0.001	(0.612, 0.678)	54.5	-608.2
Age in years	0.004	0.291	(-0.003, 0.01)			0.003	0.293	(-0.002, 0.008)		
Model 9: 87										
Health-related quality of life at baseline	0.733	<0.001	(0.539, 0.927)	34.2	-377.3	0.701	<0.001	(0.564, 0.837)	36.6	-377.4
Assessor-reported functional status at baseline (Barthel)	0.001	0.212	(-0.001, 0.003)			0.001	0.141	(-0.000 0.003)		
Model 10: 128										
Health-related quality of life at baseline	0.669	<0.001	(0.572, 0.767)			0.628	<0.001	(0.592, 0.664)	55.0	-608.2
Self-reported Functional Status at baseline (NEADL)	0.004	0.015	(0.001, 0.007)			0.005	0.091	(-0.001, 0.011)		
Model 11: 128										
Health-related quality of life at baseline	0.622	<0.001	(0.517, 0.726)	50.6	-607.9	0.606	<0.001	(0.538, 0.674)	55.3	-608.2
(Worse) mental health at baseline (GHQ-12)	-0.014	0.017	(-0.025, -0.003)			-0.012	0.001	(-0.019, -0.005)		
Model 12: 108										
Health-related quality of life at baseline	0.64	<0.001	(0.584, 0.696)	61.9	-499.0	0.639	<0.001	(0.588, 0.689)	62.3	-498.9
Engagement with reablement (HRERS-RV)	0.009	<0.001	(0.008, 0.01)			0.01	<0.001	(0.008, 0.012)		
Service Level Characteristics										
Model 13: 127										
Health-related quality of life at baseline	0.698	<0.001	(0.591, 0.805)	48.9	-602.1	0.674	<0.001	(0.604 0.745)	52.9	-607.1
Single Team Model (ref: No vs Yes)	0.034	0.545	(-0.057 0.125)			-0.013	<0.001	(-0.015 -0.010)		
Intervention Characteristics										
Model 14: 128										
Health-related quality of life at baseline	0.711	<0.001	(0.578, 0.843)	48.2	-607.8	0.679	<0.001	(0.601, 0.758)	53.3	-608.1
Intervention fidelity (ref: partial vs complete) (ERPC)	0.025	0.7	(-0.102, 0.152)			0.011	0.842	(-0.094, 0.116)		
Model 15: 128										
Health-related quality of life at baseline	0.711	<0.001	(0.547, 0.876)	47.9	-607.8	0.677	<0.001	(0.576, 0.778)	53.2	-608.1
Duration of Reablement (weeks)	0.002	0.796	(-0.015, 0.019)			0	0.986	(-0.013, 0.013)		
Model 16: 127										
Health-related quality of life at baseline	0.699	<0.001	(0.604, 0.793)	49.5	-602.1	0.673	<0.001	(0.600, 0.745)	52.9	-607.1
In-house vs outsourced reablement workers	-0.049	0.413	(-0.165, 0.068)			0.017	<0.001	(0.013, 0.022)		

* Accounting for clustering by site
** Accounting for clustering by site, in addition to using site as an explanatory variable.

Table 56: Association between T1 ASCOT SCT4 index score and predictor variables

Characteristic	Without controlling for site	Controlling for site
Service user characteristics		
Age, in years	0.001 (0.000 to 0.002)	0.001 (-0.001 to 0.002)
Gender	0.024 (-0.001 to 0.050)	0.021 (-0.004 to 0.045)
Key physical health-comorbidities Coefficient on 1 key comorbidity Coefficient on 2 or more key comorbidities	 0.031 (-0.016 to 0.078) 0.015 (-0.008 to 0.037)	 0.019 (-0.029 to 0.067) 0.010 (-0.009 to 0.029)
Living situation	0.003 (-0.024 to 0.031)	-0.009 (-0.058 to 0.040)
Perceived financial situation	0.017 (-0.018 to 0.051)	0.031 (0.016 to 0.045)
Support by family and friends	-0.029 (-0.061 to 0.003)	-0.046 (-0.104 to 0.013)
Mental health at baseline (GHQ-12)	-0.014 (-0.019 to -0.009)	-0.013 (-0.017 to -0.009)
Functional status at baseline (modified Barthel index)	-0.001 (-0.002 to -0.000)	-0.001 (-0.002 to -0.000)
Health-related Quality of Life (EQ-5D 2017)	0.050 (-0.107 to 0.207)	0.046 (-0.084 to 0.175)
Functional status at baseline (NEADL)	0.000 (-0.006 to 0.006)	0.000 (-0.007 to 0.007)
Engagement with reablement (HERS)	0.006 (0.002 to 0.010)	0.006 (0.001 to 0.010)
Reason for referral	0.039 (-0.001 to 0.078)	0.034 (0.008 to 0.060)
Service/Intervention characteristics		
Duration of reablement	0.007 (0.004 to 0.011)	0.006 (0.002 to 0.010)
Intervention Fidelity	0.033 (0.009 to 0.058)	0.024 (-0.001 to 0.050)
Type of provider (outsourced vs in-house)	-0.041 (-0.093 to 0.012)	-0.011 (-0.014 to 0.008)
Single vs multiple team model	0.034 (0.000 to 0.070)	0.000 (-0.003 to 0.003)

Note: controls for score at entry (95% confidence interval)

Table 57: Regression models: T1 Barthel Index scores and predictor variables

	Version A*					Version B**				
Assessor-reported functional status at discharge (Barthel)	**Coef.**	**P-value**	**95% CI**	**llik**	**BIC**	**Coef.**	**P-value**	**95% CI**	**llik**	**BIC**
Explanatory Variables:										
Model 1: 96										
Assessor-reported functional status at baseline (Barthel)	0.629	<0.001	(0.359 0.899)	-407.9	27179.5	0.601	<0.001	(0.305, 0.898)	-406.7	26479.7
Individual level Characteristics										
Model 2: 96										
Assessor-reported functional status at baseline (Barthel)	0.625	<0.001	(0.351, 0.900)	-407.9	27158.5	0.598	<0.001	(0.298, 0.899)	-406.7	26466.2
Gender (ref: Female vs Male)	-1.008	0.42	(-1.980, -0.036)			-0.937	0.024	(-1.749, -0.126)		
Model 3: 96										
Assessor-reported functional status at baseline (Barthel)	0.597	<0.001	(0.354, 0.840)	-406.5	26352.0	0.549	<0.001	(0.294, 0.804)	-404.3	25138.6
Living alone (ref: No vs Yes)	5.991	0.278	(-4.834, 16.816)			7.900	0.083	(-1.040 16.841)		
Model 4: 93										
Assessor-reported functional status at baseline (Barthel)	0.664	<0.001	(0.413, 0.915)	-393.7	25481.3	0.643	<0.001	(0.372, 0.914)	-393.1	25120.4
Sufficient money (ref: No vs Yes)	6.246	<0.001	(3.650, 8.841)			5.256	<0.001	(4.466, 6.047)		
Model 5: 96										
Assessor-reported functional status at baseline (Barthel)	0.633	<0.001	(0.368, 0.899)	-407.9	27142.3	0.604	<0.001	(0.320, 0.888)	-406.7	26476.7
Referral Reason (ref: Return to home vs Remain at home)	1.268	0.532	(-2.708, 5.243)			0.583	0.735	(-2.794, 3.961)		
Model 6: 96										
Assessor-reported functional status at baseline (Barthel)	0.619	<0.001	(0.395, 0.843)	-405.9	25681.9	0.587	<0.001	(0.341, 0.833)	-404.0	24978.5
Informal carer involved (ref: No vs Yes)	-12.94	<0.001	(-16.592, -9.291)			-13.21	<0.001	(-15.59, -10.83)		
Model 7: 96										

Assessor-reported functional status at baseline (Barthel)	0.611	<0.001	(0.379, 0.843)	-405.8	25980.4	0.596	<0.001	(0.348, 0.844)	-405.3	25665.6
Physical health key co-morbidities (ref: none vs one)	-7.036	0.002	(-11.516, -2.555)			-5.739	<0.001	(-8.942, -2.536)		
None vs two or more	-7.865	0.092	(-17.026, 1.295)			-7.128	0.112	(-15.924 1.668)		
Model 8: 96										
Assessor-reported functional status at baseline (Barthel)	0.626	<0.001	(0.350, 0.902)	-407.7	27044.8	0.602	<0.001	(0.300, 0.904)	-406.6	26410.6
Age in years	0.144	0.009	(0.036, 0.253)			0.110	0.199	(-0.058, 0.279)		
Model 9: 96										
Assessor-reported functional status at baseline (Barthel)	0.442	<0.001	(0.200, 0.684)	-398.4	22184.1	0.388	<0.003	(0.133, 0.643)	-396.0	21097.5
Self-reported Functional Status at baseline (NEADL)	1.327	<0.001	(0.910, 1.744)			1.412	<0.001	(1.048, 1.776)		
Model 10: 96										
Assessor-reported functional status at baseline (Barthel)	0.535	<0.001	(0.239, 0.830)	-404.4	25184.9	0.518	<0.001	(0.204, 0.831)	-403.4	24650.1
Health-related quality of life at baseline (EQ-5D-5L)	19.690	<0.001	(12.423, 26.957)			19.081	<0.001	(11.424, 26.738)		
Model 11: 96										
Assessor-reported functional status at baseline (Barthel)	0.629	<0.001	(0.352, 0.907)	-407.1	26662.0	0.601	<0.001	(0.298, 0.904)	-405.7	25878.4
(Worse) mental health at baseline (GHQ-12)	-0.841	<0.001	(-1.238, -0.445)			-0.914	<0.001	(-1.407, -0.421)		
Model 12: 76										
Assessor-reported functional status at baseline (Barthel)	0.623	<0.001	(0.498, 0.749)	-308.7	14680.5	0.594	<0.001	(0.558, 0.631)	-307.8	14319.7
Engagement with reablement (HRERS-RV)	1.693	<0.001	(1.471, 1.915)			1.702	<0.001	(1.501, 1.904)		
Service Level Characteristics										
Model 13: 95										
Assessor-reported functional status at baseline (Barthel)	0.626	<0.001	(0.308, 0.944)	-402.1	25996.5	0.659	<0.001	(0.353, 0.965)	-399.9	24815.9
Single Team Model (ref: No vs Yes)	-1.939	0.721	(-12.576, 8.697)			5.337	0.029	(0.544, 10.130)		

Intervention Characteristics										
Model 14: 75										
Assessor-reported functional status at baseline (Barthel)	0.676	<0.001	(0.460, 0.893)	-315.8	19611.8	0.654	<0.001	(0.416, 0.891)	-315.4	19407.2
Intervention fidelity (ref: partial vs complete) (ERPC)	0.952	0.664	(-3.348, 5.253)			1.302	0.475	(-2.267, 4.871)		
Model 15: 95										
Assessor-reported functional status at baseline (Barthel)	0.631	<0.001	(0.468, 0.793)	-402.8	26349.3	0.611	<0.001	(0.417, 0.805)	-401.9	25872.5
Duration of reablement (weeks)	-0.602	0.288	(-1.711, 0.507)			-0.414	0.386	(-1.352, 0.523)		
Model 16: 104										
Assessor-reported functional status at baseline (Barthel)	0.635	<0.001	(0.351, 0.918)	-402.2	26040.9	0.632	<0.001	(0.330, 0.934)	-400.5	25100.9
In-house vs outsourced reablement workers	1.279	0.760	(-6.937, 9.495)			-1.358	0.602	(-6.461, 3.745)		
* Accounting for clustering by site ** Accounting for clustering by site in addition to using site as an explanatory variable.										

Table 58: Regression models: T1 NEADL scores and predictor variables

	Version A*					Version B**				
Self-reported Functional Status at discharge (NEADL)	**Coef.**	**P-value**	**95% CI**	**llik**	**BIC**	**Coef.**	**P-value**	**95% CI**	**llik**	**BIC**
Explanatory Variables										
Model 1: 128										
Self-reported Functional Status at baseline (NEADL)	0.493	<0.001	(0.484, 0.503)	-340.8	927.9	0.515	<0.001	(0.451, 0.579)	-335.3	796.1
Individual level Characteristics										
Model 2: 128										
Self-reported Functional Status at baseline (NEADL)	0.489	<0.001	(0.465, 0.514)	-340.1	911.0	0.512	<0.001	(0.444, 0.581)	-335.0	795.2
Gender (ref: Female vs Male)	-0.782	0.241	(-2.088, 0.524)			-0.461	0.413	(-1.566, 0.644)		
Model 3: 128										
Self-reported Functional Status at baseline (NEADL)	0.479	<0.001	(0.438, 0.519)	-339.7	902.3	0.497	<0.001	(0.402, 0.592)	-333.4	760.7
Living alone (ref: No vs Yes)	0.931	0.237	(-0.612, 2.474)			1.194	0.075	(-0.119, 2.506)		
Model 4: 128										
Self-reported Functional Status at baseline (NEADL)	0.475	<0.001	(0.458, 0.492)	-331.1	925.8	0.499	<0.001	(0.447, 0.551)	-326.0	806.0
Sufficient money (ref: No vs Yes)	0.776	0.027	(0.089, 1.462)			0.664	0.008	(0.171, 1.157)		
Model 5: 128										
Self-reported Functional Status at baseline (NEADL)	0.500	<0.001	(0.481, 0.519)	-340.3	916.3	0.519	<0.001	(0.460, 0.578)	-335.1	796.6
Referral Reason (ref: Return to home vs Remain at home)	0.618	0.025	(0.076, 1.159)			0.383	0.344	(-0.410, 1.175)		
Model 6: 128										
Self-reported Functional Status at baseline (NEADL)	0.493	<0.001	(0.483, 0.504)	-340.6	923.5	0.515	<0.001	(0.447, 0.583)	-335.1	796.4
Informal carer involved (ref: No vs Yes)	-0.616	0.467	(-2.276, 1.044)			-0.631	0.372	(-2.014, 0.753)		
Model 7: 128										

Self-reported Functional Status at baseline (NEADL)	0.489	<0.001	(0.486 0.493)	-340.7	925.7	0.517	<0.001	(0.455 0.580)	-335.2	799.5
Physical health key co-morbidities (ref: none vs one)	-0.302	0.594	(-1.411 0.808)			0.179	0.656	(-0.608 0.966)		
None vs two or more	-0.119	0.868	(-1.517 1.280)			0.271	0.573	(-0.673 1.216)		
Model 8: 128										
Self-reported Functional Status at baseline (NEADL)	0.490	<0.001	(0.481, 0.500)	-340.7	925.0	0.512	<0.001	(0.450, 0.574)	-335.1	797.0
Age in years	-0.017	<0.001	(-0.022, -0.011)			-0.020	0.022	(-0.037, -0.003)		
Model 9: 87										
Self-reported Functional Status at baseline (NEADL)	0.387	<0.001	(0.291, 0.483)	-229.5	617.1	0.439	<0.001	(0.331, 0.548)	-224.5	509.2
Assessor-reported functional status at baseline (Barthel)	0.071	0.011	(0.016, 0.127)			0.043	<0.001	(0.024, 0.061)		
Model 10: 128										
Self-reported Functional Status at baseline (NEADL)	0.472	<0.001	(0.440, 0.504)	-340.4	917.4	0.497	<0.001	(0.432, 0.562)	-335.0	794.0
Health-related quality of life at baseline (EQ-5D-5L)	1.314	0.107	(-0.283, 2.911)			1.082	0.040	(0.048, 2.115)		
Model 11: 128										
Self-reported Functional Status at baseline (NEADL)	0.499	<0.001	(0.459, 0.539)	-340.7	925.8	0.515	<0.001	(0.427, 0.603)	-335.3	800.9
(Worse) mental health at baseline (GHQ-12)	0.047	0.739	(-0.229, 0.323)			-0.005	0.967	(-0.232, 0.222)		
Model 12: 108										
Self-reported Functional Status at baseline (NEADL)	0.474	<0.001	(0.464, 0.484)	-285.6	751.6	0.500	<0.001	(0.406, 0.595)	-278.9	606.4
Engagement with reablement (HRERS-RV)	0.147	<0.001	(0.096, 0.199)			0.176	<0.001	(0.148, 0.204)		
Service Level Characteristics										
Model 13: 127										
Self-reported Functional Status at baseline (NEADL)	0.495	<0.001	(0.458 0.531)	-336.2	875.1	0.510	<0.001	(0.445 0.574)	-332.3	782.9
Single Team model	-1.184	0.198	(-2.988 0.620)			0.174	<0.001	(0.156 0.192)		

Intervention Characteristics										
Model 14: 128										
Self-reported Functional Status at baseline (NEADL)	0.498	<0.001	(0.477, 0.518)	-340.4	917.8	0.516	<0.001	(0.447, 0.585)	-335.2	800.0
Intervention fidelity (ref: partial vs complete) (ERPC)	-0.595	0.487	(-2.273, 1.083)			-0.189	0.737	(-1.293, 0.914)		
Model 15: 128										
Self-reported Functional Status at baseline (NEADL)	0.486	<0.001	(0.473, 0.500)	-339.9	905.7	0.510	<0.001	(0.446, 0.574)	-334.9	792.6
Duration of Reablement (weeks)	-0.263	0.361	(-0.827, 0.301)			-0.163	0.506	(-0.642, 0.316)		
Model 16: 127										
Self-reported Functional Status at baseline (NEADL)	0.490	<0.001	(0.464, 0.516)	-337.8	915.9	0.510	<0.001	(0.446, 0.575)	-332.3	782.9
In-house vs outsourced reablement workers	-0.182	0.777	(-1.446, 1.082)			-0.156	<0.001	(-0.203, -0.110)		
* Accounting for clustering by site ** Accounting for clustering by site in addition to using site as an explanatory variable.										

Appendix 13: WP2b: Analytical frameworks

Box 8: Staff interviews: analytical framework

IDENTIFIERS

- Site/service:
- Staff group:
- Focus group size

DELIVERY OF REABLEMENT

- Barriers/sticking points in reablement pathway and perceived reasons
    a. referral
    b. assessment
    c. hand over from assessor to reablement workers
    d. monitoring and review
    e. discharge
    f. access to specialist support
    g. interfacing with other statutory services
    h. local voluntary sector context
- Working well/perceived good practice in reablement pathway (include examplars)
    a. referral
    b. assessment
    c. hand over from assessor to reablement workers
    d. monitoring and review
    e. discharge
    f. access to specialist support
    g. interfacing with other statutory services
    h. local voluntary sector context
- Changes over time
    a. direction of change
    b. perceived reasons
- The ideal pathway
    a. features
    b. rationale

THE IMPACT OF REABLEMENT

- Views on outcomes
    a. anticipated
    b. unanticipated
- Views on effectiveness
    a. Comparisons with homecare /other models of support
- Views on active ingredients
    a. the approach
    b. the staff
    c. the relationship between individual and staff

FACTORS IMPACTING ON OUTCOMES

- Individual

• Family • Organisational context • Delivery issues • Staff
OTHER • Other issues/topics • Researcher reflections

Box 9: Service user interviews: analytical framework

IDENTIFIERS

- ID No
- Site:
- Gender: F/M
- Age
- RT (returner); RM (remainer)
- Previous Reablement use: FU (first use) / PU (previous use)
- Household composition: Lives alone / lives with [relationship].

SHEET 1: UNDERSTANDING OF REABLEMENT

- Reason for referral to the Reablement service
- Finding out about service and initial understanding/ expectations
- Views on referral (good idea or not)
- Evidence of goals-focused approaches
- Understanding of reablement approach and objectives of the intervention (

SHEET 2: THE EXPERIENCE OF RECEIVING THE SERVICE

- Support provided
- Support not provided
- Ways Reablement Worker worked with clients
- How easy/difficult was it to work with the Workers?
- Involvement of Others in Reablement Activities
- Changes over time

SHEET 3: PERCEIVED OUTCOMES

- Difference service made
- Most important outcome/most difference
- Most enjoyable aspect
- Most difficult aspect
- Impact on close family members

SHEET 4: FACTORS IMPACTING ON OUTCOMES

- Relationship with Reablement Workers (including companionship)
- Workers' qualities, attitudes, approaches, knowledge and skills
- Timing, frequency and duration of visits
- Service delivery issues
- Other (including changes in health)

SHEET 5: END OF SERVICE AND REFLECTIONS

- Narrative of service stopping
- Feelings when service stopped
- How managing now
- Reasons would recommend service (or not)
- Suggested ways to improve service
- Researcher reflections

Appendix 14: WP2c: Services and Care Pathway Questionnaire (SCPQ) development &piloting

A 8.1. Introduction

This questionnaire was developed in order to capture service users' resource use of both statutory, voluntary and private sector services, out-of-pocket costs, and informal carer involvement. We could not identify an existing tool which collected this information with respect to the target population and of sufficient relevance to the intervention under investigation. A questionnaire was therefore developed and piloted before taking into the field. The content of the questionnaire was informed by the data needed by the project and existing tools.[51, 68-72]

A 8.1.1. Testing and adapting the draft versions

A first draft was shared with the members of the Study Steering Committee (SSC) for comment. At the same time, the PPI representatives on the SSC offered to complete the questionnaire and then comment. Comments from the SSC led us to simplify the format to enable self-completion, should study participants choose this option.

This re-drafted version (see final section this appendix) was then administered to 13 reablement service users as part of our wider piloting work. We observed that all these individuals were able to complete the form either independently or with some assistance. As they completed the form, they talked through their experiences of using services. In nine of the interviews, this narrative of service use highlighted some issues that the research team needed to consider in finalising the questionnaire. These included: how the complexity of service provision and use could be captured most simply without double-counting; the parameters of particular questions; and how best to format the questionnaire to minimise burden and confusion and thus maximise completion. We consider report each of these issues in turn.

A 8.1.2. Double-counting

Discussions with pilot participants indicated two places in the questionnaire that might be susceptible to double-counting:

'In the past 7 days, have you used a local authority transport service/taxi vouchers, etc.?' and 'In the past 7 days, have you used a voluntary transport service?'

'Since [April], have you attended an outpatient appointment? (includes mental health and consultant appointments in clinics or in GP practices) and 'In the past 7 days, have you had an appointment with a GP?'

In the first example, we were concerned about double counting because often voluntary sector transport is funded wholly or in part by social services. Unsurprisingly, participants were not aware of funding arrangements, so could not distinguish between them in their calculations nor could they always tell us the name of the transport service so we could investigate who provided/funded the services ourselves. In this instance, we decided to remove the question about voluntary sector transport and during training advised LSIs to guide participants to other transport in the section on 'other services' if they wished.

In the second example, we removed reference to GP practices from the question about outpatient appointments to avoid confusion for participants and possible double-counting.

A 8.1.3. Parameters and clarification of particular questions

The nine pilot participants indicated some degree of confusion whether the location of the service affected whether they should report its use, and also whether they should include particular services.

For example, participants were not sure whether they should include telephone appointments with clinicians as well as face-to-face appointments. We amended the questionnaire to make it clear to include both methods of having a GP consultation. One participant explained that she had had a planned stay in a rehabilitation community hospital post a planned hospital stay for a surgical procedure. She was not clear whether the days in the community hospital should be included in the numbers of nights stay for her planned

admission. Based on the team's experience we were aware that rehabilitation inpatient stays are common for this group of clients and we amended the questionnaire to include a question specifically about rehabilitation/recuperation in-patient stays. In response to participants being unsure whether they should include calls to 111 as well as calls to 999, we added a question about calling 111.

Two pilot participants were not sure which people to include when completing the question about help from family and friends (Section 5). For example, they were not sure if they should include neighbours and family who 'popped around' to keep them company rather than doing anything practical for them. For the purposes of this project, we were focused on costing the more practical elements of care and support. In the training delivered to Local Study Officers (LSO), we made clear that support that was solely focused on providing company should not be reported.

Other queries were dealt with by ensuring we trained the LSOs to know how to respond if similar questions were raised again. For example, participants who had microwave meals provided and delivered by a private company (see Q3.3) or supermarket online/delivery services (Q4.2) should not include information about these in their responses unless they were social service funded. Responding to one pilot participant's query, we advised LSOs that if a participant was given and used a piece of equipment but also returned it within the timescale of the question, this should still be recorded because for cost purposes, we were interested in whether the piece of equipment was used at all.

A 8.1.4. Wider learning and formatting the questionnaire

The piloting indicated that participants could accurately recall use of non-hospital based health services for a longer timescale than we had originally planned. We amended these questions to ask about use of services over a longer time frame than originally planned – i.e. 14 days rather than 7 days.

Those participants that contributed to the cost of a service did not always pay for them in the same timescales as we asked. For example, they might pay monthly or three-monthly for a service but we were asking about service use and payment over a fortnight. In their

training LSOs were advised to pay attention to the possible differing timescales of payments and the question and to calculate the cost for the question timescale.

Given that some participants in the pilot had several family and friends providing support, we changed the format of the question to enable them or the LSO to make notes and then sum the total hours of practical support they had received in the previous 7 days.

The question about transport use was reworded to provide clarity for completion and analysis. We amended it to ask about the number of journeys taken and whether these were one-way or return journeys, rather than how many times transport had been used.

The draft questionnaire taken forward to piloting

This is presented overleaf.

Service and Care Pathway Questionnaire (SCPQ)

The following set of questions asks whether or not you have recently used any other services.

Some questions ask about the past 2 months and some ask about the last 2 weeks.

If you have used a service recently, please write the number of times you have used a service in the box provided.

Some of the questions ask you how long you were using a service for. Please write the number of days you were receiving this service in the box provided.

We are only interested in the services that you have used for your own support. We do not need to know about services that your spouse or other family member/s have used.

Thank you

A 8.2. Section 1: Hospital Services

Over the past 2 months, have you attended an outpatient appointment? (includes mental health and consultant appointments in clinics or in GP practices)

Yes ❑ → If yes, how many times? ☐

No ❑

Over the past 2 months, have you had a planned (booked) hospital admission where you were discharged on the same day (Day Case)?

Yes ❑ → If yes, how many times? ☐

No ❑

Over the past 2 months, have you had a planned (booked) hospital admission with an overnight stay?

Yes ❑ → If yes, how many times? ☐

No ❑

→ If yes, how many nights did you stay in hospital? ☐

3a. Were you transferred to another hospital to continue your recovery?

Yes ❑ → If yes, how many times? ☐

No ❑

→ If yes, how many nights did you stay in this hospital? ☐

Over the past 2 months, have you had an unplanned hospital admission? (includes emergency admissions & non-emergency transfers from another hospital).

Yes ❑ → If yes, how many times? ☐

No ❑

→ If yes, how many nights did you stay in hospital? ☐

4a. Were you transferred to another hospital to continue your recovery?

Yes ❑ → If yes, how many times? ☐

No ❑

→ If yes, how many nights did you stay in this hospital? ☐

Over the past 2 months, have you been to hospital on other occasions not covered by the questions above?

Yes ❑ → If yes, how many times? ☐

No ❑

→ If yes, how many nights did you stay in hospital? ☐

Over the past 2 months, have you attended an accident and emergency (A&E) unit or a NHS walk-in centre?

Yes ❑ → If yes, how many times? ☐

No ❑

Over the past 2 months, have you called 999?

Yes ❑ → If yes, how many times? ☐

No ❑

A 8.3. Section 2: Other health services

In the past 14 days, have you had an appointment with a GP?

Yes ❑ → If yes, how many times? ☐

No ❑

In the past 14 days, have you had an appointment with a nurse?

Yes ❑ → If yes, how many times? ☐

No ❑

In the past 14 days, have you had an appointment with a nurse specialist?

Yes ❑ → If yes, how many times? ☐

No ❑

In the past 14 days, have you had an appointment with a therapist? (including occupational therapist, physiotherapist, speech therapist, chiropodist, podiatrist)

Yes ❑ → If yes, how many times? ☐

No ❑

A 8.4. Section 3: Social care services

Do you receive a direct payment (money from the local authority to purchase your own services)?
Yes ❑
No ❑ If yes, clarify that when we ask about their cost/contribution towards cost, we are not asking about what is paid for out of their direct payment but only from their own money?

In the past 14 days, have you received any home care from the council?
Yes ❑ → If yes, how many hours? ____
No ❑
→ Did you contribute to the cost of this?
Yes ❑ No ❑
→ If yes, how much did you pay? ____ Hour/day/week/month (delete as appropriate)

In the past 14 days, have you attended day care?
Yes ❑ → If yes, how many hours? ____
No ❑
→ Did you contribute to the cost of this?
Yes ❑ No ❑
→ If yes, how much did you pay? ____ Hour/day/week/month (delete as appropriate)

In the past 14 days, have you had meals provided? (e.g. via meals on wheels, luncheon club, etc.)
Yes ❑ → If yes, how many times? ____
No ❑
→ Did you contribute to the cost of this?
Yes ❑ No ❑
→ If yes, how much did you pay? ____ Hour/day/week/month (delete as appropriate)

In the past 14 days, have you had an appointment with someone from social services (e.g. a social worker or occupational therapist)?
Yes ❑ → If yes, how many times? ____
No ❑
→ Did you contribute to the cost of this?
Yes ❑ No ❑
→ If yes, how much did you pay? ____ Hour/day/week/month (delete as appropriate)

In the past 14 days, have you had a sitting service?
Yes ❑ → If yes, how many hours? ____ Day/Night (delete as appropriate)
No ❑

→ Did you contribute to the cost of this?
Yes ❑ No ❑

→ If yes, how much did you pay? [ ] Hour/day/week/month (delete as appropriate)

In the past 14 days, have you used a local authority transport service/taxi vouchers, etc.?
Yes ❑ → If yes, how many times? [ ]
No ❑

→ Did you contribute to the cost of this?
Yes ❑ No ❑

→ If yes, how much did you pay? [ ] Hour/day/week/month (delete as appropriate)

In the past 14 days, have you used any other social services?
Yes ❑ → If yes,
No ❑

Name of service	Hours used	Contribute to cost	If yes, how much?
		Yes ❑ No ❑	
		Yes ❑ No ❑	
		Yes ❑ No ❑	
		Yes ❑ No ❑	
		Yes ❑ No ❑	

A 8.5. Section 4: Services provided by voluntary organisations or charities

In the past 14 days, have you used a befriending service? Yes ❑ → If yes, how many times? No ❑ → Did you contribute to the cost of this? Yes ❑ No ❑ → If yes, how much did you pay?		Hour/day/ week/month (delete as appropriate)
In the past 14 days, have you used a shopping service? Yes ❑ → If yes, how many times? No ❑ → Did you contribute to the cost of this? Yes ❑ No ❑ → If yes, how much did you pay?		Hour/day/ week/month (delete as appropriate)
In the past 14 days, have you used a voluntary transport service? Yes ❑ → If yes, how many times? No ❑ → Did you contribute to the cost of this? Yes ❑ No ❑ → If yes, how much did you pay?		Hour/day/ week/month (delete as appropriate)
In the past 14 days, have you used an advice service? Yes ❑ → If yes, how many times? No ❑ → Did you contribute to the cost of this? Yes ❑ No ❑ → If yes, how much did you pay?		Hour/day/ week/month (delete as appropriate)

In the past 14 days, have you used any other voluntary services?
Yes ❑ → If yes, which services
No ❑

Name of service	Hours used	Contribute to cost	If yes, how much?
		Yes ❑ No ❑	
		Yes ❑ No ❑	
		Yes ❑ No ❑	
		Yes ❑ No ❑	
		Yes ❑ No ❑	
		Yes ❑ No ❑	

Section 5: Help from family or friends

In the past 14 days, have you had any care/support from a relative or friend?	
Yes ❑ → No ❑	If yes, how many hours?

A 8.6. Section 6: Adaptations to your home

In the last 2 months, have you had any MAJOR adaptations to your home?
Yes ❑ → If yes, what major adaptations
No ❑

Major adaptation	Cost to you?
❑ Downstairs conversion for WC/washroom	
❑ Downstairs extension for bedroom	
❑ Downstairs extension for en suite bedroom	
❑ Downstairs extension for WC/washroom	
❑ Level access shower	
❑ Stair lift (straight)	
❑ Stair lift (complex)	
❑ Through floor lift	
Other	

In the last 2 months, have you had any MINOR adaptations to your home?
Yes ❑ → If yes, what minor adaptations
No ❑

Minor adaptation	How many?	Cost to you?
❑ Bed moved to downstairs room		
❑ Doorways widened for wheelchair access		
❑ External handrail fitted		
❑ Internal handrail fitted		
❑ New path laid		
❑ Outside lighting installed		
❑ Over bath shower fitted		
❑ Ramp to front/back door created		
❑ Raise/lower electrical/light switches		
❑ Step to front/back door created		
Other		

A 8.7. Section 7: Equipment

In the last 2 months, have you received any equipment?
Yes ❑ → If yes, what equipment
No ❑

Minor adaptation	How many?	Cost to you?
❑ Adapted telephone		
❑ Bath seat		
❑ Commode chair		
❑ Entry phone		
❑ Hoist		
❑ Keysafe		
❑ Mobility scooter		
❑ Pendant alarm		
❑ Perching stool		
❑ Portable ramp		
❑ Pressure relieving mattress or overlay		
❑ Profiling bed		
❑ Raised chair seat		
❑ Raised toilet seat		
❑ RaisING chair seat		
❑ Shower chair on wheels		
❑ Walking frame		
❑ Wheelchair (manual)		
❑ Wheelchair (active user)		
❑ Wheelchair (electric powered)		
Other		

Section 8: Services you pay for yourself

In the last 2 months, have you paid privately for any health care services?
Yes ❑→ If yes, which services
No ❑

Service	How many times?	Cost to you?

Appendix 15: WP2c: Additional information

Unit costs

Table 59: Unit costs

Item	Unit cost, 2016 £	Source	Notes
Section 1: Hospital services			
Hospital outpatient appointment	119.70	NHS reference costs 2016[19]	Average consultant led, non-consultant led and outpatient procedures.
Day case	733.31	NHS reference costs 2016[19]	Average day case
Excess bed stay for planned hospital admission	361.67	NHS reference costs 2016	Over 4 nights (average length of stay)
Transfer to another hospital for recovery	331.63	NHS reference costs 2016	Average unit cost for rehabilitation
Excess bed stay for unplanned hospital admission	298.41	NHS reference costs 2016	Over 8 nights (average length of stay)
Other hospital admissions	389.10	NHS reference costs 2016	Regular day or night admissions
A&E or walk-in centre	137.74	NHS reference costs 2016	Emergency medicine
999 or 111 calls	7	NHS reference costs 2016	Ambulance calls
Other health care services (rounded to units)			
GP appointment	36	PSSRU 2016 p154[18]	Per surgery consultation of 9.22 minutes including direct care staff costs and qualification costs
Nurse appointment	11	PSSRU 2016 p152[18] PSSRU 2015 p183	Nurse based at GP practice including qualification costs: £44 per hour Average contact duration is 15.5 minutes (PSSRU 2015)
Nurse specialist appointment	13	PSSRU 2016 p151 PSSRU 2015 p184	Nurse band 7 including qualification costs: £52 per hour Assumes Average contact duration is 15.5 minutes (PSSRU 2015) as per nurse based at GP practice.
Therapist: occupational therapist, physiotherapist, speech therapist, chiropodist, podiatrist	9	PSSRU 2016 p194	Allied health professionals band 5: £34 per hour Assumes Average contact duration is 15.5 minutes (PSSRU 2015) as per nurse based at GP practice.
Social care services			

Item	Unit cost, 2016 £	Source	Notes
Home care, per appointment	12	PSSRU 2016 p169	Face-to-face weekday: £24 per hour Assume 30 minutes per session (ref UKHCA 2016 report)
Day care, per hour	13	PSSRU 2016 p37	£61 per client attendance 2.88 hours per attendance
Meals, per meal	4	Glendinning et al p201;[2] inflated to 2015-16	
Social service appointment: social worker	15.5	PSSRU 2016 p165 & p168	Average between social worker cost (Per hour of client-related work) and occupational therapist cost Assumes average contact duration is 15.5 minutes (PSSRU 2015) as per nurse based at GP practice.
Sitting service, per hour	21	PSSRU 2016 p94	Home sitting for disabled children, assumed generalisable for sitting service to older adults
Local authority transport service, per journey	0.55	Research briefings to parliament[73]	In 2013/14, there were over 15 million passenger trips provided by community transport organisations. In 2015, the Department of Transport estimated that £7.8 million were paid to community transport services from the Bus Service Operator's Grant + £200,000/year to the Community Transport Association. =£8.0 million/15 million trips=55p Inflated to 2016
Services provided by voluntary organisations or charities			
Befriending service, per session	7.7	PSSRU 2016 p55	£92/12 hours
Shopping service, per session	3	Supermarkets' delivery charges	Range is £1-£6, midpoint £3 selected.
Advice service, per session	32	PSSRU 2016 p131	Budgeting advice service for families
Cleaner, per hour	21	PSSRU 2016 p146[18]	Housekeeping assistant is at Agenda for change band 1. Mid point band 1 is £15,500/year.[74] Calculated from the ratio wages/hourly cost band 2.
Informal care			

Item	Unit cost, 2016 £	Source	Notes
Informal care, per hour	15.72	ONS annual survey of hours and earnings: 2016 Provisional results.[21]	Average hourly pay (gross)
Adaptations to home			
Downstairs conversion for WC/washroom	10,134	PSSRU 2016 p106-7[18]	
Downstairs extension for bedroom	27,468	PSSRU 2016 p106-7[18]	
Downstairs extension for en-suite bedroom	34,587	PSSRU 2016 p106-7[18]	
Downstairs extension for WC/washroom	23,199	PSSRU 2016 p106-7[18]	
Level access shower	4,782	PSSRU 2016 p106-7[18]	
Stair lift (straight)	1,927	PSSRU 2016 p106-7[18]	
Stair lift (complex)	4,693	PSSRU 2016 p106-7[18]	
Bed moved to downstairs room	40	PSSRU 2016 p106-7[18]	
External handrail fitted	42	PSSRU 2016 p106-7[18]	
Internal handrail fitted	28	PSSRU 2016 p106-7[18]	
Outside lighting installed	256	PSSRU 2016 p106-7[18]	
Over bath shower fitted	108	PSSRU 2016 p106-7[18]	
Ramp to front/back door created	316	PSSRU 2016 p106-7[18]	
Raise/lower electrical/light switches	80	PSSRU 2016 p106-7[18]	
Step to front/back door created	481	PSSRU 2016 p106-7[18]	
Equipment			
Adapted telephone	23	Glendinning et al 2010 p202, inflated to 2016 [2, 18]	
bath seat	40	Glendenning et al 2010 p202, inflated to 2016	
commode chair	188	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
entry phone	119	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
grab rail	112	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
hoist	1123	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
keysafe	47	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
magnifier	9	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
pendant alarm	100	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
perching stool	58	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
portable ramp	95	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
raised chair seat	51	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
raised toilet seat	30	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
raising chair seat	743	Glendenning et al 2010 p202, inflated to 2016[2, 18]	

Item	Unit cost, 2016 £	Source	Notes
shower chair on wheels	356	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
shower seat	49	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
special tin opener	14	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
tap turners	16	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
transfer boards	61	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
walking frame	69	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
walking stick	14	Glendenning et al 2010 p202, inflated to 2016[2, 18]	
Wheelchair (manual), per year	95	PSSRU p96	
Wheelchair (active user), per year	191	PSSRU p96	
Wheelchair (electric powered), per year	443	PSSRU p96	
Profiling bed	1139	Health and Safety Laboratory RR764 2010, p37 inflated to 2016[18]	Mid-point of the observed range of costs for electric profiling beds.
Pressure mattress	13.5	NICE CG179 2014 p279, inflated to 2016[18]	Average of rental cost per day for constant and alternating pressure mattresses.
Pressure cushion	29	Supplier online[75]	Invacare Propad profile pressure cushion

SCPQ: extent of missing data

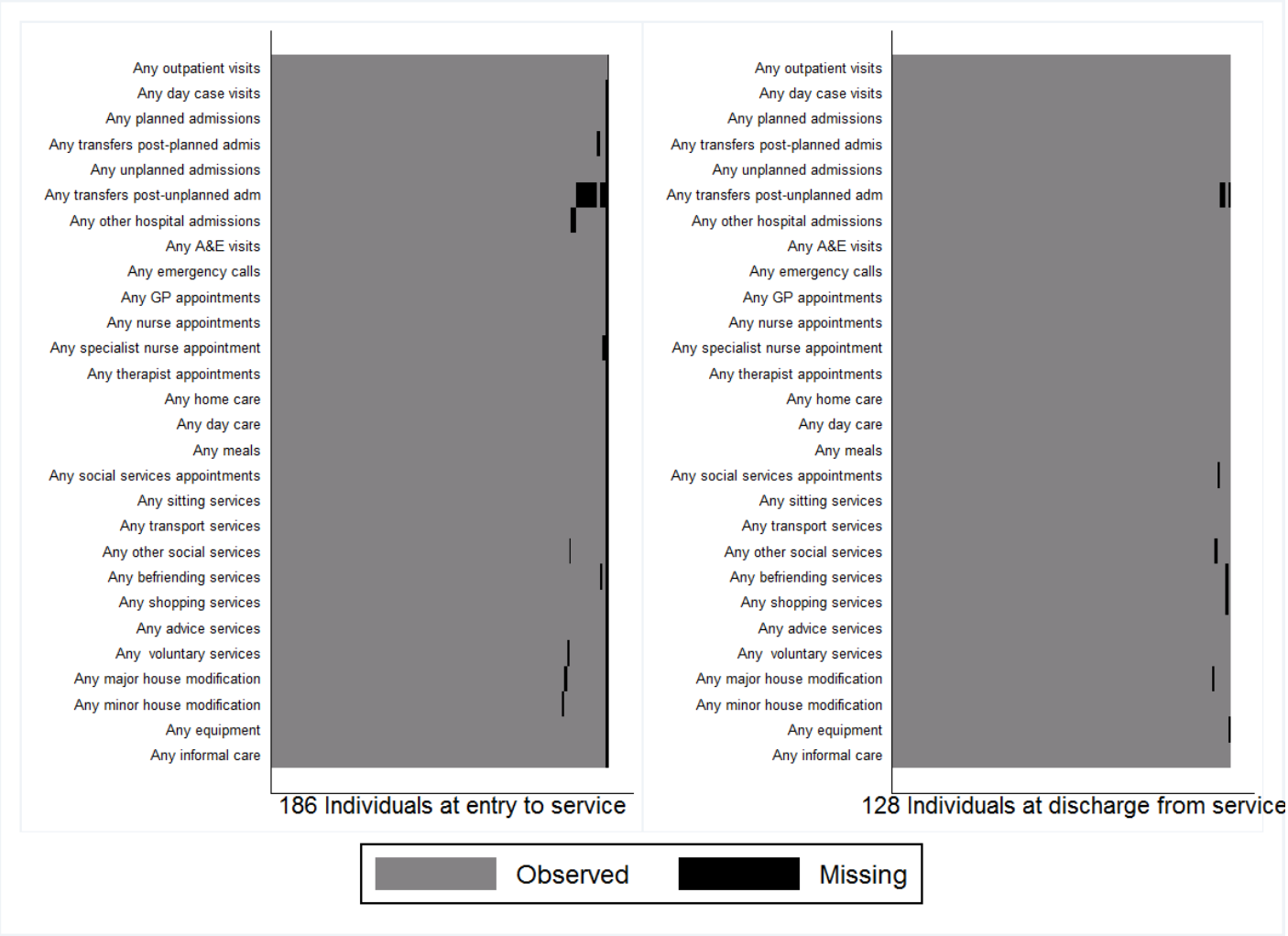

Figure 22: Missing information: resource use - T0 and T1

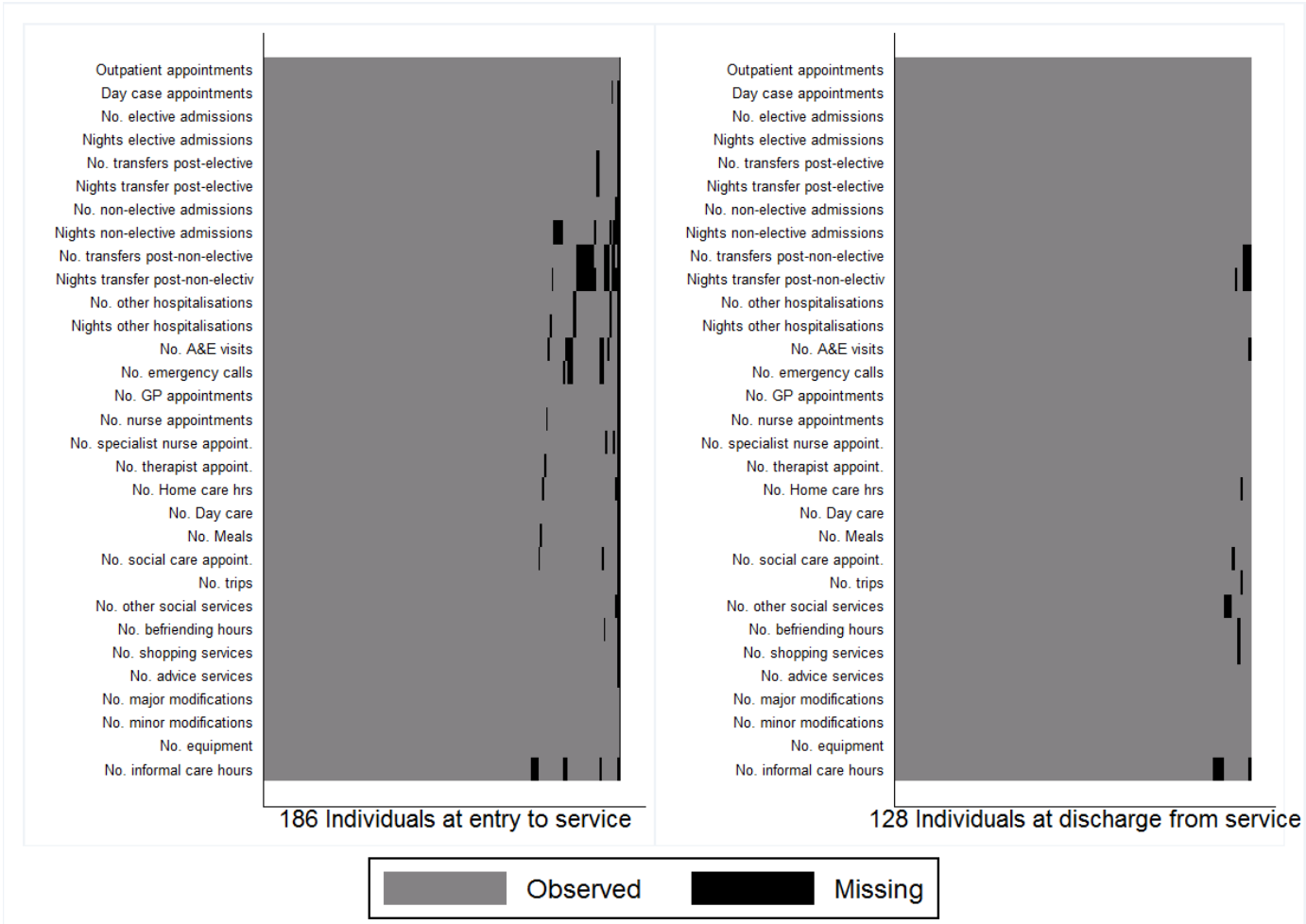

Figure 23: Missing information: intensity of resource use - T0 and T1

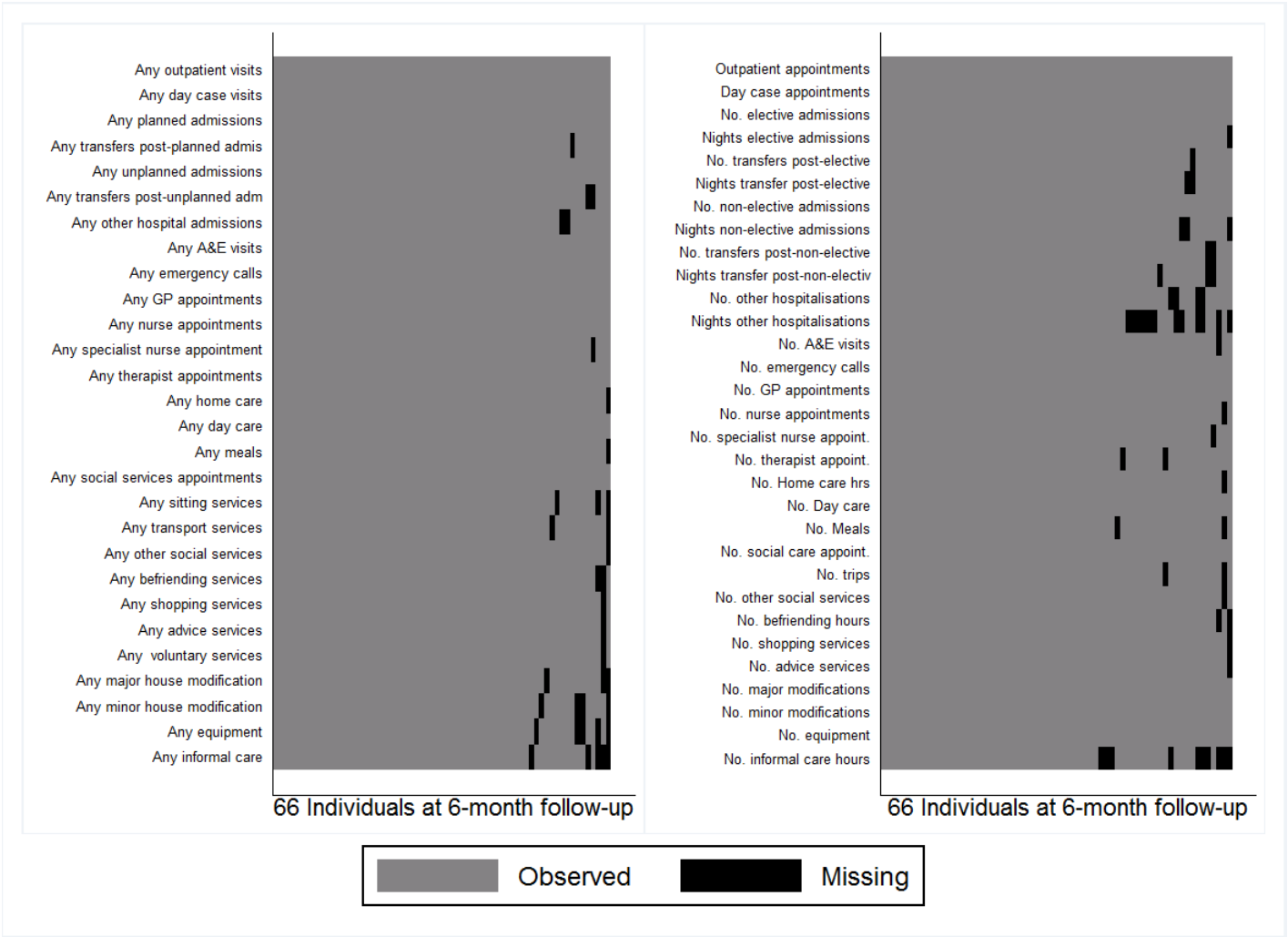

Figure 24: Missing information: resource use and the intensity of resource use - T2

Appendix 16: WP3: Analytical frameworks

Service lead/manager interviews: analytical framework

CHART1 – HISTORY AND CONTEXT

- Interviewee title/background/experience
- Year service set up & how long service offered to PWD
- Aims/objectives of the service for PWD
- Funding and commissioning arrangements (started as a pilot or mainstream funding)
- Barriers/facilitators in setting up the service
- Changes in service design since started

CHART2 – DESCRIPTION OF THE SERVICE

- Inclusion/exclusion criteria (including how these decisions are made and views on appropriateness of criteria)
- Knowledge of who has/has not have dementia and problems arising
- Referral routes
- Types of interventions and the duration of the intervention
- Ways the service organised/adapted to accommodate the needs of PWD (eg longer sessions, same person visiting, more experienced person)
- Advantages and disadvantages of organising/adapting the service in this way
- How goals are set, who is involved and how (including details provided by any other organisation)
- Details of ongoing assessments and monitoring progress
- What happens at the end – when clients are discharged – when clients need ongoing support
- Existence and details of any follow-up support provided

CHART3 – STAFF, TRAINING AND LINK WITH OTHER SERVICES

- Professional skills within the team
- Details of training opportunities
- Any differences between training for managers/all staff/staff working with PWD
- Views on adequacy of staff training and issues arising
- Suggestions for any useful dementia specific training
- Working with professional skills outside the service

CHART4 – VIEWS ON THE ADVANTAGES &DISADVANTAGES OF DIFFERENT TYPES OF RABLEMENT SERVICES SUPPORTING PWD

- Dementia specific reablement service
- Generic reablement with protocol
- Generic reablement without protocol

CHART5 – OUTCOMES, BARRIERS/FACILITATORS

- Views on positive outcomes to assess the success of reablement for PWD
- Views on reablement working for PWD
- Views on user-centred facilitators/barriers for reablement working for PWD
- Views on organisational facilitators/barriers for reablement working for PWD
- Views on the extent to which the service has met its' desired/intended objectives
- Views on the extent to which the NHS supports specialised services

CHART6 – MESSAGES FOR OTHER SERVICES AND SUGGESTIONS FOR IMPROVEMENT

- Messages for meeting the reablement needs of PWD
- What would have done differently with hindsight
- Suggestions for improvement

CHART7 – COST OF THE SERVICE

- Details of any database/record of service users kept (including how many use the service & time spent with and contacts per user)
- Details of records of what other services PWD use/how is it recorded/how linked up the service is to other services PWD might use
- Number of PWD receiving the service per month
- Existence/details of waiting list for the service – how many people & how long on the waiting list
- Existence/details of a separate budget
- Changes to the budget in the last 12 months and reasons for that
- Cost estimates of providing the service to PWD
- Views on whether providing specialist service more costly than providing a generic service
- Existence/details of additional resources required for PWD (eg staff time/more skilled staff/equipment)
- Views on how any additional financial resources would be spent – in the reablement service in general or in the reablement service for PWD (including reasons for that)
- Existence/details of any financial constraints the service is currently facing

Reablement worker interviews: analytical framework

CHART1- HISTORY AND CONTEXT

- Interviewee title/background/experience (inc. length of time working in the reablement team in general/in the team supporting PWD)
- Current case load
- Interviewee roles/responsibilities (supporting all/people with dementia)
- Training opportunities (including any specific dementia training)

CHART2 –REABLEMENT IN PRACTICE

- Types of intervention
- Differences in the way they work with PWD (eg longer sessions, more visits)
- Knowledge of client's condition (degree of dementia progression) including problems arising when lack of knowledge
- Goal setting (who is involved, how goals are decided & access to life stories)
- Details of on-going assessments & monitoring progress
- Existence/details of any outcomes measures used for PWD (including views on adequacy of tools)
- What happens at the end – when clients are discharged – when clients need ongoing support (including %s discharged altogether)
- Any delays in securing appropriate support for PWD (including issues arising)
- Existence and details of any follow-up support provided
- Details of any reablement work with the family

CHART3 –EXPERIENCES &VIEWS ABOUT REABLEMENT WORKING FOR PWD

- Does it work equally/differently with different groups of PWD (eg level of progression, family circumstances, age, referral route)
- Views on positive outcomes to assess the success of reablement for PWD

- Details of actual benefits of reablement for PWD (eg changes in functional ability, independence, quality of life, risk of entering residential care, social life)

CHART4 – FACILITATORS & BARRIERS

- Views on advantages and disadvantages of having a specialist service/ protocol for PWD
- Views on user-centered factors enhancing/constraining the benefits of the reablement for PWD
- Views on organisational factors enhancing/constraining the benefits of the reablement for PWD

CHART5- MESSAGES FOR OTHER SERVICES & SUGGESTIONS FOR IMPROVEMENT

- Messages for meeting the reablement needs of PWD
- Suggestions for improving the potential benefits of the reablement for PWD