An independent review of Shared Lives for older people and people living with dementia

Delivered by:

PPL

With partners
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1 Executive summary

PPL, with Cordis Bright and Social Finance has, over the past 6 months undertaken an independent review to assess Shared Lives respite care and day care for older people and people living with dementia.

The main finding is that **Shared Lives offers a care solution which provides high quality outcomes to service users and family/unpaid carers, and which is a sustainable option for commissioners**

The five key messages coming out of this review are as follows:

1. **Respite care is important, however the challenge is that individuals are not getting as much respite as they should. Further, a review of literature suggests that “traditional” respite is not achieving its full potential: greater personalisation is needed**

Respite care and short breaks provide a valuable service to family/unpaid carers who need short respite from their daily caring duties. This is important, because without respite there is a significant risk of carer breakdown. This can in turn lead to a much higher incidence of hospital readmissions for the individuals being cared for. One study has concluded that carer breakdown or fatigue was a significant factor behind 62% of hospital readmissions.

The recent CQC State of Health and Care report stated that 25% of carers have not received a single day away from caring in five years.

> “Rising demand for [social care] services due to an ageing population and years of underfunding have left adult social care services in crisis... As a result, many vulnerable people are being forced to rely on friends and family or are unable to access care at all. At the same time, the combined impact of reductions in fees paid by local authorities, staff shortages and the costs of paying those working in the sector the National Living Wage is forcing increasing numbers of care providers to leave the market. These problems are exacerbating pressures on the NHS, with the number of bed days lost due to delays in discharging patients from hospital attributable to social care having risen by nearly 50 per cent in the two years to the end of March 2017.”

**The King’s Fund, ‘What are the priorities for health and social care?’ August 2017**

Multiple reviews looking at family/unpaid carer outcomes for respite have reported that the potential of respite in delivering outcomes will only be effective when respite is provided in a more individualised manner, and is designed to meet the needs of the carer. However, the CQC’s 2016/17 state of health care and adult social care in England report stated that whilst quality of care services have improved overall, there is significant variation in the quality of services.

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2. Evidence shows that Shared Lives is able to offer a good quality, high impact solution to this challenge, offering a number of positive outcomes including increased independence, choice, and control for service users.

Shared Lives respite care and day support provides a personalised, flexible service, which – from the range of qualitative evidence reviewed – has been shown to deliver high quality care to service users, family/unpaid carers, and commissioners. For example a key benefit of the Shared Lives model is that the same Shared Lives carer can provide day care and respite when needed, which leads to reduced confusion caused by multiple environments for different forms of care. For family/unpaid carers, the Shared Lives model has been shown to deliver increased wellbeing, reduced feelings of social isolation, and reduced likelihood of carer breakdown.

“This [Shared Lives] model offers people more ‘natural’ support in an environment that is ‘someone's home’ - people respond more positively within these environments than in a residential model where they are living with a larger number of people who will also have demanding needs”

Social Care Commissioner (September 2017)

3. The costs of the Shared Lives approach are broadly in line with (and in some cases more affordable) than “traditional” respite provision.

The costs of Shared Lives are generally in-line with, and in some cases more affordable than “traditional” respite and day care provision (or is likely to be in the instance of Northern Ireland, if a new scheme is established).

- Day care: The evidence suggests that Shared Lives day care provision is in line with the costs that commissioners would expect to pay for “traditional” day care provision – there is no more than 10% difference between the costs. Evidence suggests costs for Shared Lives are slightly cheaper than “traditional” forms in Wales and Scotland, and slightly more expensive in England and Northern Ireland.
- Respite care: Local Authority-run Shared Lives respite schemes are cheaper in Wales and Scotland than “traditional” forms. Whilst in England and Northern Ireland the cost of Shared Lives is slightly more expensive than “traditional” forms.

This comparison should be viewed in the context of overall market sustainability (see message 4 below).
4. Shared Lives is an important option for commissioners seeking to meet their market sustainability duties

Legislation across the four nations emphasises the duty for Local Authorities to provide sustainable, high quality support for its carers.

Shared Lives schemes are taking a rigorous approach to the pricing of respite care and short breaks. Their approach focuses on ensuring costs are fully recovered so that the service can be both sustainable, and available.

Further research by Cordis Bright has found that the pricing approach offered by “traditional” providers of respite care appears not to take into account the “true” cost of delivering a respite service. Shared Lives schemes do not have the opportunity to cross-subsidise in this manner. However their realistic approach to costing their services does suggest that it may be a more sustainable and available option for commissioners in the longer term.

5. The Shared Lives approach has great potential to make savings in terms of reduced reliance on more expensive health services

The positive outcomes from Shared Lives are likely to lead to reduced requirement for health services. This has the potential to lead to cashable savings for the health commissioners.
2 Purpose of this review

2.1 Shared Lives background
Shared Lives, through its network of 8,000 Shared Lives carer members, provides care to 13,000 people in 153 local Shared Lives schemes across the UK. The premise of Shared Lives is based around a Shared Lives carer sharing their home with an adult in need of care, to encourage meaningful relationships, independent living skills and community integration.

Shared Lives is increasingly being used to deliver short breaks / respite care and day support to vulnerable people across the UK. Currently 48% of Shared Lives arrangements provide short breaks and day support (see Figure 2-1 below).

Figure 2-1: Usage of day support and short breaks for Shared Lives

Type of Shared lives arrangement by % of overall use

- Short breaks: 28%
- Day support: 52%
- Other: 20%

Source – Shared Lives State of Sector reports for England, Wales, Scotland and Northern Ireland

2.2 Why this review is needed
Shared Lives’ respite service for older people and users with dementia is different to “traditional” forms of respite care, as explained further in Section 3 below. This independent review explores the results this model delivers to its users, and also how it compares to “traditional” forms. This is not only important for recipients and family/unpaid carers who want the best outcomes for themselves but also for care commissioners who want to make the best available decisions for their populations. Without the comparison between these two services, commissioners (or individuals) cannot make informed decisions.
3 Comparing Shared Lives’ day care and respite care with “traditional” forms

3.1 The Shared Lives model

Shared Lives focus on providing a flexible, personal service which encourages independence and can reduce impact on health/care services. Shared Lives Plus gives the following definition of Shared Lives care:

“Shared Lives care offers people an alternative and highly flexible form of accommodation and/or care or support inside or outside the Shared lives carer’s home. Shared Lives arrangements are set up and supported by Shared Lives schemes and the care and accommodation people receive is provided by ordinary individuals, couples or families in the local community. This alternative enables individuals taking up a Shared Lives opportunity and the Shared Lives carer/s to enjoy shared activities and life experiences. Shared Lives enables a wide range of vulnerable people to live independent lives, have their health and well-being promoted and can reduce the need for admission to hospital or residential care”

In terms of respite care, the Shared Lives offer is as follows:

“Whilst Shared Lives is often used as a long-term support, it is increasingly being made available as a short breaks (sometimes known as respite) option to complement other arrangements. In short breaks Shared Lives arrangements a person will stay with a Shared Lives carer from one night to several weeks. Short breaks are usually accessed by people using long term Shared Lives arrangements, to have a break from staying with their main Shared Lives carer. They are also being increasingly used by family carers, as an alternative to traditional respite. Shared Lives can also be used as day support, where a person receives support from a Shared Lives carer during the day. Part of the support will be provided at the Shared Lives carer’s home and then the person will be supported to access activities of interest in the local community.”

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Case study – Beth, Shared Lives short breaks user

Beth, 87, lives with her daughter and son in law. Beth has dementia and her short-term memory and attention span is now poor. She also has hearing loss but does not like to wear her hearing aid and her eyesight is also becoming quite difficult, despite her glasses.

Beth is a private person and says she “keeps herself to herself”. She does not like crowds or noisy places as she finds it quite confusing if a lot is going on and cannot hear people if there is a lot of noise.

A referral was made to Shared Lives Fife to identify a carer who could provide some short breaks for Beth. Carers Anne & Bill, were identified and a visit was arranged to introduce them to Beth. Introductions and an initial overnight stay went well and both Beth and her daughter and son in law were happy with the match.

Beth has now had several short breaks with Anne and Bill and has stated she enjoys spending time with them. She can occasionally get restless and agitated and needs reassurance about when her daughter is returning but Anne & Bill can offer this and support Beth to ensure her short break is a happy one.

“Shared Lives allows us to continue to care for our mother at home despite her progressing dementia. She has really bonded with the Shared Lives Fife carers, where we know she is totally safe. This innovative care service is second to none and has our full admiration” - Beth’s daughter

3.2 Approach of this review

This review tests how the Shared Lives model of respite care compares to “traditional” forms. In order to do this we have evaluated the Shared Lives model across three areas:

1) **Outcomes** – a comparison of outcomes which occur for service users, family/unpaid carers, and care commissioners, as a result of using Shared Lives short breaks and respite care for older people and people with dementia, versus “traditional” forms. See Section 1 for more detail; and

2) **Direct care costs** – comparison of the direct care costs to care commissioners of Shared Lives short breaks and respite care for older people and people with dementia, versus “traditional” forms. See Section 5 for more detail;

3) **Impact on broader health system** – a comparison of the impact on health services, in terms of possible cashable savings, as a result of using Shared Lives short breaks and respite care for older people and people with dementia, versus “traditional” forms. See Section 6 for more detail.
4 Outcomes comparison for Shared Lives versus “traditional” forms

4.1 Introduction:
The aim here was to investigate the outcomes of Shared Lives provision compared to “traditional” forms of day care and respite care for the service user, family/unpaid carer, and care commissioner.

4.2 Approach

4.2.1 Outcomes for the Shared Lives model
The identification of outcomes for Shared Lives was largely drawn from those Shared Lives schemes that already offer respite services for older people and people with dementia. Feedback from a number of Shared Lives users, their family members, Shared Lives carers and scheme staff was collected and reviewed, with a view to consolidate and standardise different themes or comments into a set of outcomes with minimal duplication.

In some cases feedback compared Shared Lives provision against alternative / traditional forms of respite; where for example an individual had had a negative experience of “traditional” respite, and had their needs much better met when using Shared Lives. In other cases the feedback noted simply the positive outcomes of Shared Lives, where otherwise it appeared that the individual and their family were receiving no support.

Outcomes were then summarised, and standardised, before being validated with Shared Lives Plus and a number of Shared Lives schemes.

4.2.2 Outcomes for “traditional” forms
Appendix E shows the descriptions of “traditional” day care and respite care which we have used to underpin this research. The identification of outcomes of “traditional” forms of respite and day care was undertaken via a literature review of relevant search terms. Relevant literature was synthesised to pull out key themes. A detailed outline of the methodology, findings and references utilised in the review can be found in Appendix C.

4.3 Comparing the Shared Lives model to “traditional” forms of respite care
As part of our review of the Shared Lives model, and “traditional” forms of respite care, we identified some key differences between the Shared Lives model of respite care, and “traditional” forms. While there will be some local variation, the characteristics below are broadly what service users can expect from the different care models. These are characteristics of care – we focus on the outcomes to the service user/carer/care commissioner in the subsequent sections.
Table 4-1 – The key differences and similarities between Shared Lives and “traditional” forms of respite care

<table>
<thead>
<tr>
<th>Component</th>
<th>Shared Lives respite care</th>
<th>“Traditional” respite care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care always delivered by same carer</td>
<td>Usually</td>
<td>No</td>
</tr>
<tr>
<td>Level of flexibility around length of stay</td>
<td>High</td>
<td>Medium</td>
</tr>
<tr>
<td>Regular activities personalised to user</td>
<td>High</td>
<td>Medium</td>
</tr>
<tr>
<td>Number of users per carer</td>
<td>Low</td>
<td>Medium</td>
</tr>
</tbody>
</table>

4.4 Key findings for service users

4.4.1 Outcomes for service users – Shared Lives model

The outcomes below have been gathered directly from those who use Shared Lives – service users, their families, carers, and Shared Lives scheme staff. As far as we are aware, there are no systematic reviews of outcomes for service users of Shared Lives respite. As a result, we have focused on the qualitative evidence available, from which the following outcomes emerge as the key aspects of Shared Lives respite care:

- Reduced confusion caused by new people
- Reduced confusion caused by new environments
- Reduced confusion or upset caused by unfamiliar / unduly sterile type of environment
- Reduced confusion caused by multiple environments for different forms of care (where the same Shared Lives carer can provide day care and respite when needed)
- Slower decrease (or increase) in physical abilities / life skills
- Increased independence, choice and control
- Reduced social isolation and loneliness
- Increased sense of wellbeing / mental health

Case study – Brigita, Shared Lives short breaks user

“As an older person, Brigita was already frail and when her health broke down further it was clear that recovery might take some time. Instead of going into hospital, Brigita was given an initial 6 week short break with Shared Lives – which was able to be extended to allow her to recover fully.

Originally from Eastern Europe, Brigita’s English is limited and she felt isolated – which was further exacerbated by falling ill. Using Shared Lives addressed not just her ill health but also this isolation, giving her a sense of community and belonging. Within her Shared Lives ‘family’ Brigita felt that she could ‘not have to worry about anything but getting better’, and tells everyone how grateful she is to her Shared Lives family for the support and friendship they give her.”
4.4.2 Outcomes for service users – “traditional” forms

There is no evidence from systematic reviews of positive outcomes for service users as a result of accessing “traditional” residential respite\(^6\), with multiple literature reviews finding no robust evidence that respite has any demonstrable benefits on cognition, function or physical health.

Whilst these literature reviews also demonstrated that there is no robust evidence that respite has any demonstrable adverse effects on service user’s cognition, function or physical health, researchers have highlighted the potential of commonly-available forms of respite care to result in negative outcomes such as care recipient distress\(^7\).

The literature suggests that a criticism of “traditional” respite care relates to difficulties associated with people receiving respite in unfamiliar settings. For example, a narrative review of the impact of respite on older people, with a focus on dementia respite, reported that future directions for this type of care may need to use more flexible or innovative methods of delivery, such as host-family respite\(^8\).

However, outcomes associated with day care are more positive with a recent systematic review reporting that day care is an effective strategy for reducing behavioural problems and possibly improving sleep quality\(^9\).

Further, qualitative research has reported evidence of day care contributing to\(^10\):

- Improved emotional and psychological wellbeing
- Reduced isolation and loneliness
- Physical wellness
- Independence and control

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\(^6\) Mason et al., 2007; Maayan et al., 2014; Neville et al., 2015
\(^7\) Shaw et al., 2009
\(^8\) Tang et al., 2011
\(^9\) Vandepitte et al., 2016
\(^10\) Tower Hamlets, 2015
4.6 Key findings for family/unpaid carers

4.6.1 Outcomes for family/unpaid carers – Shared Lives model

It is notable that outcomes reported for the Shared Lives model of care often focus on the individualised nature of the care, and how well-tailored it can be for family/unpaid carers and for service users alike. As such, positive outcomes reported include:

- Increased wellbeing / mental health due to ‘time off’
- Reduced feelings of social isolation
- Reduced likelihood of carer breakdown

The case study below shows how the personalised approach taken by Shared Lives led to more positive outcomes for both Harold (the service user), and his Shared Lives carer (Lynne), compared to the negative outcomes when using “traditional” forms of respite care.

**Case study – Harold, Shared Lives respite care user**

“In April of this year Rochdale Shared Lives was approached by Harold’s daughter Lynne who gave up her job as a college lecturer to look after her dad who has dementia. Previously, when Lynne had to go in hospital, Harold went for respite in a nursing home. Although Lynne had invested many hours researching and visiting nursing homes, when Harold returned home, she described her dad as ‘losing more of himself’. At the time of contacting Shared Lives, Lynne was planning her wedding - but had intense fears of leaving her dad in a “traditional” respite setting again.

The scheme advised Lynne that they could help, and after a period of careful matching, a suitable carer was identified. Karen is a Shared Lives carer who lives very near to Harold and visits the same Tesco that Harold regularly enjoys visiting. Her husband, Vincent, remembered Harold as a former next door neighbour when he was a child.

Although Lynne had been really concerned about leaving her dad, her fears disappeared after Harold’s first period of respite care with Karen and Vincent. Harold returned home happy, with ‘no deterioration’, to Lynne’s relief.

She and her husband are now planning on taking regular weekend breaks away and are planning a fortnight away next summer when Harold will stay with Karen.”
4.6.3 Outcomes for family/unpaid carers – “traditional” forms

Joint research by Carers UK and other partners surveying over 3,000 UK family/unpaid carers reported that having somebody to help with caring, thereby enabling them to have a break and recuperate, is important in preventing carers from reaching breaking point\textsuperscript{11}.

There is mixed evidence from systematic literature reviews on impact of respite care on “carer burden”\textsuperscript{12}. There is tentative evidence that whilst respite should alleviate “carer burden”, current provision is not meeting full potential. However, day care has been shown to have a positive effect on “carer burden”\textsuperscript{13}.

Substantive qualitative research has highlighted high satisfaction and positive perceptions of carers regarding respite care\textsuperscript{14}.

Some evidence from systematic literature reviews on mental health, including depression\textsuperscript{15}.

Positive evidence of impact of respite care on maintaining physical health of carers\textsuperscript{16}.

However, multiple reviews looking at family/unpaid carer outcomes for respite have reported that the potential of respite in delivering outcomes will only be effective when respite is provided in a more individualised manner, and is designed to meet the needs of the carer\textsuperscript{17}.

\textsuperscript{11} Carers UK, 2012
\textsuperscript{12} Pickard, 2004; Mason et al., 2007; Lopez-Hartmann, 2011; Shaw et al., 2009
\textsuperscript{13} Pickard, 2004; Davies and Fernandez, 2000
\textsuperscript{14} Pickard, 2004; Davies and Fernandez, 2000
\textsuperscript{15} Mason et al., 2007; Lopez-Hartmann, 2011
\textsuperscript{16} Ibid.
\textsuperscript{17} Shaw et al., 2009; Neville et al., 2015
4.8 Key findings for care commissioners

4.8.1 Outcomes for commissioners – Shared Lives model

As with outcomes for individuals and for family/unpaid carers, outcomes of the Shared Lives model for commissioners have been gathered expressly for this report. As before, whilst there has been no systematic review of commissioners, the focus has been on interviews and questionnaires which tested commissioners’ views concerning Shared Lives.

Commissioners who use Shared Lives widely attested to the quality of care it delivers, which they often ascribe to the personalised nature of the care.

- Individuals able to stay at home (with a Shared Lives carer) for longer
- Reduced demand for residential / nursing care
- Reduced reliance on primary / secondary care (qualitative evidence)

Further, informally commissioners reported a belief that Shared Lives was responsible for reducing pressures on other services (by meeting individuals’ needs at home for longer), but there is little direct evidence of this available.

Case study – Oxfordshire County Council

In December 2013, Oxfordshire County Council sought the views of families who support their relative at home about the respite services they receive and how they felt adult respite services should be provided in the future, to best support the person with a learning disability, carer and family.

500 questionnaires were sent out to families and 149 were returned.

For the Shared Lives Respite scheme the feedback was positive and several people wanted us to provide more of this service. It was described as "flexible" and person centred.

One of the ‘Key Messages’ from the responses was simply: “More Shared Lives Respite”

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18 Oxfordshire County Council website, “Respite (Short Breaks) for Adults with Learning Disabilities”, Summary of Results: https://consultations.oxfordshire.gov.uk/consult.ti/RespiteforadultswithLD/consultationHome
4.8.3 Outcomes for commissioners – “traditional” forms

There is evidence to suggest that family/unpaid carer wellbeing is a key factor in hospital admissions, readmission and delays in the transfer of care\(^{19}\). Indeed, the recent State of Caring Report reported that without replacement care for carers, carers are often pushed to breaking point which can result in them having to give up work, stop caring, or potentially lead them to go into hospital themselves\(^{20}\).

Whilst qualitative research has indicated that respite care is essential in helping family/unpaid carers to continue their caring role\(^{21}\).

There is conflicting evidence regarding the impact of respite on admission to institutional care\(^{22}\).

However, effectiveness of respite and day care services are dependent on quality of care and individualisation of support to meet needs of the family/unpaid carer\(^{23}\).

“Respite care is only respite if the same quality of care is offered to the patient in a respite facility that is offered at home.”\(^{24}\)

4.9 Availability of Shared Lives and “traditional” forms

| 25% [of carers] have not received a single day away from caring in five years\(^{25}\) |
| 20% of carers providing 50 hours or more of care per week are receiving no support from their caring role\(^{26}\) |

Currently, family/unpaid carers find it difficult to access respite care. Cordis Bright’s experience of working with “traditional” providers of respite care offered in care homes suggests that these organisations can struggle to make their service available on a sustainable basis. For example, research which Cordis Bright produced for health and social care commissioners in Suffolk provides some insight\(^{27}\). In section 2.8.3 of this research report, we learn that 89% of local providers responding to a survey say that they offer respite care. However, numerous other pieces of evidence suggest that this respite care is very difficult to access in practice, since providers inevitably prioritise longer-term placements over a short-term respite placement (see sections 2.8.2, 2.8.4 and 3.2.1, for example).

Shared Lives can offer additional flexibility and supply into a market which is currently struggling to provide sufficient availability of respite care.

\(^{19}\) Carers Trust, 2015  
\(^{20}\) Carers UK, 2016  
\(^{21}\) Vandepitte et al., 2016a; Vandepitte et al., 2016b; Shaw et al., 2009.  
\(^{22}\) Mittelman et al., 1996; Pickard, 2004; Mason et al., 2007  
\(^{23}\) Shaw et al., 2009; Neville et al., 2015;  
\(^{24}\) Strang, 2000  
\(^{26}\) Office for National Statistics, 2011  
4.10 So what?
Evidence shows that Shared Lives respite care and day support provides a personalised, flexible service, which – from the range of qualitative evidence reviewed – has been shown to deliver consistently high quality of care to service users, family/unpaid carers, and commissioners. For example a key benefit of the Shared Lives model is the reduced confusion caused by multiple environments for different forms of care; whereas in Shared Lives the same carer can provide day care and respite when needed.

This quality has also been acknowledged by the independent regulator of all health and social care services in England, the Care Quality Commission (CQC). The CQC, in its 2016/17 state of health care and adult social care in England report, highlighted Shared Lives’ quality of care as being particularly beneficial.

“There is considerable variation if we look at the ratings across different types of services. Community social care services (for example supported living and Shared Lives) were rated the best overall when compared with other services”

Care Quality Commission, ‘The state of health care and adult social care in England 2016/17’

Whilst “traditional” forms of respite care and day support can deliver positive outcomes, evidence suggests the potential of respite in delivering outcomes will only be effective when respite is provided in a more individualised manner, and is designed to meet the needs of the family/unpaid carer.

Therefore Shared Lives offers a good quality solution to the challenge of variation in quality of “traditional” forms of respite care and day support.

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28 CQC (2017). The state of health care and adult social care in England
5 Direct care costs to care commissioners

5.1 Introduction:
The aim here was to examine and compare the costs of Shared Lives with “traditional” forms of care within all four nations. These costings should help commissioners to make informed choices on the services they need in order to improve outcomes for individuals.

We would like to highlight that cost is just one factor to consider when reviewing different care models, and in Section 4 we present the outcomes associated with Shared Lives, and “traditional” forms.

We have also investigated how sustainable the Shared Lives model is compared to “traditional” forms.

5.2 Approach

5.2.1 Care costs for the Shared Lives model
Data on the cost of Shared Lives respite and day care provision was calculated in two parts:

1) Direct Shared Lives carer costs:
   - Information on the fees paid to Shared Lives carers in each country was gathered directly from Shared Lives schemes by Shared Lives Plus, and included data from both local authority-run and independently-run schemes;
   - No data was available for Northern Ireland, where there are currently no Shared Lives services providing respite or day care services for older people, in the absence of which an average figure was calculated for comparison purposes from the Scottish and Welsh figures; and
   - Where information was submitted by schemes, costs given referenced the period of time for which a Shared Lives carer was paid, from which we were able to calculate an average cost per 24 hour period of care (respite / short breaks) and per hour for day care.

2) Additional scheme-level costs:
   - Figures for the additional scheme-level costs of providing or expanding these types of provision was calculated separately, and then added to the fee paid to Shared Lives carers; and
   - A full break down of the approach to calculating the scheme level costs is available in Appendix A.

3) The length of a day
   - The available data shows that the average length of a Shared Lives day care session is 6 hours.

5.2.2 Care costs for “traditional” forms
Direct care costs for “traditional” forms of respite and day care were found by sending Freedom of Information requests:

- Freedom of Information requests were sent to 210 local authorities and health and social care trusts across England, Wales, Northern Ireland and Scotland;
- There was a 77% response rate overall. Responses were collated and analysed to calculate average lowest, highest and overall average of residential respite and day care;
• Responses provided an average daily cost for day care. This was converted to an hourly cost, based on an average day of “traditional” day care lasting 5 hours (see section 8.2.1.1 below which shows how we arrived at this figure); and
• A detailed breakdown of the methodology and findings of the FoI requests can be found in Appendix B.

5.3 Key findings
Comparison between the cost of “traditional” forms of short breaks / respite and day care as commissioned by local authorities, and the cost of these services as provided by Shared Lives schemes show:

• Regarding respite care:
  o Whilst in England and Northern Ireland the cost of Shared Lives respite provision is more expensive than the average cost of “traditional” forms of short breaks and respite care provided in a residential care home, LA-run Shared Lives respite schemes are cheaper in Wales and Scotland than the average cost of “traditional” forms.
  o The range of costs of respite care is wide, across all the nations, and the cost of Shared Lives is well within the range of costs which commissioners would currently expect to pay (see Figure 8-2)

• Regarding day care:
  o The evidence suggests that Shared Lives day care provision is in line with the costs that commissioners would expect to pay for “traditional” day care provision – there is no more than 10% difference between the costs
  o The cost of Shared Lives day care provision is slightly more expensive than “traditional” forms in England and Northern Ireland.
  o However, in Scotland “traditional” forms of day care are slightly more expensive than Shared Lives provision.
  o Further, “traditional” forms of day care in Wales are the same price as individually-run Shared Lives day care provision, and slightly more expensive than LA-run provision.

Therefore, the costs of Shared Lives are generally in-line with, and in some cases more affordable than “traditional” respite and day care provision (or is likely to be in the instance of Northern Ireland, if a new scheme is established).
Figure 5-1 – Financial comparison of Shared Lives with “traditional” forms of care – respite care

<table>
<thead>
<tr>
<th>“Traditional” forms of short breaks and respite care provided in a residential care home</th>
<th>England</th>
<th>Scotland</th>
<th>Northern Ireland</th>
<th>Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>FOI data requested per night or per 24 hour period</td>
<td>£81.27</td>
<td>£80.54</td>
<td>£73.21</td>
<td>£79.61</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Shared Lives provision (including scheme investment)</th>
<th>England</th>
<th>Scotland</th>
<th>Northern Ireland</th>
<th>Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>Short break/nightly rate</td>
<td>LA</td>
<td>£96.26</td>
<td>£77.40</td>
<td>£98.77</td>
</tr>
<tr>
<td></td>
<td>Ind.</td>
<td>£104.59</td>
<td>£85.73</td>
<td></td>
</tr>
</tbody>
</table>

Source: Appendices A and B

Figure 5-2 – Financial comparison of Shared Lives with “traditional” forms of care – day care

<table>
<thead>
<tr>
<th>“Traditional” forms of day care</th>
<th>England</th>
<th>Scotland</th>
<th>Northern Ireland</th>
<th>Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost per hour (assumes a day lasts 5 hours on average)</td>
<td>£8.80</td>
<td>£9.17</td>
<td>£8.58</td>
<td>£8.68</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Shared Lives provision (including scheme investment)</th>
<th>England</th>
<th>Scotland</th>
<th>Northern Ireland</th>
<th>Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost per hour (assumes a day lasts 6 hours on average)</td>
<td>LA</td>
<td>£8.99</td>
<td>£8.50</td>
<td>£9.32</td>
</tr>
<tr>
<td></td>
<td>Ind.</td>
<td>£9.23</td>
<td>£8.74</td>
<td></td>
</tr>
</tbody>
</table>

Source: Appendices A and B

5.4 Accessing sustainable respite care

5.4.1 Sustainability of care provision

The market for the provision of social care is fluid, with providers entering and exiting the market regularly. The departure of Southern Cross from the care home market in 2011 created a heightened focus on the need to ensure sustainable provision. Across the four nations, legislation has been imposed to try to achieve this sustainable provision:

29 In fact, a good proportion of Southern Cross’s homes continued to operate as care homes, but the 30,000 or so residents in their care all experienced a high degree of uncertainty and change.
• In Wales, the 2014 Social Services & Well-Being Act imposes duties on Local Authorities to work to promote the well-being of those who need care and support, or family/unpaid carers who need support,
• In Scotland, the 2016 Carers Act puts emphasis on the duty of Local Authorities to provide support for its family/unpaid carers.
• In England, the 2014 Care Act introduced new duties on Local Authorities to facilitate a vibrant, diverse and sustainable market for high quality care and support in their area, for the benefit of their whole local population, regardless of how the services are funded.
• In Northern Ireland, the 2002 Carers and Direct Payment Act places a duty on HSC Trusts to inform carers of their legal right to a care assessment, gives carers the right to an assessment of their own and to be considered for services to meet their own need and gives HSC Trusts the right to provide personal social services to support carers directly.

Even among smaller providers, there is clear evidence that the market is regularly changing, making sustainable provision for individuals difficult to secure. For example, the Public Policy Institute for Wales note an overall loss of 30 care homes in Wales, during the period 2012-2015\(^\text{30}\) \(^\text{31}\). Similarly, CQC’s State of Care Report for England 2017 indicates a continued decline in the number of care home beds (with nursing care experiencing particular difficulties). Whilst the overall declines may appear modest, they should be set against the significant increases in the older population that we are currently and will continue to experience.

For “traditional” respite care, which relies on the availability of care home beds, this instability undermines efforts to provide sustainable respite care.

5.4.2 Availability of “traditional” respite care
Cordis Bright’s experience of working with “traditional” providers of respite care in care homes offers supports the view that these organisations can struggle to make their respite service available on a sustainable basis. For example, research which Cordis Bright produced for health and social care commissioners in Suffolk provides some insight\(^\text{32}\). In Section 2.8.3 of the report, we learn that 84% of local providers responding to a survey say that they offer respite care. However, numerous other pieces of evidence suggest that this respite care is very difficult to access in practice, since providers inevitably prioritise longer-term placements over a short-term respite placement (see Sections 2.8.2, 2.8.4 and 3.2.1, for example). Commissioners have also offered anecdotal examples of the challenges in accessing respite care in a traditional care home, where longer term placements are prioritised and the price charged can be subject to increases once the individual has arrived and their needs fully assessed.

\(^{30}\) Moultrie, K and Rattle, N (2015) The Care Home Market in Wales: Mapping the Sector PPIW
\(^{31}\) Whilst it is clear that this resulted in a net loss of care homes, we have no evidence to determine whether this resulted in a net loss of beds overall, although it is reasonable to assume the numbers of beds reduced.
5.4.3 Approaches to pricing

Further research by Cordis Bright has found that the pricing approach offered by “traditional” providers of respite care appears not to take into account the “true” cost of delivering a respite service. Our research found that whilst the average price of respite care in England (according to the Freedom of Information request) is £81.27, the average price of a residential care bed in 2015-2016 was £85.43\(^3\). The price of a respite care placement ought really to be higher than the cost of a residential placement because there are numerous additional costs involved in delivering a short-term respite placements (additional administration, marketing, handover time etc.). The current pricing approach of “traditional” respite care appears to mask these true costs, presumably cross-subsidising them from the provision of wider residential placements. Traditional respite care purchased by commissioners also benefits from an additional cross-subsidy: as fewer and fewer people qualify for state-funded social care, there is an increase in privately-purchased provision\(^3\) which can also allow the true cost of respite provision to be reduced.

Shared Lives schemes do not have the opportunity to cross-subsidise in this manner. However their realistic approach to costing their services does suggest that it may be a more sustainable and available option for commissioners in the longer term.

Anecdotally, we find evidence that the pricing of “traditional” respite care may be changing. The results of our Freedom of Information request show averages. However within these averages, a small number of extremely high responses were received (e.g. ranging from £200-£500 per night). It is difficult to speculate as to the reasons for this: it could simply be a mistake. However it may represent the beginnings of a change in pricing behaviour among “traditional” respite care providers who are realising the true costs of respite care and its value to the wider social care market. It will be interesting to see whether this is a trend that develops in future. If it does, the pricing approach adopted by Shared Lives schemes will become all the more favourable to Commissioners.

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\(^3\) [Link](https://www.gov.uk/government/statistics/personal-social-services-expenditure-and-unit-costs-england-2015-to-2016) Personal Social Services Expenditure and Unit Cost data is only available in this form for England. A UK-wide or country-by-country comparison is not available.

\(^3\) Personal Social Services Service User Survey 2016-2017 show that 35% of respondents “top-up” their state-funded care. Data concerning the amount of care which is entirely privately purchased are difficult to establish, but anecdotal evidence from care providers indicates that this is an increasingly important part of their income streams. In Suffolk for example (see report above) the local authority purchases 39% of available care beds. Some of the remaining 61% will be purchased by neighbouring local authorities and local health commissioners, but private payers will constitute a significant proportion of this market.
5.6 So what?
The evidence suggests that the costs of Shared Lives are generally in-line with, and in some cases more affordable than “traditional” respite and day care provision (or is likely to be in the instance of Northern Ireland, if a new scheme is established).

The cost of Shared Lives, for both respite care and day care, falls well within the range of costs which commissioners would currently expect to pay for more “traditional” forms of respite and day care.

Shared Lives schemes are taking a rigorous approach to the pricing of respite care and short breaks. Their approach focuses on ensuring costs are fully recovered so that the service can be both sustainable, and available.

This review finds that Shared Lives is likely to be an important sustainable option for commissioners seeking to meet their duties under the care act.
6  Impact on broader health system

6.1  Introduction:
So far, the review has focused on the impact of Shared Lives respite care on the service user, the family/unpaid carer, and the care commissioner. In this section, we investigate the impact that Shared Lives’ respite care has on its users’ level of healthcare service usage. We want to understand if Shared Lives’ respite care adds value to health commissioners, by reducing the burden on healthcare service usage.

6.2  The case for reduced healthcare service usage
There are many reasons why healthcare service usage may be higher amongst older people and people living with dementia. Figure 6-1 below shows key reasons which drive this.

Figure 6-1 – The link between adverse effects in social care and healthcare service usage

- Increased carer breakdown
- Increased patient loneliness
- Increase in hospital readmissions
- Increase in GP visits

Literature suggests that carer breakdown may be correlated with hospital admission of the recipient of care. For example:

- One study concluded that carer breakdown or fatigue was a significant factor behind 62% of hospital readmissions.\(^{35}\)
- A whole systems study tracking a sample of people over 75 years old who had entered the health and social care system found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent.\(^{36}\)

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\(^{24}\) Ellaway et al. (1999). Someone to talk to? The role of loneliness as a factor in the frequency of GP consultations. British Journal of General Practice.
Studies have also shown that increased levels of loneliness, and reduced levels of independence may be correlated with the number of GP appointments. For example:

- One study found that average GP visits nearly doubled when a patient felt lonely most of the time compared with never\(^24\)

From Section 4.6.1 we know that the Shared Lives model of respite care leads to a reduced likelihood of carer breakdown. From Section 4.4.1 we know that the Shared Lives model of respite care leads to reduced levels of loneliness, and increased levels of independence. It is reasonable to conclude that there may be a link between the Shared Lives model of respite care, and a reduction in health service usage.

6.3 Approach
Although there is a theoretical link between the Shared Lives model and a reduction in healthcare service usage, this review aimed to find a direct link.

A three-pronged approach was taken in order to establish any quantifiable impact on healthcare service usage. This consisted of a literature review, surveys and user interviews. Financial modelling was also carried out to estimate the financial benefits of any service reduction.

6.4 Key findings
There was an absence of available evidence to draw any robust conclusions around the impact of Shared Lives respite care on healthcare service usage. However based on the theoretical case made above, and anecdotal evidence, we believe this absence of evidence does not mean evidence of absence, and that further work needs to be done to investigate this link.

Three separate methods were used in an attempt to quantify the service utilisation in individuals who use “traditional” respite care and Shared Lives – these were a literature review, surveys and user interviews.

6.4.1 Literature review
We performed a literature review of published evidence which looked at whether there was evidence of changing healthcare service usage if using a respite care model similar to that of Shared Lives, versus “traditional” forms. Perhaps unsurprisingly, the literature review did not find anything substantive in terms of evidence. This is due to the fact that this is a very specific comparison to be making, and the Shared Lives model is relatively new and unique.

When trying to look at national datasets, such as Hospital Episode Statistics, in order to attempt to assess numbers of respite care recipients using services, respite care users were not identified within the dataset thus conclusions could not be made.

6.4.2 Surveys
We created a survey which we sent to Shared Lives respite care carers, service users, and care commissioners. As part of this survey we asked these individuals if Shared Lives respite care led to reduced healthcare service usage compared to using “traditional” forms of respite care.

Response rates were very low, and of those responses, only a very small percentage answered the question around healthcare service usage. Therefore we have not been able to use the results in a meaningful way.
6.4.3 User interviews
Whilst not directly applicable to this review, case studies from other Shared Lives services have spoken about the positive impact of Shared Lives on reducing health care usage.

**Case study – Becky, Shared Lives short breaks user**

*Becky is a very quiet and shy individual but, due to the Shared Lives carer Annie’s sensitive approach, she has opened up to her and they are developing a supportive relationship. This has been the longest Becky has lived independently without being readmitted to hospital. She is feeling positive about the future at present and is exploring further education and voluntary work with the support of Annie.*

6.5 Modelling scenario
Given the theoretical, and anecdotal, case for reduced impact on healthcare service usage if individuals use the Shared Lives respite model, we believe it is useful to provide an illustrative example of the savings which could be possible if certain healthcare usage reductions were achieved.

We created a financial model to estimate the impact of any decreased health service usage. This is based on the ‘theory of change’ set out in Section 6.2 above, in that the most likely reductions could be seen in GP appointments, hospital non-elective admissions (NELs), A&E appointments, and outpatient appointments.

We have provided estimates of savings to the local health commissioner from a respite care/short breaks Shared Lives scheme of 75 older people/people with dementia. This is based on that cohort of 75 Shared Lives service users seeing the reduced healthcare service usage set out in Table 6-1 below.

**Table 6-1: Possible impact to healthcare commissioner of reduced healthcare service usage**

<table>
<thead>
<tr>
<th></th>
<th>High saving scenario</th>
<th>Medium saving scenario</th>
<th>Low saving scenario</th>
</tr>
</thead>
<tbody>
<tr>
<td>75 people</td>
<td>75 people</td>
<td>75 people</td>
<td></td>
</tr>
<tr>
<td>635 GP appointments</td>
<td>339 GP appointments</td>
<td>85 GP appointments</td>
<td></td>
</tr>
<tr>
<td>14 NELs</td>
<td>7 NELs</td>
<td>2 NELs</td>
<td></td>
</tr>
<tr>
<td>24 A&amp;E appointments</td>
<td>13 A&amp;E appointments</td>
<td>3 A&amp;E appointments</td>
<td></td>
</tr>
<tr>
<td>180 Outpatient appointments</td>
<td>96 Outpatient appointments</td>
<td>24 Outpatient appointments</td>
<td></td>
</tr>
<tr>
<td>£92,351 saving per year</td>
<td>£49,254 saving per year</td>
<td>£12,313 saving per year</td>
<td></td>
</tr>
</tbody>
</table>

*Source: Appendix D.*
7 Conclusions

- Our research finds that short breaks and respite care are critical for a number of reasons. However we know that family/unpaid carers are not accessing short breaks and respite as much as they should. This research also indicates that the types of short breaks and respite which have “traditionally” been available have mixed evidence of a positive impact on service users and carers. This is a significant challenge for the individuals involved, and the wider health and social care system which relies on people being supported in their own home for as long as possible.

- Findings from our literature review suggests that the type of flexible, personalized and familiar support which Shared Lives can offer may be more beneficial for family/unpaid carers and service user than some “traditional” forms. There is increasing recognition (including from CQC) that the Shared Lives offer has an important role in the suite of available care provision.

- Our research demonstrates that the costs of the Shared Lives solutions are in line with (and in some cases more affordable) than “traditional” respite and day care provision.

- In addition, as the assumptions / modelling show, the service has potential to make savings in terms of reduced usage of health services.

- Finally, there is evidence to suggest that the Shared Lives pricing approach may be more sustainable for the effective delivery of respite care services, than “traditional” forms.
8 Appendices

8.1 Appendix A – Calculation of true cost of providing new Shared Lives respite / short breaks and day services

8.1.1 Methodology

In order to calculate the cost of Shared Lives it is necessary to recognise two elements of the cost of Shared Lives care:

1. the fee paid to a Shared Lives carer
2. an additional set of costs associated with the work of the scheme to recruit, train and monitor carers – and generally to run an effective Shared Lives scheme.

Information on the fees paid to Shared Lives carers for existing day care, respite and short breaks services in England, Scotland and Wales was gathered through Shared Lives Plus, directly from Shared Lives schemes in the three countries. From this, an average fee was calculated for each service, for each country. In the case of Northern Ireland, where no Shared Lives services for respite / short breaks or day care currently exist, an average of the fees paid in Wales and Scotland was taken (recognising that fees in England are higher across the range of Shared Lives services, and hence less comparable to likely fees in Northern Ireland).

With regards to calculating the scheme-level cost of providing Shared Lives services, no data was directly available from Shared Lives schemes. As a result, a series of assumptions had to be made to calculate the likely costs to a scheme of expansion of existing day care / respite / short breaks services – or of beginning to offer these services (slightly but importantly different to ‘traditional’ long term models of Shared Lives care) where no such services were previously provided (this is explicitly the case in Northern Ireland, but from the State of Shared Lives report we can also see that this is similarly the case for a number of existing schemes in the other three countries which offer a large proportion of long term arrangements but no respite / day care).

8.1.2 Assumptions

Our assumptions for calculating the scheme-level cost of expanding / beginning to offer Shared Lives day care / respite / short breaks services built on the following key requirements for being able to successfully provide this model of Shared Lives care:

- Human resource (time)
- Marketing and advertising outlay
- Investment in training / skills development to underpin the quality of the new services
- Additional operating costs from increased scheme activity, e.g. mileage, telephone usage etc.

The above categories of cost are those used in the 2013 Shared Lives and Dementia report\textsuperscript{37} from Shared Lives South West and Innovations in Dementia, whose authors discussed their assumptions and fed into those made for this report.

\textsuperscript{37} Bell, J. & Litherland, R. (2013). Shared Lives and Dementia, pp45 - 46
Having identified and initially verified the key cost categories, a number of stakeholders were asked for their views on what an appropriate ‘investment’ would be for a scheme to provide new services to approximately 45 service users per year.

It is additionally necessary to note that two slightly different versions of the same cost categories were discussed; one for a scheme that sits within a Local Authority and one for an independently managed scheme. The latter includes a contribution to average scheme running costs / overheads, which – in the experience of Shared Lives Plus and the report authors – are not usually factored in by Local Authority schemes (due to the pre-existence of office space and economies of scale for those elements such as electricity etc.).

For England, Scotland and Wales (assuming the pre-existence of a Shared Lives scheme who would seek to expand their short breaks / respite / day care offer) the following assumptions were confirmed as appropriate by this group of stakeholders:

<table>
<thead>
<tr>
<th>Item</th>
<th>Breakdown</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated costs for local authority schemes to invest to develop new services for OP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shared Lives worker with responsibility for OP</td>
<td>Minimum 3 days per week* at c £25k p.a. plus 18% on costs</td>
<td>£17,700.00</td>
</tr>
<tr>
<td>Additional admin / finance support</td>
<td>5 hrs p/w (min) @ £16k plus 18% on costs</td>
<td>£2,697.14</td>
</tr>
<tr>
<td>Mileage</td>
<td>5000 miles @ 45p per mile</td>
<td>£2,250.00</td>
</tr>
<tr>
<td>Additional staff training</td>
<td></td>
<td>£3,000.00</td>
</tr>
<tr>
<td>Carer recruitment</td>
<td></td>
<td>£2,500.00</td>
</tr>
<tr>
<td>Advertising new service</td>
<td></td>
<td>£2,000.00</td>
</tr>
<tr>
<td>Total cost of internal scheme investment required to offer improved / new services</td>
<td></td>
<td>£30,147.14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item</th>
<th>Breakdown</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated costs for independent schemes to invest to develop new services for OP</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shared Lives worker with responsibility for OP</td>
<td>Minimum 3 days per week at c £25k p.a. plus 18% on costs</td>
<td>£17,700.00</td>
</tr>
<tr>
<td>Additional admin / finance support</td>
<td>5 hrs p/w (min) @ £16k plus 18% on costs</td>
<td>£2,697.14</td>
</tr>
<tr>
<td>Mileage</td>
<td>5000 miles @ 45p per mile</td>
<td>£2,250.00</td>
</tr>
<tr>
<td>Additional staff training</td>
<td></td>
<td>£3,000.00</td>
</tr>
<tr>
<td>Carer recruitment</td>
<td></td>
<td>£2,500.00</td>
</tr>
<tr>
<td>Advertising new service</td>
<td></td>
<td>£2,000.00</td>
</tr>
<tr>
<td>Total cost of independent scheme investment required to offer improved / new services</td>
<td></td>
<td>£37,647.14</td>
</tr>
</tbody>
</table>

In Northern Ireland it is necessary to assume that schemes would be newly established expressly for the purpose. As a result, a different set of assumptions have been made, on the basis of no existing infrastructure on which to build:

<table>
<thead>
<tr>
<th>Item</th>
<th>Breakdown</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Estimated costs for the set-up of a new scheme to develop new services for OP (N. Ireland)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Estimated costs for the set-up of a new scheme to develop new services for OP (N. Ireland)

<table>
<thead>
<tr>
<th>Service</th>
<th>Frequency</th>
<th>Rate</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared Lives manager</td>
<td>5 days per week at £32k p.a. plus 18% on costs</td>
<td>£37,760.00</td>
<td></td>
</tr>
<tr>
<td>Shared Lives worker</td>
<td>Minimum 3 days per week* at c £25k p.a. plus 18% on costs</td>
<td>£17,700.00</td>
<td></td>
</tr>
<tr>
<td>Additional admin / finance support</td>
<td>2 days per week @ £16k plus 18% on costs</td>
<td>£7,552.00</td>
<td></td>
</tr>
<tr>
<td>Mileage</td>
<td>10000 miles @ 45p per mile</td>
<td>£4,500.00</td>
<td></td>
</tr>
<tr>
<td>Staff training</td>
<td></td>
<td>£3,000.00</td>
<td></td>
</tr>
<tr>
<td>Carer recruitment</td>
<td></td>
<td>£3,000.00</td>
<td></td>
</tr>
<tr>
<td>Advertising</td>
<td></td>
<td>£3,000.00</td>
<td></td>
</tr>
<tr>
<td>Annual scheme running costs</td>
<td></td>
<td>£30,000.00</td>
<td></td>
</tr>
<tr>
<td><strong>Total cost of independent scheme investment required to offer improved / new services</strong></td>
<td></td>
<td><strong>£68,752.00</strong></td>
<td></td>
</tr>
</tbody>
</table>

On all of the above we recognise that different stakeholders, different areas, different types of schemes will have different views on ‘the best way’ to meet the challenge of expanding / beginning to offer Shared Lives day care / short breaks / respite; those assumptions made should be taken as an indication of the likely cost components, not a recommendation or fixed model. We also recognise that while assumptions have taken into account three different types of scheme (local authority-run, independent and brand new), that they do not factor in other national differences – a level of detail that we were unable to explore within the parameters of this project.

8.1.3 Per unit pricing / cost allocation

Having arrived at the above figures regarding the additional annual cost that each of the three types of scheme might have to incur in order to expand / begin to offer Shared Lives day care / short breaks / respite, it was then necessary to factor this cost into the cost of care to enable a comparison between the (per unit) cost of “traditional” forms of care and the (per unit) cost of Shared Lives forms of care.

This was approached as follows:

- Original assumption that scheme expansion allows an additional **45 individuals** to access Shared Lives day care / short breaks / respite
- Of which, a further assumption is that **30** of those individuals utilize 24-hour respite / short breaks provision for an average of 20 days per year, per individual
- And that **15** of those individuals utilize day care, for an average of 2.5 days per week, 47 weeks per year

On the basis of the above, each scheme provides **600 units of 24 hour respite provision**, and **1,762.5 units of day care provision**. Using these figures, we were then able to spread the annual scheme costs of expansion between the units of care, from which we derived a figure to add the original figure of the fees paid to Shared Lives carers for each of the different forms of care.

Proposal for distribution of additional cost across new services

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Hourly day care provision</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>24 hour respite provision</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People (x)</td>
<td>30</td>
<td>People (x)</td>
</tr>
<tr>
<td>Hours per day</td>
<td>24</td>
<td>Hours per day (h)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6.05</td>
</tr>
</tbody>
</table>
### Proposal for distribution of additional cost across new services

<table>
<thead>
<tr>
<th>Days respite per year (y)</th>
<th>20</th>
</tr>
</thead>
<tbody>
<tr>
<td>Days per week (y)</td>
<td>2.5</td>
</tr>
<tr>
<td>Weeks (z)</td>
<td>47</td>
</tr>
<tr>
<td>24 hour periods per year</td>
<td>600</td>
</tr>
<tr>
<td>Units (days) per year</td>
<td>1762.5</td>
</tr>
<tr>
<td>Hours per year</td>
<td>10663.13</td>
</tr>
</tbody>
</table>

#### 8.1.4 Findings

The below table summarises the findings and gives a final per unit fee – which includes both the direct fee to Shared Lives carers, plus a proportion of the scheme level costs.

Using these figures, we were then able to compare the ‘total’ cost of the Shared Lives unit of care with those figures gathered from local authorities on the rates paid for “traditional” care.

<table>
<thead>
<tr>
<th>Comparison of prices for respite care</th>
<th>Eng - *LA</th>
<th>Eng - *Ind</th>
<th>Scot - LA</th>
<th>Scot - Ind</th>
<th>Wales - LA</th>
<th>Wales - Ind</th>
<th>N.I</th>
</tr>
</thead>
<tbody>
<tr>
<td>24 hour respite provision</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SL Cost per 24hrs (paid to Shared Lives carers, not inc scheme costs)</td>
<td>£62.76</td>
<td>£43.90</td>
<td>£44.50</td>
<td>£44.20</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SL Cost per 24hrs incl scheme investment</td>
<td>£96.26</td>
<td>104.59</td>
<td>£77.40</td>
<td>£85.73</td>
<td>£78.00</td>
<td>£86.33</td>
<td>£98.77</td>
</tr>
<tr>
<td>FOI data (traditional care)</td>
<td>£81.27</td>
<td>£75.39</td>
<td>£79.61</td>
<td>£73.21</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saving / additional cost of SL</td>
<td>-£14.99</td>
<td>-£23.32</td>
<td>-£2.01</td>
<td>-£10.34</td>
<td>£1.61</td>
<td>-£6.72</td>
<td>-£25.56</td>
</tr>
</tbody>
</table>

| Day care provision                    |           |            |           |            |           |            |     |
| SL Cost per hour (paid to Shared Lives carers, not inc scheme costs) | £8.05 | £7.56 | £7.50 | £7.53 |           |            |     |
| SL Cost per hour incl scheme investment | £8.99 | 9.23 | £8.50 | £8.74 | £8.44 | £8.68 | £9.32 |
| FOI data (traditional care)           | £7.27 | £9.04 | £7.18 | £7.09 |           |            |     |
| Saving / additional cost of SL         | -£1.72 | -£1.96 | £0.54 | £0.30 | -£1.26 | -£1.50 | -£2.23 |

*LA = local authority run scheme, Ind = Independent scheme.
8.2 Appendix B – Freedom of Information request analysis

8.2.1 Methodology

Freedom of Information requests were sent to 210 local authorities and health and social care trusts across England, Wales, Northern Ireland and Scotland.

The following questions were asked:

This request concerns the fees that [your local authority] paid for care services for adults aged 65 and over in the last financial year (2016-2017).

1. We are interested know more about the prices paid (per night, or per 24 hour period) for respite care in a residential care home.
   A) What is the most expensive price paid?
   B) What is the cheapest price paid?
   C) What is the average of all prices paid?

2. We are interested to know more about prices paid for day care (per day).
   A) What is the most expensive price paid?
   B) What is the cheapest price paid?
   C) What is the average of all prices paid?

3. We are interested to know more about any provisions or assumptions which [your local authority] makes during the resource allocation process for direct payments.
   A) Do you make notional provision for respite care? If so, how much is allocated per night?
   B) Do you make notional provision for day care? If so, how much is allocated per day?

4. We are interested to gather data concerning outcomes for people as a result of the interventions addressed in questions 1, 2 and 3 above. Do you have any relevant data which you can direct us to?

Responses were collated and analysed to calculate average lowest, highest and overall average of residential respite and day care.

8.2.1.1 Understanding the average length of a day care session

For the purposes of calculating average hourly cost of day care, we have investigated the average length of a day care session. The data is limited. However, the most reliable figure we could find comes from PSSRU’s Unit Costs of Health and Social Care (2016), p 28 concludes that the average length of a day care session is 4.6 hours. There are three caveats to consider regarding this figure:

1) This figure relates to the day care which local authorities provide themselves. Day care which is provided by charities or other independent providers may differ in length.
2) This figure relates to day care provision for older people in general, rather than older people with dementia more specifically. However for the purposes of our calculations, this is probably not a significant concern.
3) This figure is based on the activities in ten local authorities which responded to PSSRU’s Freedom of Information request.

As a result of these three caveats, we have “rounded up” the figure to an average of 5 hours per day, to ensure that our calculations and assumptions are realistic.

8.2.2 Response rate

Overall, there was a 77% response rate to the FoI request for questions concerning respite care, and a 73% response rate for questions concerning day care, across all four nations.

A breakdown of response rates by the four nations is provided in Figure 8-1 below.

Figure 8-1: Breakdown of FoI response rates

<table>
<thead>
<tr>
<th>Country</th>
<th>Responses concerning respite care</th>
<th>Responses concerning day care</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK (n=210)</td>
<td>77%</td>
<td>73%</td>
</tr>
<tr>
<td>England (n=151)</td>
<td>77%</td>
<td>75%</td>
</tr>
<tr>
<td>Scotland (=32)</td>
<td>78%</td>
<td>66%</td>
</tr>
<tr>
<td>Wales (n=22)</td>
<td>68%</td>
<td>68%</td>
</tr>
<tr>
<td>Northern Ireland (n=5)</td>
<td>100%</td>
<td>80%</td>
</tr>
</tbody>
</table>

8.2.3 Findings

8.2.3.1 Findings regarding residential respite care

Findings from the FoI requests in response to the questions regarding prices paid for residential respite care are outlined in Figure 8-2.

Figure 8-2: FoI findings – cost of “traditional” residential respite care

<table>
<thead>
<tr>
<th>Country</th>
<th>Minimum</th>
<th>Average</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK (n=161)</td>
<td>£61.85</td>
<td>£80.75</td>
<td>£151.35</td>
</tr>
<tr>
<td>England (n=116)</td>
<td>£59.98</td>
<td>£81.27</td>
<td>£162.11</td>
</tr>
<tr>
<td>Scotland (=25)</td>
<td>£66.96</td>
<td>£80.54</td>
<td>£127.53</td>
</tr>
<tr>
<td>Wales (n=15)</td>
<td>£67.81</td>
<td>£79.61</td>
<td>£121.02</td>
</tr>
<tr>
<td>Northern Ireland (n=5)</td>
<td>£72.40</td>
<td>£73.21</td>
<td>£112.12</td>
</tr>
</tbody>
</table>

8.2.3.2 Findings regarding day care

Findings from the FoI requests in response to the questions regarding prices paid for day care are outlined in Figure 8-3 Figures are provided for a day of day care. As detailed in Section 8.2.1.1, we have delivered conservative calculations which assume that a day of day care lasts 5 hours.

Figure 8-3: FoI findings – cost of “traditional” day care
<table>
<thead>
<tr>
<th>Country</th>
<th>Minimum cost per hour (day = 5 hours)</th>
<th>Average cost per hour (day = 5 hours)</th>
<th>Maximum cost per hour (day = 5 hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK (n=154)</td>
<td>£5.86</td>
<td>£9.16</td>
<td>£18.03</td>
</tr>
<tr>
<td>England (n=114)</td>
<td>£5.10</td>
<td>£8.80</td>
<td>£19.63</td>
</tr>
<tr>
<td>Scotland (=21)</td>
<td>£6.49</td>
<td>£9.17</td>
<td>£12.20</td>
</tr>
<tr>
<td>Wales (n=15)</td>
<td>£6.99</td>
<td>£8.68</td>
<td>£12.15</td>
</tr>
<tr>
<td>Northern Ireland (n=4)</td>
<td>£7.29</td>
<td>£8.58</td>
<td>£12.32</td>
</tr>
</tbody>
</table>

8.2.3.3  Respite and day care: funding available to those with direct payments

The Freedom of Information request included the following questions:

We are interested to know more about any provisions or assumptions which [your local authority] makes during the resource allocation process for direct payments.

A) Do you make notional provision for respite care? If so, how much is allocated per night, or per 24 hour period?

B) Do you make notional provision for day care? If so, how much is allocated per day?

Authorities found this a difficult question to answer, and rates of use-able responses were therefore relatively low, as shown in Figure 8-4 below.

Figure 8-4 Summary of responses concerning direct payments

<table>
<thead>
<tr>
<th>Country</th>
<th>Responses concerning respite care</th>
<th>Responses concerning day care</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>21%</td>
<td>20%</td>
</tr>
<tr>
<td>England</td>
<td>21%</td>
<td>21%</td>
</tr>
<tr>
<td>Scotland</td>
<td>22%</td>
<td>16%</td>
</tr>
<tr>
<td>Wales</td>
<td>23%</td>
<td>14%</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>20%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Using this data, Figure 8-5 shows the average “notional provisions” which authorities make for older people in receipt of direct payments. These figures vary slightly but not significantly from the data gathered as a result of our main questions, concerning the prices which Local Authorities themselves pay. Figure 8-5 offers some insight into the amounts paid by those who have control of their funds. By extension, this could also offer clues about the amounts which private payers may also be able or willing to pay. However we would be cautious about drawing firm conclusions in this regard.
Figure 8-5 Average notional provisions made for those with direct payments.

<table>
<thead>
<tr>
<th>Country</th>
<th>Average notional provision for respite per night or 24 hour period</th>
<th>Average notional provision for day care per hour (day= 5 hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK</td>
<td>£79.36</td>
<td>£8.56</td>
</tr>
<tr>
<td>England</td>
<td>£73</td>
<td>£8.41</td>
</tr>
<tr>
<td>Scotland</td>
<td>£94</td>
<td>£9.67</td>
</tr>
<tr>
<td>Wales</td>
<td>£100</td>
<td>£8.19</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>£73</td>
<td>-</td>
</tr>
</tbody>
</table>
8.3 Appendix C – Literature review

8.3.1 Introduction

The aim of this rapid evidence assessment was to conduct a review of literature, case studies and data sources concerning outcomes achieved via “traditional” respite care, including comparators ‘day care’ and ‘private payments’. Relevant search terms (such as “respite”, “day care”, “private payments” + “outcomes”) were searched using Google, Google Scholar and JSTOR to find relevant material. This review summarises the key themes identified within the literature.

8.3.2 Review

8.3.2.1 Outcomes for family/unpaid carers

Latest census data revealed that 20% of carers providing 50 hours or more of care per week are receiving no support with their caring role (Office for National Statistics, 2011). The recent State of Caring Report reported that without replacement care for carers, carers are often pushed to breaking point which can result in them having to give up work, stop caring, or potentially lead them to go into hospital themselves (Carers UK, 2016). Joint research by Carers UK and other partners surveying over 3,000 UK carers reported that having somebody to help with caring, thereby enabling them to have a break and recuperate, is important in preventing carers from reaching breaking point (Carers UK, 2012).

However, research regarding outcomes of respite for carers has been somewhat conflicting. A literature review undertaken by PSSRU into the effectiveness of support and services to informal carers of older people reported that there is evidence to suggest that day care and institutional respite care can be effective in reducing the negative psychological effects of caring for carers (Pickard, 2004). However, systematic reviews looking at the impact of respite for carers of frail elderly have found contradictory results regarding the effect of respite on “carer burden”. Whilst some have reported that this type of support can be helpful in reducing “carer burden” (Mason et al., 2007; Lopez-Hartmann, 2011), others have found no evidence of this impact (Shaw et al., 2009).

Further, literature reviews looking more specifically at the use of respite for carers of people with dementia have also found mixed results. Whilst one review found no evidence of any benefit of respite care with dementia or their caregivers for any outcome including caregiver burden (Maayan et al., 2014), an additional review found evidence of impact of respite services on providing relief and decreasing the burden of carers (Neville et al., 2015).

However, multiple reviews looking at carer outcomes for respite have reported that the potential of respite in delivering outcomes will only be effective when respite is provided in a more individualised manner, and is designed to meet the needs of carer (Shaw et al., 2009; Neville et al., 2015). Further, outcomes in this area are dependent on quality of service provision, due to poor-quality care leading carers to continuing to worry about care recipient, being unable to relax and feeling guilt (Shaw et al., 2009). Research undertaken with family caregivers of persons with dementia reported a quote from a caregiver (Strang, 2000):

*Respite care is only respite if the same quality of care is offered to the patient in a respite facility that is offered at home.*

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**PPL**

**CordisBright**

**Social Finance**
Whilst there has been some evidence in systematic reviews of impact of respite services on mental health (including depression), physical health and anger (Mason et al., 2007; Lopez-Hartmann, 2011), none of these reviews have found an effect of respite on caregiver’s anxiety (Lopez-Hartmann, 2011; Shaw et al., 2009). However, additional research has reported that external respite care does provide carers with time for self-care, provides them relief from the caring role, and respite services can be proactive to ensure comfort and safety of the person with dementia so that the carer has no concerns (Adler, 1992, Beisecker et al. 1996, Wishart et al. 2000, Perry & Bontinen 2001, Madeo et al. 2008, Stockwell-Smith et al. 2010).

Whilst systematic reviews highlight conflicting evidence of outcomes for carers receiving respite, qualitative evidence paints a more positive picture. Several studies have highlighted that carers are highly satisfied with respite (Ashworth and Baker, 2000; Parahoo et al., 2002; van Exel et al., 2006; van Exel et al., 2008; Zarit et al., 1999), and consider it as instrumental in maintaining the physical and mental health of carers (Ashworth and Baker, 2000; Beisecker et al., 1996; Leong et al., 2001; Pearson, 1996). This is supported by surveys undertaken with carers, with one study reporting that 17% of carers who had taken a break of more than a few hours suffered mental ill-health, compared to 36% of carers who did not have such a break since they began caring (Singleton et al., 2002). More recently, results from a survey of over 3,000 UK carers reported that 61% of carers thought their health would be improved by more regular breaks from caring (Carers UK, 2012). Further, as part of this research multiple carers reported positively on the impact of respite on their quality of life:

“Increased respite has improved my own quality of life. I have been able to spend some time on my own interests and also have a break away! Woo hoo!”

“Extra respite has given me more time to have some normal life, catch up on my sleep and recharge my batteries.”

A recent review of the use of respite by carers of people with dementia concluded day care has more favourable effects on caregivers than temporary residential care (Vandepitte et al., 2016). However, a literature review undertaken by PSSRU found mixed results regarding the effectiveness of day care for carers (Pickard, 2004). Whilst some studies found that day care could enhance the objectively measured well-being of some carers and reduce the emotional distress experienced by them, some reported no effects. However, despite not always being associated with changes in their psychological health, day respite care is often associated with very high levels of satisfaction on behalf of carers. One study carried out in England and Wales found that day care reduced stress for about 85% of the carers of users (Davies and Fernandez, 2000). Further, day care had beneficial effects on subjective burden experienced by carers of users with severe cognitive impairment and carers in paid employment. The same study additionally found that decreases in carer stress had a significant impact on the older person’s ability to stay in the community for extended periods of time. This study suggested that it may be cost-effective to increase day care, particularly for older people with cognitive impairment or behaviour disturbances, in order to maximise user’s length of time in the community or reductions in “carer burden”.

More recently, a scoping review of adult day centre programmes and associated outcomes found that the use of day care has positive health-related, social, psychological, and behaviour outcomes for care recipients and caregivers (Ellen et al., 2016). This was supported by a review of respite by carers of people with dementia, which reported that evidence from methodologically-robust research shows that the use
of adult day care centres lead to decreases in carer stress and burden (Neville et al., 2015). One carer, as part of a survey for Carers UK regarding their health and wellbeing, stated that (Carers UK, 2012):

“Day care has given me the chance to have five hours a week when I don’t need to feel responsible for the person I care for.”

8.3.2.2 Outcomes for commissioners

There is a considerable amount of evidence that shows that carer wellbeing is a key factor in hospital admissions, readmission and delays in the transfer of care (Carers Trust, 2015). For example, research has shown that carer breakdown or fatigue was a significant factor in 62% of readmissions of patients to hospital (Williams, 1991). Further, a whole systems study tracking a sample of people over 75 years old who had entered the health and social care system found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent (Castleton, 1998). Regarding admittance to residential care, stress on carers was highlighted by 38% of social workers as a main reason for admitting new residents to a residential place, with this proportion increasing to 44% for local authority residential places (Bebbington et al., 2001).

Providing carers with breaks, emotional support and access to training has been found to significantly delay the need for the person receiving care to go into residential care (Mittelman et al., 1996). However, literature reviews regarding the impact of respite care on admissions to residential care has been conflicting. Whilst a literature review undertaken by PSSRU reported that respite care in general was associated with delayed admission to institutional care (Pickard, 2004), a more recent systematic review reported no reliable evidence of respite care delaying entry to residential care (Mason et al., 2007).

Research specifically regarding care recipients with dementia has been more promising, with multiple systematic reviews concluding that the use of respite programmes may support carers in continuing their caring role for longer (Eagar et al., 2007; Parker et al., 2008). A more recent review of literature regarding informal caregivers of persons with dementia found that day care specifically accelerated placements to nursing homes, thereby potentially having a negative impact on the health care system (Vandepitte et al., 2016). However, the impact of respite on accelerating care placements has been attributed to a number of factors, including: caregivers waiting too long to use day care; caregivers of day care users being more likely to be overburdened; and amount of day care being insufficient to affect caregiver burden (McCann et al., 2005; Kuzuya et al., 2012).

Despite conflicting evidence regarding the impact of respite care on maintaining the carer role, substantial qualitative research has indicated high satisfaction and positive perceptions regarding respite care (Vandepitte et al., 2016a), and have led researchers to conclude that “breaks are crucial if caregivers are to continue to keep their loved ones home” (Vandepitte et al., 2016b; 2). Further, synthesis of qualitative research regarding respite for frail elderly reported that a recurring theme throughout the studies was the “essential nature of respite for maintaining and continuing the caring role” (Shaw et al., 2009; 77). One study reported that the majority of caregivers perceived that respite enabled them to endure in their caring role, instead of becoming fatigued and burned out (Piercy and Dunkley, 2004).

A review of respite and short breaks provision for adult carers of adults in the Highland Partnership Area reported that respite is, “in principle, believed by all involved to be invaluable” (McDonald and Macleod, 2016;) and included a quote from one health and social care worker:
“We cannot underestimate the value of respite. I feel confident in saying it is respite that plays a huge part in maintaining the home situation for as long as possible in the majority of cases.”

Indeed, feedback from carers as part of a review of older people’s day services in Tower Hamlets reported that day care allows carers with ‘me time’ to maintain their own wellbeing and manage other personal responsibilities and needs, which in the long run enables them to continue to provide support to the cared for person with less “pressure and stress” (Tower Hamlets, 2015; 25).

8.3.2.3 Outcomes for service users

Systematic reviews of literature have found no evidence of positive outcomes for service users as a result of accessing respite (Mason et al., 2007; Maayan et al., 2014; Neville et al., 2015). Further, researchers have highlighted the potential of respite care to result in negative outcomes such as care recipient distress (Shaw et al., 2009), particularly for care receivers with dementia due to this exacerbating their confusion (Ashworth and Baker, 2000). However, concerns about the quality of care have been raised in reviews regarding impacts of respite on care recipients, with inadequate staff levels and frequent staff changes, resulting in a lack of continuity, highlighted as specific aspects of institutional respite care (Shaw et al., 2009). Indeed, a narrative review of the impact of respite on older clients, with a focus on dementia respite, reported that future directions for this type of care may need to use more flexible or innovative methods of delivery, such as host-family respite (Tang et al., 2011). Host-family respite was reported to be particularly useful for people in early-stage dementia, due to the setting being more natural and less threatening than a residential or nursing home (Shanley, 2006). Whilst there is a lack of research regarding host-family respite, the little evidence available reports that host-family respite was effective in addressing the needs of care recipients (Arksey et al., 2004).

Research regarding outcomes associated with day care reveals more positive evidence of impact for service users. A recent systematic review on the effectiveness of respite care in supporting informal caregivers of persons with dementia reported that day care is an effective strategy for care recipients, due to this type of care reducing behavioural problems and possibly improving sleep quality (Vandepitte et al., 2016). Further, qualitative research has highlighted that respite provides service users with an opportunity for socialisation, which was felt to have an important role in health improvements such as mental health and well-being (Valadez et al., 2005). Indeed, feedback from carers as part of a review of older people’s day services in Tower Hamlets reported that day care has: improved the emotional and psychological wellbeing of the cared for person; reduced isolation, loneliness and risk of depression; kept the cared for person physically well through exercise and awareness of heath, and supported cared for people to retain independence and control, daily living skills and interaction (Tower Hamlets, 2015). Further, one care recipient reported as part of focus groups with service users of day care services that day care:

“Lifts your mood…and then you can get on with the rest of things”

8.3.2.4 Direct payments

According to Age UK, carers should be able to play a full role in planning how an older person’s personal budget is to be used, especially if some of this budget is designated for breaks or respite care that can also benefit the carer (Age UK, 2012). Indeed, the Department for Health’s (2009) guidance on direct payments encourages purchasing of flexible respite care as an innovative use of carer’s direct payments.
Interviews with family carers found that respite or short breaks were considered as a potential advantage of individual budgets, due to the support that could be provided using this budget such as to relieve pressure from the carer, or provide care when the carer is sick or on holiday (Moran et al., 2013). Further, it was reported that these small changes were expected to have a significant positive impact on the health and wellbeing of the family carer by reducing pressure on them.

8.3.3 Key findings
- There is a lack of recent conclusive and rigorous research regarding outcomes achieved via “traditional” respite care.
- Whilst there is conflicting evidence from systematic reviews of literature regarding impact of respite and day care on outcomes for carers, commissioners and service users, there is some evidence from these reviews and qualitative research in support of:
  - Outcomes for carers, including: reduction in negative psychological effects of caring; “carer burden”; mental health (including depression); physical health; anger; relief from caring role; and satisfaction.
  - Outcomes for commissioners, including: carer’s ability to maintain and continue the care role.
  - Outcomes for service users (only for day care), including: behavioural problems and sleep quality (for service users with dementia); emotional and physical wellbeing; reduced isolation and loneliness; independence and control; daily living skills and interaction.
- Whilst research indicates that day care has more favourable effects for carers and service users, negative impacts were seen for day care (and respite) for care recipients with dementia specifically for residential and nursing admission, due to difficulties for them adapting to new physical environments and persons.
- Effectiveness of respite and day care services are dependent on quality of care and individualisation of support to meet the needs of the carer. Further, whilst there is a lack of research regarding outcomes associated with host-family respite, this was reported to be a useful option for service users with early-stage dementia, and effective in addressing the needs of carers and care recipients (Tang et al., 2011).
- Whilst there is little research available regarding the use of direct payments in respite and day care, it was reported that this budget could be used for respite to relieve pressure from the carer, and provide care when carer is sick or on holiday.

8.3.4 References
Age UK (2011). Effectiveness of day services. Summary of research evidence.


Carers Trust (2015). Caring about older carers: providing support for people caring later in life.

Carers UK and partners (2012). In Sickness and in Health.

Carers UK (2014). Carers at breaking point.


8.4 Appendix D – Healthcare service usage modelling

The actual health service utilisation amongst the 65+ population in England was obtained from various sources (see table below). We then used these numbers alongside the 65+ population to get an idea of the average health service utilisation per a 65+ resident.

Table 8-1 Average health utilisation per person aged 65+

<table>
<thead>
<tr>
<th>Metric</th>
<th>Number (millions) – for over 65s</th>
<th>Per over 65 pop</th>
</tr>
</thead>
<tbody>
<tr>
<td>[1] Population</td>
<td>9.9</td>
<td>-</td>
</tr>
<tr>
<td>[2] A&amp;E visits</td>
<td>4.3</td>
<td>0.43</td>
</tr>
<tr>
<td>[3] NEL admissions</td>
<td>2.4</td>
<td>0.24</td>
</tr>
<tr>
<td>[4] Outpatient appointments</td>
<td>31.7</td>
<td>3.21</td>
</tr>
<tr>
<td>[5] GP visits</td>
<td>111.6</td>
<td>11.30</td>
</tr>
</tbody>
</table>

Source: [1]: 2016 ONS; [2], [3]: 16/17 HES; [4]: 15/16 HES; [5]: National Audit Office, Department of Health and NHSE: Stocktake of access to general practice in England, November 2015

It is difficult to be sure exactly what the healthcare cost savings could be upon the implementation of Shared Lives. However given that the ‘theory of change’, outlined in section 6.2, suggests a reduction, a range of scenarios of healthcare utilisation reduction were modelled to test any potential healthcare monetary savings. A theoretical cohort of 75 Shared Lives users were modelled as well as their health service utilisation based on the 65+ rates above.

Table 8-2 Estimated health service usage amongst a cohort of 75 Shared Lives users based on average utilisation rates for 65+ residents

<table>
<thead>
<tr>
<th>Activity</th>
<th>Activity per over 65 pop</th>
<th>Activity per cohort of 75</th>
</tr>
</thead>
<tbody>
<tr>
<td>[A]</td>
<td>[B] = [A] * 75</td>
<td></td>
</tr>
<tr>
<td>A&amp;E visits</td>
<td>0.43</td>
<td>33</td>
</tr>
<tr>
<td>NEL admissions</td>
<td>0.24</td>
<td>18</td>
</tr>
<tr>
<td>Outpatient appointments</td>
<td>3.21</td>
<td>241</td>
</tr>
<tr>
<td>GP visits</td>
<td>11.30</td>
<td>847</td>
</tr>
</tbody>
</table>

Source: [A]: Table [8-1]

Three scenarios were then created - ‘low’, ‘medium’ and ‘high’ savings, these had overall savings of 10%, 40% and 75%, respectively. Given that the average health service utilisation amongst care recipients could be higher than the average for all 65+ residents, we have provided a high top-range to model any potential theoretical savings.

The savings in each scenario are the total health service utilisation within the cohort minus the saving indicated in the scenario’s percentage. See below for the table showing the three scenarios and their respective savings. The calculations for one of the scenarios is also shown to demonstrate how this was done for all three scenarios.
Table 8-3 Estimated health service usage amongst a cohort of 75 Shared Lives users

<table>
<thead>
<tr>
<th>Activity saved</th>
<th>High scenario</th>
<th>Medium scenario</th>
<th>Low scenario</th>
</tr>
</thead>
<tbody>
<tr>
<td>Activity saved</td>
<td>75%</td>
<td>40%</td>
<td>10%</td>
</tr>
<tr>
<td>A&amp;E visits saved</td>
<td>24</td>
<td>13</td>
<td>3</td>
</tr>
<tr>
<td>NEL admissions saved</td>
<td>14</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Outpatient appointments saved</td>
<td>180</td>
<td>96</td>
<td>24</td>
</tr>
<tr>
<td>GP visits saved</td>
<td>635</td>
<td>339</td>
<td>85</td>
</tr>
</tbody>
</table>

These savings were then multiplied by the average cost of each service to calculate the overall theoretical savings per cohort. NHS 15/16 reference costs were used to obtain the average cost of a non-elective admission (NEL), outpatient appointment (OP) and accident and emergency appointment (A&E). The GP appointment average cost was taken from the PSSRU units of cost and social care 2016.

Table 8-4 average cost per health activity

<table>
<thead>
<tr>
<th>Activity</th>
<th>Price</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>£36.00</td>
<td>PSSRU - Units of cost and social care 2016 - Table 10.3b</td>
</tr>
<tr>
<td>NEL</td>
<td>£3,058.00</td>
<td>NHS reference costs - 15/16</td>
</tr>
<tr>
<td>OP</td>
<td>£136.79</td>
<td>NHS reference costs - 15/16</td>
</tr>
<tr>
<td>A&amp;E</td>
<td>£137.00</td>
<td>NHS reference costs - 15/16</td>
</tr>
</tbody>
</table>

Table 8-5 Estimated savings amongst a cohort of 75 Shared Lives users

<table>
<thead>
<tr>
<th>[K]</th>
<th>[L]</th>
<th>[M]</th>
<th>[N]</th>
<th>[K<em>G] + [L</em>H]+[M<em>I]+[N</em>J]</th>
</tr>
</thead>
<tbody>
<tr>
<td>635 GP appointments</td>
<td>14 NELs</td>
<td>24 A&amp;E appointments</td>
<td>180 Outpatient appointments</td>
<td>£92,351 saving per year</td>
</tr>
<tr>
<td>339 GP appointments</td>
<td>7 NELs</td>
<td>13 A&amp;E appointments</td>
<td>96 Outpatient appointments</td>
<td>£49,254 saving per year</td>
</tr>
<tr>
<td>85 GP appointments</td>
<td>2 NELs</td>
<td>3 A&amp;E appointments</td>
<td>24 Outpatient appointments</td>
<td>£12,313 saving per year</td>
</tr>
</tbody>
</table>
8.5 Appendix E – “Traditional” day care and respite care

We recognise that respite care and day care take many forms and agreed definitions are difficult to establish. However, for the purposes of this review, we have identified the following descriptions which indicate the types of “traditional” forms of care against which we are generally comparing Shared Lives schemes.

The NHS publication Carers Direct – Respite Care provides a useful summary of the different types of respite care (including day care). The definitions highlighted in bold best describe the “traditional” forms of respite and day care to which the line of questioning explored in the Freedom of Information request can most reasonably be compared.

Respite care can include:
- Residential or nursing care where the person you’re looking after goes for a short stay in a residential or nursing home.
- Day-sitting services, where someone comes into your home during the day to care for the person you look after.
- Night-sitting service where someone comes to your home to care for the person you look after, letting you get a good night’s sleep.
- Daycare, where the person you’re looking after goes to a day centre or take part in activities away from home.
- Holidays by yourself or with the person you care for.

Age UK’s report Effectiveness of Day Services – summary of research evidence (October 2011) provides additional information concerning “traditional” forms of day care.

The term ‘day services’ covers a diverse range of services and activities, which cater for a variety of people and needs, and serve a number of different purposes, most of which are broadly preventive including:
- Providing social contact and stimulation
- Reducing isolation and loneliness
- Maintaining and/or restoring independence
- Providing a break for carers
- Offering activities which provide mental and physical stimulation
- Enabling care and monitoring of very frail and vulnerable older people
- Offering low-level support for older people at risk
- Assisting recovery and rehabilitation after an illness or accident
- Providing care services such as bathing and nail-cutting
- Promoting health and nutrition
- Providing opportunities for older people to contribute as well as receive.

These aims can be achieved in a number of different ways. What distinguishes day services is that they are delivered outside people’s own homes and are generally building-based.