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Developing an outcome measurement tool for Shared Lives

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Purpose of the project

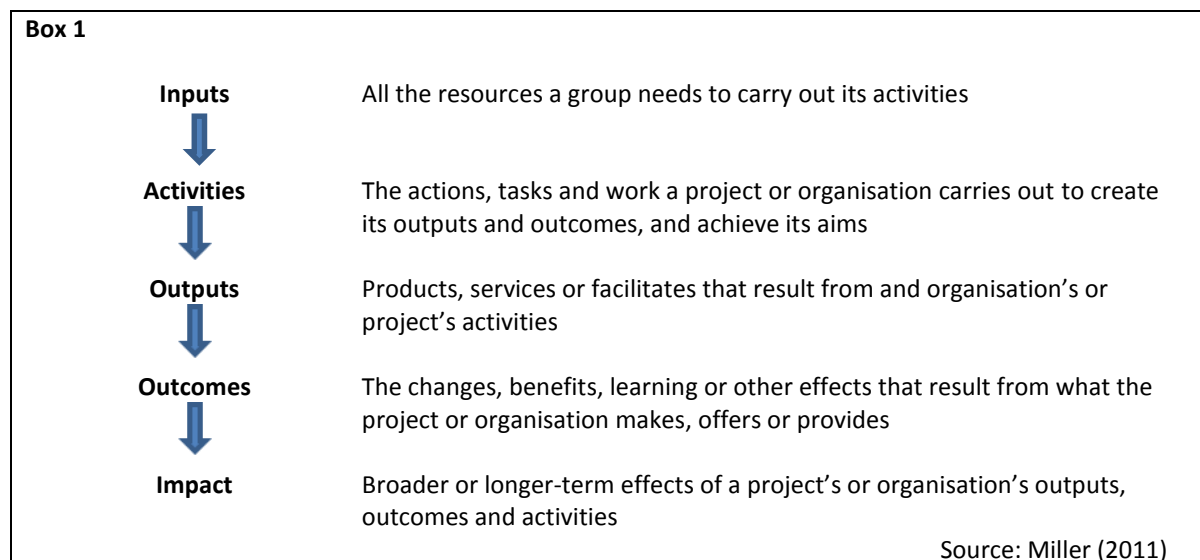
Shared Lives Plus commissioned the Personal Social Services Research Unit at the University of Kent to develop an outcome measuring tool for Shared Lives. The purpose was to be able to more easily demonstrate the benefits of Shared Lives locally, regionally and nationally. The tool needed to be easy to use as part of current processes, co-produced with Shared Lives users, carers and schemes and evidence-based.

Definition of outcomes

The following definition of outcomes was used for this project:

Outcomes: The changes, benefits, learning or other effects that result from what the project or organisation makes, offers or provides (Kazimirski & Pritchard, 2014)

Box 1 shows where ‘outcomes’ fit in the context of other concepts involved in what an organisation does and what it hopes to achieve. An outcomes-focused service or organisation is one which meets the goals, aspirations and priorities of the individuals that use that service (Glendinning, Clarke, Hare, Maddison, & Newbronner, 2008).



Development of the tool

The development process included two main elements: a desk-based review covering existing outcome measurement tools, literature on measurement and literature on Shared Lives, and consultation with stakeholders in a variety of ways.

Desk-based review

Existing outcomes tools and frameworks were reviewed, with a focus on those of relevance to the social care sector. The Care Act (2014) introduced a duty on local authorities to promote ‘wellbeing’

and to use this as a guiding principle when making decisions about individuals. The wellbeing principles set out in Clause 1 of the Care Act (2014), presented in Box 2, are useful as a guiding framework for the development of any outcomes measuring tool.

Box 2

Section 1 of the Care Act: Wellbeing outcomes

- Personal dignity
- Physical and mental health, emotional wellbeing
- Protection from abuse and neglect
- Control over day-to-day life
- Participation in work, education, training, recreation
- Social and economic wellbeing
- Domestic, family and personal relationships
- Suitability of living accommodation
- Contribution to society

Measurement tools

There are numerous tools available for measuring quality of life and wellbeing. The review focused only on those which appeared to have relevance to the social care sector. A summary spreadsheet of the tools reviewed, including the areas of quality of life measured and how these map to the wellbeing outcomes from the Care Act, is available on request from the authors.

One of the key challenges in measuring the outcomes of social care is that a broad measure of wellbeing or quality of life is likely to fail to pick up on the impact of social care interventions as questions are not specific enough (Netten, 2011). Some widely-used tools were, for the purposes of the current project, too broad in what they aimed to measure. For example, the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; <http://www2.warwick.ac.uk/fac/med/research/platform/wemwbs/>) aims to reflect mental wellbeing, including concepts such as 'feeling optimistic about the future' and 'feeling relaxed'. Tools that focus on broader wellbeing tend not to map across to all aspects of the Care Act wellbeing outcomes, focusing on mental health and emotional wellbeing. The tools identified were often too long or complex to be easily used with people with learning disabilities, the main client group for Shared Lives services.

Tools such as the ASCOT (<http://www.pssru.ac.uk/ascot/>) and the POET (<http://www.in-control.org.uk/what-we-do/poet-%C2%A9-personal-outcomes-evaluation-tool.aspx>), are designed specifically for the measurement of social care outcomes. Nonetheless, they may fail to capture some of the key outcomes of Shared Lives, such as feeling part of a family or valued by the community. It is acknowledged that the areas of quality of life measured through ASCOT are broad and multifaceted, and that when an intervention or service is designed to have an impact on any particular aspect or quality of life, there is value in measuring that aspect in more detail (Netten, 2011). For example, when an intervention is focused on social participation, additional measures of loneliness and social networks would be of value. This approach was taken when developing the tool for Shared Lives, using the ASCOT domains (alongside the Care Act wellbeing outcomes) as a guiding framework.

Other tools, such as the Better Futures tool designed for housing-related support (<http://www.ccpscotland.org/hseu/information/better-futures/>), and the Outcomes Star family of tools (<http://www.outcomesstar.org.uk/>) were too tailored to particular services to be directly applicable to Shared Lives. However, many of the tools reviewed used concepts or approaches to measurement that could be learned from for the development of the Shared Lives tool.

Shared Lives schemes were asked via email if they used any tools for measuring the outcomes of their service. Seven schemes responded, and in general seemed to record 'personal outcomes' or goals which service users hoped to achieve through Shared Lives. This approach is clearly useful as part of daily practice, but a more structured way of collecting outcomes data would be of value alongside this.

Literature on measurement

The review of the literature on measurement raised a number of relevant points:

- The 'agree-disagree' format, where respondents are given a statement to agree or disagree with, can be problematic as it is a cognitively complex task (Czaja & Blair, 2005; Fowler, 1995). Respondents can tend towards agreement ('acquiescence bias'), particularly if they have more severe cognitive or language difficulties (Krosnick, 2002, (Beadle-Brown et al., 2012).
- One way to avoid these problems is to provide concrete answer choices representing different attitudes (De Vaus, 1993), although some authors have suggested that this approach may also prove challenging for some people with a learning disability (Beadle-Brown, et al., 2012).
- Providing 3-5 answer categories is optimal to balance sensitivity of the scale and complexity (DeVellis, 2003). However, use of a middle category representing 'no opinion' or 'neither agree nor disagree' can provide an easy 'opt-out' for participants who don't want to state an opinion, so may be best avoided.
- Research has found that some people with learning disabilities were able to use a 4-point answer scale, but not all (Turnpenny et al., 2015).
- Face-to-face methods, rather than self-completion, are best for people with a learning disability. Use of visual prompts (e.g. smiley/ sad faces) is helpful (Beadle-Brown, et al., 2012).
- People with learning disabilities are not a homogenous group; it is unlikely that a single questionnaire will work for all (Finlay & Lyons, 2002)

As well as considering the best format for the tool, a decision was needed on how best to measure the impact of Shared Lives. Possible approaches that would fit in with practice include:

- Taking a 'before-after' approach, where outcomes are captured before an intervention begins and then at a later point in time.
- Asking individuals what specific areas of their lives would be like in the absence of the service, known as the 'capacity for benefit' approach and used in the ASCOT.
- Asking whether different aspects of life are better or worse because of the service, used in the POET.

Consultation with stakeholders

Consultation with stakeholders involved working with six Shared Lives schemes. Information on the practicalities of collecting outcomes information was gathered through phone conversations with scheme managers. Meetings were held with different groups of people to discuss which outcomes were relevant to Shared Lives, including:

- A roundtable meeting involving representatives of the six schemes.
- A meeting of Shared Lives managers from a regional managers' forum, from schemes offering long term, respite, short breaks and day support to a wide range of client groups.
- A focus group with Shared Lives clients with mental health problems, all using long term support (with some respite support).
- A focus group with Shared Lives clients, some with a learning disability and some who were older people, using a mix of long term, respite and day support.
- A Shared Lives carers' forum, with carers providing long term and respite placements.

Consultation with Shared Lives users from two other schemes was also planned, but was not possible within the timeframe due to difficulties with gaining research governance approval.

Individuals using Shared Lives were asked about:

- Context
 - The type of support received from Shared Lives and how long for.
 - Other services used both before and in addition to Shared Lives, and how they compared to Shared Lives.
- The best things about Shared Lives and the areas of their life that it has the greatest impact on.
- The areas of life they would like Shared Lives to have an impact on that it doesn't currently.

Shared Lives carers and scheme practitioners were asked similar questions about the areas of life that Shared Lives had an impact on, both from a professional perspective and that of the service user. They were also asked about the practicalities of using one tool to measure outcomes for different client groups and different types of Shared Lives, how the tool could fit with existing review processes, and the appearance and format of the tool.

There were similar responses across all consulted groups regarding the outcomes relevant for Shared Lives. Box 3 shows the main areas of quality of life identified, with examples of the typical things mentioned.

Information on the outcomes relevant for Shared Lives was also collected through an email request via Shared Lives Plus to schemes (7 schemes responded), and from the small amount of literature on Shared Lives. Shared Lives Plus's stated goals regarding the outcomes for the service were also considered:

‘Our members are individual Shared Lives carers, Shared Lives schemes, Homeshare providers and micro-enterprises. They use different approaches to enable people to achieve goals such as: being in control of their services and their lives, pursuing ordinary lives within their chosen families and relationships, and being valued by their communities and feeling like they belong’ (Source, Shared Lives Plus, <http://sharedlivesplus.org.uk/index.php/about-shared-lives-plus>).

All the information was gathered together and mapped to the domains of wellbeing from the Care Act and the domains covered in the ASCOT (see Appendix 1). The key domains identified were developed into questions for the draft tool.

Box 3

Feeling part of a family

- Helping out around the house and garden
- Building relationships with SL carer’s extended family
- Emotional not professional relationship

Friendships and relationships

- Opportunities to meet new people, romantic relationships
- Relationships with biological family encouraged

Community living

- Going to church, to the local British Legion, working in the local shop, attending a local sewing club, gardening for others in community

New activities and experiences

- Doing activities you wouldn’t do or be able to do without the support of the SL carer
- Going on holiday, going on a plane for the first time

Independence and choice

- Support to gain independent living skills
- Greater independence – chance to do what you like, go where you want

Physical health

- Exercise with SL carer
- Assistance with medication
- Assistance with healthy eating
- Support for attendance at medical appointments

Emotional and mental health

- Boosted by being part of a family, building self-esteem
- Continuity of relationship with SL carer supports emotional health

Security

- Sense of peace of mind through having a home to go to
- Continuity of relationship with SL carer

Draft tool

The draft tool contained questions linked to six areas of outcome. These were:

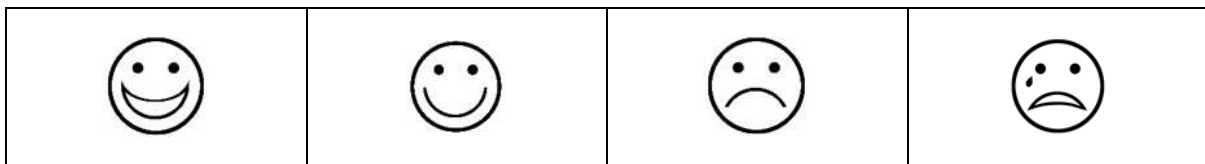
- Family and personal relationships
- Involvement in the local community
- Occupation and participation
- Control over daily life
- Physical wellbeing
- Emotional wellbeing.

The domains map broadly onto the majority of the Care Act and the ASCOT domains. The areas not covered were:

- Dignity: This concept was not often mentioned by those consulted with.
- Safety/ protection from abuse or neglect: The key issue here seemed to be feelings of security due to feelings of belonging to a family, rather than physical safety. An optional question on sense of security was included under the 'Emotional wellbeing' domain.
- Suitability of living accommodation: The key issue here was being in a family-like environment, which is covered in some way by the question on being part of a family. In addition, a question on living accommodation would not be applicable to all users of SL; for example, those using SL for day support may answer the question with reference to their usual living accommodation rather than the SL carer's home.

Structure of the draft tool

There were one or more questions under each domain. Two formats were presented for each main question, with the aim of consulting on which approach to use. The first was in 'ASCOT style', based on a new Easy Read version of ASCOT (ASCOT-ER): a question with four answer options to choose from. The second option was the same question in the form of a statement with which the individual is asked to say whether they agree or disagree. Again, there were four options. For both questions, a show card can be used to help pick an answer based on four smiley/sad faces. This show card was developed as part of the review of the ASCOT-ER tool and looks like this:



It was suggested that one key question was chosen for each domain (two for the family and personal relationships domain). These questions would form the core tool, and scores could be summed to give an overall outcome score, should this be appropriate. However, additional questions may be added in – for example, specific questions on social networks, or on participation in work, education, training or volunteering – and these options were also presented.

Change or the impact of Shared Lives could be captured in two ways using the tool. The questions can be asked before (or very soon after) an individual starts using Shared Lives, and then again at later points in time. Questions were also included that asked directly about the impact that Shared Lives has on each area of the person's life, which would be particularly useful for existing Shared Lives users.

Webinar

The draft tool was sent to Shared Lives Plus for feedback, and a webinar was held for representatives from the schemes. The aim was to present the draft tool and gain participants' input in developing the tool further. The slides used in the webinar can be seen in Appendix 2, and the draft tool which

was circulated prior to the webinar in Appendix 3. Participants were asked a number of focused questions:

- Have the most important areas of Shared Lives-related quality of life been covered?
- Do the questions appear to measure what they are intended to measure?
- Which response format would work best?
- Will the questions be easily understood by Shared Lives users?
- Will the questions be easily understood by Shared Lives staff?

The general consensus from the group was that the areas of quality of life proposed were appropriate, the questions would be understood (with some modification), and that the ASCOT answer format was preferred to 'agree-disagree' format.

Participants also provided guidance regarding the best timing for initially administering the tool. For new Shared Lives users, this could take place at the 'arrangement agreement' meeting to provide a 'baseline' measure. Other points discussed included the possible need for different versions of the tool for different types of Shared Lives support or for different client groups, and the relative merits of line drawings of smiley/sad faces or photographs to assist in answering questions. It was also suggested that photographs may be useful in aiding understanding of the quality of life concepts.

Pilot

The draft tool was amended to include only the preferred answer format, and two additional questions to record whether anyone other than the Shared Lives user and staff member was present during completion (and if so who that person was), and how much help the Shared Lives user required to answer the questions. Questions were also included about the impact of Shared Lives on each area of quality of life.

Two schemes were asked to pilot the tool over a three week period. These two schemes were those in which research governance approval had been granted; a third scheme was unable to take part within the time period.

The aim of the pilot was for each Shared Lives scheme to use the outcome measurement tool with a minimum of ten clients/service users across client groups (and with as many as possible during the time frame). The objective was to assess how easy the tool was to use and understand by staff and users of Shared Lives and make changes on the basis of the pilot.

Scheme staff were given an information sheet about the pilot asking them to complete the tool face-to-face with clients, outside of normal review procedures, and to complete a feedback questionnaire for each client. The feedback questionnaire asked for staff's opinions on the purpose, usefulness and ease of use of the tool, as well as how easily the questions were understood by the Shared Lives user. It also asked for opinions on how the tool could be improved. Feedback questionnaires were to be returned to PSSRU, but not the completed tools, therefore meaning that no actual data from individual service users was received. Copies of the information sheet, pilot tool and feedback questionnaire can be seen in Appendix 4.

Findings

Ten feedback forms were completed (although not all fully) and returned. A summary of the pilot participants is shown in Table 1. The majority of Shared Lives users involved (and possibly all) were people with learning disabilities, which needs to be borne in mind when interpreting the findings.

Table 1: Summary of pilot responses

		Scheme 1	Scheme 2
Placement type	Long term/ residential	1*	3
	Short breaks/ respite	1	0
	Day support	1	0
	Information missing	0	4
Client group	Learning disabilities	3	3
	Information missing	0	4
Total		3	7

* Also received short breaks support

Table 2 shows Shared Lives staff opinions of the tool. These were reasonably positive, although two people disagreed that the tool was simple and easy to use.

Table 2: Shared Lives staff opinions of the tool

	Strongly agree	Agree	Disagree	Strongly disagree
Understood purpose of tool	6	1	0	0
Belief that tool will be useful for work	3	4	0	0
Tool is simple and easy to use	0	5	1	1

Note: information only returned by 7 participants

Table 3 shows how well or otherwise Shared Lives users appeared to understand to questions under each area of quality of life (as rated by Shared Lives staff). Understanding was clearly varied, with some having little difficulty but others having problems understanding the concepts. The following issues were highlighted in the feedback from the Shared Lives scheme staff who completed the tool with service users:

- Some clients needed the questions rewording significantly using simplified 'everyday' language, in order to answer them. However it was noted that in one case this was due to communication difficulties rather than an issue with the questions themselves.
- Supplementary examples from the service user's own life were often needed to help answer the questions. These examples were provided by the Shared Lives carer who was present during completion.
- Some respondents had difficulty answering the questions relating to more abstract concepts. 'Community' and 'mental health' were noted as needing a lot of explanation and examples. Questions on 'occupation' and 'control' were also found to be more difficult to answer in one service user's case.

- Some respondents had difficulty in understanding the subtle differences between the four response levels. However this was aided in one case by using the show cards.
- For five users, support was needed to answer the ‘impact’ questions. Particular difficulty was had if there had been a negative response to the preceding question. Three of these cases were reported by one staff member.

Table 3: Could the Shared Lives user understand the questions?

	Strongly agree (%)	Agree (%)	Disagree (%)	Strongly disagree (%)
Family and personal relationships	1	4	1	1
Involvement with the community	0	5	1	1
Occupation and participation	1	4	2	1
Control over daily life	1	3	2	1
Physical wellbeing	1	4	1	1
Emotional wellbeing	0	5	1	1

Note: information only returned by 7 participants

Clearly there are some difficulties with understanding elements of the tool. However, it is important to be aware of the fact that only 10 responses were received, and it is likely that they were all concerning people with learning disabilities. While this is the largest client group served by Shared Lives, it would have been useful to have other perspectives reflected, and further work is likely to be needed to ensure the tool is usable with as many Shared Lives clients as possible.

Revisions to the tool – April 2015

During the pilot period, feedback was also received from Shared Lives Plus on some of the issues raised during the webinar, as well as some amendments to consider to the questions, as follows:

- One tool would be preferable to different versions.
- Some of the ‘optional’ questions presented in the draft tool were seen as crucial, particularly those around social support. Asking about employment status would also be beneficial.
- A question on safety may be useful to include if it ties in with what schemes are expected to report during Care Quality Commission inspections.
- Given that there is no agreement in the sector on the relative merits of line drawings for smiley faces versus photographs, using line drawings would be acceptable for this tool.
- The phrase ‘Shared Lives carer’s family’ would be better replaced by ‘Shared Lives carer’s household’ to reflect the fact that not all Shared Lives carers have a ‘family unit’ around them.

Following this feedback and the findings from the pilot, the following changes have been made to the tool:

- Guidance for Shared Lives staff has been amended to make it clear that it is fine for them to simplify the questions to aid the Shared Lives user’s understanding, and to use additional examples relevant to the user’s situation.
- Additional guidance has been added on the reasoning behind asking the questions on the impact of Shared Lives (as it was felt that difficulties may have been due in part to a lack of understanding on the staff members’ part), and the questions themselves reworded slightly.
- Additional questions on social support, employment status have been added in.

It has been agreed that there will be one version of the tool. Producing multiple version (e.g. for different client groups or types of support) would mean that data wouldn’t be directly comparable across the different types of SL support so there would be problems aggregating the data.

Further development

Given the limited response to the pilot, and particularly the lack of representation from different client groups, further testing would be beneficial. It would also be useful to explore how some of the more abstract concepts could be better defined to make them easier for people with learning disabilities to understand. One possibility would be to test out the use of pictures to illustrate the questions, although this is outside of the scope of the current project.

Other issues for consideration:

- If seen as important by Shared Lives plus, a question on frequency of contact with family could be added in to the tool to correspond to that on contact with friends.
- If it is apparent that other Shared Lives users have difficulty in answering the questions on the impact of the Shared Lives carer, the format could be changed as follows. It may aid understanding to have the question broken down into two parts.

1. Does the support that you get from your Shared Lives carer affect your social life?	
	Please tick (✓) one box
Yes	<input type="checkbox"/>
No	<input type="checkbox"/>
Don't know	<input type="checkbox"/>
2. If yes, does it make your social life better or worse?	
	Please tick (✓) one box
It makes it better	<input type="checkbox"/>
It makes it worse	<input type="checkbox"/>
Not applicable (answer to question 1 was no/don't know)	<input type="checkbox"/>

- The question of whether to include ‘safety’ as an outcome in the tool needs to be resolved. As noted earlier, feelings of security related to the relationship with the Shared Lives carer, rather than physical safety, appeared to be more important to users and carers we spoke to, and a question could be included to capture this. However, schemes need to demonstrate to CQC that they are able to keep people safe from abuse and harm – a different issue. The ASCOT-ER tool includes questions on feelings of safety in the home and outside of the home which may suit this purpose. However, while this kind of question would work well for people using long-term/ residential Shared Lives support, it may be problematic for those using other types of Shared Lives support where the Shared Lives carer’s home is not the user’s main home.

Recommendations for administration of the tool

Work with the Shared Lives schemes has resulted in the following recommendations:

- The tool should be used by Shared Lives staff face-to-face with service users, rather than as a self-completion exercise. This would help to facilitate the participation of those with communication or language difficulties.
- The Shared Lives staff member should complete the tool with the Shared Lives user outside of routine review, given that review procedures differ between schemes and are carried out in some cases by care management teams.
- For new users of Shared Lives, the tool should be completed at the time of the arrangement agreement meeting.
- Consideration then needs to be given to the most meaningful time to collect follow-up data, particularly for short breaks or infrequent day support.
- The amount of assistance given to arrive at the answers should be recorded, as should the presence of other people such as the Shared Lives carer, in order to facilitate analysis of the validity of the tool. There are questions at the end of the tool for this purpose.

The final version of the tool is now being used by Shared Lives Plus. If you would like a copy of the tool, ‘My Shared Life’, please contact Shared Lives Plus or the authors.

References

- Beadle-Brown, J., Ryan, S., Windle, K., Holder, J., Turnpenny, A., Smith, N., . . . Whelton, B. (2012). Engagement of People with Long-Term Conditions in Health and Social Care Research: Barriers and Facilitators to Capturing the Views of Seldom Heard Population. DP 2850. Canterbury: QORU.
- Czaja, R., & Blair, J. (2005). *Designing survey: A guide to decisions and procedures Undergraduate research methods and statistics in the social sciences*. New York, NY: Putnam: SAGE Publications, Inc.
- De Vaus, D. A. (1993). *Surveys in social research* (3 ed.). London: UCL Press.
- DeVellis, R. (2003). *Scale development: Theory and applications. Applied social research methods series*. Thousand Oaks: CA: SAGE Publications, Inc.
- Finlay, W. M. L., & Lyons, E. (2002). Acquiescence in Interviews With People Who Have Mental Retardation. *Mental Retardation*, *40*(1), 14-29. doi: 10.1352/0047-6765
- Fowler, F. J. (1995). *Improving survey questions. Design and evaluation*. Thousand Oaks, CA: Sage Publications, Inc.
- Glendinning, C., Clarke, S., Hare, P., Maddison, J., & Newbronner, L. (2008). Progress and problems in developing outcomes-focused social care services for older people in England. *Health & Social Care in the Community*, *16*(1), 54-63.
- Kazimirski, A., & Pritchard, D. (2014). Building your measurement framework: NPC's four pillar approach. London: New Philanthropy Capital.
- Netten, A. (2011). Overview of outcome measurement for adults using social care services and support. Methods review 6. *National Institute for Health Research, School for Social Care Research, London*, 12.
- The Care Act. (2014). The Care Act. London, UK: The Stationery Office.
- Turnpenny, A., Caiels, J., Crowther, T., Richardson, L., Whelton, B., Beadle-Brown, J., . . . Rand, S. (2015). Developing an Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT). Discussion Paper 2891. Canterbury: QORU.

Appendices

Appendix 1: Outcomes identified as relevant to Shared Lives

Summary of information drawn from literature, reports, Shared Lives Plus and consultation with schemes, practitioners, users and carers.

Care Act wellbeing domains	Personal dignity/ treating individual with respect	Physical and mental health, emotional wellbeing	Protection from abuse and neglect	Control by individual over day-to-day life	Participation in work, education, training, recreation	Social and economic wellbeing	Domestic, family and personal relationships	Suitability of living accommodation	Individual's contribution to society	Other areas
Ascot domains of social care-related QoL	Dignity	Personal cleanliness and comfort, Food and drink	Personal safety	Control over daily life	Occupation	Social participation and involvement	Social participation and involvement	Accommodation cleanliness and comfort		
Literature, reports etc.										
NAAPS 2009 Evaluation of quality, outcomes and c-e of SL in the SE. Outcomes identified by SL users.		Physical and emotional wellbeing; Increase in self-esteem	Being safe	Living the life the person wants; Having choices & being in control; Developing confidence/ skills/ independence	Developing confidence/ skills/ independence; Having difference experiences; Having a job	Having wider social networks; Integration in community	Having wider social networks; Ongoing relationship between person and SL carer; Being part of SL carer's family & networks; Building own relationships; Sustaining relationships with relatives			

Care Act wellbeing domains	Personal dignity/ treating individual with respect	Physical and mental health, emotional wellbeing	Protection from abuse and neglect	Control by individual over day-to-day life	Participation in work, education, training, recreation	Social and economic wellbeing	Domestic, family and personal relationships	Suitability of living accommodation	Individual's contribution to society	Other areas
Ascot domains of social care-related QoL	Dignity	Personal cleanliness and comfort, Food and drink	Personal safety	Control over daily life	Occupation	Social participation and involvement	Social participation and involvement	Accommodation cleanliness and comfort		
Your Voice Counts – ULO working with SL users – positive things about living in SL (Alex Fox blog 10-11-2014)			Feeling safe and supported			Getting together with other SL users (likeminded people)	Living as part of a family; Getting together with other SL users (likeminded people)	Living as part of a family		Having a pet
Your Voice Counts – Draft report. (note: outcomes not the focus; participants asked what it was like living in SL). See 'measuring a good life' at the end of report.		Help with depression.	Feeling safe.	SL carers help to make decisions. Have freedom, but know people care about them. Would like more choice over meals. Support to manage finances valued.	Would like more opportunities to cook meals. Support to manage finances valued.		Living with a family/ feeling part of a family was important to users. Enjoy seeing extended family. Would like opportunities to socialise with other SL users.	Support to move into own flat if needed.		

Care Act wellbeing domains	Personal dignity/ treating individual with respect	Physical and mental health, emotional wellbeing	Protection from abuse and neglect	Control by individual over day-to-day life	Participation in work, education, training, recreation	Social and economic wellbeing	Domestic, family and personal relationships	Suitability of living accommodation	Individual's contribution to society	Other areas
Ascot domains of social care-related QoL	Dignity	Personal cleanliness and comfort, Food and drink	Personal safety	Control over daily life	Occupation	Social participation and involvement	Social participation and involvement	Accommodation cleanliness and comfort		
Shared Lives South West – annual review 2013/14. Themes from questions to users on outcomes		Eating well	Feeling safe		Work, hobbies, holidays		Feeling loved; Being part of a family; Personal relationships			Pets
Information from schemes regarding approach to outcomes measurement										
Scheme 1 – information from admin officer re categories of outcomes measured at review		Health Stability/ maintenance		Independent living skills	Holidays Employment/ work Independent living skills Leisure & hobbies Learning/ education		Relationships			

Care Act wellbeing domains	Personal dignity/ treating individual with respect	Physical and mental health, emotional wellbeing	Protection from abuse and neglect	Control by individual over day-to-day life	Participation in work, education, training, recreation	Social and economic wellbeing	Domestic, family and personal relationships	Suitability of living accommodation	Individual's contribution to society	Other areas
Ascot domains of social care-related QoL	Dignity	Personal cleanliness and comfort, Food and drink	Personal safety	Control over daily life	Occupation	Social participation and involvement	Social participation and involvement	Accommodation cleanliness and comfort		
Scheme 2 – information from SL officer re outcomes SL achieves			Maintain safe & secure lifestyle	Daily living skills	Holidays; Increased confidence, skills, independence; Employment; Education; Daily living skills	A voice and place in the community, community inclusion, to be valued in society; Increased social networks; Decrease in social isolation	Relationships with SL carer's extended family; Increased social networks; Decrease in social isolation	Maintain safe & secure lifestyle in ordinary life environment; A home they can call their own	A voice and place in the community, community inclusion, to be valued in society	Person-centred approach; Opportunity to move on to a lifestyle which suits changing needs. Continuity of care
Scheme 3 - information from SL officer re outcomes SL achieves		Feeling settled and happy in placement; Improved health & wellbeing			Accessing community activities; Learning skills; Other achievements	Accessing community activities				


Care Act wellbeing domains	Personal dignity/ treating individual with respect	Physical and mental health, emotional wellbeing	Protection from abuse and neglect	Control by individual over day-to-day life	Participation in work, education, training, recreation	Social and economic wellbeing	Domestic, family and personal relationships	Suitability of living accommodation	Individual's contribution to society	Other areas
Ascot domains of social care-related QoL	Dignity	Personal cleanliness and comfort, Food and drink	Personal safety	Control over daily life	Occupation	Social participation and involvement	Social participation and involvement	Accommodation cleanliness and comfort		
Consultation with practitioners, users, carers										
Consultation with regional SL scheme managers' forum members (03-12-14)		Support for mental health/ wellbeing (e.g. reduced need for contact with psychologist, reduced contact with police). Support for physical health – e.g. healthy eating, physical appearance. Stability.	Safety. (SL seen as safer than previous settings) Stability.	Independence – learning independent living skills, trying new things out. SL offers informed choice, awareness of opportunities available.	Living ordinary lives – shopping, opportunities to go out on dates. Opportunity to experiment, try new things out. Learning independent living skills. Opportunities to travel. Having fun.		Living with a family. SL carers seen as friends/ family. Friendships. Romantic relationships. Relationships with biological family (encouraged/ supported). Social contact.		Making a contribution to family life.	
Roundtable meeting with representatives from 6 schemes & SLP (04-12-14)	Being listened to. Feeling valued.	Emotional and mental health. Physical health.	Safety and security	Independence. Choice.	New activities and experiences. New skills.	Social inclusion. Community living. Feeling valued.	Feeling part of a family. Friendships and relationships.		Community living. New skills. Feeling valued.	

Care Act wellbeing domains	Personal dignity/ treating individual with respect	Physical and mental health, emotional wellbeing	Protection from abuse and neglect	Control by individual over day-to-day life	Participation in work, education, training, recreation	Social and economic wellbeing	Domestic, family and personal relationships	Suitability of living accommodation	Individual's contribution to society	Other areas
Ascot domains of social care-related QoL	Dignity	Personal cleanliness and comfort, Food and drink	Personal safety	Control over daily life	Occupation	Social participation and involvement	Social participation and involvement	Accommodation cleanliness and comfort		
Scheme 4 - focus group with people with mental health issues (15-01-15)		SL helps maintain physical and emotional health (e.g. not drinking, managing depression, medication). Gives peace of mind' (re. accommodation, finances)	SL gives sense of safety and security. 'Having a place to go home to'.	SL enables independence and choice – e.g. travelling alone, going to football.		Being part of SL helps feel part of local community. Help with running of household (ironing, gardening). Holidays (e.g. going on plane for first time)	Importance of being part of a family. Involved with friends & family of SL carers.		Able to help others in the community – would like to do more. Able to help with running of household.	
Scheme 5 - Consultation with SL carers' forum (16-01-15)		Help to manage diet, take exercise, attend medical appointments. Emotional health boosted by being part of family.	Stability – continuity of care.	Independence. Develop independent living skills.	Develop independent living skills. Opportunities for holidays.	Opportunities to access community activities. Being part of community, giving something back. Opportunities for work/ volunteering.	Feeling part of a family. Sense of belonging. Relationships with SL carers' extended families and friends. Importance of the caring relationship. Company, friendship, opportunities to meet people.			

Care Act wellbeing domains	Personal dignity/ treating individual with respect	Physical and mental health, emotional wellbeing	Protection from abuse and neglect	Control by individual over day-to-day life	Participation in work, education, training, recreation	Social and economic wellbeing	Domestic, family and personal relationships	Suitability of living accommodation	Individual's contribution to society	Other areas
Ascot domains of social care-related QoL	Dignity	Personal cleanliness and comfort, Food and drink	Personal safety	Control over daily life	Occupation	Social participation and involvement	Social participation and involvement	Accommodation cleanliness and comfort		
Scheme 6 - focus group with people with learning disabilities (20-01-15)	Care is very personalised, 1 to 1.			SL enabled users to have choice and control. Allowed them to do what they want/ go where they want.	SL enables users to take part in new/ varied hobbies & interests. Enabled them to take part in everyday activities (e.g. going shopping, having haircut). SL users enjoyed going on holiday with carers. Take part in running of household (cooking, washing up)	SL enabled them to take part in activities in local community.	Users commented that felt part of SL carer's family. Taking part in running of household helps with this. Get to know SL carers well.	Living as part of family.	Example of SL user knitting presents for babies in family. Able to help with running of household.	

Care Act wellbeing domains	Personal dignity/ treating individual with respect	Physical and mental health, emotional wellbeing	Protection from abuse and neglect	Control by individual over day-to-day life	Participation in work, education, training, recreation	Social and economic wellbeing	Domestic, family and personal relationships	Suitability of living accommodation	Individual's contribution to society	Other areas
Ascot domains of social care-related QoL	Dignity	Personal cleanliness and comfort, Food and drink	Personal safety	Control over daily life	Occupation	Social participation and involvement	Social participation and involvement	Accommodation cleanliness and comfort		
Additional information from SLP										
Big Lottery indicators					No. of people in training, employment, volunteering.	No. of people who have increasing social and informal networks. No. of people who report reduces social isolation and loneliness	No. of people newly supported by SL who report: 1. An increased sense of belonging. 2. An increased sense of being valued/ active citizens			
SLP stated goals				Service users in control of their services and their lives	Service users pursuing ordinary lives within their chosen families and relationships;	Service users pursuing ordinary lives within their chosen families and relationships; Service users being valued by their communities and feeling like they belong	Service users pursuing ordinary lives within their chosen families and relationships; Service users being valued by their communities and feeling like they belong		Service users being valued by their communities and feeling like they belong	

Appendix 2: Presentation slides used in webinar

<p>University of Kent LSE THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE</p> <p>PSSRU Personal Social Services Research Unit</p> <h3>Developing an outcome measuring tool Shared Lives - Webinar</h3> <p>4th March 2014 14.00-15.30</p> <p>www.pssru.ac.uk</p>	<h3>INTRODUCTION AND AIMS</h3> <p>www.pssru.ac.uk</p>
<h3>Introductions & 'ground rules'</h3> <ul style="list-style-type: none">• Welcome• How the webinar will work & some ground rules:<ul style="list-style-type: none">– PowerPoint presentation– All on mute– Allocated time for Q&A – again, raise your hand  <p>www.pssru.ac.uk</p>	<h3>Overall project aims</h3> <ul style="list-style-type: none">• To develop an outcome measuring tool for Shared Lives<ul style="list-style-type: none">– Easy to use as part of current processes– Co-produced with Shared Lives users, carers, schemes– Evidence-based• Online portal• Outcomes: The changes, benefits, learning or other effects that result from what the project or organisation makes, offers or provides. <p>www.pssru.ac.uk</p>
<h3>Aims of today</h3> <ul style="list-style-type: none">• Continue development of the tool with your input• Explain the development process• Present the draft tool<ul style="list-style-type: none">– Administering the tool– Areas of quality of life– Structure (question format etc.)• Q&A, feedback• Next steps <p>www.pssru.ac.uk</p>	<h3>THE DEVELOPMENT PROCESS</h3> <p>www.pssru.ac.uk</p>

Desk-based review (1)

- Desk-based review
 - Literature on outcomes of Shared Lives
 - Existing frameworks and tools
 - Measurement of outcomes, question format
- Frameworks - the Care Act, clause 1 'promoting individual wellbeing'
 - Personal dignity
 - Physical and mental health, emotional wellbeing
 - Protection from abuse and neglect
 - Control over day-to-day life
 - Participation in work, education, training, recreation
 - Social and economic wellbeing
 - Domestic, family and personal relationships
 - Suitability of living accommodation
 - Contribution to society

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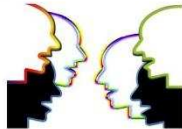
Desk-based review (2)

- Measuring wellbeing
 - Many tools too broad
 - Many tools too long, or not appropriate for all (e.g. people with learning disabilities)
- Measuring outcomes of social care – tools still too broad, missing key elements of Shared Lives
- Question format
 - Agree-disagree vs. statements
 - 3-5 categories
 - Face-to-face methods best
 - Use of visual cues such as show cards

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Consultations

- A focus group with Shared Lives clients with mental health problems
- A focus group with Shared Lives clients, some with a learning disability and some who were older people
- A roundtable meeting involving representatives of the six schemes
- A Shared Lives carers' forum
- A meeting of Shared Lives managers from the London Boroughs Shared Lives forum



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Consultations- Users of SL

- Context
 - Type of support received from SL and how long for
 - Other services used both before and in addition to SL, and how they compare to SL
- Best things about SL and the areas of life that it has the greatest impact on
- Areas of life they would like SL to have an impact on that it doesn't currently

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Consultations- SL Carers and Practitioners

- What outcomes are relevant for SL?
 - What aspects of people's lives does SL have the most influence on?
 - What outcomes would be the most important to users of the service?
- Different outcomes relevant for different client groups?
- Different outcomes relevant for different types of SL?
- Existing review processes
- Appearance of tool

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Consultations- Findings

Similar responses across all groups regarding relevant outcomes for SL users:

- Feeling part of a family
 - Helping out
 - Extended family
- Friendships and relationships
- Community living
- New activities and experiences
 - Hobbies
 - Holidays
- Independence and choice
- Physical health
- Emotional and mental health
- Security
 - Peace of mind
 - Continuity



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Drawing it all together

Care Act	Personal dignity/ having individual with respect	Physical and mental health, emotional wellbeing	Protection from abuse and neglect	Control by individual over day-to-day life	Participation in work, education, training, recreation	Social and economic wellbeing
Accot	Dignity	Personal relationships and comfort, food and drink	Personal safety	Control over daily life	Occupation	Social participation and involvement
Outstanding focus group - Mental Health (25/01/15)		It helps maintain physical and emotional health (e.g. not drinking, managing depression, medication). Gives peace of mind (the accommodation, finances)	It gives sense of safety and security (having a place to go home to)	It enables independence and choice (e.g. travelling alone, going to football)		Being part of a local community (help with running of household (shopping, gardening), holidays (e.g. going on plane for first time)
Consultation with SL carers' forum (28/01/15)		Helps to manage daily life (exercise, attend appointments, emotional health) boosted by being part of family.	Stability - continuity of care.	Independence. Develop independent living skills.	Develop independence living skills. Opportunities for holidays.	Opportunities to social community activities. Being part of community, giving something back.

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QUESTIONS & ANSWERS

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THE DRAFT TOOL

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Administering the tool

- Completed face-to-face by Shared Lives officer with Shared Lives user
- Recommendations following consultation:
 - Conducted outside of routine review process
 - Careful consideration of best timing
 - Record any assistance to arrive at answers, presence of others
 - Simple, tick box format for ease of completion by Shared Lives officer
- Online portal

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Areas of quality of life (1)

- Family and personal relationships
 - Personal relationships with friends and family
 - Feeling part of Shared Lives carer's family
 - Social networks, social isolation, loneliness
- Involvement in the community
 - Feeling part of the community
 - Making a contribution
- Occupation and participation
 - Recreation, hobbies, holidays
 - Education, learning
 - Work, volunteering



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Areas of quality of life (2)

- Control over daily life
 - Having choices over daily life
 - Living the life the person wants
 - Support from Shared Lives carers in making decisions
 - Independence, independent living skills
- Physical wellbeing
 - Support to maintain physical health (incl. medication)
 - Healthy lifestyle: eating well, exercise
 - Personal appearance
- Emotional wellbeing
 - Support to main mental health (incl. medication)
 - Stability
 - Increased confidence, increased self-esteem

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Structure of the tool (1)

- 6 areas of quality of life
- 1-2 key question for each area: the core tool
- Choice of two formats
- 4 answer options for each, use of show cards as appropriate:



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Structure of the tool (2)

- Additional questions added in as required
- Measurement of change, impact of Shared Lives
 - Complete tool before (or just after) starting Shared Lives, then at later date
 - Ask about the impact of Shared Lives



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An example...

Core question 1

This question is about feeling part of the community. Things that might help you feel part of the community could be:

- Going to local groups and activities
- Using local services such as shops, pubs or the library
- Volunteering or working in the local community
- Feeling valued by local people

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An example...

Option A

Do you feel part of the community?

- I feel part of the community. It's great.
- I feel part of the community most of the time. It's ok.
- I feel part of the community, but not enough. It could be better.
- I don't feel part of the community at all.

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An example...

Option B

Think about if you agree or disagree with the following statement:

"I feel part of community, as much as I would like to be."

- Strongly agree
- Agree
- Disagree
- Strongly disagree



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An example...

Impact of Shared Lives

Does the support you get from Shared Lives affect how involved you feel in the community?

- Yes, it helps me feel more involved
- Yes, but it makes me feel less involved
- No

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QUESTIONS & ANSWERS

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6 areas of quality of life

- Have we covered the most important areas of SL-related quality of life?

Family & relationships, involvement with the community, occupation & participation, control over daily life, physical wellbeing, emotional wellbeing

- Do the questions appear to measure what they are intended to measure?

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Response format

Do you feel part of the community?

- I feel part of the community. It's great.
- I feel part of the community most of the time. It's ok.
- I feel part of the community, but not enough. It could be better.
- I don't feel part of the community at all.

I feel part of community, as much as I would like to be.

- Strongly agree
- Agree
- Disagree
- Strongly disagree

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Administering the tool

Will the questions be easily understood

- By Shared Lives users?
- By Shared Lives staff?

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SUMMARY & NEXT STEPS

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Next steps

- Incorporate feedback from today
- Piloting questions with Shared Lives users in your schemes, feedback from users and practitioners
- Continued development of portal, testing with schemes

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THANK YOU!

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Appendix 3: Draft tool Shared Lives outcomes tool

Areas of quality of life and draft questions

- There are six areas of quality of life, with 1-2 core questions for each area.
- For each core question, 2 answer formats are presented (options A and B). Option A follows the format used in the new easy-read (ER) version of the ASCOT (Adult Social Care Outcomes Toolkit). Option B is in ‘agree-disagree’ format. Preferred format to be agreed.
- The questions will be completed face-to-face by Shared Lives practitioners with the person using Shared Lives. The tool will not be document for self-completion by the Shared Lives user. ‘Show cards’ with smiley/sad faces corresponding to each answer option can be used if appropriate.
- Some questions have been taken directly from the ASCOT-ER (amended slightly in most cases to make them more relevant to Shared Lives).
- There are also additional optional questions presented, which could be asked as required to provide additional information.

1. Family and personal relationships

Concepts included in this area:

- Personal relationships with friends and family
- Feeling part of the SL carer’s family
- Social networks, social isolation, loneliness

Question on SL carer’s family

Question option A (ASCOT-ER format)	Question option B (Agree/ disagree format)	SL impact question	Additional optional questions
<p>This question is about feeling part of your Shared Lives carer’s family. Things that help you feel part of the family could be:</p> <ul style="list-style-type: none"> • feeling welcome in their home • taking part in family activities and events • helping out with family life, such as cooking or housework 	<p>This question is about feeling part of your Shared Lives carer’s family. Things that help you feel part of the family could be:</p> <ul style="list-style-type: none"> • feeling welcome in their home • taking part in family activities and events • helping out with family life, such as cooking or housework 	<p>N/A</p>	<p>NOTE: considered additional question on relationship with SL carer but felt this relationship, rather than being an outcome, is instrumental in achieving good outcomes in other domains.</p>

<p>Do you feel a part of [SL carer's] family?</p> <ul style="list-style-type: none"> • I feel part of the family. It's great. • I feel part of the family most of the time. It's ok. • I feel part of the family, but not enough. It could be better. • I don't feel part of the family at all. 	<p>Think about if you agree or disagree with the following statement:</p> <p>I feel part of [Shared Lives carer's] family</p> <ul style="list-style-type: none"> • Strongly agree • Agree • Disagree • Strongly disagree 		
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Question(s) on other personal relationships with friends and relatives

Question option A (existing question, taken from ASCOT-ER)	Question option B (Agree/ disagree format)	SL impact question	Additional optional questions
<p>This question is about your social life. Social life means spending time with people you like. This could be friends, family or people in your community.</p> <p>How do you feel about your social life?</p> <ul style="list-style-type: none"> • I see the people I like as much as I want. It is great. • I see the people I like sometimes. It is OK. • I see the people I like but not enough. It could be better. • I do not see the people I like at all. And I feel lonely. 	<p>This question is about your social life. Social life means spending time with people you like. This could be friends, family or people in your community.</p> <p>Think about if you agree or disagree with the following statement:</p> <p>I see the people I like as much as I want. It is great.</p> <ul style="list-style-type: none"> • Strongly agree • Agree • Disagree • Strongly disagree 	<p>Does the support that you get from Shared Lives affect your social life?</p> <ul style="list-style-type: none"> • Yes, it makes it better • Yes, it makes it worse • No 	<p>Questions to capture social networks: These questions are about your family. Think about the people you are related to by birth or marriage.</p> <ol style="list-style-type: none"> 1. How many of your family members do you see or speak to at least once a month? None/ One/Two or More 2. How do you feel about the amount of contact you have with your family? Very happy/ quite happy/ quite unhappy/ very unhappy 3. Impact question: Does the support that you get from Shared Lives affect your contact with your family? Yes, it makes it better/ Yes, it makes it worse/ No.

			<p>These questions are about your friends. Think about all of your friends, including those who are part of [SL carer's] family.</p> <p>1. How many of your friends do you see or speak to at least once a month? None/ One/Two or More</p> <p>2. How do you feel about the amount of contact you have with your friends? Very happy/ quite happy/ quite unhappy/ very unhappy</p> <p>3. Have you made any new friends since Shared Lives has been supporting you? Yes/ No.</p> <p>4. Impact question: Does the support that you get from Shared Lives affect your contact with your friends? Yes, it makes it better/ Yes, it makes it worse/ No.</p> <p>Question to capture loneliness: Think about if you agree or disagree with the following statement: There are enough people I feel close to.</p> <ul style="list-style-type: none"> • Strongly agree • Agree • Disagree • Strongly disagree
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2. Involvement in the community

Concepts included in this area:

- Feeling part of the community
- Making a contribution

Question on feeling part of a community

Question option A (ASCOT-ER format)	Question option B (Agree/ disagree format)	SL impact question	Additional optional questions
<p>This question is about feeling part of the community. Things that might make you feel part of the community could be:</p> <ul style="list-style-type: none"> • going to local groups or activities • using local services such as shops, pubs or the library • volunteering or working in the community • feeling valued by local people <p>Do you feel part of the community? (Response options a):</p> <ul style="list-style-type: none"> • I feel part of the community. It's great. • I feel part of the community most of the time. It's ok. • I feel part of the community, but not enough. It could be better. • I don't feel part of the community at all. 	<p>This question is about feeling part of the community. Things that might make you feel part of the community could be:</p> <ul style="list-style-type: none"> • going to local groups or activities • using local services such as shops, pubs or the library • volunteering or working in the community • feeling valued by local people <p>Think about if you agree or disagree with the following statement: I feel part of the community, as much as I would like to be.</p> <ul style="list-style-type: none"> • Strongly agree • Agree • Disagree • Strongly disagree 	<p>Does the support that you get from Shared Lives affect how involved you feel in a community?</p> <ul style="list-style-type: none"> • Yes, it helps me feel more involved • Yes, but it makes me feel less involved • No 	<p>N/A</p>

<p>(Response options b; to attempt to capture whether being involved in the community is actually important to the individual):</p> <ul style="list-style-type: none">• Yes, I am involved as much as I would like to be.• Yes, I am involved enough. It's ok.• Yes, I am involved, but not enough. It could be better.• No, I don't feel part of the community at all.			
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3. Occupation and participation

Concepts included in this area:

- Recreation, hobbies, holidays
- Education and learning (including, e.g. independent living skills)
- Work
- Volunteering

Question(s) on what people do with their time

Question option A (existing question, adapted from ASCOT-ER)	Question option B (Agree/ disagree format)	SL impact question	Additional optional questions
<p>This question is about how you spend your time. Think about all the things you do during the day. You could think about:</p> <ul style="list-style-type: none"> • Your free time • Hobbies, learning new skills, holidays • Going to work, college, or volunteering • Housework. <p>Think about if:</p> <ul style="list-style-type: none"> • You can choose the things you do • You enjoy the things you do • You have enough things to do. <p>How do you feel about the way you spend your time?</p> <ul style="list-style-type: none"> • I spend my time how I want. It is great. 	<p>This question is about how you spend your time. Think about all the things you do during the day. You could think about:</p> <ul style="list-style-type: none"> • Your free time • Hobbies, learning new skills, holidays • Going to work, college, or volunteering • Housework. <p>Think about if:</p> <ul style="list-style-type: none"> • You can choose the things you do • You enjoy the things you do • You have enough things to do. <p>Think about if you agree or disagree with the following statement: I can spend my time how I want, doing things I enjoy.</p>	<p>Does the support that you get from Shared Lives affect the way you spend your time?</p> <ul style="list-style-type: none"> • Yes, in a good way • Yes, but in a bad way • No 	<p>Question on work etc. status: Are you currently taking part in any training, education, paid work or volunteering?</p> <ul style="list-style-type: none"> • Yes, training • Yes, education • Yes, paid work • Yes, volunteering <p>[Could change time frame to ‘during the last year’]</p> <p>Question on informal learning: Are you currently learning any new skills, such as how to cook, manage finances, looking after yourself?</p> <ul style="list-style-type: none"> • Yes • No <p>Question on holidays:</p>

<ul style="list-style-type: none"> • I do enough of the things I like. It is OK. • I do some of the things I like. But I would like to do more. • I do not do the things I like. It is really bad. 	<ul style="list-style-type: none"> • Strongly agree • Agree • Disagree • Strongly disagree 		<p>Have you been on holiday in the last year?</p> <ul style="list-style-type: none"> • Yes • No <p>[If yes] Was that the first time you had been on holiday?</p> <ul style="list-style-type: none"> • Yes • No
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4. Control over daily life

Concepts included in this area:

- Having choices over daily life
- Living the life the person wants
- Support from SL carers in making decisions
- Independent living skills/ independence

Question on control over daily life

Question option A (existing question, taken from ASCOT-ER)	Question option B (Agree/ disagree format)	SL impact question	Additional optional questions
<p>This question is about choice in your daily life. Having a choice means that you can decide what to do. Think about the choices you have.</p> <p>How do you feel about choice in your daily life?</p> <ul style="list-style-type: none"> • I have as much choice as I want. It's great. • I have enough choice. It's ok. • I have some choice. But I would like more. • I have no choice. It's bad. 	<p>This question is about choice in your daily life. Having a choice means that you can decide what to do. Think about the choices you have.</p> <p>Think about if you agree or disagree with the following statement: I have as much choice as I want. It's great.</p> <ul style="list-style-type: none"> • Strongly agree • Agree • Disagree • Strongly disagree 	<p>Does the support that you get from Shared Lives affect how much choice you have in your daily life?</p> <ul style="list-style-type: none"> • Yes, it helps me have more choice • Yes, but it makes me feel like I have less choice • No. 	<p>Separate question on control over the SL service?</p>

5. Physical wellbeing

Concepts included in this area:

- Support to maintain physical health
- Eating well
- Exercise
- Personal appearance
- Help with medication

Question on physical health

Question option A (ASCOT-ER format)	Question option B (Agree/ disagree format)	SL impact question	Additional optional questions
<p>This question is about your physical health. Think about how healthy you feel, whether you are able to eat healthy food, and whether you do any exercise.</p> <p>How do you feel about your physical health?</p> <ul style="list-style-type: none"> • I feel as healthy as I want. It's great. • I feel healthy enough. It's ok. • I feel quite healthy. But I could be healthier. • I don't feel healthy at all. It's bad. 	<p>This question is about your physical health. Think about how healthy you feel, whether you are able to eat healthy food, and whether you do any exercise.</p> <p>Think about if you agree or disagree with the following statement: I feel as healthy as I want.</p> <ul style="list-style-type: none"> • Strongly agree • Agree • Disagree • Strongly disagree 	<p>Does the support that you get from Shared Lives affect your physical health?</p> <ul style="list-style-type: none"> • Yes, it makes it better • Yes, it makes it worse • No 	<p>N/A</p>

6. Emotional wellbeing

Concepts included in this area:

- Support to maintain mental health
- Help with medication
- Stability
- Increased confidence
- Increased self-esteem

Question on emotional health

Question option A (ASCOT-ER format)	Question option B (Agree/ disagree format)	SL impact question	Additional optional questions
<p>This question is about your emotional health. Think about how you feel in your mind. Think about whether you feel worried, anxious or depressed, or whether you feel happy and confident.</p> <p>How do you feel about your emotional health?</p> <ul style="list-style-type: none"> • I feel as happy as I want. It's great. • I feel happy enough. It's ok. • I feel quite happy. But sometimes I feel down. • I don't feel happy at all. I often feel down. 	<p>This question is about your emotional health. Think about how you feel in your mind. Think about whether you feel worried, anxious or depressed, or whether you feel happy and confident.</p> <p>Think about if you agree or disagree with the following statement: I feel as happy as I want. It's great.</p> <ul style="list-style-type: none"> • Strongly agree • Agree • Disagree • Strongly disagree 	<p>Does the support that you get from Shared Lives affect your emotional health?</p> <ul style="list-style-type: none"> • Yes, it makes it better • Yes, it makes it worse • No 	<p>Question on sense of security This question is about how safe and secure you feel. [Definition to be worked up if included].</p> <p>Do you feel safe and secure?</p> <ul style="list-style-type: none"> • I feel very safe and secure • I feel quite safe and secure • I do not feel safe and secure enough • I do not feel at all safe and secure

Appendix 4: Pilot materials

Shared Lives Plus outcome measurement tool

Shared Lives Plus commissioned the Personal Social Services Research Unit at the University of Kent to develop an outcome measuring tool for Shared Lives. The purpose is to be able to more easily demonstrate the benefits of Shared Lives locally, regionally and nationally. It needed to be easy to use as part of current processes, co-produced with Shared Lives users, carers and schemes and evidence-based.

Our definition of outcomes is *'the changes, benefits, learning or other effects that result from what the project or organisation makes, offers or provides'*.

How we developed the tool

We conducted a desk-based review of the literature on outcomes of Shared Lives, existing frameworks and tools, the measurement of outcomes and question formats.

We have worked with six Shared Lives schemes. We conducted consultations with Shared Lives clients with mental health problems, with a learning disability and older people. We held a roundtable meeting involving representatives of schemes and a webinar with various stakeholders. We consulted with a Shared Lives carers' forum and scheme manager forum.

Piloting the outcome measurement tool

The aim of the pilot is for each Shared Lives scheme to use the outcome measurement tool with a minimum of ten clients/service users across client groups. However, the more users of Shared Lives we include in the pilot the better we can refine and amend the tool for wider use. We want to assess how easy the tool is to use and understand by staff and users of Shared Lives and make changes on the basis of the pilot.

The tool is designed to be used by Shared Lives staff face-to-face with service users and outside of normal review procedures. It measures seven areas of quality of life with 1 to 3 questions for each. We suggest that for a two week period staff complete the tool with any clients they plan to see/visit.

We would be grateful if you could return a feedback form for each client that you see. We do not need copies of the completed tool returned. Freepost envelopes are provided but how these are returned to us is up to individual schemes (one at a time, collated by an administrator and so on), **please could you make sure they are in the post by Wednesday 1 April.**

What will happen next?

We hope to get input from three schemes and will feed back any changes we make on that basis. The tool will then be incorporated into an online portal where the outcomes information can be stored. Shared Lives Plus will distribute information about this later in the year.

Any questions

If you have any questions please contact your scheme manager or you can contact us directly: **Lisa Callaghan** telephone: 01227 827891, email: L.A.Callaghan@kent.ac.uk, **Nadia Brookes** telephone: 01227 823807, email: N.K.brookes@kent.ac.uk, or **Sinead Rider** telephone: 01227 823863, email: S.Rider@kent.ac.uk.

Outcome Measurement Tool for Shared Lives – Shared Lives staff feedback

Many thanks for participating in the pilot of the outcome measurement tool for Shared Lives. After using the pilot tool we would like you to complete this brief questionnaire. If you do this with more than one user of Shared Lives you only need answer questions A and B once.

Please indicate the extent of your agreement or disagreement for each of the following statements below by placing a tick in the appropriate box according to the following scale:

1 – Strongly agree 2 – Agree 3 – Disagree 4 – Strongly disagree

A. I understand the purpose of the outcome measurement tool

Strongly agree	1	2	3	4	Strongly disagree

B. I believe the outcome measurement tool will be useful for my work

Strongly agree	1	2	3	4	Strongly disagree

C. The outcome measurement tool is simple and easy to use

Strongly agree	1	2	3	4	Strongly disagree

D. The user of Shared Lives could understand the question(s) about:

Family & personal relationships					
Strongly agree	1	2	3	4	Strongly disagree
Involvement with the community					
Strongly agree	1	2	3	4	Strongly disagree
Occupation & participation					
Strongly agree	1	2	3	4	Strongly disagree
Control over daily life					
	1	2	3	4	

Strongly agree					Strongly disagree
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The user of Shared Lives could understand the question(s) about:

Physical wellbeing					
Strongly agree	1	2	3	4	Strongly disagree
Emotional wellbeing					
Strongly agree	1	2	3	4	Strongly disagree

E. If you have indicated 3 or 4 for any of the statements above please tell us how the outcome tool could be improved

F: Additional information

Name of Scheme	
Your name	
Placement type of service user	
Client group of service user	