

ASSESSING OLDER ADULTS' CURRENT AND EXPECTED  
'SOCIAL CARE RELATED QUALITY OF LIFE' IN ORDER TO INVESTIGATE THE  
IMPACT OF CARE SERVICES

by

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## Abstract

Extra care housing schemes are housing with care communities that allow for independent ownership of residences, flexible care packages, disability conscious design and on site facilities. The impact of support and care services within extra care housing schemes was explored through comparisons of quality of life in a sample of 83 extra care housing residents across seven schemes in England (62 female, mean age 80 years). A measure of 'social care related quality of life' reflected the current contributions of care and support services to aspects of residents' lives ranging from personal care to social participation. This was compared to residents' imagined view of their life in the absence of care and support services, described as their expected 'social care related quality of life'. A lower estimated quality of life was recorded when residents considered their lives without care and support services, demonstrating the importance of services. The differences between current and expected 'social care related quality of life' suggest that care and support services are valuable in maintaining a satisfactory quality of life.

## Acknowledgements

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## Introduction and reflection

The three elements of my thesis demonstrate the diversity of research placements within Clinical Psychology. My first placement was investigating the role of modelling and eating behaviour in adolescents. The sample compared adolescents with type 2 diabetes, obese adolescents and healthy weight adolescents. As part of a larger experiment, they consumed a standardised meal with their parent which was recorded. I coded and analysed the resulting sample of 52 video files. At the beginning of my placement I had planned to work on investigating a relationship between gestational diabetes and postnatal depression, but as I began the process of applying for a research passport it became clear that the paperwork would not be processed in time; additionally an amendment was required for the study. This process was a good experience as it showed me the strict regulations that govern research. I completed a Good Clinical Practice course which gave me an opportunity to learn more about how research projects are structured and to see how the information about ethics taught on the MRes course is applied to NHS settings. It was beneficial to learn about the hierarchy of responsibility and teamwork within an NHS based research project. Although I could not recruit participants, I sent out follow up postnatal questionnaires to existing participants. We considered alternatives for my placement and settled on assisting analysis in the modelling and eating behaviour study. I used literature searching techniques that were described in an MRes workshop to explore the literature concerning modelling, imitation and food intake. This enabled me to devise ways to define modelling and measure it from the behaviours observed in the video data.



My second placement was based at an Early Intervention Service, running computerised cognitive remediation therapy sessions with service users with schizophrenia. The program was well designed to gradually increase in difficulty and allow users to practise cognitive tasks and increase their abilities in subsequent trials. A variety of tasks in the program tested and developed cognitive skills such as working memory capacity, attention, task switching, and visual memory. During the therapy sessions, my role involved talking about the areas service users wanted to improve and how it affected their daily lives, explaining the aims of the program and discussing the types of strategies they might use in each task. We worked together to identify tasks they found more difficult and spent more time trying out the various strategies provided by the program as well as devising our own. I helped them to recognise their strengths and we regularly reviewed their progress through the program's score book. I read instructions aloud when necessary to prevent service users skipping ahead and making errors, particularly in tasks where the rules or aim would change throughout the task. Early Intervention Service team meetings reviewed case histories of clients which gave me a better idea of the care pathways involved in Early Intervention and allowed me to see the contributions of differently qualified members of the team to the overall treatment plans. Regular supervision meetings gave me an opportunity to discuss the placement, and reflect on my learning. I used neuropsychological tests from the WAIS, WMS and D-KFES to measure cognitive functioning, giving me the opportunity to record and score performance on these tests. During this placement I worked with another MRes student, and an honorary assistant psychologist, allowing us to give one-to-one attention and support to service users. I presented a poster on this topic at the

School of Psychology Research Event, and later at the university's Research Poster Conference. I had the opportunity to explain the poster to psychology students, judges, non-psychology students and members of the public, which meant I was often explaining psychological concepts and the implications of the cognitive remediation program to people without any prior knowledge of the area.

The final placement involved visiting various housing with care retirement communities (known as extra care housing) to explore the impact of care and support services on residents' quality of life. Case studies of extra care housing and interviews with residents were part of a larger project by ASSET which is exploring how to provide social care for older adults in a way that maximises quality of life and is cost effective. I worked with two researchers from the University of Worcester to interview residents. We travelled to several schemes across the UK, and met many different personalities! This gave me a good idea of the variance in scheme facilities, staff attitudes, residents' experiences and the positive and negatives of extra care housing. These placements presented some of the different challenges of working with particular groups. At the Early Intervention Service, attendance and commitment to the program were particular problems. Service users tried the program sessions at least once but did not attend regularly at subsequent sessions which eventually led to several dropping out. For the ASSET project, interviews with extra care housing residents sometimes led to information that conflicted with information provided by staff (for instance who was in receipt of care services), or residents had difficulty providing specific answers to questions about finances and care hours.

In summary, the MRes has given me a variety of experience working with populations with different ages ranging from adolescent to young adult to older adult, different physical and mental health needs, and different treatment providers.

## THE INFLUENCE OF MODELLING ON EATING BEHAVIOUR

## Reflection on Placement

This study compared obese adolescents, adolescents with Type 2 Diabetes and normal weight adolescents on various measures relating to eating behaviour, and from a range of testing methods including fMRI, questionnaires and observation. My role was to look at the behavioural aspect of the study where participants were observed eating a meal with their parent. One of the study's aims was to investigate the relationship between parent and adolescent in regards to eating behaviour and food choices, particularly the effects of restriction. Role modelling and imitation were areas to explore, to determine whether parent behaviour was congruent with their restriction of the adolescent's diet. The lunch provided contained some food items that were high in fat and sugar, and should be avoided by participants who are obese or who have diabetes. I used Obs Win 32 software to study the video data and record what was eaten throughout the lunch, which allowed me to compare the food choices made by both adolescent and parent. This is software I had not encountered before, and it was interesting to see how such a tool aids interpretation of behaviour. I would feel confident using this software in future behaviour studies. I learnt about the impact of restriction, parental role in meal choices, and the effect of social eating on consumption, healthy eating choices and attitudes towards weight. My first method of defining modelling had the criteria that modelling occurred within a time period of 3-15 seconds after the other person has taken their bite, and it occurred only if the adolescent was eating a different item and then changed items to be the same as the parent (and vice versa). This method did not allow continued eating of the same items to be recorded, a comparison could not be made about what happened after a

specific food item was eaten, and activity outside of the time frame was not recorded. To address these problems, I recorded what happened after each of the eight food items was eaten, which gave a more thorough record of consumption (see Method for further details). Group meetings with all the researchers involved in this project gave me insight into the teamwork involved in a longitudinal study. This placement has taught me about observation and behavioural coding. It allowed me to consider how behaviour can be interpreted and ways to define imitation in terms of time lapsed between behaviours, similarity of choices made and mimicry of physical actions. It also allowed me to consider the impact of observation on behaviour and the constraints of an experimental setting.

### The influence of modelling on eating behaviour

A healthy diet is desirable. Parents and caregivers are responsible for teaching their children healthy eating behaviour, as genetic predispositions to like certain foods can be modified by experience (Benton, 2004). There are many strategies that parents can employ to control their children's diet. They often impose restrictions, particularly in response to weight gain or a diagnosis such as diabetes, but it has been shown that chronic restrictions on the diet can actually result in greater consumption of food, and the use of restriction does not allow the child to learn to regulate their own energy intake (Birch & Fisher, 2000). In the current study, obese adolescents who consumed more calories from the lunch were observed to be given more verbal restriction by their parent. Adolescents who received greater restriction went on to consume more calories in the absence of hunger, when the parent was no longer present. This supports previous findings with younger children that they will eat more of restricted foods if given free access to them (Fisher & Birch, 1999). Fisher and Birch offered children (aged four to six) two similar foods but restricted access to one of them to see how the children reacted. They observed a high frequency of positive comments about the restricted food, and negative comments about restriction. Both foods had been rated previously as neutrally liked, and access to the control food was not restricted. Restricting access to a particular food increased the children's intake of that food in comparison to times when the food was freely available, and increased the child's preference for that food. The act of restricting a particular food increases the desire for that food, which results in more consumption. These negative impacts of restriction have led to the suggestion that being a positive

parental role model should be considered as an alternative strategy (Scaglioni, Salvioni & Galimberti, 2008). Children who observe their parents eating fruits and vegetables tend to prefer similar food types (Birch & Fisher, 1998), and children's consumption of fruit, berries and vegetables can be predicted by parent's consumption of fruit, berries and vegetables (Vanhala, Laitinen, Kaikkonen, Keinanen-Kiukaanniemi & Korpelainen, 2011). In healthy weight children only, their preference for vegetables was also a predictor of vegetable consumption. This shows that parental consumption of healthy food items increases the child's likelihood of eating similar foods, and parental preference for food types has an influence over the food preferences of their children.

Eating in the company of others can affect the quantity of food eaten, which has implications for those who need to restrict their intake due to their weight. It has been observed that people tend to eat more when eating with others than by themselves, as consumption can increase by up to 30% when eating in a group (Patel & Schlundt, 2001). This can be explained in terms of social facilitation; people desire to eat an appropriate amount, and are guided by the eating behaviour of the group (Herman, Roth & Polivy, 2003). When members of the group continue to eat past satiety, this permits other members to continue eating, and portion sizes are judged according to the consumption of others. Hermans et al. (2012) found that there was a higher chance of women taking a bite of food within 5 seconds of their eating companion taking a bite. They conclude that this eating behaviour is related to behavioural mimicry where people unconsciously copy another's behaviour. Mimicry can be almost automatic, and has been found in alcohol studies where taking a sip is more likely directly after seeing a companion take a sip (Larsen, Engels, Souren,



Overbeek & Granic, 2010). It is hypothesized that activation in the motor system when observing another person performing an action leads to the increased likelihood of implementing that action (Knoblich & Sebanz, 2006). Hermans et al. (2012) found that mimicry was strongest at the beginning of the meal when both confederate and participant were three times more likely to mimic behaviour within the first ten minutes compared to the last ten minutes. They used only female participants and confederates, as modelling is stronger when the model and confederate are the same gender (Conger, Conger, Constanzo, Wright & Matter, 1980). In terms of the current study, this suggests that the parent and adolescent pairs of the same gender will show greater modelling effects.

Goldman, Herman and Polivy (1991) believed hunger would reduce the effect of modelling, but they recorded strong modelling effects in participants who had not eaten in the previous 24 hours. The deprived participants ate small amounts when a confederate eater ate small amounts despite their own hunger, demonstrating the strong influence of modelling on eating behaviour. The above studies suggest that when adolescents eat in a family context, their eating behaviour is governed by the eating behaviour of their parents and siblings who are present at the meal. Videon and Manning (2003) surveyed adolescents and discovered that those who ate more family meals a week reported better consumption of fruits, vegetables and dairy products, and were less likely to skip breakfast. Of adolescents who ate six or seven meals a week with at least one parent present, two thirds reported poor consumption of vegetables. Of adolescents who ate three or less family meals a week, three quarters reported poor consumption of vegetables. Therefore family meals can affect the consumption of different food types. Family meal times may provide opportunities

for parents to be a role model, and allow them to educate adolescents about healthy eating.

It is not purely the quantity of food that can be affected by modelling, eating attitudes and opinions about food can also be imitated. Snoek, Engels, Janssens and van Strien (2007) found higher incidences of emotional eating corresponded with adolescent's reports of low maternal support and high psychological control, in younger adolescents. In older adolescents, only high control was associated with more occurrences of emotional eating. There were moderate correlations between adolescents' and parents' emotional eating, suggesting that this behaviour could be the result of modelling. Correlations between parents and their nine to thirteen year old children for internal motivations, such as eating if they felt sad, and for body dissatisfaction provide further evidence of modelling of eating attitudes (Brown & Ogden, 2004).

As adolescence is a time where peer influences are particularly important, the impact of peer modelling is larger, and alternative role models must be considered. Nineteen percent of foods eaten by adolescents are similar to those consumed by peers and friends (Kinard & Webster, 2012). The effectiveness of certain people as models can vary according to the weight of the model and the imitator. If the confederate and participant are both obese, modelling effects are stronger (De Luca & Spigelman, 1979). Obese participants did not eat as much when the confederate was of normal weight and eating a large amount, in comparison to when the confederate was obese and eating a large amount. Healthy weight participants' intake was not affected by the weight of a confederate. In a similar study, overweight females were found to be more inhibited when eating with another person, unless

that person consumed a large quantity of food (Conger et al., 1980). This suggests that if parents and adolescents are both overweight, they will influence each other's eating behaviour more. Barthomeuf, Droit-Volet and Rousset (2011) found a difference in children and adult's desire to eat certain foods that were modelled by an obese eater. Normal weight adults showed a decrease in desire to eat a food when in the presence of an obese eater who expressed enjoyment of that food, even if the adult liked that food. However, when children (mean ages 5.2 and 8.3 years) liked the particular food, their desire to eat was unaffected by the weight status of the other eater. This suggests that the weight statuses of people eating together can affect whether modelling occurs and to what degree. Social Learning Theory states that imitation is stronger when the person is similar to, or liked by, the imitator (Bandura, as cited in Snoek, van Strien, Janssens & Engels, 2009). This could mean they are more likely to copy their same sex parent, as they are biologically similar and likely to have common characteristics. Although some of the studies described were conducted with younger children, the evidence from adolescent and adult studies also demonstrates the influence of others on eating behaviour. In the current study it is expected that parents and adolescents will be influenced by the eating rate and consumption of the other person, as they will use cues from the other person about acceptable eating behaviour. The study aims to identify any modelling of eating behaviour, such as imitation of food choices. This could be from either the parent imitating the adolescent's eating behaviour or the adolescent imitating the parent's eating behaviour. Another aim is to identify any differences in the behaviour of obese adolescents, adolescents with type 2 diabetes and normal weight controls.

## Method

### *Participants*

Fifty eight adolescents (47 female) with a mean age of 15.6 years (SD = 1.9, ranging 12 to 18.9 years) and 57 parents (54 female) participated in the study. Six participants were excluded from analysis. One adolescent was a twin of another participant, and did not participate in the eating aspect of the study. One had been excluded from prior analysis due to incomplete data, one was excluded because the adolescent did not eat any of the lunch items, one was due to incomplete recording of the lunch, one was due to the fact that the parent only ate tomatoes, and one was because the parent's face was covered by a burka during eating so bites could not be recorded. Of the remaining participants, 20 adolescents were normal weight controls with a BMI within a normal range (mean BMI = 21.53, range was 17.3 to 26.4), 19 were obese adolescents (mean BMI = 34.84, range was 26.3 to 87.7) and 13 were diagnosed with Type 2 Diabetes (mean BMI = 32.26, range was 17.3 to 57.1). Adolescents with type 2 diabetes were recruited from paediatric diabetes clinics in the West Midlands, East Midlands and North West. The adolescents with normal weight were recruited through school in the West Midlands and obese adolescents were recruited through paediatric obesity clinics in the West Midlands. Obesity was defined using age specific BMI from the International Obesity Task Force (Cole et al., 2000, Cole et al., 2007). Inclusion criteria were that the adolescents had no major medical conditions, no learning disabilities, were able to read and understand English, and were under the care of a permanent caregiver. Adolescents with diabetes were required to have been diagnosed with type 2

diabetes for a least a year, have had no major alterations to diabetes medication for the previous six months, and have well controlled diabetes ( $HbA1c < 8 \text{ mmol/l}$ ).

### *Stimuli*

Adolescent and parent received identical lunches consisting of eight items. They were: a sandwich on medium sliced white Hovis bread containing 20g of Flora Original and 40g of mature cheddar cheese (22.5 g protein, 32.46g carbohydrates, 31.7g fat), a Chicago Town four cheese pizza (17.6g protein, 48.2g carbohydrates, 18.8g fat), 25g of ready salted Walkers crisps (1.48g protein, 12.43g carbohydrates, 8.53g fat), 50g of cherry tomatoes (0.44g protein, 1.96g carbohydrates, 0.1g fat), strawberry Activia yoghurt (4.4 g protein, 15.5 g carbohydrates, 4.0 g fat), a clementine (per 100g: 0.9g protein, 8.7g carbohydrates, 0.1g fat), a Granny Smith apple (per 100g: 0.4g protein, 11.8g carbohydrates, 0.1g fat) and Maryland double chocolate chip cookies (approximately 24g, 1.49g protein, 16.3g carbohydrates, 0.23g fat). Food items were weighed individually before being given to participants, and re-weighed afterwards to allow calculation of consumption of macronutrients.

### *Measures and Materials*

A hunger rating scale (see Appendix 1a) was administered to participants before and after lunch. The scale required them to indicate their current feelings (e.g. hunger, thirst) by marking a line on a scale which ranged from 'not very' to 'extremely'. BMI was calculated from height and weight measures taken by researchers. The Dutch

Eating Behavior Questionnaire (Van Strien, Frijters, Bergers, & Defares, 1986) was completed by participants to obtain measures of their external, emotional and restrained eating behaviours. Adolescents completed an adolescent version.

Parenting style was determined from observations of parent behaviour during the meal, including restrictive behaviours, involvement, control, and positive and negative vocalisations about food. Instances of behaviour were recorded on a coding sheet (see Appendix 1b). Parental control was also measured using the coding sheet, and was the total of verbal and physical restrictive behaviours displayed by the parent throughout the meal time. Parenting style was divided into 4 types:

- Authoritarian (pressure to eat, nagging, restrictions, demands, controlling, negative vocalizations)
- Authoritative (positive vocalizations, modelling, supportive, encouragements, positive incentives)
- Permissive (not demanding, allows freedom) which divides into two types:
  - Indulgent (Involved but not demanding)
  - Withdrawn (uninvolved)

Participants were filmed using two Sony video cameras linked to PIP 422 and PIP 444 Extron video processors. Cameras were wall mounted at approximately 2.1m.

### *Procedure*

The behavioural aspect of this study is the focus of this report, however participants did take part in other tasks. In the behavioural part of the study, parent and adolescent were seated in a room that contained a table and two chairs, and two wall mounted cameras. Informed consent had been obtained, and the participants were aware that they would be filmed. A hunger rating scale was completed to obtain a baseline measure of hunger. Participants had been on site since 8.30am and lunch was served between 12 and 1pm. Participants received a tray of food each, and were instructed to eat as much as they liked or until they were satiated. They were asked specifically to eat only from their own tray and to refrain from sharing food. A litre of water was provided to drink. Participants could eat the lunch as they desired in an unspecified time period (mean duration = 19.2 minutes, with a range of 9.5 to 33.7 minutes). After the meal, trays were removed and weighed, and the hunger rating scale completed again.

### *Coding Modelling*

Eating behaviour for both parent and adolescent was coded from the video footage using ObsWin 32 software (Martin, Oliver & Hall, 2000). Each bite by each person was recorded according to which of the eight food items was eaten, allowing a sequence of consumption to be produced. The time was divided into two segments; one was 0-5 seconds after the other person's bite was taken, and the other was over 5 seconds after the other person's bite was taken. This was based on Hermans et al.

(2012)'s study which defined a 'sensitive period' of up to five seconds after one person took a bite as the time where mimicry of bites would occur. This meant that there were four potential outcomes; same food item eaten within five seconds of the other person eating it, a different food item eaten within five seconds, same item eaten longer than five seconds after the other person's bite and different item eaten after five seconds. This allowed mimicry of the same item to be measured, either within the sensitive period of five seconds or in a longer period, as well as being able to determine whether there was mimicry of bites independent of food item.



## Results

Several different measures of modelling were taken, meaning various comparisons can be made, according to time period and food items consumed (see Table 1).

Table 1. *Mean modelling scores.*

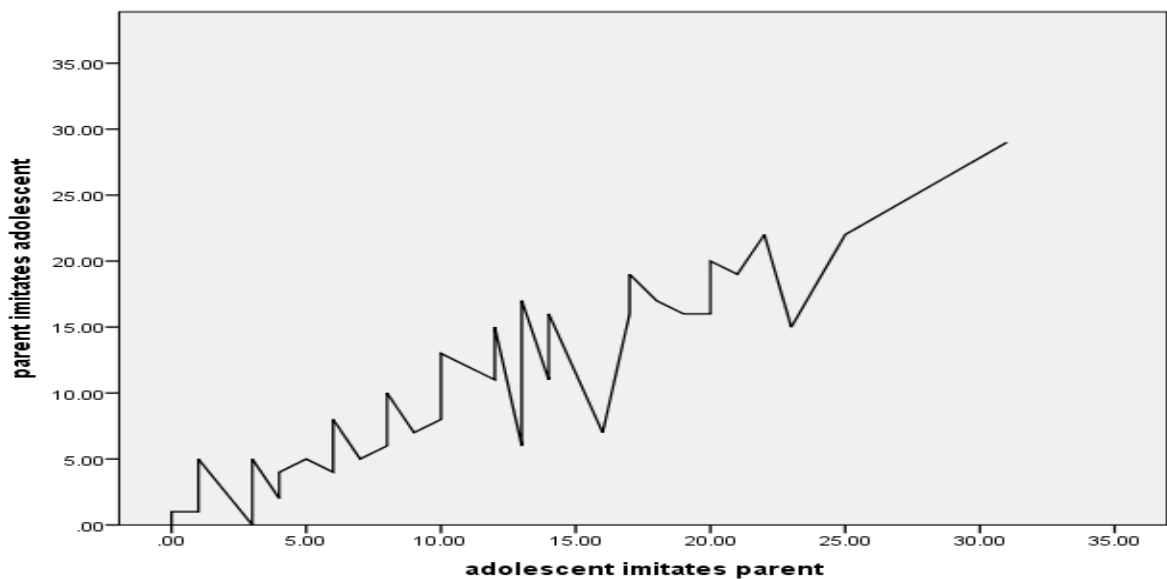
	Modelling score within 5 seconds (mean)	Adolescent imitating parent (mean)	Parent imitating adolescent (mean)	Mimicked bites (mean)	Non-mimicked bites (mean)
Control (N = 20)	6.4 (6.3)	11.4 (8.4)	10 (7.5)	35.75 (17.4)	36.50 (8.4)
Obese (N = 19)	5 (5)	8.6 (6.7)	8.3 (6.6)	36.58 (18.7)	31.79 (10.8)
Type 2 Diabetes (N = 13)	5.9 (3.4)	12 (6)	11.3 (5.7)	29.68 (15.1)	32.31 (15.7)

Note. SD in parentheses.

*Modelling defined as eating the same food item, irrespective of time*

A strong positive correlation of  $r_s = 0.921$ ,  $p = 0.01$  (2-tailed), was found between adolescent imitating parent and parent imitating adolescent (see Figure 1). This shows that if one type of modelling occurred, the other type was more likely to have occurred, suggesting that both people in the pair were equally influential over the other's eating behaviour. Modelling here was defined as eating the same food item, whether that was within the sensitive period of five seconds, or outside of it. This means the individuals' choice of

food item was affected by the choice of the other person. However, there were no significant differences between the three groups of adolescents (obese, control and type 2 diabetes) on incidences of modelling for either parent imitating adolescent or adolescent imitating parent. For adolescent imitating parent:  $H = 2.579$  (2,  $N = 52$ )  $p = 0.275$ . For parent imitating adolescent:  $H = 1.952$  (2,  $N = 52$ )  $p = 0.377$ . This means that in this observation there are no significant differences in modelling behaviours that could be directly related to BMI or a diagnosis of diabetes.



*Figure 1.* Positive correlation between the two modelling types, across all participants.

*Modelling as taking bites within five seconds of the other person taking a bite, regardless of the food type*

The distribution of mimicked bites (all bites taken within five seconds of the other person taking a bite) was the same across each group,  $H = 1.207$  (2,  $N = 52$ )  $p = 0.547$ , as were non-mimicked bites (all bites taken longer than five seconds after the other person took a bite),  $H = 3.461$  (2,  $N = 52$ )  $p = 0.177$ . This indicates no differences in eating behaviour between groups.

There were no significant differences in the distribution of observed parental control (restriction) across the three groups ( $H = 0.239$  (2,  $N = 52$ )  $p = 0.887$ ). The means for each group were: 3.4 for control, 3.57 for obese adolescents and 3.38 for adolescents with type 2 diabetes. A correlation between adolescent imitating parent and observed parental control (restriction) was not significant ( $r_s = 0.080$ ,  $N = 52$ ,  $p = 0.573$ , 2-tailed), meaning that there was no significant interaction between the amount of restriction given to the adolescent and the adolescent's imitation of parental eating behaviour. To test if there was a difference in modelling due to age, participants were split into younger adolescents (12-15 years,  $N = 30$ ) and older adolescents (15-18 years,  $N = 22$ ) but no significant differences were found in modelling between these two groups,  $U = 305$ ,  $p = 0.643$ .

Table 2. *Distribution of parenting styles.*

	Permissive withdrawn	Permissive Indulgent	Authoritative	Authoritarian
Overall percentage	38.5	30.8	23.1	7.7
Number per group				
Control	4	10	4	2
Obese	9	4	4	2
Type 2 Diabetes	7	2	4	0

When considered by parenting style (permissive indulgent, permissive withdrawn, authoritative, authoritarian, see Table 2) there are significant differences in mimicked modelling (the adolescent imitating the parent, bites taken within 5 seconds)  $H = 8.769$  (3,  $N = 52$ )  $p = 0.033$ . There is a significant difference between permissive indulgent and authoritative ( $H = -15.865$ , (3,  $N = 52$ )  $p = 0.35$ ). An external eating score obtained from the DEBQ compared to modelling did not reveal a significant correlation. For parent imitating adolescent, and parental external eating score (mean = 2.16):  $r_s = -0.40$ ,  $p = 0.781$ , 2-tailed. For adolescent imitating parent, and adolescent external eating score (mean = 1.83):  $r_s = 0.030$ ,  $p = 0.832$ , 2-tailed. As previous research suggests an influence of similarity on modelling behaviour, adolescent-parent pairs were grouped according to whether they were both the same gender (73.1%) or different genders. No significant differences were found for modelling within 5 seconds ( $U = 252.000$ ,  $p = 0.772$ ) or for adolescent imitating parent ( $U = 221.000$ ,  $p = 0.352$ ) and parent imitating adolescent ( $U = 231.500$ ,  $p = 0.476$ ).

## Discussion

The behavioural aspect of this study did not reveal any significant differences in modelling behaviour between the three groups, suggesting that modelling and adolescent's eating behaviour was not associated with BMI or a diagnosis of diabetes, during the period of observation. It appears that both adolescent and parent can influence the eating behaviour of the other as hypothesized, and as imitation of one person increases, so does imitation of the other. This has implications in terms of dieting for obese adolescents or those with type 2 diabetes, as encouraging parents to take part in the diet could help improve outcomes. Observation occurred only of one meal which may not provide sufficient data to assess their eating behaviour in general. The experimental setting may have had an impact on both adolescents' and parents' consumption of food. Although participant pairs were alone whilst eating, they were aware of being filmed and may have been influenced by demand characteristics to choose options they perceived as healthy. Impression management studies indicate that food intake is affected by the desire to put forward a certain impression and avoid the negative characteristics associated with overeating (Herman, Roth & Polivy, 2003). In the presence of an observer who does not eat, participants tend to eat less than in conditions where the confederate eats a small amount (Conger et al., 1980). This effect could have inhibited eating. The researchers were not physically present during the lunch but awareness of judgement can affect consumption. Polivy, Herman, Hackett and Kuleshnyk (1986) led participants to believe that the researchers would be aware of how

much they had eaten after the study, which inhibited the participants' intake for both dieters and non-dieters. Participants in this study were aware that they were being filmed, and knew that the researchers were interested in what they ate, including overall intake, therefore intake and food choices may not have been representative of their normal eating habits. Parenting style and amount of restriction used might also have been affected as parents may not have wanted to be seen in a negative way.

The study contains a larger number of mothers and daughters as opposed to fathers and sons, but the majority of parent-child eating behaviour studies focus on mothers, as they have been shown to be more involved in child feeding practices and spend more mealtimes with their children than fathers (Haycraft & Blissett, 2008). There are more female adolescents which is important as restriction is often increased for overweight girls (Birch, Fisher & Davidson, 2003). An expansion of the study could compare eating behaviour for father and daughter, father and son, mother and son, mother and daughter. Further studies would need to include more male adolescents in the sample to allow a comparison of gender differences in all three groups.

As there was no enforced time limit to the lunch, this meant duration varied considerably. De Castro's (1990) time extension hypothesis asserts that meal duration extends as the number of people present at the meal increases, resulting in increased intake. However it is unclear whether the presence of others increases the amount of time taken to eat, and therefore leads to an increase in consumption, or whether the presence of others increases the consumption which extends the meal time. This effect could be occurring in the experiment as there was a moderate

positive correlation between total calorie consumption and duration ( $r = 0.417$ ,  $p = 0.01$ , 2-tailed). Further studies could impose a set time period for consumption.

Mimicry is often attributed to the desire to create a bond or rapport when socialising, and has been found to be effective at increasing liking for an unknown person (Hermans et al., 2012). Confederates are rated as being more liked by the participant when the confederate had mimicked their mannerisms, and additionally the interaction rated more highly (Chartrand & Bargh, 1999). As mimicry is increased when forming bonds with strangers, its use between familiar people may be diminished. In this study, mimicry between parent and adolescent may be minimal due to the well-established nature of their relationship.

This study suggests that there were no significant differences between the groups of obese, type 2 diabetes and healthy weight adolescents in terms of modelling and eating behaviours. Therefore other influences and motivational factors could be explored in future research, particularly the impact of parenting style.

COMPUTERISED INTERACTIVE REMEDIATION OF COGNITION TRAINING FOR  
SCHIZOPHRENIA WITH YOUNG ADULTS WITHIN AN EARLY INTERVENTION  
SERVICE



## Placement Aims

- ▶ Learn how to gather cognitive measures using neuropsychological tests
- ▶ Plan and implement sessions of computerised Cognitive Remediation Therapy
- ▶ Obtain post therapy measures of cognitive functioning
- ▶ Gain experience in an NHS setting

The aim of this placement was to plan, prepare and lead sessions of a newly developed computerised Cognitive Remediation Therapy (CRT) program for young people with Schizophrenia, within an NHS Early Intervention Service. This involved learning how to use the Computerised Interactive Remediation of Cognition Training for Schizophrenia (CIRCuiTS) program, and learning how to administer a selection of neuropsychological tests to measure service users' baseline and post-treatment cognitive functioning. I learnt to administer each test, and I experienced being tested. This allowed me to reflect on how I might improve my administration. I calculated scores from these tests and wrote the results up in letters to service users and their GPs, outlining the findings and what they meant. Another aim of the placement was to gain experience working in an NHS setting. I attended a training course on using the ePEX system, and subsequently used the system to record all contact with service users, including details of progress in CIRCuiTS sessions. Seven service users were invited to attend sessions, although drop out was high and attendance

was inconsistent, which meant only one service user had completed all sections of the program by the end of the placement.

## Contents

- What is CRT?
- The CIRCuiTS program
- Cognitive deficits in Schizophrenia
  - **What they are**
  - **Why**
  - Influence of other factors
- Neuropsychological testing
- Findings from the neuropsychological tests

### What is CRT?

- ▶ “a behavioural training based intervention that aims to improve cognitive processes with the goal of durability and generalization” *Cognitive Remediation Experts Workshop (Florence, Italy, April 2010)*


### What is Computerised Interactive Remediation of Cognition – Training for Schizophrenia?

- computer program that aims to improve cognitive skills.
- strategies are used to improve performance, along with gradually increasing task difficulty and the support of a therapist.


Cognitive Remediation Therapy has been used to improve cognitive skills such as memory, attention and flexible thinking, traditionally using pen and paper tasks.

CIRCuiTS is a computer version designed by researchers at the Institute of Psychiatry. The program provides strategies to improve performance and aims to achieve errorless learning by gradually increasing task difficulty, and utilising the support of a therapist.


## Computerised Interactive Remediation of Cognition – Training for Schizophrenia




Examples of tasks from the program:



Copying and recalling an image after a delay



Code breaking



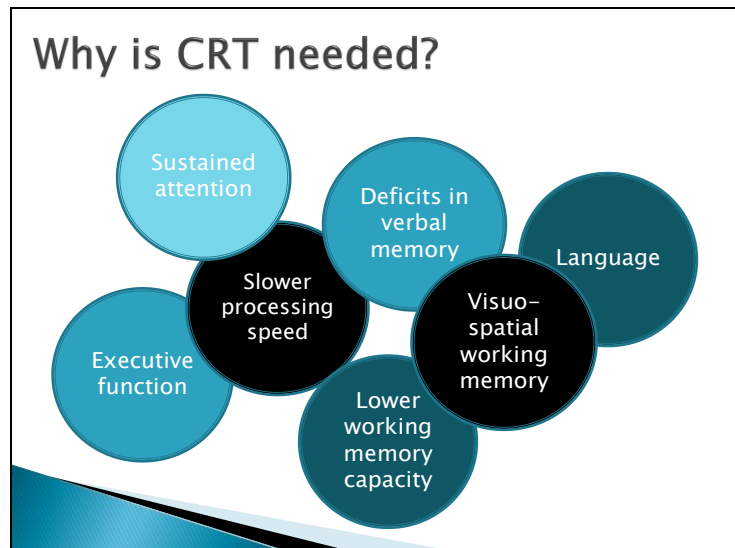
Identifying components of an image

The program rotates through a series of tasks which increase in difficulty, giving plenty of opportunity for skills to be practised and developed. Examples include recalling a list of words, recalling an image, comprehension, pressing keys in response to targets appearing on screen, and some are linked to everyday activities e.g. planning a bus journey and following a map. Some tasks are split into a learning phase (e.g. learning a list of words) which is followed by the recall phase after a delay.

## Does CRT work?

- ▶ CRT has a **small to moderate durable effect** on cognitive outcomes
- ▶ Computerised CRT has the same effect as traditional pen and paper methods
- ▶ There is a small to medium effect on functioning

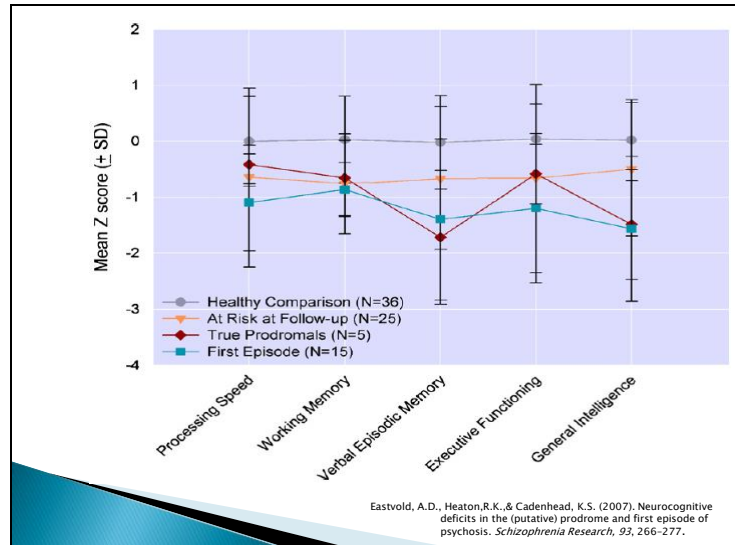
A meta-analysis by Wykes et al. (2011) demonstrated that CRT had a small to moderate effect on cognitive outcomes, which was durable. There was a small to medium effect on functioning at post treatment and at follow up. There were significant effects of CRT for attention, processing speed, verbal working memory, verbal learning and memory, problem solving/reasoning and social cognition. Computerised CRT had the same impact as other types of CRT.



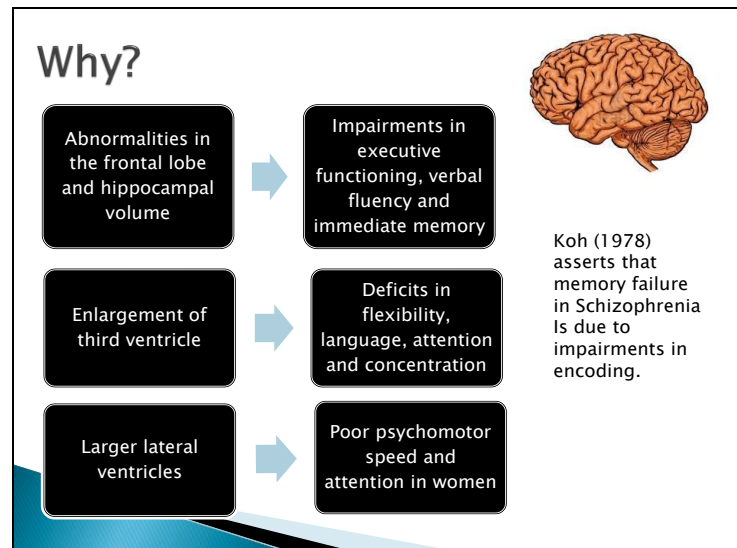
Why did we need to do CRT? There are several cognitive problem areas that have been identified in people with Schizophrenia, although there is a lot of variation. Joyce, Hutton, Mutsatsa, and Barnes (2005) found a specific impairment in working memory, regardless of whether their participants had a low premorbid IQ or a preserved high/average IQ. Han et al. (2012) found that working memory, language, delayed memory and total Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) scores were significantly lower compared to controls. Deficits have been found in higher cognitive functions such as sustained attention, executive function, verbal and visuo-spatial working memory, language skills, explicit learning and motor processing (Bilder et al., 1992). Insight is often lacking in those with Schizophrenia, and has been shown to have a small but significant correlation with cognitive functioning (Aleman, Agrawal, Morgan & David, 2006). A strong correlation between performance on the Wisconsin Card Sorting Test and insight suggests that cognitive flexibility plays a key role in being able to

compare one's own thoughts and behaviours to symptoms of mental illness and therefore have good insight (Drake & Lewis, 2003).

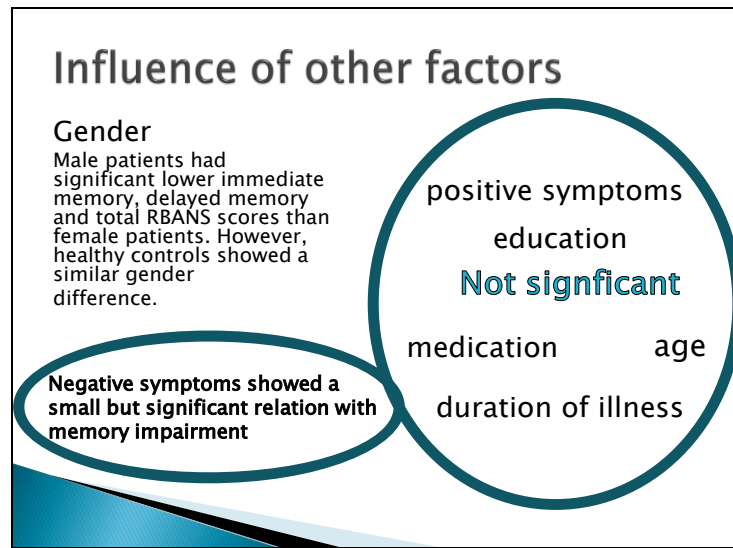




This graph by Eastvold, Heaton and Cadenhead (2007) highlights the differences between healthy controls, people with first episode schizophrenia, those at risk of developing psychosis and those who were at risk and had developed psychosis by the time of the follow up a year later (named the ‘true prodromals’). These measures were taken before progression of illness into first episode psychosis. At risk criteria include attenuated psychotic symptoms, and a decline in overall functioning. All three clinical groups showed impairments in processing speed, working memory, verbal episodic memory, executive functioning and general intelligence compared to controls, and the three groups had relatively equal impairments in working memory (effect size range = 0.79 to 1.03). The true prodromals had the largest effect sizes compared to controls in verbal episodic memory performance and general intellectual functioning, which was similar to those in the first episode. This suggests that scores in these areas may be more important in identifying the risk of developing psychosis.



A variety of differences in the brain have been observed in people with schizophrenia. Cognitive impairments in executive functioning, verbal fluency and immediate memory have been attributed to abnormalities in the frontal lobe and hippocampal volume. Deficits in cognitive flexibility, language, attention and concentration are associated with an enlarged third ventricle, relative to the whole brain volume (Antonova, Sharma, Morris & Kumari, 2004). People with schizophrenia have been found to have third ventricle to brain ratios of twice that of controls (Bornstein, Schwarzkopf, Olson & Nasrallah, 1992). Larger lateral ventricles are associated with poor psychomotor speed and attention/concentration in women with schizophrenia, but not men (Antonova, Sharma, Morris & Kumari, 2004). Encoding impairments have been put forward as the primary cause of memory failure in schizophrenia (Koh, 1978, as cited by Gold et al., 2000).



What other factors influence cognitive deficits? Han et al. (2012) found that male patients had lower immediate memory, delayed memory and total RBANS scores than female patients. However this pattern was found for healthy controls too. A meta-analysis of the moderating variables of executive functioning found no significant correlations between cognitive functioning and age, duration of illness, medication, or level of education (Selfridge & Zalewski, 2001). Positive symptoms did not have a significant effect on memory impairment whereas negative symptoms had a small significant relationship (Aleman, Hijman, de Haan, & Kahn, 1999; Stirling, Hellewell & Hewitt, 1997). Negative symptoms include blunted affect, emotional withdrawal, passive-apathetic social withdrawal, poor rapport, difficulty in abstract thinking, lack of spontaneity & flow of conversation, stereotyped thinking (as measured by PANSS).


## Key points

- ▶ Heterogeneity in the pattern and level of performance among patients with schizophrenia
- ▶ Wide range of brain structures implicated
- ▶ Subgroup consisting of 20% of the Schizophrenia population who have average to above average intelligence and perform well on cognitive tests

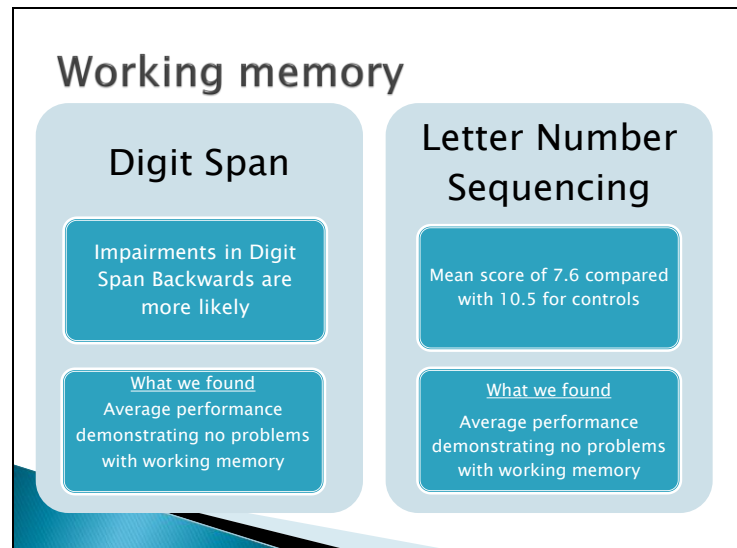
A word that appears frequently in literature about cognitive functioning in schizophrenia is 'heterogeneity'. There are a wide range of different findings surrounding cognitive functioning and the involvement of various brain structures. Lower levels of intellectual functioning are usually recorded for those with schizophrenia compared to controls, but there is a subgroup of about 20% of the schizophrenia population who have average to above average IQ and perform well on cognitive tests (Weschler, 2009).

## Neuropsychological Testing

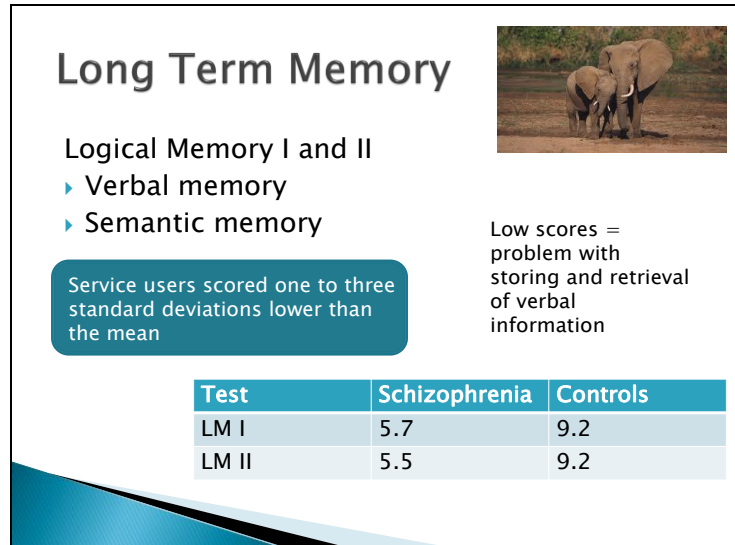
WAIS	D-KEFS	WMS
<ul style="list-style-type: none"><li>• Digit Span</li><li>• Letter Number Sequencing</li></ul>	<ul style="list-style-type: none"><li>• Verbal Fluency</li><li>• Trail Making</li><li>• Colour-Word Interference</li></ul>	<ul style="list-style-type: none"><li>• Logical Memory I and II</li><li>• Visual Reproduction I and II</li></ul>



Before service users began the CIRCuiTs sessions, baseline measures of their cognitive functioning were obtained using neuropsychological tests. The tests took about an hour to complete and consisted of the Digit Span and Letter Number Sequencing from the Weschler Adult Intelligence Scale (WAIS), Verbal Fluency, Trail Making and Colour-word Interference from the Delis-Kaplan Executive Functioning System (D-KEFS) and Logical Memory I and II, and Visual Reproduction I and II from the Weschler Memory Scale (WMS).



The tests cover different components of cognitive functioning. Working memory was measured by the Digit Span and Letter Number Sequencing tests. Impairments in Digit Span backwards are more frequently reported than deficits in Digit Span forwards (Stirling, Hellewell & Hewitt, 1997). Digit Span forwards is a test of attention whereas the backwards and sequencing conditions place more demands on working memory. For Letter Number Sequencing, Dickenson, Iannone, Wilk and Gold (2004) found a mean score of 7.6 for those with schizophrenia, compared with 10.5 for controls. The majority of our service users performed within the average range for both tests, demonstrating no difficulties with working memory.



Logical Memory was the most prominent problem area as scores in this task were very low, ranging from one to three standard deviations lower than the mean. This task asked participants to recall a news story that had been read aloud to them, requiring them to recall semantically related verbal information. Scores were low for immediate recall, and delayed recall (after a period of 25-30 minutes). Low scores indicated a problem with storing and retrieval of verbal information, and recalling semantic content. This means service users may experience difficulty remembering information that is spoken to them, and may need it repeated. A recognition task, where questions were asked about the content of the story, resulted in some low scores, indicating difficulties in the initial encoding and storing of verbal information. Poor performance on Logical Memory has been found previously in people with schizophrenia (Gold et al., 2000). Wilson (1996, as cited by Gold et al., 2000) reported impairments in immediate recall, delayed recall, and percentage retained scores in a sample of people with first episode schizophrenia. Large effect sizes have


been found for group mean differences on Logical Memory I and II, with means of 5.5 and 5.7 for those with schizophrenia, compared to 9.2 for controls (Weschler, 2009).



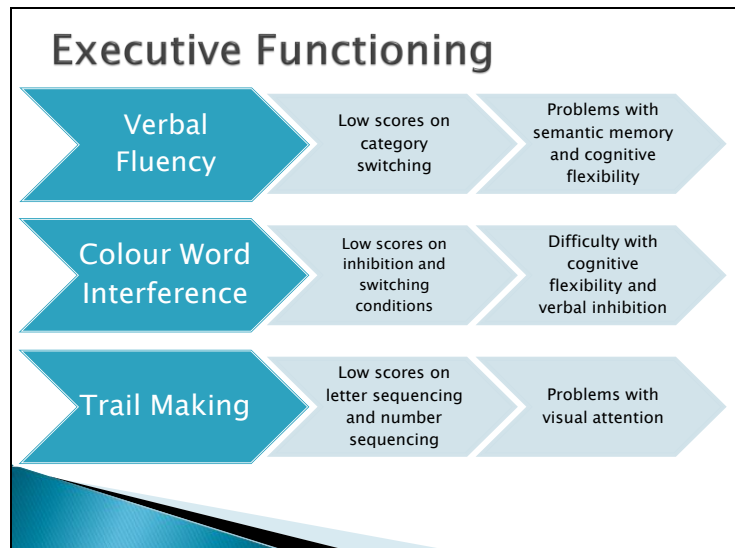
## Executive Functioning

- ▶ Attention and the ability to concentrate
- ▶ Inhibition = control over responses
- ▶ Cognitive flexibility (adaptability)
- ▶ Processing speed

Lowest scoring WAIS Index with a mean score of **77.7** for those with Schizophrenia, compared to **94.7** for matched controls.

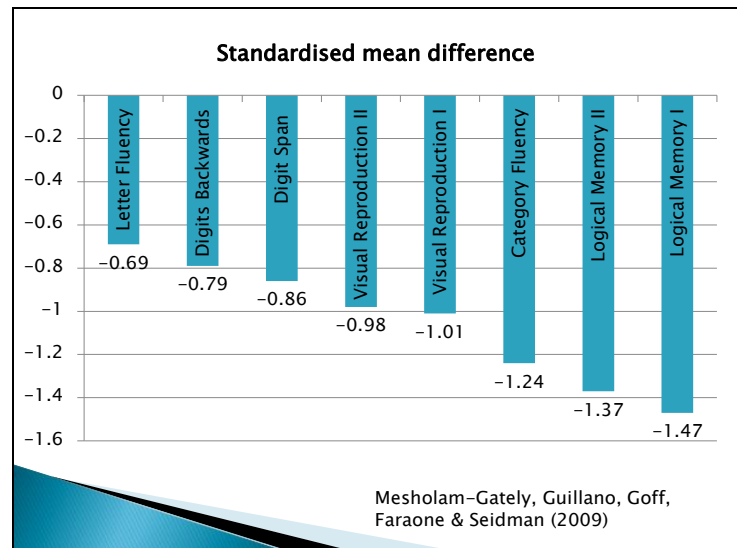


Executive functioning refers to cognitive skills such as attention, concentration, inhibiting responses, cognitive flexibility and processing speed. People with schizophrenia scored between 1 and 1.5 standard deviations below controls on measures of executive functioning (Selfridge & Zalewski, 2001). Processing speed has been identified as a consistent predictor of social competence and living skills, work skills and community behaviours (Bowie et al., 2008). People with schizophrenia score lowest on the Processing Speed Index of the WAIS, with a mean of 77.7 compared to 94.7 by matched controls (Weschler, 2009).

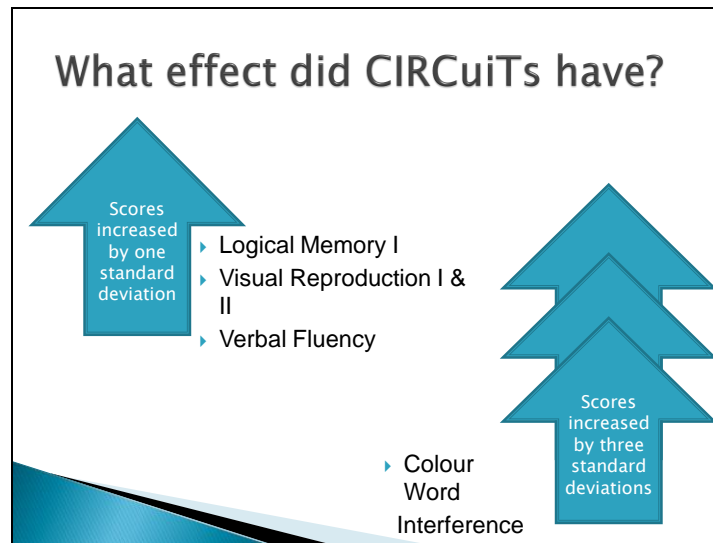


Executive functioning was assessed by tasks from the D-KEFS. In the Verbal Fluency test, the category switching condition posed the most problems. This condition required service users to alternate between giving the name of a fruit and a piece of furniture. This requires cognitive flexibility to switch between two aims. Scores on Letter and Category Fluency conditions were mostly average, showing that service users could retrieve suitable items from memory using a strategic approach. Low scores on this condition relate to a problem with semantic memory and rapid retrieval of words from memory. The Colour Word Interference task identifies any difficulties in verbal inhibition. Poor performance on the inhibition aspect (where you must inhibit the response to read the word as you are required to say the colour of the ink) means that participants struggle to prevent an incorrect response, and may find it difficult to adapt quickly to new rules. In one condition, two aims must be switched between in order to complete the task correctly, which requires cognitive flexibility. In the Trail Making test, lower than average scores on letter sequencing and number sequencing were found, suggesting some difficulties with attention, inhibition and cognitive

flexibility. A meta-analysis of studies into cognition in first episode schizophrenia found medium-sized deficits in fine motor speed and dexterity which would contribute to lower scores in the other conditions (Mesholam-Gately, Guillano, Goff, Faraone & Seidman, 2009). However, the majority of our service users achieved average scores for motor speed, meaning low scores on other conditions are not due to reduced motor speed. Low scores are likely to be due to difficulty with cognitive flexibility and visual attention.



This graph illustrates results from a meta-analysis by Mesholam-Gately, Guillano, Goff, Faraone and Seidman (2009), which identifies medium to large deficits for people with first episode schizophrenia compared to controls. The numbers refer to standardised mean difference, and a negative score means that those with first episode schizophrenia are performing worse than controls. The areas with the largest standardised mean difference are Logical Memory I and II. A wide range of tests from various sources were used to compile different domain areas. Impairments were the most pronounced in the immediate verbal working memory domain which had the highest standardised mean difference of -1.20.



Only one service user completed the full CIRCuiTs program by the end of the placement and was able to be re-tested using the same neuropsychological tests. The results showed improvements in performance on Logical Memory, Visual Reproduction, Colour Word Interference and Verbal Fluency. Scores increased by one standard deviation on Visual Reproduction I and II, Logical Memory I and Verbal Fluency. The greatest increase in score was for the inhibition condition in the Colour Word Interference, with the score increasing by three standard deviations.

ASSESSING OLDER ADULTS' CURRENT AND EXPECTED  
'SOCIAL CARE RELATED QUALITY OF LIFE' IN ORDER TO INVESTIGATE THE  
IMPACT OF CARE SERVICES

### *What is extra care housing?*

Extra care housing is a type of housing with care, and is frequently portrayed as a more 'homely' alternative to care homes (Elderly Accommodation Counsel, 2013). It caters to a variety of care needs, and is aimed at varying levels of dependency. Extra care housing takes many forms; the key features are self-contained accommodation units for older adults, support staff on site delivering 24 hour flexible care packages, communal facilities, access to domestic care and meal provision, and activity groups (Baker, 2002, as cited by Croucher, Hicks & Jackson, 2006). The schemes are designed to allow residents to retain their independence whilst also providing convenient services on site ranging from meeting rooms, shops and cafés to hairdressers, gyms and ICT suites, which vary according to the size of the establishment. Buildings often include facilities to make self-care easier, such as walk-in showers. Costs have been found to be the same or lower in extra care housing compared with care homes (Netten, Darton, Bäumker & Callaghan, 2011). Analysis of matched samples of those moving into residential care and those moving in to extra care housing found that there were higher levels of functional and cognitive ability in extra care housing (Netten, Darton, Bäumker & Callaghan, 2011). People who moved into extra care housing had less need for help with daily living activities, and such a move was more likely to be planned and pre-emptive of future difficulties, rather than a response to a sudden care need. Callaghan, Netten and Darton (2009) found that 45.2% of extra care housing residents interviewed were receiving care, and 33% rated their quality of life as 'very good'.

### *Social care related quality of life*

The World Health Organisation defines quality of life as encompassing an individual's beliefs about their status in life including their expectations and aims, which are affected by their health, mental state, relationships, environment, values and level of independence (The WHOQOL Group, 1998). Abrams (1973, as cited by Farquhar, 1995) defined quality of life as being dependent on a person's satisfaction or dissatisfaction with aspects of their life. This study focuses on social care related quality of life (SCRQoL) as measured by the Adult Social Care Outcomes Toolkit (ASCOT. Netten et al., 2011. See Appendix 2f). SCRQoL refers to an individual's quality of life that is affected by social care services. Social care services include receiving personal care, assistance with practical tasks such as shopping and cleaning, and access to social activities. These services are necessary when individuals require help to meet their needs due to physical and mental illnesses or impairments, and are often continuous over many years. Social care services help to compensate for the impact of impairments on functioning and to maintain service users' quality of life. They can help improve quality of life by meeting basic physical needs, assisting with activities of daily living, providing activity groups and helping service users to access events and public facilities. Social care aims to build service users' skills in terms of coping with physically limiting illnesses, and to give them a feeling of safety in the knowledge that they have support available. Services often need to increase as illnesses progress and it may become more difficult to maintain some aspects of quality of life, such as carrying out activities of daily living, as health deteriorates.



SCRQoL is split into eight domains by the ASCOT INT4 tool to reflect the range of services and contributing factors to quality of life. These domains are control over daily life, personal cleanliness and comfort, food and drink, personal safety, social participation and involvement, occupation, accommodation cleanliness and comfort, and dignity (see Table 3). ASCOT was developed as a social care equivalent measure to the Quality-adjusted Life Year (QALY) which is used to assess cost effectiveness of health interventions. The principles behind ASCOT incorporated Sen's ideas of functioning and capabilities (1985, as cited by Netten et al., 2012). According to Sen, using our resources to achieve functioning gives us well being. Capabilities relate to whether people are able to choose their experiences, as they may choose not to do activities because they don't want to, or they may be unable to have that element of choice, possibly due to the restrictions of physical and mental health conditions. ASCOT aims to identify whether people can do things the way they want to and choose things they enjoy rather than simply measuring the things they do. This is important as some people may choose not to participate in certain activities. The wording of ASCOT INT4 reflects this idea as it uses phrases such as, "I am able to present myself the way I like", "I have as much social contact as I want," which emphasizes whether people feel aspects of their life meet their needs and preferences rather than rating them as good or bad, high or low. The ASCOT measure of current SCRQoL has been found to be significantly correlated with other measures of wellbeing, including a strong correlation with the CASP-12 measure of quality of life in older people (Netten et al., 2012). ASCOT also correlated with satisfaction with services (Caiels, Forder, Malley, Netten & Windle, 2010). People

who were very satisfied with the services had a higher current SCRQoL than those who were quite satisfied, and those who were not satisfied.

Table 3: *ASCOT domains (INT4).*

SCRQoL Domain	Definition
Control over daily life	The individual has the freedom to choose what to do and when to do it.
Personal cleanliness and comfort	The individual is able to present themselves as they wish, maintaining their own standard of personal hygiene and appearance.
Food and Drink	The individual feels they are able to eat and drink at appropriate times and that they have a suitable diet that is varied and tailored to their dietary requirements.
Personal Safety	The individual feels safe in their environment with no fear of physical/mental harm or fear of being a victim of a crime such as theft.
Social participation and involvement	The individual is able to be involved in a community if they wish, and able to have relationships with friends or family.
Occupation	The individual is able to be involved in meaningful activities of their choosing.
Accommodation cleanliness and comfort	The individual is satisfied with their home and feels their surroundings are clean and comfortable.
Dignity	The effect of care services on the individual's sense of wellbeing, including how having care services may impact on their self-esteem.

### *ASCOT Domains*

Social participation and involvement is an important domain covered by ASCOT. The impact of being involved in a community and having social contact has been researched extensively, and social relationships have been identified as a key factor of quality of life amongst people aged 65 and above (Gabriel & Bowling, 2004). There is an association between higher levels of social engagement and lower mortality

rates (Flacker & Kiely, 2003). In a report about 15 extra care housing schemes, 90% of residents reported that they had made new friends as a result of moving, and 85% felt positive about their social lives and did not feel lonely (Callaghan, Netten & Darton, 2009). A case study of an extra care housing scheme in Bradford found that half of the residents had felt lonely and isolated in their previous homes, and nearly two-thirds now had a good social life as a result of moving to the scheme (Bäumker, Netten & Darton, 2008). ASCOT measures were taken before and after moving into the scheme, and all domains apart from food and drink showed significant differences, with the most significance being found in the social participation domain. This indicates that residents' needs are being met by the scheme to a greater extent than at their previous homes. Residents who reported feeling lonely were more likely to have rated their health as bad and to be receiving care. They were also more likely to be single, divorced or widowed. Men are at greater risk of social isolation (Evans & Vallely, 2007) possibly due to the fact that they are usually a minority group in retirement communities. Receiving care can impact residents' social lives as regular contact with care staff provides social interaction and enables them to attend social groups. Due to the importance of these interactions to some residents, Evans and Vallely (2007) suggest that the implementation of key workers should be a priority to allow better relationships to develop between worker and resident.

Closely related to social participation is 'occupation' which refers to having sufficient activities to engage in, and opportunities for mental stimulation. Social care services can help service users to attend activities, day centres or clubs. Many extra care housing schemes run activities on site such as exercise groups, hobby groups and talks from outside speakers. Callaghan, Netten and Darton (2009) found that

75% of residents in extra care housing were fully involved in activities they had chosen and did not feel bored. Seventy percent took part in an activity at least once or twice a week, and described friendship as the main benefit of social activities. In the smaller schemes, 13 % stated that activities were not sufficient and 9% often felt bored. Activities undertaken for fun, mental stimulation and social interaction are positively related to wellbeing, whereas activities done only to pass the time are negatively related to wellbeing (Everard, 1999). Having a health problem that limited activity had a negative impact on wellbeing.

An individual's sense of control over their daily life may be affected by their inability to perform certain tasks, needing care and having care staff arrive at particular set times. Care and support services have been found to have a positive impact on peoples' control over their daily lives. Eighty-five percent reported that care and support services helped them to have control over their daily lives. Thirty-one percent of those also rated themselves as having as much control over their daily lives as they wanted, 47% had adequate control, and only 4% had no control. Of those who said services did not help them, 27% had as much control as they wanted, but 12% had no control over their daily lives (The NHS Health and Social Care Information Centre, 2012). The extra care housing buildings and environment can have an impact on people's perception of control. As many older people have reduced mobility and physical impairments, building design and facilities can be related to residents' ability to control their environment (Parker et al., 2004). Gabriel and Bowling's (2004) survey of quality of life identified neighbourhood and home environment to be one of the top contributors to quality of life. However, part of this was related to having positive relationships with neighbours and good access to

facilities, as well as being proud of their own homes. This survey was conducted among people living in their own homes, who were not residents of retirement villages, care homes or extra care housing schemes.

Security is one of the most important reasons for choosing extra care housing according to over 90% of a sample of 949 extra care housing residents (Netten, Darton, Bäumker & Callaghan, 2011). Feelings of safety can be increased by reducing the likelihood of events such as falls or injuries, and reducing the amount of potential harm such incidents could cause i.e. with the quick provision of assistance if accidents do occur (Netten et al., 2002). In a survey of 35 extra care housing schemes, the majority said that safety features of the scheme maintained or improved health and well-being. Thirty-one of the schemes identified flexible access to care, promotion of self-care, social activities and the encouragement to participate in social activities/retain social networks as other factors that maintained or improved health and well-being (Institute of Public Care, 2007). In another study, residents felt a sense of security from the knowledge that staff were on site at all times and the buildings were well designed to minimise the risk of accidents. Residents also felt less worried about crime and intruders (Croucher, Hicks & Jackson, 2006). In contrast, 35% of participants in the Adult Social Care Survey indicated that they did not feel safe, and rated their quality of life as 'bad' or 'so bad that it couldn't be worse' (The NHS Health and Social Care Information Centre, 2012).

In terms of personal care received by extra care residents, a previous study found 20% required assistance with dressing, and getting around (Bäumker, Netten and Darton, 2008). Seventy percent of that sample reported the ideal state of personal cleanliness (that they felt clean and able to present themselves the way

they liked) before moving to extra care housing, which increased to 95% of participants after the move. Many extra care sites have restaurants or cafes, and meal provision provides an opportunity for interaction between residents (Hanover Housing Group, 2009).

Dignity in this context refers to the impact of having care services on the individual's self-esteem, and whether the way they are helped and treated by care providers has an effect on the way they feel about themselves. As some of the tasks that people require assistance with are very personal, the way care is given and its standard affects service users' wellbeing. In the Adult Social Care Survey (The NHS Health and Social Care Information Centre, 2012), 38% of those who were extremely or very satisfied with the care and support services also rated their quality of life as good or so good it could not be better, whereas 41% of those who were extremely/very dissatisfied with the services rated their quality of life as very bad or so bad it could not be worse.

### *The influence of other factors*

Health has a large impact on quality of life, and many definitions of quality of life focus on physical health and ability. In the Adult Social Care Survey (The NHS Health and Social Care Information Centre, 2012) 65% of participants who rated their health highly also rated their quality of life highly. Of those who rated their health as 'very bad', 33% also rated their quality of life as 'very bad' or 'so bad it could not be worse.' Health was related to satisfaction with care services, as only half of those

with bad health reported that they were extremely or very satisfied with their care services, in comparison to 82% of those in 'very good' health. Eight percent of people describing themselves as being in 'very bad' health said they were very or extremely dissatisfied with the care and support they were receiving. When asked to give reasons for indicating a positive quality of life, the majority (53%) of a sample of over 85 year olds from Hackney stated social contacts, followed by health (47%) and in comparison to others' situations (46%). Conversely, 80% of 65-85 year olds from Essex listed material circumstances as a reason for their positive quality of life (Farquhar, 1995).

This study aims to report the social care related quality of life for extra care housing residents, with a comparison of scores for the different domains, and the influence of other variables such as amount of care received, age, and ability to perform activities of daily living. We expect to find that current SCRQoL will be higher than expected SCRQoL, due to the compensatory nature of services, the increased opportunities for social contact and the safety features of the sites. We expect that residents in receipt of care will show a greater difference in score between current and expected SCRQoL, meaning their SCRQoL gain scores will be larger than those who do not require services. SCRQoL gain should increase as care needs increase. Participants who are less able to complete activities of daily living should have a lower expected SCRQoL as they would experience more difficulty without care and support services. We expect to find that personal safety and social participation and involvement are domains where the current SCRQoL will be highest, as these areas have been identified as important qualities of extra care housing in previous research.

## Method

### *Participants*

Participants were recruited from extra care housing schemes in five local authority areas in the midlands, north east, south west and a borough of London. As part of the larger ASSET project (<http://assetproject.wordpress.com>) an online survey was given to local authority commissioners to establish how adult social care in housing with care schemes is commissioned. This led to the identification of three broad models of commissioning, distinguished by the way care was delivered. This could be through 'commission' which is when an organisation is paid by the local authority to deliver care in a scheme that is managed by another housing provider, 'provide' which is a local authority care team delivering the care in a scheme run by themselves or another housing provider, or 'tender' which is when the local authority run a scheme and invite organisations to bid for the care provision. The three models were single system (only one of these three approaches used to deliver care), dual system (two approaches used) and multi-system (all three approaches used). Five local authority areas from different parts of England were chosen to include all three models, as well as a mix of rural and urban areas. Once the areas were selected, two extra care housing schemes were chosen per area. These ensured a range of different housing with care providers, and different scheme characteristics. This report uses data from 7 schemes (see Table 4). All sites had a lift, lounge, garden, shop, hairdressing salon and dining room. Other facilities available at some schemes were:

- Jacuzzi



- Swimming pool
- Bar/pub
- Library
- Assisted bathing facility
- Hobby room
- Activities room
- Café
- Guest facilities
- Restaurant
- Community centre
- Laundry

Table 4. *Extra care housing scheme characteristics.*

Scheme	Number of flats	Urban/rural	Number of participants
1	45	Urban	13
2	60	Urban	15
3	59	Rural	16
4	32	Urban	8
5	135	Urban	7
6	67	Urban	14
7	41	Urban	10

Data from 102 participants was collected; however, 19 were removed from analysis due to missing or partially completed data because SCRQoL cannot be calculated without answers to all domains. Participants may have declined to answer some questions, or had difficulty understanding some of the concepts of the ASCOT INT4. The sample consisted of 83 participants (62 female) with a mean age of 80 years old (age range 59-99 years. Schemes operated on the basis of admission from the age of 55 years old). The majority lived alone and described their ethnicity as 'white British', and 45.8% were widowed. Table 5 outlines participant characteristics. Participants were recruited via their scheme manager, and had to have the capacity to give informed consent and be able to take part in a face to face interview with researchers.

Table 5. *Characteristics of participants in 7 extra care housing schemes.*

	Number of participants	Percentage
<b>Gender</b>		
Female	62	73.5
Male	21	26.5
<b>Age</b>		
55-64	7	8.4
65-74	19	22.9
75-84	23	27.7
85+	34	41.0
<b>Marital status</b>		
Single	9	10.8
Married/living as married	18	21.7
Divorced/separated	18	21.7
Widowed	38	45.8
<b>In receipt of care or support</b>	68	81.9
<b>Ethnicity</b>		
White	81	97.6
Declined to answer	2	2.4

## *Measures*

### *ASSET Resident Interview Schedule (ASSET, 2013, see Appendix 2a).*

The ASSET Resident Interview Schedule contained 63 questions which covered participant demographics and various aspects of living at an extra care housing scheme such as the amount and type of care received, meals, social contact, social activities and accessibility of the scheme. There were sections about health complaints and contact with health services, mobility, continence, wellbeing and the ability to perform activities of daily living. Questions about personal finances were included to determine the cost of care and contributions of local authorities, social services and benefits such as disability living allowance. Many answers were divided into categories which were represented on show cards (Appendix 2b). These show cards were used as a visual prompt to enable participants to choose their answer from set categories if they were unsure. A minority of answers were open ended, with the majority being restricted to specific answering options which formed ordinal categories.

### *ASCOT INT4 (version 3.0., Appendix 2f).*

ASCOT INT4 (version 3.0) from the Adult Social Care Outcomes Toolkit (Netten et al., 2011) was used to obtain a measure of Social Care Related Quality of Life (SCRQoL). The INT4 consists of 23 questions which measure the impact of care services through current and expected SCRQoL. Current SCRQoL is the participants' present social care related quality of life, which incorporates the impact of the care

services and support they currently receive. Expected SCRQoL is based on participants' estimation of their quality of life in a hypothetical situation where they do not have their current support and services, or help from other sources. These factors were measured for each of the eight domains of SCRQoL, and answers were divided into four options which reflect four levels of needs: ideal state, no needs, some needs and high needs (Netten et al., 2011). Ideal state means the individual's needs have been fully met. No needs means the individual has no needs or minor, temporary needs. Some needs means the individual has needs that are frequent or important enough to impact their life, and high needs refers to needs that can have serious consequences if they are not met. The top two levels of ideal state and no needs increase the sensitivity of recording high SCRQoL as they differentiate between needs being met but not perceived as satisfactory, and needs being met in the best possible way (Netten et al., 2012). Table 6 illustrates these needs as they correspond to answers.

Table 6. *ASCOT INT4 options from the food and drink domain and their corresponding needs levels.*

ASCOT options	Need Level	Description
I get all the food and drink I like when I want	Ideal state	The desired state where needs are met to the standards and preferences of the individual
I get adequate food and drink at OK times	No needs	Needs have been met
I don't always get adequate or timely food and drink	Some needs	Needs that are frequent and important
I don't always get adequate or timely food and drink, and I think there is a risk to my health	High needs	Needs that would have health implications if not met

Each domain was assessed using three questions; one about participants' current situation, followed by a filter question which asked if the support or services they received had an effect on the domain, and a third question which asked them to imagine how that aspect of their life would be if they did not receive the care and support they currently received. This gave scores for current SCRQoL and expected SCRQoL. The difference between current and expected SCRQoL created SCRQoL gain, which provided an idea of the impact of services on the individuals' quality of life. The phrasing of the questions were tailored to include the name of the particular extra care housing scheme, or references to the type of specific support they had mentioned in the resident interview schedule.. ASCOT has shown good re-test reliability (Caiels, Forder, Malley, Netten & Windle, 2010) as mean scores for current SCRQoL remained stable for sub groups (e.g. those with high level needs) at re-

testing. Comparisons of the administration route found no significant differences between scores obtained through interview or self-completed questionnaires. The wording of the domain questions and responses has been validated using cognitive interviewing (Netten et al., 2012). Interviews were audio recorded using an Olympus WS-550m digital voice recorder. Audio files were identified with a code and destroyed after data entry.

### *Procedure*

The project was commissioned and funded by the Department of Health's NIHR School for Social Care Research. Ethical approval for the study was granted by the National Social Care Research Ethics Committee. The managers of selected schemes were approached to take part in the study and were given information about the aims of the project. An email invitation was sent which included the link to the project website (<http://assetproject.wordpress.com/>). Attached to the email were the project information sheet for professionals (Appendix 2c), information sheet for participants (Appendix 2d), consent form (Appendix 2e), ASCOT INT4 and the ASSET resident interview schedule. If schemes agreed to take part, the manager was asked to invite participants from their scheme to participate, providing they had the capacity to consent. Each scheme was visited for a maximum of five consecutive days, with up to five researchers conducting face to face, structured interviews with residents and staff. Participants had been given information sheets (Appendix 2d) which outlined the aims of the study and what would be involved. They had indicated their desire to take part and an interview time had been agreed through the care

manager. Participants were interviewed in their own flats or in a designated room at the scheme, if they preferred. Before the interview began, they were reminded of the aims of the study and what their participation would involve, including being reassured of the anonymity and confidentiality of their data. If they still wished to take part, a consent form was discussed and signed (Appendix 2e). Part of this form included consenting to have the interview recorded. After consent was obtained, the digital voice recorder was turned on. Each participant was asked to be interviewed for roughly an hour. The actual length of interview varied according to each participant, and no specific time limit was adhered to. The ASSET Resident Interview Schedule was completed first, followed by the ASCOT INT4 (which typically took 15-20 minutes). Interviewer prompts for the ASCOT INT4 were tailored to include references to the specific services being used by the participant e.g. using the name of the extra care scheme, or referring to services they had mentioned in the ASSET Resident Interview Schedule. For the hypothetical questions, it was made clear that those referred to a situation where the participant would not receive any care and support services or help from other sources such as family or friends. If participants did not wish to talk about a particular aspect or it was not applicable to them, those sections were not completed. As questions about quality of life are personal and could be upsetting to those who view their quality of life to be low, interviewers were sensitive to the needs of participants and offered to stop the interview, or terminated certain lines of questioning if appropriate.

## *Analysis*

ASCOT INT4 data was entered into the data entry tool provided by ASCOT (downloaded from <http://www.pssru.ac.uk/ascot/instruments.php>). The filter question, which asked about whether the support and services had an impact on the domain, resulted in a response of 'yes', 'no' or 'don't know'. In the case of participants who stated 'no' to this question and/or did not receive care or support for a particular domain, their current score for the domain was used in the expected answer to reflect that their experience would remain the same in the absence of care and support services (Netten et al., 2011). As services did not have an impact on this aspect of the participants' lives, their rating of this aspect should be exactly the same if they lived elsewhere. The dignity domain was only relevant to participants who received care or support as it asked about the way participants were helped and treated by care staff. However, dignity was included in the calculation of the expected SCRQoL score for those who did not receive care, using the option that there is no impact e.g. 'Having help does not affect the way I think or feel about myself.' Each domain is preference weighted according to research with service users and general population samples (Netten et al., 2012) which used best-worst scaling techniques and time trade off. The ASCOT INT4 data entry tool uses this scoring system and weightings to calculate individual current and expected SCRQoL, with scores between 1.00 and -0.17. A score of 1.00 equates to 'ideal' SCRQoL and a score of 0.00 indicates a state equivalent to being dead from a quality of life perspective. This means that negative scores (maximum of -0.17) produce a SCRQoL that is considered worse than death. Current SCRQoL score was calculated from weighted ratings for the



current domains (questions 1, 4, 7, 10, 13, 16, 19 & 23, see Appendix 2f), and expected SCRQoL from questions about their hypothetical SCRQoL in the absence of services (questions 3, 6, 9, 12, 15, 18 & 21, see Appendix 2f). SCRQoL gain is the difference between current and expected SCRQoL. If expected SCRQoL score is higher than current SCRQoL, this will produce a negative SCRQoL gain score. Negative SCRQoL gain scores mean that services are failing to exert a positive impact on quality of life, or failing to meet the needs that they are designed to meet.

## Results

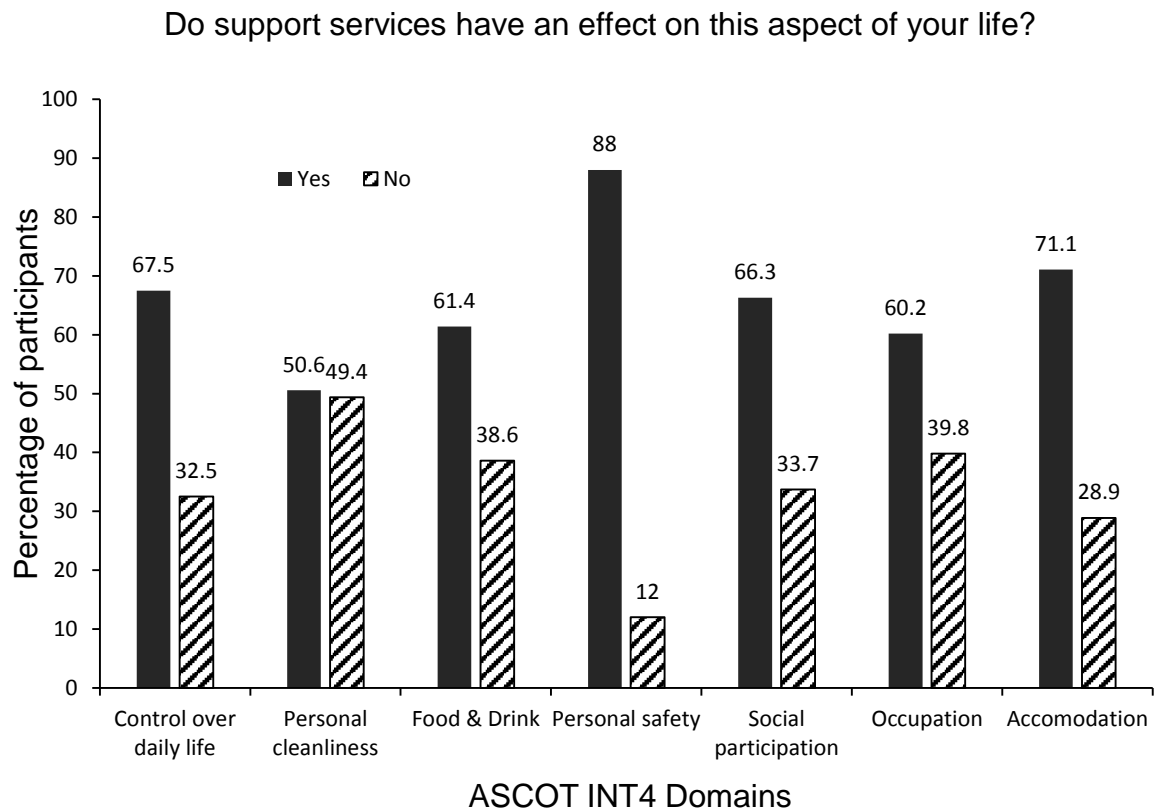
The overall sample means revealed a current SCRQoL of 0.91 ( $SD = 0.11$ ), with an expected SCRQoL of 0.52 ( $SD = 0.29$ ) and a SCRQoL gain of 0.39. The majority stated that care and support services had an impact on all domains (see Figure 2), particularly personal safety. This shows that the care and support services provided by extra care housing, and the environment of living in extra care housing contributed to improving their residents' quality of life. Expected SCRQoL is much lower than current SCRQoL, showing the lower level of quality of life that participants estimate they would experience in the absence of services. Table 7 shows the distribution of needs for current and expected SCRQoL for each domain, and Table 8 shows the responses to the dignity domain questions.

The majority of participants reported the ideal state in each domain for current SCRQoL, whereas responses for expected SCRQoL were more spread across needs levels. Personal cleanliness and comfort was the domain with the highest satisfaction for current SCRQoL, with 86.7% of participants reporting the ideal state. This is closely followed by personal safety, as 85.5% reported the ideal state for their current SCRQoL. Personal safety showed the biggest difference between current and expected SCRQoL. Of the 71 who reported that they currently felt as safe as they wanted (ideal state), 25 reported that in the absence of care and support services they would not feel at all safe, and only 14 reported that they would still feel as safe as they wanted. In terms of the dignity domain, only 10.8% of participants felt that having help undermined the way they felt about themselves, and 54.2% stated that the way they were helped and treated made them feel better about themselves.

Table 7. *Participant needs in each domain, for current and expected SCRQoL.*

ASCOT INT4 Domain	Current SCRQoL		Expected SCRQoL	
	Number	Percentage	Number	Percentage
Control over daily life				
Ideal state	<b>60</b>	<b>72.3</b>	<b>28</b>	<b>33.7</b>
No needs	17	20.5	15	18.1
Some needs	6	7.2	23	27.7
High level needs	0	0	17	20.5
Personal cleanliness and comfort				
Ideal state	<b>72</b>	<b>86.7</b>	<b>42</b>	<b>50.6</b>
No needs	10	12.0	12	14.5
Some needs	1	1.2	17	20.5
High level needs	0	0.0	12	14.5
Food and Drink				
Ideal state	<b>69</b>	<b>83.1</b>	<b>40</b>	<b>48.2</b>
No needs	11	13.3	16	19.3
Some needs	2	2.4	12	14.5
High level needs	1	1.2	15	18.1
Personal Safety				
Ideal state	<b>71</b>	<b>85.5</b>	18	21.7
No needs	9	10.8	15	18.1
Some needs	2	2.4	20	24.1
High level needs	1	1.2	<b>30</b>	<b>36.1</b>
Social participation and involvement				
Ideal state	<b>61</b>	<b>73.5</b>	<b>30</b>	<b>36.1</b>
No needs	19	22.9	13	15.7
Some needs	3	3.6	22	26.5
High level needs	0	0.0	18	21.7
Occupation				
Ideal state	<b>55</b>	<b>66.3</b>	28	33.7
No needs	13	15.7	12	14.5
Some needs	15	18.1	<b>33</b>	<b>39.8</b>
High level needs	0	0.0	10	12.0
Accommodation cleanliness and comfort				
Ideal state	<b>58</b>	<b>69.9</b>	22	26.5
No needs	24	28.9	16	19.3
Some needs	1	1.2	<b>25</b>	<b>30.1</b>
High level needs	0	0.0	20	24.1

Note. **Bold** indicates the most frequent rating for that domain



*Figure 2.* Responses to the filter question which asks whether care and support services have an impact on each domain.

Table 8. *Dignity domain responses.*

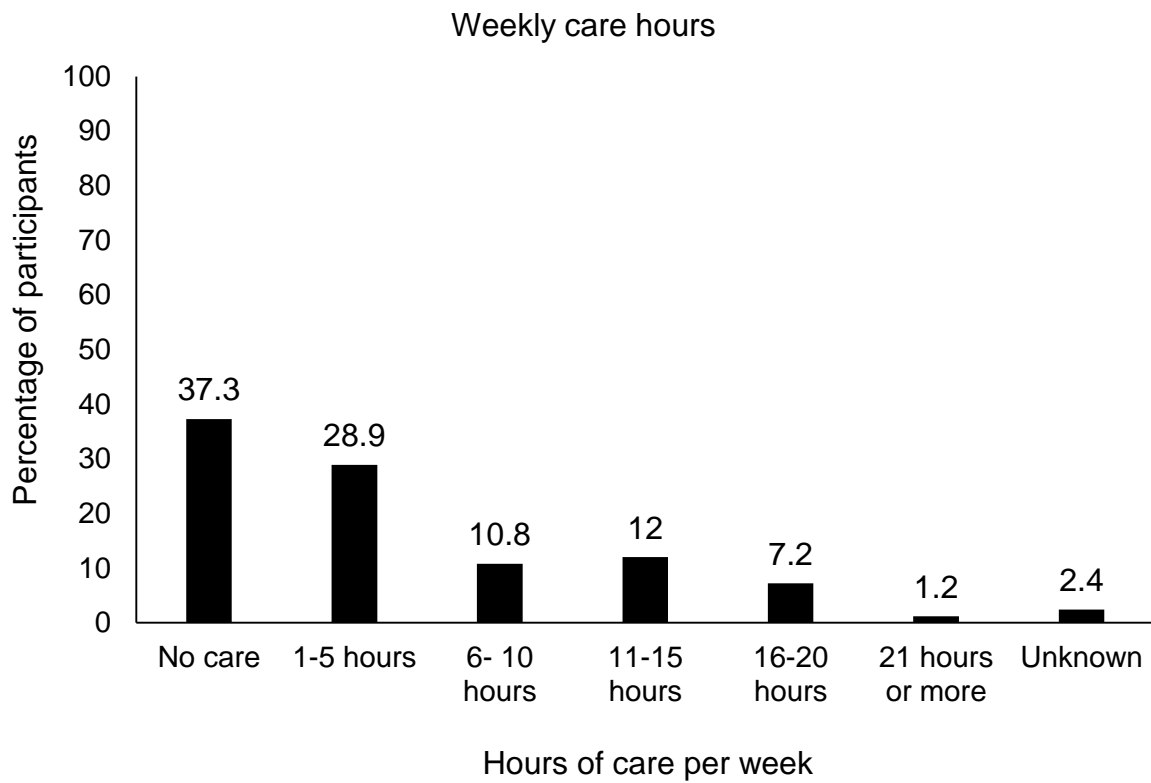
Question		Number	Percentage
1	Having help makes me think and feel better about myself	35	42.2
	Having help does not affect the way I think or feel about myself	39	47.0
	Having help sometimes undermines the way I think and feel about myself	7	8.4
	Having help completely undermines the way I think and feel about myself	2	2.4
2	The way I'm helped and treated makes me think and feel better about myself	45	54.2
	The way I'm helped and treated does not affect the way I think or feel about myself	34	41.0
	The way I'm helped and treated sometimes undermines the way I think and feel about myself	3	3.6
	The way I'm helped and treated completely undermines the way I think and feel about myself	1	1.2

SCRQoL gain had a range of -14 to 1.08. Six participants rated their expected SCRQoL as higher than their current SCRQoL, resulting in a negative SCRQoL gain score. This suggests that care and support services were not meeting their needs, or they believed certain aspects of their lives would be better if they were not living in extra care housing. Four out of six of these rated their expected SCRQoL for safety as higher than current SCRQoL, and half chose the response that having help or the way they were treated undermined how they felt about themselves. Other domains that were rated higher for expected SCRQoL than current SCRQoL were control over daily life, occupation, accommodation cleanliness and comfort, and food and drink.

Sixty-eight participants received care and/or support services from their scheme.

Support refers to services such as having help with paperwork and having shopping

done. A comparison of those who did and did not receive care and/or support revealed significant differences for SCRQoL gain ( $U = 279.00$   $p = 0.006$ ). Those who did not receive any care or support from their scheme had a mean SCRQoL gain of 0.19 (mean current SCRQoL = 0.93, mean expected SCRQoL = 0.73) with an expected SCRQoL that ranged from 0.32-0.96. The participants who did receive care or support had a mean SCRQoL gain of 0.43 (mean current SCRQoL = 0.91, mean expected SCRQoL = 0.48). This demonstrates the positive impact of living at an extra care housing scheme, even without having care and support services. Fifty participants received care from staff at their scheme, which was defined as assistance with personal care, domestic tasks, meals and laundry. Figure 3 shows the categories of weekly care hours they received. Out of those who received care, the most participants received the smallest bracket of care hours per week (1-5 hours). No significant differences were found for care hours (groups shown in Figure 3) and current SCRQoL ( $H = 4.33$  (5,  $N = 81$ )  $p = 0.503$ ) which demonstrates that the care and support services were compensating people for the effects of long term illness and disability. As hypothesised, there were significant differences for expected SCRQoL ( $H = 37.57$  (5,  $N = 81$ )  $p < .001$ ), and SCRQoL gain ( $H = 37.32$  (5,  $N = 81$ )  $p < .001$ ). This supports the hypothesis that there will be a difference in gain between those in receipt of different amounts of care and those who do not receive care, as those who receive care would experience a reduced SCRQoL in the absence of care and support services.



*Figure 3.* Number of weekly care hours received by participants.

When comparing individual domains and care hours, significant differences were found for expected SCRQoL in the domains of control over daily life, personal cleanliness and comfort, food and drink, occupation, and accommodation cleanliness and comfort. Dignity also showed significant differences between groups of care hours. Table 9 details the findings of these tests.

Table 9. *Significant results from a Kruskal Wallis analysis of care hour groups and SCRQoL.*

Domain	Variable	Test statistic ( <i>H</i> )	P value
Control over daily life	Expected SCRQoL	32.747	$p < 0.01$
Personal cleanliness and comfort	Expected SCRQoL	37.268	$p < 0.01$
Food and drink	Expected SCRQoL	23.435	$p < 0.01$
Occupation	Expected SCRQoL	12.043	$p = 0.034$
Accommodation cleanliness and comfort	Expected SCRQoL	29.310	$p < 0.01$
Dignity	Both questions	12.010 22.641	$p = 0.035$ $p < 0.01$

Note.  $N = 81$ ,  $df = 5$ .

### *Health.*

Health was rated as 'fair' most often by participants, with 39.8% choosing that option, followed by 36.1% who rated their health as 'good'. Only 10.8% rated their health as 'bad' or 'very bad'. A comparison of current SCRQoL across ratings of health did not find any significant differences ( $H = 2.826$  (5,  $N = 83$ )  $p = 0.727$ ). There were no significant differences for ratings of health and expected SCRQoL ( $H = 2.629$  (5,  $N = 83$ )  $p = 0.757$ ) or SCRQoL gain ( $H = 2.185$  (5,  $N = 83$ )  $p = 0.823$ ).



### *The influence of other factors*

There were no significant differences between men and women for current SCRQoL ( $U = 690.5$ ,  $p = 0.839$ ), expected SCRQoL ( $U = 566.5$ ,  $p = 0.281$ ), or SCRQoL gain ( $U = 789.5$ ,  $p = 0.221$ ). There were no significant correlations between age and any of the SCRQoL measures. Previous research has found that older adults without a partner experience higher levels of loneliness (De Jong Gierveld & Van Tilberg, 2006) which could have a negative impact on their quality of life. The distributions of current SCRQoL and expected SCRQoL were the same across categories of marital status. However, the distribution of gain was different across marital status ( $H = 8.029$  (3,  $N = 83$ )  $p = 0.045$ ), with gain being highest for those who were single. From a comparison of schemes, there were significant differences in current SCRQoL ( $H = 23.245$ , (6,  $N = 83$ )  $p = 0.001$ ) and SCRQoL gain ( $H = 20.709$ , (6,  $N = 83$ )  $p = 0.002$ ).

### *Social participation and involvement.*

Amount of social contact was assessed by asking participants to estimate how often they did certain social activities using the categories 'most days', 'weekly', 'monthly' and 'never'. As Figure 4 shows, the majority speak to someone on the phone most days (60.2%), don't use text or email (75.9%), speak to neighbours at the scheme most days (80.7%) and most have weekly visits from friends or relatives who don't

live at the scheme (44.6%). There was a significant correlation between speaking to neighbours and current SCRQoL social participation domain ( $r_s = 0.391$ ,  $p = 0.01$ ).

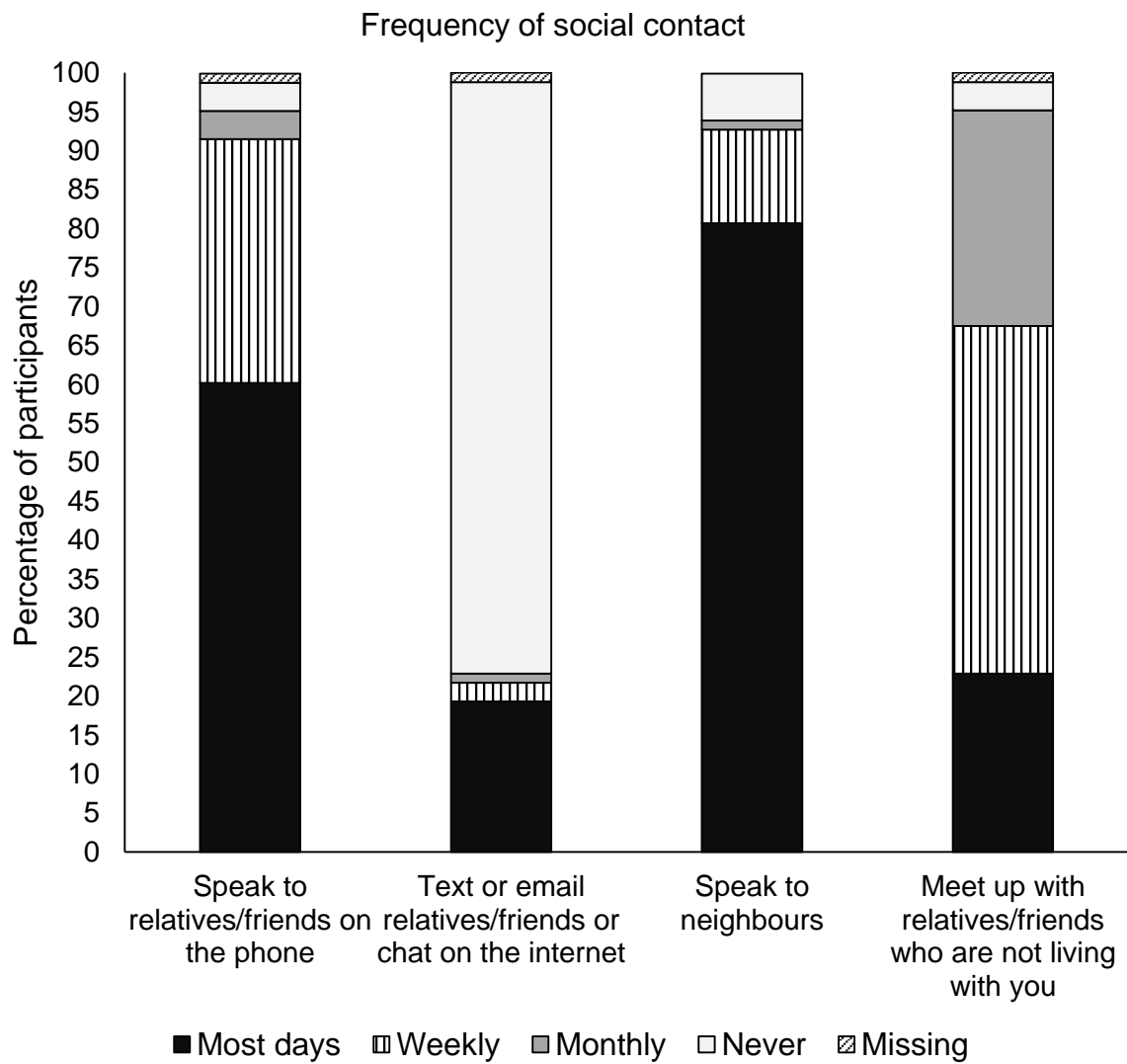


Figure 4. Frequency of social contact.

Since moving into the scheme, 55.4% of participants said their social contact was better than before and 41% said it was not ( $N = 80$ ). Of the 61 who reported the ideal state for their current social SCRQoL, 17 reported that in the absence of services, they would have some social contact but not enough, and 13 reported that they would have little social contact and feel isolated. Only 27 chose the ideal state for their expected SCRQoL.

### *Activities of Daily Living.*

The questions about activities of daily living required participants to rate their ability to perform daily tasks, with the options:

- 1) I can do this without help
- 2) I have difficulty but manage on my own
- 3) I can only do this with help
- 4) I cannot do this.

For eight out of the fifteen tasks, the majority responded that they could perform those tasks without help (see Table 10). Using the stairs was the task that most people could not do, with 60.2% indicating they could not manage. Getting in and out of bed was the most difficult task to do without help, with 33.7% stating that they had difficulty but managed on their own. Total ADL score was calculated from the number value assigned to each response, meaning a higher ADL score related to a lower ability to complete activities of daily living and a higher dependency on the help of

others. Total ADL score correlated positively with SCRQoL gain ( $r = 0.478$ ,  $p = 0.01$ ,  $N = 81$ ) and negatively with expected SCRQoL ( $r = -0.554$ ,  $p = 0.01$ ,  $N = 81$ ). This shows that those who were less able to complete tasks rated their expected SCRQoL as lower than those with better ability. The positive correlation with SCRQoL gain confirms that those with lower ability and more dependence on services gain the most impact from care and support services.

Table 10. *Ability to perform activities of daily living (percentages).*

ADL	I can do this	I have difficulty	I need help	I can't do this
Getting in and out of bed *	<b>56.6</b>	33.7	1.2	7.2
Washing face and hands	<b>80.7</b>	10.8	6	2.4
Showering/having bath	41	8.4	41	9.6
Dressing	45.8	21.7	26.5	6
Using the toilet	<b>78.3</b>	13.3	3.6	4.8
Eating	<b>79.5</b>	9.6	9.6	1.2
Taking medication*	<b>66.3</b>	8.4	16.9	7.2
Getting around indoors	<b>60.2</b>	34.9	1.2	3.6
Using stairs	19.3	15.7	4.8	<b>60.2</b>
Going out*	37.3	10.8	42.2	8.4
Shopping*	24.1	9.6	32.5	32.5
Housework*	20.5	7.2	27.7	43.4
Paperwork*	<b>51.8</b>	6	15.7	25.3
Preparing snacks and hot drinks*	<b>71.1</b>	8.4	3.6	15.7
Preparing hot meals	31.3	14.5	14.5	37.3

\*N = 82.

Note. **Bold** indicates majority answer.

## Discussion

The distribution and mean scores for current SCRQoL, expected SCRQoL and SCRQoL gain reflect the positive impact of care and support services, and the environment of extra care housing. Mean current SCRQoL was 0.91 (maximum score 1.00) demonstrating a high level of satisfaction with the aspects of quality of life measured by ASCOT. Research into life satisfaction found that it tended to decrease with age up to 50 or 60 years old, then increased or remained stable (Mastekaasa et al. 1988, as cited by Sarvimaki & Stenbock-Hult, 2000). The demographics of the ASSET sample were similar to those of a large study into characteristics of extra care housing residents, with a sample of over 600 (Darton et al., 2012) The mean age in that sample was 80.5 years old, with the majority being white (95.6%) females (66%). This study found no differences in quality of life between men and women, which supports findings by Karjalainen (1984, as cited by Sarvimaki & Stenbock-Hult, 2000).

Health did not show a significant interaction with quality of life. Many studies have found that people with long term illnesses report quality of life that is similar to those with less severe illnesses or people who are classed as healthy. Ogden and Lo (2011) found that a homeless population rated their health as 'fine', 'ok' or 'well' using likert scales, despite indicating they experienced a variety of physical and psychological health problems in their qualitative answers. This phenomenon has been the focus of work by Rapkin and Schwartz (2004) who suggest appraisal and response shift account for discrepancies between self-reported and external observation of an individuals' quality of life. Response shift occurs when people change their standards and values in response to external factors such as illness or

life events. People often use a 'frame of reference', and recall incidences from their life experiences to assess their quality of life. These incidences are judged using standards of comparison. Comparisons may use the individual's functioning prior to illness, comparisons to others' circumstances and characteristics, past experiences of illness, loss of functioning or capabilities, and information from medical professionals. Ogden's study showed that the homeless group judged their current quality of life by comparing their current situation to their past experiences, e.g. poor sleeping circumstances were viewed as positive in the context of previous more negative circumstances. Cancer patients who compared themselves favourably to other patients sustained their quality of life despite a decline in health and worsening of symptoms (Hagedoorn, Sneeuw, & Aaronson, 2002). Participants in the current study may be using older adulthood as their frame of reference, therefore they consider their health in terms of how it compares to others of a similar age or how it compares to a culturally defined idea of aging and health, rather than how it compares to the wider population. These ideas link to the theory of adaption. Adaption of quality of life expectations has been identified as a complication in assessing the impact of social care (Netten et al., 2012). As people adjust to the limitations of requiring social care, they may adapt their expectations, resulting in lowered expectations (negative adaption) or if they may have adapted to having a high level of capability (positive adaption). These viewpoints lead people to rate situations differently to their previous expectations. An important factor to consider in adaption is how recent the changes are. For those who have experienced a change in their functioning for a substantial period of time, they will have altered their expectations and adopted different frames of reference to someone who has recently

experienced a change. The disability paradox demonstrates these ideas as over half of people with a serious disability, which severely limits their activities of daily living and opportunities for social interaction, reported that they had excellent or good quality of life (Albrecht & Devlieger, 1999). This high quality of life was related to adaption as accepting impairments was a theme that emerged from qualitative answers. Other contributors to high quality of life were feeling in control of their minds and bodies, having an attitude of belief in their abilities to do things, having a purpose/meaning in life and having a faith or religion. Feeling satisfied when comparing themselves to others in similar situations was another factor that contributed to high quality of life, which supports the idea of the influence of reference groups and comparisons when making quality of life judgements. For people with no disabilities, 80-85% have reported being satisfied or very satisfied with their quality of life. Perceptions of the able bodied population and health professionals show they believe people with disabilities have a low quality of life, although this is clearly not the case from the self-reported data. Of those with disabilities who reported poor or fair quality of life, the experience of pain and fatigue were common themes. Other factors included lack of control over mental activities and the feeling of lacking purpose or meaning.

Volkman's rubber band model (1951, as cited by Ogden & Lo, 2011) suggests that likert rating scales are interpreted differently and adjusted to the individual's perception of acceptable extremes for the scale. Discrepancies between findings from the likert scale and qualitative answers (Ogden & Lo, 2011), suggest that scales may result in overly positive results which could also be occurring in this study. Further research could consider including Rapkin and Schwartz's (2004)



Quality of Life Appraisal Profile (QOLAP) which is designed to be administered through interview, alongside a quality of life measure. It allows participants to define quality of life, and to give their reasoning for their answers to the quality of life measure. Qualitative responses would be particularly useful from the participants who rated their expected SCRQoL as higher than their current SCRQoL, to pinpoint the aspects of care and support services that are unsatisfactory.

Sampling of participants was achieved through the relevant scheme managers, meaning convenience sampling methods were used that were influenced by the scheme manager's knowledge of their residents. This carries a risk of bias in the sample. There is an issue with participants' varying degrees of understanding of the ASCOT hypothetical situation. One problem with measuring the impact of social care is that there is no clear start or end to the services provided by social care, as most care is ongoing and gradually increases as illnesses become more limiting. This means true before and after measures cannot be taken (Netten et al., 2012), and the hypothetical nature of the expected SCRQoL questions are necessary to gain an understanding of the impact of services. Some participants required further explanation and rephrasing of the hypothetical questions which could have introduced interviewer bias. Some residents compared life in their previous homes to their current situation when considering the hypothetical questions. This means they may be thinking of factors about their previous home which are more positive than their current situation, e.g. proximity to family, neighbours and shops, and memories of family life at their previous residence. Although it was stressed that in the hypothetical scenario no other help would compensate for services, some participants may have been answering on the assumption that family members and

other support networks would provide care in the absence of services. Rowles (1983) found a relationship between attachment to places and wellbeing which was particularly important for older people with limited mobility who have lived in one place for a long period of time. The bond between people and places grows stronger with age, and has been found to be stronger for women (Giuliani & Feldman, 1993, as cited by Evans, 2009). This means the elderly, female dominated sample may have had a strong attachment to their previous homes, which could have impacted on their answers to the hypothetical situation. Self-reported data always carries a risk of error due to inaccurate recall, and some participants lacked knowledge about certain answers to questions, for instance their level of care, benefits they receive and other questions relating to their personal finances. This could be resolved by accessing residents' care plans.

The ASCOT tool has been found to correlate well with other measures of QOL, and was able to detect changes in QOL as a result of social care and health services more consistently compared to the EuroQol (Caiels et al., 2010). The EuroQol measures five dimensions of health: mobility, self-care, usual activities, pain, and anxiety/depression. ASCOT also had convergent validity with measures such as ADLs and satisfaction ratings. ADL scores correlated with ASCOT in this study to demonstrate that those with a higher need for care rated their expected SCRQoL as lower and had a larger SCRQoL gain. This reflects the importance of care and support services in compensating people for their difficulties with activities of daily living. The compensatory nature of services is further demonstrated in the lack of significant differences for current SCRQoL between people who received different amounts of care.

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## Appendix 1a: Hunger Rating Scale

**HOW TO COMPLETE A RATING SCALE**

'A rating scale is a line with two end points which each show the most extreme and opposite feelings or opinions you might have about something. Above the line is a question.

When making a rating you should:

1. Read and think about the question.
2. Read and think about BOTH end points.
3. Place a single line on the rating scale that marks exactly where your opinion lies between the two ends of the scale. See the example below'.

**Example:**

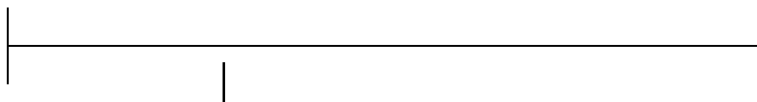
How **THIRSTY** do you feel right now?

Not at all

Very

**Thirsty**

**Thirsty**



**Thank you for your participation**

How HUNGRY do you feel right now?

NOT AT ALL

EXTREMELY

How THIRSTY do you feel right now?

NOT AT ALL

EXTREMELY

How FULL do you feel right now?

NOT AT ALL

EXTREMELY

How strong is your DESIRE to eat right now?

NOT AT ALL

EXTREMELY

## Appendix 1b: Observed Lunch Coding Sheet

ID	Time=start of meal (A*)	Time=end of meal (A*)

**Adolescent Behaviour**

Positive vocalizations about food (A*; example how many times)	Negative vocalizations about food (A*; example how many times)	Pressure on parent to eat (how many times, what food and example)

**Parent Behaviour**

Positive vocalizations about food (P*; example how many times)**		Negative vocalizations about food (P*; example how many times)**	
Pressure to eat: verbal (P*; any instruction or demand to eat; how many times and examples)		Physical prompt to eat (P*; how many times and examples)	
Sandwich		Sandwich	
Pizza		Pizza	
Fruit		Fruit	
Yoghurt		Yoghurt	

Cookie		Cookie	
Tomatoes		Tomatoes	
Crisps		Crisps	
<b>Verbal restriction</b> (P*; how many times and examples)		<b>Physical restriction</b> (P*; how many times and examples)	
Sandwich		Sandwich	
Pizza		Pizza	
Fruit		Fruit	
Yoghurt		Yoghurt	
Cookie		Cookie	
Tomatoes		Tomatoes	
Crisps		Crisps	
<b>Teenager Accepts/rejects prompts</b>		<b>Parenting style:***</b>	
Accept	Reject	Control Involvement	Style

**Other**

<b>Sharing /eating food off each other's plates</b> (Y/N and who)	<b>Topic(s) of conversation</b>	<b>Other</b>

A\* adolescent

P\* parent

\*\* not coded as pressure or restriction

\*\*\* make a case for specific parenting style, examples

- Authoritarian (pressure to eat, nagging, restrictions, demands, in control, negative vocalizations)
- Authoritative (positive vocalizations, modelling, supportive, encouragements, positive incentives)
- Permissive (no demands, do what you like ): Indulgent (Involved but not demanding), withdrawn (not involved)

## Appendix 2b: Showcards

**SHOWCARD 1**

- 1) 1–5 hours a week
- 2) 6–10 hours a week
- 3) 11–15 hours a week
- 4) 16–20 hours a week
- 5) 21 hours a week or more

## SHOWCARD 2

- 1) I can do this without help from anyone
- 2) I have difficulty but manage on my own
- 3) I can only do this with help from someone
- 4) I cannot do this



## SHOWCARD 3

- 1) I am continent
- 2) I have occasional accidents
- 3) I am incontinent

## SHOWCARD 4

1) Most Days

2) Weekly

3) Monthly

4) Never

Don't know

## SHOWCARD 5

- Hobbies or social club
- Exercise group
- Local community or neighbourhood groups
- Health groups
- Information or education group
- Organised group trips or visits
- Other: Please give me details

## SHOWCARD 6

- 1) Every day or nearly every day
- 2) 2-3 times per week
- 3) Once a week
- 4) Less often

## SHOWCARD 7

- 1) Once
- 2) 2 or 3 times
- 3) 4 or 5 times
- 4) 6 or more

**SHOWCARD 8****White:**

1. White British
2. White Irish
3. Any other White background

**Mixed/Multiple Ethnic Groups:**

4. White and Black Caribbean
5. White and Black African
6. White and Asian
7. Any other mixed/multiple ethnic background

**Asian or Asian British:**

8. Indian
9. Pakistani
10. Bangladeshi
11. Chinese
12. Any other Asian background

**Black / African / Caribbean / Black British:**

13. Caribbean
14. African
15. Any other Black background

**16. Arab**

17. Any other ethnic group
18. Decline to answer
- 19.

## Appendix 2c: Project information sheet for professionals

**Project Information Sheet for Professionals****Title of Project:****Adult Social Services Environments and Settings (ASSET)***Invitation*

We would like to invite you to take part in a research project. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please take time to read this leaflet carefully and ask the project team if you have any questions. Please also feel free to discuss the project with colleagues. You will have at least 3 days to decide if you want to take part.

**What is the purpose of the study?**

Extra care housing schemes and retirement villages (known collectively as 'housing with care') have become increasingly popular in the UK during the past ten years. The government has provided significant funding for these settings because of their capacity to support independence for older people in their own homes. Housing with care is very popular among those living in such schemes for a range of reasons, including the opportunities for social interaction, the availability of comprehensive facilities on site, and because the physical environment is purpose built to meet the needs of older people. This study aims to explore how best to provide adult social care in housing with care schemes in England, in order to maximise quality of life for residents and make the best use of resources.

**Why have I been invited to take part?**

You have received this invitation because you are a professional with experience of housing and/or social care for older people.

**Do I have to take part?**

No. It is up to you to decide whether or not you want to take part in this study. Please take your time to decide; we will wait for at least 3 days before asking for your decision. If you decide not to take part or to withdraw from the study at any

point, it will not affect any service you receive. If you do decide to take part you will be asked to sign a consent form.

### **What will the research involve?**

If you agree to take part you will be contacted by one of the research team. They will to arrange a convenient time to come and talk to you about your experiences and/or knowledge of providing social care and support for older people housing with care settings. Before the interview the researcher will ask for your written consent to take part. The interview will last for up to an hour and if you agree it will be tape recorded. If you were to lose capacity to consent during the study no further data would be collected but your identifiable data already collected with consent would be retained and used in the study.

### **Are there any risks to taking part?**

The research does not involve any investigations or treatments that might put you at risk.

### *Will the information I give stay confidential?*

Everything you say/report is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else. The information you give may be used for a research report, but it will not be possible to identify you from our research report or any other dissemination activities. Personal identifiable information (e.g. name and contact details) will be kept for up to 3 months after the project ends in January 2014 and then destroyed. The research data (e.g. interview transcripts) will be securely stored and may be used for further research purposes.

### **What will happen to the results of the research study?**

The findings of this study will be reported to the research funders and shared with housing and social care organisations. They will also be presented at conferences and published in academic and professional journals.

If you wish to receive a summary of the research findings please tell the researcher who visits you.

### **Who is organising and funding the research?**



This research has been funded by the School for Social Care Research, which is part of the National Institute for Health Research Programme. This project has been given a favourable opinion by the Social Care Research Ethics Committee.

### **What happens next?**

Please keep this information sheet and feel free to discuss taking part with others as appropriate. If you do decide to take part, please contact a member of the research team using the details below.

### ***Thank you for taking the time to read this information***

If you decide to take part of you have any questions, concerns or complaints about this study please contact one of the research team using the details below.

#### **Simon Evans**

Senior Research Fellow  
University of Worcester

[REDACTED]

[REDACTED]

#### **Robin Darton**

Senior Research Fellow  
University of Kent

[REDACTED]

[REDACTED]

If you would like to speak to an independent person who is not a member of the research team, please contact John-Paul Wilson at the University of Worcester, using the following details:

John-Paul Wilson  
Research Manager  
Graduate Research School  
University of Worcester

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

## Appendix 2d: Project information sheet for participants

**Project Information Sheet for Residents and Relatives****Title of Project:****Adult Social Services Environments and Settings (ASSET)***Invitation*

We would like to invite you to take part in a research project. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please take time to read this leaflet carefully and ask the project team if you have any questions. Please also feel free to discuss the project with family or friends. You will have at least 3 days to decide if you want to take part.

**What is the purpose of the study?**

This study aims to explore how best to provide adult social care in housing with care schemes (retirement villages and extra care housing) in England, in order to maximise quality of life for residents and make the best use of resources.

**Why have I been invited to take part?**

You have received this invitation because you (or a family member) live in a housing scheme.

**Do I have to take part?**

No. It is up to you to decide whether or not you want to take part in this study. Please take your time to decide; we will wait for at least 3 days before asking for your decision. If you decide not to take part or to withdraw from the study at any point, it will not affect any service you receive. If you do decide to take part you will be asked to sign a consent form.

**What will the research involve?**

If you agree to take part you will be contacted by one of the research team. They will to arrange a convenient time to come and talk to you about the care and support you receive. Before the interview the researcher will ask for your written consent to take part. The interview will last for up to an hour and if you agree it will be tape recorded.

If you were to lose capacity to consent during the study no further data would be collected but your identifiable data already collected with consent would be retained and used in the study.

### **Are there any risks to taking part?**

The research does not involve any investigations or treatments that might put you or the person you care for at risk. However, it is possible that you will find it distressing to talk about your social care and support needs. If so, you will be able to have a break or end the interview completely. The researcher will offer to mention your distress to an appropriate member of the housing scheme staff, but this would only happen if you agree to it. The researcher would also offer to give you details of suitable local support services.

### *Will the information I give stay confidential?*

Everything you say/report is confidential unless you tell us something that indicates that you or someone else is at risk of harm. We would discuss this with you before telling anyone else. The information you give may be used for a research report, but it will not be possible to identify you from our research report or any other dissemination activities. Personal identifiable information (e.g. name and contact details) will be kept for up to 3 months after the project ends in January 2014 and then destroyed. The research data (e.g. interview transcripts) will be securely stored and may be used for further research purposes.

### **What will happen to the results of the research study?**

The findings of this study will be reported to the research funders and shared with housing and social care organisations. They will also be presented at conferences and published in academic and professional journals.

If you wish to receive a summary of the research findings please tell the researcher who visits you.

### **Who is organising and funding the research?**

This research has been funded by the School for Social Care Research, which is part of the National Institute for Health Research Programme. This project has been given a favourable opinion by the Social Care Research Ethics Committee.

### **What happens next?**

Please keep this information sheet and feel free to discuss taking part with family and friends. If you do decide to take part, please either contact the research team using the details below, or tell a member of staff at your housing scheme.

***Thank you for taking the time to read this information***

If you decide to take part of you have any questions, concerns or complaints about this study please contact one of the research team using the details below.

**Simon Evans**

Senior Research Fellow  
University of Worcester

[REDACTED]

[REDACTED]

**Robin Darton**

Senior Research Fellow  
University of Kent

[REDACTED]

[REDACTED]

If you would like to speak to an independent person who is not a member of the research team, please contact John-Paul Wilson at the University of Worcester, using the following details:

John-Paul Wilson  
Research Manager  
Graduate Research School  
University of Worcester

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

## Appendix 2e. Consent form

**Participant Consent Form****Title of project:****Adult social care settings and environment (ASSET)**

Participant Identification Number for this study:

Name of Principal investigator(s): Simon Evans

**YES****NO**

I confirm that I have read and understood the information sheet dated 02/05/12 (version 2) for the above study and have had the opportunity to ask questions.

☐
☐

I confirm that I have had sufficient time to consider whether I want to take part in this study

☐
☐

I understand that I do not have to take part in this research and I can change my mind at any time.

☐
☐

I agree to the research interview being audio taped

☐
☐

I agree to my interview being kept for future research purposes

☐
☐

Name of participant \_\_\_\_\_

Date \_\_\_\_\_ Signature \_\_\_\_\_

Name of person taking consent \_\_\_\_\_

Date \_\_\_\_\_ Signature \_\_\_\_\_