The Development of a Measure of Social Care Outcome for Older People

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PSSRU Discussion Paper 1690/2

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Summary

Chapter 1

1. An essential element of identifying Best Value and monitoring cost-effective care is to be able to identify the outcomes of care. In the field of health services, use of utility-based health related quality of life measures has become widespread, indeed even required. If, in the new era of partnerships, social care outcomes are to be valued and included we need to develop measures that reflect utility or welfare gain from social care interventions. This paper reports on a study, commissioned as part of the Department of Health's Outcomes of Social Care for Adults Initiative, that developed an instrument and associated utility indexes that provide a tool for evaluating social care interventions in both a research and service setting. Discrete choice conjoint analysis used to derive utility weights provided us with new insights into the relative importance of the core domains of social care to older people. Whilst discrete choice conjoint analysis is being increasingly used in health economics, this is the first study that has attempted to use it to derive a measure of outcome.

2. A reference group of about 70 individuals was set up drawn from local authority senior and middle managers, the Department of Health, academics, representatives of voluntary organisations and care managers. Two waves of consultation took place with this group: first about the key domains or objectives and second about the structure of the measure. In addition nine social workers completed the initial version of the measure for ten elderly people and fed back views about the practicality of the measure.

Chapter 2

3. Five domains were identified as the key areas of outcome of social care:

- Food and nutrition;
- Personal care;
- Safety;
- Social participation and involvement; and
- Control over daily life.

4. The initial measure that was circulated was simplified and refined on the basis of the reference group feedback, further consultation and the experience of the care managers and completion of the instrument by care managers on the behalf of 40 individuals. Vignettes based on these cases (see appendix B) were used to complete the core of the instrument by 54 individuals, including three groups of care managers. These exercises were used to refine the guidance further.

Chapter 3

5. The final instrument and associated guidance is shown in appendix A. For each of the five domains there is a question about current levels of unmet need. Respondents are asked to identify whether informal carers and/or services play a role in meeting needs and what the level of need would be in the absence of any

service intervention. An additional section identifies serious events that have occurred over the previous month.

6. Investigations into the reliability and validity of the measure suggested it was both valid and reliable. For test-retest reliability, levels of absolute agreement exceeded 85 per cent and Kappas exceeding 0.6 for all items bar one. All the results were at least equivalent to those reported for the widely used CAN on which the instrument was based. As predicted, morale was significantly correlated with current levels of met need ($R^2=0.42$) and functional ability with levels of met need expected in the absence of services ($R^2=0.48$). There was no association between morale as measured by PGC and functional ability as measured by Barthel.

Chapter 4

7. After extensive pre-pilot and pilot exercises a sample of 356 older people were interviewed to establish their preferences using discrete choice conjoint analysis on a set of 27 scenarios that reflected different levels of unmet need in all domains. Checks were included in the questionnaire for consistency and an analogue scale used to rate the same scenarios in order to allow tests of concurrent validity.

8. Fifty-eight of the respondents repeated the exercise in order to allow us to investigate test-retest reliability. Forty-nine were interviewed using the same descriptions but with an additional attribute included indicating a hypothetical level of monetary benefits that the individual was receiving, in order to investigate whether (and if so at what rate) people traded money against levels of unmet need. A sub-sample of 65 people was followed up one year later with a revised design.

Chapter 5

9. The results of the analysis indicated that the most important domain was personal care, followed by social participation and involvement, followed by control over daily life, followed by food, followed by safety.

10. Although rated highly by respondents on a simple ranking exercise, the domain of sense of safety was insignificant for several of the models run and, if two tailed tests were used, showed an inconsistent pattern of preferences in the main model. The follow-up study suggested that in part this could be due to the generalised nature of the description of unmet need compared with other domains. Nevertheless, when a more specific description was used relating to falls, the domain was still ranked lowest of all the domains.

11. Social participation and involvement, however, was rated much more highly than was apparent on the initial ranking exercise. Results from the piloting work suggested that social participation might be seen as a protective factor: the situation could not get too terrible while you were seeing others, as they would notice and ensure something was done. If you were isolated anything could happen.

12. Preferences were not associated with gender but were associated with age, living circumstances and reporting both some impairment and currently receiving services. People aged 85 and over were more concerned about food and nutrition and less concerned about social contact than younger respondents. People who lived with others weighted social participation and involvement much higher than

those who lived alone. Disabled people in receipt of services ranked food and nutrition highest, followed by social participation (see table 5.7).

13. The inclusion of a monetary domain allowed the estimation of the monetary value to respondents associated with each domain. These were based on of willingness to accept benefits in compensation for unmet need and were relatively high (summing to over £1,300). This suggests that there is surplus benefit associated with receipt of services (see table 5.8).

14. The approach to establishing preferences was checked for validity and reliability. There were good indications of test-retest reliability (Kappa=0.65) and validity when comparing predicted scores with ratings based on the analogue rating scale (R^2=0.81).

Chapter 6

15. Two utility indexes were generated (see table 6.1). The first reflects the statistical model, omitting domains and levels of unmet need that were not found to be statistically significant. In order to create a more sensitive index that has values for all the levels of met and unmet need included in the measure, the second index combines the results of the main model and the monetary model.

16. The indexes can be used in a number of ways to measure outcome:

- The difference in the Index based on current levels of met need across different populations (e.g. social service areas or those cared for in care homes and in private households);
- The difference between the Index based on current levels of met need before and after the introduction of a social care intervention;
- The difference between the Index based current levels of met need and the Index based on expected levels of met need;
- In large enough samples the probability of the serious events listed in the instrument could be established and compared between groups.

In all instances it would be important to allow for factors such as variations in levels of dependency

17. More work is needed to investigate the most appropriate ways to investigate differences in perceptions, to incorporate objective risks and sense of safety and to identify utility weights with nationally representative samples. Specific investigations into groups of interest, such as ethnic minorities, would also both potentially provide alternative utility indexes reflecting the perspectives of these groups.

1 Background

An essential element of identifying Best Value and monitoring cost-effective care, both key policy objectives (Department of Health, 1998), is to be able to identify the outcomes of care. This report describes the results of a project, commissioned as part of the Department of Health's Outcomes of Social Care for Adults Initiative, to develop a measure of outcome of social care for older people. In this chapter we consider what we mean by social care before outlining the type of measure developed and the method adopted.

1.1 Measuring outcomes of social care

In the introduction to the White Paper *Modernising Social Services* (Department of Health, 1998) the role of social services is broadly defined as making: 'provision for those who need support and are unable to look after themselves.'

The objective of health care interventions is to prevent, cure or mitigate impairment or at the very least, maintain functioning at as high a level as possible. Social care, on the other hand, is concerned with managing or reducing the effect of impairment on people's daily lives. Health-based outcome measures that pick up changes in functions or ability are thus often inappropriate to social care services where the objective is to meet the needs created by the impairment, such as helping people with personal care tasks or fostering social integration.

The production of welfare (PoW) approach to evaluating social care provides a theoretical basis for linking resources, needs and outcomes (Knapp, 1984). To date, work based on this approach has used measures of outcome developed for the specific intervention under consideration or well established scales devised to assess aspects of welfare such as morale, depression or carer stress. However, such measures have not developed a utility score reflecting the welfare or benefit derived from social care. In contrast to this there has been an attempt in the economics literature to develop generic scales to measure cross-diagnosis outcomes. Examples of this include the Rosser Distress and Disability Matrix (Rosser and Kind, 1978), EQ5D (EuroQol Group, 1990) and more recent attempts to give utility scores to SF36 health outcome states (Brazier et al., 1998). The use of such generic measures in assessing the benefits of health and long-term care for elderly people has been criticized on the basis that they are not sufficiently sensitive to change in relevant dimensions and more programme-specific measures are required (Donaldson et al., 1988). There is clearly a need for a utility measure specific to the social care of elderly people but sufficiently generic to provide a comparable measure of outcome over a wide variety of types of social care intervention. This need is made more urgent by the current policy emphasis on partnerships between health and social care agencies (Department of Health, 2000).

The reason that current generic measures are not sensitive to care for elderly people is that they do not take account of the dimensions that are important to users in the provision of social care for elderly people. The concept of commodities in the Social Production of Welfare, a development of the PoW approach (Netten and Davies, 1990) provides a useful link between measures of needs, social care provision, and outcomes for elderly people. Members of a household produce commodities such as housework in order to provide welfare or utility for household members. Welfare agencies become involved when there is insufficient capacity within the household or informal networks to supply the household members with an adequate level of basic commodities. Packages of care provide (or facilitate the production of) commodities such as housework, personal care, ensuring people are fed, and so on. While it is possible to estimate the weekly costs of activities associated with these commodities there is a need to link these activities to outcomes for individuals.

1.2 The type of measure

The primary objective of the study was to develop a measure of outcome for social care that could perform a similar function to that which QALYS provide for health care (Williams, 1985). QALYs provide an indicator that weights time, in the form of life expectancy, to reflect experience of health-related quality of life. This type of measure does not assess clinical-level outcomes: the type of measure that gives deeper insight into individual cases. It should, however, allow the measurement of outcomes for individuals for analysis at a population level: does this area or intervention appear to be more successful in generating welfare than an alternative?

The measure should:

- Reflect the relative value that elderly people put on the welfare (and improvements in welfare) resulting from social care services.
- Incorporate all those domains or commodities that are the concern of social care agencies and that could be examined straightforwardly in relation to the costs of service provision.
- Allow the identification of the level of commodities being produced or reduction in unmet need (in terms of capacity to benefit) over the same period that costs of services are estimated.
- Allow ratings to be made by the individual service user and by an assessor such as a care manager or social worker. This would mean both perspectives on outcomes could be measured and compared and allows the user perspective to be reflected directly wherever feasible.
- Be applicable for people living in both private households and communal establishments.
- Be applicable to both mentally alert elderly people and people with impaired cognitive functioning.

1.3 Method

The first task was to develop the instrument itself. This required that first we identified the commodities or domains that should be included and then how these are measured.

In order to reflect the range of perspectives concerned with both the delivery and receipt of social care for older people, a reference group was set up of local authority social service department managers and care managers, voluntary organisation representatives, Department of Health policy customers and academic observers. Two waves of consultation with this group took place. The first consultation was about the domains of social care. The second was about the structure of the measure.

The development of the instrument was an interactive process which tested the practicality of the measure. Nine care managers completed the initial draft instrument for ten older people. Adaptations were made to the instrument and 30 care managers completed the revised version, together with information about the basis for ratings made. This information was used to form the basis of vignettes which briefly described need circumstances of older people (see appendix B) for further testing the measure. In all 54 people, mostly care managers, rated six vignettes in terms of the core domains of the instrument. Fifteen of the care managers participated in one of three groups, which were used to explore the measure itself and issues in interpreting the vignette information.

The aim of the second stage of the project was to attach weights that reflect elderly people's preferences for each domain and the level of need met within each domain. The principal approach to identifying preferences was discrete choice Conjoint Analysis (Ryan and Farrar, 2000; Ryan, 1999a; Ryan, 1999b). This is a technique which enables us to establish the relative importance of different attributes of a service or situation by presenting people with choices. After extensive piloting, 356 older people were interviewed and presented with a series of vignettes that described situations of varying levels of need for each domain (or attribute) corresponding to those in the measure. These were used both to present discrete choices and to rate using an analogue scale. The choices included situations where there was only one rational response, in order to allow tests of internal consistency. About two weeks after the initial interview, 107 people were re-interviewed. Fifty-eight of these repeated the exercise in order to allow us to investigate test-retest reliability. Forty-nine were interviewed using the same descriptions, but with an additional attribute included indicating a hypothetical level of financial benefits that the individual was receiving, in order to investigate whether (and if so at what rate) people would be prepared to trade money against levels of unmet need. Trading money against attributes allows a monetary estimate of the equivalent of willingness-to-pay, or in this case, willingness-to-accept valuation of the attributes (Van der Pol and Cairns, 1998).

An inconsistent finding in the domain of safety led us to question aspects of the original design. In order to investigate this, 65 people were re-interviewed a year later with an amended questionnaire.

The third stage of the project was to test the measure itself for reliability and validity in a research setting. A total of 58 older people were interviewed using the instrument, 31 identified through three local authority social services departments, the remainder through provider and carer organisations. In nine cases the interview was conducted with the carer. A sub-sample of 27 people were re-interviewed two weeks later in order to identify whether results using the measure are stable over a limited period of time. Care managers completed the instrument for 41 cases. The detailed results of this study are reported elsewhere (Netten et al., 2002a).

Chapter 2 of this report describes the identification of the domains. Chapter 3 describes the development of the structure of the measure itself and summarises findings about validity and reliability of the instrument. Chapter 4 describes the rationale for and design of the fieldwork for establishing preferences. Chapter 5 describes the results of the analysis and evidence about reliability and validity of this process. Chapter 6 summarises the ways in which the instrument could be used at its current state of development and identifies ongoing and future work that would enhance the wider applicability of the findings of the project as a whole.

2 The Domains

We adopted a top-down approach to identifying the domains to be included in the measure. First we identified likely domains based on general principles and experience as observers of the field of social care. We then consulted a reference group that represented a wider range of observers and key interests in the purchase and provision of social care. This chapter reports on the background to the initial identification of domains, the consultation process and the results of this process.

2.1 Background

When defining the domains we need to be clear that social care is concerned with managing or compensating for the effect of impairment on an individual by meeting the needs created by the impairment. Thus, for example, if physical impairment results in problems of mobility, social care would be concerned with the effect of this in terms of the individual getting sufficient meals or becoming socially isolated. So we need to identify which effects or areas of need are central to social care.

Older people can experience outcomes of social care both as a result of their own impairment and from caring responsibilities for others. It was decided at an early stage that the measure should focus just on outcomes from meeting needs that result from personal impairment. This is not to suggest that outcomes for carers are not of importance. But a separate measure reflecting the different ways in which they benefit from service interventions is needed.

Comprehensive pre-existing measures of need were taken as a starting point. The Camberwell Assessment of Need (CAN) and the Camberwell Assessment of Need for the Elderly (CANE) were used. The CAN (Phelan et al., 1995) was designed to provide a comprehensive assessment of the clinical and social needs of people with mental illness and has been tested for validity and reliability. The CANE (Orrell et al., 1997) is based on the CAN and has been developed as a needs assessment scale for elderly mentally ill people. These are profile measures that can be used to indicate outcome in that the pattern of needs have changed over time. Our objective was to develop an index measure (Ryan, 1997) that reflects levels of wellbeing associated with unmet need.

In order to identify which areas of need it was appropriate to consider as potential domains, and whether any further domains should be included, five factors were taken into account:

1. The domains covered by the measure should incorporate the most important aspects of life where impairment can impact and social service agencies have a key role to play.

2. The measure was not intended to cover factors that affect levels of need. Instruments that are intended to identify specific conditions or impairments (such as the Mini Mental State Instrument) can better measure these. However, the measure should cover all domains of relevance whether the cause of impairment is dementia, other mental health problems or physical impairment.

3. Similarly the way a need is best met will depend on context and the type of impairment. The aim is to identify *whether* the need is met, not *how*. Thus the domains (or areas of need) should apply to all types of care setting.

4. While the provision of social care will, in certain circumstances, be expected to affect other aspects of quality of life, these other aspects of life do not then become the domains of social care. For example, for many older people spiritual development is a matter of considerable importance in their lives. If care is provided within a residential setting the degree to which older people have access to spiritual advisors will be an important dimension of quality of care. This does not mean, however, that spiritual development has become a domain of social care.

5. In addition to ensuring the domains are relevant to social care it is important that they are amenable to weighting to reflect the preferences of older people. The aim is to establish the relative importance of the different domains by using conjoint analysis. In this people are presented with a number of different scenarios and are asked to rank or rate them in order of preference (see chapter 4). Determining which scenarios to present will depend on the number of domains and the number of levels within each domain. Previous work has suggested that eight domains are the maximum that is manageable, but in general the fewer the better (Pearmain et al., 1991).

2.2 Initial domains

On the basis of these factors members of the project team identified eight domains. These and the rationale for selecting them are briefly described below.

Looking After the Home

If an older person does not have the physical or mental ability to clean his or her home independently, help may be provided by a relative, neighbour, or home care worker. The outcome of the intervention would provide the individual with a clean place in which to live.

Food

An older person may find it hard to feed themselves adequately, as a result of problems in cooking meals or being able to do their own shopping. Social service interventions might include Meals on Wheels or home care provision that includes shopping and/or cooking. The outcome would be that the individual is adequately fed with appropriate and timely meals.

Self-Care

Physical and mental impairment may result in older people not being able to bath, dress or manage the WC. Home care services providing personal care or 'supervision' may ensure these tasks are achieved, whilst aids or adaptations to the home may enable individuals to produce their own personal care. The need is met when the older person is personally clean and dressed appropriately.

Physical Safety

Enabling adults to live as safe a life as possible is a key objective of social services (Department of Health, 1998). Threats to an individual's safety may come from self-neglect, falls, abuse or neglect by others. Many social care interventions are the result of concerns about 'risk' to older people. But risk is a poorly defined term as it incorporates probability of an event and seriousness of the event or its consequences.

There are three different aspects to achieving a 'safe' outcome:
- Reducing the probability of occurrence of specific events (such as falls);
- Reducing the level of harm resulting from the occurrence (such as being left after a fall for a long time or suffering serious injury); and
- Increasing an individual's sense of being safe and secure.

In addition there are the concerns of others. If somebody is suffering from dementia he or she may have no particular concerns while those around them may be very worried about the individual coming to some harm.

For the purposes of the initial consultation, this domain was specified both in terms of reducing the probability of events which would result in physical harm to the individual and about helping elderly people to feel safe and secure.

Daytime Activities

As a result of physical or mental impairment an older person may not be able to organise or attend activities. Interventions such as attendance at day care facilities, or organised activities in residential care, are aimed at achieving an adequate level of occupation. The nature of the occupation will affect other aspects of life such as physical exercise, spiritual development or social entertainment. Better transport facilities or advice about services available may be of help in enabling older people to undertake their preferred type of activity. The need is met when the older person feels they have enough to do and are adequately occupied during the day.

Company

Impairment may result in an older person experiencing social isolation and the lack of anyone to turn to in times of emotional crisis. This may be alleviated through service interventions that improve social contact, such as attending day centres, or volunteer visits. The need would be met if the individuals felt they had sufficient social contact with others and people to turn to for emotional support.

Money Management

As a result of cognitive or physical frailty older people may find difficulty in managing their own finances. They may need advice, or assistance and information on methods of paying bills. The need would be met if their finances were adequately managed and they were claiming all the benefits to which they are entitled.

Autonomy and Choice

Once an individual has need for care in any of the previous domains there is the issue of level of control over the way care is provided and the maximisation of a level of autonomy and independence. Interventions should enable choice, provide information and empower the individual to decide what best suits their own needs. Choice was a key objective of the NHS and Community Care Act (1990). Promotion of independence is a key objective of the current administration (Department of Health, 1998). The need is met if the individual feels they have as much independence and as much control as possible over the way care is provided.

2.3 Reference group consultation

The reference group was established both to inform and assist in the development of the measure. The group consisted of local authority managers, academics, care managers, providers, and officials from the voluntary sector.

Between October and December 1997 a total of 96 people were approached by letter to participate as reference group members. Of the 96 persons approached, 65 agreed to participate in the first wave of consultation. The remaining 31 were unable to participate but wished to receive further information on the study; did not reply to the letter inviting them to participate; or replied to the letter, but declined to take part as reference group members.

Respondents were encouraged to complete a questionnaire describing eight domains relative to social care outcome for older people, and consult with other relevant colleagues before replying. Twenty participants took the opportunity to consult with other members of local authorities, Department of Health officials, and research teams, care management and social work teams and individual service users. As a result a further 17 questionnaires were received as part of this wider consultation. Thus, 80 participants received the questionnaire following the initial letter introducing them to the study, including persons used as wider reference group members.

Of the 80 people contacted, 65 completed and returned the questionnaire. The breakdown of respondents and non-respondents is shown in box 2.1.

BOX 2.1: REFERENCE GROUP RESPONSE TO INITIAL CONSULTATION EXERCISE

Perspective	Respondents	Non-Respondents
Academics	16	5
Voluntary organisations	11	3
Local authorities	36	7

Each section within the questionnaire presented a description of unmet need within each area (or domain), an example of social care interventions which may address this need, and the social care outcome if the need is met. Respondents were asked to go through the domains identified and consider whether they regarded them as important objectives of social care services. The respondents were also asked to identify how important each domain was (on a scale of 1–5) and comment on its relevance to social care outcome. Respondents were also offered the opportunity of presenting any new domains for inclusion within the measure.

2.4 Results

Respondents scored the domains food, self-care, and autonomy and choice as the most important areas in which social care outcome could be measured. For the most part respondents thought worry about safety was important as an issue as actual levels of physical risk. Looking after the home, daytime activities, company and money management were seen as less important. When broken down by the respondent perspective, the results showed little variation although respondents in the voluntary sector gave a much higher rating of importance to physical safety (including worries about physical safety) than respondents in any of the other groups. One respondent within the academic group felt they could not rank the domains one against the other as they felt that all the domains in their own way were important, and could not be expressed in these general terms.

Text responses to each domain within the questionnaire were extracted in order to analyse common themes. The responses were then analysed by respondent perspective (local authority responses were split into senior managers, middle managers, and lower managers). A small-scale content analysis was conducted on the grouped responses.

Looking after the Home/Food/Self-Care

There was general agreement by the reference group respondents that the domains of Personal Care, Food and Looking after the Home tended to overlap. Academic respondents wished to 'argue the case for merging of domains, both household/personal care routine', whereas voluntary sector respondents saw the domain of food as something which 'closely associates with "looking after the home" and involves physical and mental health gain as well as personal choice'.

Although factors affecting people's ability to undertake activities in these areas are related, and on occasion the way social care is delivered will mean actions will result in joint production, in these areas nevertheless, the *outcomes* are distinct. Being fed is not related to the cleanliness of the house any more than social contact. Personal care is only related when the activity is actually spooning food into people's mouths.

There was a concern that the food domain should cover issues of quality in addition to quantity of food. There are a number of different aspects of quality: for example, nutritional value, timeliness, and cultural appropriateness. All of these are relevant and need to be addressed when considering whether an individual's need has been met in this domain. However, fundamentally the issue is about making sure that people have an adequate level of nutrition. The title of the domain was changed therefore to *Food and Nutrition*.

Traditionally home help services have been concerned with providing basic cleaning services, but it was not a great surprise to find that respondents from local authorities no longer regarded this as a priority area. Increasingly authorities have pointed individuals in the direction of privately organised cleaning services with the implication that public subsidy is administered through benefit payments rather than through social care agencies. However, a number of observers identified that many elderly people regard home cleanliness as very important. Through further discussions it became clear that, although social care agencies are still purchasing and providing home cleaning services, the primary objective is not to keep the home clean. Such services are provided when hygiene levels mean there is a physical or social threat or such interventions are needed in order to maintain an individual's sense of self-worth and other interventions are already in place (such as meeting personal care needs). In each of these cases the outcome would be measured through another domain: Safety, Social Integration and Involvement, or Control over Daily Life. On this basis it was decided there was no need for a further domain which covered cleanliness of the home.

Safety

For the most part respondents saw worry about safety as much an issue as actual levels of physical risk. When considering safety as a domain that is to be weighted against other domains, people cannot trade off other people's concerns or anything about actual physical risk without getting unacceptably specific. It was decided, therefore, to restrict the domain to worry about safety. In order to allow monitoring levels of incidence of the types of event that were the cause of concern the instrument would include a separate section (see chapter 3).

One respondent identified that feeling safe and secure goes beyond just physical safety. For example, if somebody feels intimidated (perhaps by a carer) there may be no fear of physical abuse but verbal abuse and bullying may be a cause of concern. It was decided that the domain should be broadened, therefore, to general feelings of safety and security.

Company/Daytime Activities

A number of respondents suggested merging the domains of Company and Daytime Activities and giving the merged domain a new title. One local authority respondent stated:

'Company is the wrong title, should be around the person's involvement in the community/personal relationships'.

Both academic respondents and those from the voluntary sector reflected this view with one respondent suggesting a joining of domains to become 'Activities and Company' with the emphasis being on a range of activity for the service user.

It became clear that 'occupation', independent of the social aspect or any rehabilitative aim associated with other domains, was not a central objective of social care of elderly people. While this issue may be important for younger client groups the expectation that people over 65 are normally retired means that occupation only becomes an issue when people are moved from their normal surroundings by the process of care, i.e. institutional care. It was therefore agreed to merge the domains of Company and Daytime Activities into one domain under the heading of *Social Participation and Involvement* that would incorporate social support and activity.

Money Management

Respondents differed in their views of this domain as a social care objective. Many respondents felt that money issues were important and particularly the risk of financial abuse. But a Department of Health comment was:

'This is not really an outcome but more a process to achieve other outcomes, e.g. if a person has difficulty managing finances, help may be required to ensure bills are paid and no financial abuse occurs'.

On the basis of such comments it was decided to exclude this domain from the measure. Money management for the most part is instrumental in achieving other aims, such as control over daily life, rather than an outcome in its own right.

Autonomy and Choice

There is considerable policy emphasis on providing choice, and maximising people's level of independence. The importance of these concepts is echoed by older people's expression of what they want out of services (Qureshi, 1998; Clarke et al., 1998). Respondents had a number of interesting comments to make about this domain particularly concerning the hierarchy of need involved with the domain, and again how far the domain is central to achieving social care outcome. A Department of Health comment suggested:

'Only when all other needs are met will people worry about choice. If choice can affect outcome in terms of other domains that is a different matter, but in this case isn't choice part of the process and not an outcome?'

A local authority respondent commented that the domain was unclear and made suggestions for a change of title:

'Clarify what domain is about as autonomy/choice/independence/control cannot all be used interchangeably'.

The reference group also identified linked issues such as feelings of self-worth and dignity as potential additional domains.

Clearly any measure which purports to identify the outcome of social care interventions, should identify the aspects of care that reflect the individual's sense of choice, control and independence. It is important, however, that we use concepts that focus on the end state or outcome. Although choice and decision making are relevant issues, the end state is the level of independence or autonomy that an individual has as a result of the process of being able to exercise choice or make decisions. For the second wave of consultation, therefore, the domain was termed 'Autonomy and Control'.

However, the second wave of consultation identified that again, we were trying to identify more than one aspect of life within a single domain, and that this caused difficulties when putting the measure into practice.

Terms such as independence and autonomy are often used to mean that an individual is physically and mentally able to conduct activities of daily living: outcomes that are not feasible for many people, and which are better measured by functional indicators such as Barthel. Moreover, the term autonomy means little to many elderly people, and when disabled people use the term independence they interpret it in a number of different ways (Fiske and Abbott, 1998). But their key concern, when faced with alternative patterns of care, although often described in terms of independence, is the degree to which they feel they will have a level of control over their daily lives (Clarke et al., 1996). It is this aspect of independence that social care services can expect to influence and that is experienced by service users as fundamental to quality of life (Qureshi, 1998). It was therefore decided to include a domain *Control over Daily Life* to replace the initial domain of autonomy and choice.

2.5 Conclusion

Box 2.2 summarises the result of the consultation exercise. The total number of domains was reduced to five. This was a very desirable outcome from the perspective of attaching utility weights to the domains. Each of the domains represents a key objective of publicly funded social care. It was interesting to note that although very different processes had been used to derive the domains of outcome, there was considerable similarity with the domains identified by Qureshi (1998) based on discussions with groups of older people.

BOX 2.2: DOMAINS OF SOCIAL CARE OUTCOME

Old domains	**New domains**
Looking After the Home	
Food	Food & Nutrition
Personal Self-Care	Personal
Physical Safety	Safety
Company	Social Participation & Involvement
Daytime Activities	
Money Management	
Autonomy & Choice	Control over Daily Life
Total: 8 Domains	**Total: 5 Domains**

The next step is to specify how these domains are to be incorporated in a specific measure of social care outcome.

3

The Instrument

In broad terms the outcome of social care is the impact, effect or consequence of a service or a policy (Nocon and Qureshi, 1996). For the type of measure we were developing we defined outcome as a change in individuals' utility states resulting from meeting need through social care interventions. The derivation of the relative value of the utility gained from different states is considered in the next chapters. Here we consider the structure of the measure that is needed for us to identify the outcome.

The improvement in welfare or utility resulting from a package of care is the outcome of that intervention. Ideally we want to measure difference between the current level of met need and the level of unmet need that would have existed if the social care intervention had not taken place. In practice this is far from straightforward. Clearly we can measure current levels of unmet need and this is the core of the measure as (given appropriate weights) it represents the current level of utility in each of the domains in which we are interested. Measuring changes in levels of unmet need before and after an intervention are measures of outcome of that intervention, once allowances have been made for the effect of other factors such as changes in underlying levels of impairment or informal care. However, such change measures do not necessarily reflect the full impact of service interventions as it is far more usual for people's needs to increase over time, so service packages are built up gradually. Thus any measure of change based on a 'before-after' approach only reflects changes in packages, not the full impact of the package of care.

The development of any measure is necessarily an iterative process. Here we describe the exercises that were undertaken and their rationale and identify the issues that arose in the process of development to explain the final design of the instrument. There were six stages in the development of the measure:

- A draft instrument was prepared based on the requirements for the measure and other instruments.
- The reference group was consulted about this initial draft of the measure and it was adapted.
- Nine care managers completed the draft instrument for ten older people. In the light of the feedback from this exercise the instrument was amended and the care managers asked to comment on the revised version.
- Thirty care managers from three local authorities completed the revised version together with comments indicating the basis for the coding.
- Examples provided by care managers in the earlier stages were used as a basis for vignettes that were used in a larger sample (54) to test the consistency with which people coded the core domains of the instrument and the adequacy of guidelines provided.
- A further 13 care managers tried the finalised instrument for practicality.

The results of the development process and testing of the instrument for validity and reliability are described below. The final version of the instrument is in appendix A.

3.1 The basis of the instrument

In chapter 2 it was identified that we used the domains used in the CAN and CANE as a starting point. We also used the structure of these instruments in developing the outcome measure, because:

- They had been used successfully in practice.
- They can be completed from the perspective of the assessor, the elderly person and/or the carer.
- Their structure allows identification of the level of unmet need and level of input from formal and informal sources to be identified separately.

The CAN and CANE both start by identifying for a given domain whether there are any problems at all in this area of the individual's life. If there is a problem the level of the problem is established, and the level of input from informal carers and services and the level of need for services identified. There is also an indicator of whether the help given is regarded as appropriate and whether they are satisfied with this level of help. Each question can be coded from the perspective of the individual, a staff member or a carer.

Initially the structure was adapted to differentiate between whether all needs had been met and there was a moderate problem resulting from unmet need as these levels were combined in the CAN and the CANE. Questions about whether the help was of the 'right type' and whether the person was satisfied were replaced by a question about whether the individual was as independent as possible in this domain of his or her life.

The domain of safety needed special attention, however, because of the diverse nature of outcomes to be measured (see chapter 2). The identification of subjective levels of concern about safety was treated in the same way as other domains. In order to measure objective levels of probability of events occurring, however, we have to be able to identify whether or not they actually happen. A *serious events* section was added to the instrument that identified whether a number of specific events had occurred or not over the preceding three months. A question was also asked about whether the individual had come to any serious harm as a result of this or any other incident. The events specified covered the types of incident known to be of concern anecdotally.

Clearly this part of the instrument cannot be included as part of a utility measure. However, the section would allow the monitoring of whether interventions do appear to reduce the levels of risk of specified events that are of concern to social care agencies.

3.2 Levels of unmet need

The core of the instrument is the section for each domain that identifies the level of unmet need. Defining the levels of unmet need was based on the following principles:

- As far as possible the levels should be 'grounded' to ensure that those completing the instrument do so consistently.
- As with the domains themselves the levels should reflect the expectations of what services would appropriately provide.

- The levels that services meet will vary because of resource constraints and policy variations - the measure should be able to reflect this.
- The levels should reflect what is appropriate by policy makers, practitioners and elderly people.
- The measure should be able to reflect changes in level of met need.
- The examples given should be easily incorporated into the method by which preferences are elicited for the conjoint analysis.

Four levels of need have been identified:

- *No problem:* impairment has no effect on this domain
- *All needs met:* impairment affects the domain but there are no unmet needs
- *Low unmet needs:* impairment affects the domain and there is capacity to benefit, either as a result of low level of need with no help received or the help received is inadequate leaving some aspects of unmet need
- *High unmet needs:* impairment has a substantial effect on the domain, to the point that if the situation were to persist there would be a long or short term mental or physical health risk. If any help is received it has a negligible impact.

These final definitions of low and high unmet need were refined during the process of consulting and testing the measure that is described below.

3.3 Consultation and initial testing of the instrument

Between June and July 1998 a total of 70 people who had agreed to participate in the first wave of consultation as part of the reference group were circulated materials asking them to comment on the clarity and appropriateness of the full draft of the OPUS measure and associated guidelines. Thirty-four responded to the material, which included a combination of closed questions concerning clarity and appropriateness of levels within the measure and for any further comments related to the OPUS instrument. Respondents were also asked about 15 incidents listed as serious events. One of the objectives of the consultation exercise was to identify whether all types of incident had been covered and whether any regarded as out of the scope of concern of social care agencies had been included.

During June 1998 nine care managers administered the OPUS measure as part of an initial assessment with an older person. The participants were located in three local authorities, two counties and one London borough. The instrument was returned with comments on the assessment by the end of July 1998. The primary objective was to identify how well the instrument worked in practice. After analysing the responses of the reference group and the written feedback from the care managers a revised version of the measure was fed back to the care managers followed by telephone interviews.

The revised version, including space for care managers to indicate the basis for coding, was then sent to 90 social workers in six social services departments. Just 30 care managers in three of the authorities responded. Of these, 15 also included an anonymised client assessment form. This gave us both demographic details and a further check as to the consistency of staff ratings together with their comments on the measure and within the client assessment profile. This allowed an evaluation to be undertaken of the consistency of the codings made by the care managers.

3.3.1 Results

In general, both the reference group and the care managers at all stages found the measure easy to understand. Overall comments were favourable concerning the instrument's face-validity and structure. All the care managers generally viewed the instrument as straightforward to complete. The measure was simplified and refined further in the light of the results of the consultation exercise. In the follow-up telephone interview the five managers contacted considered the revised version (see appendix A) easier than the initial instrument used during an assessment with an older person.

The initial assessments using the draft instrument were conducted on a sample that varied in terms of important characteristics. There were eight women and two men (one care manager completed the measure for two individuals). Their mean age was 83, ranging from 74 to 91. Seven of the older people were widowed, two were married, and one person was single. Half of them lived alone. Eight lived in private accommodation and two in sheltered housing. Eight were known to social care services prior to the assessment, and six had carers. Within the group two of the older people suffered from dementia, the other eight had a combination of respiratory and physical problems.

Among the 30 cases there were 10 men and 20 women. Their mean age was 85, ranging from 69 to 96. The majority, 20 of the people were known to social services prior to the assessment. Of the 20 for whom information about living circumstances was provided, 13 lived alone, four with other people and three were resident in a care home. Of those living in private households, 21 had an identified carer.

3.3.2 Levels of unmet need

During the consultation process a senior care manager suggested including a medium level of need in order to bridge the gap between ambiguities of low and high need. On consideration it was decided not to introduce a further level. Ambiguities will always exist between levels. Unless the levels are clearly grounded in specific aspects of need more levels will introduce more ambiguities.

Definitions of unmet need reflect the results of refining initial proposals based on the CAN and CANE in the light of consulting the reference group, referring to the literature where appropriate, and feedback from care managers. The resulting levels of unmet need are described below for each domain.

Food and Nutrition

Met need constitutes a nutritious, varied and culturally appropriate diet with a person receiving three meals a day at regular, timely intervals. This may constitute a hot meal or equivalent within a hygienic environment for the preparation of food. A distinction is made between no problem and full met need when the individual is able to prepare his/her own food independently. Activities to meet the need may include shopping and cleaning the home in a way that facilitates the hygienic preparation of meals.

Low unmet need would occur if, for example, the individual could feed themselves but was unable to prepare hot meals. It would also occur if services were providing meals but these were culturally inappropriate or at odd times of the day.

High unmet needs occur when, for whatever reason, the individual is not getting an adequate diet, as this could clearly result in a health risk.

In the cases assessed by the care managers the family met all food and nutrition needs in six of the cases. In the one case where low level needs had been identified it was due to the poor quality of the meals provided by the agency. High level needs in this area were identified for three of the ten elderly people. Comments included:

'Although fiercely independent, client is not getting enough food and nourishment due to her immobility'.

In this instance the older person's view was reflected in a 'no problem' score.

When the revised version was used with the larger group of care managers there was agreement between the researcher and the care manager in all but four cases. In two of these there was insufficient information for an independent coding. On the basis of the discrepancies the guidance was clarified to identify the importance of health risks.

Personal Care

The need levels for the domain of Personal Care are based on an examination of a number of scales that are designed to measure ability to do activities of daily living (ADL). These included the Katz (Katz et al., 1963), the Gutmann scale (Wright et al., 1981), and Isaac and Neville's approach to interval needs (Isaac and Neville, 1976). When categorising need levels such scales make the distinction between lower level needs such as bathing and dressing and higher level needs such as those associated with using the WC or incontinence, where immediate assistance is required.

In the instrument if the person has no difficulty with ADL tasks then they are coded as 'no problem'. Needs are fully met if the individual is personally clean and dressed for the daytime or bed as required. Lower level needs occur if the person is not dressed (including, for example, partially dressed due to problems with buttons) or occasionally unwashed. High level needs occur where the person is often dirty, for example, from poorly managed incontinence or inadequate help in getting to the WC.

Three of the older people assessed had all their need met in this domain. Five of the clients[1] had low level unmet needs. Comments given included:

'More help needed to assist bathing although client reluctant to accept it, carer finds it more difficult to handle'.

One of the clients coded as having high level needs would probably be coded as low level needs as a result of adjustments in the definitions of the levels. For the other high-level unmet need, the client could no longer wash/dress/toilet herself.

In the cases provided by the larger group of care managers, again there were discrepant codings in two of the 30 cases, and insufficient information in a further two. In one case the coding simply seemed to be a mistake: all the information given showed no need at all in this area but the individual was coded with high level needs. In the other case where there was a discrepancy it appeared the coding reflected the basic level of need rather than the level of need remaining once services were being received. It is clearly important to emphasise this to people completing the questionnaire but no particular amendment was required in the instrument or the guidance.

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[1] This includes one case recoded on the basis that the care manager was not sure how to code the case as the elderly person had low level needs but was receiving no help. Further guidance on this issue is now provided.

Safety

There is no problem if the individual feels safe and secure. Fully met needs are distinguished from this state as some intervention is required in order to stop the individual (or carer or staff member – depending on which perspective is being coded) worrying about the elderly person's personal safety. Supervision and monitoring by informal carers, alarms and regular visits from home care services are all types of help that could be used to increase a sense of safety. Potential threats to safety include all those itemised in the list of serious events, the final section of the measure. These cover threats to physical wellbeing, such as falls, getting lost and abuse such as being verbally or physically bullied by a carer.

In the initial trial there was some confusion over the recording of who had worries about safety. This has been clarified by further guidance. The measure should be able to pick up concerns of others, as interventions may affect them where an individual has cognitive impairment and limited awareness of physical risks. However, when deriving utility weights it will only be possible to reflect how elderly people feel about their own sense of safety. To reflect the impact on others' wellbeing would require a separate measure.

A suggestion was made by a member of the reference group to restrict the domain to indoor risks, as including outdoors can lead to very complicated situations about concern over safety on the streets which may not be at all related to age or frailty. However, in practice it may be concerns about the surrounding environment that lead to interventions to increase feelings of safety and security so it was decided to be over inclusive in the guidance.

In one of the ten cases assessed there were no concerns at all about the individual's safety. In three cases the person was living with their family so it was felt that all needs were met both by the elderly person themselves and the care manager. In three instances low levels of unmet need were recorded when reflecting the perspective of the care manager and the carer. In one instance the elderly person (who had dementia) felt there was no cause for concern and this was, in itself, the cause of worries for the carer. In another instance the elderly person has had a fall in the past, and was unattended for long periods during the day. In three instances high levels of care manager concern about safety were identified. In two cases the cause for concern was falls and in the third medication. In one case the elderly person themselves was not asked for their views, one older person was very worried and the other had low levels of concern.

Among the cases provided by the larger group of care managers there was insufficient information to code the case in four instances but no examples of disagreement between the researcher and the care managers.

Social Participation and Involvement

There would be no problem, or needs would be fully met for Social Participation and Involvement if the individual is content with their level of emotional support, general social contact and level of community participation. No problem is coded when no help is required to reach this state. Needs are indicated when people feel lonely and socially isolated. Low level needs are distinguished from high level needs by frequency of unmet need: if the individual occasionally feels lonely the needs would be categorised as low, if they feel almost entirely isolated the needs would be high.

What constitutes the difference between 'lonely or socially isolated at times' and 'socially isolated with little or no contact from others' has to be judged by the individual. Some people are content with very low levels of contact with other people. The issue of the quality of the contact is bound up in the subjective nature of the rating. Elderly people can feel socially isolated in a residential care setting where others surround them. The questions of who they see and whether they get adequate emotional support from the contacts has again to be judged subjectively. If there is insufficiently frequent contact of the type the older person wants then the coding should reflect whether they feel this constitutes a sense of overall isolation (high level needs), or occasional feelings of loneliness (low level needs).

In five cases the care manager assessed the elderly person as having all needs met in this domain. In three cases there were low unmet needs. One comment was:

'Has carer support but little real social support/company'.

In two instances high levels of need were identified. In one instance:

'Person is normally housebound and dependent on spouse who becomes irritated by level of dependency so withdraws from conversation and social interactions'.

This was the domain that caused most difficulties in coding amongst the larger group. In five out of the 30 instances the researcher would have coded the case differently on the basis of the information provided. In six further cases there was insufficient information. There were three issues:

Time — It appeared that in some assessments the assessor was making speculative judgments rather than coding the present situation. Within the guidance we needed to make explicit to staff that they should be coding 'what the current situation is'. A similar theme to this was also that of 'collapsing' social networks, which might facilitate higher need. Again this focus is speculative and codings should reflect the situation at the time of the assessment/visit rather than speculation about what might happen.

Coding as a protest — In a couple of instances codings were inappropriate as they were based on the staff's preconception of the level of services their client 'should' or 'ought to be getting', rather than their unmet needs. In such instances we needed to make clear that codings should reflect the actual situation.

Getting on with people — Some discrepancies occurred as a result of subjective ideas around socialisation with others. If a person 'didn't like mixing' or 'getting on with people' this was seen as a problem within some assessments. In the guidance we identified that social isolation (as opposed to choosing to be alone) can result from either the person not being able to get in contact with others, or unable to relate to the others with whom they come into contact.

It was also decided on the basis of the responses that within the guidelines we needed some examples of need within a residential care setting.

Control over Daily Life

There is no separate code distinguishing 'no problem' from 'all needs met' for this domain as the distinction is superfluous and was found by care managers in the early stages to create problems for those completing the instrument. All needs are met when the individual feels they have as much control as possible over their daily life. There are high level needs when the individual feels no sense of control: that his or her life is entirely in the hands of others. Low level needs exist when the situation is not that extreme but the individual still feels they could have more control.

The domain included in the initial draft to the reference group and care managers used a domain entitled ‘Autonomy and Control’. Chapter 2 identifies that, as a result of the feedback, it was decided to change this to ‘Control over Daily Life’. Consultation with care managers suggested that the problems found in coding should have been overcome by the revised-version. Coding and comments for the ten sample assessments tended to reflect the problems of the scope of the domain tested.

In the sample of 30 cases there was one instance where the coding simply seemed to be wrong – as the comment directly contradicted the coding made. In another example where the fact that the individual was receiving help with finances was interpreted as lack of control. However, although there was little evidence of difficulty in coding, this is a very difficult domain to provide independent information to indicate a sense of control or lack of it. This became particularly clear in the vignette exercise (see below).

3.3.3 Levels of input from carers and services

In the instrument that was circulated to the reference group and the care managers there were two questions in each domain that attempted to identify the level of input from carers and services. These followed the CAN and CANE model and were retained on the basis that changes in the levels of these inputs may be responsible for changes in the levels of met need. Feedback suggested that the questions worked reasonably well with some reservations about particular levels and wording.

However, on further consideration it was decided that, although the questions would provide some valuable contextual information, it would not be possible to incorporate them into the measure itself. We need to establish if there was any input into the domain from these sources and thus whether any outcome could be inferred. However the actual level of input to a specific domain could only be identified if the service or carer was only producing one commodity. For many services and most informal care there is joint production: the same activity produces more than one type of benefit. Moreover, the levels themselves could not be linked to the level of met need in any systematic way without some major assumptions (such as high input will result in high levels of need being met).

It was decided, therefore, to simply establish whether or not the carer and services did provide any help in the domains of Food and Nutrition, Personal Care, Safety and Social Participation and Involvement. Defining whether the input was positive or negative in terms of control over daily life appeared to create more problems than it solved. In a research setting, service input can be measured better by such instruments as the CSRI (Beecham et al., 1992). Informal care input may be established through time spent on care, measures of opportunity costs of informal care (Netten, 1993), or measures of carer burden (e.g. Deimling, 1994).

3.3.4 Independence

It was hoped that incorporating a question about whether individuals are facilitated to be as independent as possible within each domain would provide an additional dimension to met need that could be incorporated within the measure. Two problems emerged. First, the question itself caused problems with many respondents concerned in each domain about the wording and how the question would work. In practice care managers did not experience too many problems in answering the question. However, it also became clear that to identify a level of met need over and above fully met needs, which reflected that the person was as independent as possible, but did not imply the person needed no help at all, created considerable difficulties. If this distinction could not be made very clear then it would not be possible to include this aspect of outcome in the weighting exercise. It was decided therefore to omit this question from the instrument.

3.3.5 Serious events

When responding to the serious events section of the instrument, the consensus of opinion within the reference group was that the fifteen items on the list were reasonably comprehensive. Respondents were asked to indicate for which events they felt publicly funded social care had a role in prevention or reducing the risk of occurrence. The incidents which scored highest were, 'setting the home on fire', and 'suffering from extreme cold/hypothermia' (65%, n=22), with those scoring lowest being, 'not taking important medication' and 'being bullied' (38%, n=13), or 'being a victim of crime' outside the home (23%, n=8).

We have retained all the items on the list on the basis that it is straightforward to omit any event from analysis but data which has not been gathered can not be included.

Further consultation with care managers identified a few more examples of events of concern. Some events, such as bereavement, were outside the scope of the measure as these precipitate needs. The events we wish to monitor are the type which services are used to prevent or to mitigate their consequences. The full list to date is shown in the current version of the instrument (appendix A).

Care managers felt that a shorter period than the three months used in the initial instrument would be more appropriate. The information is likely to be more reliable over a shorter period. The final version asks about levels of incidence over the previous month.

3.3.6 Levels of need in the absence of services

Ideally we wish to identify the difference between the levels of met need with and without services in order to measure outcome. We can measure how the levels of need change over time. However, it is only in situations where basic levels of need for help and input from carers have remained unchanged, but services have been introduced, that we can identify that the change in levels of met need are measuring the output of services. Moreover, as identified above, for more dependent people the situation will more usually be an increase in service levels so we can only measure the incremental outcome by measuring change over time. We can use multivariate analysis to analyse the differences in outputs of service interventions by standardising for other factors to explore the impact of services. However, we are still some way from the ideal.

It was decided therefore, to try another approach, where we directly ask what the level of need would be in the absence of service interventions. Clearly with such a hypothetical question there are reservations about reliability. However, initial testing of the measure suggested that in practice people had no problems in answering the questions, test-retest reliability was high and responses correlated with other measures of functioning and morale as would be expected (see below and Netten et al., 2002a).

Care managers who were interviewed about the revised measure felt the question was very practical. One care manager claimed that the question is already being asked within their team implicitly when an assessment of need is done. However, they were unsure about the reliability of this section of the measure, as it would be very difficult to predict what would actually happen. One respondent felt it would not be reliable as an objective measure. The majority of respondents felt that results would interpret the care manager/social workers intuition of the client being assessed. In practice, however, the instrument distinguishes the perspective being taken and, when interviewed directly as part of the ongoing validation work, older people found no problem in responding.

3.4 Testing the instrument using vignettes

In order to test the reliability of the measure we administered a series of vignettes describing situations with varying levels of unmet need in each of these domains to groups of professionals and other observers. The vignettes were based on the examples returned to us by care managers in the previous stage, described above (see appendix B for an example). We asked respondents to complete the core domains of the instrument for each of the vignettes so we could test whether different people would rate the same circumstances in the same way. Guidance on completing the instrument was provided. Each respondent rated six vignettes. On average the exercise took between 30 and 40 minutes to complete.

Between April and May 1999, 63 questionnaires were administered either by post or during group discussions. In total fifty-four people (85%) completed and returned the questionnaire. Respondents consisted mainly of managers and front-line social work staff, drawing on contacts in five local authorities, but also included a few academic students and research staff in London and Kent. Staff in three authorities took part in the group discussions. These people were asked to rate the vignettes individually initially and then discuss any problems or concerns they had with their ratings.

When coding safety we asked respondents to rate the information from the perspective of a key worker for the older person.

3.4.1 Results

Generally there was a good level of agreement across the six vignettes. In particular the majority of respondents agreed with our own hypothesised code within all levels of need across the five domains in three of the vignettes. However, two of the vignettes seemed to present particular problems. This was most apparent within the domains of Safety (61% agreement between raters) and Control (63% agreement between raters) where there was disagreement with our hypothesised codes. Reasons behind the disagreement became more apparent within the group discussions.

After completing the questionnaire the groups in the three authorities were all asked:
- Did you have any particular problems in completing the vignettes? Did you feel you were lacking information? If so — what information from which vignettes?
- Were any domains particularly difficult to code for?

Not only did the groups single out certain domains covering the six vignettes as been problematic but also came up with a couple of related themes to the exercise more generally.

Group A (3 respondents)

Generally the group felt that there was a lack of information which made assumptions about Control over Daily Living hard to rate within the vignettes. An interesting point raised by one respondent was whether a refusal to do something should be interpreted as a lack of control given the information presented. All members agreed that they had been inherently cautious when coding, as opposed to a more ‘gut reaction’ score that they would have rated during a duty referral.

Respondents found one vignette within the domain of Food and Nutrition confusing when looking at the time-span of service delivery and were not sure how to rate ‘occasional’ in terms of Low Need or Met Need.

Group B (5 respondents)

The domain of Control over Daily Living was again hard to score according to group discussion. Respondents were not sure if this domain was just about client choice or more than that. In some cases respondents felt they had to base their ratings on perception, as there was not enough information to make a clear decision about the levels of need they should rate. Again members within the group raised the subject of duty referrals. One respondent explained that for a duty referral, information based on an initial visit would be gathered and passed on to someone else who may not have the same perceptions of client need as the person who made the initial visit.

Group C (7 respondents)

Once again the group felt that it was difficult for an outsider to assess Control over Daily Living and that this was a domain that would be difficult to rate across all the vignettes. The feeling was that better guidance would help in reaching decisions on need, as this was an area that was open to differing interpretation. For Food and Nutrition in one vignette, one respondent was left with the worry of how much help was being received and did not know whether to use caution in rating the level of need, or assume there was a risk and check it out within a care situation. Also within the Control over Daily Living section of this domain respondents were unable to confidently rate, as it was apparent that the person was refusing control but it was unclear within the information given whether this should be rated positively or negatively. In another vignette respondents felt there was little to suggest that the client would be at risk in terms of safety. Generally it was felt this vignette was difficult in trying to measure consistency across the domains. Respondents tended instead look holistically at the vignette as opposed to singling the individual domains out when scoring. In the domain of Safety it was felt that it was hard to count individual elements of risk across other domains as areas of need. It was explained to the group that within the actual measure a separate indicator of serious events was a helpful guide when measuring the degree of need a person may have within Safety, this however was not made explicit within the information presented in the vignettes exercise.

Overall

The vignette exercise was helpful in identifying overall a reasonable level of consistency in ratings made. However, there were problems in describing situations without virtually providing the expected coding. This was particularly true in the domain of Control. The groups also identified situations for other domains where insufficient information had been provided. These problems meant that the vignette exercise could not be used as an indicator of inter-rater reliability.

3.5 Practicality and timing

In order to identify the practicality and how long it took to complete the revised instrument, 13 care managers who had no previous experience of earlier drafts completed the revised instrument for one case each. It took them between 10 and 20 minutes to complete the entire instrument, including making brief comments about why the codings had been made. The managers generally felt that the instrument was easy to comprehend.

3.6 Validity and reliability of the measure

For the purpose of testing validity and reliability we conducted a small, free standing study of 58 users of services. The results are described in more detail in Netten et al. (2002a). In order to assess construct validity we included two instruments: the Philadelphia Geriatric Centre (PGC) measure of morale (Lawton, 1975) and the Barthel index of functional ability (Rodgers et al., 1993). Neither of these directly reflects what the instrument is intended to measure, but we would expect morale to have some association with levels of met need and functional ability to be associated with levels of met need in the absence of services. As predicted, morale was significantly correlated with current levels of met need ($R^2=0.42$) and functional ability with levels of met need expected in the absence of services ($R^2=0.48$). There was no association between morale as measured by PGC and functional ability as measured by Barthel.

The evidence suggested good test-retest reliability, with levels of absolute agreement exceeding 85 per cent and Kappas exceeding 0.6 for all items bar one. All the results were at least equivalent to the CAN on which the instrument was based. The domain where test-re-test reliability appeared lowest was expected levels of concern about Safety in the absence of services (69 per cent complete agreement and Kappa=0.52). This is an aspect of wellbeing which is particularly susceptible to changes in perception as a result of external events.

Levels of agreement between care managers and older people's ratings of unmet need were low. Percentages of complete agreement were around 50 per cent for most domains and Kappa levels around 0.2. Similar results have been identified by other investigations of need assessment (Bauld et al., 2000; Morrow-Howell et al., 2001; Slade et al., 1996). A qualitative assessment of four cases in this study suggested that care managers lacked detailed knowledge of the users, their feelings and their informal networks.

3.7 Conclusion

The structure of the instrument has been designed to be relatively simple to complete but, it is hoped, sufficiently sensitive to the key aspects of outcome that we are measuring. An iterative procedure was used to develop and test the instrument using those most accustomed to assessing levels of met need: care managers. The levels of met need were grounded by reference to the long or short-term implications for mental and physical health. In all the domains unmet need could reveal itself in a wide variety of ways. Any attempt to further sub-divide levels runs the risk of building in problems of reliability. Initial tests suggest the instrument as it stands is both valid and reliable. We also wanted to restrict the number of potential domains and levels in order to ensure that we attached utility weights in a valid and reliable way. We turn to that process of identifying preferences in the next chapter.

4 Establishing Preferences

Once the domains and levels within each domain had been identified the next objective was to specify a method for quantifying the scale on a basis that reflects the values of elderly people in terms of the relative weights of the domains or dimensions. Such weighting allows us to identify the benefit resulting from the receipt of help: the improvement in wellbeing that would not otherwise have occurred.

An important issue in establishing utility weights is whose preferences should be reflected: society's, those who are benefiting or may benefit from the intervention, or just those who have experience of the intervention (Ubel et al., 2000; De Wit et al., 2000). Chapter 5 discusses this issue further. For the purposes of the design of the fieldwork it was decided to restrict the sample to people over the age of 60 who may or may not have experience of social care services. The objective was to have a sample that was likely to have an understanding, directly or indirectly, of the type of situation that arises as a result of chronic impairment in older age, and that was likely to reflect the values of those in receipt of services.

This chapter briefly considers the theoretical basis to establishing utility weights, ways of establishing weights and, in the light of this, what the resultant scores can be said to measure. For the weights to have any meaning it is essential that the means by which they are achieved is demonstrated to be reliable and valid. To this end we report the results of the feasibility and exercises which explored issues of presentation, acceptability and practicality. The final design of the fieldwork is then described.

4.1 Approaches to attaching utility weights

A number of different methods have been used in the literature to date to estimate utilities, including visual analogue (Nord, 1991), standard gamble (McNeil et al., 1978) and time trade-off (Torrance et al., 1972). Standard gamble is the gold standard because it relates most closely to expected utility theory, i.e. maximisation of health gain under conditions of uncertainty. However, it has been shown in the literature that results from such studies are often highly inconsistent (Dolan et al., 1996a). Time-trade off was developed as a result but this technique is not appropriate in an area where individuals are not concerned with giving up years of life but with aspects of care. Whilst visual analogue is the easiest of the three commonly used techniques, it has no theoretical basis.

Contingent valuation or willingness-to-pay techniques have also been used to evaluate the importance of health outcomes to individuals (Donaldson, 1990; Diener et al., 1998). The use of money has the additional benefit that there is the observed link between a cardinal measure that is routinely used to estimate the benefit accruing from consumption of goods and services. As such, if we were able to identify how much people would be prepared to pay it would be possible to develop a measure that could be used as part of a cost benefit analysis. However, there are a number of problems with this approach, particularly with respect to older people (Ryan, 1998).

An alternative method is *conjoint analysis* (CA). Conjoint analysis is used to establish the relative importance of different attributes in the provision of a good or service, as well as to estimate the overall utility of a given commodity, with levels of given attributes. Previous studies applying this technique have shown that respondents find conjoint analysis questions relatively easy to answer and that responses are internally consistent and theoretically valid (Ryan and Hughes, 1997; Ryan et al., 1998; Ryan, 1999c).

Conjoint analysis has its origins in mathematical psychology and market research (Luce and Tukey, 1964; Cattin and Wittink, 1982). It has also been used extensively in transport economics (Louviere and Hensher, 1982; Journal of Transport Economics and Policy, 1988) and environmental economics (Opaluch et al., 1993; Hanley et al., 1998; Swallow et al., 1992). It has been recommended by H.M. Treasury as a method of valuing the quality of public services (Cave et al., 1993), and is now being applied in the area of health care (Ryan and Farrar, 2000; Vick and Scott, 1998; Bryan et al., 1998; Propper, 1995; Harwood et al., 1994; Propper, 1990).

The discrete choice method of eliciting preferences for CA allows individuals to respond to alternatives. The data are analysed using random effect probit regression in LIMDEP (Greene, 1991). Weights are then derived from the regression coefficients in the estimated model. These weights reflect the relative importance to older people of the domains and levels within the domains. The ratio of these weights will reflect the degree to which individuals are prepared to forgo levels within one attribute or domain of the scale to have more of another. From the weights it is possible to estimate a utility index (Ryan, 1997).

The objective here was limited to developing a measure that is at least as close to a utility indicator as any of the current measures used to identify health care outcomes (such as EQ5D). Like EQ5D it is a generic measure of utility, but is focused on aspects of quality of life affected by social care rather than health care. It is important that the method of establishing preferences is straightforward and meaningful for elderly people or a poor response rate will result in a biased sample. Approaches such as time trade off (TTO) and standard gamble (SG) are inappropriate given the issues we are addressing. These require that people trade life expectancy off against quality of life. While in health care this is a legitimate trade-off, in social care maintenance life expectancy is not altered by the intervention. The choices in TTO and SG would be inappropriate, and possibly for older people, offensive.

Willingness to pay was regarded as a legitimate approach which should be investigated, but the nucleus of the approach used to establishing preferences was discrete choice conjoint analysis, which has the advantage of being both theoretically sound and apriori appeared relatively straightforward for respondents. If cost is included as a domain or attribute then conjoint analysis allows us to estimate willingness to pay or willingness to accept (depending on the way the attribute is described) indirectly. Analogue rating scales have been widely used and have been argued to yield cardinal results (Green et al., 1972). A combination of these approaches allows us to examine the convergent validity of the results of these with the results of discrete choice conjoint analysis.

Clearly, for all the approaches used, the practicality and validity of the process needed to be tested.

4.2 Feasibility and pilot testing of approaches to establishing preferences

The first issue to be considered was whether, given the subject area being covered, people felt able to put themselves in hypothetical situations and make choices. If they can, do they appear to be trading off different attributes (as is assumed in the analysis)? Problems arise in identifying relative weights for all attributes if people do not in practice consider all the attributes, but focus on a single attribute that dominates their decision making. This is termed lexicographic preference. It is possible that when we are dealing with such basic aspects of welfare that one attribute may dominate people's views.

An important design issue was whether, for the main study, it would be possible to ask people to complete questionnaires rather than interview them directly. The original design assumed that self-completion questionnaires would be employed as these have been used successfully in the past (Ryan and Hughes, 1997; Ryan et al., 1999). However international guidance over the use of contingent valuation techniques recommends that interviews are used (National Oceanic and Atmospheric Administration, 1993).

Establishing valid responses depends in part on presentation (Farrar and Ryan, 1999). Comparing two situations, each with five attributes means there is a lot of information to be absorbed and analysed when making choices. The information needs to be presented in a way that enables people to make considered choices. A number of alternative presentations were considered. One decision was whether to present the information in a list format in which each attribute is separately identified or in a 'chunked' format, where a piece of text describes a situation. There is evidence that the latter is easier for people to absorb and understand (Baddeley, 1983). In each case there is then the issue of ordering of the attributes and general presentation.

One way to test the validity of the results of the analysis is to compare predicted results with another measure of strength of preference. One approach is to include a rating scale that would give an indication of how much better people felt the preferred situation to be. The scores of actual preferences could then be compared with values predicted by the model. The best way of presenting these ratings needed to be identified.

If we included a cost or charge domain we could estimate willingness-to-pay for each level and domain and the weighted measure would be demonstrably cardinal. Before going down this route it was important to test out the practicality and acceptability of including a monetary attribute. If money were to be included as an attribute, then appropriate levels need to be used in the discrete choice options. Willingness-to-pay methods could be used to identify initial appropriate levels. During the feasibility stage, the issues to be investigated were whether willingness-to-pay could be used in practice (either to establish levels or as an alternative approach alongside discrete choice) and whether including a monetary attribute within the discrete choice approach was acceptable and practical.

To summarise the objectives of the feasibility interviews and discussions were to establish:

- whether people were able to make choices between alternative scenarios indicating different levels of unmet need in each of the domains;
- whether the choices they made appeared to be meaningful with evidence of trading off different domains;

- whether there were any indications of lexicographic preferences (where one attribute is so dominant no other attribute is taken into consideration in making choices);
- whether self-completion questionnaires were an appropriate method of gathering the information;
- which type of presentation people found easiest in absorbing and processing the information;
- the practicality of including a rating scale to indicate the strength of the preferences of individuals;
- the feasibility of including a cost dimension in the discrete choices;
- whether willingness to pay approaches could be used either as an alternative to the discrete choice option or to set levels of a monetary attribute to be used as part of the discrete choice approach.

Initial approaches to presentation of discrete choice and willingness to pay questions were first tested out on one interview and a discussion with a group of about 10 older people. On the basis of the issues arising from these exercises a revised questionnaire was developed and four further interviews were conducted. This provided the basis for the full questionnaire which was tested on 17 further older people who were all interviewed in their own homes.

4.3 Results

In both the feasibility exercise and the pilot the interview began by asking people to rank each of the domains or attributes in order of importance. This worked well in getting people thinking about the domains and making difficult choices. People varied in the ways in which they ranked the domains and their comments about their reasoning provided valuable insights. There were striking variations in attitudes to safety. For some feeling safe and secure was absolutely fundamental, while another person's attitude was :

> I don't feel too bothered about safety and security. I have reached 62 years old so whatever happens now is a bonus…

It was also interesting to note that as part of the reference group exercise the view had been expressed by more than one observer that some domains (such as food and personal care) were basic. Others (such as control) could be regarded as 'icing on the cake' — lower level needs in terms of Maslow's hierarchy of needs. However, when ranking the domains in the group session, control over daily life came out top. The argument put forward by one woman and agreed by the others was that if you had control over your daily life then you could make sure all the other domains were sorted out to your satisfaction.

The fact that some people could identify particular domains as of particular importance might have led to concerns about lexicographical preferences. In practice as respondents were presented with different options they weighed up the attributes and other issues emerged. For example, nobody identified social participation and involvement as the most important attribute in the ranking exercise but as people discussed their reasons for choosing different options it became clear that for several people contact with others conferred a protective factor. The situation couldn't get too terrible while you were seeing others, as they would notice and ensure something was done. If you were isolated anything could happen. Overall the comments suggested that when different combinations of attributes were presented it was possible to make a reasoned choice and to trade-off unpleasant alternatives.

When making decisions about situations, on the whole people felt it was easier to say which was worse than better. In each case the situation presented included having some level of unmet need so phrases as ‘which situation would you *prefer* to be in?’ seemed inappropriate. This came out of the individual and group exercise and in subsequent interviews. However, during the interview people alternated – sometimes choosing a preferred option, on other occasions identifying the worse option. This has implications for the reliability of responses that are not checked carefully.

Necessarily a number of choices had to be presented one after the other. This became a little monotonous after a while. In an interview it is possible to interweave the choices with some discussion about the issues raised. It is also possible to include other ranking exercises and if it appears that people are not reading the options carefully to check back on the decision made. There would be some concerns, however, that if people were simply completing a questionnaire that they would start to tick boxes at random simply to get the task completed.

4.4.1 Presentation

There were two aspects of presentation: the description of the scenarios for the conjoint analysis and the method of rating using analogue scales. In the feasibility exercise most people preferred the scenarios presented as a piece of text rather than a list that described the level of each attribute separately. However, it was found helpful to separate out the text of each option into two sections: one of which described the domains where there were no unmet needs, and the other identifying the levels of unmet need (see appendix C).

Straight rating scales of how strong the preference was, where very strong preferences for the two situations were identified as end points of a spectrum, were not successful in the initial interviews. However, it was clear from discussion about the decisions being made that some decisions were much easier to make than others. We tried a two-stage approach (i) Which situation is worse? (ii) How much worse is it? This process worked well with some respondents, who tended to revisit their initial decision, validating the response. Once they had confirmed the decision they had made they did not experience any problems in rating how much worse one situation was than another. However, during the pilot exercise, which incorporated an overall rating in addition to the discrete choice process, the use of two scales was found to be too confusing for respondents. As a result for the mainstage single analogue scale was used at the end of the questionnaire to rate each scenario (see appendix C).

4.4.2 Including a cost dimension and willingness to pay

In the feasibility exercise some very clear messages came across about the issue of including money. Willingness to pay questions were asked in the first interview and as part of the group session. These questions did not work well. Open-ended valuation was virtually impossible and people did not like very wide differences between levels or very high levels of possible payments being presented. The issue of affordability dominated discussions. Willingness to pay questions were omitted from the subsequent interviews but it was interesting to note that, in response to including money as an attribute in a discrete choice question, without any prompting one respondent said:

> You would have to be very careful particularly in asking the question ‘Would you be willing to pay for something.’

She thought money was a very emotive issue. The same respondent and others quoted examples of people who have plenty of money and relatively high levels of impairment but in practice will not pay for people either to help them in the home or with personal care tasks.

When money was included as an attribute it was phrased as ‘you are paying £5 per week’. Values were selected from the lower end of what services might cost and ranged between nothing and £50 per week. The four respondents had no problems themselves with the question but they were all on relatively high incomes. The respondent who felt it was not possible to ask about willingness to pay felt that the means of presentation worked well, although another respondent asked how long the payment would be expected to continue for.

The initial interview with a woman who was on a very low income made it clear that she could not afford anything other than her current living expenses. This raised the concern that, if asked to make choices including levels of payment at anything other than very low levels, the money issue would dominate, so whatever the options presented the cheaper option would always be chosen. Given the strength of feeling about the issue it is also possible that people would refuse to make choices where they felt both options were too costly. However, if the levels were all set too low those people who had reasonable levels of income would not take the money attribute into consideration at all unless they were indifferent to the two options presented.

4.5 Mainstage design

The objectives of the mainstage fieldwork were to provide us with sufficient data to:

- derive an overall model of preferences for people over 60 for the domains and levels of met need within the domains;
- investigate attaching monetary valuations to preferences;
- investigate whether preferences are associated with characteristics or living circumstances of older people;
- investigate the validity of predicted utility scores by obtaining ratings of the same scenarios by the same respondents; and
- investigate the reliability of responses in terms of consistency and test-re-test reliability.

While the results of feasibility exercise were encouraging it was clear that there were potential dangers to the validity of the findings. These included people changing from identifying the worse option to the preferred option during the process of making decisions and tiring of the process and not considering the complicated options carefully. This suggested that in order to ensure that we were accurately reflecting people’s views it was necessary to conduct interviews, which allow checks to be made, rather than rely on self-completion questionnaires.

Appendix C contains a selection of discrete choice scenarios. Respondents were asked about their knowledge and experience of social care services before the domains of the measure were described. An initial ranking exercise of the domains was used to accustom people to considering the issues. This was followed by a series of discrete choices between scenarios that were then rated on a scale of 0–10. On this scale 10 represented the best possible care situation and 0 the worst possible care situation. Respondents were then asked for some demographic and household information.

4.5.1 Scenarios and choices

The discrete choices depend on the number of possible scenarios, which is determined by the number of attributes and levels. For the purposes here no distinction was made between no unmet need and there being no needs to meet in that domain. This was because social care interventions are primarily aimed at ensuring need is met rather than reducing impairment. Thus for these purposes the measure consists of five attributes or domains with three levels for each attribute. When money is included as another attribute, potentially it adds a very large number of extra levels. As a result the number of total possible scenarios is so large that they cannot all be presented to individuals. In order to select a manageable number of scenarios that will be sufficient to generate utility measures for all possible scenarios the software package SPEED was used (Bradley, 1991). This identified 27 orthogonal[1] scenarios described in terms of the domains and levels within the domains.

From the feasibility interviews we were confident that people could cope with 14 choices, but as we were asking people to rate all the scenarios individually as well it was felt advisable to use two questionnaires, each including half the scenarios. Providing each sub-sample is large enough and there is no significant difference in the preferences shown by the sub-samples this is a valid way of identifying overall preferences (Pearmain et al., 1991). In order check whether people are making logically consistent judgements, two of the choices in each questionnaire needed to be such that logically one of the scenarios should always be chosen over the other. The model will allow for random error. We assumed one inconsistent choice could be random error but if two were made it is more likely to indicate a lack of understanding or that the individual was not taking it seriously. The ‘logical choice’ combination of options from one questionnaire was also included in the other questionnaire. This meant that each interview contained six scenarios, with eight discrete choices to be made.

At the time of the design of the study most work in health economics had randomly set scenarios against each other for the purposes of making discrete choice. We used a city block approach in order to decide which scenarios should be compared with which (Dolan, 1998). This identifies the number of steps apart each scenario is from each other. A step occurs when one level in one domain is different (e.g. high and low needs in food and nutrition). Within each domain the maximum distance is two so for five domains the maximum possible distance is 10. Distances between the scenarios were measured as a whole, without distinguishing the number of steps within each domain. The overall distance measure was categorised in terms of high (7-9 steps apart), medium (4-6 steps apart) and low (1-3 steps apart) in order to ensure that each questionnaire included at least two of each distance level.

Subsequent work in the field of health service preferences has drawn on work (Zwerina et al., 1996) that has identified the importance of ensuring that:

- in addition to the overall set of scenarios, the individual choices are orthogonal;
- the design is balanced so distances between levels are reasonably equally represented for all domains; and
- there is minimum overlap.

A review of the choices specified using the city block approach suggested that there were no important violations of orthogonality or overlap but the design was not balanced. In the domain of Safety this resulted in a lack of opportunity for individuals to trade off in situations where high level need was in one scenario and no needs were in the other scenario. An additional fieldwork exercise was incorporated to check for the impact of amending the design to ensure all conditions were completely met (see below). The effects of this are discussed in chapter 5.

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[1] Orthogonality ensures the absence of multicollinearity in the model.

4.5.2 Including a monetary attribute

Ideally we would like an indication of the amount of money people would be willing to pay to have needs met in each of the domains. However, problems encountered in the pilot stage (see above) suggested that this might cause difficulties. Moreover, presenting scenarios where people were paying money for services that were not meeting needs was counter-intuitive. A more plausible situation was one in which benefits were received as a result of impairment. Such an approach estimates willingness-to-accept financial recompense for a more disadvantaged situation than the respondent is currently in (Adamowicz, 1998).

In order to identify appropriate levels, information was drawn about the cost of service packages from a large-scale study of community care of older people. The distribution of the social care element of package costs in this study was used as a starting point for setting weekly additional benefit levels. Seven levels were used in all: £0, £20, £50, £100, £150, £200 and £300 (see appendix C for an example scenario). A SPEED analysis indicated that 27 scenarios were required as before. The monetary domain was included in the original scenarios (see appendix C, scenario C2).

4.5.3 Characteristics and living circumstances

Information was collected about age, gender, household composition, self-assessed view of impairment and service receipt in order to allow an investigation of the impact of these factors on preferences and estimated weights. The sample was monitored in order to ensure that there was a sufficiently large group for each of these characteristics to be analysed separately. Information was also collected about ethnic origin and indicators of income: sources of income, home and car ownership.

4.5.4 The sample

There was no intention in this exploratory study to attempt to get a nationally representative sample of older people. It was seen as more important that within the resources available we could investigate the feasibility of the approach and factors that were associated with preferences. To this end a convenience sample of people over the age of 60 was drawn from 14 day centres, contacts with voluntary organisations for older people and individual contacts.

The sample size was determined on the basis of several considerations:

- when using regression analysis, the minimum sample size has to be more than the number of independent variables to retain sufficient degrees of freedom (Maddala, 1983);
- work in conjoint analysis has suggested that samples of between 30 and 100 are sufficient (Pearmain et al., 1991); and
- the sample was to be divided in two to allow each group to make just eight choices and rate 16 of the 27 scenarios that were identified as necessary by the SPEED programme.

It was identified above that as an exploratory study investigating whether it was possible to identify utility weights for an indicator of social care outcome it was not seen as essential to get a representative sample of the general population. However, it was important that we had sufficient numbers in each sub-sample that we wish to test for factors associated with preferences. Previous studies that have examined the effect of various factors on preferences have sampled between 100 and 150 individuals and have found that the number of respondents in some (but not all) subgroups have been insufficient for meaningful analysis (Vick and Scott, 1995; Chakraborty et al., 1993). It was estimated that a sample of 300 would be sufficient to enable the data to be analysed by the subgroups envisaged. In the event the final sample was 356 people.

In order to ensure that we were getting a sufficiently large group of each characteristic to be tested, the sample was monitored during the fieldwork to ensure that enough men and people who live alone were included.

In order to test reliability of the method used to establish preferences all those interviewed were asked if they would be prepared to be interviewed again. The first 58 who were prepared to be re-interviewed were interviewed again two weeks later using the same questionnaire. Once we were sure we had enough cases to investigate test-re-test reliability, the remaining 49 people who were prepared to be re-interviewed completed a version of the questionnaire that included a monetary domain.

An anomalous result relating to safety in the main model suggested that the conditions for identifying choices may have been violated in the initial design (see above). A sample of 65 people who had been in the original sample were re-interviewed using the same scenarios but with different choices. Information about the low weighting that safety had been given was discussed with respondents, and the exercise repeated with a more specific example to investigate whether the way that unmet need levels was described had affected choices made. Worries about falling was used as the example as this had been identified most frequently by service users in the early stages of using the instrument in a research setting (see chapter 3, section 3.6)

4.6 Conclusion

The feasibility and pilot exercises provided invaluable information for the design of the mainstage fieldwork. The results suggested that the discrete choice approach to identifying preferences was manageable and likely to produce valid and reliable results. The mainstage fieldwork itself was designed to investigate these issues as well as to estimate a model of preferences based on a convenience sample of people aged 60 and over. The next chapter describes the results of that exercise.

5

Weighting the Measure to Reflect Utility Gain

Previous chapters have identified that a key aspect of the measure is to weight it to reflect the expected benefit gain to those in receipt of services. In order to produce final weightings we would want a representative sample of the group whose preferences we wish to reflect, be that society as a whole, older people in society or users of services. The objective in this study was more limited. We wanted to identify the feasibility of attaching weights in a valid and reliable way, what those weights would be based on our sample, and factors associated with significant variations in preferences.

This chapter starts by describing the sample of older people who were interviewed, before outlining the analysis used to attach utility weights. The results for the main model are reported, and factors associated with variations in preferences identified. The results of tests of validity and reliability are followed by a discussion of the results.

5.1 Characteristics of the sample

In total 356 people were interviewed. Table 5.1 shows the characteristics of the sample. Compared with people over 60 in the general population, people in our sample were more likely to be female: 72 per cent compared with 57 per cent (ONS, 2000a), and were older. Seventeen per cent were 85 or over compared with 10 per cent of the general population in 1999 (ONS, 2000a). In terms of ethnic origin just nine people (2 per cent) in our sample were non-white. This is very close to the proportion in the over 65 population as a whole (3 per cent; ONS, 2000b).

The high proportion who were widowed or single accounts for the fact that nearly two thirds (61 per cent) lived alone. In the 1998/99 GHS survey just 32 per cent in this age group lived alone.

Together these characteristics suggest a group more like service users than the population as a whole (Bebbington et al., 1996). Table 5.2 shows that 35 per cent had some level of experience of care services. However, although over half (55 per cent) were interviewed in a day centre or club, only 9 per cent claimed any experience of day care services. This would suggest that these centres were seen as general social activities rather than sources of 'care'. While experience of impairment was widespread (58 per cent identified some form of health condition or impairment) just a fifth of the sample identified themselves as both receiving some type of care services and suffering from some sort of impairment. This was used as the definition of service user in the analyses described below.

Table 5.1: Characteristics of people in the sample

	Number	%
Gender		
Male	98	28
Female	258	72
Age		
Under 85	272	83
85+	54	17
Ethnic origin		
White	346	98
Black	5	1
Asian	3	1
Other	1	>0
Marital status		
Married	106	30
Single	32	9
Widowed	215	61
Household composition		
Lives alone	218	61
Lives with others	137	39
Tenure		
Owner occupied	167	48
Rented	150	43

Table 5.2: Experience of services and impairment

	Number	%
Any care services	123	35
Knowledge/experience of		
Home care	80	23
Meals services	16	5
Day care	33	9
Any impairment	204	58
Current service user withi impairment	71	20

Identifying socio-economic circumstances is not straightforward, particularly with retired elderly people. Information was collected about home and car ownership to provide some indication of income levels. Half of the sample lived in their own home and about a third owned a car. As would be expected, people who owned their own home were much more likely to own a car than those who did not (54 per cent compared with just 11 per cent in rented accommodation). Just under a third (31 per cent) identified an occupational pension as an important source of income.

5.2 Analysis of preferences

Three approaches were used to identify preferences: ranking the domains, discrete choices and rating using an analogue scale. The rankings were simply used as an indication of respondents first reactions to the named domains.

The responses to the discrete choice questions were tested to ensure that people were responding on a rational basis. Choices were included where one scenario was worse for all domains, so that the logical choice was that the respondent should choose it as worse. It was assumed that high unmet needs were worse than low unmet needs which in turn are regarded as worse than no unmet needs. Five such choices were included (three in interview A and two in interview B). To allow for random error, respondents were allowed to fail one test, but any respondent who failed two tests was judged to have failed the test for rationality and was subsequently dropped from the analysis.

The discrete choices were then analysed using random effects probit regression (the form of the model is described in section 5.3). The main model used all valid observations (excluding those who failed consistency checks) in the full dataset. In order to test whether characteristics of individuals were associated with preferences, separate models were run for men and women, over and under the age of 85, people living alone or with others, and those using services and with an impairment or not. In each case the models were tested to see if there was any significant difference between the groups.

For the main model, and all models where significant differences were found, the model was adjusted to take out differences in levels within domains and occasionally a whole domain, where no significant association with preferences were found. The coefficients of these models were then standardised so that within each model the best possible care situation ranked 1 and the worst 0. These ‘utility weights’ were then used to compare the results of the different models. Necessarily the sample sizes for the sub-analyses were smaller than for the main sample so some differences between the models may be due to domains or levels not reaching statistical significance rather than any fundamental differences in preferences.

A similar model was run on the responses when the additional attribute of level of financial benefits was included in the description of the situation that people were choosing between (see appendix C situation C2). The ratio of the coefficient between this financial attribute and other domains allows us to estimate to what extent people were prepared to trade off money against each level of met need in each domain. This provides the basis for estimating the monetary value people placed on having needs met.

The rating of each scenario using the analogue scale was used to validate the results by testing correlations between the values predicted by the model and the average scores given.

5.3 Results

Ranking

Table 5.3 shows the proportion of the sample that ranked each domain first and the average ranking score, when people were initially presented with the information about the areas of need met by social care interventions and asked to put them in order of importance. The domains of Control over Daily Life or Safety were ranked highest by two thirds of the sample.

These initial rankings were found to be associated with personal characteristics. Men were more likely to rate meals higher ($p<0.01$) while women rated personal cleanliness higher ($p<0.01$). Seeing people was more important to service users ($p<0.01$) and those who attended day centres ($p<0.01$). Safety was less important among those who had identified themselves as having an impairment ($p<0.01$).

Table 5.3: Initial ranking of domains

Domains	Per cent placing first	Average rank
Control over Daily Living	34	2.46
Safety	32	2.37
Personal Care	18	2.78
Food and Nutrition	10	3.45
Social Participation	6	3.54

The main model

Twenty-one individuals, 15 from interview A and six from interview B, were regarded as making two irrational choices. For the main model 326 individuals were included after rationality checks and missing age data, giving 2564 observations of choices.

The function estimated was of the form:

$$\Delta V=\delta_1\text{Food and nutrition} + \delta_2\text{Personal Care} + \delta_3\text{Safety} + \delta_4\text{Social Involvement} + \delta_5\text{Control over daily living} + e \quad (1)$$

That is that the preferred situation is a function of each of the five domains. Within the domains, however, there are three levels of unmet need that cannot be assumed to have a linear relationship with people's preferences: we cannot assume that people feel equally strongly about moving from high to low unmet need and low to no unmet need in each domain. In order to allow for this a series of dummy variables was required for each domain, with the reference category for each domain being high unmet need. This then gives the following function:

$$\Delta s=\alpha_1\text{Food no unmet need} + \alpha_2\text{Food low unmet need} + \alpha_3\text{Personal no unmet need} + \alpha_4\text{Personal low unmet need} + \alpha_5\text{Safety no unmet need} + \alpha_6\text{Safety low unmet need} + \alpha_7\text{Social no unmet need} + \alpha_8\text{Social low unmet need} + \alpha_9\text{Control no unmet need} + \alpha_{10}\text{Control low unmet need} + e \quad (2)$$

The estimated model is shown in Table 5.4. While for the most part the directions of effect were as would be expected, there are some unexpected findings and some instances where the move from one level of unmet need to another within a domain was non-significant. Table 5.5 shows a revised model where those levels that were not significantly different are combined. The combined levels were low and no unmet needs for food and nutrition and for control over daily life. Safety showed a contra-intuitive finding which was that high and no unmet needs should be combined with low unmet need as the reference category. This did not occur when the monetary attribute was included (see below). In that model the domain was given the same overall weighting compared to other domains as in the main model, but the reference level was high unmet need and no and low unmet needs were combined (see table 5.8).

Safety was found throughout almost all the analyses, to be given the lowest weight of all the domains. The inconsistency in the main model arises from this factor, together with the description of unmet need in this domain and the design of the set of choices presented to respondents. In order to investigate the effects of these factors, an additional piece of fieldwork was undertaken. The findings from this fieldwork indicated that there was no major problem with the results of the main study, as the rankings and utility weightings of each domain resulting from models run on these data were very similar to the main model (see appendix D). When respondents were given the original description that was used to specify levels of unmet need in the domain of safety, the domain was not taken into consideration when trading off the different scenarios: there was no significant association with

Table 5.4: The main model

Domains	Coefficient	Standard error	p
Food and nutrition			
No unmet needs	0.5397	0.0968	0.001
Low unmet needs	0.5711	0.1073	0.001
Personal care			
No unmet needs	1.0462	0.0847	0.001
Low unmet needs	0.5220	0.0665	0.001
Safety			
No unmet needs	-0.0677	0.1207	0.575
Low unmet needs	-0.4195	0.1586	0.008
Social participation			
No unmet needs	1.0153	0.0833	0.001
Low unmet needs	0.6081	0.1038	0.001
Control over daily living			
No unmet needs	0.6096	0.0698	0.001
Low unmet needs	0.5274	0.1093	0.001
Number of observations 2564			
McFadden R^2 0.345			

Table 5.5: Main model with combined levels

Domain	Coefficient	Standard error	P
Food and nutrition			
No/low unmet needs	0.4713	0.0566	0.001
Personal care			
No unmet needs	1.1048	0.0680	0.001
Low unmet needs	0.5351	0.0542	0.001
Safety			
No/high unmet needs	0.2971	0.0635	0.001
Social participation			
No unmet needs	0.9859	0.0563	0.001
Low unmet needs	0.5778	0.0721	0.001
Control over daily living			
No/low unmet needs	0.6323	0.0641	0.001
Number of observations 2564			
McFadden R^2 0.345			
% of correct predictions 80.5%			

preferences. This was also true for these respondents when a separate model was run for them based on their responses to the original questionnaire. Once attention had been drawn to the domain and its low ranking, and the description was made more specific (worries about falling, rather than safety generally) the domain was taken into consideration when making choices. However it still was given the lowest rank (see appendix D).

Another slight inconsistency in the main model was the rating of low levels of unmet need for food and nutrition slightly (though non-significantly) higher than all needs met. However, significant differences were found in the different levels of unmet need for this domain in the follow-up study (see appendix D). Again the rank of the domain as a whole was the same as in the main model.

Chapter 6 discusses the amendments that need to be made to the results of the main model when identifying a utility based scoring system. For our purposes here, we continue to use the results of the statistical model shown in table 5.5 to estimate utility weights and as a basis for comparison when examining the characteristics that are associated with variations in preferences for the domains of outcome in social care.

In order to identify a utility scale where 0 is the worst possible care situation and 1 the best, the coefficients were rescaled to anchor the 'best case' scenario to a value of one. This best case scenario occurs when there are no unmet needs in each domain. Table 5.6 shows the scale based on the model shown in table 5.5. The scores shown indicate the increase in welfare obtained as a result of moving from a situation of high unmet need in each domain to the level of unmet need shown. Thus for example, moving from a situation where you feel isolated to a situation where you see people as often as you want implies an increase in utility of 0.2824 (or 28.2 per cent if the score was scaled to 100). However if you only moved to a situation where, although not isolated, you would like to see people more often, your utility increase would be 0.193. The increase in the utility score gained from moving from low to no unmet need is the difference between the two scores, in this case 0.1064.

Table 5.6: Utility weights from main models

Domain	Rescaled coefficient
Food and Nutrition	
No/low unmet needs	0.1350
Personal care	
No unmet needs	0.3164
Low unmet needs	0.1533
Safety	
No/high unmet needs	0.0851
Social participation	
No unmet needs	0.2824
Low unmet needs	0.1655
Control over daily living	
No/low unmet needs	0.1811

Note:: The reference category is high unmet need with the exception of safety where it is low unmet need

Clearly the endpoints of the scale are arbitary. We could as easily use a score from 0–10 or 0–100. This type of ratio scale allows us to infer that if the total utility score changes from 0.2 to 0.3 or 0.5 to 0.6 the same level of increased benefit has occurred. However, it is not necessarily cardinal. Like measures of temperature, it does not allow us to say that a move of 0.4 is twice a move of 0.2.

The utility weights show clearly that, for the respondents, the domain of greatest importance is personal care, followed by social participation and involvement, followed by control over daily living, followed by food and nutrition. The question then raised is how much confidence can we put in these weights. Table 5.5 gives the standard errors of the coefficients in the model, which gives an indication of the confidence that we can put in the value of the coefficients. However, we know we do not have a sample that is representative of any particular group. How much do the characteristics of individuals and their circumstances affect preferences?

Variations in preferences

It was identified above that we wanted to test whether individual characteristics or living circumstances influenced people's preferences. Appendix E gives details of the segmentation analyses run to investigate this issue. Table 5.7 shows the resulting utility weights where there were significant differences. In each case the

Table 5.7: Utility weights based on models reflecting individual characteristics

Domain	Main model (n = 326)	Age 85+ (n = 54)	Living with others (n = 127)	Receiving services and impaired (n = 63)	Interviewed in day centre (n = 196)
Food and nutrition					
No/low unmet needs	0.1350	0.2297	0.1313	0.2537	0.1093
Personal care					
No unmet needs	0.3164	0.2640	0.2790	0.1904	0.3864
Low unmet needs	0.1533	0.1352	0.1508		0.1874
Safety					
No/high unmet needs	0.0851	0.1643	0.0968	0.0540	0.0
Social participation					
No unmet needs	0.2824	0.2032	0.3059	0.3543	0.2994
Low unmet needs	0.1655		0.1525		0.1930
Control over daily living					
No unmet needs	0.1811	0.1388	0.187	0.1477	0.2048
Low unmet needs		0.0		0.0	

Note: With the exception of safety the reference category is high unmet need. Where two categories are combined a single value is shown reflecting the utility weight for both categories

results for the comparator group (for example, younger respondents compared to the 85 and over group for whom results are shown) were very similar to the main model.

With the exception of safety the reference category is high unmet need. Where two categories are combined a single value is shown reflecting the utility weight for both categories.

In order to check whether recruiting people to the sample through day centres was influencing the results we also ran separate models for those interviewed in day centres and elsewhere. Although the hypothesis that the preferences were different could not be rejected (see appendix E), in practice the only real difference between the models was that the safety domain did not reach statistical significance at all for those interviewed in day centres.

No significant differences were found in preferences based on gender. However, age, living circumstances and people who defined themselves as having an impairment and using services, were significantly associated with different preferences.

People aged 85 and over were more concerned about food and nutrition and less concerned about social contact than younger respondents. The domain of food and nutrition was ranked second, only below personal care in importance, compared to ranking fourth out of the five domains in the main model. While younger respondents indicated a significant improvement in wellbeing resulting from having low level needs met in the domain of social participation and involvement, older respondents did not distinguish the levels. This indicated that as long as they did not feel totally isolated they were prepared to put up with not seeing people as much as they would like. Of the other two domains, they also ranked safety above control over daily living, a very unusual finding in the context of the other models. However, their overall ranking – personal care over food and nutrition over social participation over safety over control – could be seen as closer to a Maslow hierarchy of needs than was true for the overall results.

The overall ranking of those who lived alone and those who lived with others was the same except for the much higher weighting given by those who lived with others to social participation and involvement. This group rated social participation and involvement higher than any other domain when making their choices between different scenarios. The lack of any similar finding for people interviewed in day centres suggested that this was not a result of a peculiarity in the sampling procedure. It may be that those for whom social participation and involvement is most important are most likely to ensure that they live with others. However, an alternative explanation is that those who live on their own have learned to cope with feelings of loneliness and isolation (perhaps after the death of a spouse) and so are less concerned than those who were anticipating such feelings.

Those people identified as current service users showed another set of preferences. For this group social participation was ranked highest, followed by food and nutrition, followed by personal care, followed by control over daily living followed by safety. Service users were significantly more likely to be aged over 85 (30 per cent compared with 17 per cent of non-users, $p<0.05$), live alone (79 per cent compared with 57 per cent of non-users, $p<0.001$) and be interviewed in a day centre (77 per cent compared with 49 per cent of non-users, $p<0.001$). However, the other analyses suggest that their preferences were not related to these characteristics. Without further evidence we can only speculate that these preferences may be related to their experiences of impairment and service receipt (see discussion in section 5.6 below).

Monetary valuation of having needs met

Table 5.8 shows the results of the analysis of preferences when the monetary attribute was included. Each scenario had an additional sentence which identified a level of benefits being paid (see appendix C, situation C2).

The ranking and the relative weighting of each attribute was virtually identical to the main model, with the exception that the safety attribute behaved as we would hypothesise it should (with high level needs scoring lower levels of utility than low level needs). Table 5.8 also shows the monetary value that a move from high level needs to the level of needs shown would be worth (in terms of the level of benefits respondents would be willing to accept in compensation). It is important to be clear that this is not the same as willingness to pay, as studies have consistently shown that the value that people attribute in willingness-to-accept studies is higher than the amount they would be willing to pay. Assuming an additive utility

Table 5.8: Utility and monetary weights of domains

Utility weights	Monetary model (n = 45)		
	Coefficients	Monetary valuation £ per week	Utility weights
Food and nutrition			
No/low unmet need	0.4281	252	0.1895
Personal care			
No unmet need	0.7010	412	0.3103
Low unmet need	0.4026	237	0.1782
Safety			
No/low unmet need	0.1900	112	0.0841
Social participation			
No unmet need	0.4897	288	0.2167
Control over daily living			
No/low unmet need	0.4506	265	0.1994
Benefits (£)	0.0017	n/a	n/a

Note: In all cases the reference category is high unmet need. Where two categories are combindd a single value is shown reflecting the utility or monetary weight for both categories function (as we have throughout) the total value moving from high level needs to all needs met in all domains is £1,318 per week.

In all cases the reference category is high unmet need. Where two categories are combined a single value is shown reflecting the utility or monetary weight for both categories.

5.4 Validity

In order to test construct validity (the degree to which we are measuring what we intend to measure) we need an alternative measure of preferences. The rating score given by respondents for each of the vignettes using an analogue rating scale provided this. The predicted utility score based on the main model and the average rating score for the 27 scenarios were significantly correlated ($R^2=0.81$, $p<0.01$; Spearmans Rank $R^2=0.88$, $p<0.01$). This finding was despite including the contra-intuitive weightings for safety, confirming again the low weight put on this domain by respondents.

5.5 Reliability

In order to look at reliability a sub-sample of the original respondents was randomly selected. There were 47 individuals for whom there was full information on two separate occasions. The period of time between the completion of the two questionnaires ranged from eleven to sixty days, with a mean gap of nineteen days. A comparison of the responses from these two questionnaires also indicated whether respondents understood the task that was asked of them in the questionnaire. If respondents were unable to understand the nature of the experiment and therefore gave random answers to the questionnaire, not based on true underlying preferences, then we would expect a different pattern of random answers to be provided in the second questionnaire.[1]

The comparison of the responses was carried on at two levels. The first examined the raw responses and the level of agreement across the two questionnaires. The second compared estimated models.

Raw responses

The simplest approach considers how many exact agreements were observed. This is broken down by each pairwise choice that was offered to the respondents between which they had to express a preference. Table 5.9 reports the percentage agreement on each choice and table 5.10 the total level of agreement.

In terms of total responses, we see from table 5.10, that of the 375 choices, 308 responses (82 per cent) were in exact agreement across the two times that the respondent completed the questionnaire. However, these raw agreement figures do not take into consideration the possibility that some agreement over questionnaires might occur by chance. The Kappa statistic takes this into consideration. A Kappa value of 1 indicates perfect agreement, a value of 0 indicates no agreement better than chance, and negative values indicate agreement worse than chance. The Kappa statistic derived from the responses shown in table 10 is 0.64, which indicates good strength of agreement (Altman, 1991).

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[1] This assumes that preferences exist and are stable over time. A difference in results across questionnaires may be explained by violations of either of these axioms, and not by an unreliable instrument.

Table 5.9: Percentage agreement by choice for each choice presented

Choice	Disagreements	Percentage agreement	Absolute difference in predicted utility scores
Interview A1	1 out of 26	96.2	0.53
Interview A2	3 out of 26	88.5	0.30
Interview A3	4 out of 26	84.6	0.25
Interview A4	4 out of 26	84.6	0.35
Interview A5	3 out of 26	88.5	0.46
Interview A6	5 out of 26	80.8	0.16
Interview A7	5 out of 27	81.5	0.22
Interview A8	14 out of 26	46.1	0.04
Interview B1	2 out of 20	90.0	0.46
Interview B2	4 out of 21	80.9	0.13
Interview B3	5 out of 21	76.2	0.03
Interview B4	4 out of 21	80.9	0.28
Interview B5	2 out of 21	90.5	0.53
Interview B6	7 out of 21	66.7	0.13
Interview B7	2 out of 21	90.5	0.28
Interview B8	2 out of 21	90.5	0.33

Table 5.10: Total levels of agreement of choices in original questionnaire and at follow-up

		Preferred situation at follow-up		
		A	B	Total
Preferred situation originally	A	179	34	213
	B	33	129	162
	Total	212	1633	375

It is interesting to note that the choices where there was the lowest level of agreement were also the choices where the predicted utility scores from the main model were closest. For example, in choice A8, where there was only 46 per cent agreement, the differences in the predicted utility scores was 0.04, compared with the overall average difference in scores of 28. This is what would be expected if the model was predicting utilities appropriately, as similar scenarios in terms of utility weighting would be most difficult to choose between. In such instances people would be more likely to choose differently on different occasions.

Likelihood test

The second comparison of the two questionnaires was carried out at the modelling level. A log-likelihood test identified whether the coefficients on the attributes were the same in the model derived from the first questionnaire compared with those derived from the second questionnaire. The analysis was based on the pooled sample of responses from the two questionnaires and the model as estimated by the separate responses for the two questionnaires. Three models were estimated. In the first the coefficients were constrained so they were the same from both questionnaires. The separate models were estimated for each questionnaire. These were then compared. The test was based on the 47 individuals for whom we had two questionnaires. The hypothesis that the coefficients were the same from both questionnaires could not be rejected at the 95% level, with a test statistic of 10.76 and critical value c2(10) =18.31. This indicated that responses from the first questionnaire gave reliable results in terms of the estimated weights assigned to the five domains.

5.6 Discussion

Using conjoint analysis to establish the utility weights associated with outcomes for social care had not been attempted before and at the start of the study the use of conjoint analysis in health care evaluations was relatively new. It is not surprising, therefore that some problems were encountered in the process. However, further investigation of these has allowed us to evaluate the implications of problems in the main model and provided us with information that allows us to adjust utility weights for the instrument itself. The final weightings are described in chapter 6. Here we discuss the substantive and methodological implications of the findings.

Monetary valuation of preferences

The value of establishing a monetary estimate of the benefit achieved by meeting people's needs is that this can be set against the costs of meeting those needs to provide a measure of the benefit gained. Moreover, it allows us to compare the value of the benefits against other types of intervention where a monetary estimate of the benefits has been established. In the field of environmental economics this has been used to examine the economic efficiency of policies and practice that have environmental consequences (Mitchell and Carson, 1989; Adamowicz et al., 1998).

The monetary estimates of the value of the domains were based on willingness to accept financial benefits instead of having needs met in each of the domains. The values were considerably higher than the costs of meeting these needs in practice, suggesting a substantial net benefit to society. However, we do have to be cautious in drawing such conclusions as willingness to accept values tend to be higher than willingness to pay. Moreover, in practice we will be measuring outcomes as reductions in met need. In such cases the appropriate valuation is willingness to pay.

In this study we have focused primarily on estimating utility weights based on conjoint analysis model coefficients.

Ranking of importance of the domains

There appeared to be little relationship between the overall rank given by the sample at the start of the interview and the ranking of domains based on the conjoint analysis model. Other observers have identified different levels of importance attached to attributes when a simple ranking of importance is compared with the results of conjoint analysis (Ratcliffe, 2000). In those studies this has been put down to context: the implications of decisions are made clear when individual decisions are made in a way that is not true when simple rankings are made. Moreover, in our study the initial domains were presented as positives, for example social participation was presented as seeing people as often as you like. In the decision process the implications of having unmet needs were drawn out. For social participation it was made clear that unmet needs result in feelings of isolation.

Some of the relationships between the initial ranking and personal characteristics were illustrated above. This was not an exhaustive description as we are not using these rankings for anything other than an indicator of people's initial reaction to the domains. Some of the characteristics mirrored effects found in our models, for example the greater importance of social participation to service users. However, other associations were not found in the conjoint analysis, for example no gender effect was found.

The major difference between the rankings and the conjoint analysis was that social participation and involvement, which was ranked lowest of the domains initially, was ranked much more highly in virtually all the estimated models. The reverse was true of safety, which ranked lowest in all but one of the models, but was the top ranked domain if average ranking of importance is used.

Safety

In chapter 2 some of the problems in measuring the concept of safety were identified. There are three important components: the seriousness of the event, the probability of occurrence and worries or concerns about safety. People can feel safe when risks of serious events are relatively high (for example travelling by car) and feel unsafe when risks are relatively low (for example, fear of crime among older people). In the instrument we include a separate section for measuring actual probability of events with some indication of their consequences. In the domains we have just included the sense of safety.

The follow-up study reported in appendix D showed that some of the low rating of sense of safety might be due to the less specific wording used to identify unmet need. When people were presented with the original scenario descriptions but a re-designed set of choices, the domain was not statistically significant. This may be due in part to the characteristics of this follow-up sample (the domain was non-significant for this sub-sample of individuals when their responses to the original questionnaire were used). However, once attention had been drawn to the domain and the wording made more specific it did become more significant, and was given a higher weighting than in the main model, although it remained at the lowest level of importance compare with other domains. This presents us with some difficulties as it indicates the domain should be included as significant, but non-specific wording means that generalised concerns about safety are difficult to capture.

The wording of the safety domain had deliberately been left vague as the domain was intended to cover a wide variety of aspects of feeling safe and secure. However, in practice outcomes in social care will be the result of meeting specific safety concerns. There is no reason to expect that people will feel the same about concerns about falls as concerns about other aspects of safety, such as fear of crime. This suggests that more work is needed to identify how people feel about different aspects of their safety and the impact of the events themselves on wellbeing.

Social participation and involvement

Social participation and involvement was identified as having a protective factor in our discussions with respondents in the feasibility stage. Moreover, social isolation is associated with increased levels of morbidity and mortality (Broadhead et al., 1983; Casell, 1976; Cobb, 1976; House et al., 1988). This suggests that the high weighting given by the sample as a whole and most sub-groups reflected an appropriate indication of its importance relative to other domains. Although the models varied, the highest weighting given to this domain was by those who lived with others and service users. It is possible that this reflected the concerns of older people about losing spouses or being left alone, prior to the event.

There may be an interaction with other domains as people were judging scenarios as a whole. For example, worries about safety might not be well founded if you were seeing people as much as you wanted to. This interpretation is based on some of the responses to the feasibility exercises reported in chapter 4. It did not prove possible to test interaction terms in these models. Future work might investigate other forms of the model, although these linear, non-interactive forms behaved well and predicted a high proportion of correct decisions.

Variations in preferences

Variations in preferences among different sub-groups raise a number of issues, particularly when we note the rather different ordering by service users and older people in the sample. Studies of preferences for health states have also found a difference between those who have direct experience and those who do not. Using the time trade off (TTO) approach to expressing preferences a number of authors have found that once people are applying the approach to themselves they were very reluctant to trade off life years for improved health (Sprangers, 1996). This occurred even in situations where current health state is very poor and life expectancy is very low (Tsvestat, 1995; Fowler et al., 1995). De Wit et al. (2000) also found that patients rated hypothetical health states higher than non-patients.

A common explanation for this is that once they have a chronic condition people change their 'internal yardstick' of what is acceptable (Sprangers, 1996). This has been termed psychological adaptation (Heyink, 1993; Loewenstein and Schkade, 1999), a state in which people's expectations are lowered so that decreased levels of functioning no longer bother them. An alternative but related explanation is given by the theory of cognitive dissonance (Festinger and Carlsmith, 1959; Younger et al., 1977). This occurs when people are very unhappy, so they change their attitudes and re-interpret the situation as a method of coping. In care situations this would result from it being difficult for people to identify how poor their quality of life is. These explanations are different to 'scale of reference bias' which occurs when people who are asked to compare their health states do so by comparing themselves to other people who also have a particular health problem rather than others who are well. This has been used as an explanation for higher ratings of health states among older people (Groot, 2000).

The results of the models shown here have not yielded absolute values about different health state but we can compare the results with ratings given to scenarios using the analogue scale. There was no evidence of service users rating the scenarios with unmet need higher than non-service users. However, in the conjoint analysis model, service users did not appear to distinguish between different levels of unmet need, where the sample as a whole had done. This may partly be a statistical effect, due in part to the smaller sample size for this group, although we might have hypothesised that users would be more sensitive to unmet need so a larger effect would be observed.

A similar finding has been identified in analyses of health state preferences. De Wit et al. (2000) and other observers (Badia et al., 1996; Kind and Dolan, 1995) have found less of a range of values used by those who had experienced being a patient, compared with those who have not had the experience. This has been termed 'valuation compression'. De Wit et al. (2000) suggest that this term implies error associated with patient valuations, but in fact the opposite may be the case. Lack of experience of being a patient may lead to individuals exaggerating the differences between different health states. However, De Wit and colleagues argue that 'outsiders' may be able to differentiate between different health states better than patients may themselves, being less influenced by specific, and possibly biased, information.

Alternatively, we could infer that, in the absence of experience, people are unsure about their preferences, that they are not 'complete', or well formed prior to interview. If they are not complete, values may be constructed rather than revealed in the process of answering choice related questions (Shiell et al., 2000). In the marketplace, trial and error means that people quickly recognise their values, so preferences for particular types of goods are likely to be complete. The same cannot be said of health and social care. There are three ways in which we might expect expressed preferences to change:

- People have complete and reliable values but a significant life event which changes these;
- People have incomplete values that are clarified in response to life events;
- People have incomplete values that are clarified in response to questioning.

In practice it is likely to be very difficult to separate the first two of these. A small-scale study by Sheill et al. (2000) suggested that completeness of preferences about health states could not be taken for granted.

Apart from the discrepancy between the initial ranking and subsequent ratings of the domains resulting from the conjoint analysis, there was little evidence of lack of completeness among the sample. We have discussed above the probable reasons for the differences between the ranking and rating. Older people had been chosen as the sample group in part because it was anticipated that they would be aware of the issues: that their preferences would be complete. Although we do not have information about changes in people's circumstances that might lead to greater knowledge and thus completeness of views, we do have some information about stability of preferences over time. Indications of test-retest reliability and validity of the approach used to establishing preferences were good. The Kappa value here (.64) was comparable to that found by Bryan et al. (2000) who found a good level of reliability (Kappa = 0.65) when respondents were followed up with a discrete choice postal questionnaire two weeks after initially identifying their choices. Moreover, it is interesting to note that the overall pattern of preferences a year later in the follow-up sample was very close to the original model suggesting stable preferences over time. Straight comparison of the predicted utility scores with people's valuations of the scenarios confirmed the other evidence that the main model was based on reliable evidence that reflected preferences.

The above discussion suggests that the differences in estimated utility weights were most likely to be due to life events (growing older, having impairments, and becoming a service user) affecting preferences. The models suggest that for these groups food and nutrition is a more important issue than for other groups, but social participation and involvement is the key domain for the service users in our sample. While the differences are of interest, and worth pursuing with further research, we have much more confidence in the results of the main model, based on the full sample, when it comes to identifying utility weights for our instrument. The next chapter discusses the scoring and use of the instrument and further work that could build on the results reported here.

6 The OPUS Measure: Current Status and Future Development

The project was always designed to be experimental: to evaluate whether it would be possible to derive a measure of outcome that could reflect the benefit gain of social care interventions. To some extent the policy agenda has overtaken the project with the core policy objective of integrating health and social care for older people (Cm4818-1, 2000*)*. However, in some ways this makes the development of an outcome measure for social care all the more important, as with the more sophisticated development of outcome measures in health the benefit gains in social care could easily be overlooked or marginalised.

The previous chapters have described the development and testing of the measure to date. This chapter describes the instrument and derived utility index, summarises the ways in which the instrument could be used at its current state of development and identifies future work needed.

6.1 The instrument and utility index

The instrument that we have developed together with guidance for coding is shown in appendix A. Chapter 3 discussed the background to the format and rationale for the structure. The format in appendix A is appropriate when care managers or key workers who have in depth information about an individual or access to different perspectives on an individual are completing it. It is very straightforward to adapt for use in surveys where the interviewer has no previous knowledge of the individual, using show cards to ask people how they would rate their current level of unmet need and levels of need in the absence of service interventions. This type of format was used in the validation work and in a study of self-funded people admitted to care homes (Netten et al., 2002b). In the former case older people themselves were interviewed, in the latter relatives of the older people.

In deriving the index the aim is to identify our best estimates of the weights that should be used to reflect levels of utility among people with different levels of unmet needs as measured by our instrument. For the most part we found fairly consistent results although there were some characteristics which seemed to be associated with age and experience of impairment and receiving services. In chapter 5 we discussed the fact that similar findings had been identified for health related quality of life about different sets of preferences associated with patients and non-patients. Such findings have raised issues about which perspective should be reflected in utility-based measures of health related quality of life. The Paretian[1] approach that underpins cost benefit analysis suggests that it is the values of those people whose welfare is affected by an intervention that should

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[1] Pareto optimality is a definition of efficiency of allocation that underpins much of welfare economics. Paretian optimal allocation occurs when no change can be made where there will be welfare gain to any individuals without loss of welfare to other individuals (Henderson and Quandt, 1971).

count in an appraisal. However, a consensus panel convened by the United States Public Health Service (USPHS) has concluded that public values or utility estimates should be used as the basis of cost effectiveness measurements (Gold et al., 1996). There are a number of arguments for this including that CEA is a tool for determining how to allocate scarce societal resources so society at large should determine the values.

Despite the USPHS verdict, the debate continues amongst experts about whose values should be used as there is often a large discrepancy between the values of patients and the public (Ubel et al., 2000). Williams (1991) suggested that the patient perspective vs the general population perspective is not a matter of right and wrong: both perspectives may lead to legitimate outcomes depending on the specific decision making context. The choice of perspective is primarily a normative choice. However, De Wit (2000) has argued that if patient values are used in societal decision making this effect may lead to a lack of sensitivity to discriminate between treatments, possibly leading to lack of discrimination when in fact differences between the treatments exist.

Ideally we would identify a variety of utility weights that could be used to create indexes of levels of wellbeing based directly on models which reflected the preferences of a nationally representative sample of users of services, older people generally or the population as a whole. This would allow users of the index to reflect the most relevant group to the purpose of the study and to conduct sensitivity analysis to investigate the impact on conclusions of using different perspectives. This was beyond the scope of this study. The sample used, while helpful in identifying sources of variation in preferences was not designed to be nationally representative. However, the results do provide us with a useful starting point in identifying utility weights.

We use as a basis the main model that was based on the whole sample. This provides the largest numbers, so we have most confidence in the results and the nine subsequent analyses, with the exception of the user sub-sample and people over 85, revealed basically the same overall ordering of the domains. While the results are of interest, the user sample is too small and unrepresentative for us to recommend as a basis for the overall weighting, although the results presented in table 5.7 could be used for that purpose. It should be noted that the characteristics of the main sample are closer to users of services generally than the general population (see chapter 5).

Table 6.1 shows two sets of weights, each using 0 and 100 as the end points of the scale. The limited Index reflects just those domains that were found to be statistically significantly greater than zero and those levels which were statistically significantly different to each other. While technically correct this model does not reflect variations in levels of utility where we would expect to see them, for example between low and no unmet need in the domains of food and nutrition and control over daily life. It also excludes the domain of safety, which the monetary model and follow up model using the falls definition found to be significantly associated with preferences. Moreover, the limited scoring basis would mean in practice that the instrument was likely to be even less sensitive to changes in people's circumstances than the original measure.

In order to provide a full index that provides a more sensitive measure and that has face validity in ascribing different utility weights to differences in levels of met need we have adapted the results of the main model. For no unmet need the full index weights are all the same as in the main model reported in table 5.6. In addition we have included a separate weight for low unmet need in the domain of Control over daily living based on the coefficient in that model.

Table 6.1: The OPUS utility index

Domain	Limited index values	Full Index values
Food and nutrition		
No problem	14.1	13
No unmet needs	14.1	13
Low unmet needs	14.1	10
High unmet needs	0	0
Personal care		
No problem	35.3	32
No unmet needs	35.3	32
Low unmet needs	17.6	15
High unmet needs	0	0
Safety		
No problem	0	9
No unmet needs	0	9
Low unmet needs	0	4
High unmet needs	0	0
Social participation		
No problem	29.3	28
No unmet needs	29.3	28
Low unmet needs	19.3	17
High unmet needs	0	0
Control over daily living[1]		
No unmet needs	21.3	18
Low unmet needs	21.3	16
High unmet needs	0	0
Maximum index[2]	100	100
Minimum index[3]	0	0

Notes: 1. No 'no problem level' is included in the measure for this domain.
2. Attained when 'no unmet need' or 'no problem' in all domains.
3. Attained when 'high unmet need' in all domains.

The utility weights estimated from the main model were very close to the weights estimated from the model that included a monetary attribute shown in table 5.8 and in appendix E (table E.18). In this model some of the inconsistencies that were evident in the domains of Safety and Food and nutrition are absent. We use this model as the basis of adaptations for the values of low and high unmet needs in these domains. For no unmet needs the utility weighting of Safety in the monetary model was virtually identical to that in the main model. We use the coefficients from the monetary model to identify consistent weightings for low and high unmet need. The weighting for no unmet need was slightly higher for Food and Nutrition for the monetary model so it was not possible to directly transfer the results from this into the OPUS Index. For this domain therefore, the ratio between no and low unmet need in the monetary model was applied to the weight for no unmet need in the main model to identify an index weight for low unmet need.

The OPUS index is simply the sum of the index weights. So for a person who has all needs met in all domains, with the exception of social participation and control over daily living, where there are low level unmet needs, the full utility index would be 86, the limited utility index would 90. Alternatively if an individual had high level unmet needs in all domains except personal care, where there were low level unmet needs, and safety where there were no needs, the full utility index would be 24, the limited utility index would be 18.

6.2 Using the instrument in practice

Initial indications suggest the instrument is a practical tool that can be used in a cost utility analysis or as part of an assessment or review interview to provide local authorities with a monitoring or evaluation tool.

The weights we have obtained can be used in several ways. Firstly, it is possible to calculate an outcome index for individuals and groups following the introduction of a social care package. These can be compared across social care packages and conclusions made concerning which package of care have the greatest effect on welfare or utility. For example, we could compare a community care package which resulted in individuals having all needs met apart from low unmet need in the domain of social participation, with residents in care homes who had all needs met apart from experiencing high unmet need in the domain of control over daily life. The full utility index for the former would be 88 and for the latter 82. The limited utility index would be 90 for the former and 79 for the latter. As demonstrated in chapter 5, it is possible to link such indexes to the socio-economic characteristics of respondents. This has been done in the health status literature (Feeny et al., 1994; Dolan et al., 1996b).

An alternative approach is to use the difference between the Index based current levels of met need and the Index based on expected levels of met need to reflect the expected utility gain from all services received. This is appropriate where there is no point at which unmet needs in the absence of services could be directly assessed, for example the move from hospital to the community and incremental increase in service provision.

It is also possible to combine the weights with information on time in the given scenario in the way that health related quality of life indicators are used to weight life expectancy to produce QALYs (Williams, 1995; Dolan, 1996). The period of time would depend on the context. For example, if the interest was in the impact of care management arrangements we could identify the length of time between when the assessment was undertaken and the package put in place to meet needs to produce a measure of quality adjusted life days or weeks. In other instances where there were long-term consequences, such as admission to care homes, we might want to weight months or years in different care settings.

In order to make decisions about optimal care packages, the utility index needs to be combined with costing information within the framework of cost-utility analysis. Thus, future research could combine the utility index with costing data for each of the scenarios to provide cost-utility ratios. These ratios could provide an indicator of whether the extra cost incurred by moving from one configuration to another is justified in terms of extra benefit or utility (McIntosh et al., 2000).

Incorporation in assessment and reviews and subsequent scoring would allow local authorities to monitor the level of unmet need in individuals approaching them and the subsequent levels of benefit accruing as a result of interventions. This could be done from the perspective of the individual, the carer and the assessor. Independent evaluations of service users would also allow comparison across areas or local authorities in levels of welfare among existing clients. In addition to the measure of overall utility the instrument includes indicators of serious events, such as falls, getting lost and so on. In large enough samples the probability of these events occurring could be established and compared between groups of interest. This would facilitate a more objective evaluation of risk when putting in place service interventions.

It is important that in interpreting the results that the measure is seen in context. Allowances need to be made for levels of impairment (or casemix) and levels of informal support. The National Service Framework for Older People (Department of Health, 2001) provides guidance about proposed assessment tools for health and social care.

In addition to the core domains the instrument includes indicators of whether inputs from services and informal carers affect that domain. These provide helpful contextual information, but if changes in domains are to be linked to changes in levels of input in a research setting other measures will be needed. We suggest that the CSRI (Beecham and Knapp, 1992) should be used. This measures service input and includes an indicator of informal care input. Care needs to be taken in interpretation of the results of the informal care input as people tend to double count time. However, time spent on each of the domains together with an indication of other activities and total level of input can be used to indicate whether changes in met need could be ascribed to informal care input rather than service activity. It also would indicate whether services are substituting for carers, so outcomes would be for the carer rather than the older person him or herself. This, of course, begs the question how we measure outcomes for carers (see below).

6.3 Further work needed

For the instrument itself, more work is needed to validate and test reliability. The aim is to include the instrument in future large-scale evaluations. This will provide the scope for further tests of validity and reliability. Such exercises will also provide a further opportunity for testing the implications and acceptability of the two utility indexes derived.

An important issue to be addressed is the different perspectives of older people, their carers and professionals. If we are to measure outcomes for older people on the basis of their perspective and that of their carers, we need to resolve differences between these views and the perspective of professionals who are responsible for commissioning services to obtain the intended outcome. More work is needed to investigate what differences reflect and how these should be addressed when measuring outcomes.

The issue of measuring the outcomes of interventions aimed at improving both objective probabilities of serious events and the sense of safety requires further investigation. The results of the conjoint analysis suggested that generalised concern about safety was not weighted very highly in people’s preferences, but that specific worries might have different utility weighting. More work could explore how worries about different aspects of safety affect people, so pointing the way forward to any adaptations of the domain concerned with feelings of safety and consequent weighting of the index. Separate work is needed to identify the impact of the events themselves (identified in the ‘serious events’ section of the instrument) so providing a utility weighting that could be linked to probability of events occurring. Such work would best be undertaken in a wider context than just social care as the preventative agenda is very much a joint one with health services, and fear of crime is a concern of the criminal justice system.

Although we have provided an initial set of weights that reflect the preferences of our sample we have identified a number of issues in the process. If we are to be satisfied that we have weighting that accurately reflects the preferences of users, older people generally or the general population we need nationally representative samples of those groups. The evidence of this study suggests that conjoint analysis provides us with a reliable and valid approach for attaching utility weights. The sub-sample interviewed using a monetary attribute suggested that it would be straightforward to include this in a larger study and so identify a monetary measure of the utility gain. In order to refine the scoring system we would see a need for a larger scale study that would provide a representative sample of the group of interest. We suggest it would be particularly productive to identify a representative sample of older people and to link the exercise to establishing preferences for health care outcomes.

The variation in preferences found is of interest in its own right. While we may not want to identify different scorings for each potential sub-group, the results of this study indicate that it would be important to ensure studies are representative in terms of age structure. However, for some sub-groups, such as ethnic minorities, we might hypothesise that different cultures would affect preferences that should be reflected in a different wellbeing system. It is likely that a user specific index would also be useful. Exploratory work with users generally might identify important factors that should be reflected to make samples nationally representative.

It was identified above that the expected outcome for social care interventions will sometimes be expected for the carer rather than, or in addition to the older person. There is a need for a linked measure that reflects the utility gain for carers.

6.4 Conclusion

In the field of health use of utility-based health related quality of life measures has become widespread, indeed even required. If social care outcomes are to be valued and included we need to develop equivalent measures. This study has taken us a few steps along that road. The instrument and the associated utility indexes provide a tool for evaluating social care interventions in both a research and service setting. The discrete choice conjoint analysis exercise provides us with a new insight into the relative importance of the core domains to older people. Whilst discrete choice conjoint analysis is being increasingly used in health economics, this is the first study that has attempted to use it to derive a measure of outcome.

While interventions often err on the side of risk avoidance the evidence here suggests that feeling safe is less a priority than other domains. Being personally clean and socially integrated are what matters most to older people. Our measure allows us to reflect that in a quantitative way. Conjoint analysis has already demonstrated its strengths in the field of health care. As health and social care draw more closely together there would appear to be considerable potential, both for further development of the instrument itself and the use of conjoint analysis in the field of social care.

Appendix A

The Instrument

INSTITUTE OF
PSYCHIATRY

THE MAUDSLEY
CEMH

HERU
University of Aberdeen

PSSRU
at the University of Kent at Canterbury,
the London School of Economics
and the University of Manchester

OLDER PEOPLE'S UTILITY SCALE SOCIAL CARE

(OPUS-SC)

A MEASURE OF OUTCOME OF SOCIAL CARE OF OLDER PEOPLE

SOCIAL CARE IS CONCERNED WITH HELPING PEOPLE COMPENSATE FOR NEEDS CREATED BY IMPAIRMENT. THIS MEASURE AIMS TO IDENTIFY TO WHAT DEGREE ANY NEEDS HAVE BEEN MET. WHEN CODING QUESTION A IN EACH SECTION PLEASE REFLECT THE LEVEL OF NEED REMAINING ONCE ALL HELP BEING RECEIVED FROM WHATEVER SOURCE HAS BEEN TAKEN INTO CONSIDERATION.

1. FOOD & NUTRITION

ASSESSMENTS		
USER	CARER	STAFF

A) DOES THE PERSON GET ENOUGH APPROPRIATE FOOD TO EAT? ☐ ☐ ☐

Are you able to prepare your own meals?
Are you getting enough nutritious food?

0 =	NO PROBLEM	e.g. Able to buy and prepare appropriate meals.
1 =	ALL NEEDS MET	e.g. Sufficient, varied, timely meals.
2 =	LOW UNMET NEEDS	e.g. Does not always get appropriate food but there is no health risk.
3 =	HIGH UNMET NEEDS	e.g. Inadequate diet potentially resulting in a health risk.
9 =	NOT KNOWN	

IF RATED 0 or 9 GO TO SECTION 2 (PERSONAL CARE)

B) DOES THE PERSON RECEIVE HELP FROM *FRIENDS OR RELATIVES* WITH GETTING ENOUGH APPROPRIATE FOOD TO EAT? ☐ ☐ ☐

1= YES 2 = NO

C) DOES THE PERSON RECEIVE HELP FROM *SERVICES* WITH GETTING ENOUGH APPROPRIATE FOOD TO EAT ☐ ☐ ☐

1= YES 2 = NO

IF YES:

D) WHAT WOULD THE PERSONS LEVEL OF NEED BE IF THEY DID NOT RECEIVE HELP FROM SERVICES WITH GETTING ENOUGH APPROPRIATE FOOD TO EAT? ☐ ☐ ☐

(Assuming any current level of help from *friends or relatives* remains the same)
If you did not have these services what would happen?
or *If this service was not available what would be the effect?*

1 =	ALL NEEDS MET	e.g. Sufficient, nutritious, timely meals.
2 =	LOW NEED	e.g. Would not always get appropriate food but there would be no health risk.
3 =	HIGH NEED	e.g. Would have inadequate diet potentially resulting in a health risk.
9 =	NOT KNOWN	

2. PERSONAL CARE

ASSESSMENTS
USER CARER STAFF

A) DOES THE PERSON HAVE DIFFICULTY WITH SELF-CARE? ☐ ☐ ☐

Do you have any difficulty with personal care like washing, dressing, getting up and going to bed, going to the toilet etc.?
Do you ever need help? Do you always get the help you need?

0 =	NO PROBLEM	e.g. Able to keep clean and appropriately dressed.
1 =	ALL NEEDS MET	e.g. Always clean and appropriately dressed.
2 =	LOW UNMET NEEDS	e.g. Occasionally unwashed or not properly dressed.
3 =	HIGH UNMET NEEDS	e.g. Often dirty, with poor personal hygiene.
9 =	NOT KNOWN	

IF RATED 0 or 9 GO TO SECTION 3 (SAFETY)

B) DOES THE PERSON RECEIVE HELP FROM *FRIENDS OR RELATIVES* WITH PERSONAL CARE? ☐ ☐ ☐

1= YES 2 = NO

C) DOES THE PERSON RECEIVE HELP FROM *SERVICES* WITH PERSONAL CARE? ☐ ☐ ☐

1= YES 2 = NO

IF YES:

D) WHAT WOULD THE PERSONS LEVEL OF NEED BE IF THEY DID NOT RECEIVE HELP FROM SERVICES WITH PERSONAL CARE? (Assuming any current level of help from *friends or relatives* remains the same) ☐ ☐ ☐

If you did not have these services what would happen?
or *If this service was not available what would be the effect?*

1 =	ALL NEEDS MET	e.g. Would be always clean and appropriately dressed.
2 =	LOW NEED	e.g. Would be occasionally unwashed or not properly dressed.
3 =	HIGH NEED	e.g. Would be often dirty, with poor personal hygiene.
9 =	NOT KNOWN	

3. SAFETY

USER CARER STAFF

A) ARE THERE WORRIES ABOUT THE PERSONS SAFETY INDOORS OR WHEN GOING OUT?

☐ ☐ ☐

Do you feel safe and secure at home or when going out?
Are you worried about getting hurt e.g. having a fall?
Do you feel frightened by anybody?

PLEASE NOTE THAT "STAFF AND "CARER" CODINGS SHOULD REFLECT STAFF & CARER'S CONCERNS ABOUT THE OLDER PERSONS SAFETY. THE USER CODE REFLECTS HOW THE OLDER PERSON FEELS.

0 =	NO PROBLEM	e.g. No worries about safety.
1 =	ALL NEEDS MET	e.g. Support such that there are no worries about safety.
2 =	LOW UNMET NEEDS	e.g. Some worries about safety.
3 =	HIGH UNMET NEEDS	e.g. Extremely worried about safety.
9 =	NOT KNOWN	

IF RATED 0 or 9 GO TO SECTION 4 (SOCIAL PARTICIPATION & INVOLVEMENT)

B) DOES THE PERSON RECEIVE HELP FROM *FRIENDS OR RELATIVES* TO REDUCE WORRIES ABOUT SAFETY?

☐ ☐ ☐

1= YES 2 = NO

C) DOES THE PERSON RECEIVE HELP FROM *SERVICES* TO REDUCE WORRIES ABOUT SAFETY?

☐ ☐ ☐

1= YES 2 = NO

IF YES:

D) WHAT WOULD THE PERSONS LEVEL OF NEED BE IF THEY DID NOT RECEIVE HELP FROM SERVICES TO REDUCE WORRIES ABOUT SAFETY?

☐ ☐ ☐

(Assuming any current level of help from *friends or relatives* remains the same)
If you did not have these services what would happen?
or *If this service were not available what would be the effect?*

1 =	ALL NEEDS MET	e.g. There would be no worries about safety.
2 =	LOW NEED	e.g. There would be some worries about safety.
3 =	HIGH NEED	e.g. There would be extreme worries about safety.
9 =	NOT KNOWN	

4. SOCIAL PARTICIPATION & INVOLVEMENT

USER CARER STAFF

A) DOES THE PERSON NEED HELP WITH ESTABLISHING AND MAINTAINING SOCIAL CONTACT

☐ ☐ ☐

Are you visited or able to visit people as often as you would like?
Do you wish you had more social contact with others?

0 =	NO PROBLEM	e.g. Regular contact with people and able to organise and do all desired social activities.
1 =	ALL NEEDS MET	e.g. Sees people as often as would like.
2 =	LOW UNMET NEEDS	e.g. Feels lonely and socially isolated at times.
3 =	HIGH UNMET NEEDS	e.g. Socially isolated with little or no contact from others.
9 =	NOT KNOWN	

IF RATED 0 or 9 GO TO SECTION 5 AUTONOMY & CONTROL)

B) DOES THE PERSON RECEIVE HELP FROM *FRIENDS OR RELATIVES* IN FINDING OR KEEPING REGULAR SOCIAL PARTICIPATION & INVOLVEMENT?

☐ ☐ ☐

1= YES 2 = NO

C) DOES THE PERSON RECEIVE HELP FROM *SERVICES* IN FINDING OR KEEPING REGULAR SOCIAL PARTICIPATION & INVOLVEMENT?

☐ ☐ ☐

1= YES 2 = NO

IF YES:

D) WHAT WOULD THE PERSONS LEVEL OF NEED BE IF THEY DID NOT RECEIVE HELP FROM SERVICES IN FINDING OR KEEPING SOCIAL PARTICIPATION & INVOLVEMENT?
(Assuming any current level of help from *friends or relatives* remains the same)
If you did not have these services what would happen?
or *If this service was not available what would be the effect?*

☐ ☐ ☐

1 =	ALL NEEDS MET	e.g. Would see people as often as would like.
2 =	LOW NEED	e.g. Would be lonely and socially isolated at times.
3 =	HIGH NEED	e.g. Would be socially isolated with little or no contact from others.
9 =	NOT KNOWN	

5. CONTROL OVER DAILY LIVING

USER	CARER	STAFF
☐	☐	☐

A) DOES THE PERSON HAVE AS MUCH CONTROL AS POSSIBLE OVER DAILY LIVING?

Do you feel you have as much control over your daily life as possible? For example, do you feel you have choice over when and how services are delivered and what they do for you? Can you get out when you want to and do you feel your finances are appropriately managed?

1 =	ALL NEEDS MET	e.g. Has as much control over daily living as possible.
2 =	LOW UNMET NEEDS	e.g. Has some control over daily living but could have more.
3 =	HIGH UNMET NEEDS	e.g. Has no control over daily living.
9 =	NOT KNOWN	

IF RATED 9 GO TO SECTION 6 (SERIOUS EVENTS)

☐ ☐ ☐

B) DOES THE PERSON RECEIVE HELP FROM *FRIENDS OR RELATIVES* WITH CONTROL OVER DAILY LIVING?

1= YES 2 = NO

☐ ☐ ☐

C) DOES THE PERSON RECEIVE HELP FROM *SERVICES* WITH CONTROL OVER DAILY LIVING?

1= YES 2 = NO

IF YES:

☐ ☐ ☐

D) WHAT WOULD THE PERSONS LEVEL OF CONTROL OVER DAILY LIVING BE IF THEY DID NOT RECEIVE HELP FROM SERVICES?
(Assuming any current level of help from *friends or relatives* remains the same)
If you did not have these services what would happen?
or *If this service was not available what would be the effect?*

1 =	ALL NEEDS MET	e.g. Would have as much control over daily living as possible.
2 =	LOW NEED	e.g. Would have some control over daily living but could have more.
3 =	HIGH NEED	e.g. Would have no control over daily living.
9=	NOT KNOWN	

6. SERIOUS EVENTS

In many cases social care is provided in order to prevent or reduce serious threats to physical and mental welfare. This section is intended to identify whether any such incidents have taken place.

PLEASE IDENTIFY WHETHER ANY OF THE FOLLOWING SERIOUS EVENTS HAVE OCCURRED WITH THE CLIENT YOU ARE ASSESSING WITHIN THE LAST MONTH. DO NOT READ THIS LIST OUT – ONLY IDENTIFY THOSE EVENTS YOU KNOW ABOUT AS A RESULT OF THE ASSESSMENT.

Please tick all that occurred

Health related

1. SUFFERED FROM FOOD POISONING ☐

2. HAS THE PERSON VISIBLY LOST WEIGHT IN A WAY THAT MAY ☐

CONSTITUTE A HEALTH RISK?

3. FELL OR HAD A FALL (IF TICKED YES PLEASE SPECIFY A – E BELOW) ☐

a. Was the person left for a long period after a fall? ☐

b. Was the fall in the home? ☐

c. Was the fall outside? ☐

d. Did the fall involve admission to hospital? ☐

e. Has the person’s health deteriorated because of a fall? ☐

4. ATTEMPTED SUICIDE/EXPRESSED SUICIDAL TENDENCIES? ☐

5. INAPPROPRIATE TAKING OF MEDICATION ☐

e.g. unintentional overdose or non-compliance

6. SUFFERING FROM EXTREME COLD/HYPOTHERMIA ☐

Environmental

7. PERSON WAS A VICTIM OF CRIME (IF TICKED YES PLEASE SPECIFY A or B) ☐

a. Inside the home ☐

b. Outside the home ☐

8. LEFT THE GAS UNLIT e.g. burnt saucepans, gas left on for some time ☐

9. GOT LOST (either at daytime or night) ☐

10. SET HOME ON FIRE/FLOODED HOME (IF TICKED YES PLEASE SPECIFY A, B or C) ☐

a. Resulting in loss of home ☐

b. Resulting in major damage ☐

c. Resulting in minor damage ☐

Abuse

11. SUFFERED PSYCHOLOGICAL/SEXUAL ABUSE ☐

12. WAS BULLIED ☐

13. BEEN PHYSICALLY HURT BY SOMEBODY ☐

a. Relative or carer ☐

b. other ☐

14. HURT SOMEBODY ELSE ☐

15. SUFFERED FINANCIAL ABUSE (by relatives or carers) ☐

Neglect

16. EVIDENCE OF SELF NEGLECT OR BEING NEGLECTED BY CARER ☐

17. SERIOUS INCONTINENCE/TOILETING PROBLEMS e.g. left soiled for a long time ☐

18. UNABLE TO GET HOLD OF HELP WHEN NEEDED ☐

FINALLY	**Yes**	**No**
19. DID THE PERSON COME TO SERIOUS HARM DURING THE LAST MONTH?	☐	☐
a. As a result of any of the incidents identified (please specify below)		☐
b. As a result of another incident (please specify below)		☐

OLDER PEOPLE'S UTILITY SCALE
SOCIAL CARE

OPUS-SC

A MEASURE OF OUTCOME OF SOCIAL CARE OF OLDER PEOPLE

Guidance for users

If using this instrument please refer to Netten et al (2000) *The development of a measure of social care outcome for older people*, PSSRU Discussion Paper 1690, Personal Social Services Research Unit, University of Kent at Canterbury.

STRUCTURE OF MEASURE

The measure is designed as a tool for assessment of key social care outcomes. The "outcome" of a service package is identified by examining changes in level of met need and the degree this is related to service input. The measure is based on the CAN[1] and the CANE[2].

There are five principal domains within the measure. For each domain there are four questions covering met and unmet need, whether the person receives help from friends or relatives, whether the person receives help from local services, and what the persons level of need would be if they did not receive help from services. An added section is entitled **Serious Events,** which is to be used alongside the domain of Safety.

The measure includes the views of the service user, their carer and a staff member, typically the care manager. The time scale of the assessment is the last month, and this relatively short time should be stressed in interviews.

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[1] Phelan, M., Slade, M., Thornicroft, G., Dunn, G., Holloway, F., Wykes, T., Strathdee, G., Loftus, L., McCrone, P. And Hayward, P. (1995) *The Camberwell Assessment of Need* (Research Version 3.0) Manual.

[2] Orrell, M., Thornicroft, G., Phelan, M., Abas, M, and Woods, R. (Oct 1996-Sep 1997) *The development of a short, valid, multi-agency needs assessment scale for the elderly mentally ill by adaptation of the Camberwell Assessment for Needs project funded by North Thames R&D.*

QUESTION A

Asks if there is currently a problem in each topic area (in the last month). The objective is to identify the level of outstanding need that is not currently being met by either services or informal care. For each topic suggested questions to ask are in *italics*.

- If there are high unmet needs then **Rate 3**
- If there are low unmet needs then **Rate 2**
- If all needs are met than **Rate 1**
- If there is no problem **Rate 0**
- If you/person does not know **Rate 9**

High unmet need is scored when a person is incapable of looking after themselves and needs a high level of support, which they are not receiving. Low unmet need could occur when a person is getting no help and has low levels of need or when a person is getting help but not all needs are being met. If there is potential for physical harm or mental health problems immediately or as a result of the situation continuing over a period of time then the unmet needs are high.

All needs met indicates that a person is capable of looking after themselves and is receiving sufficient help in all areas. The difference between 'all needs met' and 'any unmet need' is that the individual or assessor feels they could benefit from further help in this domain. No problem is distinguished from all needs met when a person has the ability to perform tasks independently so does not need any help. This would mean that no help is required in order for the individual to supply their own personal needs (whether or not this is produced at a household level in practice). If the person rates 0 or 9 then go to the next page, otherwise complete the remaining questions.

QUESTIONS B and C

These questions ask about:

- Whether the person has received help from friends or relatives in this area of their life during the last month.
- Whether the person has received help from local services in this area of their life during the last month.

The objective is to establish whether any help is being provided by the informal sector or services within each of the domains with the ratings of 0=NO and 1=YES and 9=NOT KNOWN. **ONLY** if the person is receiving services that help them in the domain go on to question D. Otherwise go on to the next section.

QUESTION D

This question identifies what the persons level of need would be if they did not receive help from services in each topic area. For each topic suggested questions to ask are in *italics.* The aim is to assess the person's level of need without any input from services but given the current level of help from friends or relatives**.**

- If there would be high need then **Rate 3**
- If there would be low need then **Rate 2**
- If all needs met by friends or relatives then **Rate 1**
- If you/person does not know **Rate 9**

DOMAINS

1. FOOD AND NUTRITION

Definition

Met need constitutes a nutritious, varied and culturally appropriate diet with a person receiving three meals a day at regular, timely intervals. This may include a hot meal or equivalent prepared within a hygienic environment, either provided by family/friends or services. A distinction is made between no problem and full met need when the individual is able to prepare and eat his/her own food independently. This process includes shopping and being able to keep the home\kitchen in a way that facilitates the preparation of meals. If somebody just receives help with shopping then they should be coded as all needs met (1). Low need would occur if, for example, the timing of meals was erratic or the person got few (if any) hot meals or the food was culturally inappropriate. High need is distinguished from low need when the individual receives an inadequate diet that could potentially result in a health risk. This could happen within a community or residential care setting for example, and is particularly likely as a result of diabetes.

Activities

Service interventions which may help facilitate full met need may include receiving meals on wheels, attending lunch clubs, home-help preparing meals and doing the individual's shopping. This would also include supervision by a neighbour, friend, or carer when preparing and cooking meals. Cleaning of the kitchen environment or adaptations to the environment are also relevant within this domain when they help to facilitate preparation of food/meals.

2. PERSONAL CARE

Definition

Met need constitutes ensuring that a person who is not able to carry out their own personal care is personally clean and comfortable, presentable in appearance and is in bed or up at appropriate times of the day. A distinction is made between no problem and full met need when the individual is able to carry out their own personal care tasks without any formal supervision. Low need would occur if a person were not getting sufficient help with washing or dressing. High need is distinguished from low need when a person suffers from inadequate toileting or management of incontinence. This is applicable to both a community or residential care setting and an example of this may involve an individual being left wet or dirty for periods of time. If the person has high need levels but is getting help that means they have a few remaining needs they should be clarified as 'low need'. If this help is completely inadequate they should be clarified as 'high need'.

Activities

Activities include help with aspects of personal care such as bathing, washing, and dressing at a pace suitable to the individuals normal pattern of life. If the individual suffers from incontinence this would also include toileting at appropriate intervals of the day and associated laundry.

3. SAFETY

Definition

Met need constitutes the individual feeling safe and secure. No problem is distinguished from met needs when activities or other interventions are required in order to stop the individual or others worrying about their personal safety. People's perceptions of safety can vary considerably. Please ensure you distinguish how the older person feels about his or her own safety from how the carer feels about the older person's safety. The "staff" assessment should reflect the staff member or assessors concerns about the older persons safety. Examples of high unmet need would include concerns over potential abuse (physical or financial by staff) or physically inadequate buildings.

Activities

Supervision and monitoring by care managers/key workers or informal carers and regular visits from home care services are all levels of help to reduce the individual's sense of feeling unsafe. Similarly, alarms and other adaptations to the home are sources of help as a precaution to the risk of falls, and a function of ensuring help from social care agencies in the event of an emergency.

4. SOCIAL PARTICIPATION & INVOLVEMENT

Definition

Social isolation (as opposed to choosing to be alone) can result from either a person not being able to get in contact from others or being unable to relate to the others with whom they come into contact. Codings should reflect the situation at the time of assessment rather than speculation about what might happen and should reflect individual preferences for this domain. Needs would be fully met if the individual is content with their level of emotional support, general social contact and level of community participation. No problem is distinguished from met need when a person receives emotional support through community participation independently and without the need of intervention by social and/or informal care agencies. Low need occurs when, for example, there is insufficient emotional support or an individual cannot participate in the community as much as they would wish. High level unmet need occurs when individuals become socially isolated with little or no contact from others and/or are distressed by their perceived level of isolation. An example of this in a community setting may include a person with little or no visitors, never being able to move away from the confines of their home. In a residential care setting this would include being left within the home without anyone to speak to either in their room, or isolated within communal seating arrangements. Or in both settings this could include no attempt being made to overcome communication difficulties.

Activities

Service interventions include the use of day services such as lunch clubs; day centres, transport facilities and organised activity via voluntary sector organisations. Informal sector interventions include regular visits and outings with family and friends.

5. CONTROL OVER DAILY LIVING

Definition

Need is fully met when a person is judged (by themselves, the carer, or staff member) to have optimal control of their life. This would mean that nothing more could be done to give the person a sense of control. This is likely to be quite a frequently unmet need in residential care as it takes considerable effort in this setting to allow all individuals to have as much control as they possibly could over their daily life. High unmet need examples would include situations where a person has no choice over clothing, bathing times, meals, mealtimes, when and if they can go out and so on. As with other domains perceptions may vary and the coding for the elderly person, staff/assessor or carer ratings should reflect these.

Activities

A wide variety of activities may be associated with enabling the individual to have as much control as possible. This may range between an individual with dementia being given choice over what clothes they wear each day, interpretation for an individual with communication difficulties or home cleaning services for those whose perception of control is rooted in their home environment.

SERIOUS EVENTS

The objective of this section is to identify actual level of occurrence of the events that constitute a serious risk to the welfare of older people with disabilities. Please identify whether any of the events have occurred during the past month (questions 1-18) and, whether the person came to serious harm as a result (question 19).

Appendix B

Vignettes Used for Testing the Measure

INSTITUTE
OF
PSYCHIATRY

THE MAUDSLEY
CEMH

HERU
University of Aberdeen

MEASURING SOCIAL CARE OUTCOME FOR OLDER PEOPLE (SocQol)

PSSRU
at the University of Kent at Canterbury,
the London School of Economics
and the University of Manchester

VIGNETTES EXERCISE

Please read the six vignettes that describe situations of met and unmet need. We would like you to complete the prototype of the instrument for each of the vignettes on the adjacent page by ticking one of the four boxes within each of the five domains. We can then test whether different people will rate the same circumstances in the same way. Guidance on completing the instrument is provided. It is planned that each respondent will rate six vignettes. The exercise should take between 30 and 40 minutes at most. Please note that this is not a test and we do appreciate your participation in this exercise.

Code ☐☐☐☐☐

NAME (Optional):

OCCUPATION:

DATE:

Please return to:
Paul Smith, Personal Social Services Research Unit, Cornwallis Building, University of Kent at Canterbury, Canterbury, Kent, CT2 7NF.
Tele: 01227 827194 Fax: 01227 827038 email: p.smith-9@ukc.ac.uk

Vignette 1

Mrs A lives with and is cared for by her husband. She suffers from generalised osteo-arthritis and osteoporosis. For the most part Mrs A walks with a zimmer frame. Her husband is very supportive and caring and provides all meals, as Mrs A is unable to do this independently. Mrs A needs assistance with all aspects of personal care, although she can use the toilet independently during the day. Home-care assists with personal care during the day, and her husband assists with any domestic tasks and manages all her finances. All appropriate benefits are being received. Although very caring, Mrs A's husband is unsteady on his feet, and has occasionally got into difficulties when helping her. There are some concerns that they may hurt themselves. They have refused an alarm system, however. Mrs A doesn't socialise very much and her reduced mobility has had little affect on her social participation. If she goes out or friends call, her husband assists her. Mrs A likes to make decisions about her care package. She is happy with her current care package.

Vignette 2

Mr B has been in a nursing home for two years (self-funded). His capital is now below £16,000 and he will now require funded assistance through social services. Mr B is 92 years old. Since suffering a stroke Mr B needs assistance with mobility and all aspects of personal care. One person helps him to wash and dress himself. He also has assistance with toileting, as he does not open his bowels himself. Mr B appears confused at times and has recently had a few falls. A staff member has found him on the floor in the morning. Mr B feels very isolated; he finds it hard to communicate with staff and has been frequently left on his own within his room. Mr B needs help making sure he gets enough to eat as he does try to feed himself but loses interest. Staff provide him with occasional hot drinks and snacks during the day. Mr B's sensory loss is quite pronounced and although he has a new hearing aid his comprehension is poor. Mr B chooses not to take control over activities of daily living, but prefers to leave this in the hands of staff and social services.

Vignette 3

Mr C is terminally ill with lung cancer. He wishes to die at home. His wife is able to prepare his meals and drinks, but is unable to provide the level of personal care required during the day. Mr C requires assistance with all aspects of personal care, washing, dressing, oral hygiene, toileting, and laundry. Initially, Mr C was able to walk and transfer with two people, but as his illness worsened he became prone to falling and a hoist was required for transfers. Mobility has ceased and Mr C has fallen on a number of occasions. His wife cannot lift him but still tries to do so, putting them both at risk. This problem means he is also left soiled for periods of time. Due to a mix up he is currently receiving no nursing support. Mr C receives emotional support from his wife but he does not go out of the house with his family and friends. Mr C feels despondent at being confined to the hospice or his home. He is unable to take part in any activities of daily living due to his illness and is unhappy at being so dependent on other people. Mr C reminisced about playing golf and missing his former active life.

Vignette 4

Mrs D lives alone. Her son manages to shop for her weekly although this is sometimes difficult due to work commitments and living 20 miles away. He is unable to ensure that Mrs D cooks and eats the food provided and according to her son she is losing weight. Mrs D appeared neglected and her clothes were dirty. Mrs D suffers from occasional incontinence and feels she "has let herself go" since her radiotherapy. She is fiercely independent and refuses the help of social services but feels unable to manage her house and activities of daily living, as she would wish. She never has mixed with people other than her family, and generally prefers her own company. Recently, Mrs D's son persuaded her to have an alarm system installed to monitor her safety and summon help if she has a fall. He telephones her regularly and spends weekends with her as he has done since he left home.

Vignette 5

Mrs E has difficulties with her mobility and uses a zimmer frame to walk around her home safely. A package of care was designed to meet Mrs E's specific needs by formal support networks as the family had withdrawn support except for managing finances. Mrs E has previously tried meals on wheels and had not enjoyed these, so arrangements were made with a local cafeteria to prepare a hot lunch daily which the home care collects and delivers each day. Although cold food is left she is unable to get hot meals and snacks, particularly during the evening. Mrs E needs help with shopping and some preparation of meals of which her neighbour occasionally helps her. Mrs E is able to wash her hands and face but requires the use of a chair at the sink to do this. She is able to access and use the toilet independently. At times however, she has problems dressing and waits in her night-clothes until lunchtime when her homecare arrives. Mrs E has regular visits from occupational therapy and physiotherapy to ensure maximum mobility. An emergency communication system has also been installed. Mrs E has attended a day centre in the past but now chooses to remain at home; she has a neighbour who visits each day and brings her a daily paper to read. A large package of care has been provided to respect Mrs E's wishes to remain in her own home rather than moving to residential care.

Vignette 6

Mr F is unable to prepare a main meal due to his sensory disabilities and cannot read the dates and cooking instructions on the packaging. His private carer who he only employs for an hour a week tries to keep a check on his fridge and on many occasions throws food away, which is out of date or contaminated. Mr F has suffered food poisoning on occasions but still refuses help from social services therefore hygiene standards are questionable. His carer feels that additional support is required for him to maintain a reasonable standard of hygiene. Mr F is at risk of falling out of bed and attempting to walk on his own and is unable to summon help. He has refused help in the form of day services and an alarm system. He rarely has visitors and has refused offers of transportation by a neighbour to a nearby lunchclub. Mr F has no friends who call as they have all passed on. He requires and is dependent on the help of his private carer. Although he can determine what his carer does, he is unable to control the times at which she is able to visit him. The carer is restricted by her work and can only visit Mr F at certain times during the week.

1. Food & Nutrition

		Please Tick
a) NO PROBLEM	e.g. Able to buy and prepare appropriate meals.	☐
b) ALL NEEDS MET	e.g. Sufficient, varied, timely meals.	☐
c) LOW UNMET NEEDS	e.g. Does not always get appropriate food but there is no health risk.	☐
d) HIGH UNMET NEEDS	e.g. Inadequate diet potentially resulting in a health risk.	☐

2. Personal Care

		Please Tick
a) NO PROBLEM	e.g. Able to keep clean and appropriately dressed.	☐
b) ALL NEEDS MET	e.g. Always clean and appropriately dressed.	☐
c) LOW UNMET NEEDS	e.g. Occasionally unwashed or not properly dressed.	☐
d) HIGH UNMET NEEDS	e.g. Often dirty, with poor personal hygiene.	☐

3. Safety

		Please Tick
a) NO PROBLEM	e.g. No worries about safety.	☐
b) ALL NEEDS MET	e.g. Support such that there are no worries about safety.	☐
b) LOW UNMET NEEDS	e.g. Some worries about safety.	☐
c) HIGH UNMET NEEDS	e.g. Extremely worried about safety.	☐

4. Social Participation & Involvement

		Please Tick
a) NO PROBLEM	e.g. Regular contact with people and able to organise and do all desired social activities.	☐
b) ALL NEEDS MET	e.g. Sees people as often as would like.	☐
c) LOW UNMET NEEDS	e.g. Feels lonely and socially isolated at times.	☐
d) HIGH UNMET NEEDS	e.g. Socially isolated with little or no contact from others.	☐

5. Control over daily living

		Please Tick
a) ALL NEEDS MET	e.g. Has as much control over daily living as possible.	☐
b) LOW UNMET NEEDS	e.g. Has some control over daily living but could have more.	☐
c) HIGH UNMET NEEDS	e.g. Has no control over daily living.	☐

Appendix C

Example Scenarios Used in Discrete Choice Analysis Fieldwork

1. Main questionnaire example scenario

SITUATION A
DESCRIPTION

You have sufficient, varied, timely meals and you are always clean and appropriately dressed. You also have as much control over daily living as possible.

But, you have some worries about safety and you feel lonely and socially isolated at times.

2. Main questionnaire example scenario – no unmet safety needs

SITUATION E
DESCRIPTION

You have sufficient, varied, timely meals and you have no worries about safety.

But, you are often dirty with poor personal hygiene. You also feel lonely and socially isolated at times and you have no control over daily living.

3. Financial attribute questionnaire example scenario

SITUATION C2

You are always clean and appropriately dressed and you have no worries about safety. You also have as much control over daily living as possible. You do not always get appropriate food but there is no real health risk and you feel lonely and socially isolated at times. You are receiving benefits of £150 per week.

4. Follow-up study example scenario with low level unmet needs about safety expressed in terms of falling

SITUATION FA

DESCRIPTION

You have sufficient, varied, timely meals and you are always clean and appropriately dressed. You also have as much control over daily living as possible.

But, you have some worries about falling and you feel lonely and socially isolated at times.

5. Follow-up study example scenario with low level unmet needs about safety expressed in terms of falling

SITUATION FB
DESCRIPTION

You have an inadequate diet potentially resulting in a health risk and you are often dirty, with poor personal hygiene. You are extremely worried about falling and hurting yourself and you are also socially isolated with little or no contact from others. You have some control over daily living but could have more.

Appendix D

Analysis of Follow-Up Study

This analysis was undertaken to investigate the concerns over the safety attribute results. While safety was consistently indicated to be the least regarded attribute, it was regarded as problematic in that it was often seen to be internally inconsistent. A priori, we would expect a reduction (or at least no significant change) in utility from moving from a level of no unmet needs through low unmet needs to high unmet needs. However, it was found that in some analyses, the two extreme levels of high unmet needs and no unmet needs were insignificantly different from each other, while the level between them of low unmet needs indicated a significantly lower utility level.

There were potentially two reasons for this result. The first was that the definition of safety or its use in the interview was in some way confusing to the respondents and that they incorrectly identified the three levels of the safety attribute over which to trade with the other attributes. It was the most general and the least described in the scenarios, as it was simple a no worries, some worries or extremely worried about safety descriptions. The second reason might be due to a design fault of the questionnaire that meant that there might not be enough variation over the situations to correctly identify the safety attribute levels and their trading with the other attributes and their levels.

In order to investigate this a follow-up study was carried out. The aim was to look at the effect of a change of design and a change in the definition of the safety attributes. In order to isolate any potential cause, first the new design of the experiment was put to the respondents, but with the original definition of the safety attribute. While the previous design had adequate levels of orthogonality and minimal overlap it was not particularly well balanced. The new design ensured that there was a similar number of different levels compared for each domain. The respondents were then asked to repeat the exercise, but this time with the new design of questionnaire and a new definition of the safety attribute. The new definition was a narrower concept of safety, that there were no worries about falling, moving to some worries about falling through to extremely worried about falling and hurting yourself.

The safety questionnaire was completed by 65 individuals who had participated in the original survey. Tests of inconsistencies were carried out on both the original definition and new design part of the questionnaire and the new definition and new design part of the questionnaire. These two parts were regarded separately and so any inconsistent response from one part was not carried over the second part of the questionnaire. A respondent was regarded as inconsistent and therefore excluded from the analysis if they answered inconsistently in two occasions. One respondent was regarded as inconsistent in both parts of the questionnaire. One individual could not identify which situation they regarded as worse and replied both/neither to all situations. These responses were excluded from the analysis. This left 64 individuals in the new design, original definition analysis, and 62 individuals in the new design and new safety definition analysis.

New design, old definition

Table D.1 shows the model estimated when all levels of all the domains are included.

Table D.1: Original safety definition, new design

Domains		Coefficient	Standard error	p
Food and nutrition				
No unmet needs		0.8232	0.1587	0.001
Low unmet needs		0.3342	0.1695	0.049
Personal care				
No unmet needs		1.4858	0.2365	0.001
Low unmet needs		0.3135	0.1621	0.053
Safety				
No unmet needs		0.193	0.1591	0.225
Low unmet needs		-0.1433	0.2403	0.551
Social participation				
No unmet needs		0.9224	0.1719	0.001
Low unmet needs		0.5820	0.2791	0.037
Control over daily living				
No unmet needs		0.6476	0.1374	0.001
Low unmet needs		0.4612	0.1403	0.001
Number of people	64			
Number of observations	483			
McFadden R^2	0.374			

Table D.2 shows the model estimated when only those levels shown to be statistically significantly different to each other are included. The safety attribute

Table D.2: Original safety definition, new design, re-categorised

Domains		Coefficient	Standard error	p
Food and nutrition				
No unmet needs		0.6958	0.1371	0.001
Low unmet needs		0.2779	0.1483	0.061
Personal care				
No unmet needs		1.4002	0.1776	0.001
Low unmet needs		0.2654	0.1272	0.037
Social involvement				
No/low unmet needs		0.7391	0.1160	0.001
Control over daily living				
No/low unmet needs		0.4985	0.1017	0.001
Number of people	64			
Number of observations	483			
McFadden R^2	0.364			
% of correct predictions	78.3			

was dropped from the analysis as the attribute levels were not statistically significant from each other. This meant that Safety was not considered or traded against the other domains. Both social participation and control over daily living indicated that the no unmet need level could be merged with the low unmet need level and that this new merged category could then be compared against the high unmet need level.

The results were encouraging in that they were very similar to the original model, suggesting that the impact of any design problems were minimal. Compared to the original model, that is the same definitions but different experimental design, the most obvious difference is that the safety attribute was no longer included in the model. However, this was also true when the model was run on the original decisions made in the first questionnaire by these respondents. There was some difference in the re-categorisation of the attribute levels. Notably, the food attribute remained very much distinct in all three levels possible, whereas in the original design, the analysis indicated that no and low unmet needs were not distinct levels from each other. This was true both for the full sample and for the sub-sample of individuals who were followed up. The opposite was true for social involvement. There the original design indicated that no and low unmet needs should be kept as distinct categories while in the new design, they could be merged. In terms of the ranking of the attributes, from best to worst case scenario, individuals regarded personal care over social involvement over food over control over daily living. This is the same ordering as for the main model.

New design, new definition

Table D.3 shows the results of the analysis when the new, more specific definition of having unmet needs in the domain of safety was used. In table D.4 the model is re-categorised to take into consideration that low unmet needs of safety was not found to be statistically significantly different from high unmet needs of safety at the 10 per cent level. The same was true for low unmet needs and high unmet needs in terms of social involvement. No unmet needs and low unmet needs in terms of control over daily loving were also not significantly different from each other and could therefore be merged. For food and nutrition no and low unmet

Table D.3: New safety definition, new design

Domains		Coefficient	Standard error	p
Food and nutrition				
No unmet needs		0.7013	0.1612	0.001
Low unmet needs		0.4069	0.1530	0.008
Personal care				
No unmet needs		0.9615	0.1955	0.001
Low unmet needs		0.2585	0.1463	0.077
Safety				
No unmet needs		0.5657	0.1326	0.001
Low unmet needs		-0.1001	0.2416	0.679
Social participation				
No unmet needs		0.9530	0.1643	0.001
Low unmet needs		0.1014	0.2242	0.651
Control over daily living				
No unmet needs		0.8660	0.1409	0.001
Low unmet needs		0.7403	0.1345	0.001
Number of people	62			
Number of observations	473			
McFadden R^2	0.333			

Table D.4: New safety definition, new design, re-categorised

Domains	Coefficient	Standard error	p
Food and nutrition			
No unmet needs	0.7014	0.1331	0.001
Low unmet needs	0.4306	0.1424	0.003
Personal care			
No unmet needs	0.9258	0.1465	0.001
Low unmet needs	0.2855	0.1164	0.014
Safety			
No unmet needs	0.5301	0.1226	0.001
Social participation			
No unmet needs	0.9115	0.1250	0.001
Control over daily living			
No/low unmet needs	0.8094	0.1053	0.001
Number of people 62			
Number of observations 473			
McFadden R^2 0.331			
% of correct predictions 77.0			

needs were kept separate as they were distinct at the 5.5% significance level. Personal care low unmet need was kept separate from high unmet needs as it was distinct at the 7.7% level.

The ranking of the attributes in terms of the move from the worst case scenario to the best case scenario indicated that personal care was regarded over social involvement over control over food with safety once again being the least regarded attribute. This is the same ranking as the original model with the original experimental design and original definition of the safety attribute.

Table D.5 shows the estimated utility weights based on the analyses of the two sets of choices provided.

Table D.5: Utility weights of domain for follow-up sample

Domains	Type of wording used in safety domain	
	Falls (n = 64)	Original wording (n = 62)
Food and nutrition		
No unmet needs	0.1809	0.2087
Low unmet needs	0.1110	0.0834
Personal care		
No unmet needs	0.2387	0.4200
Low unmet needs	0.0736	0.0796
Safety		
No unmet needs	0.1367	0.0
Low unmet needs	0.0	0.0
Social participation		
No unmet needs	0.2350	0.2217
Low unmet needs	0.0	0.2217
Control over daily living		
No/low unmet needs	0.2087	0.1495

Note: The reference category is high unmet need. Where two categories are combined a single value is shown reflecting the utility weight for both categories.

Appendix E

Results of Segmentation Analysis

The following tables show the estimated initial model for each subgroup as described in chapter 5 for the main analysis. Non-statistically significantly different levels within domains are then grouped as indicated and the reduced model estimated. The utility values shown in table 5.7 are the re-scaled coefficients for each group based on the reduced model.

E.1 Age Analysis

Table E.1: 85 and over full model

Domains		Coefficient	Standard error	p
Food and Nutrition				
No unmet needs		0.6407	0.2429	0.008
Low unmet needs		0.7869	0.2834	0.006
Personal care				
No unmet needs		0.9673	0.2207	0.001
Low unmet needs		0.5849	0.1691	0.001
Safety				
No unmet needs		-0.2152	0.3475	0.536
Low unmet needs		-0.7254	0.4096	0.077
Social involvement				
No unmet needs		0.8349	0.2043	0.001
Low unmet needs		0.6164	0.2639	0.020
Control over daily living				
No unmet needs		0.5310	0.1655	0.001
Low unmet needs		0.3122	0.2859	0.275
Number of people	54			
Number of observations	419			
McFadden R^2	0.291			

Grouped levels

Domains	Category
Food and nutrition	No unmet need and low unmet needs
Safety	No unmet needs and high unmet needs
Social	No unmet needs and low unmet needs
Control over daily living	Low unmet needs and high unmet needs

Table E.2: 85 and over reduced model

Domains		Coefficient	Standard error	p
Food and Nutrition				
No/low unmet needs		0.7249	0.1515	0.001
Personal care				
No unmet needs		0.8333	0.1704	0.001
Low unmet needs		0.4266	0.1228	0.001
Safety				
No/high unmet needs		0.5187	0.1355	0.001
Social involvement				
No/low unmet needs		0.6415	0.1559	0.001
Control over daily living				
No unmet needs		0.4380	0.1153	0.001
Number of people	54			
Number of observations	419			
McFadden R^2	0.2762			
% of correct responses	78.5			

Table E.3: Age under 85 main model

Domains		Coefficient	Standard error	p
Food and nutrition				
No unmet needs		0.5279	0.1097	0.001
Low unmet needs		0.5367	0.1220	0.001
Personal care				
No unmet needs		1.0634	0.0946	0.001
Low unmet needs		0.5098	0.0737	0.001
Safety				
No unmet needs		-0.0486	0.1354	0.720
Low unmet needs		-0.3685	0.1817	0.043
Social involvement				
No unmet needs		1.0487	0.0942	0.001
Low unmet needs		0.6109	0.1168	0.001
Control over daily living				
No unmet needs		0.6267	0.0799	0.001
Low unmet needs		0.5584	0.1220	0.001
Number of people	272			
Number of observations	2145			
McFadden R^2	0.359			

Grouped levels

Domains	Category
Food and Nutrition	No unmet need and low unmet needs
Safety	No unmet needs and high unmet needs
Control over daily living	No unmet needs and low unmet needs

Table E.4: Under 85 reduced model

Domains	Coefficient	Standard error	p.
Food and nutrition			
No/low unmet needs	0.4659	0.0615	0.001
Personal care			
No unmet needs	1.1049	0.0750	0.001
Low unmet needs	0.5227	0.0611	0.001
Safety			
No/high unmet needs	0.2772	0.0707	0.001
Social involvement			
No unmet needs	1.0295	0.0595	0.001
Low unmet needs	0.5970	0.0800	0.001
Control over daily living			
No/low unmet needs	0.6433	0.0722	0.001
Number of people 272			
Number of observations 2145			
McFadden R^2 0.359			
% of correct responses 80.9			

E.2 Living alone/with others analysis

Of our initial sample of 326, there were three more individuals who had missing data about living circumstances.

Table E.5: Living alone full model

Domains	Coefficient	Standard error	p
Food and nutrition			
No unmet needs	0.5741	0.1270	0.001
Low unmet needs	0.6489	0.1407	0.001
Personal care			
No unmet needs	0.9707	0.1082	0.001
Low unmet needs	0.4754	0.0897	0.001
Safety			
No unmet needs	-0.1711	0.1626	0.293
Low unmet needs	-0.5248	0.2053	0.011
Social involvement			
No unmet needs	0.9089	0.1047	0.001
Low unmet needs	0.6455	0.1377	0.001
Control over daily living			
No unmet needs	0.5097	0.0873	0.001
Low unmet needs	0.3687	0.1325	0.005
Number of people 196			
Number of observations 1546			
McFadden R^2 0.308			

Grouped categories

Domains	Category
Food and nutrition	No unmet need and low unmet needs
Safety	No unmet needs and high unmet needs
Control over daily living	No unmet needs and low unmet needs

Table E.6: Living alone reduced model

Domains		Coefficient	Standard error	p
Food and nutrition				
No/low unmet needs		0.4383	0.0757	0.001
Personal care				
No unmet needs		1.0813	0.0874	0.001
Low unmet needs		0.4841	0.0722	0.001
Safety				
No/high unmet needs		0.2551	0.0852	0.003
Social involvement				
No unmet needs		0.8414	0.0710	0.001
Low unmet needs		0.5641	0.0919	0.001
Control over daily living				
No/low unmet needs		0.5577	0.0776	0.001
Number of observations	1546			
McFadden R^2	0.306			
% correct predictions	83.4			

Table E.7: Living with others full model

Domains		Coefficient	Standard error	p
Food and Nutrition				
No unmet needs		0.5528	0.1582	0.001
Low unmet needs		0.5747	0.1809	0.001
Personal care				
No unmet needs		1.1179	0.1357	0.001
Low unmet needs		0.6179	0.1032	0.001
Safety				
No unmet needs		-0.0309	0.1806	0.864
Low unmet needs		-0.4418	0.2389	0.064
Social involvement				
No unmet needs		1.2697	0.1335	0.001
Low unmet needs		0.6466	0.1612	0.001
Control over daily living				
No unmet needs		0.7541	0.1096	0.001
Low unmet needs		0.7403	0.1651	0.001
Number of people	127			
Number of observations	994			
McFadden R^2	0.428			

The same groupings of levels of met need within domains were made as for the group who lived alone.

Table E.8: Living with others reduced model

Domains	Coefficient	Standard error	P
Food and nutrition			
No/low unmet needs	0.5364	0.1049	0.001
Personal care			
No unmet needs	1.1400	0.1112	0.001
Low unmet needs	0.6161	0.0864	0.001
Safety			
No/high unmet needs	0.3956	0.0992	0.003
Social involvement			
No unmet needs	1.2497	0.0889	0.001
Low unmet needs	0.6233	0.0991	0.001
Control over daily living			
No/low unmet needs	0.7642	0.1005	0.001
Number of observations 994			
McFadden R^2 0.428			
% correct predictions 79.04			

E.3 Service users

Service users were defined as those who both were currently receiving services and had some type of impairment. Seventy-one cases identified themselves as such from the original sample. Once inconsistent respondents are eliminated from the sample, along with missing values for impairment status and current service care and age data to remain consistent with the initial analysis. This leaves 63 individuals who report themselves as having an impairment and receiving services. This is compared against the remaining 258 individuals who although might class themselves as disabled (122), or care receiving services (16), but not both. The joint sample now consists of 321 individuals compared to the original analysis of 326. This means a further five individuals have had to be eliminated from the analysis due to the missing values of the new variables that signal their impairment and service status.

Table E.9: Disabled and receive care services full model

Domains	Coefficient	Standard error	p
Food and nutrition			
No unmet needs	0.6003	0.2413	0.013
Low unmet needs	0.6670	0.2508	0.008
Personal care			
No unmet needs	0.6842	0.1819	0.001
Low unmet needs	0.4280	0.1910	0.025
Safety			
No unmet needs	-0.3408	0.3169	0.282
Low unmet needs	-0.5697	0.3336	0.088
Social involvement			
No unmet needs	0.8243	0.1860	0.001
Low unmet needs	0.7328	0.2836	0.010
Control over daily living			
No unmet needs	0.3483	0.1641	0.034
Low unmet needs	0.2501	0.2397	0.297
Number of people 63			
Number of observations 495			
McFadden R^2 0.24			

Regrouped categories

Domains	Category
Food and nutrition	No unmet need and low unmet needs
Personal care	No unmet needs and low unmet needs
Safety	No unmet needs and high unmet needs
Social	No unmet needs and low unmet needs
Control over daily living	No unmet needs and low unmet needs

As before low unmet needs in safety is kept as a separate category since it is significantly different from high unmet needs at the 10 per cent level. The control category can be merged in two ways, first as seen by the initial results, the category of low unmet needs is insignificantly different from the high unmet needs category. However, at the same time, no unmet needs is not significantly different from low unmet needs. Meanwhile the two extremes on each side of low unmet needs are significantly different from each other.

Table E.10: Disabled and receive care services reduced model

Domains	Coefficient	Standard error	P
Food and nutrition			
No/low unmet needs	0.5198	0.1171	0.001
Personal care			
No/low unmet needs	0.3901	0.1212	0.001
Safety			
No/high unmet needs	0.1106	0.1221	0.365
Social involvement			
No/low unmet needs	0.7259	0.1311	0.001
Control over daily living			
No/low unmet needs	0.3026	0.1406	0.031
Number of people 63			
Number of observations 495			
McFadden R^2 0.2257			
% of correct responses 74.7			

Table E.11: Not disabled and receive care services full model

Domains		Coefficient	Standard error	p
Food and nutrition				
No unmet needs		0.5942	0.1093	0.001
Low unmet needs		0.6310	0.1227	0.001
Personal care				
No unmet needs		1.1308	0.0993	0.001
Low unmet needs		0.5710	0.0733	0.001
Safety				
No unmet needs		-0.0598	0.1437	0.678
Low unmet needs		-0.4560	0.2022	0.024
Social involvement				
No unmet needs		1.0874	0.1042	0.001
Low unmet needs		0.6151	0.1184	0.001
Control over daily living				
No unmet needs		0.6460	0.0842	0.001
Low unmet needs		0.5541	0.1290	0.001
Number of people	258			
Number of observations	2029			
McFadden R^2	0.382			

Regrouped categories

Domains	Category
Food and nutrition	No unmet need and low unmet needs
Safety	No unmet needs and high unmet needs
Control over daily living	No unmet needs and low unmet needs

Table E.12: Not disabled and receive care services reduced model

Domains		Coefficient	Standard error	P
Food and nutrition				
No/low unmet needs		0.5265	0.0661	0.001
Personal care				
No unmet needs		1.1992	0.0778	0.001
Low unmet needs		0.5896	0.0607	0.001
Safety				
No/high unmet needs		0.3356	0.0766	0.001
Social involvement				
No unmet needs		1.0559	0.0653	0.001
Low unmet needs		0.5847	0.0791	0.001
Control over daily living				
No/low unmet needs		0.6718	0.0743	0.001
Number of people	258			
Number of observations	2029			
McFadden R^2	0.381			

The difference in behaviour between service users as defined here and other respondents was confirmed by a likelihood test. $\chi^2 = 22.48$ was compared to the 95 per cent critical value of $\chi^2(10) = 18.31$. Thus the null hypothesis, that the coefficients on the attribute levels are the same for the disabled and care service receiving individuals as compared to those individuals who are not both disabled and receiving care services, was rejected.

E.4 Place of interview

The interviews of the original 356 subjects were carried out in seven types of location. The distribution of location of interview is given in table E.13.

Table E.13: Place of interview

Place of interview	Frequency
Own home	126
Day centre/lunch club	196
Residential care/nursing home	14
Daughter's home	1
Royal British Legion	10
Parent's home	1
Friend's house	6
Missing information	2
Total	356

The analysis was therefore carried out on the 326 individuals as identified in the earlier analysis, but also excluding two additional individuals who did not have information on their place of interview.

Table E.14: Day centre interviewee full model

Domains		Coefficient	Standard error	p
Food and nutrition				
No unmet needs		0.3638	0.1310	0.006
Low unmet needs		0.3182	0.1482	0.032
Personal care				
No unmet needs		1.0749	0.1164	0.001
Low unmet needs		0.4978	0.0906	0.001
Safety				
No unmet needs		0.0002	0.1629	0.999
Low unmet needs		-0.2922	0.2083	0.161
Social involvement				
No unmet needs		0.8759	0.1106	0.001
Low unmet needs		0.4873	0.1448	0.001
Control over daily living				
No unmet needs		0.5278	0.0923	0.001
Low unmet needs		0.5176	0.1500	0.001
Number of people	196			
Number of observations	1353			
McFadden R^2	0.292			

For this analysis, the safety attribute falls out of the analysis since the safety attribute levels are not statistically distinct from each other (at the 5 per cent level or 10 per cent level). This effectively means that safety is not considered/traded with the other attributes. The food and nutrition attribute has the no unmet needs and low unmet needs levels merged as individuals do not make a statistical distinction between these two levels. Similarly the no unmet needs and low unmet needs in terms of control over daily living are merged into one category to be compared against high unmet needs.

Table E.15: Day centre interviewees reduced model

Domains		Coefficient	Standard error	P
Food and nutrition				
No/low unmet needs		0.2922	0.0759	0.001
Personal care				
No unmet needs		1.0327	0.0895	0.001
Low unmet needs		0.5009	0.0731	0.001
Social involvement				
No unmet needs		0.8001	0.0687	0.001
Low unmet needs		0.5159	0.0938	0.001
Control over daily living				
No/low unmet needs		0.5474	0.0803	0.001
Number of people	196			
Number of observations	1353			
McFadden R^2	0.285			
% of correct predictions	77.6			

The remaining 151 individuals who were interviewed at the places other than the day-care centres or lunch clubs are now analysed. Table E.16 reports the results from the full model.

Table E.16: Non day interviewee full model

Domains		Coefficient	Standard error	P
Food and nutrition				
No unmet needs		0.7623	0.1540	0.001
Low unmet needs		0.9041	0.1795	0.001
Personal care				
No unmet needs		1.0677	0.1345	0.001
Low unmet needs		0.5987	0.1026	0.001
Safety				
No unmet needs		-0.1375	0.2121	0.517
Low unmet needs		-0.5623	0.2902	0.053
Social involvement				
No unmet needs		1.2365	0.1439	0.001
Low unmet needs		0.7995	0.1555	0.001
Control over daily living				
No unmet needs		0.7728	0.1170	0.001
Low unmet needs		0.5898	0.1713	0.001
Number of people	151			
Number of observations	1195			
McFadden R^2	0.424			

The attribute levels are now re-categorised according to the statistical findings of which attribute levels are distinct from each other. The food and nutrition attribute, once again, has the no unmet needs and low unmet needs levels merged, as individuals do not make a statistical distinction between these two levels. The no unmet needs and low unmet needs in terms of control over daily living are merged into one category to be compared against high unmet needs. Low unmet needs for safety is statistically significantly different from high unmet safety needs, at the 5 per cent level. However, no unmet needs are not significantly different from high unmet needs. This means that once again, the results suggest a merging together of the two extreme safety attribute levels.

Table E.17: Non day centre interviewees reduced model

Domains	Coefficient	Standard error	P
Food and nutrition			
No/low unmet needs	0.6555	0.0899	0.001
Personal care			
No unmet needs	1.2307	0.1112	0.001
Low unmet needs	0.6315	0.085	0.001
Safety			
No/high unmet needs	0.2901	0.0983	0.003
Social involvement			
No unmet needs	1.1572	0.0915	0.001
Low unmet needs	0.6965	0.1224	0.001
Control over daily living			
No/low unmet needs	0.8271	0.1087	0.001
Number of people 151			
Number of observations 1195			
McFadden R^2 0.420			
% of correct predictions 83.8			

A log likelihood test indicates that the two different groups of interviewees should be treated separately. The unrestricted log likelihood value of -1116.124 (unrestricted in the sense that the two groups are allowed to differ) is compared against the restricted model's likelihood value (restricting the two groups to be treated as one) of -1131.695. This gives a test statistic of 31.14 which is greater than the 95% critical value of $\chi^2(10)$ =18.31. The null hypothesis of the same coefficients for the day care centre interviewees and the non day-care centre interviewees can therefore be rejected.

E.5 Inclusion of monetary domain

The monetary attribute was included as a level of weekly benefit in the situations from which the respondents made discrete choices. It was assumed that weekly benefits were 'good' and so the higher the weekly benefit in a situation, the more likely the respondent will be to prefer that situation. The values of the weekly benefit ranged from a zero value, £0, up to a maximum of £300 per week. The intermediate weekly benefits are £20, £50, £100, £150, and £200. This questionnaire was given to 49 individuals. Once again the test for inconsistent responses considered individuals who, on at least two occasions, made what was deemed irrational choices. Only four individuals chose inappropriately on more than one occasion. This reduced the sample to 45 individuals. The model estimated was as the main model but including the additional monetary domain.

Table E.18: Monetary full model

Domains	Coefficient	Standard error	P
Food and nutrition			
No unmet needs	0.5385	0.1414	0.001
Low unmet needs	0.4045	0.1425	0.005
Personal care			
No unmet needs	0.7262	0.1178	0.001
Low unmet needs	0.3789	0.1605	0.018
Safety			
No unmet needs	0.4427	0.1405	0.002
Low unmet needs	0.2333	0.1343	0.082
Social involvement			
No unmet needs	0.4442	0.1502	0.003
Low unmet needs	-0.0843	0.1282	0.511
Control over daily living			
No unmet needs	0.5045	0.2168	0.020
Low unmet needs	0.2681	0.1833	0.144
Benefits (£)	0.00227	0.00069	0.001
Number of people 45			
Number of observations 622			
McFadden R^2 0.251			

The need levels merged based on statistical differences were not the same as the original pooled model. The safety attribute ‘behaves’ better than in the original model. Now no unmet needs are merged with low unmet needs.

Regrouped categories

Domains	Category
Food and nutrition	No unmet need and low unmet needs
Safety	No unmet needs and low unmet needs
Social	Low unmet needs and high unmet needs
Control over daily living	No unmet needs and low unmet needs

Table E.19: Reduced monetary model

Domains		Coefficient	Standard error	P
Food and nutrition				
No/low unmet needs		0.4281	0.1115	0.001
Personal care				
No unmet needs		0.7010	0.1093	0.001
Low unmet needs		0.4026	0.1244	0.001
Safety				
No/low unmet needs		0.1900	0.1022	0.063
Social involvement				
No unmet needs		0.4897	0.1105	0.001
Control over daily living				
No/low unmet needs		0.4506	0.1625	0.006
Benefits (£)		0.00171	0.00064	0.008
Number of people	45			
Number of observations	622			
McFadden R^2	0.238			
% of correct predictions	75.2			

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