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## Developing a measure of social care outcome for older people

Interim Report

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The **PERSONAL SOCIAL SERVICES RESEARCH UNIT** undertakes social and health care research, supported mainly by the United Kingdom Department of Health, and focusing particularly on policy research and analysis of equity and efficiency in community care, long-term care and related areas—including services for elderly people, people with mental health problems and children in care. The PSSRU was established at the University of Kent at Canterbury in 1974, and from 1996 it has operated from three sites:

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## SUMMARY

1. An essential element of identifying Best Value and monitoring cost-effective care, key policy objectives (Department of Health, 1998), is to be able to identify the outcomes of care. This paper reports on 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.
2. There is a need for a measure in the field of social care that can compare outcomes over a range of different circumstances, which links directly to the objectives of social care for elderly people and that reflects welfare gain from services. The aim of this project is to devise such a measure.
3. 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 have taken 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.
4. 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.
5. The initial measure that was circulated has been simplified and refined on the basis of the reference group feedback, further consultation and the experience of the care managers. The instrument to be tested in the next stage of the project 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.

6. A small group of older people have been interviewed with a view to identifying the practicality of different approaches to establishing weights to reflect the relative importance of the domains incorporated in the measure.
7. While the results of the 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. For these reasons we do not consider self-completion questionnaires an appropriate way forward. With interviews we are satisfied we would have some confidence in the findings.
8. Initial investigations into including a financial dimension suggested that, although this would provide a valuable perspective to the results, there were serious concerns if this were included as part of the main survey of older people's preferences. Re-interviewing a subsample of older people would potentially allow this aspect to be explored in more depth. If successful it may be possible to draw some wider conclusions about the main sample. If unsuccessful it would provide some useful methodological insights.
9. The next steps are to test the measure itself and to conduct the fieldwork required for estimating weights. This requires:
  - Care managers using the measure in practice for a sample of older people. This will allow examination of practicality, construct validity and consistency. This is currently in the field;
  - Testing the measure on a sample of 30 or more care managers for inter-rater reliability;
  - Piloting the approaches to be used to establish preferences on 20 older people;
  - Mainstage fieldwork: interviewing 300 older people;
  - Re-interviewing 50 respondents to establish test-re-test reliability;
  - Re-interviewing 50 other respondents incorporating a financial dimension.

## **SECTION I BACKGROUND**

An essential element of identifying Best Value and monitoring cost-effective care, key policy objectives (Department of Health, 1998), is to be able to identify the outcomes of care. This paper reports on 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 section we consider what we mean by social care before outlining the type of measure to be developed and the method being 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 and disability or at the very least, maintain ability at as high a level as possible. Social care, on the other hand, is concerned with managing or impacting upon the effect of disability (or handicap). Health-based outcome measures that pick up changes in ability are thus often inappropriate to social care services where the objective is to meet the needs created by the disability 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, to date, 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), EuroQol (EuroQol Group, 1990) and more recent attempts to give utility scores to SF36 health outcome states (Brazier, 1993). 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.

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 is to develop a measure of outcome for social care that could perform a similar function to that which QALYS provide for health care. This type of measure does not measure 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 which 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 is to develop the instrument itself. This requires that first we identify commodities or domains that should be included and then how these are measured. Section II of this report describes the identification of the domains and section III the development of the structure of the measure itself. 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 have taken place. The first consultation was about the domains of social care. The second was about the structure of the measure. In addition nine care managers completed the initial draft instrument for ten older people.

The second stage of the project is to attach weights that reflect elderly people's preferences for each domain and the level of need met within each domain. Section IV describes the approaches considered, and the initial exploratory work that has been conducted with a small sample of elderly people to establish the feasibility and practicality of methods of establishing older people's preferences. Once the approach has been piloted a sample of 300 elderly people will be interviewed and the results analysed to identify how scores should be weighted to reflect the relative benefit from meeting needs in each domain.



In the initial design the validity and reliability checks of the measure were all conducted during the third stage of the project. During this stage the measure would be incorporated into an ongoing research project (Challis, 1998). However, further consideration has led us to bring forward initial tests of the measure to ensure that there is some evidence of validity and reliability before attaching utility weights to the measure.

The project lasts for three years. This report focuses on the results of the first year in which the measure has been developed and initial exploratory work has been conducted about establishing the preferences of older people. The second year will focus on initial tests of validity and reliability and the estimation of utility weights. The next steps involved in this process are described in Section V. The third year will be used to put the measure into practice in a research setting to test the measure further, and to investigate how preferences of service users compare with older people generally.

## **SECTION II DOMAINS**

Outcomes are achieved when the objectives of the provider or purchaser of care are achieved. We need to clarify these objectives if we are to identify the key domains of social care. We have adopted a top-down approach, therefore, 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 section 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 disability (or handicap) on an individual by meeting the needs created by the disability. Thus, for example, if physical disability 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 disability 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 disability. 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 should be developed.

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.

In order to identify which areas of need were 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 key aspects of life where disability can impact and social service agencies have a key role to play.
2. The measure is not intended to cover factors that affect levels of need. Instruments that are intended to identify specific conditions or disabilities (such as the Mini Mental State Instrument) can better measure these. However, the measure should cover all domains of relevance whether the cause of disability 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 disability. 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 Section IV). 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.

## ***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 adequately feed themselves, 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 disability 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 are very worried about the individual coming to some harm.

For the purposes of the initial consultation the 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 disability 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***

Disability 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 benefits they are entitled to.

### ***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, information, and empowering 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 to both inform and assist in the development of the measure. The group consists 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 either unable to participate but wished to receive further information on the study; did not apply to the letter inviting them to participate; or replied to the letter, but refused 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 table 1.

**Table 1: Reference group response to initial consultation exercise**

<b>PERSPECTIVE</b>	<b>RESPONDENTS</b>	<b>NON-RESPONDENTS</b>
Academics	16	5
Voluntary Organisations	11	3
Local Authorities	36	7
Department of Health	2	0
<b>TOTALS</b>	<b>65</b>	<b>15</b>

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 saw worry about safety as much 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, 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 anymore 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, it is not keeping the home clean that is



the primary objective. Such services are provided when hygiene levels mean there is a physical or social threat or when such interventions are needed in order to maintain an individual's sense of self-worth. 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 as 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 section III).

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 persons 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 agreed

therefore, 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 these comments it was decided to exclude this domain from the measure. Money management for the most part is instrumental in achieving other aims, 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 aspect 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 people with disabilities 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 are experienced by service users as fundamental to quality of life (Qureshi, 1998). It was decided, therefore to include a domain *Control over daily life* to replace the initial domain of autonomy and choice.

## **2.5 Conclusion**

Table 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.

**Table 2 Domains of social care outcome**

<b>OLD DOMAINS</b>	<b>NEW DOMAINS</b>
Looking after the home	
Food	Food & Nutrition
Personal self-care	Personal self-care
Physical safety	Safety
Company/Daytime Activities	Social Participation & Involvement
Money Management	
Autonomy & Choice	Control over daily life
<b>TOTAL: 8 Domains</b>	<b>TOTAL: 5 Domains</b>

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

## **SECTION III STRUCTURE OF THE MEASURE**

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 are developing here we define 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 section. Here we consider the structure of the measure that is needed for us to identify the outcome.

Ideally we want to measure the actual level of met need and the level of unmet need that would have existed if the social care intervention had not taken place. The difference between the two is the outcome. 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. Changes in levels of unmet need represent changes in utility states that we may be able to link to specific interventions or policies. But in such interpretations we have to be clear that need is met, for most people, primarily through informal care and levels of disability can and do change over time.

In developing the measure we used the CAN and CANE as the initial model. The rationale for this and adaptations are described below. The reference group was consulted about the initial draft of the measure and ten care managers asked to complete the instrument for an older person. In the light of the feedback from this exercise the instrument was amended and the care managers asked to comment on the revised version. The results of this process are described below.

### ***3.1 The initial draft of the measure***

There were a number of reasons for using the CAN and CANE as starting points in developing the instrument itself:

- 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 section II). 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 can not 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 were identified:

- *No problem*: disability has no effect on this domain.
- *All needs met*: disability affects the domain but there are no unmet needs.
- *Low unmet needs*: disability affects the domain and there is either a low level of need with no help received or the help received is inadequate leaving some aspects of unmet need.
- *High unmet needs*: disability has a substantial effect on the domain and if any help is received it has a negligible impact.

This should provide sufficient levels to differentiate between where services are meeting needs entirely and where there are remaining needs.

### ***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 SCOOP 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 SCOOP 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.

In addition, during June 1998 nine care managers administered the SCOOP 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.

### ***3.4 Results***

In general, both the reference group and the care managers using the measure 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 assessments conducted using the draft instrument were of 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.

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 (see above). On consideration it was decided not to introduce a further level. Ambiguities will always exist between levels – more levels will introduce more ambiguities. The aim will be to clarify appropriate coding through guidance. As evidence is collected by testing the measure in practice, illustrative examples will be provided to assist further in grounding the measure.



### ***3.4.1 Levels of unmet need***

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 & nourishment due to her immobility”.

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

#### ***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<sup>1</sup> 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 of definitions of the levels. The other high level unmet need client could no longer wash/dress/toilet herself.

### ***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 well-being, such as falls, getting lost and abuse such as being verbally or physically bullied by a carer.

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<sup>1</sup> 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.

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 these 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' well-being 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. In the event it was decided to be over inclusive in guidance but to keep this decision under review.

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 people (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 is 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.

### ***Social Participation & 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: 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”.

### ***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 the care managers 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”. Section II 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. Codings and comments for the ten sample assessments tended to reflect the problems of the scope of the domain tested.

### ***3.4.2 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 and Knapp, 1992). Informal care input may be established through time spent on care or measures of carer burden (Deimling, 1994).

### ***3.4.3 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.

#### ***3.4.4 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).

At present 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. This approach will be kept under review.

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 revised version asks about levels of incidence over the previous month.

#### ***3.4.5 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 be

reasonably sure that the change in levels of met need are measuring the output of services. We can also 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 bound to be problems in establishing reliability. However, it is included at present to allow an assessment of its practicality in use. If it appears to be working well, approaches to establishing reliability will be explored at a later date.

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. Clearly the question has to be asked in practice before we can evaluate whether elderly people themselves feel they can answer the question.

### ***3.5 Conclusion***

The structure of the instrument has been designed to be relatively simple to complete but it is hoped, sensitive to the key aspects of outcome that we are measuring. Through consultation and preliminary testing of a draft measure the approach has been refined and simplified. Section V describes the next stages of testing the instrument. The next section addresses the problem of attaching weights to the levels of unmet need for each domain.

## **SECTION IV WEIGHTING THE MEASURE**

Once the domains and levels within each domain have been identified the next objective is to identify 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. From this it will be possible to identify the benefit resulting from the receipt of help: the improvement in well-being that would not otherwise have occurred.

This section briefly considers the type of respondent who will be included in the main sample, ways of establishing weights and, in the light of these, 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 on a pre-pilot exercise which has explored issues of presentation, acceptability and practicality.

### ***4.1 Sample***

The main sample will consist of 300 people all over the age of 60, 100 of whom will be re-interviewed about a month later (see Section IV for the rationale for the size of the sample). Such respondents are assumed to know about, or have considered the impact of, the type of scenario to be presented but would not be in receipt of social care services. The final stage of the project will investigate whether those people in receipt of social services would demonstrate different preferences to the general population of people over 60.

### ***4.2 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., 1996). 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.



Willingness-to-pay has 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. (personal communication with Mandy) Given the sensitivity of asking older people on low incomes about monetary issues, there are

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; van der Pol and Cairns, 1998).

CA 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 (Journal of Transport Economics and Policy, 1988; Hanley et al., 1998; Swallow et al., 1992) and environmental economics (Opaluch et. al., 1993). 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 (Harwood, et. al., 1994; Propper, 1995; Ryan and Hughes, 1997; Vick and Scott, 1998; Bryan et al., 1998; Ryan, forthcoming).

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.

The degree to which any of these approaches can be said to deliver a cardinal measure of utility is debatable. While an ordinal scale reflects the relative ordering of different states a cardinal scale is able to demonstrate the strength or intensity of utility. The ideal scale would therefore

be cardinal, since if an intervention cost twice as much we would be able to tell whether the benefits are also twice as much.

The objective here is 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 EuroQol). While the nucleus of the approach to be used is discrete choice conjoint analysis it was felt important to supplement this in order to allow an appraisal of the degree to which it would be valid to treat any derived weightings as a cardinal measure. If cost is included as a domain or attribute then conjoint analysis will allow us to estimate willingness to pay indirectly. Ranking and rating exercises have been argued to yield cardinal results (Green et al., 1972). If we combine these approaches we can examine the convergent validity of the results of these with the results of discrete choice CA.

#### ***4.3 Pre-pilot testing of approaches to establishing preferences***

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 and standard gamble are inappropriate given the issues we are addressing. Willingness to pay is a legitimate approach which should be investigated but we have assumed that the discrete choice approach to conjoint analysis described above would be the most practical and deliver the most valid results. Clearly the practicality and validity of the process needed to be tested.

The first issue to be considered is 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 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 is 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., forthcoming). However international guidance over

the use of contingent valuation techniques recommends that interviews are used (National Oceanic and Atmospheric Administration, 1993)

Establishing valid responses will depend in part on presentation (Farrer and Ryan, forthcoming). 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 attributes and general presentation.

Implicitly the approach to analysing the choices made assumes that the more people choose A over B the stronger the preference. In practice what is being measured is consistency of choice, not strength of preference. In order to test the relationship between consistency and strength of preference it was decided 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. At this pre-pilot stage the best way of presenting these ratings needed to be identified.

If we include 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 is 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. At this pre-pilot 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 pre-pilot 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 small group of about 10 older people. On the basis of the issues arising from these exercises a revised questionnaire was developed (see Appendix A) and four further interviews were conducted. All those interviewed were female with an age range from 62 to 74. The occupations of the last four interviewees were two retired nurses, a retired schoolteacher, and a retired personnel manager. None of these had any disabilities but the first interviewee was on a very low income (just above income support level), had difficulties in some areas of daily living and had daughters who lived locally and visited regularly.

#### ***4.4 Results***

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. Things 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 includes 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 are 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.

#### ***4.5.1 Presentation***

Most people preferred the mode of presentation that described each situation 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 B). However, in a couple of cases people did say they would prefer a list. For the pilot, therefore, we propose to explore the issue further to identify whether it would be appropriate to have alternative types of presentation available.

#### ***4.5.2 Rating scales***

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 decided to use a two-stage process during the remaining interviews (i) Which situation is worse? (ii) How much worse is it?

The two-stage decision process worked well. Respondents 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 (see Appendix B for the type of scale used).

#### ***4.5.3 Including a cost dimension and willingness to pay***

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 disability 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 the lady 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 are all set too low those people who have reasonable levels of income would not take the money attribute into consideration at all unless they were indifferent to the two options presented.

#### ***4.6 Conclusion***

An important aspect of the first stage of this study was to investigate the practical issues and their implications for the design of the exercise required in order to attach utility (or approximations of utility weights) to the domains and levels within the domains.

The limited pre-pilot exercise clarified a number of important issues. First it appeared that people were able to make discrete choices that reflected their preferences about the domains covered by the measure. While the issue of lexicographical preferences can not be ruled out entirely, first indications are that this is not a major issue. However, if the dimension of

payment is included in a way intended to reflect the degree people will trade money off against other attributes, there is a serious concern that those on lower levels of income would show lexicographical preferences. This would both reduce the effective sample and bias the results.

For the main sample, therefore, we do not think it appropriate to include a financial attribute as the danger of invalidating the results is too severe. However, including a financial attribute would widen the generalisability and applicability of the measure in a cost-benefit context. The pre-pilot exercise has not demonstrated that it is impossible to include this attribute. Indeed the form of presentation worked well. The problem arises in setting levels at appropriate levels that will yield valid results. We propose, therefore to conduct an exploratory study with a sufficiently large sub-sample that if the results are positive we could make some inferences about the marginal rate of substitution of money for meeting need in the domains. If the exercise is not successful it should provide us with a valuable insight into practical and analytical nature of the problems. Section V describes the proposed design.

While the results of the 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. For these reasons we do not consider self-completion questionnaires an appropriate way forward. With interviews we are satisfied we would have some confidence in the findings.



## **SECTION V NEXT STEPS**

There are two strands to the study to be developed during the next stage. The first is to establish the validity and reliability of the measure. The second to design and conduct the fieldwork necessary for attaching weightings to the domains and levels within the domains.

### ***5.1 Validity and reliability of the measure***

In the original proposal it was intended to investigate reliability and validity entirely during the third stage of the project, when the measure was applied in a research setting. It was decided, however, that at least some validity and reliability issues should be addressed at an earlier stage as these may have implications for the weighting exercise.

The revised measure has been sent to five local authorities to be completed by care management staff. The objective is to get at least 30 completed instruments returned with brief descriptions of the reason for the codings made and an anonymised assessment form providing more detailed background information about the case. The analysis of these will provide data about practicality (what problems arise in practice), construct validity (the degree that the information about variations between the individual clients is reflected in variations in codings) and consistency (the degree to which care managers code similar circumstances in the same way).

Assuming that the measure performs well at this stage we will then test inter-rater reliability by constructing a series of vignettes from a small sample of the cases assessed. Care managers will be asked to complete the instrument for the cases on the basis of the vignettes provided. All those who participated in the initial testing of the measure will be asked to participate with further care managers contacted to ensure an adequate number of responses to test inter-rater reliability.

### ***5.2 Weighting the domains***

The pre-pilot stage has provided valuable insights into the process of establishing people's preferences. Building on these we shall pilot the design with 20 elderly people during the spring of 1999. The issues that need to be considered in the design of the mainstage fieldwork for

establishing preferences are: the method; the structure of the questionnaire; and the size and structure of the sample.

### ***5.2.1 The method***

The objective of the exercise is to establish valid indicators of utility levels associated with the domains covered by the instrument. In order to achieve this we need to ensure that the replies to the questionnaires are consistent and reflect what people are intending to convey. Moreover we need to have an understanding of the stability of the preferences revealed (indicated by test-retest reliability). In section IV we also discussed the desirability of including a monetary component and whether the measure could be used as a cardinal indicator even if not linked directly to money.

In order to ensure that we are accurately reflecting people's views it is necessary to conduct interviews, which allow checks to be made, rather than self-completion questionnaires. Consistency of replies can be checked as part of the analysis, although early checks on the ability of the individual to cope with the type of questions presented will be built in to the beginning of the questionnaire.

In order to test whether people's preferences are stable we will ask all those interviewed if they would be prepared to be interviewed again. A random sample of 50 will be selected and the interview re-administered one month later. A further 50 will be interviewed with an adapted version of the questionnaire that includes a monetary domain. Should this latter exercise prove successful it would allow the effects of including a monetary attribute on preferences, given the overall stability of preferences.

There is some evidence that the results of ranking exercises can be used to derive a cardinal measure (Green et. al., 1972). The feasibility of including some ranking exercises will be investigated as part of the pilot. If these prove practical later analyses will investigate the issue of cardinality and the sensitivity of the results to different approaches to attaching weights.

### ***5.2.2 The structure of the questionnaire***

The data collection instrument will include information about age, gender, health-state and caring status in order to allow an investigation of the impact of these factors on preferences and estimated weights. We will pilot an indicator of income (asking for main source of income).

The initial ranking exercise of the domains will be used to accustom people to considering the issues. This will be followed by a series of discrete choice options.

Determining the discrete choices depends on the number of possible scenarios, which is determined by the number of attributes and levels. The measure consists of five attributes or domains with three levels for each attribute. If money were included it would add another attribute with potentially a very large number of levels. At this level 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 will be used (Bradley, 1991).

Initial decisions will be made relatively straightforward with clearly preferable options. This helps people to get into the process and allows the interviewer to assess if the interview may need to be terminated if it becomes clear that people cannot cope with the process.

People will be asked to rate strength of preferences in addition to the discrete choice. In order to allow alternative approaches to estimating preferences to be explored we will also pilot a ranking exercise. After people have made three discrete choices they will be asked to rank the six options. This may also serve to break up the interview to make the process less monotonous.

### ***5.2.3 The sample***

In section IV it was identified that all the respondents would be over 60 years of age.

Potential sources for the sample include GP lists and clubs for people over 60. We wish to investigate at this stage whether gender, age, or income has an effect on the type of preferences. Information about health-state and caring status will be collected but the principal investigation into these factors will take place as part of the third stage of the project. The difficulties of

establishing adequate numbers of older people from different ethnic origins and the diversity of ethnic origins are such that we propose that the influence of ethnic origin should be investigated as part of a separate study at a later stage. This could take on board any lessons learnt as part of this exercise.

The sample size is 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 analysis of sub-groups or segments of the population needs to be considered. The minimum figure of between 30 and 100 should apply to each subgroup of interest.

Although it is not essential to get a representative sample of the general population on all potential characteristics it is important to have sufficient numbers in each sub-sample that we wish to test. If differences are found the results can then be weighted to reflect the national population. 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). The figure of 300 will be sufficient to enable the data to be analysed by the subgroups envisaged.

### ***5.3 Conclusion***

The first stage of the project was to design the measure and undertake initial investigations into the feasibility of establishing preferences using a variety of approaches. Initial results both about the practicality of the measure developed and the discrete choice approach to establishing preferences are encouraging. The next steps are to test the measure itself more extensively and to pilot the approach to establishing preferences. Once the measure is finalised, and the practicality of the approach to establishing preferences established, the main survey of preferences will take place.

## **APPENDIX A**

The instrument to be tested at the next stage and accompanying guidance are on the following pages. Pages asking care managers to give more details about reasons for codings for each domain have been omitted.

## **APPENDIX B**

An example of the most successful form of presentation of discrete choices and the rating scale indicating strength of preference are shown on the following pages. These are presented to respondents in the form of show cards.

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