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# HEDS Discussion Paper 11/13

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# **What is dignity? A literature review and conceptual mapping**

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## **Abstract**

### **Background**

Whilst dignity is a prominent issue in health care, no standardised questionnaire exist that capture the multi-faceted nature of it. Those questions that do exist cannot be used in cost-effectiveness analysis as they lack the relevant measurement properties required. This study describes the work done to date on a programme of research undertaken in collaboration between the University of Sheffield and the Devices for Dignity (D4D) Project that assesses what is meant by dignity and to what extent it relates to more readily recognised concepts used within health services research.

### **Methods**

A literature review was undertaken based on documents known to the authors and the Devices for Dignity (D4D) project based in Sheffield, together with references 'pearl grown' from the documents plus *ad hoc* electronic searches. A qualitative framework was used to identify those concepts that were used in the literature and an attempt made to show how each of these were related in a 'conceptual map'. A possible set of questions was then developed that linked to the conceptual map.

### **Results**

Only a few journal articles were found that explored the concept of dignity in theoretical terms. Most articles took a nursing perspective and so were largely focused on carer-patient interactions, although other aspects of the care process were also included, such as the care environment. Others took a broader perspective and looked at dignity as a concept across all aspects of life. A wide range of pre-existing questions were identified from the literature that attempted to measure dignity directly, or indirectly through factors that are thought to influence it. Other concepts and questions related to dignity were identified that encompassed notions of patient satisfaction, patient experience, autonomy, control, self-esteem and quality of life.

We developed our own conceptualisation of dignity that attempts to describe the links between dignity, the environment, processes of care, capabilities, functionings and well-being. This framework is thought to work quite well in describing the various influences on dignity, capturing all the identified concepts and linking into an overall model of well-being that has been developed by Sen in the broader economics literature.

### **Conclusions**

Many different definitions and conceptualisations of dignity exist in the literature. Consequently it is unclear what it means, how it should be measured and how it relates to other concepts used in health technology assessment. We have developed a conceptual map of dignity and well-being that is capable of incorporating the vast majority of the care-related issues highlighted in the literature. This appears to be a valuable starting point for further research to measure dignity, and apply it in health technology assessment alongside generic instruments such as the EQ-5D.

### **Key words**

Outcome measurement, dignity, health care, well-being, satisfaction.

## **Background**

The importance of dignity within health care has been increasingly recognised in recent years. Central to this was the Dignity in Care Campaign which aims to “end tolerance of indignity in health and social care services through raising awareness and inspiring people to take action” (<http://www.dignityincare.org.uk/DignityCareCampaign/>). This in turn produced a ten point dignity challenge (Cass 2009), guidelines from the Nursing and Midwifery Council (NMC 2009) together with other initiatives from voluntary sector organisations (for example, Magee 2008).

Whilst dignity is a prominent issue in health care, no standardised questionnaire exists that capture the multi-faceted nature of it (Magee 2008). Furthermore, those questions that do exist cannot be used in cost-effectiveness analysis as they lack the relevant measurement properties required. Consequently, interventions that have a large, positive, impact on a patient’s dignity may not look cost-effective because the impacts are not captured by the outcome measures currently used within economic evaluation, such as the EQ-5D (Rabin et al 2001).

It is felt that the lack of a validated questionnaire, together with its exclusion from economics evaluation, produces a situation where dignity is largely ignored in health technology assessment despite its undoubted importance to health policy. The Valuing Dignity Project is a collaboration between the University of Sheffield and the Devices for Dignity (D4D) programme which is a nationally funded initiative based within Sheffield Teaching Hospitals NHS Foundation Trust (STH). The project is planned to have three phases; first, a literature review and conceptual mapping exercise, second, a survey of patients using a set of patient reported dignity questions to help generate a short dignity questionnaire, and third, a valuation exercise to produce a tariff for the dignity questionnaire.

This literature review and conceptual mapping is described in this Discussion Paper. Within this work we; (i) review the concept of dignity and associated issues, (ii) identify questions relating to dignity and associated issues, (iii) develop a conceptual map of dignity and its relationship to other concepts used in health services research and, (iv) develop a set of possible questions that can be used to measure dignity.

## **Methods**

Electronic searches were undertaken to identify how dignity has been used in relation to health care. Usage of the term ‘dignity’ were described and different concepts that underlie its use were identified. Qualitative research techniques were used to identify broader themes that characterise the overarching concept of dignity and brought together in a conceptual map. Existing questions relating to the different dignity themes were highlighted, and other potential questions constructed. The conceptual map and dignity questions were validated through focus groups consisting of people with long-term care needs.

## Searches

A lot of literature exists on dignity and its role in health services; however, the context within which the term 'dignity' is used is highly variable, and the publications that relate to 'dignity' generally exist within the grey literature. Consequently, initial attempts at undertaking very structured searches produced a lot of irrelevant information. We therefore undertook a dual approach to identifying literature. First, we used our own knowledge and expert advice to identify key policy documents and reports relating to dignity, then used these to pearl grow a set of core references. This approach was expected to produce a relatively narrow set of concepts, but these would be highly relevant to the current policy perspective. Second, we would undertake more traditional database searches of the academic literature to identify wider uses of the term 'dignity'. These broader searches would be supplemented by searches of the Web. Due to the incredibly variable way in which 'dignity' is used in the literature and described in search terms, a formal search strategy was abandoned and replaced with independent ad hoc searches by three members of the research team (SP, SD, PS). One further limit on our searches and reviews was that our focus was on patient-based studies of dignity, i.e. those starting with primary data collection from patients, rather than professional views of what dignity is, or what constitutes dignified care.

Whilst the literature relating to dignity is central to our work, it was felt that there are other concepts that are related to it, but which would not be captured by our searches. So, for example, notions of patient experience and patient satisfaction could be considered to be related to dignity. In order that these concepts are not missed by our mapping exercise, we have highlighted the related literature.

## Analysis

The purpose of the analysis was the identification and development of categories (which is sometimes termed a 'thematic analysis'). This was pursued by following an abbreviated framework approach (Richie and Lewis, 2003); familiarisation, identification and mapping (with indexing and charting omitted due to resource constraints).

As part of the familiarisation and identification process, pre-existing questions were extracted from the documents. In addition, the results of the conceptual mapping were used to highlight areas where questions did not fully capture the identified concepts. In these areas, additional questions were generated by the research team.

## Results

### Review of key documents and 'pearl grown' references

The documents and references identified in this part of the search are shown in Box 1 and are summarised in turn below. In order to keep the review concise, those articles that are cited by the key document are highlighted, where appropriate, within the review of the referring document.

#### Box 1: Key documents (*italicised*) and 'pearl grown' references

- *Department of Health. The Dignity challenge.*
- *Department of Health. Public perceptions of privacy and dignity in hospitals. DH, 2007.*
- *Cass E, Robbins D, Richardson A. Dignity in care. SCIE Guide 15. SCIE, 2009.*
- *Magee H, Parsons S, Askham J. Measuring Dignity in Care for Older People. Help the Aged, 2008.*
- *Netten A, Burge P, Malley J, et al. Outcomes of Social Care for Adults (OSCA). Interim Findings. PSSRU, 2009.*
- *Baillie L, Gallagher A, Wainwright P. Defending dignity – challenges and opportunities for nursing. London: RCN, 2008.*
- *Nursing and Midwifery Council. Care and respect every time: new guidance for the care of older people. NMC, 2009.*
- *Haddock J. Towards further clarification of the concept "dignity". Journal of Advanced Nursing 1996; 24: 924–931.*
- *Jacelon C, Connelly T, Brown R, et al. A concept analysis of dignity for older adults. Journal of Advanced Nursing 2004; 48: 76–83.*
- *Malley J, Netten A. Putting people first. Development of the putting people first user experience survey. PSSRU, 2009.*
- *Netten A, Malley J, Forder J, Flynn T. Outcomes of social care for adults (OSCA). First consultation exercise feedback. PSSRU, 2009.*
- *Wiggins R, Netuveli G, Hyde M, et al. The evaluation of a self-enumerated scale of quality of life (CASP-19) in the context of research on ageing: a combination of exploratory and confirmatory approaches. Soc Indic Res 2008.*

#### *The Dignity Challenge (2006)*

The Dignity Challenge is a Department of Health initiative, and whilst it is generally attributed to Care Services Minister, Ivan Lewis, the original source document is unclear. It outlines 10 aspects of care that should be present in care services. The Social Care Institute for Excellence (SCIE) Adult Service Guide 15, perhaps, describes these most fully together with a number of 'dignity tests' associated with each challenge and examples of good practice that have been developed by existing care providers.

The tests tend to be structure and process based. For example in relation to 'privacy' (Challenge 6) two of the tests are: (i) do we have quiet areas or rooms that are available and easily accessible to provide privacy? (ii) do staff actively promote individual confidentiality, privacy and protection of modesty?



### *Public perceptions of privacy and dignity in hospitals (2007)*

This was a Department of Health funded study that focused on mixed sex wards and impact on dignity. Its use of 6 focus groups and 2000 questionnaires was focused on the acceptability of mixed sex wards but also examined definitions and perceptions of dignity.

The study found that privacy and dignity are second only to quality of treatment in importance. In descending order of importance the aspects of dignity and privacy were; clean hospitals (58%), being kept informed (43%), having medical staff explain procedures carefully (40%) and privacy (33%).

### *Dignity in care (2009)*

This document, produced by the Social Care Institute for Excellence (SCIE) recognises that dignity consists of many overlapping aspects. However, it uses a standard dictionary definition as a starting point for its work. This being:

*“a state, quality or manner worthy of esteem or respect; and (by extension) self-respect. Dignity in care, therefore, means the kind of care, in any setting, which supports and promotes, and does not undermine, a person’s self-respect regardless of any difference.” (Cass 2009, p6)*

Previous research (Haddock 1996, Jacelon et al 2004) was also examined. Together all this research was used to identify four overlapping ideas relating to dignity. These are reproduced in Box 2.

### **Box 2: The meanings of dignity within the SCIE Adults’ Service Guide**

Research with older people, their carers and care workers has identified dignity with four overlapping ideas:

- Respect, shown to you as a human being and as an individual, by others, and demonstrated by courtesy, good communication and taking time
- Privacy, in terms of personal space; modesty and privacy in personal care; and confidentiality of treatment and personal information
- Self-esteem, self-worth, identity and a sense of oneself, promoted by all the elements of dignity, but also by ‘all the little things’ – a clean and respectable appearance, pleasant environments – and by choice, and being listened to
- Autonomy, including freedom to act and freedom to decide, based on opportunities to participate, and clear, comprehensive information.

Source: Cass 2009.

In tandem with this, a DH survey of older people and their carers identified ten specific areas relating to dignity. These were; respect, communication, social inclusion, autonomy, privacy, hygiene and personal appearance, mealtimes, complaints, whistleblowing and abuse. This longer list is a mix of broad concepts (e.g. respect) and specific aspects relating to the process of care (mealtimes).

### *Measuring Dignity in Care for Older People (2008)*

This study was undertaken by the Picker Institute on behalf of Help the Aged. The aim was to make recommendations on the best way to measure their nine domains of dignified care

identified in a previous report (Levenson 2007). These domains are personal hygiene, eating and nutrition, privacy, communication, pain, autonomy, personal care, end-of-life care and social inclusion. A literature review of qualitative studies was undertaken and their results mapped onto the nine domains as a way of further validating them. Existing policy documents and patient surveys were then examined to identify indicators that related to each of the nine domains. The allocation of indicators to domains was also reported separately by three principal care settings; hospital, residential care, community. Finally, patient questions were identified that addressed different aspects of the domains and indicators. Most questions were described as self existing, whilst others were new for the report.

This process is perhaps best illustrated through an example. So for the **domain** ‘autonomy’, one possible **indicator** was ‘information to support decision making’ (identified in Burton 2007) and to which was assigned the **patient question** “Were you given the information you needed before you decided to come and live here?” The number of indicators and questions for each domain is given in Table 1.

**Table 1: Summary of domains, indicators and questions identified by Magee et al**

<b>Domain</b>	<b>Number of indicators (number without associated questions)</b>	<b>Number of possible questions</b>
Autonomy	11 (2)	12
Communication	6	11
Eating and nutrition	7 (1)	8
End-of-life	10 (9)	1
Pain	5	7
Personal	4	12
Personal care	5 (2)	4
Privacy	9 (2)	13
Social inclusion	7	10

It should also be noted that further classifications and concepts were also used in the report. Focus group work identified other issues that were felt to be separate from the nine domains (i.e. physical handling and staff attitudes), and two additional domains were used to classify ‘spare’ indicators (i.e. general respect and other). Also, four further themes were thought to cut across the nine domains; these were choice, control, staff attitudes and facilities.

#### *Outcomes of Social Care for Adults (OSCA)*

OSCA is a HTA funded project aimed at producing an outcome measure for adult social care. There are three documents relating to its development (Netten, Burge, Malley, et al 2009, Malley and Netten 2009, Netten, Malley, Forder, et al 2009) which are useful in identifying the underlying source of their approach to defining and measuring dignity.

The concept of dignity within OSCA derives from the Adult Social Care Outcomes Toolkit (ASCOT). The questions from this toolkit were subsequently mapped against five main themes identified within the Department of Health’s *Putting People First* (PPF) initiative in

adult social care. These themes were quality of life, choice and control, inclusion and contribution, health and well-being and dignity and safety. Three questions from ASCOT were thought to relate to dignity – personal care, dignity and clean and comfortable accommodation. From this, OSCA developed a single concept of dignity; “the negative and positive psychological impact of support and care on the service user’s personal sense of significance” (Netten et al 2009, Netten et al 2009).

Whilst still under development, the preferred measure of dignity examines “the impact of the way services and support affected people’s sense of personal worth.” This was to be addressed by the question:

*Thinking about the way you are helped and treated, and how that makes you think and feel about yourself, which of these statements best describes your situation?*

- *The way I’m helped and treated makes me think and feel better about myself*
- *The way I’m helped and treated does not affect the way I think or feel about myself*
- *The way I’m helped and treated sometimes undermines the way I think and feel about myself*
- *The way I’m helped and treated completely undermines the way I think and feel about myself*

From work with users, the developers recognised that self-worth was also influenced by the need for help (as opposed to the way in which they were helped). They propose to examine this further by the addition of the following related question:

*Which of these statements best describes how having help to do things makes you think about feel about yourself?*

- *Having help makes me think and feel better about myself*
- *Having help does not affect the way I think or feel about myself*
- *Having help sometimes undermines the way I think and feel about myself*
- *Having help completely undermines the way I think and feel about myself*

*Towards further clarification of the concept of dignity*

Haddock (1996) undertook an unstructured review of the literature and applied concept analysis to both its findings plus qualitative interviews and case studies. She highlights the different definitions and distinctions in the use of the term dignity. For example, she states that “Distinctions are clearly made between *having* dignity, as an aspect of the self, *being treated as if one has* dignity, and actively *giving* dignity to another as if it were a commodity” (Haddock 1996, p925, italics in the original text).

Her qualitative analysis of 15 interviews generates a description of “the dignified self” which contains notions of self-respect, self-confidence, pride and trust, which have been espoused elsewhere. Communication is put at the centre of changes to dignity, although this is broadly defined as including behaviour and surroundings.

Drawing all the various data sources together, Haddock produces an operational definition of dignity as follows:

*“Dignity is the ability to feel important and valuable in relation to others, communicate this to others, and be treated as such by others, in contexts which are perceived as threatening. Dignity is a dynamic subjective belief but also has a shared meaning among humanity. Dignity is striven for and its maintenance depends on one’s ability to keep intact the boundary containing beliefs about one-self and the extent of the threat. Context and possession of dignity within oneself affects one’s ability to maintain or promote the dignity of another” (Haddock 1996, p930).*

### **Review of key electronic search documents**

The documents and references identified in this part of the search are shown in Box 3 and are summarised in turn below. These sources exclude those that were identified in the ‘pearl growing’ approach in 3.1, even though many were found again in our electronic search.

#### **Box 3: Key electronic search documents**

- Chockinov HM et al. The Patient Dignity Inventory: A Novel Way of Measuring Dignity-Related Distress in Palliative Care. *Journal of Pain and Symptom Management* 2008;36:559-571.
- Jacobson, N. 2007. Dignity and health: a review. *Social Science & Medicine*, 64, 292-302.
- Jacobson, N. 2009. A taxonomy of dignity: a grounded theory study. *BMC International Health and Human Rights*, 9, (1) 3.
- Clark J. Defining the concept of dignity and developing a model to promote its use in practice. *Nursing Times* 2010;106(20)16-19.

#### *The Patient Dignity Inventory: A Novel Way of Measuring Dignity-Related Distress in Palliative Care*

This study represents the first major application of the Patient Dignity Inventory (PDI) which was developed previously by the same research team. It was developed from a conceptual model of dignity in the terminally ill which identified three key themes; illness-related issues, dignity conserving issues and social dignity issues. The sub-themes within the dignity conserving issues were; continuity of self, role preservation, legacy, maintenance of pride, hopefulness, autonomy/control, acceptance and resilience. Each of these maps onto at least one of the 25 statements of the PDI. Each statement is rated on a 5-point Likert scale.

Whilst this is a direct attempt to measure dignity through a self-reported measure, it is very much focused on end-of-life care both in terms of the underlying model (e.g. legacy), and the wording of the questions (e.g. ‘I feel that I am no longer able to mentally fight the challenges of my illness’). However, a few questions may be relevant to broader patient populations, for example, those relating to self- worth/ value, control, privacy and respect. Examples of statements relating to these are “Not feeling worthwhile or valued”, “Feeling like I don’t have control over my life”, “Not feeling supported by my community and

friends”, “Not feeling supported by my health care provider” and “Not being treated with respect or understanding by others”.

### *Dignity and health: a review*

Jacobson undertook a review across philosophy, theology, law and political theory to examine the meaning of dignity before proposing key distinctions and socio-political areas to which concepts of dignity have been applied. The paper highlights the problems that have been uncovered by attempts to define dignity in the broader literature. These include its encompassing and imprecise nature (which makes it virtually un-useable in any practical sense) and the inherent subjectivity of the concept which makes its use in applied work difficult.

The key distinction that Jacobson makes is between ‘human dignity’ and ‘social dignity’. The former she describes as “the inherent and inalienable value that belongs to every human being simply by virtue of being human” (Jacobson 2007, p294). Much of the related literature around this dichotomy is essentially theological/philosophical and in its most applied form, socio-political (when discussed in terms of equity and justice).

Social dignity differs by being “contingent, comparable and contextual. It is experienced, bestowed, or earned through interaction in social settings” (Jacobson 2007, p294). Within social dignity, additional concepts of ‘dignity-of-self’ and ‘dignity-in-relation’ are identified. The former being described in term such as self-respect, self-confidence and integrity although this can only be fully recognised within a social context, for example, by viewing how others act. Dignity in relation, on the other hand, reflects notions of worth through actions, or based on merit.

When examining how concepts of dignity can be applied, Jacobson notes the growing interest of ‘dignity in care’. She highlights that the two main strands to this work relate to end-of-life care (as exemplified by Chochinov) and standards of care for health professionals.

### *A taxonomy of dignity*

This paper builds on Jacobson’s earlier review by undertaking 64 interviews with a range of individuals, and using a grounded theory approach to identify concepts of dignity and its determinants. She finds that the data generated by the interviews mapped very closely to the two concepts of human dignity and social dignity identified in the previous review. This is then extended further by constructing notions of ‘dignity encounters’ that impact on dignity, ‘dignity violations’ and ‘dignity promoters’. These latter three concepts provide an insight into possible mechanisms for impacts on social dignity, and therefore, a list of process-based issues that may be useful to measure in our work.

### *Defining the concept of dignity and developing a model to promote its use in practice*

This paper, in common with Jacobson highlights numerous approaches to defining dignity and groups them together in three different groups; dignity “as a possession of capabilities and autonomy”, or “as a right” or “as a multifaceted concept”. Clark develops this further by developing a model central to which is the distinction between ‘self-regarding dignity’

(e.g. feeling like an individual) and ‘other regarding dignity’ (e.g. being seen as an individual’).

One further point to note is that Clark makes a distinction between dignity and self-esteem, but notes that the impact of dignity on self-esteem is important. In particular:

“...individuals experience a positive sense of self worth if they are thought about or treated positively by others. Self esteem is therefore raised if others regard us with high esteem and treat us with dignity, whereas it is lowered if we are regarded without esteem and treated without dignity” (Clark 2010, p19)

### Identified questions

Across the literature reviewed above and other associated surveys known to the authors, 22 questions directly relating to dignity were been identified. One interesting point is that, unsurprisingly, many of the questions use the word ‘dignity’ despite the fact that there appears to be very little consensus on what is meant by ‘dignity’. Asking directly about dignity could run the risk of prompting responses that relate to different aspects of life – a sort of patient generated index – which could be of differing importance (and therefore should be assessed/scored differently). Alternatively, it could be argued that what is causing the loss of dignity is unimportant. What is of importance is the degree of dignity loss.

Two further sets of questions have been identified through links with local health care Trusts. Both Sheffield Primary Care Trust (SPCT) and Sheffield Teaching Hospitals NHS Foundation Trust (STH) undertake surveys of patient experiences. SPCT has developed the Dignity and Respect Questionnaire which appears to be based directly on The Dignity Challenge, with virtually all the ten questions mapping directly onto the ten points in the Challenge. Within STH, a broader quality assurance initiative is underway which includes questions relating to dignity and factors thought to be associated with dignity. In these sets of questions, dignity is explicitly addressed, together with process factors.

### Associated concepts and questionnaires

Whilst the interest in dignity has only taken on real significance in recent years due to the Dignity Challenge, other topics in health services research and the broader social sciences have already examined patient experiences and notions of self-worth. Perhaps of greatest significance to the measurement of dignity within health care is the work looking at patient satisfaction and patient experience. Whilst the literature on patient satisfaction in particular is vast, two short measures have established themselves within the UK NHS, and these contain questions that appear to cover some of the issues identified in our literature review. These are the Medical Interview Satisfaction Scale (MISS)(see Meakin 2002, Hollway 2004 for examples of applications) and the Patient Experience Questionnaire (PEQ-15) (see Jenkinson 2002, 2003 for examples of applications). Selected questions that link with some of the concepts seen so far are given in Box 4:

#### Box 4: Selected questions within the MISS and PEQ-15

MISS	PEQ-15
The doctor seemed interested in me as a person	When you had important questions to ask a nurse, did you get answers that you could

<p>The doctor seemed warm and friendly to me</p> <p>The doctor seemed to take my problems seriously</p> <p>The doctor gave me chance to say what was really on my mind</p>	<p>understand?</p> <p>Did doctors talk in front of you as if you weren't there?</p> <p>Did you want to be more involved in decisions made about your care and treatment?</p> <p>Overall, did you feel you were treated with respect and dignity while you were in hospital?</p> <p>Did the doctors or nurses give your family or someone close to you all the information they needed to help you recover?</p>
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In more practical terms, routine assessment of patient experience is now part of the NHS. The two most conspicuous examples of this are the Adult Inpatient Survey (the 2009 version is available at <http://www.nhssurveys.org/survey/745>) and the General Practice Assessment Questionnaire (GPAQ) (available at <http://www.gpaq.info/>). The Adult Inpatient Survey incorporates all but two of the PEQ-15 questions, and so is not discussed further here.

Whilst a lot of the GPAQ does not tally well with the issues raised in earlier sections, for example the availability of appointments, Section 10 relates well to the process of care, albeit with the reference to the caregiver being confined to the doctor. In this section the patient is asked "Thinking about when you consult your usual doctor, how do you rate the following:" which are answered on a six point scale from 'very poor' to 'excellent' (Box 5).

**Box 5: Questions relating to GP consultations within the GPAQ**

**Thinking about when you consult your usual doctor, how do you rate the following:**

- a) How thoroughly the doctor asks about your symptoms and how you are feeling?
- b) How well the doctor listens to what you have to say?
- c) How well the doctor puts you at ease during your physical examination?
- d) How much the doctor involves you in decisions about your care?
- e) How well the doctor explains your problems or any treatment that you need?
- f) The amount of time your doctor spends with you?
- g) The doctor's patience with your questions or worries?
- h) The doctor's caring and concern for you?

One further questionnaire that has been developed and has relevance to our work is the Perceived Control in Hospital Scale (Polimeni 2002). Analysis of this questionnaire shows three factors; respect/communication, lack of dignity and day-to-day control. The issues covered by the lack of dignity scale related to asking permission, privacy, dignity and embarrassment. However, this scale has rarely been used.

Another questionnaire that has an emphasis on control and autonomy is the CASP-19, which has been used as a quality of life measure for older people (Wiggins et al 2008). The statements within this instrument are rated on a four point Likert scale, 'often', 'sometimes', 'not often' or 'never'. The statements relating to control and autonomy, which were shown as important concepts in the previous section are shown in Box 6 below.

**Box 6: Statements relating to control and autonomy in the CASP-19 questionnaire**

**Control**

My age prevents me from doing the things I would like to do

I feel that what happens to me is out of my control

I feel free to plan for the future

I feel left out of things

**Autonomy**

I can do the things I want to do

Family responsibilities prevent me from doing the thing I want to do

I feel that I can please myself what I do

My health stops me from doing the things I want to do

Within the broader social sciences, measures have been constructed to examine various psychological constructs that have been linked to dignity within our review. Of greatest prominence is the Rosenberg Self-Esteem Scale (RSES) which requires subjects to indicate the degree to which they agree with a series of statements on a four point scale from strongly agree to strongly disagree (Rosenberg 1965). A score between 0 and 30 is then produced, with a score of less than 15 indicating self-esteem.

However, the RSES focuses on trait self-esteem and as such is unlikely to vary much as a consequence of short-term social interactions. If we accept that we want to assess the notion of social dignity espoused by Jacobson (2007), then a measure of state self-esteem would be preferred. One such measure is available (Heatherton 1991). However, this measure was developed with a very specific context in mind – college students – and as such, one of the domains is irrelevant to other situations as it relates to educational performance, whilst the other two domain contain some questions that have limited relevance (e.g. 'I am dissatisfied with my weight').

Alternatively, a single-item scale that is potentially relevant to both trait and state self-esteem has been developed (Robins et al 2001). However, the scale is based on responses to the statement "I have high self-esteem" on a five point scale, may be problematic due to the lack of a clear understanding of the term among the general population.

The WHOQOL-BREF is also worth noting as it is a HRQoL questionnaire that attempts to cover aspects of life beyond just health, such as, physical environment, information needs and satisfaction with oneself (Skevington et al, 2004). However, these questions do not seem well suited to our particular use, for example, "How healthy is your physical environment?" is too narrow as it relates just to 'healthy-ness' as opposed to its wider impacts on the individual.



## Conceptual mapping

Across the literature we have highlighted many different issues related to dignity, which are summarised, by study, in Box 7. Key differences can be seen in the way in which dignity is addressed. In particular:

- Patient assessed (e.g. self-respect) vs. service assessed (e.g. availability of quiet rooms)
- Process (e.g. communication) vs. structure (e.g. single sex wards)
- Positive (e.g. presence of autonomy) vs. negative (e.g. absence of abuse)
- Subjective (e.g. self-esteem) vs. objective (e.g. cleanliness)
- Context specific (e.g. pain relief) vs. contextless (e.g. respect)
- Inherent (e.g. human dignity) vs. derived (e.g. social dignity)

Whilst the last point is a more philosophically based dichotomy, the remaining five pervade the literature and the attempts to measure dignity. It may even be possible to classify all the issues highlighted in Box 7 in terms of these five characteristics, e.g. respect could be classified as a patient assessed, subjective, positive and contextless concept that could be influenced by process and structural service traits.

**Box 7: Issues relating to dignity identified in the literature**

<p><b>Dignity Challenge</b>  Personalised care  Independence  Choice  Control  Listen  Support  Privacy  Engage  Confidence  Self-esteem</p>	<p><b>DH 2007</b>  Privacy  Clean facilities  Informed  Single sex  Staff attitudes  Gowns/nightwear  Noise  Toilets/washing</p>	<p><b>Cass 2009</b>  Esteem  Respect  Self-respect  Sense of identity  Courtesy  Communication  Taking time  Privacy  Confidentiality  Self-esteem</p>	<p><b>Haddock 1996</b>  Worth  Esteem  Self-respect  Self-concept  Self-confidence  Self-control  Control of environment  Pride of self  Trustworthy  Happy with self  Humorous  Autonomous  Independent  Private  Positive self-identity  Communication  Behaviour  Appearance  Surroundings  Comfortable with oneself  Treated by others  Appreciation  Caring  Humanity  Feel important and valuable</p>
<p><b>Magee 2008</b>  Personal hygiene  Eating and nutrition  Privacy  Communication  Pain  Autonomy  Personal care  End-of-life care  Social inclusion  Physical handling  Staff attitudes  Respect  Inclusion  Choice  Control  Staff attitudes  Facilities</p>	<p><b>RCN 2008</b>  Worth of self  Worth of others  Respect  Value  Physical environment  Organisational culture  Attitudes and behaviours of staff  In control  Valued  Confident  Comfortable  Decision making</p>	<p><b>Self-worth</b>  Identity  Appearance  Environment  Listened to  Autonomy  Information  Social inclusion  Hygiene  Appearance  Mealtimes  Complaints  Whistleblowing  Abuse</p>	<p><b>Self-worth</b>  Identity  Appearance  Environment  Listened to  Autonomy  Information  Social inclusion  Hygiene  Appearance  Surroundings  Comfortable with oneself  Treated by others  Appreciation  Caring  Humanity  Feel important and valuable</p>
<p><b>Daily Mail 2009</b>  Help from nurses  Empathy from nurses  Courtesy  Respectful  Valued as an individual  Involved in decisions  Eating  Pain relief  Hygiene  Safe  Secure  Noticed</p>	<p><b>Chockinov 2008</b>  Continuity of self  Role preservation  Legacy  Pride  Hopefulness  Autonomy/control  Resilience  Self-worth  Privacy  Respect</p>	<p><b>Netten 2009</b>  Sense of significance  Personal worth</p>	<p><b>Beach 2005</b>  Respect</p>

## **Existing conceptualisations**

Cass (2009) talked about self-esteem, self-worth and identity being “promoted by all the elements of dignity” and issues such as appearance and environment. This conceptualisation separates ‘dignity’ from both service issues and patient assessed issues. As such it fails to define dignity in terms of possible attributes, but instead specifies those issues that relate to dignity. This apparent separation of dignity from interactions and their psychological impacts can be seen as reflecting the distinction between human and social dignity highlighted by Jacobson. In other words, inherent human dignity is supplemented by social dignity that is in turn influenced by be interactions with other persons and the broader environment.

An alternative conceptualisation of dignity and how it relates to other issues is given within the RCNs working definition of dignity. Here, dignity is characterised by the feelings and behaviour of individuals in relation to the worth of value of themselves and others. Examples of these feelings and behaviours are given, together with those that are present when dignity is absent (e.g. humiliation). Relations with people and the broader environment are highlighted as influencing feelings/behaviours, and hence dignity.

The view that dignity can be affected by the worth of others is a potentially important issue, and is highlighted in other studies. A consequence of this is that the dignity of an individual can be affected by the perceived dignity of others, even if their own interactions with staff and the environment are positive.

Another conceptualisation is given by Haddock, which also appears to highlight the importance of the dignity of other people, although the description given by Haddock is unclear. She sees interaction with people and the environment (labelled as ‘communication’ by Haddock) as impacting on the dignified self and modifying negative impacts on it. Again, dignity is not defined within this conceptualisation, but personal feelings and traits are listed, which by and large mirror those seen previously.

Clearly, no single definition nor conceptualisation of dignity is widely supported within the literature. Consequently, if we are to measure dignity, we feel that we must develop a framework that captures the various concepts described to date and which links them together around a definition of dignity that is compatible with the notion of social dignity that appears most relevant to the policy context of interest. Furthermore, in order that our work can be integrated within future health technology assessments, our framework should link with aspects of health and well-being.

## **Preferred conceptualisation**

For the purposes of evaluating the impact of health services and technologies on the dignity of patients, we feel that equating it to the concept of self-worth, whilst being simplistic, helps focus our minds on the perceptions of patients rather than measurement of processes and structures. As Haddock (1996) points out, the word dignity is derived from the Latin word ‘dignus’ meaning ‘worthy’. Related to the notion of self-worth are other concepts that are listed in Box 7, such as, self-esteem, self-respect and self-concept.

For much of the following discussion, equating dignity to self-esteem is of no consequence. However, it becomes important when trying to derive an unambiguous question relating to dignity; as was highlighted previously, using the term 'dignity' directly within a question risks measuring different things for different people. One potential problem with this is that some in the literature make a distinction between dignity and self-esteem, however, these people also recognise that dignity influences self-esteem (e.g. Clark 2010). So, even if this alternative characterisation is believed, then our focus on self-esteem will capture the effect of health care on dignity to some extent.

From the previous sections it is clear that many issues can have an impact on dignity, with a key distinction made by many researchers being structure and processes. We adopt this distinction, but redefine their scope slightly, to produce 'environment' (e.g. living conditions, noise and the dignity of others) and 'processes of care' (e.g. communication and respect). This distinction highlights that interactions with care providers relate to a specific context (of receiving care), which needs to be separated out if dignity is also to be measured in the wider population.

However, from the issues in Box 7 we feel that there are two further categories of influence on dignity. So, for example, 'autonomy' is a right or attribute that exists separately from the environment or processes of care, but which can be influenced by them. Likewise, 'pain' is an aspect of health related quality of life that exists separately from the environment or processes of care, but which can be influenced by them. However, 'autonomy' and 'pain' are clearly different concepts.

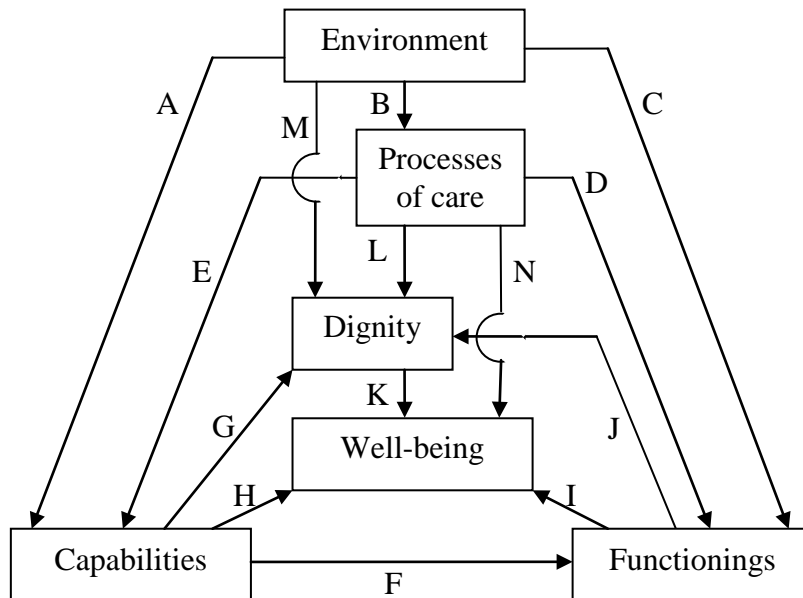
In order to draw all of these concepts together within a single framework, we feel that Sen's capabilities approach is useful (Sen 1985). Sen's work has been used to re-examine well-being by economists and it distinguishes between the capabilities of individuals, their functionings and the utility derived from both. So, functionings (e.g. absence of pain) can only exist if associated capabilities are present (e.g. access to pain relief). Once this distinction is made, we can link 'environment', 'processes of care', 'capabilities' and 'functionings' to 'dignity' and 'well-being' (Figure 1). Within this conceptualisation, it should be noted that we are referring to social dignity as opposed to human dignity.

As a way of validating this conceptualisation, we have examined how many of the issues within Box 7 can fit within it and produced examples of how these inter-relate. These inter-relations are labelled alphabetically within Figure 1.

As highlighted earlier, environment describes the living and care conditions of patients including the plight of others. This can directly influence our capabilities (A), for example by limiting our privacy; the processes of care (B), for example through cleanliness; our functionings (C), for example by its impact on mood; and our dignity (M). The processes of care can directly influence our capabilities (E), for example by the provision of information (to make us capable of making an informed decision); influence our functionings (D), for example by its effect on health; our dignity (L), for example, in the case of courtesy to patients and our well being for example by its direct effect on happiness. Consistent with Sen's framework, capabilities influence functionings (F), for example by allowing choices to

be made. Also consistent with Sen’s framework, both capabilities and functionings can influence well-being (H, I). However, we have placed dignity as an independent (K), but potentially modifying factor (G, J).

**Figure 1: Conceptualising dignity within Sen’s capability approach**



One further aspect of this conceptualisation is worth noting; dignity directly produces well-being, as does health-related quality of life (in the form of functionings). So, just as HRQoL can be seen as generating utility (in the EQ-5D, for example), then so can dignity. In which case the issue is raised as to whether dignity could/should form part of the descriptive system in utility instruments.

### Preferred questions relating to dignity

#### *Direct measures of dignity*

Equating dignity with self-worth and setting it within the capabilities approach of Sen, also allows us to examine the usefulness of alternative direct measures of dignity. The OSCA approach to defining and measuring dignity appears broadly consistent with our view; their definition being “the impact of the way services and support affected people’s sense of personal worth.” However, their question (Box 8) appears to capture the notion of worthiness, but is focused on care. If dignity is to be measured in wider populations (including those not receiving care) then a less specific version of the question is required. One possible version of this, which is based on the OSCA question is also shown in Box 8.

### **Box 8: OSCA dignity question and an alternative general population version**

#### **OSCA dignity question**

Thinking about the way you are helped and treated, and how that makes you think and feel about yourself, which of these statements best describes your situation?

- The way I'm helped and treated makes me think and feel better about myself
- The way I'm helped and treated does not affect the way I think or feel about myself
- The way I'm helped and treated sometimes undermines the way I think and feel about myself
- The way I'm helped and treated completely undermines the way I think and feel about myself

#### **Possible general population dignity question\***

Thinking about the way you live in terms of your surroundings and contact with other people, and how that makes you feel about yourself, which of these statements best describes your situation?

- The way I live makes me feel better about myself
- The way I live does not affect the way I feel about myself
- The way I live sometimes undermines the way I feel about myself
- The way I live completely undermines the way I feel about myself

\* As well as changing 'helped and treated' to 'live', we have removed 'think about myself' to make the wording less repetitive.

#### *Indirect measures of dignity*

Other measures of the factors influencing dignity can also be identified. Whilst not direct measures, these would provide explanatory information as to the causes of reduced dignity. Following our extension of the capabilities approach set out in Figure 1, any attempt to provide a wide coverage of factors should address issues in the environment, processes of care, capabilities and functionings boxes. This process can be simplified by noting that 'functionings' relate very closely to the notion of health-related quality of life (HRQoL), especially when applied to health-related policy and well-being. Consequently, using an appropriate and validated measure of HRQoL would remove any need for us to develop our own set of questions. In this regard, we would suggest the use of the EQ-5D as it is simple and short enough to be administered alongside the other questions we propose.

In terms of the key issues within environment, processes of care and capabilities, we have re-examined Box 7. The list of issues below, under each category, represents a long list which can hopefully be shortened following the pilot work in Phase 2 of this study.

#### Environment

- Safety
- Cleanliness
- Privacy
- Social inclusion
- Dignity of others

#### Processes of care

- Communication with staff (e.g. provided with information, listened to, involvement in decision making)
- Attitudes of staff (e.g. respect, empathy, treated as an individual)
- Personal hygiene, appearance (are these are probably more appropriately considered functionings?)

#### Capabilities

- Autonomy/independence
- Control

For each of these we have identified questions from the literature or suggest our own. These are presented in Table 2.

**Table 2: Possible questions relating to environment, processes of care and capabilities**

Issue	Questions	Source
Environment, safety	<p>Could you tell me which of the following statements best describes how safe you feel?</p> <ul style="list-style-type: none"> <li>• Generally I feel as safe as I want</li> <li>• Generally I feel adequately safe</li> <li>• I feel less than adequately safe</li> <li>• I don't feel at all safe</li> </ul>	ASCOT (Malley and Netten, 2009)
Environment, cleanliness	<p>Could you tell me which of the following statements best describes how clean and comfortable your surroundings are at home and elsewhere?</p> <ul style="list-style-type: none"> <li>• They are as clean and comfortable as I want</li> <li>• They are adequately clean and comfortable</li> <li>• They are less than adequately clean and comfortable</li> <li>• They are not at all clean or comfortable</li> </ul>	Adapted from ASCOT (Malley and Netten, 2009) to be less specific
Environment, cleanliness	<p>Could you tell me which of the following statements best describes how clean and comfortable your surroundings are where you are cared for?</p> <ul style="list-style-type: none"> <li>• They are as clean and comfortable as I want</li> <li>• They are adequately clean and comfortable</li> <li>• They are less than adequately clean and comfortable</li> <li>• They are not at all clean or comfortable</li> </ul>	Adapted from ASCOT (Malley and Netten, 2009) to be more specific
Environment, privacy	<p>Could you tell me which of the following statements best describes the privacy you get in situations where you want it?</p> <ul style="list-style-type: none"> <li>• I get all the privacy I need in situations where I want it</li> <li>• I get an adequate amount of privacy in situations where I want it</li> <li>• I get less than an adequate amount of privacy in situations where I want it</li> <li>• I get no privacy in situations where I want it</li> </ul>	Generated for the purposes of this study
Environment, social inclusion	<p>Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?</p> <ul style="list-style-type: none"> <li>• I have as much social contact as I want with people I like</li> <li>• I have adequate social contact with people</li> <li>• I have some social contact with people, but not enough</li> <li>• I have little social contact with people and feel socially isolated</li> </ul>	ASCOT (Malley and Netten, 2009)



**Table 2: Suggested questions relating to environment, processes of care and capabilities (cont...)**

Issue	Questions	Source
Processes of care, personal hygiene	Thinking about your personal care, by which we mean being clean and presentable in appearance, which of the following statements best describes you situation? <ul style="list-style-type: none"> <li>• I feel clean and am able to present myself the way I like</li> <li>• I feel adequately clean and presentable</li> <li>• I feel less than adequately clean or presentable</li> <li>• I have poor personal hygiene, so I don't feel at all clean or presentable</li> </ul>	ASCOT (Malley and Netten, 2009)
Processes of care, communication	Thinking about the way in which you have been cared for, which of the following statements best describes the care you receive? <ul style="list-style-type: none"> <li>• I am always provided with all the information I need in a clear and understandable way</li> <li>• I am usually provided with all the information I need in a clear and understandable way</li> <li>• I am rarely provided with all the information I need in a clear and understandable way</li> <li>• I am never provided with all the information I need in a clear and understandable way</li> </ul>	Generated for the purposes of this study
Processes of care, communication	Thinking about the way in which you have been cared for, which of the following statements best describes the care you receive? <ul style="list-style-type: none"> <li>• I am always involved in the decisions that affect me</li> <li>• I am usually involved in the decisions that affect me</li> <li>• I am rarely involved in the decisions that affect me</li> <li>• I am never involved in the decisions that affect me</li> </ul>	Generated for the purposes of this study
Processes of care, communication	Thinking about the way in which you have been cared for, which of the following statements best describes the care you receive? <ul style="list-style-type: none"> <li>• I am always listened to when I talk to staff</li> <li>• I am usually listened to when I talk to staff</li> <li>• I am rarely listened to when I talk to staff</li> <li>• I am never listened to when I talk to staff</li> </ul>	Generated for the purposes of this study

**Table 2: Suggested questions relating to environment, processes of care and capabilities (cont...)**

Issue	Questions	Source
Processes of care, attitudes with staff	Thinking about the way in which you have been cared for, which of the following statements best describes the care you receive? <ul style="list-style-type: none"> <li>• I feel that my carers are warm and friendly to me</li> <li>• I feel that my carers show some warmth and friendliness to me</li> <li>• I feel that my carers show little warmth and friendliness to me</li> <li>• I feel that my carers show no warmth and friendliness to me</li> </ul>	Generated for the purposes of this study
Processes of care, attitudes of staff	Thinking about the way in which you have been cared for, which of the following statements best describes the care you receive? <ul style="list-style-type: none"> <li>• My carers seem interested in me as a person</li> <li>• My carers show some interest in me as a person</li> <li>• My carers show little interest in me as a person</li> <li>• My carers show no interest in me as a person</li> </ul>	Generated for the purposes of this study
Processes of care, attitudes of staff	Thinking about the way in which you have been cared for, which of the following statements best describes the care you receive? <ul style="list-style-type: none"> <li>• My carers always seem to take my problems seriously</li> <li>• My carers usually seem to take my problems seriously</li> <li>• My carers rarely seem to take my problems seriously</li> <li>• My carers never seem to take my problems seriously</li> </ul>	Generated for the purposes of this study
Capabilities, autonomy	Could you tell me which of the following statements best describes how much independence you have over your daily life? <ul style="list-style-type: none"> <li>• I can do everything without help from others</li> <li>• I can do many things without help from others</li> <li>• I can do a few things without help from others</li> <li>• I can do nothing without help from others</li> </ul>	Generated for the purposes of this study
Capabilities, control	Could you tell me which of the following statements best describes how much control you have over your daily life? <ul style="list-style-type: none"> <li>• I have as much control over my daily life as I want</li> <li>• I have adequate control over my daily life</li> <li>• I have some control over my daily life</li> <li>• I have no control over my daily life</li> </ul>	ASCOT (Malley and Netten, 2009)

## Discussion

A comprehensive review of dignity in health would be an enormous task. Jacobson (2007) reviewed around 150 book sources to develop her overview and classification, but even this is a small proportion of the estimated 12,000 sources she recognises as existing. We have tried to examine that section of the literature that is most relevant to health and social care and the UK policy context. However, by focusing on studies that include collection of data from patients, we have endeavoured to keep our analysis and conclusions centred on patient values.

Given the prominence of dignity within the literature and health policy it is perhaps curious then, that so few clear definitions of dignity exist. Also, whilst many questions exist relating to dignity, they do not attempt to define it – for example, the National Inpatient Survey simply asks, “overall, did you feel you were treated with respect and dignity while you were in the hospital?” This is problematic as the literature shows that dignity can mean different things to different people; Jacobson in particular shows a clear distinction between ‘human dignity’ and ‘social dignity’, which we feel demonstrates a clear need to focus, and define in some way, ‘social dignity’.

In addition, the literature shows that separate from the concept of dignity are factors that influence it, in direct and indirect ways. In many ways, these are the factors that have drawn the attention of organisations when trying to identify situations where dignity can be reduced – e.g. privacy, autonomy, etc. Of particular note within these factors are those associated with the care process, and this is possibly because of the literature being dominated by health and social care bodies.

When trying to draw all of these facets together we used self-esteem as an operational definition of dignity, then developed a conceptual framework that shows how different groups of factors can influence dignity. In doing this, we have been cognizant of the need to separate out the process of care as an independent factors, so that the framework remains relevant to members of the public that are not receiving face-to-face care. From the perspective of health technology assessment – and D4D – an undue focus on interactions between patient and carer would be of limited use, as many of the devices are used in the absence of face-to-face nursing, for example.

Based on this framework we have developed a set of questions that tap into each of the individual factors that link to dignity. However, we also appreciate other approaches to assessing dignity, including explicitly asking about dignity. Consequently, work is required to test out our proposed questions on people with long-term care needs, together with other related scales and questions.

### *Links to ASCOT/OSCA*

We recognise the overlap with initiatives undertaken by the Personal and Social Services Research Unit (PSSRU). We have used the same underlying concept of self-worth or self-esteem used within OSCA to define dignity and based our direct measure on a question developed by them. In addition, six of the fourteen indirect questions are based around

questions used within ASCOT. Given this degree of overlap, it is worth considering how our work differs from theirs. Firstly, the OSCA/ASCOT work is focused on the care of older people, which makes some of their questions irrelevant to the context of our research. Consequently, using their questionnaires in their entirety would not be sensible. Secondly, the questions we have listed in Table 2 represent a long-list, which will be pared down following patient-based survey work. One result from this could be that much fewer OSCA/ASCOT questions will remain. Thirdly, we have based our questions around an explicit conceptual framework of dignity, whilst the OSCA and ASCOT initiative were developed from an alternative starting point of ‘what is important to older people?’. The fact that there is overlap is not surprising given that we have also highlighted overlaps with other concepts such as patient experience and health related quality of life. Finally, we should also recognise that we propose to generate a scoring tariff that will be capable of being used within economic evaluation, which has not been attempted within ASCOT, but which is central to OSCA.

#### *An alternative approach to developing a dignity questionnaire*

Whilst developing a dignity questionnaire has the advantage of offering a comprehensive assessment of all the issues identified within the framework set out in Figure 1, it does produce some problems. One of these is how to use the scores within an economic evaluation. The preferred instrument within economic evaluation is the EQ-5D, which will need to be used in any evaluation alongside any dignity measure. Whilst the dignity measure will give further information as to the degree of change in dignity, we do not know the value of any such change.

In order to make this judgement we need to know the ‘exchange rate’ between QALYs (or more specifically, the EQ-5D scores that lie beneath them) and the dignity score. This could be produced by a separate valuation exercise, however, an alternative approach would be to bolt-on a dignity domain to the EQ-5D. This would still require a valuation exercise (that would essentially produce a new tariff for the ‘EQ-6D’, but would have the practical advantage of producing a single questionnaire.

Such an approach has been undertaken on previous occasions in attempts to rectify perceived weaknesses of the EQ-5D classification system. Krabbe et al, added in a sixth domain relating to cognition. The resultant instrument was found to generate different from the original instrument an retained good content validity, although subsequent work discovered that it did not improve significantly on the original instrument (Wolf 2003). In other work, Yang (2008) examined the effect of adding a sleep dimension to the EQ-5D, although found that it had little effect. Perneger (2001) went further, and examined the effect of adding a further 5 domains to the EQ-5D. However, only in the case of Yang and colleagues was an alternative utility algorithm produced (Yang 2008).

On examination of this possible approach, it seems inevitable that we would need to adopt the approach of asking directly about “dignity” such that the question is framed in a manner that is consistent with the EQ-5D. One possible formulation is given Box 9.

**Box 9: Proposed direct dignity question that is compatible with the EQ-5D**

**Dignity**

I feel that I live with dignity

I feel that I live with some dignity

I feel that I live with very little dignity

*Future research*

The next phase of this project is to undertake a patient survey using our dignity questions. It is expected that related questions, e.g. measure of self-esteem or life satisfaction, will also be included to examine the degree that they are measuring the same concept. We also anticipate including the EQ-5D and the proposed bolt-on questions to examine the degree to which dignity is not related to health-related functionings. Analysis of the survey data will examine the factor structure of the data and the reliability of the questions within any identified domains. From this analysis, a dignity questionnaire will be identified that will form the basis of future confirmatory work, and a shorter descriptive system that will be focus of valuation work.

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