

## Development of a self-report measure of capability wellbeing for adults: the ICECAP-A.

Al-Janabi, Hareth; N Flynn, T; Coast, Joanna

DOI:

[10.1007/s11136-011-9927-2](https://doi.org/10.1007/s11136-011-9927-2)

*Citation for published version (Harvard):*

Al-Janabi, H, N Flynn, T & Coast, J 2011, 'Development of a self-report measure of capability wellbeing for adults: the ICECAP-A.', *Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation*. <https://doi.org/10.1007/s11136-011-9927-2>

[Link to publication on Research at Birmingham portal](#)

### General rights

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

### Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact [UBIRA@lists.bham.ac.uk](mailto:UBIRA@lists.bham.ac.uk) providing details and we will remove access to the work immediately and investigate.

# Development of a self-report measure of capability wellbeing for adults: the ICECAP-A

Hareth Al-Janabi · Terry N Flynn · Joanna Coast

Accepted: 2 May 2011 / Published online: 20 May 2011  
© The Author(s) 2011. This article is published with open access at Springerlink.com

## Abstract

**Purpose** The benefits of health and social care are not confined to patient health alone and therefore broader measures of wellbeing may be useful for economic evaluation. This paper reports the development of a simple measure of capability wellbeing for adults (ICECAP-A).

**Methods** In-depth, informant-led, interviews to identify the attributes of capability wellbeing were conducted with 36 adults in the UK. Eighteen semi-structured, repeat interviews were carried out to develop a capability-based descriptive system for the measure. Informants were purposively selected to ensure variation in socio-economic status, age, sex, ethnicity and health. Data analysis was carried out inductively and iteratively alongside interviews, and findings were used to shape the questions in later interviews.

**Results** Five over-arching attributes of capability wellbeing were identified for the measure: “stability”, “attachment”, “achievement”, “autonomy” and “enjoyment”. One item, with four response categories, was developed for each attribute for the ICECAP-A descriptive system.

**Conclusions** The ICECAP-A capability measure represents a departure from traditional health economics outcome measures, by treating health status as an *influence* over broader attributes of capability wellbeing. Further work is

required to value and validate the attributes and test the sensitivity of the ICECAP-A to healthcare interventions.

**Keywords** Capability approach · Health economics · Outcome measurement · Quality of life · Qualitative research

## Abbreviations

ICECAP-A ICEpop CAPability measure for adults  
ICEPOP Investigating choice experiments for the preferences of older people

## Introduction

Systematic comparison of the costs and benefits of healthcare interventions through economic evaluation is now a routine element of the healthcare decision-making process [1]. In healthcare, standard welfare economics, which would require benefits to be valued in monetary terms, is generally eschewed in favour of measuring the value of healthcare in terms of its contribution to health status and length of life. Length and quality of life can be combined to generate quality adjusted life years (QALYs) [2, 3]. Although QALYs have the advantage of measuring health benefits from interventions across a diverse range of clinical areas on a common scale, there is increasing concern that the health status measures that underpin QALYs are not sufficiently sensitive or appropriate to the objectives in a number of areas of healthcare, such as mental health [4], social care [5] and public health [6] and for certain groups, such as older people [7], those near death [8] and carers [9]. Healthcare policy in these areas may be geared towards helping individuals maintain independence,

---

H. Al-Janabi (✉) · J. Coast  
Health Economics Unit, Public Health Building, University  
of Birmingham, Edgbaston, Birmingham B15 2TT, UK  
e-mail: h.aljanabi@bham.ac.uk

T. N Flynn  
University of Technology Sydney, Broadway,  
PO Box 123, Sydney, NSW 2007, Australia

dignity, comfort or social interaction [10, 11], and these benefits may be neglected by solely using measures of health gain. A simple generic measure of wellbeing, which goes beyond health, may therefore be useful for comparing the benefits of a diverse range of health and social care policies.

Previous work has developed constructs of wellbeing, referred to as psychological wellbeing and based on the psychological literature, finding domains of self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life and self-growth to be important [12]. Another prominent conception of wellbeing, subjective wellbeing [13], focuses on measuring and identifying determinants of happiness.

The capability approach is an alternative framework for conceptualising wellbeing for public policy that defines wellbeing in terms of what an individual can ‘do’ and ‘be’ in their life [14]. The approach advocates assessing capability (what an individual *can* do) rather than functioning (what they actually *do*) to avoid imposing a particular idea of what a good life constitutes and to reflect the importance of freedom to choose [15, 16]. The paper refers to this notion from this point on as ‘capability wellbeing’. Whilst the capability approach was pioneered in human development research, focusing on basic capabilities such as being able to have shelter and being able to be nourished, there is recognition that measuring more complex capabilities can be useful for public policy [14, 17]. In operationalising the approach, a key challenge is to identify an appropriate set of capabilities and determine how these can be measured to assess outcomes for individuals. Previous work in this area has involved attempts by philosophers to generate lists of capabilities, for example Nussbaum’s list of 10 central human capabilities [18, 19], but these do not reflect the deliberative approach advocated by Sen [16, 19]. An approach focused more on obtaining information about important capabilities from members of the public has previously resulted in the development of a measure of capability wellbeing for older people (the ICECAP-O), which resulted in a measure with five attributes (attachment, security, role, enjoyment, control) [20]. There is no, however, such measure available for the entire adult population, which would be the preferred option for use in economic evaluation.

If, like QALYs, such a measure is to be useful for economic evaluation, there are a number of constraints on the development of the measure [21]. First, there is a need for the measure to be valued using a method whereby the relative importance of different attributes (dimensions) can be ascertained. Such valuation exercises can only cope with relatively small numbers of attributes and levels of those attributes (response categories) within an instrument. Second, there is a need for the measure to cover the entire

wellbeing ‘space’ such that all levels of wellbeing from full wellbeing to no wellbeing can be captured.

This paper reports a qualitative study to elicit concepts and develop items for a capability wellbeing measure for the general adult population for use in economic evaluation (ICECAP-A: The ICEpop CAPability measure for Adults). The study aimed to explore, using in-depth interviews, what was important to individuals in their lives to determine a set of conceptual attributes for the capability wellbeing measure (phase 1) (The terminology of “attributes” is used to retain consistency with previous work [21]). It also aimed to establish meaningful lay terminology for the measure (phase 2). Subsequent work will report the valuation and psychometric testing of the measure.

## Methods

### Sampling

Informants were selected for interview from four electoral wards in England. Wards were chosen to maximise the socio-economic diversity of the sample (with one ward from each quartile of the national index of multiple deprivation scores [22]) and to ensure ethnic diversity and representation from both urban and rural areas. A short invitation letter and screening questionnaire were sent to randomly selected individuals within these wards ( $n = 150$  for all wards except the most deprived, where  $n = 350$ ). For the first phase of interviews, individuals who responded were purposively sampled on the basis of their age, sex, self-perceived health and ethnicity. Younger age groups were less well represented, so three individuals aged under 30 were identified using the ‘snowball’ technique [23]. For the second phase, a sub-sample of informants from the first phase was re-interviewed. Interviewing for both phases continued until saturation [24] was achieved. Written consent was taken from all informants, and the study protocol was approved by the University of Birmingham’s Life and Health Sciences Ethical Review Committee (ERN\_08-93).

### Interview conduct for phase 1

In-depth interviews [23] predominantly in informants’ own homes were used to explore what was important to individuals in their lives. Other people were not present during the interview. Each interview began with a set of straightforward background questions to find out about the informant’s living arrangements, health, family and work. These ‘content mapping’ [23] questions helped to provide the context for the rest of the interview. The questions also

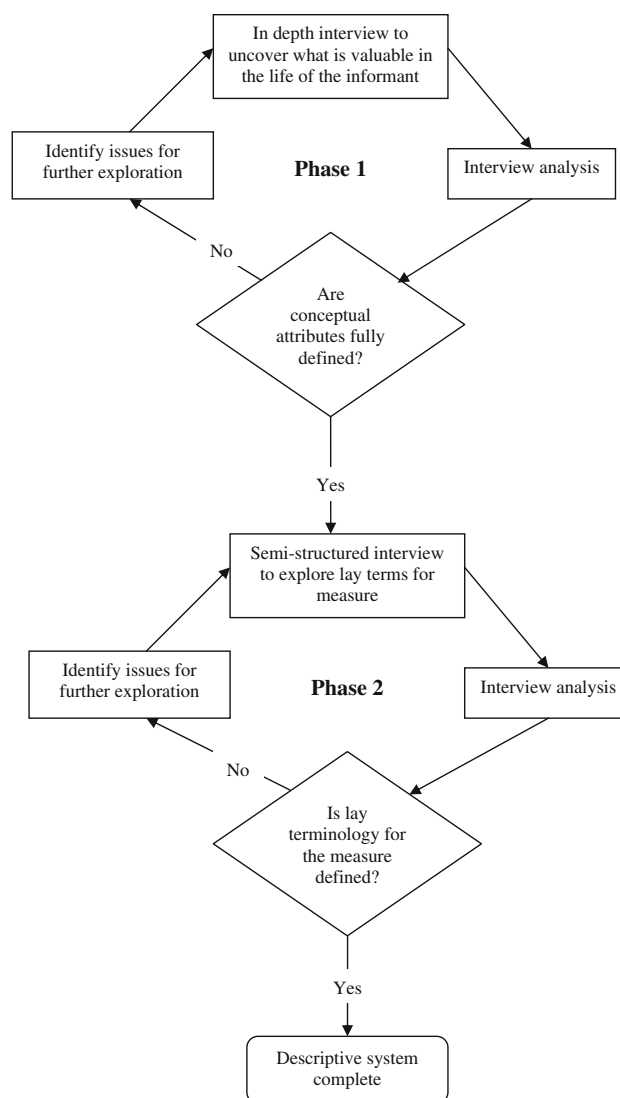
led naturally into ‘content mining’ questions to find out more about what informants valued in their lives. If, for example, the informant mentioned the presence of a health problem at the beginning of the interview, this response could be probed in terms of how it affected their life. A topic schedule (see [Appendix](#)) was used to ensure that issues such as friendships, religion, social activities, finances and politics were introduced later in the interviews if they did not arise naturally. As the understanding of the underlying attributes of capability wellbeing developed, later interviews tended to pursue fewer issues in more depth and explored the issues that less clearly fitted the emerging attributes of capability wellbeing. All interviews were conducted by HA, except one interview conducted by JC for an informant who wanted a same-sex interviewer.

### Interview conduct for phase 2

Figure 1 shows the iterative method of interviewing and analysis used in both phases on the research. The second phase of the study used semi-structured interviews to move from a set of attributes to a self-complete measure of capability wellbeing with one item per attribute. The aim was to establish terminology for the measure that was both user friendly and evoked the range of concepts intended to be covered by the attributes. Interviews were conducted and analysed iteratively as it was important to ensure that statements could be constantly refined in response to earlier feedback. Informants were asked how lists of the specific concepts related to each attribute could best be summarised and shown potential wording for attributes (derived from the phase one interviews) and asked what the terms meant to them. An example is shown in [Fig. 2](#).

### Data management and analysis

Interviews were digitally recorded and fully transcribed. Analysis was conducted iteratively and inductively, with transcripts being organised into batches of five to eight for analysis. The importance of iterative data collection and analysis for establishing content validity is outlined elsewhere [25]. Each transcript was coded in the *ATLAS.ti* qualitative data analysis package with codes initially reflecting the set of issues covered in the interviews (see ‘prompts’ in the [Appendix](#)) and the emerging understanding about how each of these issues affected capability wellbeing. For subsequent batches of interviews in phase one, the codes used reflected less the specific influences on wellbeing (e.g. work) and more the concepts that could be influenced by multiple factors (e.g. stress). This changing coding framework was used to ensure interview data were organised into themes that represented what was ultimately important in individuals’ lives rather than the external prompts introduced



**Fig. 1** Iterative interview process

during the discussion. Descriptive accounts, incorporating quotes from interviews and interpretative narrative, were produced for each batch of interviews using the coding framework for phase 1 or phase 2, as appropriate, to organise the quotes. Constant comparative analytic methods [26] were used to compare extracts across informants, and then to compare these new data to the properties of emerging themes. These themes were developed by the authors and discussed with members of an external advisory group and the study informants prior to further analysis.

Verbatim quotes from informants have been selected to be illustrative of how informants’ accounts were linked to emerging themes. Ellipses (...) are used to denote missing speech; ‘umm’, ‘err’ and repeats of words, which do not add to meaning, are removed without the use of ellipsis. Square brackets are used to clarify informants’ meaning.

**Task 1**

Ask respondents how the following issues could be best summarised (negative concepts are in *italics*): “shared history”, “security”, “convenience”, “familiar surroundings”, “sense of continuity”, “feeling relaxed”, “*stress*”, “*being worried*”, “*living with uncertainty*”

If they are unsure or require further information offer suggestions: “settled”, “relaxed and comfortable”, “secure and not worried”

**Task 2**

Ask respondents what the following terms mean to them: “settled”, “relaxed and comfortable”, “secure and not worried”

Probe anything raised that is (currently) included under another conceptual attribute.

Ask which term (if any) they prefer and why.

**Fig. 2** Establishing a lay term for ‘stability’ for the measure

## Findings

Sixty-three individuals replied to the screening questionnaire indicating that they would like to take part in the research. From these, 36 informants, selected to achieve maximum diversity in the sample, were interviewed in phase one, with 18 informants re-interviewed for phase two. Interviews (across both phases) were conducted between February and December 2009. Interviews lasted between 40 and 90 min (in phase one) and 25 and 70 min (in phase two). Table 1 shows the characteristics of the interview informants.

### Phase 1: the conceptual attributes of the measure

Following the 36 interviews in phase one, five conceptual attributes of capability wellbeing were developed; the meaning of, and key influences on, each attribute is described below.

#### Stability

The desire for a sense of continuity in life (in terms of friends, work and location) was evident from early interviews. Later interviews revealed a close link between continuity and general aversion to feeling threatened and living with uncertainty. These issues were combined as the “stability” attribute. Stability appeared to come through the interplay of various aspects of informants’ lives, including more ‘objective’ factors (such as the absence of dramatic changes in their lives) and more ‘subjective’

**Table 1** Characteristics of study informants

|                               | Interviewed for<br>phase one<br>(n = 36) | Interviewed for<br>phase two<br>(n = 18) |
|-------------------------------|--|--|
| <i>Sex</i>                    |  |  |
| Female                        | 21                                       | 11                                       |
| Male                          | 15                                       | 7  |
| <i>Age</i>                    |  |  |
| 18–29                         | 7  | 4  |
| 30–44                         | 9  | 6  |
| 45–64                         | 11                                       | 4  |
| 65+                           | 9  | 4  |
| <i>Health (self reported)</i> |  |  |
| Good                          | 23                                       | 10                                       |
| Not good                      | 13                                       | 8  |
| <i>Location (ward)</i>        |  |  |
| Deprived inner city           | 11                                       | 5  |
| Moderately deprived rural     | 7  | 4  |
| Moderately affluent suburban  | 9  | 4  |
| Affluent suburban             | 9  | 5  |
| <i>Ethnicity</i>              |  |  |
| White British                 | 29                                       | 16                                       |
| White non-British             | 2  | 0  |
| Non-white                     | 5  | 2  |

factors (such as whether informants felt stressed and were able to assign meaning to their lives):

...my health broke down again ... which came as a shock... I had to give up work immediately ...and it cast a long shadow because it’s always there in the background, you never know when it might jump on you. So you live with uncertainty. [Female, 78]

The capability to have ‘stability’ was affected by a broad range of factors. Poor health (as above), unemployment and crime (and the threat of each of these) were important negative influences. Positive influences included consistent friendships and family groups, guaranteed work, secure finances, home ownership and a strong belief system:

...whatever religion you are, when you feel horrible inside, you feel sad inside you quickly go back to your God and say “oh God, help me” don’t you? Everybody does that. [Female, 55]

#### Attachment

The importance of love, support and social contact was apparent from early interviews. These concepts were combined with concepts about affection, being close to people and belonging, to create the “attachment” attribute.

The ability to feel attached appeared to rest both on the ability to interact and on the quality of individuals' relationships. Informants expressed a desire for these relationships to be loving, honest, understanding and supportive:

At ante-natal classes ...six of us really gelled and just became the closest of friends. It was like we'd known each other for years and years and years. ... we see each other all of the time and we help each other out which is great. [Female, 32]

Attachment was strongly related to the presence of a partner, close family and good friends. Poor health and bereavement within the family were cited by a number of informants as factors in bringing them closer to other family members. The notion of feeling supported was not always related to the *amount* of practical and emotional input received, with (*cap*)*ability* to call on support being noted:

I'm not saying I don't like having them [friends] round in case they're needed, but whether I would ask for it [help] is slightly different. [Male, 62]

### Autonomy

A desire to be independent was clear from the very beginning of the interviews, with informants talking about not wanting to be a "liability" and wanting to be their "own person". Whilst factors like being able to look after oneself and independence in decision making were regularly cited, complex issues regarding privacy (not wanting living areas to be overlooked, for example) and identity (wanting freedom to be the person that they saw themselves as) were also important. These concepts were drawn together as the "autonomy" attribute:

...our privacy, our independence of thought, all those kind of things make you who you are...[Female, 22]

Home ownership, self-employment and, more generally, an individual's freedom to control their working environment were associated with greater autonomy:

...the worst humiliation to me is to be told to stop doing something really. [Male, 86]

On the other hand, poor health was an important limiting influence on autonomy, for example, through dependence on medication, through to poor health limiting an individual's ability to carry out basic activities.

### Achievement

The achievement attribute reflects the degree to which an individual is able to both move forward in their life and

attain their goals. The attribute also reflects the importance of being able to look back with satisfaction at achievements (pride) and having their role and achievements noticed by others (recognition and appreciation):

As a Physics Teacher, to do 6 years without any promotion is pretty unusual really because they're in such short supply. And I was beginning to feel left on the shelf. [Male, 28]

Individuals' ability to achieve appeared to be strongly related to their opportunities to be successful at work, to have a family and to own things. For many individuals, achievement was related to outside interests, particularly voluntary work and sport:

I do like playing ...competitive sport... it's got a bit of an edge .... I suppose through that there's a bit of an achievement thing and it's quite nice to be in a team or to be a captain for one of the teams [Male, 29]

### Enjoyment

The interviews revealed that informants sought and valued enjoyment in their lives. Enjoyment ranged from the "quiet pleasures" in life to things that were perceived to be "fun" or "exciting". Pleasure was also often gained from simply being around people (and sharing in their happiness) and from removal from the often frantic pace of everyday life:

It [TV programme] is wonderful...I'd recorded it over Christmas...And I just thought this is fantastic. So a great deal of pleasure... [Female, 60]

A number of informants mentioned periods of their life when they were depressed, felt "down" or were in pain; these were periods of their life that were clearly not enjoyable:

...obviously it's [mother's illness] been hard, it's been upsetting...and visiting her now isn't exactly a barrellful of laughs... I guess it's saddening ... [Female, 29]

The capability for enjoyment was generated by the presence of families, friends, pets, leisure activities and the countryside in the informants' lives. Key limiting factors on enjoyment included financial difficulties and poor health:

[The chest infection] just made it miserable for a week or two, I couldn't get out or about ... [Male, 75]

### Other concepts

During the interviews, informants also talked about the wider world. This discussion often arose towards the end of



interviews when informants were asked whether there was anything important to them in their lives that had not been covered. The importance of the values, actions and attitudes of other people were mentioned by a number of informants:

...we're just not learning anything... I listen to that Guantanamo thing, we're not giving people a trial ...if they're wicked they should be punished, but everybody, I don't care who they are or what they've done they must have a trial. [Female, 55]

Given that the intention with this work was to develop a measure of *personal* capability wellbeing that could be used in trials to measure the effectiveness of health and social care interventions, it was judged that issues about the type of world the informant wanted to live in lay outside what was being measured and are in fact are more akin to Sen's notion of agency wellbeing (concerned with the objectives that a person has reason to promote, even if these do not contribute to their own personal wellbeing) [15]. Issues categorised under this theme were therefore excluded from this measure of personal capability wellbeing, although the findings are being taken forward in other work.

#### Phase 2: the development of the descriptive system

The conceptual terminology for attributes, such as “stability” or “attachment”, was unsuitable for including in a self-complete questionnaire for all members of the general population. Informants commented, for example, that “stability” brought to mind being “mentally unstable”. The second phase of interviews offered the opportunity to explore the most appropriate terminology for the attributes. For reasons of space, it is not possible to report the development of each set of wording individually here (the wording explored for each attribute is given in Table 2). However, as an example, the attachment attribute was initially labelled “support and affection” (drawing on earlier interviews for terminology); informants variously indicated that the word affection was “trivial” or “random”. Words such as “love” and “friendship” were

judged by the informants to be more evocative of the concepts encompassed by the attribute. The terminology was further refined through the interviews, first to “support, love and friendship” (which was rejected because informants overly focused on issues of charitable or state support) and then finally to “love, friendship and support”. In general, developing lay terminology for attributes required a balance to be struck between keeping attributes concise (so as to keep the measure straightforward and unambiguous) and detailed (so as to invoke the range of concepts covered by each attribute).

The final lay terms (conceptual attributes are in parentheses) for the attributes were those where misunderstanding by informants was avoided, and where the meanings informants derived from them were those most closely related to the original conceptual attribute: settled and secure (stability), love, friendship and support (attachment), independence (autonomy), achievement and progress (achievement) and enjoyment and pleasure (enjoyment).

One aim when selecting levels was to cover the capability space as widely as possible, and therefore as far as possible, the bottom level for each attribute needed to represent the absence of capability and the top level, full capability. For two of the attributes, “attachment” and “enjoyment”, it was harder to find a logical expression of full capability, without measuring preferences rather than capabilities (“all that *I want*” for example) and, as a result, a top level (representing full capability on that attribute) of “a lot” was used. Given that there would be two levels at the extremes, a decision was made to have two further intermediate levels for each attribute. This represented a desire for the measure to be sensitive, yet capable of being valued using econometric techniques. To derive intermediate levels, other outcome measures were reviewed for terminology: the use of the terms “moderate” and “some” was explored with informants, along with “a lot”, “a little”, “many” and “few”. After piloting, “moderate” and “some” were rejected. Informants appeared to interpret “some” inconsistently; it could mean more or less than half. The word “moderate” on the other hand was perceived to not make sense in the context of an individual's

**Table 2** Wording explored for conceptual attributes

| Conceptual attribute | Stability   | Attachment    | Autonomy             | Achievement | Enjoyment  |
|----------------------|-------------|---------------|----------------------|-------------|------------|
| Lay terms            | Stable      | Support       | Independent          | Achievement | Enjoyment  |
|                      | Settled     | Affection     | Control              | Progress    | Pleasure   |
|                      | Secure      | Love          | Making own decisions | Success     | Fun        |
|                      | Not worried | Friendship    |                      |             | Excitement |
|                      | Relaxed     | Companionship |                      |             | Variety    |
|                      | Comfortable | Sharing       |                      |             |            |

attachment or enjoyment. The terms “quite a lot”, “a little”, “many” and “few” were acceptable and therefore used in the final descriptive system for the measure presented as Fig. 3. At this point, scores are not available for the measure, but profiles can be identified using the numbers associated with each item. For example, the state 44444 would indicate full capability on all attributes, whilst the state 11111 would indicate an absence of capability.

## Discussion

This paper has described the development of a brief, capability wellbeing measure for the general adult population. The measure aims to capture individuals' freedom to function in five key areas of their life, identified through in-depth interviews. Informants were sampled specifically to ensure wide representation and thus applicability of the final set of capabilities (and the wording). In contrast to much previous work to develop outcome measures for economic evaluation [27] (although in common with some recent studies [20, 28, 29]), qualitative methods have been used. This approach grounds the attributes in the values and terminology of the general population and ensures that a

limited set of items can be generated to cover a broad range of concepts.

This study suggests a similar, yet not identical, list of attributes for adults in general to that for older adults [20]. The attributes of “attachment”, “autonomy” and “enjoyment” are almost identical, albeit with some adjustment in wording, to three attributes in the ICECAP-O measure. The main differences for the ICECAP-A measure were in the “stability” and “achievement” attributes. “Stability” bears a strong similarity to the “security” attribute in ICECAP-O; however, the emphasis on “stability” is on the present (in terms of current feelings of comfort and continuity), as well as the future. Similarly, the “achievement” attribute in ICECAP-A goes beyond the “role” attribute in ICECAP-O, encompassing progressing and excelling in life, concepts that may not stem from having a role. In Nussbaum's list of central human capabilities [18], there are three capabilities (“emotions”, “control” and “play”), which are close equivalents to the “attachment”, “autonomy” and “enjoyment” capabilities found in this study. Whilst there are no direct equivalents for “achievement” and “stability”, these issues are also touched on in Nussbaum's list (e.g. Nussbaum's concern for security against assault is likely to come into “feeling settled and secure”). The ICECAP-A attributes are also broadly similar to those proposed in the non-capabilities-based wellbeing literature. For example, the ICECAP-A attributes of “attachment” and “autonomy” in ICECAP-A are not dissimilar to Ryff's [12] theory-derived dimensions of “positive relations with others” and “autonomy”. Ryff's dimensions of “purpose in life” and “personal growth” are similar to “achievement” in ICECAP-A, whilst “self-acceptance” has links to “stability”.

The measures that are used in economic evaluation to generate QALYs typically focus on *health*-related quality of life. These tend to go beyond a strict biomedical definition of health [30], but there is no consensus on what exactly should be measured. Current measures, such as the EQ-5D [31] incorporate attributes right across the health spectrum, from specific impairments (pain) and disabilities (mobility) to the impact of poor health on participation in life (usual activities). This raises the concern that health effects may be double counted [27]. Furthermore, health-related quality of life measures focus on selected aspects of participation in life; for example, the AQOL [32] directly considers the impact of poor health on relationships, whilst the EQ-5D does not. Full use of the capability approach in health economics entails going beyond health to consider an individual's wellbeing in a broader sense [33]. Focusing on what an individual can be and do in their life does not (conceptually at least) limit the possible ways in which healthcare interventions can impact on an individual's life. Arguably, by treating health as an influence, it is also less

Please indicate which statements best describe your overall quality of life at the moment by placing a tick (✓) in **ONE** box for each of the five groups below.

|  |                            |
|--|----------------------------|
| <b>1. Feeling settled and secure</b>   |                            |
| I am able to feel settled and secure in <b>all</b> areas of my life          | <input type="checkbox"/> 4 |
| I am able to feel settled and secure in <b>many</b> areas of my life         | <input type="checkbox"/> 3 |
| I am able to feel settled and secure in <b>a few</b> areas of my life        | <input type="checkbox"/> 2 |
| I am <b>unable</b> to feel settled and secure in <b>any</b> areas of my life | <input type="checkbox"/> 1 |
| <b>2. Love, friendship and support</b>                                       |                            |
| I can have <b>a lot</b> of love, friendship and support                      | <input type="checkbox"/> 4 |
| I can have <b>quite a lot</b> of love, friendship and support                | <input type="checkbox"/> 3 |
| I can have <b>a little</b> love, friendship and support                      | <input type="checkbox"/> 2 |
| I <b>cannot</b> have <b>any</b> love, friendship and support                 | <input type="checkbox"/> 1 |
| <b>3. Being independent</b>  |                            |
| I am able to be <b>completely</b> independent                                | <input type="checkbox"/> 4 |
| I am able to be independent in <b>many</b> things                            | <input type="checkbox"/> 3 |
| I am able to be independent in <b>a few</b> things                           | <input type="checkbox"/> 2 |
| I am <b>unable</b> to be at all independent                                  | <input type="checkbox"/> 1 |
| <b>4. Achievement and progress</b>   |                            |
| I can achieve and progress in <b>all</b> aspects of my life                  | <input type="checkbox"/> 4 |
| I can achieve and progress in <b>many</b> aspects of my life                 | <input type="checkbox"/> 3 |
| I can achieve and progress in <b>a few</b> aspects of my life                | <input type="checkbox"/> 2 |
| I <b>cannot</b> achieve and progress in <b>any</b> aspects of my life        | <input type="checkbox"/> 1 |
| <b>5. Enjoyment and pleasure</b>   |                            |
| I can have <b>a lot</b> of enjoyment and pleasure                            | <input type="checkbox"/> 4 |
| I can have <b>quite a lot</b> of enjoyment and pleasure                      | <input type="checkbox"/> 3 |
| I can have <b>a little</b> enjoyment and pleasure                            | <input type="checkbox"/> 2 |
| I <b>cannot</b> have <b>any</b> enjoyment and pleasure                       | <input type="checkbox"/> 1 |

Please ensure you have only ticked **ONE** box for each of the five groups.

**Fig. 3** Descriptive system for the ICECAP-A measure of capability wellbeing for adults



susceptible to double counting both the impairment that health problems cause and the impact that this impairment has on an individual's life.

In developing the measure, the ability to live in a good or “just” world was important to some respondents. However, it was rejected as a potential attribute for two reasons. First, such a capability is unlikely to be informative when evaluating the benefits of, for example, a new drug or surgical device in a UK context. Second, ‘living in a just world’ might be ‘too important’, in that by dominating all other attributes it cannot be quantitatively valued using proposed econometric techniques [34].

A key strength in the work is that it drew on both the capability approach and mainstream health economics approach to outcome development. This involved placing an emphasis on public participation in developing the content of the measure [19, 35] but with an end goal of generating a concise outcome measure that can be valued using econometric techniques to obtain a single index value [27]. Furthermore, the iterative nature of the interviews helped ensure face validity and provide information as to respondents' understanding of the terminology in an efficient manner.

Limitations to the work also need to be discussed. Although a diverse sample of informants was recruited, the three informants that were recruited through snowball sampling were friends of one informant and therefore there may have been less variation in the views of the younger age group in the sample. Furthermore, the sampling strategy excluded those individuals who were not on the electoral register, which will have meant that some individuals on the margins in society (in prisons and institutional care, for example) will have been excluded, as well as those who opted not to be on the electoral register. In common with other qualitative studies, one cannot be sure that different researchers would not come up with different attributes. However, the influence of a single researcher was minimised by the checking of findings with the broader research team and with informants themselves. In general, further testing of the measure's reliability and validity will be important if it is to be a credible outcome measure for use in trials and economic evaluations. Preliminary work is underway to use tests of association with socio-economic variables [36] to explore construct validity and think-aloud interviews [25] to explore the completion processes for the measure. The latter will allow further investigation of the degree to which individuals think about their freedoms in life (rather than simply their functionings) when they respond to the questions. Finally, one concern is that because the measure focuses on an individual's capability wellbeing in broader sense, the measure will be less sensitive than measures of generic health. This clearly merits consideration, but it is an issue that can only be explored

through using the measure in a variety of health and social care settings.

In conclusion, this work has generated a measure to assess health and social care interventions in terms of their impact on an individual's “capability to do and be the things that are deemed valuable in their life”. Further research will be conducted to generate index values for use with the measure using best-worst scaling [37]. Work is also required to further assess the acceptability and appropriate application of the approach; such work could proceed through interviews with potential users of the measure and healthcare decision-makers. Potentially, however, the ICECAP-A measure provides a useful step forward in the development of measures of broader wellbeing for comparing the effectiveness and cost-effectiveness of the increasingly diverse array of health and social care interventions.

**Acknowledgments** The authors would like to thank all the informants who participated in the study and Rhiannon Tudor-Edwards for comments on an earlier draft of the manuscript, presented to the Health Economists Study Group at the London School of Economics in January 2010. The authors would also like to thank the members of the external project advisory group (Richard Smith, Paul Anand, Cindy Billingham, Sarah Byford, Richard Holland, Will Hollingworth, Jeremy Horwood, Emily Lancsar, Paula Lorgelly, Emma McIntosh, Chris Salisbury) and the wider ICECAP-A project team (John Brazier, Stirling Bryan, Sam Clemens and Tim Peters) for their input into the work. This work was supported by the Medical Research Council [grant number G0701027].

**Open Access** This article is distributed under the terms of the Creative Commons Attribution Noncommercial License which permits any noncommercial use, distribution, and reproduction in any medium, provided the original author(s) and source are credited.

## Appendix

### Topic schedule for phase one interviews

#### *Background ‘content mapping’ questions to cover:*

- Age
- Household composition and tenure
- Marital status and presence of family/friends
- Caring responsibilities
- Employment
- Current health status

#### *Exploratory ‘content mining’ questions*

- How do you spend their time at moment?
- What do you like/enjoy about your life (in terms of what you do and how you feel)?

- What it is about these factors that is important? Do factors contribute differently (e.g. comparing what friends versus family bring to your life)?
- What do you dislike about your life? For example, what would you like to see change? What (if anything) are you not so happy with? What would you like more or less of?
- What are the key things that would improve your own life?

### Prompts

- Relationships with family and others (friends, neighbours, colleagues and carers)
- Religion/spirituality
- Activities (including employment, hobbies, interests and voluntary work)
- Independence, terms of decision making
- Health (including physical and mental health, personal care and the health of others)
- Surroundings (including housing and standard of living)
- Wealth/income
- Work (availability and conditions)
- Education, thought and reasoning
- Wider social issues (for example, influence of community and environment on life)

### References

1. Drummond, M., Schwartz, S., Jonsson, B., Luce, B., Neumann, P., Siebert, U., et al. (2008). Key principles for the improved conduct of health technology assessments for resource allocation decisions. *International Journal of Technology Assessment in Health Care*, 24(3), 244–258.
2. Weinstein, M., & Stason, W. (1977). Foundations of cost-effectiveness analysis for health and medical practices. *New England Journal of Medicine*, 296(13), 716–721.
3. Williams, A. (1985). Economics of coronary artery bypass grafting. *British Medical Journal*, 291, 326–329.
4. Chisholm, D., Healey, A., & Knapp, M. (1997). QALYs and mental healthcare. *Social Psychiatry and Psychiatric Epidemiology*, 32(2), 68–75.
5. Ryan, M., Netten, A., Skatun, D., & Smith, P. (2006). Using discrete choice experiments to estimate a preference-based measure of outcome—An application to social care for older people. *Journal of Health Economics*, 25(5), 927–954.
6. Chalkidou, K., Culyer, A., Naidoo, B., & Littlejohns, P. (2008). Cost-effective public health guidance: Asking questions from the decision-maker's viewpoint. *Health Economics*, 17(3), 441–448.
7. Donaldson, C., Atkinson, A., Bond, J., & Wright, K. (1988). Should QALYs be programme-specific? *Journal of Health Economics*, 7, 239–257.
8. Coast, J., Flynn, T., Sutton, E., Al-Janabi, H., Vosper, J., Lavender, S., et al. (2008). Investigating choice experiments for preferences of older people (ICEPOP): Evaluative spaces in health economics. *Journal of Health Services Research and Policy*, 13(Suppl 3), 31–37.
9. Wiseman, V. (1997). Caring: The neglected health outcome? or input? *Health Policy*, 39, 43–53.
10. Verkerk, M., Busschbach, J., & Karssing, E. (2001). Health-related quality of life research and the capability approach of Amartya Sen. *Quality of Life Research*, 10, 49–55.
11. Ryan, M., & Shackley, P. (1995). Assessing the benefits of health care: How far should we go? *Quality in Health Care*, 4, 207–213.
12. Ryff, C. (1989). Happiness is everything or is it? Explorations on the meaning of psychological wellbeing. *Journal of Personality and Social Psychology*, 57(6), 1069–1081.
13. Diener, E., Suh, E., Lucas, R., & Smith, H. (1999). Subjective well-being: Three decades of progress. *Psychological Bulletin*, 125(2), 276–302.
14. Sen, A. (1987). *Commodities and capabilities*. New Delhi: Oxford University Press.
15. Sen, A. (1993). Capability and well-being. In M. Nussbaum & A. Sen (Eds.), *The quality of life* (pp. 30–53). Oxford: Oxford University Press.
16. Alkire, S. (2002). *Valuing freedoms*. Oxford: Oxford University Press.
17. Anand, P., & van Hees, M. (2006). Capabilities and achievements: An empirical study. *Journal of Socio-Economics*, 35, 268–284.
18. Nussbaum, M. (2000). *Women and human development: The capabilities approach*. New York: Cambridge University Press.
19. Robeyns, I. (2005). Selecting capabilities for quality of life measurement. *Social Indicators Research*, 74, 191–215.
20. Grewal, I., Lewis, J., Flynn, T., Brown, J., Bond, J., & Coast, J. (2006). Developing attributes for a generic quality of life measure for older people: Preferences or capabilities? *Social Science and Medicine*, 62, 1891–1901.
21. Coast, J., Flynn, T., Natarajan, L., Sproston, K., Lewis, J., Louviere, J., et al. (2008). Valuing the ICECAP capability index for older people. *Social Science and Medicine*, 67(5), 874–882.
22. HM Government. (2011). English indices of deprivation [homepage on the internet]. London, UK: Communities and Local Government [cited April 14, 2011]. Available from: <http://www.communities.gov.uk/publications/communities/indicesdeprivation07?view=Standard>.
23. Ritchie, J., & Lewis, J. (2003). *Qualitative research practice*. London: Sage Publications.
24. Morse, J. (1995). The significance of saturation. *Qualitative Health Research*, 5, 147–149.
25. Brod, M., Tesler, L., & Christensen, T. (2009). Qualitative research and content validity: Developing best practices based on science and experience. *Quality of Life Research*, 18, 1263–1278.
26. Glaser, B. (1965). The constant comparison method of qualitative analysis. *Social Problems*, 12(4), 436–445.
27. Brazier, J., Ratcliffe, J., Salomon, J., & Tsuchiya, A. (2007). *Measuring and valuing health benefits for economic evaluation*. Oxford: Oxford University Press.
28. Stevens, K. (2010). Working with children to develop dimensions for a preference-based, generic, pediatric, health-related quality of life measure. *Qualitative Health Research*, 20(3), 340–351.
29. Stevens, K. (2009). Developing a descriptive system for a new preference-based measure of health-related quality of life for children. *Quality of Life Research*, 18, 1105–1113.
30. Boorse, C. (1977). Health as a theoretical concept. *Philosophy of Science*, 44(4), 542–573.
31. Dolan, P. (1997). Modeling valuations for EuroQol health states. *Medical Care*, 35(11), 1095–1108.
32. Hawthorne, G., Richardson, J., & Osborne, R. (1999). The assessment of quality of life (AQoL) instrument: A psychometric

- measure of health-related quality of life. *Quality of Life Research*, 8, 209–224.
33. Coast, J., Smith, R., & Lorgelly, P. (2008). Should the capability approach be applied in health economics. *Health Economics*, 17, 667–670.
  34. Flynn, T. (2010). Using conjoint analysis and choice experiments to estimate quality adjusted life year values: Issues to consider. *Pharmacoeconomics*, 28(9), 711–722.
  35. Hurley, J. (2001). Commentary on “Health-related quality-of-life research and the capability approach of Amartya Sen”. *Quality of Life Research*, 10, 57–58.
  36. Coast, J., Peters, T., Natarajan, L., Sproston, K., & Flynn, T. (2008). An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people. *Quality of Life Research*, 17, 967–976.
  37. Flynn, T., Louviere, J., Peters, T., & Coast, J. (2007). Best-worst scaling: What it can do for health care research and how to do it. *Journal of Health Economics*, 26(1), 171–189.