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Using deliberative methods to establish a sufficient state of capability well-being for use in decision-making in the contexts of public health and social care

Background: Health maximisation is unlikely to be a relevant objective for social care, where service users and the workforce have distinct priorities and needs. NICE permit use of a small number of capability-based measures for the evaluation of social care, including ICECAP-A, a measure with five attributes, each with four levels.

Aim: To establish a sufficient state of capability well-being, as defined by ICECAP-A, through public deliberation, and evaluate and critically reflect on the deliberative process.

Methods: A series of one-day/6.5 hour citizens' workshops were conducted, with recruitment from within purposively selected local authority areas. Workshops consisted of a mixture of background information, individual tasks, group discussion and voting.

Representatives from each workshop were then invited to attend a 'consensus workshop'. Follow-up interviews facilitated evaluation of the deliberative process.

Results: 62 participants took part in deliberative work, across eight workshops. Participants actively engaged and provided positive feedback about their experience. Key considerations for participants included: the realistic ability of public services to enhance some areas of well-being; not removing incentives for self-help and avoiding state intrusion; building resilience and enabling people to 'give back to society'; ensuring that people are not left with a standard of well-being that is morally indefensible. The resulting sufficient state of capability well-being (defined by ICECAP-A) was 3,3,3,3,3 (where the best possible state is 4,4,4,4,4).

Conclusion: Through a deliberative approach, representatives of the public were able to debate a complex social issue and reach a consensus decision on a sufficient state of capability well-being.

Keywords: Capability Approach; Sufficiency; Decision-Making; Deliberation; Social Care; Public Health

1. Introduction:

The capability approach is a normative framework within which to define and measure well-being (Sen 2010). Defining characteristics of the approach are the assessment of well-being in terms of functionings (achieved or observed outcomes) and - principally or ultimately - capabilities (the freedom to achieve valuable functionings) (Sen 1992). Successful social policy therefore expands capability sets (i.e. people's freedom and ability) (Sen 1999).

Constrained resources and growing demand mean there are "huge pressures facing the NHS and social care" (Barker, Alltimes et al. 2014). Institutions such as the National Institute for Health and Care Excellence (NICE) seek to promote an efficient use of resources in the NHS, informed in part by cost-utility analysis (CUA), a form of economic evaluation involving the maximisation of health functioning. In 2013 NICE extended its remit to include social care. Rather than adopting the same CUA framework for social care, as for health, NICE have acknowledged that "people using social care services and the workforce providing them have different priorities and needs" (NICE 2014).

NICE has recommended the use of a small number of alternative instruments to assess outcomes in social care (NICE 2013), which include the two capability measures: ICECAP-A (for the general adult population) (Al-Janabi, Flynn et al. 2012) and ICECAP-O (for older people) (Grewal, Lewis et al. 2006). The Zorginstituut in the Netherlands also recommend ICECAP for use in economic evaluation in the context of long-term care (Zorginstituut Nederland 2016). ICECAP-A has five attributes: stability; attachment; autonomy; achievement; enjoyment. For each attribute there are four response levels, with the worst response level on each attribute (phrased, in terms of "I am unable to..." or "I cannot have...") being coded as level 1. The best response level is phrased, for example, in terms of "being able to have all..." or "being able to have a lot of..." and is coded as 4. Coding across the five attributes defines one of 1,024 possible states of capability well-being.

The ICECAP-A was valued using best-worst scaling, giving tariff values between 0 (for the state coded as 1,1,1,1,1: 'no capability') and 1 (for the state coded as 4,4,4,4,4: 'full capability') (Flynn, Huynh E

et al. 2014). Research shows that responses to ICECAP-A and resulting scores reflect differences across different health and socioeconomic groups as anticipated, indicating construct validity (Al-Janabi, Peters et al. 2013, Goranitis, Coast et al. 2016, Goranitis, Coast et al. 2016).

Despite increasing interest in the capability approach, the conceptual framework is incomplete (Robeyns 2006) and this leads to variation in interpretation. One unresolved question relates to the choice of decision-rule. The lack of a clear decision-rule and related monetary threshold limits the ability of researchers to present the results of trials/studies in a way that is easily accessible and meaningful for decision-makers.

Various forms of sufficiency have been advocated as a decision-rule by capability theorists (Ruger 2010, Alkire and Foster 2011, Nielsen and Axelsen 2017). As a broad concept, sufficientarian approaches can be defined as “a commitment to achieving a threshold level of whichever currency of justice is deemed appropriate” (Rid 2017), or alternatively as the normative stance in which “justice is fulfilled when everyone has enough” (Nielsen and Axelsen 2017, p46). In health economics sufficiency has been investigated in an exploratory sense, as a decision-rule for use with ICECAP-A (Mitchell, Roberts et al. 2017).

Because the overarching conceptual framework is underspecified, researchers operationalising the capability approach have to make decisions based on broad principles from Sen’s writings (Nussbaum 2003). Sen advocates tackling some of the more practical steps in operationalising the capability approach (such as establishing the value of particular capabilities) via reasoned consensus, involving public discussion and democracy (Sen 1999). A related and potentially useful methodology from the political, philosophical, and increasingly the environmental economics (Sagoff 1998), literatures is public deliberation.

The objectives of this paper are twofold: (i) primarily to report on the use deliberative methods to establish a sufficient state of capability well-being, for use in informing resource allocation decisions; and (ii) in addition, to evaluate/reflect upon the *process* of deliberation. The conceptual case for

sufficient capability is made in section two , before methods and results are reported in sections three and four respectively.

2. Conceptual Framework

Several capability theorists have advocated combining capability and sufficiency, for example in Ruger's Health Capability Paradigm (Ruger 2010), in the context of the ICECAP measures (Mitchell, Roberts et al. 2015) and in the conceptual work of Nielsen and Axelsen (2017).

Nielsen and Axelsen specify that accounts of sufficiency entail a positive thesis and a negative thesis. The positive thesis is that "bringing people above some threshold is especially important"; the negative thesis that "above this threshold, inequalities are irrelevant" (p47). In addition, Nielsen and Axelsen suggest that the threshold may dictate a level below which citizens have a claim for resources (from the state), and above which they do not.

Attempts to operationalise the capability approach typically rely on an implicit or explicit assertion that some level of capabilities exists, below which no one should find themselves, and it is for this reason (Nielsen and Axelsen argue) that all capability theorists at least implicitly subscribe to the positive thesis (Nielsen and Axelsen 2017). Use of the word capabilities (in the plural) is deliberate here, given that capability as a concept is built around a belief that unidimensional approaches to assessing well-being simplify what is important in a human life and fail to account for human heterogeneity.

Given the need to consider multiple dimensions, Alkire and Foster (2011) set out two extreme positions for considering 'dimensional shortfalls': the first (the union method) states that a person is 'poor' (using the terminology of Alkire and Foster, although the terminology 'capability poor' will be used from now on) if there is at least one dimension on which the person is deprived. The intersection method identifies a person as capability poor only if the person is deprived on all dimensions. Between these extremes is what Alkire and Foster (2011) label the 'dual cut-off': a

decision is made on the basis of a cut-off within attributes and on the basis of being deprived across a specified number of attributes.

Mitchell *et al.* (2015) adapt the Alkire-Foster methodology and advocate a “sufficient capability approach”, which they illustrate in the context of the ICECAP measures. For illustration, Mitchell *et al.* arbitrarily establish an intuitively appealing sufficient state of capability, as defined by ICECAP-O (2015) and ICECAP-A (2017). The authors refer to this sufficient state as the “threshold of sufficient capability” and define it as “the level of capability at or above which a person's level of capability well-being is no longer a concern for policy” (Mitchell, Roberts et al. 2015, p73) (i.e. above which inequalities are irrelevant, the positive thesis). Existing scores for the ICECAP-A and ICECAP-O are rescaled such that zero is no capability and one is ‘sufficient capability’. This rescaling of the original scores generates ‘sufficient capability scores’. The third step in Mitchell *et al.*'s approach involves combining changes in well-being with time, to generate ‘years of sufficient capability’.

Whilst the approach advocated by Mitchell *et al.* is both conceptually appealing and (relatively) straightforward, their illustration relied on the arbitrary setting of a sufficient state of capability well-being, whereas the contribution of the work reported here is to establish a sufficient state through deliberative work with the general population.

In establishing a sufficient level for each of the five ICECAP-A attributes through deliberative work, a sufficient state of capability well-being will be defined and hence the union method is implicitly adopted: a deprivation below the sufficient level on any of the five attributes will render an individual capability poor.

3. Methods:

A series of one-day citizens' workshops (CWs) were conducted involving members of the public; these were followed by face-to-face follow-up interviews (the main purpose of which was process evaluation), and a 'consensus' workshop (bringing together representatives from the initial CWs to reach a final, arbitrated conclusion). Ethical approval was obtained from the Science, Technology, Engineering and Mathematics Ethical Review Committee at the University of Birmingham [ERN_16-0027A].

Deliberative methods can be expensive and time consuming, whilst still relying on relatively small sample sizes (Coote and Lenaghan 1997), but the methodology creates a framework within which the public can address complex policy questions from a societal (as opposed to a consumer) perspective (Sagoff 1998). Abelson *et al.* (2013) state that the core principles of deliberative approaches are that: participants be informed and representative and that there be free, open and reflective debate. There are a range of deliberative approaches, from focus groups conducted over one or two hours, to citizens' juries, conducted over several days (Kinghorn, Canaway *et al.* 2017). Citizens' Workshops (CWs) have been suggested as a method which allows a "balanced combination between deliberation, independence of opinion, [and] access to information" (Álvarez-Farizo, Gil *et al.* 2009). Álvarez-Farizo *et al.* recommend that CWs include 10 to 15 participants, who receive information, pose questions and present their views; Timotijevic and Raats (2007), for example, recruited 12 participants to a CW on food-policy development.

Citizens' workshops were selected for use in this study on the basis that they would allow more time for the presenting information to and face-to-face discussion amongst participants than would focus groups, whilst being less burdensome for participants and less susceptible to participants 'dropping-out' after initial participation than any method spanning two or more days. CWs also presented an affordable opportunity to gather data within purposefully selected areas, although a complication of doing so was having a number of (potentially different) decisions reached within stand-alone

workshops. A conclusion based upon retrospective analysis of aggregated data was rejected on the basis that it would not align with the principles of deliberation, and so a 'consensus workshop' was held, which brought together representatives from each initial CW to reach a final, arbitrated decision. The consensus workshop also presented an opportunity for provisional findings and themes from initial CWs to be presented back to participants and for participants to reflect on the initial workshop content in their own time before reconvening. Because CWs are a relatively novel approach, a process of evaluation was embedded within the study design.

3.1 Citizens' Workshops: Recruitment & Logistics

For the CWs, members of the public were randomly selected from the open (edited) electoral register from within six purposefully selected local authority areas within the West Midlands region, UK. Local authority areas were selected to achieve a balance of rural and urban, as well as areas of high, mid and low deprivation (according to the Index of Multiple Deprivation (IMD), published in 2015 by the Department for Communities and Local Government).

Those selected were sent an invitation letter, information leaflet, reply form and pre-paid return envelope by post. Those expressing interest were contacted by telephone, sent a further letter confirming the date, times and venue, and (where possible) sent text message and/or email reminders. There was no follow-up to addressees from which there had been no response. In addition, leaflets were handed out in public areas and posters were sent to local church, sports and community groups and major local employers in the target geographical areas. Attempts were also made to engage with communities via social media (Twitter). The number of invitation letters sent was increased if the initial response rate was low, but financial pressure limited the scope of the mail-out. The intention was to recruit up to 12 participants per workshop (n=72).

Venues were selected for the CWs on the basis that they were as close as possible to the area from which participants were recruited. It was stated in the information leaflet that (i) lunch would be

provided; (ii) travel costs would be reimbursed; (iii) one person attending each workshop would be randomly selected to receive £100 of high street shopping vouchers.

At each CW there were three researchers present: the Principal Investigator and lead facilitator (PK), a project administrator (who noted who was speaking in order to identify participants in the transcript), and an assistant facilitator (who helped to welcome participants and respond to questions, and who offered further guidance to participants during tasks). PK is a health economist with previous experience of conducting qualitative research.

3.2 Citizens' Workshops: Content & Deliberation

CWs started with introductions from the research team and a brief overview of how the day would work. Participants introduced themselves, shared their reasons for wanting to attend, their 'starting' knowledge and any personal or professional experiences of social care and public health. Following the opening discussion, a mixture of PowerPoint and short video clips were used to provide more formal definitions of social care and public health. Participants were then given an introduction to decision-making in the context of health; they were told that the methods used in the context of health (Quality-Adjusted Life Years) may not be as appropriate in the context of social care/public health and that the ICECAP-A is permitted for use by NICE in the context of social care. Participants were then presented with four vignettes (printed within a workbook), read through the vignettes and then discussed their reaction to and thoughts on the vignettes within the group. The vignettes were intended to illustrate a range of different well-being states and represent individuals of different ages/life stages. The vignettes (summarised below and presented in Appendix A) did not specify sex, ethnicity or faith/religion:

- A person aged 19 years with depression, living with their parents

- Planned pregnancy (the person was described as being aged 29, slightly over-weight and a smoker)
- A 47 year old with a severe visual impairment, who was employed and had a partner and child
- A 68 year old with dementia, living alone, but with a son who would visit regularly

After considering the vignettes, participants self-completed ICECAP-A. Participants then went on to complete ICECAP-A on behalf of the four people described in the vignettes and to rank their well-being from worst to best; these proxy ICECAP-A responses were then shared with and discussed within the group.

The purpose of the workshop content up to this point was purely to: (i) encourage open and honest debate within the group and the forming of a positive group dynamic; (ii) provide participants with the opportunity to learn about social care, public health and decision-making organisations and processes; (iii) begin to reflect on what it would mean to experience different well-being states, as defined by ICECAP-A; (iv) begin to think about and become familiar with expressing well-being states as a sequence of five numbers (1,1,1,1,1 for the worst possible state and 4,4,4,4,4 for the best).

The primary aim of the CWs –to establish a sufficient state of capability well-being– was then explained in terms of establishing a ‘good enough level’. Participants were told that those people falling below the ‘good enough level’ would be prioritised for publicly provided/funded support, whereas those at or above the ‘good enough level’ would not be offered publicly provided support. Publicly provided support was differentiated from support from friends and family, and from obligations falling upon employers.

Initially in their workbook (and individually), participants were asked to look at the bottom/worst level (level 1) for the first attribute: “I am unable to feel settled and secure in any areas of my life”. Participants were asked to shade in the box next to this level of the attribute, on the grounds that society would not wish to leave somebody in that situation without offering them help and support.

They were then asked to consider level 2 of that attribute: “I am able to feel settled and secure in a few areas of my life” and to ask themselves the question(s) “would I be happy if society left a person in this situation without any help?”/“is this an adequate or acceptable state for a person to be in?” If the answer to these questions was no, they were asked to shade in that box as well; whereas if the answer was yes, they were asked to place a tick in the box. This exercise was repeated for all levels across all five attributes.

The standard version of the ICECAP-A questionnaire (available to download from www.birmingham.ac.uk/icecap) was reproduced within the workbook (with permission from the developers), and it was on this reproduction of the questionnaire that participants provided their responses using the system of shading and ticks outlined above.

Individual responses were shared with the group and used as a trigger for discussion and debate. Individual participants then repeated the task – i.e. they were given an opportunity to amend their responses *if they wished to do so*. These latter responses were fed back via voting keypads (separately for each attribute) and presented anonymously on the screen, in terms of aggregate responses. Two, or in some cases three, different states (sequences of attribute levels) were then identified by the PI and presented back to the group as options for group consensus. Individuals voted for one of these final options and the option with majority support was taken as the group decision.

3.3 Consensus Workshop

Between one and three participants who reported a sufficient state of well-being that was broadly similar/representative of the decision from their group were chosen to attend the consensus workshop. An effort was also made to select a mix of male and female participants, of differing ages. Recruitment to the consensus workshop was limited as it relied upon participants from the initial CWs agreeing to be contacted again. Hence, there was a need for some compromise in terms

of the degree to which they were representative of their group, and some people were also deliberately selected to add balance/represent views emerging from the groups, but which were perhaps not always reflected in the group decision.

The consensus workshop took place in Birmingham in November 2016. The day started with introductions, the PI then presented participants with a summary of results from the initial CWs. Participants had been sent a basic summary in the post, in advance of the consensus workshop and had been able to identify the decision from their own group within that summary. A range of possible sufficient states were identified, based on:

- States representing the decisions from each individual group/CW.
- The state defined by the most frequently selected attribute levels, when retrospectively analysing aggregate data (across all groups).
- The state defined by the most frequently selected attribute levels (retrospectively analysing aggregated data) by: men and women; and by younger and older adults.

Several rounds of voting were held; at each stage the least popular option was eliminated.

Discussion followed each round of voting. There was a natural consensus within the room as to the point at which the final vote was held (i.e. no new views emerging, and participants feeling sure about their preferred option).

3.4 Process evaluation

Participants from the CWs who had indicated they were willing to be contacted about the follow-up interview were sent an information leaflet and were then contacted by telephone to arrange a convenient time, date and location. The semi-structured face-to-face interview followed a topic guide (Appendix B), which covered: their prior experience of social care and public health; why they chose to take part in the research (including factors that attracted them and factors that concerned them or caused anxiety); their general reflections on the CW; completion of a series of Likert scale

questions; their thoughts on the outcome/conclusion of their CW. Participants attending the consensus workshop also completed the Likert scale questions. Five Likert scale questions were used for evaluation, each with five response levels, where 1 was the most negative response and 5 was the most positive (see Appendix C).

3.5 Analysis

The CWs, follow-up interviews and consensus workshop were all audio-recorded and transcribed verbatim. Framework Analysis was used as a framework for identifying, indexing and refining qualitative themes.

Descriptive statistics are used to summarise participant characteristics, results from the aggregated workshop data and responses to the Likert Scale questions.

4. Results:

The results section is structured as follows: Sub-section 4.1 reports on recruitment rates for the CWs and the demographic characteristics of CW participants, as well as the number of CW participants further participating in a follow-up interview and/or the consensus workshop. Sub-section 4.2 reports quantitative findings from the CWs (group decisions in relation to what the sufficient state of capability-well-being should be and trends in terms of individual responses); and sub-section 4.3 reports qualitative themes relating to participants' discussion/justification of their selected sufficient state of capability well-being. Sub-section 4.4 reports the principal findings from the study: the arbitrated sufficient level of capability well-being arising from the consensus workshop. Finally, sub-section 4.5 relates to process evaluation, drawing upon evidence from all three elements of the study (CWs, interviews and the consensus workshop).

4.1 Response Rates & Participants

A pilot CW was held (Group A, August 2016), followed by six planned CWs (September and October 2016); a further workshop date was added at the end (Group H, November 2016) due to lower than anticipated recruitment up to that point.

If the additional CW is excluded (Group H) on the grounds that recruitment differed (it included people who had expressed an interest in attending a previous CW but who had been unavailable), the initial response rate (people expressing an interest) was 2.5%. Confirmation letters were not sent to every person who expressed interest and a small number were excluded at this initial stage if their specific demographic group was significantly over-represented. Most of those excluded were women aged 65 years and over. Of the 3,485 people who were directly invited to participate (again, excluding group H), 1.6% actually attended a CW. Of those who were sent a confirmation letter (including Group H), 74.7% actually attended. The best attended CWs were both in low deprivation areas, although the recruitment rate for the pilot workshop (in an urban, high deprivation area) was also (relatively) high. The worst attended CW was in an urban, high deprivation area, known to be ethnically diverse.

[Insert Table 1 Here]

It can be seen from Table Two that recruiting younger participants (aged 18-44) proved to be challenging (and so older people were over-represented in the sample), and that there was a more positive response from females than from males.

[Insert Table 2 Here]

Fifteen of the 62 CW participants also took part in follow-up interviews and nine attended the consensus workshop.

4.2 Group Decisions and Analysis of Aggregated Data from Citizens' Workshops

This sub-section presents a summary of the group decisions (reached via voting within the CWs) and retrospective quantitative analysis of aggregated data for all 62 participants, in relation to the sufficient level of capability well-being.

In the CWs, various options were presented back to participants by the PI (based upon initial, individual responses within the group), and participants voted for one of these options. This became the 'group decision', and these group decisions are summarised in Table Three. In the case of the pilot workshop, technical issues prevented use of the voting software and so the option emerging with noticeable frequency (3,3,4,3,3) was selected as the group decision.

[Insert Table 3 Here]

Figure 1 summarises the frequency with which each level on each attribute was selected as the sufficient level, in terms of individuals' responses in the workbooks. If one identifies the most frequently selected level for each individual attribute and presents this as a sequence, the sufficient state that is defined is 3,3,3,3,3. The same sufficient state was observed with greatest frequency across most sub-samples: males and females; ages 18-44, and 65+. The sufficient state for the sub-sample of 45-64 year olds was 3,2,3,3,3.

[Insert Figure 1 Here]

4.3 Qualitative Themes: Considerations Underpinning Participants' Responses

Here, qualitative themes are summarised, reflecting the views expressed by participants in the CWs. Themes were identified from sections of the CW transcripts in which participants were reporting and discussing their responses to the task of setting a sufficient level of capability well-being. Themes were identified across the full set of transcripts.

With respect to the 'lines of argument' adopted by participants when justifying their selected sufficient level of capability well-being, some can be categorised as relating to positive lines of argument: Entitlement and aspiration; Resilience and Enablement; and Prioritising core attributes.

Others related to either a sense of realism or a more cynical view of human nature: Responsibility and Self-motivation. One stance associated with a lower threshold level related to intrusion by the state. An apparently neutral and non-political stance was informed by 'benchmarking'. Quotes are accompanied by the workshop/group identifier and the ID number of the participant within that group (e.g. A001 to A009).

Entitlement and Aspiration

Whilst some participants acknowledged that it might not be possible to achieve a 'good' standard of well-being for every person in society, all of the time, participants aligning to this stance argued that it would be morally wrong not to at least attempt to achieve such a level of well-being wherever possible. Some viewed such a level of well-being as an entitlement, others as an aspiration, and others still reported that they would feel uncomfortable advocating anything less as a minimum standard.

I opted for level four on feeling settled and secure because I think everyone should feel settled ... I just, I think everyone should have that opportunity. (F007, F, 25-34)

Resilience and Enablement

This view centres on enabling service users to 'give back to society', or at least to become sufficiently resilient so as to no longer require publicly provided support. Participants spoke of improving the well-being of service users beyond a point at which they would be still be vulnerable.

...if you get people completely independent, long run they're probably going to cost the state less. ... if it works it is going to save money in the long run (B006, F, 65+)

... if you are feeling settled and secure in all areas of your life - that you're not frightened, you're not hungry and so on and so forth - actually you are then able to focus really well as an individual and put back in to society ... (D009, F, 55-64)

The notion of resilience was linked in some cases to increased confidence and feelings of 'self-worth'.

I put a three because it seems to me that the more we can make people feel independent, the less they'll be a drain on services because they'll be thinking "Hang on, I can do this for myself". (H002, M, 55-64)

Prioritising core attributes:

The two attributes that tended to be singled out by participants as being of particular importance were feeling settled and secure (stability) and independence (autonomy). A view was often expressed that the ability to function highly in respect to one or both of these attributes would, in turn, determine a person's ability across the other attributes.

...that person has got to feel settled and secure and [have a] high degree of independence, they can then work on the rest to bring them up (E001, M, 65+)

...feeling settled and secure, that's got to be priority because ... if you're not settled and secure then you can't progress in other directions ... (A001, F, 45-54)

Realism

There were three principal considerations with respect to what was deemed to be realistic: what can public services realistically be expected to achieve (regardless of budget)? What can be achieved without excessive levels of expenditure? And, what is a realistic expectation in terms of people's ability to benefit from services?

In particular, some participants expressed doubts about the ability of public services to enable service users to feel loved or experience enjoyment and pleasure.

... I'm thinking ...[about] how much we can provide a box of love to somebody. You can have organisations, voluntary organisations, y'know, people who are friendly. They don't necessarily love the person because that's a different concept, but they care enough about them to do things for them. (G003, M, 65+)

I'm not certain that an outside intervention can give somebody enjoyment or pleasure. ...you can lay on bingo and dances ..., but there are people who won't enjoy them and there's nothing you can do to make them (H002, M, 55-64)

In terms of realism, some participants explicitly considered budgets when setting the threshold as well as in terms of framing and understanding the context of the task. There was a perception by some that vast amounts of money could be used in an attempt to achieve 'the impossible'.

...in today's society, with the limitations that we have, funding being seemingly the hugest one, we can't hold somebody's hand all the way through the process, as much as we would like to, we just can't do that. So, sometimes we just have to guide people onto the right path and then let them go. (E007, F, 45-54)

Four in an ideal world would be there for everybody wouldn't it? but it isn't an ideal world and the public purse is limited (B006, F, 65+)

Some participants felt that it would be unrealistic to expect people with certain disabilities or medical conditions to achieve high standards of well-being.

I struggled with this one because [in the vignette] I'd marked the... lady with dementia... I'd marked ... that she was a one. So 'cannot achieve and progress in any aspects'; and when I came to mark the generic one, I thought 'how likely is it that ... I'm ever gonna get a two or three [for] that particular person?' 'I can achieve and progress in many aspects of my life', y'know, in the sort of circumstances that that person is in. (G007, F, 45-54)

For some, achieving the highest level on some attributes seemed unrealistic in general:

I think the wording where it says you know 'all areas of my life' how many people can say they feel settled and secure in all areas of their life? (A004, F, 65+)

Responsibility and Self-motivation

Two related concepts here are the need for people to take responsibility for their own well-being, possibly through changes in lifestyle, and a view that whatever support is offered by the state, the

standard of well-being experienced by specific individuals will reflect the choices made by those individuals. A view was expressed by some that the state should not undermine people's motivation to help themselves.

You can't take all the responsibility away from people to look after their own wellbeing.

That doesn't do anybody any good. (F003, F, 55-64)

I think if you mollycoddle them all the way they just rely on it. (G002, M, 65+)

...that's why I chose two, because I feel ... when you help some people, they do take the Micky... They have all the support, and they don't listen to the support officer or care officer or anything... (E008, M, 35-44)

Availability of Support Versus Intrusion

It was stressed by some respondents that support should be available to those who want and need it, rather than being forced upon them and that attempts by the state to intervene in the lives of citizens could be intrusive:

...it doesn't have to be forced on them, it's the level isn't it, as a society that we agree we would offer [support]... (B005, F, 55-64)

...people don't like too much ... interference... They like their independence, they don't want to be feeling that somebody's always pushing them from behind. If ... they're happy with many, that's good enough for them and why should anybody worry them with anything more? (F003, F, 55-64)

Benchmarking

Some participants considered their own level of well-being when deciding what the appropriate threshold level should be, in this case often suggesting that they wouldn't expect support themselves. In other cases, participants also considered the circumstances of friends, family members and colleagues.

... I don't think I can ask for any more really, if I started to ask for anymore then somebody else is gonna be worse off who may need help more than me. That's how I look at it personally (D005, M, 55-64)

4.4 Consensus Workshop: Arbitrated State of Sufficient Capability Well-being

The conclusion of the consensus workshop is reported here, along with the process through which this conclusion was reached.

The various states generated from the initial CWs and reported in section 4.2 were presented as options at the consensus workshop (see Table Four).

[Insert Table 4 Here]

Option E was the first to be eliminated in the consensus workshop, having received zero votes. Options B and D were eliminated in the second round of voting, as in this round they also received zero votes. In the third round of voting, one participant changed their vote from option F to option A. Finally, option A received six votes and option C three votes. Participants in the consensus workshop accepted 3,3,3,3,3 as the sufficient state of capability well-being, and this was therefore the primary conclusion of the research. Existing tariff values (Flynn, Huynh E et al. 2014) have been rescaled to take into account the sufficient state, and these are presented in Table Five. Rescaling means that the sufficient state of capability well-being (3,3,3,3,3 - presented in bold font in Table 5) has a value of one.

[Insert Table 5 Here]

4.5 Process Evaluation

This sub-section explores: the varied life and professional experiences that participants brought to the CWs; their motivations for taking part; and reported experiences of having taken part.

Qualitative analysis drew upon: information that participants revealed about themselves during the

CWs; and participants' reflections upon the CW expressed during the follow-up interviews.

Quantitative data is drawn from participants' responses to the Likert scale questions. Quotes which have been taken from the follow-up interview are differentiated with the prefix 'I'.

Participants came with a range of experiences and differing amounts of prior knowledge, although even those with relevant professional experience often failed to differentiate clearly between healthcare and public health. Directly related professional experience included (current and retired) social workers and social care providers/managers, nurses and a clinical psychologist. Those from many other professional backgrounds (a police officer, a prison officer, a local councillor and three retired civil servants) spoke of how their job had prompted them to consider social care and social issues.

...one of the aspects of my work within the prison service is dealing with aged prisoners and along with the aging population we have an aging prison population and when it comes to social care its one aspect of the work that is increasing (IG005, M, 45-54)

Many participants had experience of having cared for and/or requested or coordinated care for relatives, some had experienced problems with their own health (mental and physical) and a small number discussed relevant voluntary work.

Although some participants felt that they had a particular type of personal or professional experience to bring to the group, many appeared to be motivated by curiosity and/or a sense of duty/citizenship:

... I felt like it was dutiful and helpful to do (IE001, F, 65+)

... first and foremost I suppose I'm nosy; secondly I think if you are in a group its surprising what comes out in a discussion ... so I just felt it [would] be interesting (ID001, F, 65+)

Others saw the workshop as a way of gaining a better understanding of the topic, improving services in the future, or were curious to hear the views of other people; a small number appeared to have deep rooted political views.

I know a lot of people who are disabled and who receive care of some kind and so I thought it might be nice to learn a little bit about what's available (D006, F, 65+)

So I came today because I would like to try and well not influence but I saw it as an opportunity if I could just change perhaps one little aspect or influence one little aspect so that certainly in my father's case people didn't have to experience what he had to. (B001, F, 65+)

Groups therefore presented a real diversity and 'melting pot' of views, perspectives and experiences, which facilitated a culture of sharing, learning and questioning (albeit with occasional frustrations). The group setting enabled participants to seek clarity in relation to the nature of the task, including the scope of their response (who the threshold would be applied to), the perspective they were being asked to adopt, as well as the logistics of providing a response. In many cases, participants within the group supported each other in terms of responding to queries or doubts. By verbally clarifying their own understanding of the task, participants reinforced the introduction and guidance that had been provided by the researcher.

...it's saying that there is a line and we provide support - whatever word you choose - to that point, but beyond that we're not going to do anything; and it's what that point is... (B005, F, 55-65)

In some cases, participants reported feeling a sense of responsibility, wanted to fully understand the ethical implications of the task before responding, or openly acknowledged the difficulty they had experienced in arriving at their viewpoint/response.

...how would that be used? Because say- then the government could say, particularly if they didn't want to put any more funding into things, "Oh, well as long as we can get everybody

up to a sort of scrape by level it'll be alright" ... No, it makes me quite anxious what it can be used for. (G006, F, 55-64)

I think the ethics of it are colossal (B005, F, 55-64)

...thinking about people and this poverty line for wellbeing, I think it's virtually impossible to do, because there are so many factors (A001, F, 45-54)

There was an acknowledgement by one participant at a workshop held within a low deprivation, rural area of the fact that they were making decisions that would potentially affect those in different types of circumstances from their own.

I think lots of people, their level of expectancy is probably a lot less than ours, sat around this table (B006, F, 65+)

Two factors that were reported to make the task more complicated both relate to the phrasing of the attributes and attribute levels on the ICECAP-A, and were: the inclusion of several concepts within a single attribute, and an acknowledgement that different people (perhaps of different ages or with different life experiences) will potentially interpret the attributes in different ways.

Again, I agree with H001 with this one. This one needs separating desperately between love, friendship and support. There's a big difference between support and love and friendship. (H004, F, 45-54)

... "in many things": doesn't it depend which things? ...I'm just saying it is conditional on what the few or many actually means otherwise you're mixing apples and pears ... (A010, M, 45-54)

... 'progress and achievement', when do you know that you've reached level 4? ... like (E005) was saying, because isn't it a state that is constantly moving throughout different periods of your life? (E007, F, 45-54)

Participants often acknowledged the views and contributions of others when setting out their own stance or viewpoint. There was some evidence of participants changing their views as a result of discussion.

I actually feel compelled to change mine to- to up, into three because of the support factor.

Maybe even four because of support, really. (H004, F, 45-54)

To be honest, when I look at that I think I should go up a level to level three (F002, M, 65+)

And of participants challenging each other, such as in this exchange:

...show them the door (D002, M, 65+)

- that's not what, as a society we mustn't do things like that. I mean you're right we are brought up in different ways but some people are more vulnerable than others and therefore they need our support (D009, F, 55-64)

Likert scale questions were completed by 18 participants. A '1' on the Likert scale was the 'most negative' response; a '5' was the 'most positive' response. The options most frequently chosen on the Likert scale questions were:

- I know a bit more about the topics now than I did before the workshop – level 4 (selected by 8 participants)
- I had trust that the information presented to me at the workshop was totally impartial (unbiased) – level 5 (selected by 13 participants)
- I enjoyed sharing my views as part of the group discussion – level 5 (selected by 10 participants)
- Six participants each selected levels 5, 4 and 3 for the question: "To what extent did you feel that your views were represented or heard during the discussion?" ("My views were represented adequately in the discussion" / "My views were well represented in the discussion" / "My views were strongly represented in the discussion").
- 8 participants selected level 4: "It is more likely that I will volunteer to take part in future research and an equal number selected level 5: "It is much more likely that I will take part in future research"

Some participants revealed that they had been apprehensive before attending the CW, and indeed some acknowledged the effort of attending, but no participants reported having had significant concerns or anxieties about taking part.

5. Discussion:

The work presented in this paper is an important first step in terms of defining a decision-rule for use within a capability-based framework for evaluating social care and public health interventions. This is the first study to involve members of the public in a deliberative process aimed at identifying a sufficient state of capability well-being (as defined and assessed by ICECAP-A). When the original scores are rescaled to reflect the sufficient state of capability well-being, they can be combined with time in order to calculate years of sufficient capability (YSC). The suggestion to use of Years of Sufficient Capability, rather than Years of Full Capability is based upon the normative claim that once a person has a sufficient level of capability well-being the moral obligation on society to provide them with additional support or resources is diminished. The state of sufficient capability well-being emerging from the research was 3,3,3,3,3:

- Able to feel settled and secure in many areas of life
- Can have quite a lot of love, friendship and support
- Able to be independent in many things
- Can achieve and progress in many aspects of life
- Can have quite a lot of enjoyment and pleasure

The same state of sufficient capability well-being was adopted in previous research (Mitchell, Roberts et al. 2017), although in that work by Mitchell *et al.* the sufficient state was set solely by the researchers as an intuitively appealing and uncomplicated option. The same state that was selected as being intuitively appealing by researchers has therefore being independently selected by the public.

Existing empirical evidence indicates that changes in the evaluative space (capability well-being rather than health) (Mitchell, Al-Janabi et al. 2015) and changes in the decision rule (sufficiency rather than maximisation) can change treatment decisions (Goranitis, J et al. 2017), but so far there is a very small body of evidence available.

Meaningful discussion did take place within all of the workshops, despite lower than expected attendance at some groups (with an actual attendance of between four and 10 participants, versus a target of 12). Older females were over-represented in the sample, along with those who described their ethnicity as white British. It is a limitation that participants' income was not recorded, but this was a deliberate decision as: (i) people feel uncomfortable reporting their income, even in anonymous surveys, and these were people that would go on to have face-to-face contact with the research team; and (ii) recruitment was from purposefully selected high, mid and low deprivation areas. The addition of the pilot workshop, held in a high deprivation area, meant that there was a similar distribution between low deprivation (n=20), mid-deprivation (n=17) and high deprivation (n=19) areas.

Invitation letters sent to those on the open electoral register proved to be the most successful recruitment method, by far. One participant was recruited via a local running club and one participant via social media (Twitter); the remaining 60 participants responded to invitation letters. This recruitment method may explain the older demographic as analysis by Ipsos MORI (MORI 2015) after the 2015 UK general election concluded that those aged 18-24 were almost half as likely to vote as those aged 65+, in other words, younger people may be less likely to register to vote and therefore not be on the electoral register. The greater political engagement amongst older people (as well as the fact that they are less likely to have childcare and employment commitments and are more likely to have had first-hand experience of social care) inevitably made them an easier demographic to recruit. An initial response rate (expressions of interest) of 2.5% is comparable to that achieved in a previous study in which participants were also recruited from the open electoral register, response rates there varied from 0.5% to 5.4% (largely according to whether the

target area was high or low deprivation) (Kinghorn, Canaway et al. 2017). It will be worth exploring alternative forms of recruitment for future research, ideally those which can be personalised or rely on personal interaction between recruiter and potential participants.

Workshop participants are most appropriately seen as representatives of the public, rather than representative, although it is worth stressing that there were representatives of different age ranges, ethnic groups, and from varied social backgrounds and geographical areas. The sufficient state agreed upon at the consensus workshop was the state best reflecting responses from most of the sub-samples (split by age and sex).

Not all groups were represented at the consensus workshop; there were no representatives from the pilot workshop (Group A) for example, although this may be explained by the significant time lag between this group and the consensus workshop (August to November). Other groups not represented at the consensus workshop were Groups B (rural, LD) and C (urban, HD). Although representatives from groups A, B and C were identified and invited (and confirmed their attendance in the case of groups A and B) the participants who had been invited did not actually attend. Group decisions from all initial workshops were, however, presented as options at the consensus workshop.

The process of deliberation appeared to work well, with positive feedback from participants. Running the workshop over 6.5 hours meant that the research team had the luxury of time: to understand participants' starting knowledge and experiences; for participants to air their own views, and put forward their own priorities and agendas (without compromising the time allocated for the task); to thoroughly explain the task, understand the reaction and reasoning of participants and provide clarity in cases where there was confusion; and, most importantly, time for learning, exposure to alternative viewpoints and experiences, and for reflection. A principal message arising from this work is that representatives of the general population are able to debate complex social issues and reach an arbitrated outcome/conclusion. This study introduced the novel element of

bringing representatives from initial groups back together to reach a final arbitrated outcome at a consensus workshop.

6. Conclusion

This work helps to define and distinguish sufficient capability as a conceptually and methodologically distinct approach from that used in cost-utility analysis; distinct in terms of the evaluative space (capability well-being), the normative conceptualisation of equity (sufficiency) and the approach taken to defining key components (participatory/deliberative). The decision to introduce sufficiency as an equity principle aligns closely with the underlying conceptual assumptions underpinning the capability approach. Sufficiency also appears to align closely with the existing practice of prioritising the most vulnerable members of society when it comes to allocating scarce social care resources.

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