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### **Should patients have a greater role in valuing health states: whose well-being is it anyway?**

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## **BACKGROUND**

Economic evaluation has become increasingly important in health care decision-making. This has resulted in a number of agencies around the world introducing guidelines for the conduct of economic evaluation. A key aspect of these guidelines is the way in which benefits should be valued, including who should value the benefits. The Washington Panel on Cost-effectiveness in Health and Medicine has been very influential in its advocacy of the use of general population values for health states (Gold et al, 1996). This has been reflected in economic guidelines produced in Canada (Torrance et al, 1996) and in England and Wales by the National Institute of Clinical Excellence in England and Wales (NICE, 2001,3).

Current practice in the estimation of health state preferences has become dominated by one paradigm, though there are important differences in methods (Brazier et al, 1999;Dolan, 2000). This approach has been used to value the main generic preference-based measures, including the EQ-5D, HUI-3 and the SF-6D (Dolan, 1997; Feeny et al, 2002; Brazier et al, 2002). Health state preferences are elicited for these instruments from a sample of the general population. Respondents are asked to value a set of abstract 'generic' states that are typically defined in negative terms (i.e. full health is the absence of ill health). The elicitation task asks the respondents to imagine they are themselves in the state and then they are asked to consider the gamble they would take to move to full health or the reduction in length of life they would be willing to make to move to full health (depending on whether they are being asked a standard gamble or time trade off question). These tasks are usually administered by an interviewer using visual props to assist the respondent with the valuation task (though researchers have used postal methods when using the rating scale to value the states). Respondents are essentially being asked for their 'off the cuff' *ex ante* valuation of the states. These resultant values have sometimes been described as social values, but this is a misleading term, since respondents are being asked to value the states from the perspective of being in the states. The resultant set of mean health state values is really an aggregation of individual valuations of those states.

As economics becomes more influential in health policy, it seems appropriate to revisit some of the arguments for using general population in this way to obtain health states compared to alternative sources, such as those who are actually in the state viz. the patient. By patient we mean the person experiencing the health state, whether or not they are seeing a health professional about their health. The aim of this paper is to review and clarify the debate on the choice between using general population and patient values by clearly separating the positive evidence from the normative arguments. In a departure from the conventional approach of economists in this field, the paper begins by examining the positive issues in the debate before examining the normative arguments. This is because some of the evidence on the reasons for observed differences between general population and patient values may have important normative implications. The paper begins by examining the importance of the discrepancy between general population and patient health state values in economic evaluation in health care. The next section examines some of the reasons given for the discrepancy between these sources of value since this has important implications for the normative question of whose values should be used. The penultimate section examines the various normative arguments. The final section explores the implications for policy and research in this field

## **THE IMPORTANCE OF WHOSE VALUES**

There is considerable evidence of significant discrepancies in health state values by illness experience and in general the evidence points to patients giving health states a higher value than members of the general population (Sackett and Torrance, 1978; Froberg and Kane, 1989; Boyd et al, 1990; Llewelyn-Thomas et al, 1993; Hurst et al, 1994). The extent of this discrepancy is much stronger where patients value their *own* health state and it is in this context that we consider the question of whose values. The potential importance of this difference can be seen in the example of colostomies where patients with colostomies rate the HRQoL of living with them to be 0.92 compared to those without colostomies of 0.80 (Boyd et al, 1990). The incremental gain from avoiding colostomies and restoring patients to full health would be more than twice as large using estimates from the non-colostomy sample compared to the patient sample. In a study of Rheumatoid arthritis patients, it was very hard to justify the large number of negative health state values generated by a general population sample for the EQ-5D since other quality of life assessments would seem to indicate that most patients felt the quality of their lives had a positive value (Hurst et al, 1994).

A recent paper by Insinga and colleagues (2003) examined the difference between the own VAS health state values for a set of EQ-5D health states and those estimated from a social VAS tariff using the UK MVH data set (Kind et al, 1998). Whilst VAS would not be regarded by many health economists as a cardinal measure of utility (Drummond et al, 1997), it nonetheless has a clear monotonic relationship to choice based methods like SG and TTO and by standardising to the anchors of full health-dead onto one to zero, it is indicative of the differences between general population and patient values. One interesting finding was that the differences were significant and that the differences varied by the severity of the state. For the five incremental differences they examined, the discrepancies in health state valuations lead to incremental differences being between 73-275% larger using population ratings compared to self-ratings. It is not hard to see that this level of discrepancy would have substantial implications for the Incremental Cost Effectiveness Ratios (ICERs). In the context of NICE, where many interventions have ICERs of between 20,000-30,000 per QALY, two or more fold discrepancies would have major implications for funding decisions given current implied thresholds (Raftery, 2001).

## **WHY DO THESE DISCREPANCIES EXIST?**

Past debates of this subject have tended to ignore the reasons for differences between general population and patient health state values and move straight into a normative debate. However, recently Ubel and others (2003) have argued that the causes of the discrepancies may in themselves have implications for whose values should be used. This section is broadly based on their proposed distinction between three causes of discrepancy: i) patients and the general population do not value the same states, ii) they use different measuring rods and iii) patients experience shifts in values that are not anticipated by the general population.

### **Valuing different states**

Eliciting values from the general population requires some means of describing the state to the general population sample. An important potential source of discrepancy in the values provided by the general population and patients are that the descriptions provided to the general population may not accurately describe the state. The

descriptive system may be insensitive to subtle differences within a dimension or simply miss out important dimensions of health altogether. This has been well illustrated by the Insinga et al (2003) study of VAS data from the UK MVH survey, where the difference between general population VAS ratings of hypothetical states and their rating of their own health state by VAS was largely due to the limitations of the EQ-5D descriptive system. Most of the difference was accounted for by the discrepancy between respondents self-rating and their separate rating of the EQ-5D state that coincidentally described their own health. While improving the descriptive systems can reduce this problem, it can never be entirely overcome.

Ubel and colleagues (2003) also suggested that general population respondents might be focusing on the negative aspects of a health state and ignoring the remaining positive features, especially so when the trade-off is with death. Such focusing may be the result of simplifying heuristic or a focusing illusion centred on those things affected by the event rather than a person's broader life. Again, there is a mismatch between what the general population are valuing compared to patients. Bringing these broader aspects of life to the respondent could reduce this mismatch.

### **Different measuring sticks**

A widely accepted phenomenon in the QoL research literature is the notion of 'response shift' (Spranger and Schwartz, 1999). One aspect of this phenomenon is a change in the way respondents report their QoL along different dimensions despite there being no underlying change. Response shift refers to a change in internal standards that may be due to aging, changing comparator groups or other changes in circumstances. It could be seen as form of adaptation to the condition. What an elderly person with major chronic health problems means by different scores is likely to differ from a healthy young person. The problem of response shift is greatest with evaluative questions, where respondents are being asked to provide an overall value for their HRQoL, such as a VAS or TTO. This makes comparisons between responses obtained from different patients groups problematic, since we cannot be sure that they are using the same measuring rod.

### **The role of perspective**

Related to the notion of differing measuring sticks is the distinction between patient and general population perspectives. A general population sample is being asked to take an *ex ante* perspective and imagine or predict the likely impact on their utility of a future state of the world. Patients are being asked to adopt an experiential perspective where they are asked to value their current state of health. There may be important normative reasons for favouring one over the other, but from a positive perspective, they generate different values. According to Kahneman and Snell (1990) people are not very good at predicting future preferences. Kahneman and Snell found that individuals' predictions of how their preferences would change over time were not accurate. For example, they were often unable to predict their preferences over different flavours of ice cream over even such a short period as one week. If preferences over flavours of ice cream are difficult to predict, how much more so will be preferences over health profiles, with which individuals are often unfamiliar due to not having had prior experience (Redelmeier *et al*, 1993).

## **Adaptation to the state**

Someone in a state of health is likely to change in a number of ways, both physically and emotionally. Physical changes include the acquisition of new skills to help cope with a disability, such as learning to use a walking cane. A person may also change the things they do in order to limit the impact of their disability or illness. Someone who once played football, following a major knee injury may take up a sport that has a lower impact on his or her knees.

The response shift literature also refers to psychological adaptations. These include a shift in the weight people place on different aspects of HRQoL and more fundamentally, change their view of what matters in life. Someone may feel that work has become less important in his or her life. People may forget about past capabilities and the pleasures they brought. People may reflect more on life and experience radical changes in values and what matters to them. People may also lower their expectations of what they can achieve. Whilst some of these changes may be regarded as laudable, Menzel et al (2002) argue that some of the psychological changes may be seen as less desirable, such as cognitive denial and suppressed recognition of full health. There might be also some doubt about the appropriateness of patients lowering their expectations.

General population respondents may fail to take in account such adaptation to the health state. When they first read the description of a state, their valuation may reflect an initial response to say going blind, rather than reflecting on what it would really be like for an extended period. In other words, they focus on the transition to the state rather than the longer term consequences. When asked about adaptation, people tend to under predict their ability to adapt (Lowenstein et al, 1997). This would tend to result in lower general population values compared to patient self-reported values.

Ubel et al (2003) also suggest two other closely related concepts; one is the contrast effect where the importance of a particular bad or good event is moderated by contrast effects. Someone experiencing a bad illness may be less affected by a minor illness than someone who has not experienced major illness before. More generally, Ubel and colleagues talk about shifting inter-and intra-personal comparisons. Our evaluation of our current health state may be partly determined by what our peers are suffering and by our own past experiences. This relates back to the earlier discussion of changing internal standards. General population will include contrast effects in both directions and so overall it is likely to be smaller than in patient groups.

The impact of adaptation, contrast effects and shifting comparisons on the size of the discrepancy between patient and general population valuations will depend on the descriptive system being used. A degree of physical adaptation to physical disability is incorporated into those descriptive systems that have 'out of skin' dimensions of role and social functioning, such as the EQ-5D (Kind et al, 1998) and SF-6D (Brazier et al, 2002). The developers of the Health Utility Index-3 (HUI-3) explicitly excluded these social dimensions of health in part to remove adaptation. However, all the generic descriptive systems take some account of psychological adaptation through dimensions concerned with mood (such as anxiety, positive affect, and depression) (Dolan, 1997; Feeny et al, 2002; Brazier et al, 2002). Indeed, it could be argued that the wording of many of the other dimensions, such as those concerned with physical

functioning and pain, contain a significant element of self-evaluation and will also incorporate a degree of adaptation. For example, does a 90 year old person reporting 'some problems with mobility' on the EQ-5D really mean the same as a 25 year old reporting this level? Whether or not it is appropriate from a normative point of view to take any account of adaptation is explored in the next section, it would seem that existing preference-based measures do take some account of adaptation.

## **NORMATIVE ARGUMENTS**

### **Patient or values from current experience values**

Economics has positive and normative components. The positive component postulates that an efficient allocation of resources is achieved where, among other things, the consumer is sovereign and provided a number of stringent assumptions are met. An important normative position of welfare economics is that the well-being of a society is simply the aggregation of the individual utility across society (though many economists would argue that it is not possible to aggregate utility in practice). Given the assumptions underpinning the conditions for Pareto Optimality do not hold, then one is really left with a normative believe in the supremacy of individual valuations of their own well-being. In the context of a compensation criterion, this might be thought to imply that it is the preferences of the losers and gainers from a change that should be elicited and not a sample of the general population who will be unaffected by the change. This would seem to suggest that patient values should be used.

One response to this is that current patients are only some of those likely to be effected by the set of decisions being informed. It could be argued that every citizen in a public system has an option to use the service and so may be gainers and losers, and so the general population would be a good proxy. However, this presumes that all citizens have an equal chance of receiving all forms of care and this is unlikely. Welfare economics does not seem to offer a clear argument for patient values over general population values.

The argument for using patient values seems to hinge crucially on the fact that patients know the states better than someone trying to imagine them. The main advantage with this approach has been argued by Buckingham (1993): *'To ask a person of 20 how s/he will value health at the age of 70 is to ask an enormous amount of their imagination. To ask a 70 year old how important their health is to them is likely to result in far more valuable information'*. Given general population values are poor proxies for patient values, this implies that patient values should be used. However, this positive fact must not be allowed to obscure the normative assumption that raw patient values should be used to inform social decisions. It assumes that society wants to incorporate all the changes and adaptations that occur in patients who experience states of ill health. This is addressed below.

### ***Ex ante* general population values**

Outside of conventional Welfarism, health economists have been more concerned with meeting the information needs of the decision maker (Culyer; 1989a&b; Richardson,1994). In public health systems, this has been taken to mean the adoption of a societal objective such as the maximisation of health (subject to equity concerns) rather than the conventional individualistic perspective of utility maximisation. The Washington Panel on Cost Effectiveness, for example, advocated a social perspective

for CEA and argued that: *'A logical extension of that reasoning would suggest that the best articulation of society's preferences for a particular state would be gathered from a representative sample of fully informed members of the community'* (p. 99, Gold et al, 1996). The Washington Panel went on to use the 'veil of ignorance' to support the use of community values, where *'a rational public decides what is the best course of action when blind to its own self-interest, aggregating the utilities of persons who have no vested interest in particular health states seems most appropriate'* (p.100, Gold et al, 1996). The social perspective for publicly funded services can also be supported on the grounds that it is tax funded (Torrance et al, 1996). A related argument is the insurance perspective. In the context of willingness to pay, it has been argued that resource allocation decisions in health care are akin to the decisions about which services should be covered by an insurance package (Gafni, 1991). Public funding can be seen as essentially public insurance and so it is the ex ante public preferences that should be used to value health states.

A social perspective does not imply the use of general population values any more than welfare economics implies patient values. Even behind a 'thin' veil of ignorance suggested by the Washington Panel, respondents might suggest that the values of those in the states be asked. When the general population are asked to undertake health state valuation tasks, they sometimes protest that they know nothing about the states they are being asked to value and suggest we approach patients who are actually experiencing the states. When asked directly whether or not they want their values to be used to inform resource allocation in health care, many members of the general population did not (Richardson et al, check).

### **Informed general population values**

The previous two normative arguments did not consider the causes of the discrepancy between patient and general population values. Ubel et al (2003) and Menzel et al (2002) have argued that this offers a more informative route for considering whose values to use in resource allocation.

The main normative debate seems to be around the extent to which adaptation should be taken into account in the values used to inform resource allocation. Members of the general population are likely to know little about adaptation to illness and therefore this will not be reflected in their health state values. The choice between patient and general population values really comes down to the extent to which these changes should be taken into account. Menzel et al (2002) tried to distinguish between 'laudable' adaptations, such as skill enhancement, activity adjustment and even altered perception of health from less desirable changes such as cognitive denial of functional health, suppressed recognition of full health and lowered expectations. There might also be a concern about differences arising from contrast effects or shifting comparisons that were identified by Ubel and colleagues (2003).

It has been argued that it is difficult to justify the extreme viewpoints of using only patients or uninformed members of the general population to obtain preferences for health measures (Fryback, 2003; Brazier, 2002). Patient values incorporate aspects of adaptation, such as the lowering of expectation that may be regarded as unacceptable for public resource allocation decisions. Furthermore, patient values are context based, reflecting their recent experiences of ill health and the health of their immediate peers. In many ways, it can be argued that patient values can not be

compared between conditions. On the other hand, the current paradigm of preference elicitation from the general population obtains values that are largely uninformed by what it is like to be in the state.

This third way accepts the general normative position that ultimately it is the values of the general population that are required to inform resource allocation in a public system, but that respondents should be provided with more information on what the states are like for patients experiencing them. This position has recently put forward by a number of commentators on the subject (Ubel et al, 2003; Fryback, 2003; Menzel et al, 2002) would be to use informed general population values. This would require the development of explicit methods for providing better ways of conveying information about the states to the general population respondents. The ways this can be done are examined in the next section, but these could include improvements in the health state descriptions and providing more information on size and nature of the adaptation experienced by patients over time. This position would be more consistent with the original recommendation of the Washington Panel that *informed* general population values should be used.

## **IMPLICATIONS FOR POLICY**

### **The impact of using direct patient values**

Somewhat ironically it has been argued that using general population values is likely to benefit patients more than using their own values. This is based on the common observation that the general population tend to give a lower value for state of ill health than patients. For any intervention aimed at curing or preventing a condition associated with ill health states, then general population values will generate a larger gain. This argument is an extremely pragmatic one, rather than a point of principle, but it is nonetheless worth addressing given a concern that moving to patient values may prejudice them in some way (Gold et al, 1996).

The argument is more complex than suggested by the Washington Panel. General population values will give a lower value to saving the lives of the unhealthy compared to the healthy, which would not be in the interests of most patient groups. Giving lower values to the lives of ill people means that life saving interventions will look less attractive than if patient values had been used and this is on top of the lower life expectancy usually associated with medical conditions (commonly referred to as the double jeopardy argument, ref). It has also been shown by Lenert and colleagues, that the general population may under value movements between severe states. This argument is based on an application of prospect theory that suggests an 's' shaped utility curve over gains and losses. Given the fact that the general population will have a higher reference point, movements between severe states will register little change since it takes place at a shallow point in the curve. Patients have a lower reference point and hence any movement will be further up the 's' shaped curve where it is steeper. This difference may also operate at more intuitive level. At extreme levels of disability the general population may be insensitive to small improvements in mobility that are highly valued by the patients.

In the context of cash-limited systems, it not so much a question of benefiting patients per se, rather it is about the direction of resource allocation. The increased use of patient values will not prejudice patients as a whole, but will result in a redirection of priorities. This may include a movement away from curative measures aimed at



achieving perfect functioning towards more life saving interventions and interventions aimed at achieving small improvements to those in most serious functioning problems. It may also results in a change in the weight given to different aspects of quality of life.

### **Strategic behaviour**

A common concern in the contingent valuation literature is that respondents will game to maximise their interests, for example by over stating the impact of a condition on their life before treatment (though whether they would exaggerate the improvement after treatment is less clear). Again this is a pragmatic issue and not a point of principle. It is a problem that may well exist already with use of self report HRQoL measures such as the EQ-5D, where patients can exaggerate the impact on their state of health (Jenkinson, 1999) wrote an interesting editorial on this issue in the Journal of Health Services Research and Policy entitled 'Death by questionnaire'). There is little concrete evidence of strategic behaviour in health care. The risk can be, however, by using the instruments on patients unlikely to be effected by the decision being informed.

## **IMPLICATIONS FOR RESEARCH**

### **Measuring patient values in the moment**

The notion of moment utility (MU) was proposed by Kahneman (2000) as a measure of happiness, though it can be applied to health (Kahneman et al, 1997). At one extreme, the total happiness by an individual over a period of time is simply the sum of every moment experienced. The ideal method for measuring MU would be to ask someone his or her level of utility at every moment in that period. The additional attraction of this concept is that it potentially avoids some of the more limiting assumptions of the QALY, such as constant proportional trade-off and linearity over time, since these moments of time are so small that duration effects do not come into play. Additive independence is achieved because the consequences of context are built into the measure. Where a previous experience hangs over current experience then this should be reflected in the person's valuation of the moment. Of course there are many problems with applying this concept, but it does provide an important insight into notion of patient values.

MU avoids the problems associated with recall. There is substantial evidence that people are poor at recalling their experiences. People recalling past experiences tend to be subject to a range of biases, such as 'peak-end' effects where they tend to focus on their peak experience and their last experience and weight more heavily than the rest of the profile. It has been observed for example, that people, who experienced two profiles identical except that one has an extra period of lower level pain at the end, say in retrospect that they prefer the profile with more pain in retrospect. The valuation of patient experience always involves a degree of recall, and there is an important research agenda that examines this in the context of health state valuation.

The measurement of MU presents some substantial research problems. Asking patients to value their own health, and to do so sufficiently frequently, raises some major practical problems. Many patients by definition are quite unwell and maybe unable or unwilling to undertake complex and quite intrusive valuation tasks. There may also be ethical concerns with asking patients in terminal conditions to imagine scenarios involving either the risk of death or shorter life expectancies. These are

very real practical problems, particularly in the use of TTO and SG, but they should not be exaggerated. Researchers in the past have used subtle and sensitive methods for eliciting preferences by SG or TTO (Torrance, 1986.)

The psychological work on experiential utility mainly uses rating scales, which have received a lot of criticism in the economics literature for lacking the choice context required to obtain a preference value, such as achieved in SG, TTO or WTP (Brazier et al, 2003). However, choice based questions present their own challenges. The accepted choice-based techniques for valuing health states, such as SG or TTO, require a respondent to either: 1) imagine the state being valued and imagine one or both of the reference states (unless the respondent is in perfect health and recognises it) or 2) where the patient being asked to value their existing state but they must imagine the prospect of two reference states. The first is the question most commonly used in general population valuation survey or any valuation study where the respondent is not being asked to value his or her own state. With the second, a respondent is being asked to imagine a state such a perfect health, that they may not have experienced for many years. Some degree of imagination is required using existing methods of preference elicitation.

### **Valuing health states linked to a generic descriptive system**

A common criticism of QALYs is that they are only concerned with the impact of health care on health rather than the recipients' utility function. Critics have been concerned with the consequent exclusion of 'non-health' attributes, such as convenience or satisfaction with the care process. Using patient values could be seen as a means of ensuring these non-health attributes become accepted within the metric. However, this need not be the case. As stated earlier, an extra welfare perspective is concerned with meeting the information needs of the decision maker and publicly funded systems may decide that health benefits have a special status over non-health benefits.

The theoretical distinction between health and happiness is beyond the scope of this paper, but in practice one approach would be to limit the definition of benefits to a prescribed list of dimensions, such as those of the EQ-5D. The implication of adopting patient values would be to administer the EQ-5D along with an own health state valuation question. This has been undertaken with some success in the valuation of the SF-12 (Lundberg et al, 1999) where the SF-12 was administered alongside a self-completed TTO question. An algorithm was generated for weighting the SF-12 by regressing its items onto the TTO response. Applying this approach requires a careful selection of respondents based on a proper design. But it offers an interesting and important practical approach to eliciting patient values for a defined descriptive system.

### **Eliciting informed general population values**

In a recent Editorial comment in Quality of Life Research Fryback (2003) concluded: *'For the quality of life research community the challenge is how to move beyond asking the public to value telegraphic health profile descriptions. We need to define an elicitation paradigm to make realistic use of patients' perceptions and values in societal evaluations'*. This is going to be a radical departure from current thinking that seems to promote a view that people's preferences are simply there to be elicited and that general population values are in some way pure and should not be

contaminated. We have argued earlier in the paper, even current attempts to achieve this state of purity fail because most descriptive systems incorporate some degree of patient evaluation through the mood dimension and those dimensions concerned with social health. Seeking more informed general population preferences is really a question of how much information.

A less radical research agenda persists around the problems of describing health states. Current descriptive systems, such as the EQ-5D have been criticised for being rather abstract and not describing what it is like for the patients. Remarkably little effort has gone into making health state descriptions more realistic. There has been work, for example, on simulating states using specs to reproduce visual impairment (Tsuchiya and, 2003) or moving onto using computer simulators. There might be scope for showing videos of patients being interviewed about their condition. Inevitably this involved a trade-off between over burdening the general population and achieving sufficient realism. It also seems appropriate to allow respondents more time to reflect on different health states and perhaps to deliberate with friends and relative as well as other respondents. Such a process better reflects the way people make such decisions in practice. This process of health state preference elicitation takes account of the fact that the process of preference elicitation is more like preference construction (Dolan, 1999; Slovic, 19....).

Finally, general population respondents could be provided with patient valuations. These should be valuations obtained at different points time in order to help respondents understand the differences between values during transition and those after a period of adaptation. The aim of achieving better informed preferences, however, is not to try to get the general population respondents to reproduce patient values. This would be better achieved using patient values directly. The purpose is to allow the general population to incorporate the raw patient values in their own valuations. Menzel and colleagues (2002) suggest rather ambitiously that perhaps the general population may be able to disentangle appropriate from inappropriate adaptation. This would require information on the types of adaptation undertaken by patients, so that respondents could decide which they would wish to take into account. This is a substantial redesign of the current methods of eliciting preference which as Fryback (2003) has pointed out, would require a major paradigm shift in this field.

## **CONCLUSIONS**

NICE has been under pressure to try to increase the role of patient representatives. Currently NICE has patient representatives on the Appraisal Committees and Guideline groups, but in many ways it is curious that patient representatives should be involved in assisting in social decisions making using (the largely uninformed values) of the general population. A better model might be for patients to be more involved in the valuation of the health states and for a committee with representatives of the general population to judge the resulting assessment of cost-effectiveness alongside other social criteria for resource allocation decision. The perversity of the current situation is illustrated by a plan at NICE to have a patient centred evaluation of technologies in addition to the current assessments of clinical and cost-effectiveness. We believe it would seem better to integrate patient values into the assessments of clinical and cost effectiveness rather than have it as a separate exercise.

While the authors of this paper are not agreed on the extent to which patient values should be taken into account nor the most appropriate method, we have identified the need for greater debate and more research. Debate needs to be better informed since there is an important research agenda to pursue in understanding the causes of the differences between patient and general population values since this may have important normative implications. The research agenda extends to ways of improving the way we describe health states, the elicitation of patient values and developing methods for obtaining informed general population preferences.

There are some real concerns with the current use of largely uninformed general population values. On the other hand, there are reasons to be concerned about the adoption of raw patient values given the concerns about lowered aspirations, different comparator groups and so forth. While there is a case for having a greater role for patient values, but this does not imply a use of raw patient values. One solution is to provide the general population sample with more information on what it is like for patients. After all, whose well-being is it anyway?

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