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Priority setting and patient adaptation to disability and illness: Outcomes of a qualitative study

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Abstract

The study examined the question of who should make decisions for a National Health Scheme about the allocation of health resources when the health states of beneficiaries could change because of adaptation. Eight semi-structured small group discussions were conducted. Following focus group theory, interviews commenced with general questions followed by transition questions and ended with a 'focus' or 'key' question. Participants were presented with several scenarios in which patients adapted to their health states. They were then asked their views about the appropriate role of the public, patients and health professionals in making social judgements of quality of life. After discussion and debate, all groups were asked the key question: 'In light of

adaptation, who should evaluate quality of life for the purpose of setting priorities in the allocation of health care?' In all groups participants presented strong arguments for and against decision making by patients, the public and health professionals. However, most groups thought a representative body which included a range of perspectives should make the relevant judgements. This is at odds with the recommendation in most national pharmaceutical guidelines. The main conclusion of the paper is that health economists and other researchers should explore the possibility of adopting a deliberative, consensus-based approach to evaluating health-related quality of life when such judgements are to be used to inform priority setting in a public system.

Keywords · Adaptation · Priority Setting · Health-Related Quality of Life · Focus Groups · Qualitative Research

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Introduction

Measuring quality of life is important if health care resources are to be allocated efficiently and fairly. This is usually done using a technique such as the Standard Gamble (SG), Time Trade-Off (TTO) or a simple Rating Scale (RS) [6]. But whose evaluations should be used when it comes to determining whether health state A is better or worse than health state B, and if so by how much? Should the measurement techniques be used with patients, health professionals or with members of the public?

A compounding problem in answering this question is that chronically ill and permanently disabled patients tend to rate their quality of life more highly than other people who are asked to imagine themselves in these health states [3, 16, 34, 41]. In large part this can be explained by two facts. First, patients adapt to life with a permanent disability or chronic illness by a variety of means, some positive and some negative, including the acquisition of increased skills, changes of goals and interests, lowered expectations and altered conceptions of ideal health [23]. This type of psychological adjustment is most discernible in patients with moderate to severe impairments. Second, and conversely, members of the public tend to focus on the immediate affects at the onset of the condition and fail to take adaptation into account [5].

This has led to debate about which is the most appropriate group to make judgements about health-related quality of life (HR-QoL) when this information will be used to set priorities in the health sector. If the evaluation of the general public is used the gains from a health program will appear to be greater than if the adapted evaluations of patients are used. This is because the public tends to rate conditions as worse and the benefit to be gained from curing or ameliorating them will appear greater [35]. The question whether assessments are made pre- or post-adaptation by the public or patients respectively can therefore have significant implications for priority setting.

The US Public Health Service Panel on Cost-Effectiveness in Medicine argued that members of the general public should be asked to act as ‘hypothetical patients’ and evaluate quality of life, when this information is to be used for priority-setting [12]. Consistent with this advice, the World Health Organization burden of disease study used non-adapted evaluations [25]. In the UK, the Guide to the Methods of Technology Appraisal states: “For the reference case, the measurement of changes in HR-QoL should be reported directly from patients and the value of changes in patients’ HR-QoL (that is, utilities) should be based on public preferences using a choice-based method” [26]. In other words, if you want to know what symptoms are associated with a health condition, ask patients; if you want to know how bad it is to have those symptoms, ask the general public.

By contrast, Nord [27], Nord, Pinto et al. [28] and Menzel, Dolan et al. [23] have suggested the use of actual patients to make the quality-of-life evaluations, a position adopted by the Swedish Pharmaceutical Benefits Board [31]: “QALY [Quality-Adjusted Life Year] weightings based on

appraisals of persons in the health condition in question are preferred before weightings calculated from an average of a population estimating a condition depicted for it...”.

A final option which has not been formally adopted in any country is to use medical practitioners to assess the quality of life. They are in the privileged position of observing patients from pre- to post-adaptation and, in contrast with individual patients, have observed sufficient cases to enable them to generalize a particular possibly idiosyncratic experience to the more general patient experience.

In light of this controversy and its importance, it is surprising that there has been little empirical investigation into the views of the public, patients and others regarding this question. The research reported here attempts to fill this gap. Through a series of focus group interviews, the public, patients and health professionals were asked for their views on who should be the decision maker in evaluations of HR-QoL, when assessments differ due to adaptation.

Method

The research question involves a number of complex arguments which require deliberation and debate. For this reason qualitative methods are more appropriate than large scale survey techniques as they permit an in-depth examination of the relevant issues. In particular, focus groups involve dynamic and rich group conversations in which individuals present ideas, hear from other participants and can question each other, and thus have the potential for producing more informed, reflective decisions than postal or web-based methods [15, 29].

The Question Route

Interviews followed the general focus group theory espoused by Krueger [17]. In this, interviews should commence with opening questions (which everyone is expected to answer) followed by a number of transition questions and ending with a final, key question. In this case, after a detailed preamble that introduced participants to the notion of HR-QoL and its measurement, interviews opened by seeking responses to questions such as: *“What do you believe your quality of life would be like if a car accident left you in a wheelchair?”* and *“Who do you think is best suited to make decisions about the quality of life of people who are wheelchair bound?”* To alert participants to the nature of adaptation, these questions were initially framed ‘in the short term’, and subsequently ‘in the long term’ – i.e. *“What do you believe your quality of life would be like after five years?”*

From the wide-ranging responses, interviews were able to progress to the transition stage. This involved questions such as: *“Should tax-payers make judgements about quality of life because their taxes fund the public health system?”* and *“Should men evaluate conditions that affect women, or younger people evaluate conditions that affect only older people?”* During this phase there was also in-depth discussion of how adaptation may be shaped positively or negatively by personality type and environmental circumstances. For example: *“What is the relevance of the fact that patients may become resigned to life with an illness or disability or find it hard to admit how poor their health really is?”* and *“What is the relevance of the fact that patients with long-term illnesses and injuries may develop new interests and goals?”* Because a number of these

arguments were likely to be unfamiliar to participants, each was projected on to a screen (at appropriate points in the interview) so that participants could reflect on the idea or question. This helped participants to engage more easily in the discussion.

Having heard and discussed these arguments, participants were asked the key question about which group(s) should be responsible for evaluating HR-QoL in light of the phenomenon of adaptation, and keeping in mind that such evaluations would have a bearing on how resources in Australia's public health system are allocated.

Group Characteristics

A total of eight groups were conducted with three types of decision makers. They were constituted as follows:

- *Three groups of health professionals (16 people)*

H1¹: Members of the Royal Australian College of General Practitioners

H2: Community GPs

H3: Members of allied health professions

- *Three groups of the general public (20 people)*

P1: Blue collar tradesmen and security personnel

P2: Post-graduate students from a variety of disciplines

1. These codes will be used later in the paper to refer to sources of quotes - i.e. H = Health Professional, P = Member of the Public, C = Consumer. 1, 2, 3 denote subsets within each of these categories.

P3: Professional researchers/evaluators

- *Two groups of consumers* (16 people)

C1: Members of a lymphoedema support group

C2: A mens' carers support group

Some controversy exists about whether it is best to use homogeneous or mixed groups. On balance the superior strategy appears to be the use of homogeneous groups [10, 15]. These increase the likelihood of group cohesion and reduce the possibility of imbalances in power or social status that can inhibit discussion. They also bring to the fore the degree to which differently constructed groups view matters from different perspectives. On the other hand, the diversity of the groups - doctors, allied health professionals, tradesmen, students and patients - maximized the likelihood of all arguments being represented. In brief, we used within-group homogeneity but between-group heterogeneity.

Of the 52 participants, 30 were male and 22 female. They were aged between 28 and 80 (with the majority being between 40-60). Each group contained 5-8 people. Characteristics of the participants appear in Table 1. Over half of the non-health professionals indicated that they had experienced moderate to extensive involvement in the public health care system. About 2/3 felt that their knowledge of Australia's health system was fair to good.

[Table 1 about here]

The protocol for the groups was developed by team members from the Centre for Health Economics at Monash University and the Centre for Program Evaluation at Melbourne University. Groups were organised and moderated by members of the Centre for Program Evaluation, and a health economist was present at each interview in order to clarify concepts or answer participants' questions. Interviews were conducted at The University of Melbourne or at community sites across metropolitan or regional Victoria. Sessions lasted approximately 1 to 1.5 hours and were taped for subsequent analysis.

Analysis

After the interviews had been carried out the tapes were transcribed in full. Transcripts were then coded, beginning with a basic set of codes established through a review of the literature. Codes were maintained, adapted, added to or collapsed following further close readings of the text. The main themes were then transferred on to Miles and Huberman-style grids [24], which provide a particularly rigorous way of dealing with qualitative data while also enabling across-group comparisons.

Results

As a preliminary exercise, group members were asked to nominate who would be in the best position to rate the quality of life of a person made a paraplegic as a result of a car accident. Responses were divided, but the individual patient, the patient's family or carers, members of the medical profession, the public and a combination of these emerged as the main candidates.

Members of the public often stated that an assessment should be made by the patient. Indeed, *“it must be the individual who makes the judgement as the general public has very little idea about what it is actually like ... we cannot know unless we are in his/her shoes”* (P1). There were others across the groups who thought that those near to the patient, such as a carer, were in the best position to assess the patient’s quality of life, because *“the carer can look from both the perspective of an able-bodied person and also know what the patient’s full potential can be”* (P3). One participant added that there could be a benefit in asking both the patient and their carers, because *“if you have information from both the individual and the family or carer then potentially you have a fuller picture”* (P2). Others thought that doctors are in a particularly advantageous position to make such judgements. The main reasons cited were that doctors have intimate contact with a wide variety of patients on a day-to-day basis (C1), and have detailed knowledge about the conditions that affect them (C2).

When considering the role that the public might play, diametrically opposed views were expressed, depending on the relative weight given to the objectivity of the public versus the experience of the individual patient. Some participants leaned towards the public, *“because you have to maintain objectivity”* and as a patient *“your judgement can be clouded”*. By contrast, others felt that members of the public *“won’t be sitting in the individual’s seat so they can’t possible know”* and *“it would need to be an informed public - and they’re not on the whole!”* (H1).

From the outset the view was often argued that it is difficult for one type of individual to assess the HRQoL of another person, and many respondents thought it would be desirable for a combination of people to work together to arrive at a valuation. Consequently, it was suggested that *“families, society and the government should play a part”* (P1), that *“an informed patient as well as the carer and medical practitioner should be involved”*(P1), and that *“everyone should contribute to the discussion including patients, carers, families, health professionals and others in the network”* (H3).

Exploring Adaptation in Greater Depth

After a wide-ranging preliminary discussion, groups were asked to consider several arguments in more detail. They were reminded that evaluations were to be used to help prioritise health programmes in Australia’s public health system. One argument considered was therefore whether tax-payers have a right to make policy-relevant evaluations of HR-QoL since their taxes fund the public health system. There was some support for this position, particularly among the health professionals. In general, however, few participants agreed with the idea that tax-payers should have a greater entitlement to make decisions than other members of the public. In fact, many were adamant that everyone, regardless of their tax-payer status, should have the opportunity to participate in decision-making, believing that *“society as a whole has a right to have some input into ethical health questions whether they are paying taxes or not”* (H2), because *“it should be all embracing”* (H1, H3, P1, P2, P3). As a corollary, the idea that those who pay *more* taxes should have a *greater* say was generally rejected.

Another argument considered was whether health states should only be evaluated by those likely to experience them. For example, should men evaluate conditions that affect women, or younger people evaluate conditions that affect older people? This provoked a quite strong response, with many participants saying that people with particular characteristics, interests or the likelihood of succumbing to a disease could skew the distribution of resources and hinder efficiency, and so a more encompassing approach is needed (H1). It was also pointed out in relation to (for example) womens' health problems that:

There are men who are affected by breast cancer such as fathers, brothers, sons, husbands. So, it is not only affecting the person who is being treated. There is the social and emotional impact on others and, therefore, they have a vested interest in the health system.... So, the father of the young children with a wife who has breast cancer could have far more to contribute than a young woman out there with no concerns (H1, C2).

Thus, a considerable number of participants came to the conclusion that it is more defensible to involve the public generally rather than possible patients only.

Constructive Adaptation

Next, groups were asked to consider some of the positive and negative aspects of adaptation itself in greater detail. Warr, Jackson et al. [45] distinguish between *resigned* adaptation, which involves passive acceptance of one's condition or reducing one's aspirations, and *constructive* adaptation, which involves active attempts to mitigate the effects of illness or disability by the

adoption of new but no less challenging goals. To begin, some of the positive aspects of adaptation were presented to participants (Figure 1).

[FIGURE 1 about here]

Participants seemed to have no difficulty grasping the distinction between these types of adaptation, and sometimes gave their own illustrative examples. They also seemed to grasp the connection between these considerations and the tendency of patients to give higher HR-QoL ratings to the conditions from which they suffer. After discussion, they were asked whether these arguments influenced their thinking about whether patients are the ones best placed to make evaluations of quality of life. Here are various responses across groups which encapsulate some of the participants' thoughts:

Full health is how you feel. You might have one leg and feel that you have full health and a full life. You might have two legs and feel miserable. So, it's a mental thing. It's whatever you think (C2). Some people just accept it and get on with life (C1). Like people who have had a stroke and have lost the use of their right arm can often transfer their skills to the other arm (C1). It might limit what they can achieve but it can open up other possibilities as well (P3). You can step outside your limitations, have no legs or whatever and reach for the stars (C2). You only have to look at the wheelchair athletes or that champion skier who only has one leg - or other paralympians and see how fulfilled they are (H2). And many deaf people don't see that they are disadvantaged at all, so I see it as being part of the argument in favour of them making assessments (H2).

Of course, just *when* patients are asked to evaluate their quality of life with a disabling or chronic condition is important - particularly whether it is during the early stages of the adaptation process or later on. While not rejecting the above arguments in support of using patients' evaluations, several discussants raised this issue of timing, asking: "*When do you measure quality of life? At the start? - but surely you can't ask someone immediately after a major trauma? - or should it be at the end?*" (C2, H3). Others noted the dynamic nature of the process of adaptation itself as it could affect any decision made. As one participant pointed out:

It also presumes that everything stays static and it doesn't. For example, people who have physical illnesses often suffer depression, but in a year's time they might be out of that depression and feel better. So you have to be careful about the timing of assessments (C2).

In several of the groups the suggestion was made that individual evaluations would have to occur regularly over a certain period, because "*it can't be a one-off thing and has to be measured over a period of time*" (P1). Others suggested measuring the process of adaptation itself, and noted how contextual factors could contribute to the success or thoroughness of the process:

What you ask the patient is very significant because you would need to trace how they adapted and changed over time. Also you have to ask yourself: Was this because they had access to rehabilitation resources so that they could maximise their potential? (H3, P3).

Resigned Adaptation

After discussion of these arguments in favour of patient evaluations, three arguments against using patient evaluations were presented for debate, based on Warr, Jackson et al.'s concept of *resigned* adaptation (Figure 2). These arguments offer an alternative explanation for why patients may give higher evaluations of their own quality of life than others, but do so in a way that casts doubt on the wisdom of using those evaluations to inform health policy. Again, participants seemed to have no difficulty understanding these arguments, and how they might militate against using the evaluations of patients. Some interviewees gave personal examples again to illustrate this point of view.

[FIGURE 2 about here]

(a) *Denial*. The possibility that patients might give higher ratings of health states because they are in denial about the full extent of their disability or illness was discussed at length.

Interviewees were able to cite real examples within their experience such as the following: “*I know someone with mental illness. They deny it and they think that everything is OK*”(C2), or “*Patients might have trouble with day-to-day living but they don’t dwell on it. My 80 year old father says that he’s fine but I know he’s not*” (H3). It was also pointed out that: “*each of us wants to get out of life as much as possible, so we probably never admit how crook [unwell] we really are!*” (C1). A health professional also commented: “*I have known people with mental*

conditions that I would say have a very low quality of life but they appear happy with their lot”

(H1). This led one GP to feel that diverting resources to a contented patient could be a waste:

If a patient has accepted and adapted to their state of health and they don't see themselves as having any deficiencies that need to be corrected by the medical system, then there is a problem if the public say that that is not good enough. They say you are 3 out of 10 but you should be 9 out of 10. Then we would be pouring all these resources in to get the patient from 3 to 9 when they are happy to accept to be 3 out of 10.... So what you are trying to evaluate is happiness. You might make them a bit healthier but they have adjusted to a certain level and so would they be any happier? (H2).

(b) Forgetting What It Was Like to be Healthy. In general participants did not agree with the suggestion that patients might forget what it was like to be healthy and so would not be in a position to make accurate evaluations. One doctor thought that only a very few patients cease to realise what full health means, and so “*it is not a majority argument*” (H2). Another member of the public, who suffers a chronic illness, was also quite forthright in refuting the suggestion:

You can't say that patients don't remember what it was like to be healthy. After all these years I still remember what it was like before the onset of my condition. You adapt, but you still remember what it was like not to have blood tests and injections and so on (P3).

(c) Lowering Expectations and Associated Factors. Another negative aspect of adaptation concerns the lowering of expectations or becoming resigned to life with a disability or chronic

illness. Some participants felt that patients were not in a position to make a valid assessment if they lowered their expectations because they had developed a pessimistic outlook (C1), were unable to adjust or achieve goals (P2), or came from a background where they were not encouraged to make the most of a situation (P1). It was also suggested that expectations would be lowered if the patient was not in possession of correct information, which might give them a more balanced or complete picture of what is possible in relation to their particular condition (C2).

Summary Views

By this stage of the interviews participants had discussed a number of issues concerning quality of life post-trauma, the process of adaptation in response to it, and the negative and positive interpretations of this process. They were now in a better position to make informed choices about which groups are best placed to evaluate health-related quality of life. Consequently, participants were asked to provide summary views about which groups policy makers should consult. The following quotes are from the end phase of the interviews.

(a) Arguments for Involving Patients. The majority of participants felt strongly about the need to involve patients in the decision-making process, as “*they are the ones who have to live with the consequences*” (P1), “*are the only people to understand how they really feel*” (C1), and because “*many are likely to have paid taxes beforehand and so should have a say*” (H2).

(b) *Arguments for Involving the Public Generally.* There was also widespread support for public involvement in order to provide a level of objectivity. Some interviewees felt that the public would: “*have a broader view*” (H1), “*are on the outside looking in objectively*” (C2) and can “*be more accurate even if not perfectly informed*” (H1).

(c) *Arguments Against Involving the Public.* However, some participants remained opposed to the idea of the public making evaluations, as they “*wouldn’t be able to put themselves in the patient’s position or to make sound judgements about adaptation*” (C1, C2), may “*under or over-estimate the extent of the patient’s problems*” (P1), “*are often swayed by the arguments of politicians*” (H1, P1), “*are ill-informed*” (H1) or may “*set the ideal of perfect physical health as being the perfect measure of quality of life*” (P3).

(d) *Arguments In Favour of a Community Representative Group.* Finally, many concluded that none of the above offered the best solution. In fact, the majority of respondents thought that evaluations should be made by a representative group that would consist of a mix of patients, carers, family members, members of the public and health professionals. As has already been noted, this idea was put forward in response to a range of discussion topics, and its popularity was confirmed when a vote was taken at the end of the session (see Table 2).

[Table 2 about here]

The most popular option, supported by 58% of group members, was that a mixed group would provide the best solution for arriving at informed yet objective evaluations of quality of life with

a long-term illness or disability, with the values of no group dominating entirely. The ensuing compilation of comments provide some of the reasons for this choice:

It has to be somewhere in the middle. You need to ask the patients and an educated public and then get a barometric reading of reality (C1, P2). There are so few things that are black and white (P1). If you choose between the two [public versus patient] then automatically you are going to cut out a lot of information that could be quite valuable - so it has to be more inclusive when seeking the information (H2). A range of inputs should be there - not just the patients or the public or just the professionals. I would like to see a more representative group making the decisions, a voted-for or nominated panel. It should be a community representative group so that the community feels that they are having a say (H1).

Discussion

From the transcripts, it is possible to distinguish three main types of reason for supporting patient or non-patient evaluations. First there were “*epistemological*” reasons. These considerations were typically raised in support of patients’ evaluations. The view was often expressed that patients have knowledge of states of impaired health that non-patients lack. Moreover, this is knowledge of a particular type, sometimes called ‘experiential knowledge’ [2]. While clinicians may have more medical knowledge than patients, patients have first-hand experience of how their symptoms affect their quality of life. As Menzel, Dolan et al. observe [23]:

Patients certainly have a better understanding of what life is like in states of impaired health, and it is their preferences, whether significantly influenced by adaptation or not, that represent what is actually experienced in the conditions that health services aim to remedy or prevent (p. 2150).

A further “epistemological” argument was that patients have knowledge of the process of adaptation itself that non-patients lack. As with knowledge of the health state, they have first-hand experience of the adaptation process and do not have to make assessments based on inference. The lack of such first-hand experience partly explains why people are poor predictors of their own emotional reactions to future events: they fail to take into account a range of adaptation processes [37, 38, 46].

Second there were reasons that were *perspectival* in nature. For example, several participants remarked that the individual patient “*is not always able to make objective assessments*”. By contrast, they felt the public, and to a lesser extent carers, would “*have a broader view*”, can offer an “*external focus*” and “*are on the outside looking in objectively*”. This is different from the epistemological argument, since it does not deny that patients have ‘first-hand’ knowledge of the health states they experience, as well as the adaptation process. Rather, it maintains that this does not always translate into greater *objectivity* of judgement, and in fact may hinder it. According to these participants an “*external focus*” provides a way of overcoming (what was perceived to be) a potential bias inherent in the subjective view of patients.

Finally, some reasons raised were *ethical* in nature. For example, since it is the resources of society that are being used to fund public health programs and services, the construction of health-state measures should reflect the preferences of the general public, even if those preferences are imperfectly formed. According to this argument, tax-payers have a *right* to be involved in priority setting decisions. As with the above two reasons, these arguments can be used to support different views – e.g. the individual patient: *“I’m paying my taxes so why shouldn’t I have a say?”* (C1) or society: *“society as a whole has a right to have some input into ethical health questions”*.

In relation to the main question – “In light of adaptation, who should evaluate quality of life for the purpose of setting priorities in the allocation of health care?” - it was apparent that participants favoured input from a number of groups when it was perceived that each had a potentially useful input or reason to be involved. The transcripts reveal cogent arguments in favour of this approach. For example: *“If you choose between the two [public versus patient] then automatically you are going to cut out a lot of information that could be quite valuable”* and *“If you have information from both the individual and the family or carer then potentially you have a fuller picture”*. Obtaining input from a range of sources can also be seen to promote social capital and support a sense of public ownership and responsibility for health systems [1, 11, 18]. Thus: *“It should be a community representative group so that the community feels that they are having a say”*. In this context “community” should be interpreted as embracing those with a particular contribution to the discussion (health professionals, patients, and others) in addition to representatives of the public.

A number of objections might be raised against the adoption of such a mixed-group approach. The first is raised implicitly by the developers of most ‘multi-attribute utility’ (MAU) instruments – broad-based instruments used in cost-effectiveness studies. These instruments, including the EuroQol-5D (EQ-5D), the Health Utilities Index (HUI), the Finnish 15D, and the Short Form-6D (SF-6D) [14, 21], advocate the use of population-based evaluations of HR-QoL. In justifying the use of population-based weights, the creators of the EQ-5D offer two explanations [4]. First:

... patients tend to rate their health states higher than the general population because of coping etc, often underestimating their need for healthcare. The EQ-5D value sets are therefore based on the values of the general population (p. 11).

However, this argument simply assumes that patients underestimate their need for healthcare, and disregards the possibility that members of the public may overestimate that need. Indeed, it disregards the possibility that there may be no objectively ‘correct’ level of treatment as “underestimate” and “overestimate” are only meaningful in relation to the level of perceived severity of a health state. Participants in our study were unconvinced by the argument, and their final assessment represented a rejection of a privileged perspective for any one group.

The second argument offered by the creators of the EQ-5D in justifying the use of population-based weights is the following:

utility analysis requires a general population-based value set (as opposed to a patient-based set). The rationale behind this is that the values are supposed to reflect the preferences of local taxpayers and potential receivers of healthcare (p. 11).

The argument is again evidence free. It simply asserts that the values should reflect the preferences of the public rather than, for example, patients. Further, there is a disjunction between the argument and the conclusion. Even if we accept that decision making should be informed by “the preferences of local taxpayers and receivers of healthcare”, it does not follow that “analysis requires a general population-based value set *as opposed to a patient-based set*”. The rationale expresses one argument for including input from the public, but not a compelling argument for *restricting* input to that group. After extensive discussion our participants concluded that the values do not need to be *either* exclusively general-population based *or* exclusively patient-based, but should reflect both.

Second, it might be thought that those participants who advocated a mixed-group approach simply did so because they were unable to decide which group should make HR-QoL evaluations. Being unable to choose, or finding the arguments in favour of patients, health professionals and the public equally persuasive, they defaulted to a ‘bit-of-everything’ solution.

However, there is again no evidence to support this suggestion. Participants gave cogent reasons for a mixed group which mitigates against the view that they were unable or unwilling to choose. For example, the following do not suggest indecisiveness: “*if you have information from both*

the individual and the family or carer then potentially you have a fuller picture”, “if you choose between the two [public versus patient] then automatically you are going to cut out a lot of information that could be quite valuable”, and “it should be a community representative group so that the community feels that they are having a say”. These arguments are forceful and relate to the efficiency of decision making and to procedural justice respectively.

More generally this objection would justify the rejection of any solution based on a compromise. Survey respondents often express a willingness to ‘trade-off’ efficiency to achieve other benefits relating to distributive or procedural fairness – for example, to benefit those with a limited potential to benefit [7, 42], or certain age groups [39, 40] or the more severely ill [32, 43]. It would be wrong to conclude that in all of these cases respondents are unable to choose, and therefore adopt a ‘bit-of-efficiency-and-a-bit-of-equity’ solution. Rather, participants value both efficiency and fairness and have a definite preference for solutions that incorporate both.

Finally there are, of course, challenges with an inclusive approach. Many of these are of a practical nature. For example, should a representative group comprising patients, members of the public, carers, etc. attempt to arrive at a consensus (a group decision) or should each member make an independent evaluation after deliberation? [44] Exactly which groups should be represented on an ‘evaluation panel’? [20] What information should such a group receive? For example, is it sufficient that they be informed about the process of adaptation or should they additionally be informed of patients’ actual evaluations? [22] These practical problems present a challenge for future research, but they do not justify a rejection of the mixed group approach, particularly in light of the problems confronting an exclusive reliance on input from one type of

group. It should also be noted that our participants were not asked how their recommendations should be implemented. The study was focused on the prior question of who should make the quality-of-life evaluations.

Conclusion

The subject of this paper has been the question of who should make judgements about HR-QoL when there is patient adaptation and when such decisions will influence how resources are allocated. Eight focus groups were conducted in which participants had the opportunity to “engage with the task in a way that aids comprehension” [8, 9, 33] – i.e. in a way which allowed them time to consider all of the alternatives carefully [19], the opportunity to seek clarification of the task [30], and to construct considered views rather than report unreflective opinions [36]. In all of the groups participants presented strong arguments for, and against, reliance on decisions being made by patients, the public or health professionals. Eventually the majority felt that there should be another option, where a number of groups have input into the decisions: *“not just the patients or the public or professionals ... a more representative group ... a voted for or nominated panel”*.

As noted, a number of national pharmacoeconomic guidelines specify *either* a patient *or* a public perspective for measuring HR-QoL. However, none of them advocates input from a range of stakeholders. Focus groups have the potential for throwing up unexpected solutions, since participants have the time to reflect and deliberate and are less bound by discipline-based ways of thinking. After considering all of the main alternatives, our participants ultimately favoured a

solution that differs from the default position contained in these definitive national guidelines. This option – the use of a representative group - should be explored by health economists and other researchers more generally as a way of reaching evaluations that are in keeping with the trend toward democratic decision-making in the health sector [13].

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Conflicts of Interests

The authors declare that they have no competing interests.

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SCREEN 1

For Patient Assessment

(i) Skill Enhancement

Some patients may improve their ability to accomplish their existing goals by undertaking the activities they have always undertaken. For example, a painter who loses their painting arm might develop skills using their other arm.

(ii) Activity Adjustment

Some patients may improve their ability to accomplish their existing goals by undertaking new activities. For example, a person who values physical exercise, but who becomes a paraplegic, might switch from cycling to aerobic exercise in a wheelchair.

(iii) Substantive Goal Adjustment

Some patients may change their goals. For example, the person who becomes a paraplegic may develop an interest in music to replace a previous interest in physical activity.

Figure 1: Arguments in Favour of Patient Assessments

SCREEN 2

Against Patient Assessment

- (i) Patients may find it difficult to admit how poor their health really is. This is because they are in denial about the full extent of their illness or disability.
- (ii) Patients may cease to realise any more what full health is like or what it would enable them to do.
- (iii) Patients may lower their expectations about what life can offer them. Rather than develop new skills or goals they become resigned to their illness, allowing it to limit what they can achieve.

Figure 2: Arguments Against Patient Assessments

Table 1: Level of Participant Involvement and Knowledge Related to the Healthcare System

Focus Group Type	Number (Gender)	Level of Health Involvement	Level of Health Knowledge
Health Professionals (H)			
H1: RACGP ¹	5 (2M, 3F)	Extensive	Very Good
H2: Community GPs	6 (4M, 2F)	Extensive	Very Good
H3: Allied Health	5 (1M, 4F)	Extensive	Very Good
Public (P)			
P1: Tradesmen	7 (7M)	2 Extensive 3 Moderate 2 Occasional	5 Good 2 Fair
P2: Students	6 (2M, 4F)	All Occasional	3 Good 2 Fair 1 Poor
P3: Researchers	7 (3M, 4F)	5 Moderate 2 Occasional	5 Good 2 Fair
Consumers (C)			
C1: Lymphoedema Support Group	8 (3M, 5F)	5 Moderate 3 Occasional	3 Good 5 Fair
C2: Men's Carers	8 (8M)	2 Extensive 4 Moderate 2 Occasional	6 Good 2 Fair
Total	52	20 Extensive 17 Moderate 15 Occasional	16 Very Good 22 Good 13 Fair 1 Poor

1. Royal Australasian College of General Practitioners

Table 2: Who Should Evaluate Health-Related Quality of Life?: Summary Findings

Option	Description	Number
1	Elicit health state valuations from patients.	10
2	Elicit health state valuations from the public responding as hypothetical patients.	1
3	Elicit health state valuations from patients, then ask the public how much importance should be attached to adaptation.	11
4	Elicit health state valuations from a representative group (patients, members of the public, health professionals, carers, etc).	30