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Tessa Sanderson¹, Sarah Hewlett¹, Pam Richards², Marianne Morris¹ and Michael Calnan³

Abstract

The nominal group technique generates quantitative data through a process of experts ranking items of interest. This article focuses on the additional collection of qualitative data from nominal groups with rheumatoid arthritis (RA) patients, used to explore the influences on prioritizing treatment outcomes. Across all groups, the top five outcomes with the highest importance scores were identified as: pain; joint damage; fatigue; activities of daily living; and mobility. Qualitative findings showed that the personal impact of RA influenced decisions on how to rank specific outcomes through four domains: disease impact; adaptation to illness; external resources and stressors; and social expectations.

Keywords

chronic illness, methodology, outcomes, participation, qualitative methods

Introduction

Consensus techniques, such as the nominal group technique (NGT) or Delphi technique, are commonly used with health professionals for developing clinical practice and setting priorities (Jones and Hunter, 1995). The aim of consensus methods is to determine the degree to which experts agree about a particular issue (Jones and Hunter, 1995). The use of such methods is valuable where unanimity of opinion does not exist because of lack of scientific evidence or the complexity of the issue. The NGT and the Delphi technique use multiple rounds of ranking

to achieve consensus. However, the NGT is conducted through face-to-face meetings to facilitate discussion and consensus-forming,

¹University of the West of England, Bristol, UK

²University of Bristol, Bristol, UK

³University of Kent, Canterbury, UK

Corresponding author:

Tessa Sanderson, Academic Rheumatology, Bristol Royal Infirmary, Bristol, BS2 8HW, UK.

Email: Tessa2.Sanderson@uwe.ac.uk

whereas the Delphi technique traditionally uses repeated postal or on-line questionnaires with summaries of individual and group ranking from previous rounds. Their systematic and democratic process equalizes decision making among participants and allows individual opinions to be informed by the community of experts (Ginsburg et al., 1997).

These consensus techniques have also been used with patients as experts of living with the condition, both in mixed groups with health professionals and patient-only groups. In relation to priority setting, the NGT has been used with people with a range of physical and mental health conditions, including chest pain (Fleck et al., 2001), chronic pain (Dewar et al., 2003) and with intellectual disabilities (Tuffrey-Wijne et al., 2007) to determine care preferences and priorities. The Delphi technique has been used with people with conditions such as multiple sclerosis (O'Hara et al., 2000), and juvenile idiopathic arthritis (Shaw et al., 2004). It is widely recognized that patients can reliably and validly express views on many dimensions of care and outcomes, although they may not be able to evaluate all aspects of the technical side of their care (Hewlett et al., 2006). Patients have a 'personal experience of disease that is not available to most researchers, which complements researchers' analytical skills and scientific perspective' (Hewlett et al., 2006: 678). Policy states that patients should have more say in decisions affecting their care (Department of Health, 2000) and that patient perspective should be incorporated into clinical drug trials (Food and Drug Administration, 2009), although user involvement is often challenging (Craig, 2008).

RA is a chronic inflammatory autoimmune disease, mainly affecting the peripheral joints, causing swollen, painful joints, and characterized by fluctuating inflammatory activity (Arnett et al., 1988). It is two to three times more prevalent among women and peak incidence is between 30 and 50 years of age (Lawrence et al., 1989). There is evidence that the assessment and valuation of outcomes for treatment of RA differ between

health professionals and patients (Hewlett, 2003). Although measurement of disease activity in RA clinical trials has been standardized by the development of 'core sets' of variables constructed by professional experts in rheumatology (Felson et al., 1993), the use of patient-reported outcomes (PROs) is not standardized and outcomes known to be important to patients, such as fatigue and coping, are commonly not assessed (Kalyoncu et al., 2009). This nominal group study was part of a larger research agenda to develop a set of patient priority treatment outcomes for pharmacological interventions in RA (Sanderson et al., 2010a, 2010b). This article focuses on the qualitative findings, and reflects on the benefits and challenges of capturing qualitative data in nominal groups.

Methods

The NGT was used with patients diagnosed with RA according to American College of Rheumatology (ACR) criteria (Arnett et al., 1988), to rate the importance of and prioritize 63 outcomes generated by patients in a previous interview study (Sanderson et al., 2010a). Participants were identified from an outpatient rheumatology unit, from both the anti-TNF (Tumour Necrosis Factor) therapy database (medications used for severe disease and where other drugs have failed), and clinical notes. Participants were purposively sampled for self-reported disease activity (Disease Activity Score (DAS) patient opinion scale), disease duration, medication, gender, age and work status. Purposive sampling is appropriate for consensus techniques where experience and knowledge of an issue is paramount (Keeney et al., 2005). Single and mixed gender groups were trialled to see whether this would affect the treatment outcomes being prioritized. Two (of the five) groups were formed only of people with experience of anti-TNF therapy, while the remaining three groups were formed with people on other types of medications. A patient was part of the steering group to ensure user collaboration in the research design. In our research

unit, the term 'patient research partner' is used, reflecting that the person is both a patient, and a partner in the research process (Hewlett et al., 2006). Ethics approval was granted by a Multicentre Research Ethics Committee (MREC) (ref. 07/H1107/138), and consent was taken before participation.

In each group that was held, three rounds of the NGT took place to facilitate the prioritization process. These rounds are reported in detail to provide a replicable method.

Round 1: Individual rating of personal importance of outcomes

The treatment outcomes were generated by other RA patients in a previous interview study (Sanderson et al., 2010a), and used participants' own words. Each outcome was printed on a separate laminated card to aid ranking, with a set provided for each participant. Each set was shuffled to ensure that the results were not biased by a particular ordering. Participants were given a sorting sheet with the instruction: 'What results would YOU want from a drug treatment when your rheumatoid arthritis is bad?' and importance categories: 'Not important', 'Important' and 'Very important'. Participants, working individually, rated the personal importance of each outcome. The number of cards to be placed in each category was neither specified nor limited. In discussion with the patient partner, with whom this process was trialled, it was decided that a second stage of ranking was required because of the potential large number of very important outcomes. Therefore, the outcomes in the 'Very important' pile were then re-ranked into 'Very important' and 'Most important' piles, again working individually. Then, only the outcomes rated as 'Most important' were retained for Round 2.

Round 2: Group consensus forming

This round was recorded and transcribed verbatim. In each group, individuals reported one

'Most important' outcome at a time to the other participants and these were written by T.S. onto a group list, on a flipchart. After three or four circuits of the group, they were asked if there were additional outcomes that were extremely important that should be added. A group discussion was facilitated by T.S. to explore why patients had selected their priority outcomes. The face-to-face nature of the NGT was chosen to allow these experts to share experiences and opinions.

Round 3: Individual ranking of priority outcomes

Working individually, participants selected their top five most important treatment outcomes from the group list in Round 2 and ranked them in order of importance. Practically, participants wrote down the top five outcomes and then wrote a number (1–5) next to each outcome to signify its ranking. It was decided to rank the top five outcomes rather than the whole group list, since, in consultation with the patient partner, it was decided that ranking a greater number would become difficult and possibly arbitrary.

After five groups were conducted, it was decided that a sufficient diversity of participants had taken part and a large number of selected priority outcomes was evident across the groups overall. The groups lasted approximately 1.5 hours.

Analyses

From Round 3 data, scores (1–5) were summed for each outcome selected across all participants. A percentage of the maximum possible score was then calculated for each outcome ((score from Round 3 / 5 × number of participants) × 100). The qualitative data from Round 2 were analysed using a Grounded Theory coding paradigm (Strauss & Corbin, 1998) for factors influencing patients' prioritization of treatment outcomes. Coding levels 1, 2 and 3 were used to identify open codes, group them

Table 1. Profile of participants.

Study code	Gender	Age	Disease duration (yrs)	RA score (1–10) ^a	Currently in flare (self-reported)	Work status	Anti-TNF therapy
1A	F	77	23	8.5	N	N	Y
1C	F	46	31	5.0	N	N	Y
1E	F	53	12	4.0	N	N	Y
1F	F	62	12	7.5	Y	N	Y
1G	F	35	2	8.0	N	N	N
1H	F	67	12	8.0	Y	N	Y
2B	M	70	21	0.0	N	N	N
2C	M	46	19	4.0	N	Y	N
2E	M	47	2	5.0	Y	N	N
3A	F	61	12	4.5	N	Y	Y
3B	F	75	22	5.0	N	N	Y
3C	F	63	17	7.0	N	N	Y
3D	F	66	11	3.0	N	N	Y
3E	F	59	19	6.5	N	N	Y
3F	F	61	36	4.0	N	Y	Y
3G	F	59	7	4.0	N	N	Y
4C	F	65	10	3.0	Y	N	N
4E	F	62	9	1.0	N	N	N
4G	F	61	8	2.0	N	N	N
5A	F	56	9	10.0	Y	N	N
5B	F	61	2	6.0	Y	Y	N
5C	M	63	24	3.5	N	N	N
5D	F	54	12	2.0	N	N	N
5E	F	62	29	9.0	Y	N	N
5F	F	79	4	8.0	N	N	N
5G	M	29	10	6.0	Y	N	Y

Note: ^aPatient opinion of disease activity (10 = worst).

into axial codes and form categories through constant comparison. Data were managed using NVivo2 software. The patient partner (P.R.) reviewed the interpretation of data with T.S.

Results

Participants recruited

Five nominal groups with 26 RA patients were conducted (Table 1). Thirty-seven participants had agreed to take part, but 11 did not attend because of flares of inflammation (including two cases of hospitalization) and anticipated

fatigue from work commitments. However, a diversity of participant characteristics was still achieved. Next, the quantitative results are presented briefly to provide context for the main focus of the article: the qualitative findings.

Quantitative results

Thirty-two outcomes (out of 63) were selected in the top five most important outcomes across all participants, indicating the diversity of priorities for participants. The top five outcomes prioritized overall by the nominal groups were 'Less pain' (43.8% of possible maximum

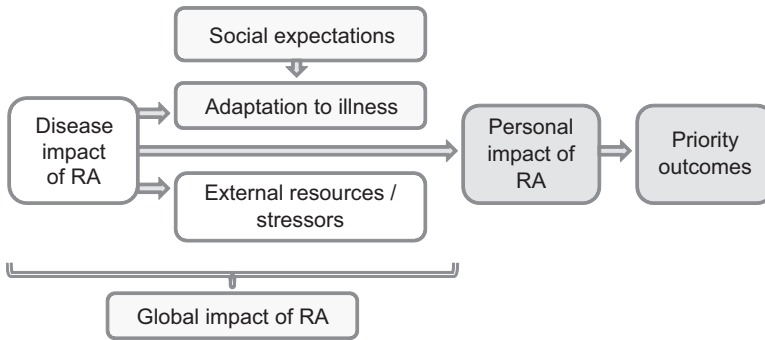


Figure 1. Factors influencing patient prioritization of treatment outcomes.

priority score for outcome), ‘No more joint damage’ (40.8%), ‘Less fatigue’ (16.2%), ‘Doing everyday things’ (14.6%) and ‘More mobility’ (13.1%). Because of the diversity of outcomes selected as most important in Round 3, a cut-off score for establishing consensus was not used and it was decided to conduct a multi-centre postal survey to make the final selection (Sanderson et al., 2010b).

Qualitative findings

The qualitative data provided insight into why specific outcomes were prioritized over others. Four major categories of influences on prioritization were identified: disease impact; adaptation to illness; external resources and stressors; and social expectations (Fig. 1). Together, these were encompassed by a fifth larger category: global impact. Each of these will now be described. Quotations have an identifier for the participant (digit identifies group) and the ranking of the relevant outcome from Round 3 where appropriate.

Global impact included the outcomes quality of life, normal life and feeling well. They were commonly prioritized in the top five because they encompassed a number of more specific treatment outcomes:

I chose it [quality of life] because it kind of covered everything. Things like less fatigue, less pain, being more able to work, being able to exercise. (5G: Quality of life = 2nd)

I think if you feel well you feel capable of dealing with everything, you’ve got more sort of stamina and a sense of getting on with things. (1F: Feel well = 1st)

However, it was clear that the meaning of these global outcomes differs from person to person and it was necessary to determine the specific outcomes encompassed by such terms.

Disease impact is a large category that included symptoms of RA, avoiding irreversible joint damage and functional impairment. The severity of RA symptoms was a key factor in the selection of priority outcomes. Pain was a dominant factor (and the first priority of the groups overall), but other symptoms such as fatigue and joint weakness were also described:

‘Less pain’ because I just think some of the other things I’ve put, like enjoying life and feeling well, actually come from that. (4E: Less pain = 2nd)

You’re too tired. I very rarely go [out]. It’s got to be something really special, and then I rest in the day because you can’t go out at night. (3C: Less fatigue = 2nd)

There was surprise from some participants that pain was ‘so far down on the list’ (4G) of priorities. Reasons given were that medication can control pain and that people can learn to live with pain. Thus other outcomes, which are perceived as uncontrollable, become more important:

The first thing I think of when I think of it [RA] is pain, and yet those other things are more important. It's just surprising, that's all. (4G: Less pain = 5th)

Once your drugs are working they can decrease the pain. (3D: Less pain = 4th)

You get used to living with pain. So long as I can get on and do other things despite the pain. (5D: Doing things I want = 3rd, Less pain not ranked)

Joint damage was ranked as the second priority by the groups overall. Partly, this was because participants perceived it as less treatable, and the cause of the other symptoms:

An awful lot of treatment that you have stops the pain, but it doesn't necessarily stop the damage to your joints. (1E: No more joint damage = 1st)

I might say 'no more joint damage' because I think everything else would flow from that. (5G: No more joint damage = 1st)

In addition, joint damage was prioritized because of the consequent functional disability, which could affect both everyday activities and valued activities, which give meaning and pleasure to people's lives:

I think it's the ultimate fear of losing [the use of] your hands. (1F: No more joint damage = 3rd)

I love housework and to not be able to do my housework would be the worst thing. (4G: No more joint damage = 1st, Doing everyday things = 2nd)

Similarly, independence and mobility were outcomes prioritized because of their contribution to increasing functional disability:

I get, not ashamed, but embarrassed, because I actually live in a sheltered scheme for elderly people, and I got in because of the disability. Some of the neighbours in the house, they're in

their 80s and they're fitter than I am. (5D: Maintain independence = 1st, in her 50s)

Problems I've seen starting in the feet and the feet affect everything, how you walk and everything. (3F: More mobility = 2nd)

Symptoms and impairment commonly affected participants' emotional well-being. Although mood-related outcomes, such as 'Better mood' and 'Less depressed' were not prioritized, the emotional influence on the choice of priority outcomes was clear:

I think you're sometimes excluded from certain things, I'm told to go sit down and not be part of what's going on and that's very frustrating. (3E: Doing everyday things = 1st)

There's times when there's things I wanna do and I can't, and I get quite irritable about that. (2B: Feel useful = 2nd)

A trade-off between different symptom- and impairment-related outcomes was commonly described in the process of prioritization. For example: 'I put here "avoid surgery", but "no more joint damage" covers that side, because if I don't have it I wouldn't need surgery, would I?' (4C: No more joint damage = 1st)

The *adaptation to illness* category of influences included patients' perceptions of both cognitive and behavioural strategies. There was recognition of the role of attitude in managing RA and this appears to have influenced the process of prioritization by decreasing the importance of specific manifestations of the condition:

If you can be in control a bit more you'd have better quality of life. (5E: Quality of life = 1st, Less pain = 5th)

I've had it [RA], like, since I was 25, so I've had it 35 years. ... I've always had to say to myself that I can do it, I can do it, no matter what. (3F: Normal life = 1st, Less pain = 5th)

Ability to self-manage symptoms was also an influence on prioritization of outcomes:

I chose that one next because I can't do anything about the weakness in my wrists, but I can take something for the pain. (4G: Weakness in wrists = 3rd, Less pain = 5th)

Trying to cope with a job is difficult. I couldn't cope with it any longer and had to retire. So I put that as not important. (3C: Able to work not ranked)

Sometimes there were indications that priorities had changed with increasing disease duration because of adaptation, knowledge about the condition or tolerance of symptoms or impairment:

Five years ago, not walking really did upset me ... I mean, why I wasn't walking ... and couldn't understand why I wasn't. But now, you see, it's 11 years. (4C: No more joint damage = 1st, More mobility = 5th)

When I first got ill, I didn't know much about the illness at all. ... It's just that over time I found ways to cope with it. (5G: No more joint damage = 1st, Coping not ranked)

Illness and treatment beliefs also played a part in how outcomes were prioritized:

Pain is more of a side-effect of the illness so it's more important to me to try and combat the illness. (5G: No more joint damage = 1st, Less pain = 4th)

There'd be no point really because if it's going to happen, it's going to happen anyway, isn't it? It's really having the drugs to stop it from happening. (1F: Feel well = 1st, No more joint damage = 3rd)

Therefore, adaptation to the condition overall and tolerance of symptoms appears to affect the ordering of priority outcomes. These factors may result in outcomes such as pain becoming less of a priority as disease duration increases.

During discussion in the groups, it was evident that *external resources and stressors* were important contextual factors in deciding priority outcomes. The presence or absence of social

support could have a large impact on how participants managed their condition:

Some of us are on their own and they probably find things a bit more difficult. Sometimes I like to try and do something myself, just perhaps getting a bottle top off, and I just have to give up. (1A)

If I get a bad day he [husband] really moans. I'm sure he would rather me go to bed than sit cosily in a chair and look miserable. (4C)

Participants' inability to work was a source of stress, and had implications for being able to afford alterations at home:

It might have stopped you going to work, your wage isn't coming in, or whatever. (5B)

When I was really bad, I still had to carry on with the mortgage payments. (2C)

If you've got all the gadgets to help you cope and you've had all the alterations, you can still be having it [RA], but you are coping quite well. (3E)

A couple of participants described the role of employers in supporting people with RA at work:

It [RA] does raise the point about awareness in the workplace, because most workplaces wouldn't recognize it [RA]. (5B)

My manager noticed it before me, because I couldn't get up the stairs very well and so he just came and tapped me on the shoulder one day. If I wanted anything picked up or run somewhere, he gave me a lad to do it. (4C)

The presence of co-morbidities is another issue that was not always considered by rheumatology health professionals, according to participants, and could be a source of further stress: 'There are these things, what some people call "complicating illnesses". There is a possible impact because of not seeing much in one eye. Will I be able to carry on working to the extent that I am?' (5D).

Overall, participants suggested that external resources and stressors may modify the influence of the direct impact of the RA and therefore the prioritization of treatment outcomes. For example, social support may alleviate the challenge of coping with severe symptoms and allow the prioritization of non-bodily outcomes, whereas stressors may make physically or psychologically managing symptoms more difficult.

Social expectations was another category that emerged in general conversation about important treatment outcomes. The perceived ability to fulfil social roles could also affect prioritization of outcomes:

I found it frustrating, you know, being young and then having children. You can't rough and tumble with the children ... That was very frustrating as a parent. (5C: Less frustrated = 2nd)

If I'm in a meeting, you know you talk with your hands and all of a sudden you have to go 'oooh' because you've hurt yourself, instantly you're turned from somebody who is in command of everything to somebody who's hurt. (2C: Able to work = 1st)

Participants appreciated that at different ages and stages of life people with RA would value different outcomes. For example, 5G, who was in his 20s, was concerned about the ability to work, whereas 5C was retired and no longer expected to work: 'I'm feeling sorry for myself, but you've got to think of the young ones, like [5G]. I had 24 years of good health, you know' (5C).

Where expectations about appropriate roles were disrupted, people's identities and social networks were negatively affected:

I'm not fanatical, but yes, I do like everything to be clean and tidy. But it's important, you know. You've become a little bit diminished as a person if you can't do those things. (4E)

I was told by the doctor to give it [work] up. You sort of lose friends and you lose the company. (3G)

Disruption of social expectations appeared to be mediated by the ability to cope and adapt to RA (Fig. 2). Where participants had accepted the impact of the RA in their lives or had positive role models for living with a long-term condition, social expectations appeared to have less influence: 'I was diagnosed 30 years ago and my father had it, so although I was young I'd seen him still carrying on with his garden and I thought "If he can cope with it, so can I"' (5E). It appears that social expectations may particularly influence the prioritization of work and domestic activity-related outcomes, but further research is required regarding the relationship between broad social influences and outcome prioritization.

Discussion

The qualitative data generated from the nominal groups with RA patients provide an insight into the influences on patients' prioritization of treatment outcomes, and the diversity in priorities between participants (the top priority, "Less pain", achieved 43.8 per cent of the maximum possible score). Although the severity of symptoms and impairments appeared to be the main factor determining prioritization of treatment outcomes, patients took into consideration the effect of self-management and adaptation, the resources available to them, stressors additional to the RA and broader social expectations. The data illustrate how it is the personal impact of RA that affects prioritization.

The personal impact of functional disability in RA has previously been recognized. For example, the Personal Impact Health Assessment Questionnaire (PI HAQ) measures the personal importance of specific activities of daily living as well as the level of disability in each activity in order to calculate a personal impact of disability (Hewlett et al., 2002). Carr et al. (2003) suggested that the relative importance of outcomes described in focus groups depended on the stage of disease and on specific situations, such as disease flare. This article reveals that adaptation, external resources and stressors, and social expectations also influence the

ranking of outcomes. This is important because studies have shown that response shift (a reconceptualization of health) may mask treatment efficacy in clinical trials and should therefore be measured alongside the traditional PROs such as pain and disability (Ahmed et al., 2004; Ring et al., 2005). The data also illustrate how the process of prioritization involved a complex series of judgements and comparisons by patients. Therefore, the patient-reported general health and global disease activity visual analogue scales that are commonly used in RA trials (Kalyoncu et al., 2009) may capture what is most important to patients at the time of completing the scale (e.g. pain), rather than assessing global variables.

The common prioritization of global outcomes such as quality of life, feeling well and normal life to encompass other important specific outcomes had not been anticipated. Despite being a logical decision by the participant, the global outcomes are often too general in a clinical or research setting to be useful in establishing treatment outcome priorities to be assessed. In collaboration with the patient partner, we decided to separate the outcomes identified as global by the nominal group participants for the presentation of the quantitative results and for the next phase of the research, a postal survey to make the final selection of priority outcomes (Sanderson et al., 2010b). Researchers considering the NGT should hesitate about the inclusion of global items in ranking exercises for this reason.

There were several benefits of using NGT with patients. First, personal views and priorities could be clarified, and atypical responses could be discussed by the group to enhance understanding of others' perspectives. Second, the patients' decision-making process was made transparent by recording the group discussion as qualitative data. Third, patients reported being empowered by expressing their priorities, and symptoms and experiences were validated. For example, RA patients report that fatigue is a common symptom of RA, but is often ignored by health professionals (Hewlett et al., 2005).

Forming a consensus in these groups that fatigue was a common priority reinforced their individual experience. Overall, the NGT was an effective and democratic method to use with patients and the majority of participants coped well with the large number of outcomes.

Collaboration with the patient partner was essential and improved both the practical facilitation of the groups and ranking methodology. Practical suggestions included supplying rubber grips to make sorting the laminated outcome cards easier for those with limited hand mobility, and holding the groups in the afternoon to allow morning joint stiffness to subside. Two stages of ranking in Round 1 were included after trialling the method with the patient partner, and this enabled patients to refine their priorities further.

The nominal groups enabled a preliminary prioritization of important treatment outcomes, which facilitated the subsequent postal survey where consensus was finalized. Where the NGT is the sole method for establishing consensus in a study, we recommended that a group list of five items (maximum) is constructed (Round 2) to avoid larger numbers of outcomes across all groups. In addition, it would be essential to determine a consensus level before the priority scores are calculated. In other NGT and Delphi studies, consensus levels have ranged from 51 per cent to 75 per cent (Endacott et al., 1999; Loughlin and Moore, 1979). Setting a consensus level is essentially an arbitrary decision, but would be aided by the inclusion of clinicians' and patient partners' opinions.

There were strengths and limitations specific to this study. Eleven participants dropped out at short notice, mainly due to a severe flare in their condition (although eight participants reporting flare did attend). This is to be expected during research with chronically ill people. Separating participants according to single or mixed gender groups appeared to have no effect on treatment outcome prioritization in the quantitative or qualitative data, but the numbers of men were small. However, having separate treatment groups was a strength and a condition of

participation by one patient because she perceived a risk of creating frustrations around access to the more expensive anti-TNF therapies and raising expectations about potential improvement. The qualitative data indicated that patients' priorities change over time, and future research could assess priorities longitudinally to capture changes in important treatment outcomes as they occur.

In conclusion, the nominal groups not only facilitated the systematic prioritization of over 60 treatment outcomes, but enabled the reasons for prioritization to be explored. The factors that influenced patients' ranking of treatment outcomes were: direct impact of RA; adaptation to illness; external resources and stressors; and social expectations. The diversity of individuals' top five priority outcomes appears to be due to variation of the personal impact of these influences on their lives. The NGT was an effective technique to use with patients and the collection of qualitative data provided valuable information for the extra resources required. User involvement in the design of the nominal groups facilitated data collection. The potential for increasing the use of nominal groups with patients as experts relies on the health care community valuing patients' experience and knowledge.

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Competing Interests

None declared.

References

- Ahmed S, Mayo N, Wood-Dauphinee S, Hanley J and Cohen S (2004) Response shift influenced estimates of change in health-related quality of life poststroke. *Journal of Clinical Epidemiology* 57(6): 561–570.
- Arnett FC, Edworthy SM, Bloch DA, McShane DJF and Cooper NS (1988) The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. *Arthritis & Rheumatism* 31(3): 315–324.
- Carr A, Hewlett S, Hughes R, et al. (2003) Rheumatology outcomes: The patient's perspective. *Journal of Rheumatology* 30(4): 880–883.
- Craig G (2008) Involving users in developing health services. *British Medical Journal* 336(7639): 286.
- Department of Health (2000) *The NHS Plan: A Plan for Investment. A Plan for Reform*. London: The Stationery Office.
- Dewar A, White M, Posade S and Dillon W (2003) Using nominal group technique to assess chronic pain, patients' perceived challenges and needs in a community health region. *Health Expectations* 6(1): 44–52.
- Endacott R, Clifford C and Tripp J (1999) Can the needs of the critically ill child be identified using scenarios? Experiences of a modified Delphi study. *Journal of Advanced Nursing* 30(3): 665–676.
- Felson DT, Anderson JJ and Boers M (1993) The American College of Rheumatology preliminary cores set of disease activity measures for rheumatoid arthritis clinical trials. *Arthritis & Rheumatism* 36(6): 729–740.
- Fleck E, Cumming P and Connolly L (2001) Using the nominal group technique to identify patient priorities for evaluating a service. *Journal of Clinical Excellence* 3(4): 205–208.
- Food and Drug Administration (2009) *Guidance for Industry: Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labelling Claims*, 18 December, UCM193282. Available at: <http://www.fda.gov/downloads/Drugs/GuidanceComplianceRegulatoryInformation/Guidances/UCM193282.pdf>.
- Ginsburg K, Menapace A and Slap G (1997) Factors affecting the decision to seek health care: The voice of adolescents. *Pediatrics* 100(6): 922–930.
- Hewlett S (2003) Patients and clinicians have different perspectives on outcomes in arthritis. *Journal of Rheumatology* 30(4): 877–879.
- Hewlett S, Cockshott Z, Byron M, et al. (2005) Patients' perceptions of fatigue in rheumatoid arthritis: Overwhelming, uncontrollable, ignored. *Arthritis & Rheumatism (Arthritis Care & Research)* 53(5): 697–702.
- Hewlett S, De Wit M, Richards P, et al. (2006) Patients and professionals as research partners: Challenges, practicalities, and benefits. *Arthritis & Rheumatism (Arthritis Care & Research)* 55(4): 676–680.

- Hewlett S, Smith AP and Kirwan JR (2002) Measuring the meaning of disability in rheumatoid arthritis: The personal impact health assessment questionnaire (PI HAQ). *Annals of the Rheumatic Diseases* 61(11): 986–993.
- Jones J and Hunter D (1995) Qualitative research: Consensus methods for medical and health services research. *British Medical Journal* 311(7001): 376–380.
- Kalyoncu U, Dougados M, Daures J and Gossec L (2009) Reporting of patient-reported outcomes in recent trials in rheumatoid arthritis: A systematic literature review. *Annals of the Rheumatic Diseases* 68(2): 183–190.
- Keeney S, Hasson F and McKenna H (2005) Consulting the oracle: Ten lessons from using the Delphi technique in nursing research. *Journal of Advanced Nursing* 53(2): 205–212.
- Lawrence RC, Hochberg MC, Kelsey JL, et al. (1989) Estimates of the prevalence of selected arthritic and musculoskeletal diseases in the United States. *Journal of Rheumatology* 16(4): 427–441.
- Loughlin K and Moore L (1979) Using Delphi to achieve congruent objectives and activities in a pediatrics department. *Journal of Medical Education* 54(2): 101–106.
- O'Hara L, De Souza LH and Ide L (2000) A Delphi study of self-care in a community population of people with multiple sclerosis. *Clinical Rehabilitation* 14(1): 62–71.
- Ring L, Hofer S, Heuston F, Harris D and O'Boyle C (2005) Response shift masks the treatment impact on patient reported outcomes (PROs): The example of individual quality of life in edentulous patients. *Health and Quality of Life Outcomes* 3: 55–62.
- Sanderson T, Morris M, Calnan M, Richards P and Hewlett S (2010a) What outcomes from pharmacological treatments are important to people with rheumatoid arthritis? Creating the basis of a patient core set. *Arthritis Care & Research* 62(5): 640–646.
- Sanderson T, Morris M, Calnan M, Richards P and Hewlett S (2010b) Patient perspective of measuring treatment efficacy: The rheumatoid arthritis patient priorities for pharmacological interventions (RAPP-PI) outcomes. *Arthritis Care & Research* 62(5): 647–656.
- Shaw KL, Southwood TR and McDonagh JE (2004) Developing a programme of transitional care for adolescents with juvenile idiopathic arthritis: Results of a postal survey. *Rheumatology* 43(2): 211–219.
- Strauss A and Corbin J (1998) Grounded Theory methodology: An overview. In: Denzin N and Lincoln Y (eds) *Strategies of Qualitative Inquiry*. London: SAGE, 158–183.
- Tuffrey-Wijne I, Bernal J, Butler G, Hollins S and Curfs L (2007) Using nominal group technique to investigate the views of people with intellectual disabilities on end-of-life care provision. *Journal of Advanced Nursing* 58(1): 80–89.