

Editorial

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Not-only-a-title

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In the course of eliciting feedback on possible titles for this new journal the comments revealed a fascinating range of views on the terminology commonly used and abused in the literature. We describe here some highlights of the exploration on the meaning and the implication of the words that led to the title chosen after much deliberation.

The working title used by the Editor, Marcello Tamburini, during the early planning stages of this journal was 'Quality of Life Outcomes'. When he issued invitations to join the Editorial Board, Clare Bradley replied that there was indeed scope for the kind of journal described and welcomed the initiative but expressed concern about the title as follows:

"I think the use of the term 'quality of life' in the title of the journal Quality of Life Research' has contributed to the confusion about the measures described within the journal. Health status measures are often referred to as quality of life measures when they are actually measuring quality of health not quality of life. There are very important differences between the two and when those differences are not recognised it can lead to erroneous conclusions. I attach a commentary that was published last year in The Lancet where I discuss these issues [1]."

"I hope you will understand why I would not want to have a journal called 'Quality of Life Outcomes' that then included papers on health status measures, patient satisfaction etc. Having said that, I think that health status and satisfaction measures are important too and I would like to see more outlets for publishing such material. Thus, rather than narrow down the content to fit the title of 'Quality of Life Outcomes', I would prefer to broaden the title to include all such measures. 'Patient Reported Outcomes' is becoming the new well-recognised phrase in this field and this might make a good title for a journal. What do you think?"

The Lancet commentary attached gave the example of the UK Prospective Diabetes Study [2] as one of many that has erroneously used a health status measure, in this case the EQ-5D (also known as the EuroQoL), as if it were a measure of quality of life. When no differences were found between EQ-5D scores of participants with Type 2 diabetes who were more intensively treated on insulin and scores of those treated less intensively with oral hypoglycaemic agents or diet alone, the UKPDS researchers concluded that the therapies were neutral in their effect on quality of life [3]. Clare Bradley pointed out that given the nature of the EQ-5D health status measure, in fact what had been shown was that the therapies had no differential effect on perceived health which is a very different matter. Perhaps surprisingly, more intensive treatment didn't make these patients feel any healthier. We don't know what it did to their quality of life because it wasn't measured. The problem of misinterpreting health status measures as if they were measuring quality of life continues and is not restricted to the EQ-5D. Speight has recently critiqued one of the many papers that wrongly describes the SF-36 as a measure of quality of life [4].

Marcello Tamburini circulated Clare Bradley's letter and attachment to 21 Editorial Board members when asking which of four possible titles they preferred and why. The four options offered were:

1. Quality of Life Outcomes
2. Health and Quality of Life Outcomes
3. Health-related Quality of Life Outcomes
4. Patient Reported Outcomes

Table 1: Background – PATIENT-REPORTED OUTCOMES 'PRO' SYMPOSIUM CONCEPTUAL AND METHODOLOGICAL ISSUES – International Society for Pharmacoeconomics and Outcomes Research

(<http://www.ispor.org> > Meetings > Past > Other Meetings onferences)

Data to evaluate the efficacy or effectiveness of treatment can come from a variety of sources, including laboratory tests, clinician evaluation, and the patients themselves. In the outcomes research community, the term "patient-reported outcomes (PRO)" is used to refer to a host of outcomes that can be provided only by the patient. Examples of these outcomes include symptom severity, perception of daily functioning, feelings of well being, global impressions of the impact of treatment on daily life, satisfaction with treatment, and health-related quality of life. The role that PROs can and should play in evaluating the efficacy of pharmaceuticals and medical devices and the means by which these outcomes are communicated to clinicians and consumers are subjects of much discussion and debate.

Over the past 2 years, representatives from ERIQA¹, ISOQOL², ISPOR³, and PhRMA HOC⁴ (now collectively called the Patient-Reported Outcomes (PRO) Harmonization Group) have been participating in discussions with the FDA about the use of health-related quality of life (HRQL) and, more recently, patient reported outcomes (PRO) in pharmaceutical research and communications. An overview of PRO Harmonization Group initiatives, meetings, presentations are at the PRO Harmonization Group website at <http://www.pro-harmonization-group.com>. This symposium will highlight activities of the PRO Harmonization Group, and provide an overview of discussions related to conceptual and methodological issues with specific examples.

1. European Regulatory Issues on Quality of Life Assessment (ERIQA) Group
2. International Society for Quality of Life Research (ISOQOL),
3. International Society for Pharmacoeconomics and Outcomes Research (ISPOR),
4. Health Outcomes Committee of PhRMA (PhRMA HOC).

The 16 immediate replies narrowed down the choice to options 2 and 4. A ballot was then taken among 63 experts in the field (most of them editorial board members of the new Journal). They were sent an extract from information presented as background to a symposium (May 19 2002) on Patient-Reported Outcomes to be held by the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) (Table 1). The results of the ballot were as follows:

Preferences and Number of Votes

- Missing 10
- No preference 2
- Preferred 'Health and Quality of Life Outcomes' 33
- Preferred 'Patient Reported Outcomes' 18

Reasons for preference were requested along with votes and those reasons are interesting (Table 2). It appeared to be accepted that 'patient reported outcomes' would cover the intended subject matter of the journal fairly well. However, there was one notable exception – we may not wish to restrict coverage to the reports of patients but may also wish to publish work that includes reports of family members and carers, and reports of people at risk of health problems who are not currently patients. However, as Deborah Lubeck pointed out 'Some quality of life studies still include instruments that are really physician completed symptom checklists that are not patient reported'. It would be an advantage to have a title that encouraged use of patient reports. Health and Quality of Life Outcomes had its own limitations concerning coverage. It

would cover health status, symptoms, and, perhaps, well being under the 'health' label as well as quality of life measures under their own banner, and these could include reports by non-patients as well as by patients. However, it seemed that certain outcomes were excluded, in particular measures of satisfaction, and this was not intended. Patient Reported Outcomes was a broader term in this respect and could include patient satisfaction. Dorothy Keininger suggested that Patient Reported Outcomes might embrace articles on utilisation and economic data and asked if the journal intended to publish such articles (it does) and she was not alone in raising this question. Thus there was concern that Patient Reported Outcomes might be too narrow in excluding non-patient community surveys, carer's reports and chart audits.

It was widely recognised that 'patient reported outcomes' was a new term and would be unfamiliar to many potential readers of this new journal. The novelty was greeted with caution by some and enthusiasm by others. There was concern that the term was 'somewhat obscure' although 'becoming better recognised' and that it was 'too cryptic' while Health and Quality of Life Outcomes was more 'self-explanatory and descriptive'. Dorothy Keininger suggested that patient reported outcomes may not be understood 'outside of the circle of researchers who follow ISPOR and the FDA' (Federal Drugs Administration). In contrast there was some suggestion that 'Maybe Patient Reported Outcomes will become the new buzz word that quality of life was...' (Anne Coscarelli), and that 'Here is a chance to be on the cutting edge of a new way of thinking about outcomes that puts the patient's view first' (Carol Buckhardt). Franco Toscani expressed a clear preference for Patient Reported Outcomes, commenting 'do you remember the term "palliative care"? When we started using

it, it looked a strange, unusual, peculiar term, and many colleagues suggested rather "continuing care". History always prizes the new and difficult, not the old and comfortable. If you need work and application for making Patient Reported Outcomes understandable, clear and accepted, well, this is part of the fun!' Catherine Acquadro was equally confident of her preference for Patient Reported Outcomes (PRO) Journal. 'As Clare tells so aptly, PRO has a broader scope, and will include HRQL (Health Related Quality of Life) as well as satisfaction with treatment, health status measures, global impression, well-being etc. Moreover the term PRO is widely accepted by regulators especially by the FDA'.

Marcello Tamburini declared himself to be 'lacerate' between the two titles, welcoming the familiarity of Health and Quality of Life and the word 'patient' in Patient Reported Outcomes. He observed that 'patient' occurs in the titles of only 17 of 4,600 biomedical journals included in Medline. A downside of Patient Reported Outcomes is that the term 'patient' has unfortunate and inappropriate connotations of passivity that Clare Bradley would rather

avoid although others have restricted their concern to the fact that a focus on patients excludes other groups of interest. The term does, however, have advantages over the old chestnut 'subjective outcomes', the reverse of which was the much-prized 'objective outcomes' (also known as 'hard outcomes') against which 'subjective outcomes' (or 'soft outcomes') came a poor second in the typical medical mind if not the psychological one.

Finally, as pointed out by John Ware in his response to the ballot, 'A noteworthy strength of 'Health and Quality of Life Outcomes' is that it recognises the crucial distinction between health and quality of life'. The majority of the Editorial Board members expressed a preference for Health and Quality of Life Outcomes. The outcomes referred to here are more specific than those encompassed by 'patient reported outcomes' and the title does not specify some outcomes that we may go on to include in the journal, such as patient satisfaction. This title has the advantage of familiarity but also makes the crucial distinction between two of the most important goals attainable – health and quality of life.

Table 2: Comments on the title of the new journal

Unfortunately, I have to say that I do not like any of the two titles. I do not like the first, because it is too much focused on qol, and you know that in respiratory medicine we prefer the term Health Status Assessment. I do not like the second, as it is too cryptic. However, considering the messages you forwarded to me, I agree that probably choosing PRO (or something similar and less cryptic) could probably represent a good strategy.

Mauro Carone, MD
"Salvatore Maugeri" Foundation
Institute for Care and Research
Division of Respiratory Disease
Veruno (NO), Italy

The title will depend to some extent on the type of papers you are looking for. One way of thinking about it is that 'health' provides the most narrow account, 'quality of life' a broader account, and 'patient reported outcomes' the broadest. I actually have a preference for the latter because it:

a. includes positive consequences of illness – something that is missed from the QOL literature

b. includes symptom reporting which is sometimes in and sometimes out of QOL reporting though often in health reporting.

However, I do not have strong feelings on this. There is a theoretical rationale which could be built up that goes beyond Clare Bradley's paper – the words reflect an underlying reality that may be important. But that is another story.

Patient reported outcomes is wider and may be more relevant to today's needs. For example, satisfaction with treatment is a patient reported outcome which can be important in the USA where HMOs are competing for patients. It doesn't matter to HMOs what patients' quality of life is, as long as they think they are getting good treatment.

Professor Michael E. Hyland
Department of Psychology
University of Plymouth, UK

The second title (Patient Reported Outcomes) is very trendy, mostly in USA where the acronym PRO is very common. I agree with you that the inclusion of the word "patient" is certainly an advancement in respect to the old concepts (and words). In addition, it may enable us to enlarge the concepts from health-related to non health-related measures, as in the field of PRO measures we are supposed to include also "out of skin measures". Do we want that? Another cons may be the fact that very soon we ought move from "patients" to "consumers" or "citizens" as preferential point-of-view, thus making non-politically correct and obsolete the title...

On the other hand, I am not fully satisfied with the first Title "Health and Quality of Life Outcomes", but to be honest with you and with the other authoritative members of the Editorial Board(s), I was not able to come out with an alternative.

Giovanni Apolone, MD
Istituto Mario Negri, Milan, Italy

I think "Patient Reported Outcomes" is much stronger, and am surprised that no one has taken it yet. I think it allows for some evolution in how we think about subjective report, epidemiology and clinical trials.

Charles S. Cleeland, Ph.D.
Chair, Pain Research Group, The University of Texas

Table 2: Comments on the title of the new journal (Continued)

M.D. Anderson Cancer Center, Houston, TX, USA

A strength of both titles is that they include "Outcomes," although I am often asked what are outcomes and outcomes of what? Patient reported outcomes has the advantage of being broader than health and opening the possibility of patient satisfaction and other outcomes. A disadvantage of "patient reported outcomes" is that there is great interest, at least in the US, in "consumers" regardless of whether or not they are "patients" in the traditional sense. Another disadvantage of PRO is that "reported" implies a distinction from "evaluated," which are sometimes intended to convey more objective and more subjective, respectively. That is one reason some of us use "assessed" to include both. For me, "patient reported" is much too specific to a particular methodology to be the title of a journal.

A noteworthy strength of "Health and Quality of Life Outcomes" is that it recognizes the crucial distinction between health and QOL and, again, it has the word "Outcomes." I believe that QOL in the broadest sense will become increasingly important in health care and as the field moves more and more in the QOL direction as it focuses on the entire economy and not just the health care segment. Hence, I like seeing it in the title, although the journal would have a major task in defining it and setting a good example with regard to the proper use of the term.

We already have "Quality of Life Research." What would be different in this new "QOL" journal? Will the new journal be more applications oriented? The answer may have implications for the title.

John E. Ware, Jr., PhD
President and C.E.O.
Quality Metric, Inc, Lincoln, RI, USA

I prefer the title, "Health and QOL Outcomes." This is familiar to most people and allows the journal to focus on areas related to QOL (both from the patients' and caregivers' perspectives) as well as other health outcomes.

Michael A. Weitzner, MD
Chief of Palliative Care
Associate Professor of Oncology and Psychiatry
Psychosocial and Palliative Care Program
H. Lee Moffitt Cancer Center, Tampa, FL, USA

I wonder whether you have considered "Patient Health and Quality of Life Outcomes" as a title?

1. It may be a bit long BUT
2. It address your feelings about "patients";
3. It includes "health outcomes" [i.e., health status, patient satisfaction, and others];
4. It includes "quality of life" which a number of respondents felt was appropriate and necessary;
5. While "patient reported outcomes" may be becoming better recognised, in addition to being considered relevant from a policy point of view, the term is also probably somewhat obscure to many potential readers, subscribers, and even authors.

If adding "patient" to "Health and Quality of Life Outcomes" makes the title too long, my preference would be for "Health and Quality of Life Outcomes" because I think it is both more self-explanatory and descriptive than "Patient Reported Outcomes" and it broadens the title focus to include many different kinds of measures.

Neil B. Oldridge, PhD
Indiana University Center for Aging Research
School of Allied Health Sciences
Regenstrief Institute for Health Care
Indianapolis, IN, USA

Both are OK I would say. I tend toward the first a little because I think the outcomes we will be measuring include the family and informal caregivers. Hence PATIENT reported outcomes might not accurately portray the real focus. On the other hand aren't there already some journals that include Quality of Life in their titles? So then how to differentiate this one from the others?

I have tried to come up with something else. Customer (or Consumer) Reported Outcomes may more accurately portray what you are doing, but the title is not appealing. I admit being terrible at titles.

David H. Gustafson, Ph.D.
Robert Ratner Professor
Industrial Engineering & Preventive Medicine
University of Wisconsin-Madison, WI, USA

I prefer either 4 or 2.

The reason I like 4 is that I think the focus should be on patient reported outcomes and that allows a little more breadth. Some quality of life studies still include instruments that are really physician completed symptom checklists, that are not patient reported.

However, if you wish quality of life in the title, then I think the health and quality of life does still allow more breadth and deals with some of the concerns addressed in the attachment you forwarded. I do think that many patient based outcome studies do focus more on health status, but that does not limit their value to our community of researchers.

I am inclined to agree that I is going to be more familiar to potential readers. I also think it is broad enough to encompass patient reported outcomes. I vote for #1!

Deborah P. Lubeck, PhD
Adjunct Professor, Department of Urology
Director Urology Outcomes Research Group

Table 2: Comments on the title of the new journal (Continued)

I also liked seeing the word "patient," but I would go with the other title (#1) because it is more accurate. QL studies typically have a clinical status parameter; it seems essential.	<p>UCSF Comprehensive Cancer Center University of California San Francisco</p> <p>Barrie Cassileth, Ph.D. Director Integrative Medicine Service Memorial Sloan-Kettering Cancer Center New York, USA</p>
I believe that this is a difficult decision for you – Health and Quality of life Outcomes is a clear and obvious title for the journal but increasingly the cognoscenti talk of patient reported outcomes. Trouble is – will clinicians who have only just come to terms with QoL understand that patient reported outcomes is essentially the same thing? Another problem is that of sounding different from the Quality of Life Research Journal. I guess on balance I'd go with Health and Quality of Life Outcomes.	<p>Lesley Fallowfield, PhD Director, Cancer Research Campaign Psychosocial Oncology Group School of Biological Sciences, University of Sussex, Brighton, UK</p>
I think the problem with the title 'Health and Quality of Life Outcomes' is that it doesn't cover all the ground that we might want. For example, patient satisfaction and psychological well-being measures are not strictly speaking quality of life measures and nor are they health measures either. These would be included in 'Patient Reported Outcomes'. It is true that Patient Reported Outcomes would seem to exclude quality of life of carers but with this one exception it includes most of the issues I would want to include and gets away from the confusion that has become attached to the term 'Quality of Life'. I would be glad to exclude proxy rating measures from the Journal and would not see it as a disadvantage to exclude these. Thus, of these two titles, I would favour Patient Reported Outcomes and I was encouraged to see that there was so much support for this.	<p>Clare Bradley, PhD Professor of Health Psychology Royal Holloway, University of London Egham, Surrey, UK</p>
My preference for the journal title would be "Health and Quality of Life Outcomes". My concern with "Patient Reported Outcomes" is that it may be too narrow in scope, for two reasons. First, as one of the board members pointed out, papers might be published that include clinician-reported measures, chart audit data, and so forth. Second, health status measures are used to survey people who might not be considered "patients" in a traditional sense (e.g., general community surveys, studies of people exposed to environment toxins, etc.). Thus, I prefer what I would consider to be a broader title.	<p>Barbara Gandek Health Assessment Lab Boston, Massachusetts, USA</p>
I prefer the Health and Quality of Life Outcomes over patient reported outcomes. I don't believe that patient reported outcomes will be understood outside of the circle researchers who follow ISPOR and the FDA. It does not seem to be a term accepted in Europe and I believe it is a very broad term which may include many patient reported outcomes which will not be covered in your journal. (I could be wrong – are you also going to publish articles on utilization and economic data?)	<p>Dorothy L Keininger, MS, BS Pharm Mapi Values, Boston, MA, USA</p>
I prefer "Health and Quality of Life Outcomes" for two reasons: a) It joins the concept of health with the concept of quality of life, giving the possibility of new developments; b) it is very important that "quality of life" is in the title of the journal. Quality of life is both a technical concept (measurement, symptoms and so on) and a philosophical one. That is a noble "double sense", that, in my opinion, should be preserved.	<p>Amedeo Santosuosso Judge, Court of Milan, Italy</p>
"Patient Reported Outcomes" will appeal to the FDA-attention seekers, if that's what they want. The term has a funny little story behind it, but it's actually a good one that covers more than QoL (satisfaction, preference, etc). Either choice is a good one. remember that after you finally make it. I can make a case either way, but in the end my sense is that those who articulated their reasons for the title: "Health and Quality of Life Outcomes" were more persuasive (especially Ruth McCorkle). In the end, I think the term "patient reported outcomes" will feel more limiting than it feels today, as it is still new. "Health and Quality of Life Outcomes" is a more-established title that has obvious meaning and recognition to many.	<p>David Cella, Ph.D. Professor, Psychiatry and Behavioral Science; Research Professor, Inst. for Health Services Research and Policy Studies, Northwestern University Director, Center on Outcomes, Research and Education,</p>

Table 2: Comments on the title of the new journal (Continued)

<p>My preference is Health and Quality of Life Outcomes, for 3 reasons: (1) "patient" is a limiting word – there are many health issues which concern people who are not patients; (2) you may not wish to limit the journal to only patient reported outcomes; (3) not everyone will readily understand the meaning of the term "patient reported outcomes," but you will have no such problem with "health and quality of life outcomes."</p>	<p>Evanston Northwestern Healthcare Evanston, IL, USA</p> <p>Carol Estwing Ferrans, PhD, RN, FAAN University of Illinois at Chicago College of Nursing 845 S. Damen Avenue Chicago, IL, USA</p>
<p>I think the problem of terminology has only partial solutions. Among the two I would prefer Health and Quality of Life Outcomes because it is quite clear what is the field. I agree that Quality of Life Outcome is incomplete and I would have doubts about the use of the term Patient reported outcomes, because I don't like the term patient (Greek and Latin etymologies have been lost completely to allow us to use this word, although common, without the risk of stigmatizing, offending etc.).</p>	<p>Luigi Grassi, MD Director Unit of Psycho-Oncology Azienda Ospedaliera Universitaria di Ferrara Arcispedale S. Anna, Ferrara, Italy</p>
<p>I have read all of these materials and I think the debate is interesting. Naming something is a very important decision and will not only remain for a long time, but define it. Although, I can tell you I have done a lot of name changing in my life. That being said, this is an interesting issue because not only do you want it to be accurate, but you want it to have an appeal. I understand the theory behind Patient Reported Outcomes and like that as a body of work to be contained in the journal, however, I personally don't find the name as appealing as the concept. My first impression is #2. To be honest, I can't think of a better name than the ones you have listed. Now one last thought. Maybe "Patient Reported Outcomes" will become the new buzz word that quality of life was... I'm not sure how that will go. This is where it helps to be forward thinking. My question about "Patient Reported Outcomes" is this, "Will your audience recognize and respond to it, now and in the future?"</p>	<p>Anne Coscarelli, Ph.D. Director, Ted Mann Family Resource Center Jonsson Comprehensive Cancer Center, UCLA, Los Angeles, California, USA</p>
<p>My own vote is for Patient Reported Outcomes. Although it seems a little out of the ordinary, that is one of the reasons I support it. Here is a chance to be on the cutting edge of a new way of thinking about outcomes that puts the patient's view first.</p>	<p>Research Psychologist UCLA School of Public Health</p> <p>Carol Burckhardt, PhD Professor of Nursing Asst. Professor of Medicine (Research) Oregon Health Sciences University Portland, OR, USA</p>
<p>I prefer Patient Reported Outcomes Journal because seems to me more appropriate to describe the large interests of the issues related with the subjective evaluation made by patients. In the future probably patients will be substitute with consumers. My preference would be #2 since it covers both health outcomes (non qol) and qol outcomes.</p>	<p>Paola Mosconi, Istituto Mario Negri, Milan, Italy</p>
<p>A. Consider for the title of the publication something like:</p> <ol style="list-style-type: none"> 1. Health and Quality of Life Outcomes 2. Health-Related Quality of Life Outcomes <p>[Justification: You might want more of an emphasis on health as the focus of the journal as opposed to other indicators of QOL e.g., social, economic, environmental, etc. Not that those aren't equally important, but perhaps just not the focus of your journal.]</p> <p>Clare Bradley raises important points about the fine distinction between health status measures and quality of life measures. I also understand your dilemma in terms of the title. I believe that Patient Reported Outcomes, although perhaps timely, is more suggestive of a clinical orientation that includes measuring the effects of medical interventions on health. If the intent of the journal is to provide a forum for exactly that, then PRO is probably appropriate. I'm not sure, however, that a section on population health assessment would necessarily be appropriate for a publication that focuses on patient-reported outcomes. Nonetheless, if the focus will be on clinical care outcomes, then the focus on PRO is probably both timely and appropriate. If, on the other hand, you want to broaden the scope beyond patients (i.e., the general population), something other than Patient Reported Outcomes would probably be better. I believe it comes down to what you foresee as the focus of the journal – will it be a forum for the clinical community, a forum for public health researchers and social scientists; or for both. If the first, PRO as a title would probably work; if the second or third, better yet, Health & QOL Outcomes.</p>	<p>Rosemarie Kobau, MPH</p>

Table 2: Comments on the title of the new journal (Continued)

<p>Absolutely the second: do you remember the term "palliative care"? When we start using, it looked as a strange, unusual, peculiar term, and many colleagues suggested rather "continuing care". History prizes always the new and difficult, not the old and comfortable. If you need work and application for making "Patient Reported Outcomes" understandable, clear and accepted, well, this is part of the fun! And a good excuse for writing everybody an explanation, and getting in touch with them!</p>	<p>Public Health Analyst CDC, NCCDPHP, DACH</p>
<p>1. Quality of Life Outcomes: <i>I prefer this because it is brief and to the point! I believe it can be inclusive of not only overall quality of life but also elements of quality of life such as health and functioning as well as symptom relief and psychological and spiritual well-being.</i> 2. Health and Quality of Life Outcomes: <i>I don't like this one as much although it is acceptable.</i> 3. Health-Related Quality of Life Outcomes: <i>This is technically correct, but seems long</i> 4. Patient Reported Outcomes: <i>I don't like this; it is too non-specific; what kinds of outcomes??</i></p>	<p>Franco Toscani, MD Director, Istituto di Ricerca in Medicina Palliativa "Lino Maestroni", Cremona, Italy</p>
<p>I agree with Dr. Bradley's concern, the journal's focus should not be limited to QoL measures. However, her title suggestion (Patient Reported Outcomes) may be too cryptic. I prefer title 2, "Health and Quality of Life Outcomes". This title encompasses a variety of health measures and is more descriptive than the others. I would also use change "Outcomes" to "Measurement" (Health and Quality of Life Measurement), but both are appropriate. My vote goes to #1, "Health and Quality of Life Outcomes".</p>	<p>Susan C McMillan, PhD, RN, FAAN Professor of Oncology Nursing University of South Florida, USA</p>
<p>I have read this letter and article with interest and fear that it has further convinced me of my ignorance in this field. I was unaware of these various distinctions, but having had them laid out so clearly they make sense. I do worry that the term 'Patient reported outcomes' is as yet a very specialised term which would not get picked up by interested non-specialist readers. For this reason I think I prefer 2. Health and Quality of Life Outcomes. However, I do not have a great deal of confidence in my view and will be interested to hear what those with a more specialised knowledge/interest feel. Having read the various responses I think I still prefer Health and Quality of Life Outcomes because of its familiarity. If one were to go for Patient Reported Outcomes you completely lose the word 'quality' which seems a shame. However, the reasons given for the second choice are persuasive, and the people arguing for it are far more expert in the field than I am. I can only speak from an ethics perspective and having tried the term out on a few colleagues none of them were familiar with it. I wish you luck in this difficult decision, and don't worry about asking me it is very important to get it right. One possibility might be Health and Quality of Life: The Journal of Patient Reported Outcomes but I presume that is too long...</p>	<p>Tom Fitzgerald Department of Medical Education University of Michigan Medical School Ann Arbor, MI, USA</p>
<p>I read Clare's comments below and I agree with them if the intent is to be broad. If the journal's intent is to published just health-related quality of life articles, then that should be reflected in the title. However, patient reported outcomes can be so broad that articles on the Beck Depression Inventory, satisfaction measures, and just about any self-report measure can be included. Is that your intent? If not, then the title should reflect what the journal wants to publish. Quality of Life can include, as you know, measurement and the like on whether your neighbourhood is safe, the quality of the schools, etc. I suspect that what the journal is interested in is health-related quality of life. If so, then the titles "Health-related quality of life outcomes" and Health and quality of life" are closer to the journal's intent.</p>	<p>Calliope (Bobbie) Farsides, B.Sc Ph.D. King's College London, England, United Kingdom</p>
<p>Clare's right and the title, from her point of view, is the most correct (obviously, you should insert also some experts in Pharmacoeconomics in the Editorial Board since such a journal could publish also cost-utility analysis or studies about utility assessment). If, on the contrary, you want to remain exactly in the field of quality of life, of its evaluation and of its outcomes "Quality of life assessment and outcomes" could be the title.</p>	<p>James W. Varni, Ph.D. Professor of Psychiatry, University of California, San Diego School of Medicine Senior Scientist, Center for Child Health Outcomes Children's Hospital and Health Center, San Diego, CA, USA</p>
<p>Clare's right and the title, from her point of view, is the most correct (obviously, you should insert also some experts in Pharmacoeconomics in the Editorial Board since such a journal could publish also cost-utility analysis or studies about utility assessment). If, on the contrary, you want to remain exactly in the field of quality of life, of its evaluation and of its outcomes "Quality of life assessment and outcomes" could be the title.</p>	<p>Fausto Roila, MD Medical Oncology, Ospedale Policlinico, Perugia, Italy</p>

Table 2: Comments on the title of the new journal (Continued)

I would strongly support the following title: Patient-Reported Outcomes (PRO) Journal. As Clare tells it so aptly, PRO has a broader scope, and will include HRQL as well as satisfaction with treatment, health status measures, global impression, well-being, etc. Moreover the term PRO is widely accepted by regulators especially by the FDA. The Institute, ERIQA, PhRMA HOC, ISPOR and ISOQOL have been at the origin of this term with the efforts of the PRO Harmonization Group (see at <http://www.pro-harmonization-group.com>). It is a new trend that we have to take into consideration.

Catherine Acquadro, M.D.
Scientific Director
MAPI Research Institute
Lyon, France

I think the new title should be Patient Reported Outcomes. I was a bit uncertain between Patient Reported Outcomes and Health-Related Quality of Life Outcomes (which would be too long) as the latter contains the magic phrase "quality of life" but I recognise it was misused and was probably the cause of the debate on the contents of quality of life. I've only a doubt: is Patient Reported Outcomes a so well recognised phrase? Surely it is not as HRQL is, but if we think it will be in next years time is ripe for the turning!

Cinzia Brunelli
Statistician, Unit of Psychology
Istituto Nazionale Tumori, Milan, Italy

Health and Quality of Life Outcomes seems to encompass the most issues. Further to the chosen title for the Journal "Health and Quality of Life Outcomes", I would like to add "Patient Reported Outcomes" is a narrow title as it addresses only one element of Health of an individual and an element of Quality of Life Outcome as perceived by an individual. While we consider the patient or the client as an equal participant and not a passive recipient of restitution and adaptive recovery, the title "Patient Reported Outcomes" would yield little as the participation and agreement in outcomes is implicit. The word that is now used is "covenant" or an agreement or participatory commitment, responsibility and obligation to support the outcome. Therapists have always emphasized partnership between the patient/client with emphasis on active participation, active involvement, and control over design of treatment plan and in their own recovery. There is enough published that talk about "patients' stories", "about their concerns", and "home care concept" have addressed restoration of meaningfulness in living, nature and meaning of interactions of professionals. Thus "Patient Reported or Oriented Outcomes" would seem to show that all of a sudden in 2003, we have become aware of "Patient Reported Outcomes" as vital to our work while as a matter of fact this has been implicit in our work. The title "Health and Quality of Life Outcomes" encompasses all these and much more and befits our intentions and the holism much more comprehensively.

Surya Shah, BAppSc, MEd, PhD, OTR
College of Allied Health Sciences
University of Tennessee, Memphis, USA

My preference go to: "Patient Reported Outcomes".

Michele Tomamichel, MD
Director, Psychiatric and Medical Psychology Service
Savosa, Switzerland

I prefer the second title [Patient Reported Outcomes], if possible with initially a subtitle to understand better the field.

Franco De Conno, MD, FRCP
Director Rehabilitation and Palliative Care
Istituto Nazionale Dei Tumori, Milan, Italy

I. Health and Quality of Life Outcomes

Charles S. Carver, Ph.D.
Department of Psychology
University of Miami, Florida, USA

Between two possible titles I prefer the first "Health and Quality of Life Outcomes", but I prefer more another, "Health and Quality of Life". It is very simple and understandable to all.

Franca Porciani, MD
Corriere della Sera,
Corriere Salute, Milano, Italy

I agree that the first choice seems better to me.

Jerome Yesavage, M.D.
Dpt of Psychiatry and Behavioral Sciences
Stanford University Medical Center, USA

I would lean toward Health and Quality of Life Outcomes.

Robert M. Kaplan, Ph.D.
Professor and Chair

Table 2: Comments on the title of the new journal (Continued)

	Department of Community Medicine University of California, San Diego, USA
I have already told you my preference about the title: "Health and Quality of Life Outcomes" and I have already told you my reasons, perhaps too concise. To come back to Clare's comments, I have some observations to make. I don't agree with Clare when she says that "Health Status measures being referred to as quality of life measures when they actually measure quality of health not quality of life..." because I think that health is part of our life. The concept of quality of life includes many aspects of the person's life (wellbeing, illness, values, expectations, relationships...). So I don't agree when she says that "... thus rather than narrow down the content to FIT the title of". I don't think it to be necessary to change names in order to advance in knowledge ("...old concept of "subjective outcome.."), on the contrary it would be important to have a bigger vision of the patient and examining him thoroughly in a global way.	Laura Gangeri, Ph.D Unit of Psychology Istituto Nazionale Tumori, Milan, Italy
According to your great experience in quality of life field, focus the journal on QoL outcomes, and specify it in the title, may openly direct the scientists toward a more patient-oriented research. For this reason I prefer the title: "Health and Quality of Life Outcomes". In this way, the content and the <i>mission</i> of your new journal are better represented.	Claudia Borreani, PhD Unit of Psychology Istituto Nazionale Tumori, Milan, Italy
I would favour the more traditional Health and quality of life outcomes	Augusto Caraceni, MD Rehabilitation and Palliative Care Istituto Nazionale Tumori, Milan, Italy
I like both titles. I also would favor including the term health status such as 'health status, QOL and Patient-reported outcomes'. Yet, such a title is fairly burdensome. What about Patient-reported Outcomes Research? That would be my favorite choice. It captures the patient as the source of data for outcomes research (a critical feature of this kind of research and quite commensurate with the United States' Institute of Medicine's recommendations for reorienting American Healthcare in the next century to focus on the patient as the core of how care is delivered and evaluated) and is broad enough to include a range of outcomes including satisfaction, economics (particularly indirect costs – something that is essentially unstudied and unreported) as well as the more familiar concepts of health status and quality of life.	John Spertus, MD MPH FACC Director of Cardiovascular Education Mid America Heart Institute Assistant Professor of Medicine University of Missouri, Kansas City, MO, USA
I think that Patient Reported Outcomes could be the best title, but the journal would need a clear explanation of the rationale. If you choose this title, the first think to ask the contributors could be to define well in the methods section which kind of PRO they are reporting in their article.	Massimo Costantini, MD Unit of Clinical Epidemiology and Trials National Cancer Institute, Genoa, Italy
I very much prefer Nr. 1 [Health and Quality of Life Outcomes], since it is brief, familiar to most people and much more "eye-catching" than Nr. 2. Both are appropriate, but Nr. 1 is actually NAMING two very important issues. I am looking forward to the new journal.	Ulrike Ravens-Sieberer, Ph.D., M.P.H. Head Research Unit Child and Adolescent Health Robert Koch Institute, Berlin, Germany
I strongly support the title "Patient Reported Outcomes" because has a broader scope and covers all the topics of interest (preferences, satisfaction other than QoL).	Giuseppe Recchia, MD Medical Director, GSK, Verona, Italy
The attached paper made some interesting points, but I don't particularly like patient reported outcomes, because it emphasizes the patient and includes subjective but not necessarily objective measures, including chart audits, proxy reports, etc. Given the comments thus far, I prefer Health and Quality of Life Outcomes. I think it would be broad enough and can include the patient and family.	Ruth McCorkle, R.N., Ph.D., F.A.A.N.

Table 2: Comments on the title of the new journal (Continued)

Director of the Center for Excellence in Chronic Illness Care
School of Nursing, Yale University, New Haven, Ct, USA

Having read your e-mail regarding the name of the new journal, I agree with Clare Bradley. I think the choice of the name should be either option 3 (Health-Related Quality of Life Outcomes) or 4 (Patient Reported Outcomes), depending on how focused you want the journal to be. My understanding of the two terms is that Health-Related Quality of Life is actually a part of Patient Reported Outcomes, the latter also including data on patient preferences and satisfaction. However, of utmost importance is the distinction between Health-Related Quality of Life and Quality of Life, which could easily be misinterpreted. Although well understood in the field, we should pull our socks up, so to speak, to ensure that the terminology we utilise reflects what is meant as accurately as possible.

Patient Reported Outcomes would be my choice. I understand that for those unfamiliar with the term, this may seem a little vague but it is receiving greater credence in the HRQoL field and wider. In view of the fact that in naming the journal we should take future considerations into account, I think this only supports the argument for "Patient Reported Outcomes" further. This title will also allow the focus of the journal to tackle issues such as patient preference and satisfaction and others patients' related outcomes. As I stated, I believe it is important for us in the field to make a concerted effort to differentiate between HRQoL and QoL. Therefore, I feel that the other option "Health and Quality of Life" does not go far enough in this endeavor.

Xavier Badia, Ph.D.
Director Health Outcomes Research Europe
Barcelona. Spain

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