



# QoLMARI

## Newsletter

December 2016

### A Word from the Chairperson

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Dear reader,

Many developments took place since the first newsletter of QOLMARI. We had a most successful seminar at the Universitas Padjadjaran (UNPAD) at September 8 and 9. Many national and international authorities were present and gave lectures on the measurement and application of quality of life, for instance in the area of the new National Health Insurance System and the monitoring of people in poor or ill circumstances. Representatives from the Indonesian Ministry of Health and from the WHO were present and showed their interest in a new measurement tool for Indonesia, the EQ-5D-5L. You can read more about these developments in this newsletter.

The QOLMARI found a basis of her activities in UNPAD, in particular in the Faculty of Psychology, thanks to the willingness of its rector Prof. Dr. Tri Hanggono Ahmad and the dean Dr. Hendriati Agustiani.

We welcome several new members. And last but not least: we have now our own website ([www.qolmari.org](http://www.qolmari.org)) enabling us to distribute this newsletter digitally.

For the coming year 2017, important news can be expected. The norm data for the EQ-5D-5L will be available, showing the ratings the Indonesian people give to their different health states. Population-wide information on their quality of life (QoL) is to be expected too. And several applications of QoL in poor people and patient groups will be made public in scientific and policy domains. Of course, we intend to organize a 2nd seminar to inform our group about these results and its consequences for the society in more detail.

With these accomplishments of the QOLMARI and intentions for 2017, I wish you:

*Selamat Tahun Baru 2017*

Prof Jan Passchier  
Chair of QOLMARI

## Symposium A Big Step Forwards for Health Policy in Indonesia: The Introduction of The EuroQol EQ-5D-5L Value Set and Other Recent Developments in Quality of Life Research and Cost-Effectiveness Analysis *Universitas Padjadjaran, 8-9 September 2016*

On 8-9 September 2016, QOLMARI in collaboration with EuroQol Research Foundation and Faculty of Psychology Universitas Padjadjaran organized a symposium titled 'A Big Step Forwards for Health Policy in Indonesia: The Introduction of The EuroQol EQ-5D-5L Value Set and Other Recent Developments in Quality of Life Research and Cost-Effectiveness Analysis.' This symposium started with the opening speech by Prof. Dr. med. Tri Hanggono Achmad, dr., Rector of Universitas Padjadjaran. The symposium was held in two subsequent sessions:

First, a session for policy makers conducted in the morning of the first day attended only by the officers of various governmental bodies, especially health-related. In this first part, the speakers focused on health-related quality of life (HRQOL) measurement and its value for health in Indonesia, the current HTA-related policies in Indonesia and the role of economic evaluation in health care decision making. The final presentation followed by a discussion was the introduction of Indonesian EQ-5D-5L value set.



*Rector of UNPAD welcoming the participants*



*The speakers during panel discussion*



*Group picture*

Second, a session for all participants started in the afternoon of the first day until the second day. Researchers from prominent Indonesian (and from other countries) universities and clinicians from Indonesian academic hospitals involved in (health-related) quality of life joined the policy makers. Most of the researchers were from medicine, psychology, pharmacy, and health economics faculties. The first presentation was about the new Indonesian universal health care (Jaminan Kesehatan Nasional/JKN), that started in 2014, and how HRQOL and health economics can help the Indonesian citizens. The speakers afterwards focused more on the scientific, methodological aspects of HRQOL and its measurement, whose values to be measured (i.e. general population, patients, or experts), cost-effectiveness analysis and the role of the EQ-5D in HTA. The new Indonesian EQ-5D-5L value set was introduced (publication in preparation) followed by a panel discussion session. Comparison between Asian countries in HTA and the use of EQ-5D were presented in the second day. The afternoon session of the second day was for parallel class QOL-research presentations where in total seven researchers presented their studies to the audiences.

In both sessions, the expert group on 'Quality of Life Measurement and its Application in the Republic Indonesia' (QOLMARI) was presented. We found a 'home base' at Padjadjaran University and received several new members.



*A participant asking question during a session*



*The EQ-5D-5L value set presentation*



*Group picture*

QOLMARI would like to thank drg. Armansyah, MPPM, Prof. Dr. Jan Passchier, Prof. Dr. Jan van Busschbach, Francis Ruiz, MSc, Dr. Nan Luo, and Fredrick D Purba, M.Psi., MSc for their invaluable knowledge sharing. We also greatly appreciate the research presentations from Aulia Iskandarsyah, PhD, Dr. Dyah Aryani Perwitasari, Dr. Sri Susilawati drg., M.Kes, Prof. Dr. Zulrizka Iskandar, MSc, Asteria Devy Kumalasari, M.Sc, and Titi Sahidah Fitriana, M.Psi. Both the Padjadjaran University and the EuroQol Group were thanked for their support of this symposium.

## WORDS FROM STAKEHOLDERS

**drg. Armansyah, MPPM** - Centre for Financing and Health Security, Ministry of Health

Currently, Indonesia has no EQ-5D-5L value set that can be used to assess quality of life (QoL). The EQ-5D-5L Symposium held by the Padjadjaran University provides an understanding of quality of life concepts, the measurement and development of the Indonesia value set, and studies using the EQ-5D-5L in Indonesia. This Indonesia value set is very useful in health technology assessment (Penilaian Teknologi Kesehatan/PTK) studies. When the National Health Insurance (Jaminan Kesehatan Nasional/JKN) was implemented in 2014, the government, represented by the Ministry of Health, is responsible for the cost control and quality control of the JKN program. One way of doing that is through health technology assessment.

In line with the implementation of JKN, the Ministry of Health established the Committee for Health Technology Assessment (Komite PTK) in 2014, consisting of clinicians and academicians who are experts in the field of health economics. This HTA Committee is in charge of conducting studies related to JKN benefits package. The final results of these studies are a memorandum of policy recommendations that can be used as considerations of investment and disinvestment of the JKN benefits package.

HTA studies that have been done all these times are economic evaluations/cost-utility analysis (CUA), which requires QoL values. Therefore, in order to obtain a valid result, which is in accordance with the condition of Indonesia, the Indonesian value set that represents the values of health states of the Indonesian society is expected to be implemented widely in HTA studies in the future. This is highly critical since the value set is useful in economic evaluation/CUA to obtain the most cost-effective intervention and to improve the quality of life of those who received the intervention.

I expect this Indonesian value set could be developed continuously by involving a larger sample from all across Indonesia considering the vast and varied characteristics of Indonesia population.

**Aulia Iskandarsyah, PhD** - Faculty of Psychology, Padjadjaran University

The Rise of a Quality of Life Research Group in Indonesia

September 8-9, 2016 can be considered as a historical moment for institutions and researchers who focused on quality of life research in Indonesia. Simultaneously with the celebration of 55th Dies Natalis, Faculty of Psychology Universitas Padjadjaran cooperated with the research group "Quality of Life Measurement and its Application in the Republic of Indonesia (QoLMARI)" and the EuroQol Research Foundation conducted an international symposium entitled "Big Step Forwards for Health Policy in Indonesia: The Introduction of The EuroQol EQ-5D-5L Value Set and Other Recent Developments in Quality of Life Research and Cost-Effectiveness Analysis". This symposium was held at Bale Sawala Universitas Padjadjaran, Jalan Raya Bandung Sumedang KM 21 Jatinangor, West Java - Indonesia. About 150 participants, consisting of the policy makers, psychologists, physicians, pharmacists, health professionals and representatives of industry were gathered and enjoyed the enlightening program.

Prof. Dr. med. Tri Hanggono Achmad, dr., Rector of Universitas Padjadjaran, in his opening speech stated the important of the event as a knowledge sharing, skills improvement and networking building to strengthen research and publication in the quality of life and other related issues in Indonesia. He also supported and emphasized the importance of the multidisciplinary research group in this research field.

Dr. Hendriati Agustiani, MSi., Dean of the Faculty of Psychology UNPAD, stated in the closing remark that the Faculty of Psychology UNPAD will be established as a home base of the Quality of Life Measurement and its Application in the Republic of Indonesia (QoLMARI) research group and that the university will provide full support to enlarge the scope of the study and improve academic outputs of the research group.

## RESEARCH PROJECTS OF MEMBERS (2016-2017)

### 1. Quality of Life of breast cancer patients in Hasan Sadikin Hospital in Bandung

This project objective is to measure quality of life of 200 patients with breast cancer treated in Hasan Sadikin Hospital in Bandung. Details about this project can be found in the next page (*Aulia Iskandarsyah and Jan Passchier*)

### 2. Quality of Life of Asthma and Tuberculosis patients in Indonesia

This project is measuring quality of life of patients with tuberculosis and patients with asthma in public health centers in Indonesia. (*Dyah Aryani Perwitasari*)

### 3. Indonesian valuation of EQ-5D-Y

This planned project will utilize Discrete Choice Experiments (DCE) in Indonesian general population to obtain value set of EQ-5D-Y, a generic health-related quality of life for youth questionnaire. (*Titi Sahidah Fitriana, Jan van Busschbach, Jan Passchier, Fredrick Purba, Joke Hunfeld*)

### 4. Comparing the EQ-5D-5L DCE data in Asian countries

This project compares Discrete Choice Experiments (DCE) data obtained from EQ-5D-5L valuation studies conducted by countries in Asian region, such as Indonesia, China, Malaysia, Japan, South Korea, Thailand, and Hongkong. (*Jan van Busschbach and Fredrick Purba*)

### 5. Quality of life of people living at the border of the Ciliwung in Jakarta

This project measures the quality of life, happiness and health-related quality of life of people living at the border of a polluted river in an Indonesian metropole (*Titi Sahidah, Fredrick Purba, Jan van Busschbach, Joke Hunfeld, Jan Passchier*)

## INTERNATIONAL PUBLICATIONS BY MEMBERS (2016)

1. Quality-Adjusted Life Years (QALYs) of Tuberculosis Patients in The Intensive and Continuous Phase in a Private Hospital of Yogyakarta, Indonesia (*Dyah A Perwitasari et al, J Pharm Biomed Sci,(2016),27-30*)
2. Treatment Adherence and Quality of Life in Diabetes Mellitus Patients in Indonesia (*Dyah A Perwitasari et al SAGE Open Vol 6, Issue 2.*)
3. Improving Type Diabetes Melitus Patients's Pharmaceutical Care by Assessing The Quality of Life and Patients's Perception (*Dyah A Perwitasari et al*)
4. Employing quality control and feedback to the EQ-5D-5L valuation protocol to improve the quality of data collection (*Fredrick Purba, et al, Qual Life Res (2016),1445-9*)

## WHY USING QUALITY OF LIFE MEASURES IN OUR STUDY ON THE EFFECT OF A PSYCHO-EDUCATION PROGRAM TO REDUCE DIAGNOSIS DELAY IN WOMEN WITH BREAST CANCER IN INDONESIA? *QOL measurement of the PERANTARA: an illustration*

*Aulia Iskandarsyah - Faculty of Psychology, University of Padjadjaran Indonesia  
Jan Passchier - Faculty of Behaviour and Movement Sciences, VU University Amsterdam, the Netherlands*

In our previous study, we informed you about our study in Bandung which develops and evaluates a self-help educational program entitled PERANTARA (pengantar PERAwataN kesehaTan payudARA). Its purpose is to stimulate women with breast cancer symptoms to come earlier to the hospital for getting a diagnosis. Because the faster the diagnosis will be made, the faster the treatment can start and the higher the probability of recovery and also better clinical outcomes. We have now finished this program, consisting of a booklet and video clip in a form of DVD. We also got the cooperation of four hospitals for participation, and made a list of outcome measures to be used. The PERANTARA provides the following information: 1) a brief explanation of breast cancer in order for the patients to have an accurate understanding and stimulation to seek information from reliable sources (oncologist); 2) an explanation of breast examination procedure to raise the patients' awareness on their symptoms and willingness to follow the procedure; 3) the recommendation to seek support from significant persons and institutions.

The short video features testimonies of two survivors who shared their stories about their conditions. The testimonies highlight breast cancer survivors experience to promote modeling on their positive attitude and social support.

Among the outcome measures are two measures of quality of life: the WHOQOL-BREF and the EQ-5D-5L. The last questionnaire is on 'Health-related Quality of Life'. All measures will be filled in before the intervention or control period, after the intervention and the control period, and at 3 months follow-up.

What is the reason for including measures for quality of life when you are focusing on the reduction of diagnosis delay?

First, it is good to mention that our primary (i.e. most important) variable is diagnosis delay. So, the main conclusion on the effectiveness of the PERANTARA is based on this outcome.

Second, the quality of life measures are included as secondary variables. Secondary implies less important than the primary variable, that is because in our study reducing diagnosis delay is our most important point of interest. The reason to measure these variables as well, is that we like to see which effect the PERANTARA has on the life of the patients. Of course we hope that it will be positive, but we are not sure. At the one hand, you may expect that the certainty of a diagnosis, of a good medical treatment and the support of the environment will increase the patient's well-being and health. At the other hand, there is also the possibility that a cancer diagnosis and the side effects of cancer treatment result in feelings of anxiety and depression, and physical symptoms like nausea and hair loss. Of course we expect that these negative consequences will diminish on the long run, but this requires a longer follow-up than we are now able to perform.

Suppose that we find that the delay is not influenced, but the quality of life is improved. In that case we conclude that the PERANTARA is not effective, unfortunately. But the positive findings on quality of life indicate that a next study is warranted to test the effect of PERANTARA on quality of life as primary variable. Because increasing quality of life is an purpose that is inherent to good medical treatment.

We look forward to see what happens, and will inform you about our findings again after one year.<sup>2</sup>

<sup>1</sup> This study is carried out by: Hari Setyowibowo. Marit Sijbrandij. Aulia Iskandarsyah. Joke A. M. Hunfeld. Jan Passchier. Sawitri S. Sadarjoen. Dharmayanti F. Badudu. Drajat R. Suardi

<sup>2</sup> If you like to correspond about this article, please send your reaction to: [j.passchier@vu.nl](mailto:j.passchier@vu.nl)

## IMPORTANT NOTE ON THE INDONESIAN VERSION OF THE WHOQOL-BREF

### *Some technical issues*

*Jan Passchier and Fredrick Dermawan Purba*

Suppose you buy a new laptop. The laptop is accompanied by a manual. Do you start with reading the manual? You probably seldom do, you like to begin immediately with your recently acquired play-tool. Until the moment that you are stuck and realize that it was better to have started by reading the manual first.

Same with questionnaires. In this note we like to share with you what we learned when applying the Indonesian version of the WHOQOL-BREF.

First, there appear to be different English and Indonesian versions of the WHOQOL-BREF. For example, there is the English version of 1998, which is attached to the manual of the WHOQOL-BREF as described in the WHO manual, developed by Harper and Power. Next, there is the English version of WHOQOL-BREF 2004 as edited by the WHO and distributed by the WHO, Geneva Switzerland.

The difference between the two English versions is that the 1998 version uses a time frame of 2 weeks: 'We ask that you think about your life in the last two weeks'. The 2004 version, however, uses a time frame of 4 weeks: 'We ask that you think about your life in the last four weeks'. The most recent Indonesian version of the WHOQOL-BREF is based on the last one.

The manual of the WHOQOL-BREF allows differences in time frame (see p44 of the Manual 1998). Reasons for a different timeframe might be the course of the disease of the patient of interest (for instance migraine is an affliction where the attacks might happen only once a month) or a the wish of the researcher to compare the results with another questionnaire that uses a four weeks time frame, such as the Health Status questionnaire Short-Form-36. Another argument of a different time frame, might be the presence of cultural differences. For comparison between studies, it is important that the researcher makes explicit which time frame he or she has applied and the reason why.

Anyway, it is good to note that the Indonesian version which is currently the official one uses the four weeks time frame.

Secondly, it is important to be attentive on the scoring of the WHOQOL-BREF. When we looked at the Indonesian WHOQOL-BREF, we saw 3 negative items: Q3, Q4, and Q26. The scores on these items have to be reversed according to the scoring key, so 1 becomes 5, 2 becomes 4 etc. This is indeed done when you look at the numbers accompanying the alternatives of these questions, which range from 5 to 1 instead of from 1 to 5. However, at the end of the questionnaire in the computations of the domain scores, it seemed if these corrections are made again by subtracting the scores from number 6.

Such a double correction would imply a low number for a high quality of life regarding these items instead of a high number for a high quality of life like in the other items. This seems not to be right.

Seeing the English version of 2004 on which it was based, this double (over)correction was also present.

However, approaching Prof Power, one of the authors of the manual, and reading the manual, revealed that the first scoring key is meant for those who do the scoring of the WHOQOL-BREF manually. The second scoring key is for those who do it by computer.

In order to avoid a confusion between the scoring 'by hand' and by the computer, the Indonesian version applies the same way of scoring for both, that is scoring each item in the same way (1 to 5) and correcting it for the negative items afterwards.

For getting the WHO-Manual of 1998, we suggest you to approach Prof Power, National University of Singapore, [psypmj@nur.edu.sig](mailto:psypmj@nur.edu.sig)

For getting the English WHOQOL-BREF version of 2004, you can approach their office in Geneva, Switzerland.

For getting the Indonesian WHOQOL-BREF version you can approach WHO field center WHOQOL instrument coordinator, [whogol@who.int](mailto:whogol@who.int)

If you have questions on this contribution, please send these to Jan Passchier: [j.passchier@vu.nl](mailto:j.passchier@vu.nl)

## RECENT DEVELOPMENT IN HEALTH-RELATED QUALITY OF LIFE IN INDONESIA

*Ahmad Fuad Afdhal, Ph.D - Center for Socio-Economic Studies in Pharmacy, Jakarta, Indonesia*

Similar in some parts of the world, Health-Related Quality of Life (HRQOL) has become a very interesting subject in Indonesia. This can be seen from activities such as conferences, seminars, panel discussions, and workshops organized in some cities in Indonesia. In addition, research in HRQOL has been done in some Universities in Indonesia. Meanwhile, as part of Pharmacoeconomics, HRQOL has been taught by some academicians throughout Indonesia.

In spite of enthusiasm to explore more about HRQOL, some limitations still exist. Some classic reasons are underlying in this matter. Among others, factors such as experts, literatures, and funds are needed to increase the level of HRQOL in terms of research quality. More importantly, it is expected that development of HRQOL will affect health policy in general and pharmaceutical policy in Indonesia.

With regard to pharmaceutical policy, research and study of HRQOL should give input in designing the policy. Such input will broaden the perspective of pharmaceutical policy. To do that experts of HRQOL should convince policy makers through research and studies which are of value for pharmaceutical policy.

Certainly the future of HRQOL in Indonesia is positive. The needs for applications of HRQOL will be increasing particularly after Indonesia has a National Social Security System which is known as BPJS (Badan Penyelenggara Jaminan Sosial). Although it is in the early stage, it is predicted that HRQOL research and study will give benefit for the Indonesian people.

### Terminology:

The rising of HRQOL research and study are positive in many ways. However, it is considered to be in its infancy. Despite its early stage, terminology has become a serious discussion. Initially, quality of life has been accepted as the common terminology. Later, Health-Related Quality of Life (HRQOL) is more preferred as it is more specific. Sometimes HRQL is used interchangeably with Quality of Life (QOL). Meanwhile some experts are adopting Patient Reported Outcomes (PROs).

Actually HRQOL itself is considered as having a loose definition. This is because a question is raised in terms of what aspects of quality of life should be included. In fact, relevant aspects may vary from study to study. Some general aspects such as physical functioning, general health, and physical symptom are popular among some experts.

One important aspect of HRQOL research and study in Indonesia, perhaps the most important one, is a cultural matter. In this regard, single-item questions on these aspects of HRQOL as for global questions about overall HRQOL, are likely to be ambiguous and unreliable. For this reason some experts prefer to develop questionnaires which are multi-measurement scales for each concepts.

### Topics:

In recent ISPOR Indonesia Chapter Conference which was held on 7 - 10 May 2016 in Jakarta, HRQOL has been an important concept in Plenary Sessions. The aspect of HRQOL was included when topics such as Pharmacoeconomic and Outcome Research for the future of Pharmacy were presented. HRQOL was also mentioned in topic presentations such Universal Health Care: Case of Indonesia and its problem solving.

Meanwhile, short courses such HRQOL weights for economic evaluations and Patient-Report Outcome Measures (PROMs): Development and Validation were given during ISPOR Indonesia Chapter Conference. These two subjects were well attended.

In addition, a research project was done to explore HRQOL among breast cancer patients. Another interesting research study was conducted in regard to HRQOL among diabetes type 2 patients, particularly comparing a group of patients with physical exercise and a control group without physical exercise. These two researches are notably interesting as these can stimulate future researches and studies about HRQOL for other diseases.

## QOLMARI MEMBERSHIP

*Fredrick Dermawan Purba - Secretary of QOLMARI Group*

Dear readers,

It has been a year since the first QOLMARI newsletter circulated among its members. We believe that many non-members also read that edition because we received many inquiries regarding the QOLMARI and its activities. During the quality of life symposium at Universitas Padjadjaran on September 2016, many participants were expressing their interest to join QOLMARI. Therefore in this second edition of QOLMARI newsletter, we would like to inform you the details of membership as described below:

- o The membership is open for anyone who has interest in quality of life research and issues in Indonesia.
- o Any scientific background and level are welcomed as long as quality of life is part of the studies or interventions conducted.
- o A curriculum vitae (pdf file), motivation letter (pdf file) and passport photo (jpg file) are three documents needed to apply for membership.
- o The official website of QOLMARI: [www.qolmari.org](http://www.qolmari.org) will provide a section for membership application in the end of January 2017. Any interested applicant who wants to submit before the end of January 2017 can send an email with the three documents attached to Fredrick Dermawan Purba: [fredrick.purba@unpad.ac.id](mailto:fredrick.purba@unpad.ac.id)

We welcome you to join us in QOLMARI. If you like to have a contribution to the next Newsletter, please submit it to us. Together we promote the quality of life research and applications in Indonesia to improve quality of life of Indonesian people.

### QoLMARI Group

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