



EQ-5D

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A brief review of concepts: health, quality of life, health-related quality of life and well-being

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Abstract

A EuroQol-funded study entitled ‘A qualitative approach to understanding what aspects of health are important to people’ is currently underway. The first stage of the study is to undertake a brief review of English language definitions of the following concepts: health, quality of life, health-related quality of life, and well-being. This report summarises the findings of the review of concepts. Data sources included: official EuroQol resources and publications; glossaries maintained by selected HTA agencies operating in English-speaking jurisdictions; other dictionaries and glossaries; published guidelines and classification systems; and a selection of articles, publications, resources and reports already known to the author. The findings are organised as follows: the concepts used to define the EQ-5D in EuroQol resources and publications; definitions of health; definitions of quality of life; definitions of health-related quality of life; and definitions of well-being. Based on the findings of the review and subsequent discussion with the study team, it was agreed that the remainder of the study will focus on health and well-being.

Keywords

health, quality of life, health-related quality of life, well-being, review, EQ-5D, definitions

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A BRIEF REVIEW OF CONCEPTS: HEALTH, QUALITY OF LIFE, HEALTH-RELATED QUALITY OF LIFE AND WELL-BEING

Introduction

The Descriptive Systems Working Group (DS-WG) was established in 2015 to explore the conceptual basis for generic health-related quality of life measures. In the March 2016 joint Working Group call for proposals, the DS-WG indicated a desire to prioritise:

- research into the concepts, definitions and criteria necessary for the development of a generic health classification system;
- qualitative research into the items/dimensions of health / health-related quality of life that are important and should be included in a generic health classification system.

Preliminary research on the latter topic has been undertaken as part of a follow-up to a valuation methodology study, and has been reported by Shah et al. (2017). However, that research was subject to a number of limitations (see section 4 of Shah et al., 2017). A new EuroQol-funded study, entitled *A qualitative approach to understanding what aspects of health are important to people*, is currently underway. This study seeks to build on the work of Shah et al. (2017) in order to address directly the DS-WG's aims and priorities using a more rigorous methodology. The aims of the overall study are:

- To understand what concepts (i.e. health *or* quality of life *or* health-related quality of life *or* well-being) and definitions should form the basis for a EuroQol generic classification system
- To develop and pilot an approach to identifying what aspects of health¹ are important to people
- To obtain the views of patients and members of the public about what aspects of health are important to them
- To produce a list of candidate items for potential inclusion in a generic classification system

The first stage of the study is to undertake a review of English language definitions of the following concepts:

- Health
- Quality of life
- Health-related quality of life
- Well-being

As stated in the proposal, the purpose:

is not to conduct a systematic or exhaustive literature review, but to ensure that the decision about which concept to focus on is appropriate and well-informed. The study team will present the stage 1 review to the DS-WG, and a joint decision will be made about which of the concepts should be the focus for the later stages of the project.

¹ Health / quality of life / health-related quality of life / wellbeing – for the purposes of this proposal, we will refer to 'health' as being the primary concept of interest, but this may change depending on the findings of stage 1.

This will be based on a judgement about what the descriptive system *ought* to be measuring. The outputs of the review will be used to develop lay definitions for use in the later stages of the project.

It is useful to develop our understanding of how these concepts are defined, since it is these definitions that will determine the appropriate outcome measures. Huber et al. (2011) note that "operational definitions are needed for measurement purposes, research, and evaluating interventions" (p.2). Given the overall study aims, it was deemed useful to also briefly review use of the relevant terms in selected EuroQol resources and publications, and in selected frameworks/classification systems.

Data sources and methodology

The data sources reflect those set out in the study proposal. These are sources that were already known to the author, supplemented by sources suggested by other members of the study team and identified through follow-up of references. No specific literature search was undertaken.

EuroQol resources and publications:

- EuroQol website: <http://www.euroqol.org/> [Accessed 16 Aug 2016]
- Brooks, R.G., 2015. *28 Years of the EuroQol Group: An Overview*. EuroQol Working Paper 15003.
- Kind, P., Brooks, R. and Rabin, R. (eds), 2005. *EQ-5D concepts and methods: a developmental history*. Dordrecht: Springer.
- The EuroQol Group, 1990. EuroQol – a new facility for the measurement of health-related quality of life. *Health Policy*, 16, pp.199-208.

Glossaries maintained by selected HTA agencies operating in English-speaking jurisdictions:

- PBAC (Australia): <http://www.pbs.gov.au/info/industry/useful-resources/glossary> [Accessed 16 Aug 2016]
- NICE (UK): <https://www.nice.org.uk/glossary> [Accessed 16 Aug 2016]

Note: The relevant terms were not found in the glossaries maintained by PHARMAC (New Zealand – <https://www.pharmac.govt.nz/tools-resources/glossary/>) [Accessed 16 Aug 2016] or CADTH (Canada – <https://www.cadth.ca/pcodr/glossary-terms>) [Accessed 16 Aug 2016].

Other dictionaries and glossaries:

- Brazier, J., Ratcliffe, J., Salomon, J.A. and Tsuchiya, A., 2007. *Measuring and valuing health benefits for economic evaluation*. Oxford: Oxford University Press.
- Culyer, A.J., 2014. *The dictionary of health economics*. Third edition. Cheltenham: Edward Elgar.
- Health Technology Assessment international (HTAi) consumer and patient glossary: A beginner's guide to words used in health technology assessment: http://www.htai.org/fileadmin/HTAi_Files/ISG/PatientInvolvement/Glossary/HTAiPatientAndConsumerGlossaryOctober2009_01.pdf [Accessed 16 Aug 2016]
- Mayo, N., 2015. *Dictionary of Quality of Life and Health Outcomes Measurement*. Milwaukee: International Society for Quality of Life Research
- Oxford English Dictionary. <http://www.oed.com/> [Accessed 16 Aug 2016]

Guidelines:

- OECD, 2013. *OECD Guidelines on Measuring Subjective Well-being*. Paris: OECD Publishing. <http://dx.doi.org/10.1787/9789264191655-en>

Classification systems:

- National Library of Medicine – Medical Subject Headings. <https://www.nlm.nih.gov> [Accessed 16 August 2016]
- World Health Organization, 2002. *Towards a common language for functioning, disability and health: ICF*. Geneva: World Health Organization.

Other articles, publications, resources and reports:

- Bowling, A., 2001. *Measuring disease: a review of disease-specific quality of life measurement scales*. Second edition. Philadelphia: Open University Press.
- Dolan, P. and Metcalfe, R. 2012. Measuring subjective wellbeing: recommendations on measures for use by national governments. *Journal of Social Policy*, 41(2), pp.409-427
- Huber, M., Knottnerus, J.A., Green, L., van der Horst, H., Jadad, A.R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M.I., van der Meer, J.W. and Schnabel, P., 2011. How should we define health? *BMJ*, 343, d4163.
- Karimi, M. and Brazier, J., 2016. Health, health-related quality of life, and quality of life: what is the difference? *Pharmacoeconomics*, 34(7), pp.645-649.
- Patrick, D.L. and Erickson, P., 1993. *Health status and health policy: Quality of life in health care evaluation and resource allocation*. New York: Oxford University Press.
- Stiglitz, J.E., Sen, A. and Fitoussi, J.P., 2009. *Report by the Commission on the Measurement of Economic Performance and Social Progress*. Available at: http://www.insee.fr/fr/publications-et-services/dossiers_web/stiglitz/doc-commission/RAPPORT_anglais.pdf [Accessed 5 Oct 2016]
- WHO, 2006. *Constitution of the World Health Organization*. http://www.who.int/governance/eb/who_constitution_en.pdf [Accessed 5 Oct 2016]

Each source was reviewed by the author, without assistance. Where appropriate, searches for the terms 'health', 'quality of life', 'health-related quality of life' and 'well-being' (with and without hyphenation) were conducted. In some cases, these searches were conducted electronically (e.g. Find feature within Adobe Acrobat Reader). In other cases, it was possible to locate the relevant definition or section manually. Relevant data (as judged by the author) were extracted into a Word document, using direct quotations where possible.

Findings

How is the EQ-5D defined in EuroQol resources and publications?

In a Health Policy paper published in 1990, the then-23 members of the EuroQol Group described their aim of jointly developing an instrument “for describing and valuing *health-related quality of life* [emphasis added]” (The EuroQol Group, 1990, p.200).

Similarly, early papers by Alan Williams and Claire Gudex – reproduced in Kind et al. (2005) – used the term *health-related quality of life*:

- “The raison d’être of the EuroQol Instrument is to provide a simple ‘abstracting’ device, for use alongside other more detailed measures of health-related quality of life (henceforth HRQoL), to serve as a basis for comparing health care outcomes using a basic ‘common core’ of QoL characteristics which more people are known to value highly.” (Williams, A. *The EuroQol Instrument*. p.1)
- “The EuroQol Instrument has two distinct contributions to make to the task of measuring health-related quality of life. First, it offers a very convenient way of collecting descriptive data about HRQoL, and about people’s own self-rating of their current health state.” (Williams, A. *The EuroQol Instrument*. p.5)
- “the EuroQol was to be a generic instrument for describing and valuing health-related quality of life (HRQoL), providing both a descriptive profile and an overall index for HRQoL.” (Gudex, C. *The descriptive system of the EuroQol Instrument*. p.19)

Brooks (2015) summarises one of the objectives that arose from the Group’s first meeting in 1987 as follows: “To develop a generic instrument to describe and value HRQoL, providing both a descriptive profile and an overall index” (p.6).

The EuroQol website currently describes the EQ-5D as “a standardised instrument for use as a measure of *health outcome*” [emphasis added]. However, on the ‘EQ-5D Nomenclature’ page within the EuroQol website (<http://www.euroqol.org/about-eq-5d/eq-5d-nomenclature.html>), the various EQ-5D instruments are defined as descriptive systems “of *health-related quality of life states*” [emphasis added]. Similarly, an EQ-5D health state is defined as “A *health-related quality of life state* profile described by the EQ-5D” [emphasis added].

Definitions of health

The Oxford English Dictionary lists seven groups of definitions for *health*, though many are irrelevant as they are archaic, colloquial, obsolete, etc. Potentially relevant definitions are presented below.

health, n.

- Soundness of body; that condition in which its functions are duly and efficiently discharged.
- By extension, The general condition of the body with respect to the efficient or inefficient discharge of functions: usually qualified as good, bad, weak, delicate, etc.
- Well-being, welfare, safety; deliverance.

The World Health Organization (WHO) definition of *health*, formulated in 1948, is: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2006, p.1).

Culyer's dictionary entry (p.231) refers to the WHO definition somewhat disparagingly:

- According to the first principle in the *World Health Organization's* constitution (revised 2006), this 'is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' Less star-gazing notions are usually embodied in practical work (including, mercifully, that of the WHO). See *Health-related Quality of Life*.

Other criticisms of the WHO definition are mentioned below.

Mayo's dictionary entry begins with the WHO definition and expands as follows:

- A state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity. Health is a fundamental human right and is considered a resource for everyday life, and not the object of living. It is a positive concept emphasizing social and personal resources as well as physical capabilities. The prerequisites for health include peace, adequate economic resources, food and shelter, and a stable ecosystem and sustainable resources use.

Huber et al. (2011) identify three main limitations of the WHO definition:

- Absoluteness of the word 'complete' – the requirement for complete health means that most people are unhealthy most of the time. This can lead to the identification of 'conditions' not previously defined as health problems, which in turn can lead to higher levels of medical dependency and risk.
- Does not account for changes in demography and the nature of disease since 1948 – whereas in 1948 acute diseases accounted for the majority of the burden of illness, today "ageing with chronic illnesses has become the norm, and chronic diseases account for most of the expenditures of the healthcare system" (p.1).
- 'Complete' is neither operational nor measurable, so the definition is not practicable.

Huber et al. call for a move away from the WHO's "static formulation" of *health* towards a dynamic concept that arose from an invitational conference of health experts held in the Netherlands in 2009: "the ability to adapt and to self manage" (p.2). The authors

contend that three domains underpin this concept: physical health, mental health and social health.

The International Classification of Functioning, Disability and Health (ICF) is described as the WHO's "conceptual basis for the definition, measurement and policy formulations for health and disability" (WHO, 2002, p.19). It sets out to provide "a standard language and framework for the description of health and health-related states" (p.2). The ICF is based on a 'biopsychosocial model' – an integration of medical and social models of disability. The model is represented by the following diagram:

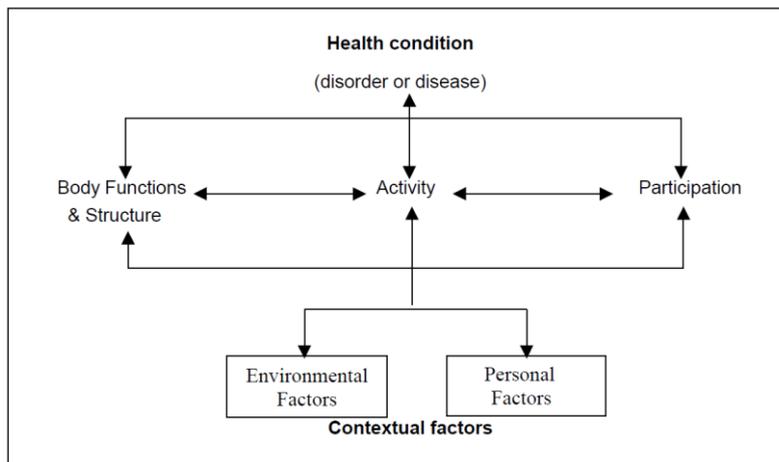


Figure 1. Representation of the model of disability that is the basis for ICF (source: World Health Organization, 2002)

Definitions:

- **Body Functions** are physiological functions of body systems (including psychological functions).
- **Body Structures** are anatomical parts of the body such as organs, limbs and their components.
- **Impairments** are problems in body function or structure such as a significant deviation or loss.
- **Activity** is the execution of a task or action by an individual.
- **Participation** is involvement in a life situation.
- **Activity Limitations** are difficulties an individual may have in executing activities.
- **Participation Restrictions** are problems an individual may experience in involvement in life situations.
- **Environmental Factors** make up the physical, social and attitudinal environment in which people live and conduct their lives.

The scope note for the Medical Subject Heading *health* within the National Library of Medicine reads as follows: "The state of the organism when it functions optimally without evidence of disease."

Definitions of *quality of life*

The Oxford English Dictionary contains the following definition of *quality of life* within its definition of the term *quality*:

- the standard of living, or degree of happiness, comfort, etc., enjoyed by an individual or group in any period or place

Culyer's dictionary entry (p.430) defines *quality of life* as follows:

- An index or profile of the quality of a year of life embodying the value judgments of selected judges, clients or others. See *Health-related Quality of Life, Quality-adjusted Life-year, Utility*.

The glossary entry provided by Brazier et al. (2007, p.332) describes *quality of life* as:

- A broad *construct* reflecting subjective or objective judgement concerning all aspects of an individual's existence, including health, economic, political, cultural, environmental, aesthetic and spiritual aspects.

Mayo's dictionary entry mentions the erroneous interchanging of terms:

- A term often used erroneously to refer to health-related quality of life or health status, but is broader than just health and includes components of material comforts, health and personal safety, relationships, learning, creative expression, opportunity to help and encourage others, participation in public affairs, socializing, and leisure. The WHO has defined quality of life as individuals' perception of their position in life in the context of the culture in which they live and in relation to their goals, expectations, standards and concerns. In the context of health research, quality of life goes beyond a description of health status, but rather is a reflection of the way that people perceive and react to their health status and to other, nonmedical aspects of their lives. According to Aristotle, quality of life would be the best kind of life, the happiest life, which is the life of virtue comprising: (i) intellectual or theoretical contemplation including scientific activity, considered the primary form of happiness; and (ii) practical or moral virtue including courage, moderation, generosity, and justice, the secondary form of virtue. In a modern context this would imply that quality of life is a life where one needs to think or contemplate aspects of life engagement and then act in a moral way or, in other words, be both smart and nice.

PBAC's glossary contains two entries for *quality of life*:

- *Quality of life* (see also *health status*)
 - The extent to which an individual perceives themselves to be able to function physically, mentally and socially.
- *Quality of life, direct description of* (see also *utility, direct elicitation of*)
 - A description of the impact of a particular *health status*, or a *health outcome* or *quality of life* obtained from the individual who is experiencing it.

Stiglitz et al. (2009) state that *quality of life* "includes the full range of factors that influences what we value in living, reaching beyond its material side." (p.216)

The scope note for the Medical Subject Heading *quality of life* within the National Library of Medicine reads as follows: "A generic concept reflecting concern with the modification and enhancement of life attributes, e.g., physical, political, moral and social environment; the overall condition of a human life".

Definitions of health-related quality of life

Note that three variants of acronym for *health-related quality of life* are commonly used: HRQL, HRQoL and HRQOL.

Culyer's dictionary entry (p.239) for *health-related quality of life* reads as follows:

- There are many empirical measures all measuring a concept related to the idea of 'health' and in widespread use in *epidemiology* and *cost-effectiveness* work.

The glossary provided by Brazier et al. (2007, p.328) contains the following entry for *health-related quality of life*:

- *As a construct*, health-related quality of life (HRQOL) refers to the impact of the health aspects of an individual's life on that person's *quality of life*, or overall well-being. Also used to refer to the value of a *health state* to an individual.

Mayo's dictionary entry defines *health-related quality of life* as:

- A term referring to the health aspects of quality of life, generally considered to reflect the impact of disease and treatment on disability and daily functioning; it has also been considered to reflect the impact of perceived health on an individual's ability to live a fulfilling life. However, most specifically HRQL is a measure of the value assigned to duration of life as modified by impairments, functional states, perceptions and opportunities, as influenced by disease, injury, treatment and policy.

In the HTAi consumer and patient glossary, the entry for *HRQoL* simply states: "See *health-related quality-of-life measures*", which in turn are defined as: "A measure of the effects of an illness to see how that illness affects a person's day-to-day life."

In NICE's glossary, the entry for *health-related quality of life* reads: "A combination of a person's physical, mental and social well-being; not merely the absence of disease."

In PBAC's glossary, the entry for *health-related quality of life* reads: "The physical, social and mental aspects that are relevant and important to the health aspects of an individual's overall wellbeing."

Patrick and Erickson define *health-related quality of life* as: "the value assigned to duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy." (p.22)

Drawing on definitions identified in the literature, Bowling (2001, p.6) defines *health-related quality of life* as:

- optimum levels of mental, physical, role (e.g. work, parent, carer, etc.) and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and well-being. It should also include some assessment of the patient's level of satisfaction with treatment, outcome and health status and within future prospects. It is distinct from quality of life as a whole, which would also include adequacy of housing, income and perceptions of immediate environment.

Karimi and Brazier (2016) note that that the term *health-related quality of life* was introduced in the literature on health status measures. They identify four categories of definition:

1. "How well a person functions in their life and his or her perceived wellbeing in physical, mental and social domains of health" (Hays and Reeve, 2010)

2. Only those aspects of quality of life (factors that impact upon an individual's life) that are part of an individual's health – i.e. excluding non-health aspects of quality of life (Torrance, 1987)
3. Aspects of quality of life that are affected by health (Ebrahim, 1995), or more narrowly, "the sub-set of important or most common ways in which health or health care impacts upon well-being" (Peasgood et al., 2014)
4. The value of health, whereby values assigned to different health states can be used in the calculation of quality-adjusted life years (Gold et al., 1996)

Definition of well-being

The Oxford English Dictionary lists three definitions for *well-being*, two of which are potentially relevant and presented below (the third refers to a thing rather than to a person or community).

well-being, n.

- With reference to a person or community: the state of being healthy, happy, or prosperous; physical, psychological, or moral welfare.
- In pl. Individual instances of personal welfare.

Culyer's dictionary entry (p.547) defines *well-being* as: "An idea related to utility but to be distinguished from health-related quality of life and the inherent 'worth' of people."

Mayo's dictionary entry defines *well-being* as:

- A construct related to what it means to be self-actualized, a distinct individual, fully functioning, and optimally developed; well-being has roots in concepts of happiness, life satisfaction and positive affect. Its core dimensions are considered to encompass purpose in life, personal growth, positive relations with others, environmental mastery, self-acceptance, and autonomy.

The OECD Guidelines on Measuring Subjective Well-being define *subjective well-being* as: "Good mental states, including all of the various evaluations, positive and negative, that people make of their lives, and the affective reactions of people to their experiences" (OECD, 2013, p.10).

The definition encompasses three elements:

- Life evaluation – a reflective assessment on a person's life or some specific aspect of it
- Affect – a person's feelings or emotional states, typically measured with reference to a particular point in time
- Eudaimonia – a sense of meaning and purpose in life, or good psychological functioning

The four *personal well-being* questions (an alternative term for *subjective well-being*) currently used by the Office for National Statistics relate to the elements above, and have been informed by the recommendations of Dolan and Metcalfe (2012):

- Life evaluation
 - Overall, how satisfied are you with your life nowadays?
- Affect / experience
 - Overall, how happy did you feel yesterday?
 - Overall, how anxious did you feel yesterday?
- Eudaimonia
 - Overall, to what extent do you feel the things you do in your life are worthwhile?

The OECD's simple model (OECD, 2013, p.33) presents various determinants of *subjective well-being*, with health status being one of those determinants (others included income, social contact and employment status).

The OECD model also describes health satisfaction as a sub-component of life satisfaction/evaluation, which in turn is one of the measurement concepts underpinning subjective well-being.

No Medical Subject Heading for *well-being* within the National Library of Medicine was found, though several related terms referring specifically to younger populations were found (*Adolescent Well Being; Adolescent Well-Being; Child Well Being; Child Well-Being; Infant Welfare; Infant Well-Being; Newborn Infant Well-Being*).

A tabular summary of definitions provided by sources that define at least two of the four concepts is provided in Table 1 below. Emboldening is used to highlight the use of one concept (*health, quality of life, health-related quality of life, well-being/wellbeing*; also other key terms *health outcome, health state and health status*) in the definition of another.

Table 1. Definitions provided by sources defining at least two of the four concepts

Source	Health	Quality of life	Health-related quality of life	Well-being
Oxford English Dictionary	<p>- Soundness of body; that condition in which its functions are duly and efficiently discharged.</p> <p>- By extension, The general condition of the body with respect to the efficient or inefficient discharge of functions: usually qualified as good, bad, weak, delicate, etc.</p> <p>- Well-being, welfare, safety; deliverance.</p>	The standard of living, or degree of happiness, comfort, etc., enjoyed by an individual or group in any period or place.		<p>- With reference to a person or community: the state of being healthy, happy, or prosperous; physical, psychological, or moral welfare.</p> <p>- In pl. Individual instances of personal welfare.</p>
Culyer's dictionary	According to the first principle in the World Health Organization's constitution (revised 2006), this 'is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.' Less star-gazing notions are usually embodied in practical work (including, mercifully, that of the WHO). See Health-related Quality of Life .	An index or profile of the quality of a year of life embodying the value judgments of selected judges, clients or others. See Health-related Quality of Life , Quality-adjusted Life-year, Utility.		An idea related to utility but to be distinguished from health-related quality of life and the inherent 'worth' of people.
Mayo's dictionary	A state of complete physical, social and mental well-being , and not merely the absence of disease or infirmity. Health is a fundamental human right and is considered a resource for everyday life, and not the object of living. It is a positive concept emphasizing social and personal resources as well as physical capabilities. The prerequisites for health include peace, adequate economic resources,	A term often used erroneously to refer to health-related quality of life or health status , but is broader than just health and includes components of material comforts, health and personal safety, relationships, learning, creative expression, opportunity to help and encourage others, participation in public affairs, socializing, and leisure. The WHO has defined quality of life as individuals' perception of their position in life in the context of the culture in which they live and in relation to their goals, expectations, standards and concerns. In the context of health	A term referring to the health aspects of quality of life , generally considered to reflect the impact of disease and treatment on disability and daily functioning; it has also been considered to reflect the impact of perceived health on an individual's ability to live a fulfilling life. However, most specifically HRQL is a measure of the value assigned to duration of	A construct related to what it means to be self-actualized, a distinct individual, fully functioning, and optimally developed; well-being has roots in concepts of happiness, life satisfaction and positive affect. Its core dimensions are considered to encompass purpose in life, personal growth, positive relations with others,

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Source	Health	Quality of life	Health-related quality of life	Well-being
	food and shelter, and a stable ecosystem and sustainable resources use.	research, quality of life goes beyond a description of health status , but rather is a reflection of the way that people perceive and react to their health status and to other, nonmedical aspects of their lives. According to Aristotle, quality of life would be the best kind of life, the happiest life, which is the life of virtue comprising: (i) intellectual or theoretical contemplation including scientific activity, considered the primary form of happiness; and (ii) practical or moral virtue including courage, moderation, generosity, and justice, the secondary form of virtue. In a modern context this would imply that quality of life is a life where one needs to think or contemplate aspects of life engagement and then act in a moral way or, in other words, be both smart and nice.	life as modified by impairments, functional states, perceptions and opportunities, as influenced by disease, injury, treatment and policy.	environmental mastery, self-acceptance, and autonomy.
Brazier et al.'s glossary		A broad construct reflecting subjective or objective judgement concerning all aspects of an individual's existence, including health , economic, political, cultural, environmental, aesthetic and spiritual aspects.	As a construct, health-related quality of life (HRQOL) refers to the impact of the health aspects of an individual's life on that person's quality of life , or overall well-being . Also used to refer to the value of a health state to an individual.	
PBAC's glossary		Quality of life (see also health status): The extent to which an individual perceives themselves to be able to function physically, mentally and socially. Quality of life, direct description of (see also utility, direct elicitation of): A description of the impact of a particular health status , or a health outcome or quality of life obtained from the individual who is experiencing it.	The physical, social and mental aspects that are relevant and important to the health aspects of an individual's overall wellbeing .	

Discussion

There clearly exists confusion about the definitions of *health*, *quality of life*, *health-related quality of life* and (to a lesser degree) *well-being*. The findings above indicate there is considerable overlap between the concepts, both in the definitions of the terms and in the ways they are used in practice.

An examination of early publications by the EuroQol Group points towards an aim for the EQ-5D to describe and measure *health-related quality of life*. The EuroQol website currently refers to both *health* and *health-related quality of life*, seemingly interchangeably. However, past usage is not necessarily a helpful guide of what should be done in the future, and the Descriptive Systems Working Group's mandate to explore the conceptual basis for generic preference-based measures seems like an appropriate opportunity to reflect on and revise (if appropriate) the EuroQol Group's use of terms.

Based on the definitions examined above, *quality of life* seems too broad a concept to accurately describe what the EQ-5D is currently seeking to measure, though often it is used as a synonym or shorthand for *health-related quality of life* – erroneously in the view of Mayo (2015). The definitions provided by Brazier et al. (2007) and Mayo (2015) indicate that *quality of life* extends well beyond people's health and any health-related aspects of their lives. It seems unlikely that the EuroQol Group would want to develop a generic preference-based measure designed to capture political aspects of a person's existence, for example. Yet that is what would be implied by focusing on *quality of life* without the *health-related* prefix.

Karimi and Brazier (2016) argue that the first two definitions of *health-related quality of life* they identified (how well a person functions in their life; aspects of quality of life that are part of health) do not distinguish it from *health*, whereas the third definition (aspects of quality of life that are affected by health) does not distinguish it from *quality of life*. I agree with the authors on these points. The fourth definition of *health-related quality of life* – a reflection of the value of health states – seems more useful, and is consistent with the definitions proposed by Patrick and Erickson (1993), Brazier et al. (2007) and Mayo (2015).

It is important to distinguish between measurement and valuation. It seems clear that the (current formulation of) EQ-5D can be used to describe or measure an individual's *health*, but it does not in itself contain a valuation element. An individual's health state – a single measurement of their health at a given point in time – can then be valued using techniques such as time trade-off which seek to understand the way that this state of *health* affects people's *quality of life*. I agree with the suggestion of Karimi and Brazier (2016) that the most meaningful way in which to use the term *health-related quality of life* is to use it to refer to the values of health states (as opposed to the health states themselves).

Based on the definitions identified above, *well-being* seems quite far removed from what the EQ-5D currently seeks to measure, though it is closely related to broader definitions of *quality of life* that are not restricted to health.

The most compelling reason for developing a generic preference-based *well-being* measure would be to foresee a shift in policy amongst decision makers. In the UK, the National Institute for Health and Care Excellence (NICE) and the Medical Research Council (MRC) have expressed an interest in capturing outcomes beyond health, reflecting both NICE's extended remit (it now makes recommendations about social care and public health, where interventions often have important non-health effects) and an increasing desire to make cross-sector comparisons and resource allocation decisions

(MRC, 2016). It is possible that other countries will follow suit, and it would be wise for the Descriptive Systems Working Group not to exclude *well-being* from the research agenda on the conceptual basis for generic preference-based measures, at least for the time being.

This review has clear limitations, particularly with respect to the choice of data sources. The focus was on dictionaries and glossaries already known to the author. Further research could place greater focus on peer-reviewed articles and books discussing these concepts. The review could also be extended to cover terms such as *health status*, *health outcome*, etc. It should be borne in mind that this review was simply a small, preliminary stage of a larger, empirical research project, and the publication of this EuroQol Working Paper was largely opportunistic (based on a desire to put the work into the public domain). A more comprehensive review using systematic methods would be welcomed.

The purpose of this review was to evaluate four concepts and to inform the decision about which concept(s) to focus on in the later stages of the study, which involve developing, piloting and applying an approach to identifying which aspects of the concept(s) in question are important to people:

- Stage 2: Development of a survey designed to understand what aspects of [*health / quality of life / health-related quality of life / well-being*] are important to people, with piloting of the draft survey in a focus group
- Stage 3: Administration of the revised survey to patient and general public samples (n=200), with the aim of generating a list of potential domains for a generic classification system, ranked by importance
- Stage 4: Checking / triangulation of the stage 3 results using a second focus group

Based on the findings of the review, it has been agreed by the study team that the remainder of the study will focus on *health* and *well-being*.

References (beyond those listed in the 'Data sources and methodology' section)

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