**QUOKKA consumer advisory group**

**Definitions of terms**

The following is intended to provide a quick reference guide to some of the technical terms and acronyms that may come up in our meetings. The terms are in alphabetical order, and words in bold/italics cross reference to another definition.

Your feedback on this glossary of terms is very welcome. If you would like further explanation of any of these, or would like to suggest more terms to add here, please let us know! Please consider this as just a starting point – I hope it is helpful.

Nancy Devlin

On behalf of the QUOKKA team

------------------------------------

**Condition specific questionnaires:** A questionnaire that asks questions about health problems relating to a specific disease or condition. They are one of two main types of questionnaires we use to measure health, the other being ***generic*** ***questionnaires.***

**Cost effectiveness analysis:** a way of assessing whether the benefits to patients justify the costs of the treatment. Benefits to patients are measured as improvements in length and quality of life, measured using ***QALYs***. The costs are usually the costs to the health care system. Cost effectiveness results are presented as the ‘cost per QALY gained’. This is the kind of evidence used in Australia by the ***PBAC*** to decide whether new treatments should be made available. The process of measuring and valuing ***HRQoL*** to estimate ***QALYs*** is shown in Figure 1.

**Generic quesionnaire:** A questionnaire that asks questions about health problems in a general way, that intends to be relevant to any kind of health problem. These questionnaire aim to describe and measure health in a way that lets us compare health between people who are well, and people who may suffer from a wide variety of health issues. A number of generic questionnaire have been developed specifically for children.

**HRQoL**: This stands for Health Related Quality of Life. This is what we are tying to measure when we ask patients (or a ***proxy***) to complete ***generic*** or ***condition specific questionnaires***. We are trying to find out how the patient feels.

**HTA:** This stands for Health Technology Appraisal. This is a process (usually run by a government committee like **PBAC** in Australia or **NICE** in the UK) for looking at the evidence about whether new types of health care (‘technologies’) are effective, and if they are cost effective. The decisions made by HTA agencies affect whether new types of health care are made available to patients.

**Hypothetical health state:** A health state described in terms of a **generic questionnaire,** which is not the state you are in right now, and may not be a health state you have ever experienced, so it is ‘hypothetical’ to you – you have to imagine what it is like.

**Instrument:** This means the same thing as ‘questionnaire’. For example, a ***generic questionnaire*** is sometimes also called a ‘generic instrument’.

**Multi-instrument comparison study:** A study which asks people to fill out lots of different questionnaires, so we can look at the way each questionnaire measures ***HRQoL***, and compare the results to find out which ones work best. In QUOKKA, project 1 is a mult-instrument comparison study, where we will compare how generic and condition specific questionnaires compare in describing children’s HRQoL.

**NICE**: This stands for the National Institute of Health and Clinical Excellence. This is an ***HTA*** organisation, which uses evidence on ***HRQoL, QALYs*** and ***cost effectiveness analysis*** to make decisions that affect what treatments are made available to patients in the UK.

**Normative:** This is a term used to mean a value judgement is involved. So for example, if we decide that children’s HRQoL should be valued by adult members of the general public, this is based on a value judgement that it is adults whose opinions are most relevant. In our QUOKKA project we will be checking with the Decision Makers’ Panel and with our consumer advisory group to help guide us in making these kinds of value judgements.

**PBAC:** This stands for the Pharmacuetical Benefits Advisory Committee. This is an ***HTA*** organisation, which uses evidence on ***HRQoL, QALYs*** and ***cost effectiveness analysis*** to make decisions that affect what treatments are made available to patients in Australia.

**Perspective:** This means the position from which something is viewed or assessed. Issues about perspective may come up in a couple of places in QUOKKA. For example, in undertaking ***cost effectiveness analysis***, the perspective usually taken in assessing costs and benefits is the ‘health system perspective’ eg. the costs taken into account are those incurred in the health care system, not by patients or their families. The issue of perspective also comes up when we ***value*** ***HRQoL***. For example, if we ask an adult to value children’s HRQoL, we need to specify what perspective they value it from - whether the adult needs to imagine being in that health state themself, or takes the perspective of a child they know, or a hypothetical child.

**Positive:** This means a conclusion or statement which is based on science and evidence and not based on value judgements.

**PRO:** This stands for Patient Reported Outcomes, and is a term often used in the US when referring to ***HRQoL*** questionnaires. Sometimes also referred to as Patient Reported Outcome Measures (PROMs).

**Proxy:** Sometimes it is not possible for patients to fill out ***condition specific questionnaires*** or ***generic questionnaires*** themselves, for lots of reasons. For example, it may not be possible for young children to fill out questionnaires themselves. In these cases, we ask someone (eg a parent or caregiver) to complete the questionnaire on this behalf, acting as a proxy for the patient, and doing their best to gauge the ***HRQoL*** of the patient. In QUOKKA project 2 we will be looking at ways of helping children to self-report their health, and of improving proxy reporting where it is needed.

**Stated preferences:** This is a set of methods we use for obtaining ***values*** and ***utilities*** for each of the health states described by a ***HRQoL*** questionnaire. There are a wide range of methods, and researchers have to make difficult choices about which of these methods to use, and also make decisions on ***normative*** issues, like whose opinions should count, and what perspective to use.

**QALY**: This stands for Quality Adjusted Life Year. This is a way of measuring the benefits of treatments to patients in a way that combines both length of life and ***HRQoL***. It is the measure of benefit used in ***cost effectiveness analysis***. See Box 1 below.

**Utilities** and **Values:** These two terms are often used interchangeably. They both refer to a number which used to summarise how good or bad any given state of ***HRQoL*** is. The number is on a scale which runs from 1 (which means full health) down through to 0 (meaning that HRQoL is so bad, its considered to be as bad as being dead). Lower utilities mean worse HRQoL. Utilities cannot be higher than 1, but it is possible for them to be less than 0, and these negative numbers mean HRQoL is so poor, its considered to be worse than being dead. Utilities and values are obtained using ***stated preference methods.*** In QUOKKA projects 3-4 we will be exploring ways of improving stated preference methods for valuing children’s HRQoL.

**Values:** see ***Utilities***.

**Value set study:** The aim of a value set study is to come up with ***utilities*** (values) for every health state described by a particular ***HRQoL*** questionnaire. Usually, but not always, the focus is on a ***generic questionnaire***. These studies involve using ***stated preference methods*** with a group of people and finding out what value they place on a selection of hypothetical health states described by the generic questionnaire. In QUOKKA project 5 we will be producing a value set for a children’s generic questionnaire.

**Weighting QALYs:** HTA organisations use evidence on ***QALYs*** and ***cost effectiveness*** to help inform their decisions. They are responsible for making decisions about health care for patients of every age, not just children; across a wide range of diseases; and consider both ways of treating illness and ways of preventing it (like vaccines). In comparing evidence, they usually assume that a QALY for any one patient – regardless of age or other characteristics – is ‘worth’ exactly the same as a QALY for any other patient. But sometimes it is argued that some QALYs – for example, children’s QALYs – should count for more than others. ‘Weighting a QALY’ for these sorts of reasons means that each of those QALYs carries a bit more importance. In QUOKKA project 6 we will be exploring whether there is support for weighting child QALYs.

**Box 1. QALYs**

1 year in full health = 1 QALY

1 year in poor health = less than 1 QALY.

For example, someone has 20 years of life ahead of them, but in each year of life they experience some pain and limitations in their activities and mobility. Their ***HRQoL*** is valued at just 0.6. So their 20 years of life = 12 QALYs.

If we could treat that person, and reduce their pain and improve their daily activities, their HRQoL could improve to 0.8. Their 20 years of life = 16 QALYs.

In each case, HRQoL would be measured by asking patient how they feel, using a ***generic or condition specific questionnaire***. The health state they describe is then assigned a utility which summarises how good or bad it is. The utilities are provided by value sets created to accompany each questionnaire, using ***stated preference methods.***

In cost effectiveness analysis, we are mainly interested in the *change* in QALYs. This is the improvement in QALYs that results from treatment. In this example, the change in QALYs is (16-12) = 4 QALYs.

**Figure 1. Evaluating health care for children using HRQol and QALYs.**

