

Marketing the quality of life

An international patient survey demonstrates how a new tool could better assess QoL

Searching for the phrase 'quality of life' (QoL) on PMLive.com generates up to 150 hits, most of which reference new medicines that have been designed to improve patients' physical and mental wellbeing. These innovative products are appreciated by patients, who count quality of life among their major concerns.

Although patients desire QoL, they do not, by all accounts, seem to be getting it from healthcare systems. One reason is that the patient perspective is not necessarily shared by national reimbursement agencies – or even by doctors. These often cite high cost and/or ineffectiveness to reject the very treatments that patients welcome. Professionally-deployed yardsticks to appraise clinical worth take little account of patients' views – a fact recognised in a recent analysis in the *British Medical Journal (BMJ)*. The *BMJ* authors called for better, standardised, validated tools to assess the patient experience from the patient's own standpoint.

A tool with such potential has just been used in a new international survey of patients, published in *HSCNews International*. The survey assessed patients' QoL using instruments fashioned by patients for patients. This is the brainchild of a loose alliance of patient organisations, academics, policymakers, and other experts, who are provisionally calling themselves the QALYity Project. The QALYity Project is spearheaded by Wales-based PatientView, an independent, global research and publishing organisation, and Together4health, a London-based consultancy. NovoNordisk funded the Project in its first year.

Founded at the end of 2006, the project has set itself the task of finding measures of

QoL that resonate with patients. The idea was originally inspired by work conducted in a completely different subject area – the Happy Planet Index (HPI). A creation of the New Economics Foundation in July 2006, the HPI gauges the success of countries by their ecological efficiency.

“Patients differ markedly in their estimation of what bolsters their QoL”

The QALYity Project's tool was devised after consulting 270 UK patient organisations. The groups identified 31 definitions of QoL that collectively take into account almost every patient's perspective on the topic. In turn, each of the 31 falls into one of three categories: access to, and excellence of, treatments and care; physical wellbeing as a result of care; or general outlook on life as a result of care.

The international QoL survey of patients tested the new measure. Over 3,400 patients from all walks of life, and from locations as far flung as the Bahamas or Bahrain, were quizzed about their QoL (and about possible improvements to it). Significant variations of opinion appeared among these patients, according to who they were, where they came from, and their medical condition. Almost 80 per cent of the patients with cancer, for instance, claimed to have a “good” or “better than good” quality of life. Yet only

40 per cent of patients with a mental health problem, and 15 per cent of patients with fibromyalgia, were willing to say the same. As many as one-third of patients told the survey that their quality of life was, at best, fair or poor.

More patient respondents nominated “getting the correct treatment, support or care” as their top priority for attaining QoL than any of the other 30 potential indicators. Almost one out of every five cancer patients named this their top QoL priority. The result is unsurprising; cancer treatments are now effective enough to extend life expectancy five years or more for many patients. Few patients with a mental health problem, however, can access optimum treatments or the psychosocial support they need to maximise their chances of getting better. Patients with fibromyalgia do even worse – little or no effective treatment is available for them.

Leaving aside the issue of receiving the correct treatment and care, patients differ markedly in their estimation of what bolsters their QoL. One-third of patients with arthritis single out: freedom from pain and discomfort; not having to fight the system for medical care; and feeling independent; as their top QoL indicators. One-third of patients with multiple sclerosis, on the other hand, opt for living with dignity, retaining independence, having access to information, and knowing that scientists are working hard to find a cure.

The survey's findings may seem obvious enough to patients. However, the results may provide a standard method for systematically analysing patients' views about their QoL, while taking account of people's idiosyncrasies.

The QALYity Project still has some way to go before it is properly validated. Should that day come, regulators and doctors may be able to better comprehend patients' needs and wants – as defined by the patients themselves.

Readers of *Pharmaceutical Marketing Europe* can obtain a free copy of the survey results by emailing info@patient-view.com

THE TOP 10 QOL PRIORITIES FOR PATIENTS

Rank	Indicator	Response %
1	Getting the correct medical treatment/care/support	12
=2	Feeling that I can retain my independence	7
=2	Coping with daily living in dignity	7
=4	Sufficiently skilled and expert healthcare professionals	6.6
=4	Not having to fight the system to receive medical care	6.6
6	Being able to lead a normal (or near-normal) life	5.5
7	Having the information that I need	5.1
8	Feeling sure that the doctor is listening to my own opinions	4.5
9	Feeling largely in control of my life	4.3
10	Being satisfied with the medical treatment/care I am receiving	4

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