

# Introducing *howRU*<sup>™</sup>

## An Instrument for Routine Health Outcomes Measurement

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### **Abstract**

This paper introduces *howRU*<sup>™</sup>, a new generic patient-reported outcome measure (PROM) for health related quality of life (HRQL), which records the level of each patient's physical and mental symptoms, limitations and dependency on four levels: none, slight, quite a lot and extreme.

*howRU* has been designed for routine capture by individuals and is appropriate for use across primary, secondary, community and social care. Patients' ratings may be treated as part of their presenting history, assisting communication between patients and clinicians.

*howRU* is quick and easy to use, easy to understand and interpret. It may be integrated with electronic patient records, facilitating case-mix based risk adjustment. It is well suited for use in audit, management, assessment of need and evaluation.

### **Introduction**

*If quality is to be at the heart of everything we do, it must be understood from the perspective of patients.* Darzi, 2008 <sup>1</sup>

*The ultimate measure by which to judge the quality of a medical effort is whether it helps patients (and their families) as they see it.* Berwick, 1997 <sup>2</sup>

Patient reported outcome measures (PROMs) have been developed to meet the need to measure changes in Health Related Quality of Life (HRQL) from the patient's point of view. This information needs to be measured routinely, adjusted for case-mix severity and published in a form that is readily understood by patients, clinicians, managers and payers. This is outcomes transparency.

Porter and Tiesberg make a strong case for outcomes transparency to foster results-based competition aligning the interests of patients, payers and providers to create a virtuous circle in which excellence is recognised and rewarded.

*Mandatory measurement and reporting of results is perhaps the single most important step in reforming the health care system.*<sup>3</sup> (Original italics)

Everyone involved in health care strives to improve patient outcomes, but unless we have and use suitable measurement instruments, we are flying blind.<sup>4</sup>

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## **Background**

HRQL measures fall into two groups, generic and condition-specific. This paper focuses on generic measures, which apply to patients with any combination of conditions, any type of treatment and any care setting including home, clinic or hospital. There is no need to identify the patient's problem before selecting the appropriate instrument.

There have been two earlier generations of these measures. The first generation, with its origins in the late 1960s, stems from the application of operations research and systems thinking to healthcare policy.<sup>5,6</sup> The second generation, developed during the late 1980s, introduced the patient as the rater and includes SF-36 and its derivatives,<sup>7</sup> the Euroqol EQ-5D,<sup>8</sup> and the Health Utilities Index (HUI).<sup>9</sup> These tools have been widely used for research and clinical trials, and shown to be reliable, valid, responsive and sensitive, but provide few direct benefits to patients or clinicians. In spite of 40 years of development, there is little routine use at the point of care.<sup>10</sup>

## **howRU**

This paper describes one of the first third-generation instruments, *howRU*, which in addition to traditional measures of effectiveness, has been designed for routine use, so that it is quick and easy to use, easy to understand and interpret and provide direct value to patients and health care professionals. It is also designed for easy integration with clinical and administrative processes and IT systems, enabling information sharing and linking to case mix data.

The conceptual basis of *howRU* is that what really matters to patients is their present and future states in terms of survival, how they feel (physical and mental symptoms) and how much they can do (disability and dependency). Typically, there may be a cause and effect relationship between physical or mental symptoms, limitations on what you can do and dependence on others. These dimensions are not independent.

The descriptive system for *howRU*, developed over a six-month iterative process with more than 150 iterations, was based on detailed domain knowledge, analysis and review of the literature covering over forty years. The objective was to capture the essence of the concepts being measured in the simplest way possible.

*howRU* has four dimensions:

- *Symptoms such as pain* – includes all physical forms of discomfort such as breathlessness, itching, dizziness or nausea.
- *Feeling low or worried* – includes all psychological states, including anxiety, feeling low and depression.
- *Limited in what you can do* – includes incapacity due to physical or psychological reasons, such as not being able to perform activities of daily living, or not being able to carry out leisure activities.
- *Dependent on others* – the need to rely on other people or equipment.

Each dimension has four possible responses or levels: *none*, *slight*, *quite a lot* and *extreme*. For purposes of data storage and analysis, each level is recorded using a 0-3 ordinal scale, with *extreme* = 0, *quite a lot* = 1, *slight* = 2 and *none* = 3.

The *slight* level reduces the risk of “ceiling” effects, where a subject chooses the best state, even though they have a mild problem, in which case no improvement can be detected. The *extreme* level similarly helps to reduce the “floor” effect, where a subject is rated in the worst state and further deterioration cannot be detected.

These four dimensions and four levels give 256 (4<sup>4</sup>) different permutations, each of which is a different health state.

## Data Collection

*howRU* can be collected in many different ways, depending on the aims and objectives of the study or ongoing routine data collection programme, for example:

- Pen and paper, with easy transcription to electronic format
- Telephone interview, optionally with VRS (voice response system)
- Access through Internet either via portals used for booking appointments or ordering repeat medication, or via Personal Health Record or social networking sites
- Patient PC or mobile-based portal, for booking appointments, ordering repeat medication etc
- Mobile telephony
- Touch-screen kiosk, for automated arrivals check-in at clinics or at the bedside.
- Entry by clinician or secretary into electronic medical records.

One method of data collection using a paper form is shown in Figure 1, which illustrates a traffic-light metaphor for the four levels using colour, position and smiley-face images.

Patients complete this form before they see their clinician and take it into the consultation. Used in this way, there is no need for the patient to enter any identification details and the clinician is responsible for ensuring that data is entered into the patient's record from where it can be extracted and analysed at a later date.

**How are you today?**

Please circle one face on each line.  
Give the form to the doctor or nurse when you go in.

	none	slight	quite a lot	extreme
Symptoms such as pain				
Feeling low or worried				
Limited in what you can do				
Dependent on others				
	(3)	(2)	(1)	(0)

**Data Protection Notice:** This information is treated as part of your personal medical record and safeguarded by data protection laws and health care regulations.  
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**howRU™**

**Figure 1 *howRU* Paper Form**

Figure 2 shows an electronic version of the form, as used on a web-browser, touch screen kiosk or mobile device. When any button is picked, it becomes brighter, standing out from the others.

How are you today?	none	slight	quite a lot	extreme
Symptoms such as pain				
Feeling low or worried				
Limited in what you can do				
Dependent on others				

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**Figure 2 howRU Electronic Form**

Ideally, *howRU* is entered into each patient's electronic patient record, which takes care of several issues including: patient identification, access control, record linkage and risk adjustment using case-mix data.

## Uses

Outcome measures are most successful when used as part of day-to-day patient care providing benefits to both patients and clinicians.<sup>11</sup>

Managers need health status and outcomes data in order to identify their population's needs and inequalities, to measure care service clinical and economic effectiveness. Comparisons between different groups need to allow for variation in case mix because, even with the best care, high-risk patients tend to have worse outcomes and higher costs. This is known as risk adjustment.<sup>12</sup>

Outcomes transparency enables payers and commissioners to promote competition and choice and identify specific needs, inequalities and problem areas, whilst driving quality improvement for their patients. In hospitals, community, primary care and social care, outcomes data can help identify wasted effort and drive up efficiency, effectiveness and productivity.

An explicit longitudinal record of *howRU* data assists continuity of care.<sup>13</sup> Traditionally, clinicians could remember their patients, but this is impossible in multi-disciplinary care and whenever the patient does not see the same clinician at each visit. Care professionals monitor patients' progress over time, assess trends and compare progress against that of similar patients. Knowledge of what happened to other patients with similar conditions can help collaboratively select the right treatment, educate and reassure the patient that they are doing as well as expected, and identify outliers from the expected pattern in the patient's journey. *howRU* data can also be used to support the assessment of suitability of referrals for specialist treatment, rehabilitation, social and residential care.

Sharing *howRU* data between patients and clinicians provides a language for patient-centred care, which patients and their families use to express their own values, preferences and needs, and understand the care and treatment options in terms that they can relate to.<sup>14</sup> *howRU* provides a way to share each patient's own perception of how they feel and what they can do with their clinicians. Traditionally every care

professional routinely asks the patient: “How are you today?” but the answer is seldom recorded in a structured manner. This information should be a standard part of each patient’s presenting history and their electronic medical record.

*howRU* supports patient-centred care by improving communication and shared understanding between patients, their clinicians and their wider support network. In this way *howRU* can enhance the doctor-patient relationship, improve mutual understanding, as well as enable safer handover and continuity of care.

## **Conclusions**

*howRU* is a generic tool for routine health outcomes measurement, which is very quick and easy to use and has been designed to meet the needs of patients, clinicians, providers and payers.

*howRU* provides management information for commissioners and care providers to measure, monitor and make transparent the performance of healthcare services, based on what matters to patients. *howRU* can also contribute to patient-clinician communication, by providing a channel between patients and care professionals, and enabling review of patient progress over time.

We all strive to improve patient outcomes, but we cannot control what we do not measure. We tend to get what we measure, so we must be careful what we ask for and measure what matters in the most straightforward way we can.

Further information about *howRU* can be found at Routine Health Outcomes web-site, [www.routinehealthoutcomes.com](http://www.routinehealthoutcomes.com).

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## **References**

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<sup>1</sup> Darzi A. *High Quality Care For All. NHS Next Stage Review Final Report*. Department of Health, June 2008  
([http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_085825](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825))

<sup>2</sup> Berwick DM. Medical associations: guilds or leaders. *BMJ* 1997; 314: 1564  
(<http://www.bmj.com/cgi/content/full/314/7094/1564>)

<sup>3</sup> Porter M and Teisberg E *Redefining Health Care: Creating Value-based Competition on Results*. Harvard Business School Press, 2006.

<sup>4</sup> Office of Health Economics Commission. *NHS Outcomes, Performance and Productivity*. London:OHE, March 2008. (<http://www.ohe.org/page/Commissionreport.cfm>)

<sup>5</sup> Rosser RM and Watts VC. The measurement of hospital output. *International Journal of Epidemiology*, 1972, 1, 361-8.

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- <sup>6</sup> Rosser RM. A health index and output measure. In: Walker SR, Rosser RM (editors). *Quality of Life Assessment: Key Issues in the 1990s*. Kluwer Academic Publishers, 1992, pages 151-178.
- <sup>7</sup> Ware JE Jr, Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care* 1992;30:473-83.
- <sup>8</sup> Oppe M, Rabin R and de Charro F. *EQ-5D User Guide*. Vol 1.0 November 2007, Euroqol Group ([www.euroqol.org](http://www.euroqol.org))
- <sup>9</sup> Horsman J, Furlong W, Feeny D, Torrance G. The Health Utility Index (HUI): concepts, measurement properties and applications. *Health and Quality of Life Outcomes*, 2003, 1:54. (<http://www.hqlo.com/content/1/1/54>)
- <sup>10</sup> Kind P. Putting the "Q" in QALYs. In Mason A and Towse A (editors) *The Ideas and Influence of Alan Williams: Be Reasonable – Do It My Way*. Office of Health Economics, 2008, 111-126.
- <sup>11</sup> Higginson IJ and Carr AJ. The clinical utility of quality of life measures. In Carr A J, Higginson IJ and Robinson P G (eds) *Quality of Life*, London: BMJ Books, 2003, pp 63-78.
- <sup>12</sup> Iezzoni L (editor) *Risk Adjustment for Measuring Health Care Outcomes*. Third edition. Chicago: Health Administration Press, 2003.
- <sup>13</sup> Guthrie B, Saultz JW, Freeman GK, Haggerty JL. Continuity of care matters. *BMJ* 2008; 337: a867. ([http://www.bmj.com/cgi/content/full/337/aug07\\_1/a867](http://www.bmj.com/cgi/content/full/337/aug07_1/a867))
- <sup>14</sup> Coulter A, Entwistle V and Gilbert D. Sharing decisions with patients: is the information good enough? *BMJ* 1999, Vol 318, 318-322. (<http://www.bmj.com/cgi/reprint/318/7179/318.pdf>)