# WEEKLY EPIDEMIOLOGICAL REPORT

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## Health Related Quality of Life (HRQoL)

**Quality of life (QoL) is a ubiquitous concept that has different philosophical, political and health-related definitions and it is difficult to measure. But on the other hand, Health-related QoL (HRQoL) is more clearly defined. Therefore, HRQoL (which is a patient-reported outcome) is usually measured to asses the impact of treatment and widely used in the treatment of cancer patients.**

### Core components of HRQoL assessment

- Physical
- Functional
- Psychological/emotional
- Social/occupational

### Why measure HRQoL?

The primary purpose of any treatment is to improve the quality of patients' lives, hopefully by curing the disease but also by ameliorating the worst symptoms for as long a period as is possible. Avoidance of iatrogenic harm, namely side-effects and other adverse events of treatment, is also imperative. Every clinician, therefore, will make implicit, subjective judgments about HRQoL when treating a patient. Unfortunately, very few clinicians make explicit, objective assessments about QoL using validated tools and instruments. Formal assessment of HRQoL is now a mandatory requirement in most clinical trials but skepticism about its true value makes most clinicians to depend on informal appraisal, believing clinical judgment to be superior to formal assessment outside a trial setting. In the past, routine usage was limited by the perception that available tests were too time-consuming to use or difficult to score and interpret, but the modern technology (computers with touch screens etc.) has changed that aspect.

Measurement of clinical parameters such as tumour volume and serum tumour markers are typical examples of primary parameters of response to treatment. However, improvements in such measures can produce little, if any, noticeable benefit for the patient or may be associated with a decline in HRQoL if the side-effect profile of treatment is high. Sometimes the outcome of clinical trials reveals only modest differences between treatments and in such circumstances HRQoL can be a helpful outcome. The US Food and Drug Administration (FDA) and the European Medicines Agency (EMEA) now often require HRQoL or patient-reported outcome (PRO) information before licensing new drugs and have issued guidance as to which instruments can be used to measure its efficacy.

### Methods in which HRQoL can improve patient care

#### Widening the parameters of benefit

In many situations; for example, when chemotherapy is given for palliation in advanced cancer, QoL is arguably the sole criterion of efficacy. Conventional parameters such as response, disease-free intervals and survival may be less relevant. For example, survival in non-small cell lung cancer may be only a few months and although meta-analyses have shown that chemotherapy produces a modest extension of life compared with best supportive care, some clinicians are reluctant to offer chemotherapy as treatment as side-effects may negate any survival gains. Clinical trials incorporating HRQoL assessments can provide more information and help clarify the relative harms and benefits of palliative chemotherapy and aid patient decisions when survival gains are meager.

#### Indicating a need for supportive interventions

Therapies of proven efficacy almost always have unwanted side-effects which may be severe enough for a doctor to reduce optimal dosing schedules or for patients to stop adhering to the recommended dose.

Systematic HRQoL assessments help delineate these side-effects and their temporal nature. This can assist in determining the types of supportive interventions that may be needed to ameliorate the worst side-effects. For example, hand and nail problems are common with Taxane( a drug used in cancer treatment) therapy; however, research has shown that wearing specially designed frozen gloves during administration of chemotherapy can prevent or minimize the impact of this distressing side-effect.

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**As a prognostic indicator**

It is well known that patients with a good HRQoL at the start of treatment fare better than those with a poorer baseline score, but there is also an increasing body of literature demonstrating the utility of HRQoL as an effective prognostic indicator.
Inpatients with colo-rectal cancer, assessment of HRQoL has been shown to provide a better estimate of survival than measurement of tumour size.

Given the uncertainty and controversy that surrounds the use of expensive agents towards the end of life which might be causing toxicity with only modest therapeutic gains, it would seem reasonable to use patients' HRQoL to aid end-of life treatment decisions. Finally, QoL could be used as a surrogate end point for survival in clinical trials.

**Decision-making**

Some novel therapies convey, at best, only modest benefits that are outweighed by the impact of side-effects; others may have demonstrably better efficacy but a challenging side-effect profile. When different treatment options are available, patients and doctors need to discuss these potential harms and benefits. This is only really possible if there has been a systematic collection of such data using reliable PROs.

**Resource allocation and health care policy**

All health care systems have to confront the economic reality of a finite budget and infinite demands. Sometimes patients are denied supportive drug treatments on the grounds of cost, but if HRQoL data are available, the benefits that accrue from their provision are useful and powerful arguments. Nausea and vomiting (N&V) was previously one of the most debilitating and HRQoL -reducing side-effects of chemotherapy and drugs such as Metoclopramide were ineffective in many patients, especially those on high-dose regimens. HRQoL data showed that the financial costs were small when considered alongside the patient burden of unremitting N&V and Ondansetron (which is relatively expensive) was made available to all the needy patients.

**Design and development of HRQoL measuring tools.**

It is also important to consider how to measure HRQoL scientifically. Measurement of PROs has recently become much more sophisticated. The development process is now more structured and HRQoL tools are rigorously tested to ensure that they are reliable, valid and responsive to change. The constructs and structure of the best instruments, such as the generic short form36 (SF-36), the European Organization for Research and Treatment of Cancer (EORTC)QLQ-C30 and the Functional Assessment of Chronic Illness Therapy (FACIT) system have been through years of development and modification. There are few reasons for developing any new tools, although refinement of existing resources and development of additional items, modules or subscales is needed if there is insufficient coverage of novel treatments or of the specific disease being examined.

**The development of FACT-G**

1. Cancer patients and oncology physicians and nurses generated a list of potential items.
2. Psychologists conducted a structured interview with patients, which began with open-ended prompt to report as many factors as possible which impact on QoL, followed by more focused questions on different aspects of QoL.
3. Oncologists reviewed the patient-generated list and added any other items they felt necessary
4. A group of 90 patients ranked the 137 items using a Likert scale (1 = little / no importance; 4 = very important) and only those rated 'very' or 'extremely important' were retained.
5. Oncologists, nurses and psychologists reviewed this list and eliminated any redundant items.
6. The final list of 38 items was reviewed to ensure reasonable content and coverage.
7. The final phase involved the piloting of different response modes and rewording of ambiguous items.

**Examples of well-regarded HRQoL instruments**

Generic instruments

SF-36 (short form 36)
FACIT (Functional Assessment of Chronic Illness Therapy)

Cancer-specific instruments

EORTC QLQ-C30 with tumour-specific modules
FACT-G with tumour and treatment-specific subscales

**Most frequently used questionnaires**

**SF-36**

Arguably the most important and frequently used generic HRQoL assessment is the SF-36.
This multi-purpose, short-form health survey is comprised of 36 questions which provide an eight-scale profile of functional health and well-being scores (physical function, role function, bodily pain, general health, vitality ,social functioning, emotional well-being and mental health) as well as composite physical and mental health summary measures and a preference-based HUI. The SF-36 has been used in literally thousands of general and specific population surveys, permitting comparison of the relative burden of diseases and differentiating the health benefits or harms of diverse treatments. The respondent burden is not great but an even shorter validated version, the SF12, comprising 12 items, is also available. The instrument has been translated using backwards and forwards methodology into approximately 50 languages.

**FACT-G**

FACT-G is part of the FACIT system. This widely used instrument has undergone many modifications; version IV currently comprises of 26 items. It is very similar in principle to the EORTC QLQ-C30 having a general questionnaire to which either tumour- or disease-specific and treatment-specific subscales or modules can be added.

**Choosing an instrument**

The choice of instrument depends very much on the reason for measurement and the primary concepts of interest. A study looking at a new analgesic for the relief of arthritis may require a specific instrument to measure pain perception; for example, the Brief pain Inventory (BPI), or a disease-specific instrument such as the Arthritis Impact Measurement Scales (AIMS), or a more generic instrument such as theSF36 to evaluate the impact of pain on other aspects of QoL and compare across other conditions where the analgesic was also indicated or licensed. When examining the impact of a specialist nurse counselling service, a good anxiety or depression scale might be more appropriate. The key issues when choosing a test are to review the instrument for coverage of items of interest and to ensure that it is valid and reliable.

**Compiled by Dr. Madhava Gunasekera of the Epidemiology Unit**

Source-What is quality of life?, available from

http://www.whatisseries.co.uk/whatis/pdfs/What_is_QOL.pdf

## Table 1: Vaccine-preventable Diseases & AFP

19th – 25th May 2012 (21st Week)

| Disease | No. of Cases by Province | | | | | | | | | Number of cases during current week in 2012 | Number of cases during same week in 2011 | Total number of cases to date in 2012 | Total number of cases to date in 2011 | Difference between the number of cases to date in 2012 & 2011 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | W | C | S | N | E | NW | NC | U | Sab | | | | | |
| Acute Flaccid Paralysis | 00 | 00 | 00 | 00 | 00 | 01 | 00 | 00 | 00 | 01 | 08 | 35 | 39 | - 10.3 % |
| Diphtheria | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | - | - | - | - | - |
| Measles | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 11 | 20 | 68 | - 70.5 % |
| Tetanus | 00 | 00 | 00 | 00 | 01 | 00 | 00 | 00 | 00 | 00 | 00 | 05 | 08 | - 37.5 % |
| Whooping Cough | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 32 | 15 | + 113.3 % |
| Tuberculosis | 90 | 52 | 06 | 05 | 10 | 00 | 00 | 00 | 07 | 170 | 146 | 3572 | 3315 | + 07.8 % |

## Table 2: Newly Introduced Notifiable Disease

19th – 25th May 2012 (21st Week)

| Disease | No. of Cases by Province | | | | | | | | | Number of cases during current week in 2012 | Number of cases during same week in 2011 | Total number of cases to date in 2012 | Total number of cases to date in 2011 | Difference between the number of cases to date in 2012 & 2011 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | W | C | S | N | E | NW | NC | U | Sab | | | | | |
| Chickenpox | 00 | 00 | 00 | 00 | 02 | 05 | 00 | 00 | 00 | 07 | 85 | 1974 | 2117 | - 06.8 % |
| Meningitis | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 12 | 236 | 379 | - 37.7 % |
| Mumps | 00 | 00 | 00 | 00 | 04 | 02 | 00 | 00 | 01 | 07 | 63 | 1899 | 1001 | + 89.7 % |
| Leishmaniasis | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 00 | 10 | 237 | 281 | - 15.7 % |

### Key to Table 1 & 2

**Provinces:** **W**: Western, **C**: Central, **S**: Southern, **N**: North, **E**: East, **NC**: North Central, **NW**: North Western, **U**: Uva, **Sab**: Sabaragamuwa.

**DPDHS Divisions:** **CB**: Colombo, **GM**: Gampaha, **KL**: Kalutara, **KD**: Kandy, **ML**: Matale, **NE**: Nuwara Eliya, **GL**: Galle, **HB**: Hambantota, **MT**: Matara, **JF**: Jaffna, **KN**: Killinochchi, **MN**: Mannar, **VA**: Vavuniya, **MU**: Mullaitivu, **BT**: Batticaloa, **AM**: Ampara, **TR**: Trincomalee, **KM**: Kalmunai, **KR**: Kurunegala, **PU**: Puttalam, **AP**: Anuradhapura, **PO**: Polonnaruwa, **BD**: Badulla, **MO**: Moneragala, **RP**: Ratnapura, **KG**: Kegalle.

**Data Sources:**

**Weekly Return of Communicable Diseases:** Diphtheria, Measles, Tetanus, Whooping Cough, Chickenpox, Meningitis, Mumps.

**Special Surveillance:** Acute Flaccid Paralysis.

Leishmaniasis is notifiable only after the General Circular No: 02/102/2008 issued on 23 September 2008.

### Dengue Prevention and Control Health Messages

**Make sure that your environment is free from water collections where the dengue mosquito could breed.**

## Table 4: Selected notifiable diseases reported by Medical Officers of Health

19th – 25th May 2012 (21st Week)

| DPDHS Division | Dengue Fever / DHF* | | Dysentery | | Encephalitis | | Enteric Fever | | Food Poisoning | | Leptospirosis | | Typhus Fever | | Viral Hepatitis | | Human Rabies | | Returns Received |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A | B | A | B | A | B | A | B | A | B | A | B | A | B | A | B | A | B | % |
| Colombo | 69 | 2976 | 0 | 45 | 0 | 5 | 0 | 82 | 0 | 24 | 0 | 60 | 0 | 2 | 0 | 23 | 0 | 1 | **08** |
| Gampaha | 0 | 2197 | 0 | 31 | 0 | 5 | 0 | 32 | 0 | 13 | 0 | 77 | 0 | 6 | 0 | 101 | 0 | 0 | **00** |
| Kalutara | 0 | 788 | 0 | 35 | 0 | 2 | 0 | 17 | 0 | 3 | 0 | 92 | 0 | 2 | 0 | 9 | 0 | 1 | **00** |
| Kandy | 4 | 688 | 0 | 35 | 0 | 1 | 0 | 11 | 0 | 11 | 0 | 25 | 0 | 63 | 0 | 12 | 0 | 0 | **09** |
| Matale | 1 | 180 | 0 | 37 | 0 | 4 | 0 | 1 | 0 | 4 | 0 | 18 | 0 | 2 | 0 | 10 | 0 | 0 | **08** |
| Nuwara | 0 | 124 | 0 | 56 | 0 | 1 | 0 | 17 | 0 | 1 | 0 | 12 | 0 | 29 | 0 | 8 | 0 | 0 | **00** |
| Galle | 0 | 449 | 0 | 36 | 0 | 3 | 0 | 6 | 0 | 10 | 0 | 59 | 0 | 21 | 0 | 1 | 0 | 0 | **00** |
| Hambantota | 0 | 205 | 0 | 18 | 0 | 1 | 0 | 2 | 0 | 9 | 0 | 26 | 0 | 21 | 0 | 5 | 0 | 0 | **00** |
| Matara | 0 | 558 | 0 | 29 | 0 | 4 | 0 | 9 | 0 | 15 | 0 | 63 | 0 | 35 | 0 | 48 | 0 | 0 | **06** |
| Jaffna | 3 | 199 | 0 | 81 | 0 | 6 | 1 | 169 | 0 | 18 | 0 | 2 | 0 | 232 | 1 | 3 | 0 | 0 | **08** |
| Kilinochchi | 0 | 20 | 0 | 6 | 0 | 1 | 0 | 18 | 0 | 39 | 0 | 3 | 0 | 26 | 0 | 4 | 0 | 1 | **25** |
| Mannar | 0 | 69 | 0 | 10 | 0 | 2 | 0 | 13 | 0 | 13 | 0 | 15 | 0 | 35 | 0 | 1 | 0 | 0 | **00** |
| Vavuniya | 0 | 26 | 0 | 6 | 0 | 7 | 0 | 4 | 0 | 4 | 0 | 14 | 0 | 0 | 0 | 1 | 0 | 0 | **50** |
| Mullaitivu | 0 | 5 | 0 | 8 | 0 | 1 | 0 | 4 | 0 | 1 | 0 | 2 | 0 | 5 | 0 | 0 | 0 | 0 | **25** |
| Batticaloa | 1 | 528 | 0 | 50 | 1 | 2 | 0 | 10 | 0 | 25 | 0 | 4 | 0 | 0 | 0 | 4 | 0 | 1 | **36** |
| Ampara | 0 | 35 | 0 | 40 | 0 | 0 | 0 | 3 | 0 | 5 | 0 | 16 | 0 | 0 | 0 | 1 | 0 | 0 | **0** |
| Trincomalee | 0 | 81 | 0 | 67 | 0 | 1 | 0 | 15 | 0 | 1 | 0 | 24 | 0 | 3 | 0 | 2 | 0 | 0 | **08** |
| Kurunegala | 8 | 516 | 0 | 51 | 0 | 6 | 0 | 43 | 0 | 9 | 1 | 61 | 1 | 16 | 3 | 30 | 0 | 2 | **17** |
| Puttalam | 0 | 330 | 0 | 23 | 0 | 4 | 0 | 5 | 0 | 1 | 0 | 19 | 0 | 8 | 0 | 1 | 0 | 0 | **00** |
| Anuradhapu | 0 | 138 | 0 | 27 | 0 | 1 | 0 | 3 | 0 | 1 | 0 | 45 | 0 | 18 | 0 | 29 | 0 | 1 | **00** |
| Polonnaruw | 0 | 80 | 0 | 11 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 17 | 0 | 2 | 0 | 26 | 0 | 1 | **00** |
| Badulla | 0 | 87 | 0 | 30 | 0 | 2 | 0 | 14 | 0 | 1 | 0 | 16 | 0 | 24 | 0 | 18 | 0 | 0 | **00** |
| Monaragala | 0 | 72 | 0 | 28 | 0 | 4 | 0 | 9 | 0 | 0 | 0 | 36 | 0 | 37 | 0 | 86 | 0 | 0 | **00** |
| Ratnapura | 21 | 644 | 0 | 87 | 0 | 23 | 2 | 28 | 0 | 2 | 0 | 115 | 0 | 18 | 0 | 48 | 0 | 1 | **22** |
| Kegalle | 2 | 561 | 0 | 27 | 0 | 6 | 0 | 12 | 0 | 5 | 0 | 50 | 0 | 23 | 1 | 201 | 0 | 0 | **09** |
| Kalmune | 0 | 123 | 0 | 79 | 0 | 1 | 0 | 5 | 3 | 26 | 0 | 2 | 0 | 0 | 0 | 6 | 0 | 1 | **15** |
| **SRI LANKA** | **109** | **11679** | **00** | **953** | **01** | **103** | **03** | **539** | **03** | **241** | **01** | **873** | **01** | **628** | **05** | **678** | **00** | **10** | **08** |

**Source: Weekly Returns of Communicable Diseases WRCD).**
***Dengue Fever / DHF** refers to Dengue Fever / Dengue Haemorrhagic Fever.
****Timely** refers to returns received on or before 25th May, 2012 Total number of reporting units 329. Number of reporting units data provided for the current week: 27
**A** = Cases reported during the current week. **B** = Cumulative cases for the year.

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Comments and contributions for publication in the WER Sri Lanka are welcome. However, the editor reserves the right to accept or reject items for publication. All correspondence should be mailed to The Editor, WER Sri Lanka, Epidemiological Unit, P.O. Box 1567, Colombo or sent by E-mail to **chepid@sltnet.lk.**

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