

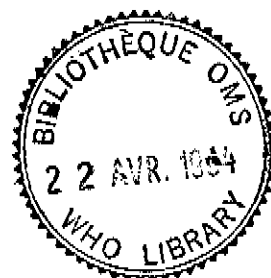
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# QUALITY OF LIFE ASSESSMENT

## AN ANNOTATED BIBLIOGRAPHY

This annotated bibliography provides an overview of some of the most important recent scientific publications concerned with the assessment of quality of life in health care settings, and current generic quality of life measures. Section I is concerned with assessment issues including: definitional, conceptual, methodological and psychometric issues. Section II briefly overviews some of the existing generic quality of life instruments and Section III gives annotated references to further recent guides and bibliographies.



DIVISION OF MENTAL HEALTH  
WORLD HEALTH ORGANIZATION  
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## Acknowledgements

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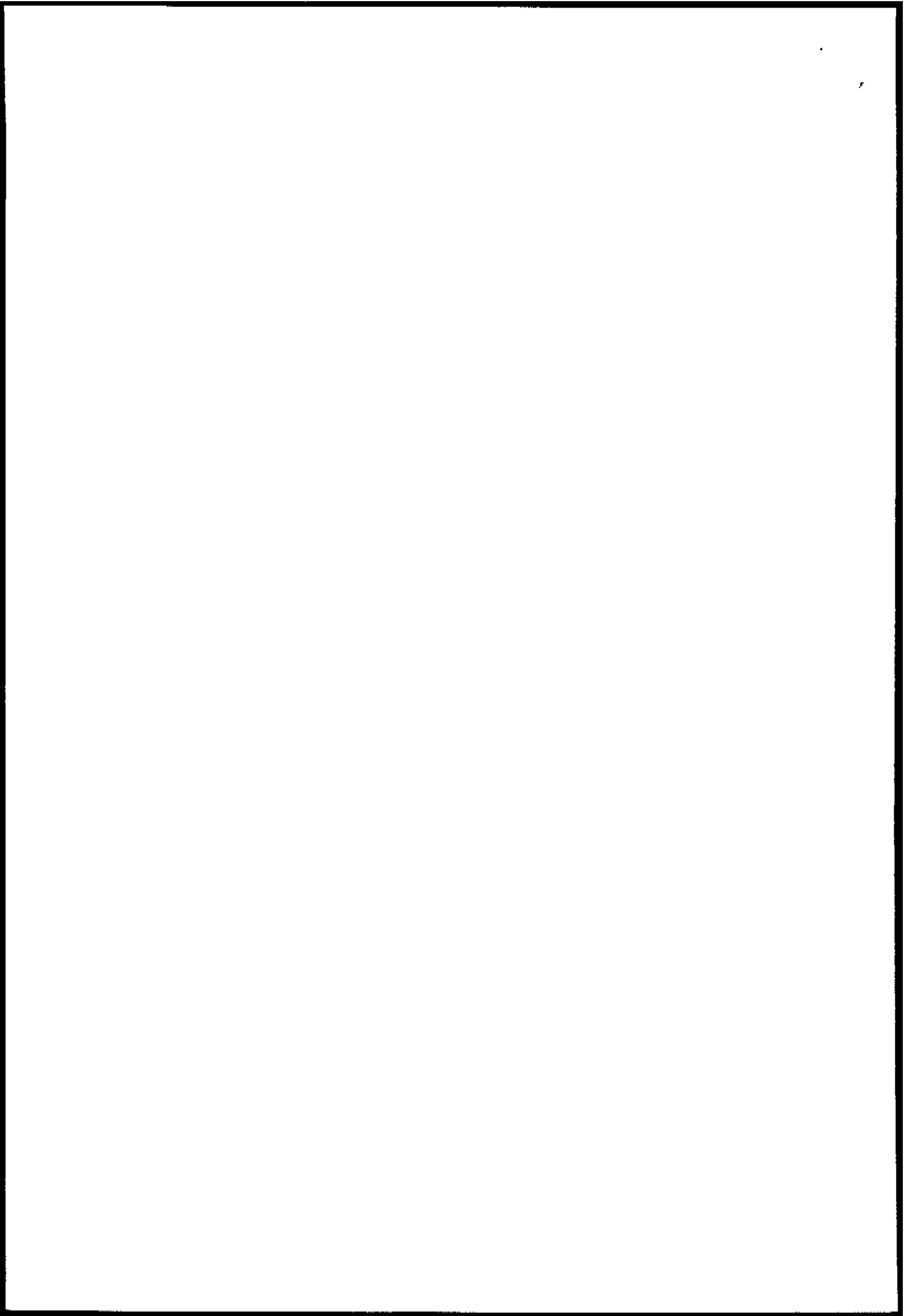
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## QUALITY OF LIFE ASSESSMENT AN ANNOTATED BIBLIOGRAPHY

### Introduction

Although there are generally satisfactory ways of measuring the frequency and severity of diseases and impairments, the measurement of the effects of these on quality of life is as yet a relatively new area. In spite of this there is a large and diffuse literature addressing various aspects of quality of life and quality of life assessment. The Medline data base cites 1520 papers with the key term "Quality of Life" in 1992, and 187 with both "Quality of Life" and "Assessment". In 1993 it identified "Quality of Life" 1570 times and "Quality of Life" and "Assessment" together 240 times. This current annotated bibliography seeks to overview some of the most important recent scientific publications concerned with the assessment of quality of life in health care settings, and current generic quality of life measures. The decision to limit the bibliography to generic instruments is a practical one, as to expand into the realm of disease specific measures would make it difficult to produce such a bibliography. The decision to use generic or disease specific measures is governed by a great many factors, and which of the two approaches to quality of life assessment is preferable depends largely on the questions being addressed. Papers in this bibliography addressing the relative merits of generic and disease specific instruments include Aaronson (1990), Guyatt, Feeny and Patrick, (1993), and Patrick and Deyo, (1989).

The first part of the bibliography is concerned with assessment issues. Selected publications addressing the following issues were included.

- a     definitional issues
- b     conceptual issues
- c     methodological issues
- d     psychometric issues

Criteria for inclusion in Section I, Assessment Issues, were:

- relevance to generic QOL assessment
- accessibility/quality of journal
- English language version
- international focus on QOL assessment

We have tended to exclude papers which focus on specific diseases or situational issues, and instruments related to these.

Section II briefly overviews some of the existing generic quality of life instruments with greatest currency and nominates several publications addressing the characteristics and psychometric properties of these instruments.

Because this bibliography does not seek to be comprehensive, Section III describes and references a number of the further guides and bibliographies that have been published recently.



## SECTION I - ASSESSMENT ISSUES

Aaronson, N.C. (1989). Quality of life assessment in clinical trials: methodologic issues. *Controlled Clinical Trials*, 10, 195S-208S.

A review of some of the central methodological issues concerning the development or selection of quality of life measures for use in clinical trials, including considerations surrounding the response scales and time frame for questions, and what psychometric properties should be considered in the evaluation of a questionnaire assessing quality of life.

Aaronson, N.C. (1990). Quality of Life research in cancer clinical trials: A need for common rules and language. *Oncology*, 4, 59-66.

Addresses measurement, research design and implementation issues surrounding clinical-trial-based quality of life studies. These include: the appropriate source of quality of life data; global versus multi-dimensional approaches; generic versus specific measures; the role of psychometrics in selecting quality of life measures; the frequency and timing of data collection; and patient accrual and differential loss to follow up.

Anderson, R. T., Aaronson, N. K., Wilkin, D. Critical review of the international assessments of quality of life. *Quality of Life Research*, 2, 369-395.

Reviews the international adaptation and use of generic quality of life measures, including the Nottingham Health Profile, Sickness Impact Profile, Medical Outcomes Short-form, the EuroQol, and Dartmouth COOP Charts. With regards to disease specific measures work on the European Research and Treatment of Cancer (EORTC) quality of life questionnaire (QLQ) and the Spitzer Quality of Life index is overviewed. Endorses the feasibility of cross-cultural adaptation of health status measures but draws attention to the need for more work on establishing the psychometric equivalence of different language versions.

Barnett, D.B. (1991) Assessment of quality of life. *American Journal of Cardiology*, 67, 41C - 44C.

A discussion of the complexities of quality of life assessment due to individual, cultural and disease differences, and presentation of the quality adjusted life year (QALY) as a possible way of overcoming some of these problems.

Bergner, M. (1985). Measurement of health status. *Medical Care*, 23, 696-704.

Describes the progress in the USA health services since 1966 and recommendations for future directions in health status measurement, a model of health status, appropriate health status measures for current health care issues, and outlines issues in health status assessment for the next decade.

Bergner, M. (1989). Quality of life, health status, and clinical research. *Medical Care*, 27, S148-S156.

A discussion of issues and problems hindering the use of health assessment measures, such as uncertainty regarding definition, methodology, and administration; and suggestions for future direction and progress in the area.

Bergner, M. and Rothman, M. L. (1987). Health status measures: An overview and guide for selection. *Annual Review of Public Health*, 8, 191-210.

Overviews the purpose and content of health status measures and outlines some practical and psychometric criteria whereby measures might be compared and evaluated with a view to selection for use.

Breslin, S. (1991). Quality of life: how is it measured and defined? *Urologia Internationalis*, 46, 246-251.

A discussion of the definition of quality of life as a subjective variable comprised of an individual's perceptions regarding level of physical, psychological, and social well-being; and the importance of quality of life measurement in medical decision making.

Bullinger, M. and Hasford, J. (1991). Testing and evaluating quality of life measures for German clinical trials. *Controlled Clinical Trials*, 12, 915-1055.

An analysis of quality of life research in Germany emphasizing the cross-cultural considerations of and current approaches to the conceptual, methodological, political, and practical issues. A presentation of work in a biometrical centre.

Bullinger, M., Anderson, R., Cella, D and Aaronson, N. K. (1993). Developing and evaluating cross-cultural instruments from minimum requirements to optimal models. *Quality of Life Research*, 2, 451-459.

Discusses the feasibility and possible approaches of international quality of life measures. Introduces some of the methods and criteria for evaluation of international measures.



Butler, R.N. (1992). Quality of life: can it be an endpoint? How can it be measured? *American Journal of Clinical Nutrition*, 55, S1267-S1270.

Recommended basic criteria in the determination of quality of life for the elderly.

Cella, D. F. (1992). Quality of Life: The concept. *Journal of Palliative Care*, 8, 8-13.

An examination of the place of quality of life assessment in palliative care. Presents an argument that quality of life is a formalised statement of the goals of palliative care, stressing its subjectivity and multi-dimensionality.

Cunney, K.A. and Perry, M. (1991). Single item v. multiple item measures of health-related quality of life. *Psychological Reports*, 69, 127-130.

A study supporting the use of single item measures of health-related quality of life when multiple measures are not suitable or not practical in application. A positive and significant correlation is found between the scores of one specific item of the Medical Outcomes Study Short-form General Health Survey and overall scores of a trial population.

Cox, D. R., Fitzpatrick, R., Fletcher, A. E., Gore, S. M., Spiegelhalter, D. J. and Jones, D. R. (1992). Quality of Life assessment: Can we keep it simple? *Journal of the Royal Statistical Society*, 155, 353-393.

General principles of study design and analysis of quality of life assessments in clinical trials are discussed, with particular reference to problems of weighting and aggregation, and technical issues arising in the analysis of clinical trials data.

Dean, H.E. (1990). Political and ethical implications for using quality of life as an outcome measure. *Seminars in Oncology Nursing*, 6, 303-308.

A presentation of ethical and political considerations regarding the use of quality of life measures as a potential means of health care resources allocation in the best interests of individuals as well as of society.

Deyo, H. E. (1984). Pitfalls in measuring the health status of Mexican Americans: Comparative validity of the English and Spanish Sickness Impact profile. *American Journal of Public Health*, 74, 569-573.

Discusses the translation of the Sickness Impact Profile into Spanish for use with the Hispanic population in the USA, and the issues arising in this process, and subsequent problems in the interpretation of the reliability and validity data. Excellent introduction to the potential difficulties that may be encountered in translating a health status measure.

Deyo, R.A. and Patrick, D.L. (1989). Barriers to the use of health status measures in clinical investigation, patient care, and policy research. *Medical Care*, 27, S254-S268.

A presentation of conceptual, methodologic, practical, and attitudinal barriers hindering the use of health assessment measures in appropriate settings and suggestions for progress and improvement.

Deyo, R.A., Diehr, P. and Patrick, D.L. (1991). Reproducibility and responsiveness of health status measures: Statistics and strategies for evaluation. *Controlled Clinical Trials*, 12, 142S-158S.

Discussion of methodological and statistical issues in the use of health status measures for gathering "responsiveness" data.

Erickson, P., Kendall, E.A., Anderson, J.P. and Kaplan, R.M. (1992). Using composite health status measures to assess the nation's health. *Medical Care*, 30, MS166-175.

A description of research in progress at the USA National Centre for Health Statistics on the evaluation of measures of the health status of the nation.

Faden, R. and Leplege, A. (1992). Assessing quality of life. Moral implications for clinical practice. *Medical Care*, 30, MS166-175.

An examination of some of the moral implications of the measurement of quality of life for clinical use in the areas of screening, monitoring, and decision making.

Feeny, G.H. and Torrance, G.W. (1985). Incorporating utility-based quality of life assessment in clinical trials. Two examples. *Medical Care*, 27, S190-S204.

A discussion of the theoretical foundations, advantages and disadvantages of the utility approach to the measurement of health-related quality of life in economic evaluation and clinical practice.

Fitzpatrick, R., Fletcher, A., Gore, S., Jones, D., Spiegelhalter, D. and Cox, D. (1992). Quality of Life measures in health care. I: Applications and issues in assessment. *British Medical Journal*, 305, 1074-1077.

Reviews the applications of quality of life measures (screening programs, audit, health care research, and clinical trials) and outlines the basic requirements that a satisfactory quality of life measure should possess (psychometric properties of reliability, validity, sensitivity to change; appropriateness and practicality).

Fletcher, A., Gore, S., Jones, D., Fitzpatrick, R., Spiegelhalter, D. and Cox, C. (1992). Quality of life measures in health care. II: Design, analysis, and interpretation. *British Medical Journal*, 305, 1145-1148.

A paper offering guidelines and recommendations for the appropriate use of quality of life instruments including factors to consider in the selection of an instrument, practical issues of administration and data collection, analysis and reporting of scores and their interpretation.

Gerin, P., Dazord, A., Boissel, J. and Chifflet, R. (1992). Quality of Life assessment in therapeutic trials: Rationale for and presentation of a more appropriate instrument. *Fundamental Clinical Pharmacology*, 6, 263-276.

Presents an argument that subjective quality of life assessment requires a different definitional and conceptual model than objective quality of life assessment. The sociological life goals model is presented as a possible contender and the application of this model to data collected in France with the Subjective Quality of Life Profile questionnaire presented.

Grant, M., Padilla, G.V., Ferrell, B.R. and Rhiner, M. (1990). Assessment of quality of life with a single instrument. *Seminars in Oncology Nursing*, 6, 260-270.

A discussion of the value for health care evaluation and research, of quality of life measurement with a single instrument that is chosen with consideration of specific objectives.

Greenfield, S. and Nelson, E.C. (1992). Recent development and future issues in the use of health status assessment measures in clinical settings. *Medical Care*, 30, MS23-41.

A broad overview of health status assessment in terms of the past, present, and future; including a description of the evolution of the paradigm of health-related thinking, barriers to full-scale use of health status measures in clinical settings, and the importance of health status assessment in future change and development of a health care system.

Greer, D.S. (1987). Quality of life measurement in the clinical realm. *Journal of Chronic Diseases*, 40, 629-630.

A discussion of the need for and barriers to the use of quality of life measurement as a means of structuring and transmitting clinical data, emphasizing the discordance between clinicians and scientists, social science and medicine. Recommendations for future accommodation of these differences and enhancement of quality of life concepts and measurement.

Guyatt, G.H., Feeny, D. H. and Patrick, D. L. (1993). Measuring health-related quality of life. *Annals of Internal Medicine*, 118, 622-629.

Outlines the importance of measuring health-related quality of life to inform patient management and policy decisions. Can be used as discriminative instruments (to measure cross-sectional differences between patients at a point in time) and longitudinal changes within patients during a period of time. Both applications must be valid, reliable, responsive to change and interpretable by clinicians and policy makers. The paper also outlines the applications and strengths and weaknesses of generic and disease specific instruments.

Guyatt, G.H., Veldhuyzen Van Zanten, S.J.O. and Feeny, D.H. (1989). Measuring quality of life in clinical trials: A taxonomy and review. *Canadian Medical Association Journal*, 140, 1441-1448

A survey of published trials in 1986, concluding that quality of life measures are not widely used in appropriate clinical settings. A framework is outlined to aid investigators in the selection of generic or specific instruments according to the purpose and focus of their trials. Generic instruments include health profiles and utility measures based on patient outcome preferences, and specific measures focus on problems associated with individual diseases.

Guyatt, G., Walter, S. and Norman, G. (1987). Measuring change over time: Assessing the usefulness of evaluative instruments. *Journal of Chronic Diseases*, 40, 171-178.

Presentation of a new index to assess an instrument's reliability and responsiveness to change.

Hadorn, D.C. and Hays, R.D. (1991). Multi-trait multi-method analysis of health-related quality of life measures. *Medical Care*, 29, 829-840.

A test of the construct validity of health-related quality of life using multi-trait multi-method analysis in the evaluation of general health perceptions, meaningful activities, outlook on life, physical suffering, self-care activities, and social relationships.

Hays, R. D. and Hadorn, D. (1993). Responsiveness to change: An aspect of validity, not a separate dimension. *Quality of Life Research*, 1, 73-75.

Outlines a position that the psychometric property of responsiveness to change, validity and reliability are inter-dependent, specifically so that there is a trade off between the responsiveness and internal consistency of a scale.

Hays, R. D., Stewart, A. L., Sherbourne, C. D. and Marshall, G. N. (1993). The "states versus weights" dilemma in quality of life measurement. *Quality of Life Research*, 2, 167-168.

A short discussion of the question of whether an assessment of health states should be weighted and, if so, in what way, with particular reference to a validity study comparing two quality of life assessment instruments.

Hollandsworth, J.G. Jr. (1988). Evaluating the impact of medical treatment on the quality of life: A 5-year update. *Social Science and Medicine*, 26, 425-434.

A comparison of studies on the impact of medical care on quality of life assessment in the period between 1980 and 1984, showing the need for a more solid consensus concerning what constitutes adequate quality of life measurement.

Holmes, C.A. (1989). Health care and the quality of life: A review. *Journal of Advanced Nursing*, 14, 833-839.

An examination of the feasibility of adopting the improvements in quality of life as an evaluation criterion for health care, with a discussion of social indicators and subjective evaluations as measures, and the role of nurses in the concept formation and evaluation of quality of life.

Hornquist, J.O. (1990). Quality of life: Concept and assessment. *Scandinavian Journal of Social Medicine* 1990, 18, 69-79.

An analysis of the concept of quality of life as a whole and divided into sub-domains, with a presentation of a chart of relevant life domains and an outline of tested rating techniques.

Hunt, S. M. (1991). Cross-cultural adaptation of health measures. *Health Policy*, 19, 33-44.

Discussion of the issues involved in adapting a health status instrument for use in different cultures, and the ways of maintaining the technical, conceptual and linguistic integrity of the source instrument in the target language. Discussion is related to the translation of the Nottingham Health Profile into a number of languages.

Jalowiec, A. (1991). Issues in multiple measures of quality of life. *Seminars in Oncology Nursing*, 6, 271-277.

A discussion of the advantages of the use of several measures over uni-dimensional and global techniques in quality of life assessment.

Jenkins, C. D. (1992). Assessment of outcomes in health intervention. *Social Science and Medicine*, 35, 367-375.

Argues that any research study that includes an assessment of health should explicitly deal with 11 conceptual and methodological issues, including defining quality of life, the multi-dimensionality of quality of life and international comparison of quality of life data.

Jenkins, C.D., Jono, R.T., Stanton, B.A. and Stroup-Benham, C.A. (1990). The measurements of health-related quality of life: major dimensions identified by factor analysis. *Social Science and Medicine*, 31, 25-3.

A report of factor analyses of 58 outcome measures suggesting the dimensions of low morale, illness symptoms, neuropsychological function, interpersonal relationships, and economic-employment. Presented with a discussion of data implications and recommendations for further research.

Karlsson, G. (1992). The health economist's point of view concerning quality of life. *Nordic Journal of Psychiatry*, 46, 95-99.

Describes how quality of life measures are used as outcome measures in economic assessments of health care. Describes the use of quality-adjusted-life-years (QALYs) as an outcome measure and the various problems with, and alternatives to QALYs.

Katz, S. (1987). The science of quality of life. *Journal of Chronic Diseases*, 40, 459-463.

A discussion of the definition of the term quality of life, medical progress leading to the relevance of its measurement, and an examination of the future challenges to its application in the study of health and illness.

Kawachi, I., Bethwaite, P. and Bethwaite, J. (1990). The use of quality-adjusted life years (QALYs) in the economic appraisal of health care. *New Zealand Medical Journal*, 103, 46-48

A discussion of the theory behind quality-adjusted-life-years (QALYs), their potential application in economic appraisal of health care, and controversies surrounding their use.

Kind, P. (undated). *The Design and Construction of Quality of Life Measures*. Discussion Paper 43. Centre for Health Economics Consortium : University of York.

Describes some of the methodological issues which lie behind the design and construction of quality of life measures and reviews some of the principal examples. The derivation of disease-specific and generic measures is documented, and a bibliography provides ready access to the main sources of reference material in the field.

Kirshner, B. and Guyatt, G. (1985). A methodological framework for assessing health indices. *Journal of Chronic Diseases*, 38, 27-36.

A discussion of the implications of instrument purpose for each stage of the development of an instrument, as well as the importance of specifying the aims of a study when selecting a measurement instrument.

Lane, D.A. (1987). Utility, decision, and quality of life. *Journal of Chronic Diseases*, 40, 585-591.

An introduction to the concept of utility and its application to the measurement of quality of life.

Lindström, B. Quality of life: A model for evaluating Health for All. Conceptual considerations and policy implications. *Soz Präventivmed*, 37, 301-106.

Discusses the potential of quality of life assessment as a resource in the Public Health sector in the sense of WHO's Health for All Strategy. Synthesises a theoretical framework of quality of life, and describes how in practice it can be used to evaluate the health resources of a population.

Lohr, K.N. (1992). Applications of health status assessment measures in clinical practice. Overview of the third conference on advances in health status assessment. *Medical Care*, 30, MS1-14.

An overview of the proceedings of a conference on health status assessment, including a presentation of papers on benefits of and barriers to the use of health status assessment, strategies for dealing with them, history of the use of health status measures, ethical considerations, empirical research, panel discussions, and methods round-tables.

Mehrez, A. and Gafni, A. (1989). Quality adjusted life years, utility theory, and healthy years equivalents. *Medical Decision Making*, 9, 142-149.

Description of the healthy-years equivalent (HYE) as an alternative measure of outcome to the quality-adjusted life year (QALY) .

Miettinen, O. S. (1987). Quality of life from the epidemiological perspective. *Journal of Chronic Diseases*, 40, 641-643.

Recognition of quality of life as an important aspect of health outcome, and the need for the development of more situation-specific scales.

Mosteller, F. (1987). Implications of measures of quality of life for policy development. *Journal of Chronic Diseases*, 40, 645-650.

A recommendation for action on the part of scientists, medical experts, and workers involved in health measurement to apply measurement methods to medical and health problems, build up substantive literature, and set research priorities with the goal of gaining court consideration of quality of life measures.

Nelson, E.C. and Berwick, D.M. (1989). The measurement of health status in clinical practice. *Medical Care*, 27, S77-S89.

A discussion concerning the reasons that quality of life measures are not currently applied in clinical situations where they would be appropriate, despite their availability and conditions that are necessary for their future widespread acceptance and use.

Najman, J.M. and Levine, S. (1981). Evaluating the impact of medical care and technologies on the quality of life: a review and critique. *Social Science and Medicine*, 15, 107-115.

A discussion of the inadequate research design of numerous studies on medical interventions which use quality of life data, and the need for reliable, validated measures which address the issue of subjective interpretation of objective quality of life changes.

Nelson, E. C. and Berwick, D. M. (1989). The measurement of health status in clinical practice. *Medical Care*, 27, S77-S89.

Analyzes both the potential and the barriers to the use of health assessment tools in practice and notes the need for better scientific evidence of their clinical utility, as opposed to their information content.

O'Boyle, C. A. (1992). Assessment of quality of life in surgery. *British Journal of Surgery*, 79, 395-398.

Discusses the theoretical underpinnings of the quality of life concept, and in practical terms outlines the applications of quality of life assessments in surgery (e.g. assessing outcome, selecting patients for surgery, policy decisions and resource allocation ...).



Olweny, C. L. M. (1992). Quality of life in developing countries. *Journal of Palliative Care*, 8, 25-30.

Emphasises the place of quality of life issues in developing world countries, where per capita spending on health is in some countries is as low as several US dollars per year. Discusses the context of quality of life within popular conceptions of health and illness in "traditional" cultures, and the changing socioeconomic climate influencing any consideration of quality of life in the developing world.

Orley, J and Kuyken, W. (1994). (eds). *International Quality of Life Assessment in Health Care Settings*. Heidelberg: Springer Verlag.

Includes a section applying expertise in quality of life assessment at national levels to a relatively new area: international quality of life assessment. That is to say, considering quality of life from an international perspective, and developing a methodology for the assessment of quality of life that can be used in more than one cultural setting.

Patrick, D.L. and Bergner, M. (1990). Measurement of health status in the 1990's. *Annual Review in Public Health*, 11, 165-183.

A prediction that the use of health status measures will increase in the areas of clinical practice and research but not in the areas of decision-making and policy, and a recommendation that this tendency be countered through the co-existence of political will, resources, data, and policy researchers.

Patrick, D.L. and Deyo, R.A. (1989). Generic and disease-specific measures in assessing health status and quality of life. *Medical Care*, 27, S217-S232.

A discussion of the distinctions between four strategies of measurement listed as separate generic and specific measures, disease-specific supplements, and batteries; and the criteria for selection which include project aims, methodologic concerns, and practical constraints.

Patrick, D.L., Sittampalam, Y. and Somerville, S.M. (1985). A cross-cultural comparison of health status values. *American Journal of Public Health*, 75, 1402.

A report of a study conducted to compare the Sickness Impact Profile health status values for samples in the U. S. A. and England. Profiles were found to be largely consistent for ill people in the two countries.

Pearlman, R.A. and Uhlmann, R.F. (1988). Quality of life in chronic diseases: perceptions of elderly patients. *Journal of Gerontology*, 43, M25-30.

A comparison of quality of life perceptions of a population of elderly patients and their physicians. Suggests a definition of quality of life as a multi-dimensional construct of health, social and other variables, and discusses implications of patient-physician differences in assessment tendencies.

Pocock, S.J. (1991). A perspective on the role of quality of life assessment in clinical trials. *Controlled Clinical Trials*, 12, 257S-265S.

A summary of some of the methodologic and practical issues regarding health-related quality of life assessment in clinical trials with emphasis on reasons for health measurement, appropriate clinical situations, statistical issues, and the need for cooperation in future studies.

Read, J.L., Quinn, R.J. and Hoefler, M.A. (1987). Measuring overall health: an evaluation of three important approaches. *Journal of Chronic Diseases*, 40, 7S-21S.

An examination of the practicability and the validity of the General Health Rating Index, the Sickness Impact Profile, and the Quality of Well-being Scale in treatment evaluation.

Rosenberg, R. (1992). Quality of life, ethics, and philosophy of science. *Nordic Journal of Psychiatry*, 46, 75-77.

Argues that a multi-dimensional approach to quality of life, whilst attempting to capture the complexity of the human condition, does not address its subjectivity. An argument is presented that a combination of 'naturalism' and 'hermeneutic' thinking is needed in quality of life assessment.

Sartorius, N. (1993). A WHO method for the assessment of health-related quality of life (WHOQOL). In Walker, S.R. and Rosser, R.M. *Quality of Life Assessment: Key Issues in the 1990's*. Kluwer Academic Publishers: U.K.

A presentation and discussion of some of the preliminary conceptual groundwork for the instrument for quality of life assessment currently being developed by the World Health Organization.

Sartorius, N and Kuyken, W. (1994). Translation of Health Status Instruments. In Orley, J and Kuyken, W. (eds). *International Quality of Life Assessment in Health Care Settings*. Heidelberg: Springer Verlag.

Outlines four broad approaches to the translation of health status measures; discusses the conceptual, semantic and technical equivalence which translation should ensure; and describes a translation methodology, which has been used in numerous international studies coordinated by the World Health Organization.

Schipper, H. (1990). Guidelines and caveats for quality of life measurement in clinical practice and research. *Oncology*, 4, 51-57.

A discussion of the development and current importance of the quality of life concept, its use and properties as well as guidelines for a standard application of quality of life measures.

Schumaker, M., Olschewski, M. and Schulgen, G. (1991). Assessment of quality of life in clinical trials. *Statistics in Medicine*, 10, 1915-1930.

An overview of the development of quality of life assessment in clinical trials in terms of clinical biostatistics including a literature survey of measurement approaches and a review of statistical methods applied to quality of life data analysis.

Siegrist, J. and Junge, A. (1989). Conceptual and methodological problems in research on the quality of life in clinical medicine. *Social Science and Medicine*, 29, 463-468.

An introductory paper on the issues of theory, validity of measurement, and benefits of quality of life assessment and implications for future complementary work between advanced medicine and social science.

Slevin, M.L., Plant, H., Lynch, D., Drinkwater, J. and Gregory, W.M. (1988). Who should measure quality of life, the doctor or the patient? *British Journal of Cancer*, 57, 109-112.

An investigation of the validity of a health professional's assessment of cancer patients' quality of life, anxiety and depression, when the patient's viewpoint is the criterion.

Smart, C.R. and Yates, J. W. (1987). Quality of life. *Cancer*, 60, 620-622.

A discussion of the importance of quality of life measurement in clinical practice as a guide to treatment decisions and the difficulty of measuring subjective parameters and changing status of the patient throughout treatment.

Steinwachs, D.M. (1989). Application of health status assessment measures in policy research. *Medical Care*, 27, S12-S26.

A discussion of health status assessment in policy research, including reflections on possible causes for the neglect of suitable measures in clinical settings, possibly due to perceptions of multi-dimensional and uni-dimensional instruments. Offers a framework for the application of health status measures to policy research with the aim of assuring the availability of appropriate health care.

Thier, S.O. (1992). Forces motivating the use of health status assessment measures in clinical settings and related clinical research. *Medical Care*, 30, MS15-22.

A presentation regarding the epidemiological trends that have rendered the study of outcomes more important in medical decision making than that of process, and a consideration of likely clinical resistance to this new perspective and the implementation of relevant measures of quality of life.

Thuriaux, M.C. (1988). Health promotion indicators for all in the European region. *Health Promotion*, 3, 89-99.

An examination of activities of the European Region of the World Health Organization in the development and use of indicators for health promotion. Presentation of findings of the 1984-1985 evaluation by European Member States of progress in the area and a discussion of problems affecting use of health indicators.

Troidl, H., Kusche, J., Vestweber, K.H., Eypasch, E., Koeppen, L. and Bouillon, B. (1987). Quality of life: an important endpoint in surgical practice and research. *Journal of Chronic Diseases*, 40, 523-528.

A discussion of the advantages both for surgeons and patients of broadening available information on treatment outcome to include quality of life variables.

Varricchio, C.G. (1990). Relevance of quality of life to clinical nursing practice. *Seminars in Oncology Nursing*, 6, 255-259.

A discussion of quality of life assessment in the field of nursing in the facilitation of health care planning and evaluation.

Veldhuyzen Van Zanten, S.J. (1991). Quality of life as outcome measures in randomized clinical trials. An overview of three general medical journals. *Controlled Clinical Trials*, 12, S234-S242.

A presentation of a study which demonstrates that reliable quality of life measurements are insufficiently utilized in clinical trials.

Ware, J. E. (1991). Conceptualizing and measuring generic health outcomes. *Cancer*, 67, 774-779.

Addresses the importance and potential of standardized assessment of patients' perspective and experience of disease and treatment impact through the use of generic measures of health status and quality of life.

Wiklund, I. and Karlberg, J. (1991). Evaluation of the quality of life in clinical trials. Selecting quality of life measures. *Controlled Clinical Trials*, 12: S204-S216.

A comparison of different quality of life measures before and after treatment of a certain population, with conclusions regarding the advantages of using disease-specific measures in detecting small but clinically important changes.

Zhan, L. (1992). Quality of life: conceptual and measurement issues. *Journal of Advanced Nursing*, 17, 795-800.

A discussion of quality of life and its importance in the field of nursing, including an historical perspective, measurement issues, concept dimensions, and approaches in utilization.



## SECTION II - SELECTED GENERIC QUALITY OF LIFE INSTRUMENTS

### Duke Health Profile

A measure to assess adult health status along four dimensions: symptom status, physical function, emotional function, and social function. The latter three can be used independently. Interviewer-administration requires approximately 30 minutes, self-administration requires approximately 10 minutes. Despite measurement difficulties, acceptable levels of reliability, convergent and discriminative validity have been demonstrated. The Duke UNC Profile was developed for use in a clinical setting as a tool for the study of medical, economic, and social intervention on health and disease.

Parkerson, G.R. Jr., Broadhead, W.E., Tse Chiu-Kit. (1990). The Duke Health Profile: A 17 - item measure of health and dysfunction. *Medical Care*, 28, 1056.

Parkerson, G.R., Gehlbach, S.H., Wagner, E.H., *et al.* (1981). The Duke-UNC Health Profile: An adult health status instrument for primary health care. *Medical Care*, 19, 806.

## EuroQol

A standardised, generic index for describing and valuing health states. Designed for self-completion by patients, it is easy to complete, taking only a few minutes. The EuroQol was simultaneously developed in Dutch, English, Finnish, Norwegian and Swedish. Spanish and Catalan versions are also available and work is in progress on French, German, and Italian versions. Classifies respondents into one of 243 health states. Intended to be used in conjunction with other quality of life instruments to aid in the collection of a reference group of data, particularly in the case of cross-national comparisons of health states. The EuroQol instrument consists of five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety / depression. Each dimension has 3 categories.

Brazier, J. Jones, N. and Kind, P. (1993). Testing the validity of the Euroqol and comparing it with the SF-36 health survey questionnaire. *Quality of Life Research*, 2, 169-180.

Carr-Hill, R. A. (1992). A second opinion: health related quality of life measurement - Euro style. *Health Policy*, 20, 321-328.

The EuroQol Group. (1990). EuroQol - a new facility for the measurement of health related quality of life. *Health Policy*, 16, 199-208.

The EuroQol Group. (1992). EuroQol: A reply and reminder. *Health Policy*, 20, 329-332.

Nord, E. (1991). EuroQol: health-related quality of life measurement. Valuations of health states by the general public in Norway. *Health Policy*, 18, 25-36.



## Health Utilities Index

There are three versions of the Health Utilities Index. The original version is comprised of four categories and a utilities calculation formula (Torrance *et al* 1982). The second version contains seven categories and two formulas, one for values and the other for utilities. (Feeny *et al* 1992; Torrance *et al* 1992). The third version was designed specifically to be broad and generalizable for use in numerous settings, including health surveys. Currently, it is in questionnaire form, and covers the categories: vision, hearing, speech, mobility, dexterity, emotional function, cognitive function, pain and discomfort. Interviewer administered.

Torrance, G.W., Boyle, M.H. and Horwood, S.P. (1982). Application for multi-attribute utility theory to measure social preferences for health states. *Operations Research*, 30, 1043-1069.

Feeny, D.H., Furlong, W., Barr, R.D., Torrance, G.W., Rosenbaum, P. and Weitzman S. (1992). A comprehensive multi-attribute system for classifying the health status of survivors of childhood cancer. *Journal of Clinical Oncology*, 10, 923-928.

Torrance, G.W., Zhang, Y., Feeny, D.H., Furlong, W.J. and Barr, R. (1992). Multi-attribute preference functions for a comprehensive health status classification system. McMaster University, Centre for Health Economics and Policy Analysis, Working Paper No. 92-18.

## Index of Health Related Quality of Life

The Index of Health-related Quality of Life is a measure of social, psychological, and physical adjustment on scales of value and utility which is designed to be combined with clinical rating scales in clinical trials. The structure is hierarchial and multi-dimensional: values are derived at each of five levels through a multi-stage scaling method designed to preserve detail and then aggregated into a single figure. One hundred and seventy-five composite health states are valued in the three dimensions of disability, discomfort, and distress. These dimensions are further sub-divided into the seven attributes: dependency, dysfunction, pain/discomfort, symptoms, dysphoria, disharmony, and fulfilment; these attributes are divided into 44 scales. Completed tests of reliability show good results (reliability defined as the extent to which the differences in score represent true differences of the characteristics under consideration). Validity varies relative to the domain. Significant correlation with other measures has been shown. Self-rated, observer-rated, and relative-rated versions are currently being tested.

Rosser, R. M. A health index and output measure. In Walker, S.R. and Rosser, R.M. (ed.s) (1988). *Quality of Life Assessment : Key Issues in the 1990's*. Lancaster: MTP Press.

Rosser, R.M., Cottee, M., Rabin, R. and Selai, C. *The Index of Health Related Quality of Life* London: RCP Publications : (in press)

### McMaster Health Index Questionnaire

A measure of physical, social, and emotional functioning developed with the aim of providing a health status questionnaire suitable for general populations which could predict a health professional's clinical assessment. 59 items are divided between the categories of physical function, social function, and emotional function. Independent scores can be obtained for each section, from 0-1. Alternative weighting schemes are available. The MHIQ shows high correlation with other standardised scales. Sensitivity is highest with self-administration. Reliability has been demonstrated to be acceptable. Questionable suitability for application to elderly populations.

Chambers, L. W., Haight, M., Norman, G. and McDonald, L. (1987). Sensitivity to change and the effect of mode of administration on health status measurement. *Medical Care*, 25 (6).

Chambers, L.W. (1988). The McMaster Health Index Questionnaire: an update. In Walker, S.R., Rosser, R.M. eds. *Quality of Life: Assessment and Application* Lancaster: MTP Press.

## Medical Outcomes Study SF-36 Health Survey

Objective is to develop a general health survey that is comprehensive, psychometrically sound and practical. Developed as a compromise between longer comprehensive health status indexes and less effective single item measures, through the combination of a number of items taken from longer measures. A profile of eight measures covers the areas of physical functioning, role functioning, social functioning, mental health, health perceptions and pain. Self-administered. Acceptable standards of reliability and validity across numerous samples population are reported. Currently in extensive use.

Brazier, J.E., Harper, R., Jones, N.M.B., O'Cathain, A., Thomas, K.J., Usherwood, T. and Westlake, L. (1992). Validating the SF-36 health survey questionnaire: New outcome measure for primary care. *British Medical Journal*, 305, 160-164.

Garratt, A.M., Ruta, D.A., Abdalla, M.I., Buckingham, J.K. and Russell, I.T. (1993) The SF-36 Health survey questionnaire: An outcome measure suitable for routine use within the NHS? *British Medical Journal*, 306, 1440-1444.

McHorney, C. A., Ware, J. E. Rogers, W., Raczek, A. E. and Lu, J. F. R. (1992). The validity and relative precision of MOS Short- and Long-form health status scales and Dartmouth Coop charts. *Medical Care*, 30, MS253-MS265.

McHorney, C, A., Ware, J. E. and Raczek, A. E. (1993). The MOS 36.Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Medical Care*, 31, 247-263.

Ware, J. E. and Sherbourne, C. D. (1992). The MOS 36-item short-form health survey (SF-36). Conceptual framework and item selection. *Medical Care*, 30, 473-483.

Ware, J. E., Snow, K., Kosinski, M. and Gandek, B. (1993). *SF-36 Health Survey: Manual and Interpretation Guide*. New England Medical Centre, MA, USA.

### Nottingham Health Profile

Designed to assess patients' subjective experience of ill health. Its development was influenced by the Sickness Impact Profile, but it emphasizes feelings, or perceived stress, rather than reports of behaviours. The content is based upon patients' accounts of their feelings when ill. A profile of illness effects is given through description of the subjective experience of ill health in six categories: physical mobility, pain, sleep, energy, emotional reactions and social isolation. Extensive testing has shown good levels of reliability and validity.

The questionnaire has been adapted for use in ten countries, according to a standard method. The questionnaire is copyrighted and should not be used without the permission of one of the instrument developers.

The European Group for Quality of Life and Health Measurement. (1989). *European Guide to the Nottingham Health Profile*. Revised edition. Hunt and McKenna.

Hunt, S. M. and McEwan, J. (1980). The development of a subjective health indicator. *Sociology of Health and Illness*, 2, 231.

Hunt, S. M., McEwan, J and McKenna, S. P. (1986). *Measuring Health Status*. Croom Helm.

Hunt, S.M., McKenna, S.P. and McEwan, J. (1989). *The Nottingham Health Profile*. Users Manual. Revised edition.

Wiklund, I. (1990). The Nottingham Health Profile - a measure of health-related quality of life. *Scandinavian Journal of Primary Health Care*, 1, 15-18.

### 15-D Questionnaire on Health Related Quality of Life

A 15-dimensional generic measure of health-related quality of life, including physical, mental, emotional and emotional functioning as well as perceived health status. Each dimension is divided into 4 or 5 levels. A health-related quality of life state is defined as a combination or profile of responses to questions at each level. Scores are determined by a computer algorithm as a function of values assigned to each dimension level and the relative importance assigned to the dimension. Responses are chosen by the subject as values between 1-100. Average weights are determined for the sample. The questionnaire is self-administered in 5-10 minutes; the valuation task time is about one hour. Good levels of reliability have been demonstrated; research on the validity of the measure is in progress.

Sintonen, H. (1981). An approach to measuring and valuing health states. *Social Science and Medicine*, 15C, 55-65.

Sintonen, H. and Pekurinen, M. (1993). A fifteen-dimensional measure of health-related quality of life (15D) and its applications. In Walker, S.R. and Rosser, R.M. *Quality of Life Assessment: Key Issues in the 1990's* United Kingdom : Kluwer Academic Publishers.

### Sickness Impact Profile (SIP)

A behavioural based measure designed to assess the impacts upon daily life activities of illness, and treatment. The Sickness Impact Profile consists of 136 statements grouped into 12 categories: work, recreation, emotion, affect, home life, sleep, rest, eating, ambulation, mobility, communication and social interaction. It is self- or interviewer-administered in 20-30 minutes. Percentage scores can be obtained for the entire measure, each category, and physical or psychosocial dimensions, from 0-100. High reliability and validity have been demonstrated; the SIP has been widely applied and scores are available for many different populations.

Bergner, M., Bobbit, R.A., Carter, W.B. *et al.* (1981). The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care*, 19, 787-805.

Bergner, M., Bobbit, R.A., Kressel, S. *et al.* (1976). The Sickness Impact Profile: conceptual formulation and methodology for the development of a health status measure. *International Journal of Health Services*, 6, 393-415.

Gilson, B. S., Gilson, J. S., Bergner, M. *et al.* (1975). The Sickness Impact Profile: Development of an outcome measure of health care. *American Journal of Public Health*, 65, 1304-1310.

Pollard, W. E., Bobbitt, R. A., Bergner, M. *et al.* (1976). The Sickness Impact profile: Reliability of a health status measure. *Medical Care*, 14, 57-67.

Read, J.L., Quinn, R.J. and Hoefler, M.A. (1987): Measuring overall health: an evaluation of three important approaches. *Journal of Chronic Diseases*, 40, 7S-21S

## SEIQoL Schedule for Evaluation of Individual Quality of Life

An instrument for measuring individual quality of life which places greater emphasis on the individual's perspective than more traditional approaches. The SEIQoL utilizes a mathematical model of individual judgements known as judgement analysis. The subject specifies five areas of life considered most important in a semi-structured interview. Visual analogue scales are used for self-rating in these areas. Judgement analysis is used to evaluate the internal reliability and validity of the individual's quantification. High internal consistency has been shown, though it is higher for healthy than for patient populations. High internal validity has been demonstrated in both populations.

McGee, H.M., O'Boyle, C.A., Hickey, A., O'Malley, K. and Joyce, C.R.B. (1991). Assessing the Quality of life of the individual: The SEIQoL with a healthy and a gastroenterology unit population. *Psychological Medicine*, 21, 749-759.

O'Boyle, C. A., McGee, H., Hickey, A., O'Malley, K. and Joyce, C. R. B. (1992). Individual quality of life in patients undergoing hip replacement. *The Lancet*, 339, 1088-1091.

O'Boyle, C. A., McGee, H. and Joyce, C. R. B. (1994). Quality of Life: Assessing the individual. In Albrecht, G. L. and Fitzpatrick, R. (Eds). *Advances in Medical Sociology, Volume V: Quality of Life in Health Care*. Greenwich, Connecticut: JAI Press.

O'Boyle, C. A., McGee, H., Hickey, A., Joyce, C. R. B. Browne, J. and O'Malley, J. (1993). *The Schedule for the Evaluation of Individual Quality of Life. Administration Manual*. Department of Psychology, Royal College of Surgeons in Ireland, The Mercer Building, Mercer Street, Dublin 2, Ireland.

O'Boyle, C. A. (in press). The Schedule for the Evaluation of Individual Quality of Life (SEIQOL). *International Journal of Mental Health*.



## The World Health Organization Quality of Life Assessment (WHOQOL)

A measure of the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. The instrument was developed in a wide range of languages in numerous different cultural settings and yields comparable scores across cultures.

An assessment in six broad domains: Physical domain; Psychological domain; Level of Independence; Social relationships; Interaction with relevant features of the Environment; and Spiritual domain. The instrument addresses quality of life at two levels of questioning: perceived objective (e.g. Do you feel that pain or discomfort limits your life?) and subjective evaluation (How satisfied are you with your personal relationships?). The instrument yields a quality of life profile across each of the domains as well as for individual facets of quality of life (e.g. Pain and discomfort; Personal relationships). The instrument is currently being field tested in some 15 countries to assess its psychometric properties.

Sartorius, N. (1993). A WHO Method for the Assessment of Health-related Quality of Life (WHOQOL). In Walker, S.R. and Rosser, R.M. (eds). *Quality of Life Assessment: Key Issues in the 1990's*. Lancaster, UK: Kluwer Academic Publishers.

World Health Organization (1993). *WHOQOL Study Protocol*. Geneva: WHO (MNH/PSF/93.9).

The WHOQOL Group. (1993). Study protocol for the World Health Organization project to develop a Quality of Life assessment instrument (WHOQOL). *Quality of Life Research*, 2, 153-159.

The WHOQOL Group (1994). The Development of the World Health Organization Quality of Life assessment instrument (the WHOQOL). In: Orley, J. and Kuyken, W. (eds) *Quality of Life Assessment in Health Care Settings*. Heidelberg: Springer-Verlag.



### SECTION III - GUIDES / BIBLIOGRAPHIES

Bergner, M. and Rothman, M.L. (1987). Health status measures: an overview and guide for selection. *Annual Review in Public Health*, 8 :191.

A discussion of health status assessment measures and criteria for evaluation and selection of instruments for clinical application including correspondence between the study and the measure, reliability, validity, sensitivity, and practicality. A comparison of the Sickness Impact Profile, the McMaster Health Index Questionnaire, the Rand Corporation study, and the index of Activities of Daily Living.

Bowling, Ann. (1991). *Measuring Health : A Review of Quality of Life Measurement Scales*. Philadelphia: Open University Press.

A discussion of conceptual issues of the measurement of quality of life with a listing of selected instruments for the measurement of functional ability, health status, psychological well-being, social networks and social support, and life satisfaction and morale.

Fallowfield, L. (1990). *The Quality of Life: the Missing Measurement in Health Care*. Human Horizons Series. London: Souvenir Press.

A discussion of the quality of life as a philosophical and methodological issue as well as from a health economist's point of view. A presentation of issues and instruments for selected chronic diseases and conditions including cancer, AIDS, cardiovascular disease, arthritis, the elderly and the dying.

McDowell, I. and Newell, C. (1987). *Measuring Health: A Guide to Rating Scales and Questionnaires*. New York: Oxford University Press.

A review of the status of health measurement in 1987, including descriptions of its theoretical and methodological bases, and descriptions of some instruments of health assessment in the areas of functional disability/handicap, psychological well-being, social health, quality of life and life satisfaction, pain and general health measurements.

Erikson, P. and Scott, J. (1993). The On-Line Guide to Quality of Life Assessment (OLGA): Resources for selecting quality of life assessments. In Walker, S.R. and Rosser, R.M. *Quality of Life Assessment : Key Issues in the 1990's*. United Kingdom: Kluwer Academic Publishers.

An information resource service created for the selection of quality of life instruments for use in clinical studies. Given the context of a particular study of application setting which requires an instrument, a computer

algorithm selects the most appropriate measure from a database of instruments. Characteristics of the study context taken into consideration include: the type and purpose of the study, characteristics of the study population, treatment benefits and side-effects, method of administration, and practical considerations of budget and time.

Patrick D. L. and Erikson, P. (1993) *Health Status and Health Policy: Allocating Resources to Health Care*. Oxford University Press, New York.

Quality of Life Bibliography and Indexes. (1990). *Medical Care*, 28.

A comprehensive collection of published works on the subject of health-related quality of life with a focus on clinical applications and conceptual issues. Three indexes list quality of life publications alphabetically by the name of the author for instruments, by therapeutic category for instruments, and by therapeutic category for papers.

Spilker, B. (1990). *Quality of Life Assessment in Clinical Trials* New York : Raven Press.

Stewart, A. L. and Ware, J. E. (1992) (eds). *Measuring Functioning and Well-being. The Medical Outcomes Study Approach*. Durham: Duke University Press.

Streiner, D.L. and Norman, G. (1989). *Health Measurement Scales - a Practical Guide to their Development and Use*. Oxford: Oxford University Press.

Presents the major issues involved in developing or assessing a health status measure. This comprehensively covers ground from the initial literature review to the development and selection of items and scaling responses, to the design and implementation of reliability and validity studies.

Walker, S.R. and Rosser, R.M. (1993). *Quality of Life Assessment : Key Issues in the 1990's*. United Kingdom: Kluwer Academic Publishers.

A presentation of the concept and philosophy of quality of life assessment and some selected instruments in major disease areas: cancer, arthritis, Parkinson's disease, respiratory disorders, hypertension, angina, psychiatry, and skin disease.

Wilkin, L., Hallam, L. and Doggett, M. A. (1992). *Measures of Need and Outcome for Primary Health Care*. London: Oxford Medical Publications.

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