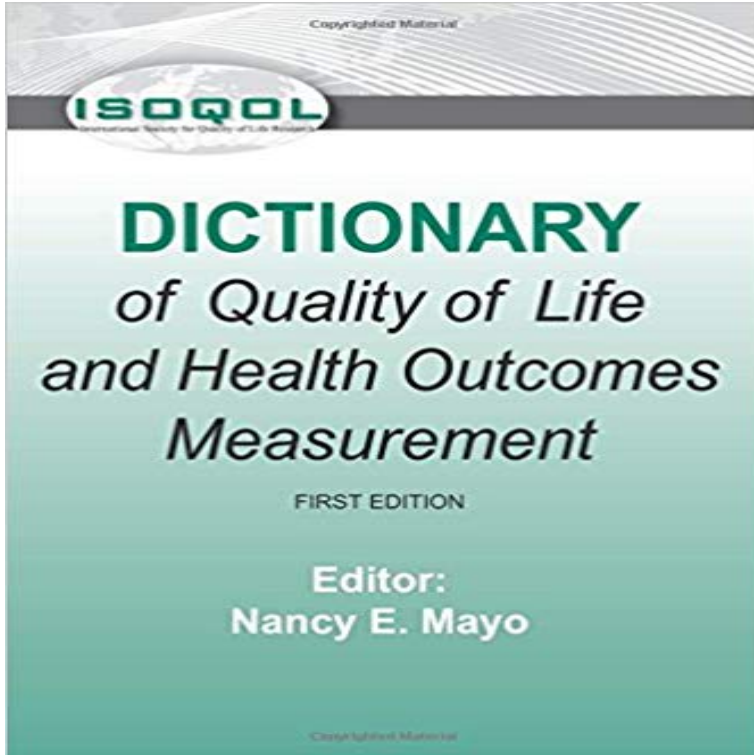


ISOQOL Dictionary of Quality of Life and Health Outcomes Measurement



Quality of Life and Health Outcomes and other terms referring to the physical, mental and emotional effects experienced by people as they encounter health challenges are in wide use and misuse in the health care and health research community. Many of these terms are used interchangeably without recognizing that they have completely different meanings and, thus, require different measurement approaches and different types of interventions if they are to be optimized. The notion of creating a dictionary of these terms arose so that novices and experts, researchers and clinicians, can commonly address these health outcome challenges.

The correct term for this collection of definitions is a vocabulary for a vertical audience as the definitions reflect the usage in QOL and health outcomes measurement rather than all usages and the definitions were written to have meaning for the novice while still being useful for the expert. As a starting point for the vocabulary, terms were chosen based on the frequency of use in journal articles focussing on of quality of life research. The terms fall broadly into 8 concepts all of which have an identified need for consistent and correct terminology: research process, measurement properties, statistics for QOL research, designs for QOL research, patient reported outcomes (PROs), theories and models, knowledge translation, and personal factors. Rather than being A malevolent literary device for cramping the growth of a language and making it hard and inelastic (Ambrose Bierce, *The Devils Dictionary*), This dictionary, however, is a most useful work. (Ambrose Bierce, *The Devils Dictionary*).

To avoid the devil, terms reflecting modern advances in outcomes research and design were included even they may not yet be in common usage in QOL research. For example, while designs like the stepped wedge or platform trials may not

yet have penetrated the world of QOL research, they will not if no one knows about them. More than 20 people contributed definitions and following editing, the dictionary was opened up for review and comment from members of ISOQOL and their suggestions and modifications were included, adding a component of peer review to the process. Editor, Nancy E. Mayo, BSc(PT), MSc, PhD James McGill Professor Fellow of the Canadian Academy of Health Sciences Department of Medicine School of Physical and Occupational Therapy McGill University nancy.mayo@mcgill.ca

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