

ISPOR Avedis Donabedian Outcomes Research Lifetime Achievement Award Presentation and Recipient Remarks: Donald Patrick and Pennifer Erickson

The 14th Avedis Donabedian Outcomes Research Lifetime Achievement Award was presented at the ISPOR 21st Annual International Meeting, on May 23, 2016, Washington, DC. At the session, the ISPOR Avedis Donabedian Award Committee Chair Mark Sculpher, PhD, introduced 2012 recipient, Donald Patrick, MSPH, PhD, to present the award. The following is Donald Patrick's introduction of Pennifer Erickson, PhD, followed by her acceptance speech.

Award Presentation

Donald Patrick, MSPH, PhD



I am pleased to introduce Pennifer Erickson as the recipient of the 2016 ISPOR Avedis Donabedian Lifetime Achievement Award. Dr. Erickson's career of dedicated service has had a significant impact on the field of health services and outcomes research and on ISPOR as a whole. Through her activities at the National Center for Health Statistics (NCHS),

her service on US government committees, her leadership of the Special Interest Group on health outcomes (formed early in ISPOR's history), her participation in ISPOR Task Forces, and her scientific contributions and publications. Dr. Erickson distinguished herself as a pioneer in the field of health economics and outcomes research.

Dr. Erickson was appointed to lead the Clearinghouse on Health Indexes at the NCHS in 1973. This was a pivotal appointment, as during the next three decades, she would serve as a chronicler of the field of health outcomes by publishing cumulated annotated bibliographies that established the importance of health outcomes in population health and in the evaluation of health services outcomes [1]. These bibliographies are a history of the field and were influential in bringing together outcomes scientists in the United States and abroad. During this time, I had the privilege of teaching with Pennifer in many different venues, including the American Public Health Association annual meetings, the Association of Health Services Research (now Academy Health), and early short courses at ISPOR.

Pennifer's government service at the NCHS culminated in her contributions to population health assessment during the 1990s and the establishment of a measure of "years of healthy life" as an indicator of progress toward the health promotion goals in Healthy People [2]. Years of healthy life is a single measure that incorporates health-related quality of life and life expectancy, which gives a more comprehensive picture of the population's health. Such a summary number would help in monitoring the nation's health, identifying health priorities, evaluating the effectiveness of interventions, and comparing the effectiveness of different interventions [3]. This methodology has been applied widely and it is even possible for you to calculate your own years of healthy life by entering your age and other information about your health and health history into a health calculator [4].

Dr. Erickson has had other important publications, including an analysis of the lifecycle of health status or PRO (patient-



ISPOR Avedis Donabedian Lifetime Achievement Award Committee Chair Mark Sculpher, MSc, PhD (l), presenter Donald Patrick, PhD, and 2016 recipient, Pennifer Erickson, PhD

reported outcomes) instruments in our field [5]. Pennifer has also worked with ISPOR's Chief Scientific Officer Dr. Richard Wilke on "Examining Item Content and Structure in Health Outcomes Instruments," published in *Value in Health* [6].

In summary, Pennifer Erickson's contributions to her field—in the US and beyond—and to ISPOR have led to the conferral of the 2016 Avedis Donabedian Lifetime Achievement Award. I congratulate her warmly and celebrate this great accomplishment.

Recipient Remarks

Pennifer Erickson, PhD



It is indeed a great honor to receive ISPOR's Avedis Donabedian Outcomes Research Lifetime Achievement Award and to join earlier awardees, especially Donald Patrick and George Torrance who, in addition to their significant contributions to the development of the science of health outcomes measurement, have been long-time contributors to and supporters of my work in collecting and disseminating information on the development and application of health outcomes measures. They have been both mentors and collaborators throughout my career.

My introduction to measuring health status—as more than the result of diagnostic tests and disease prevalence—began in 1973 when I joined the National Center for Health Statistics (NCHS) to establish the Clearinghouse on Health Indexes. When NCHS's involvement in the development of new measures waned in the early 1990s, my interest continued through the establishment of the On-Line Guide to Quality-of-Life Assessment (OLGA).

I welcome this opportunity to share some reflections that are based on 40 years of cataloguing and reporting on developments in health measurement. The growth in the types and number of instruments, as well as their eventual worldwide applications, can be grouped into five phases.

Phase 1: Foundations of Outcomes Measures (1946-1972)

The Modern Era of health outcomes measures is generally recognized as beginning after World War II. Intellectual traditions

that emerged during this phase and are fundamental today's measures include: the 1947 WHO definition of health, scaling and decision theory methods, and survey methodologies. These technologies resulted in self-reported instruments that consist of three components: multidimensional health concepts; scaling methods; and scoring systems.

Phase 2: Development of Health Indexes and Profiles (1973-1983)

The first instruments measured physical, social, and mental well-being as specified by the WHO definition, and were developed by researchers in North America and the United Kingdom. Two of the earliest measures, the Health Utilities Index and the Quality of Well-Being scale, created single scores that could be combined with mortality data to form an adjusted life expectancy metric. The first instruments that provided separate scores for each health concept in the measurement system were the Sickness Impact Profile and Nottingham Health Profile. These indexes and profiles were generic and emerged concurrently.

Disease-specific profile measures, the first of which assessed outcomes in arthritis patients, began appearing toward the end of this phase.

Phase 3: The Golden Age of Health Outcomes Measures (1984-1996)

Rapid growth in the development and application of health outcomes measures was started by a "quality-of-life" study that appeared in the *New England Journal of Medicine* in 1986. This report, which stimulated widespread development and use of disease-specific measures in pharmaceutical trials in North America and Europe, used a battery of existing questionnaires and rating scales to assess multiple health concepts; the disparate scoring systems made it difficult to interpret the findings. Thus, the batteries of tools were quickly replaced by new instruments that were fit for purpose. The new measures included diagnoses that ranged from Alzheimer's disease to urological conditions.

Consultancies emerged not only to meet the growing need for new instruments, but also to provide analytic services. Also, implementation in multinational trials resulted in the development of standardized methods for translating and culturally adapting outcomes measures.

In 1995, ISPOR became the major professional society supporting the development and use of outcomes measures in clinical studies. An early initiative was ISPOR's role in harmonizing activities between the US Food and Drug Administration (FDA), the European Medicines Agency, and industry. One result was the adoption of the term patient-reported outcomes (PRO); another was the issuance of an FDA guidance for using outcomes measures in the drug approval process.

Although almost all growth in the number of health outcomes measures was for use in clinical studies, four new generic measures were developed in this phase: two indexes, the DALY (disability-adjusted life year), EQ-5D; and two profiles, PROMIS (patient-reported outcomes measurement information system), and the SF-36.

The end of Phase III marked the end of innovations in techniques to measure health outcomes. A more complete documentation of the developments of health outcomes measures that occurred during Phases I through III has been published in *Health Status and Health Policy: Quality of Life in Health Care Evaluation and Resource Allocation* [7].

Phase 4 – Globalization [of Outcomes Measures] (1996-2015)

This phase was characterized by the application of methods that emerged in the previous phases to develop measures for a diversity of diseases, health conditions, and cultures. This is reflected by the expansion of ISPOR's membership, which now has chapters on every continent.

Phase 5 – What's Next: Post-Modern Era (2016 and beyond)

With the fundamental structures of health outcomes established, it's time to re-examine the foundations that led to the development of outcomes measures in the Modern Era and update as appropriate. For example, developments in social science research have identified new concepts, such as happiness, flourishing, and purpose in life, that are not as yet routinely included in health outcomes measures. Similarly, recent advances in understanding how people make decisions may result in advances in scoring methods.

To establish health outcomes measurement as a science, we need to develop tools, such as a classification system of health concepts. This is an appropriate role for ISPOR, given its demonstrated leadership in the field.

A major innovation to health care that will present new challenges for outcomes researchers is the task of integrating measures of health into the "internet of everything," to use Steve Case's term. Outcomes researchers need to be involved in this process from the outset to help assure that patients are treated fairly and ethically.

Throughout my career of providing health outcomes information, many people, regrettably too many to list, have generously contributed to my understanding of the measures and their uses. My aim has been to encourage collaboration across academia, industry, and government to expand the use of composite measures of health to inform decision making. Some the interactions were brief, others lasted a lifetime. Along the way, I have met many wonderful people, many of whom have become colleagues and others friends. Thank you, again.

References

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