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<u>Session 1– Invited paper</u>

MEASURING HEALTH: AN INTERNATIONAL PERSPECTIVE

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I. INTRODUCTION AND BACKGROUND

1. The measurement of health, either at individual level or population level, is an important activity both nationally and globally. To improve health and better manage health systems measurement is essential: you cannot manage unless you measure. And, you cannot measure unless you have tools and methods. An array of methods and data sources has been developed to quantify deaths, diseases and other aspects of health. Collecting and rendering these statistics comparable across countries as an international public good is one of the constitutional mandates of the World Health Organization. The improvement and standardization of methods to measure and compare health is, therefore, key components of the work of WHO, carried out in collaboration with Member States and other international organizations and research networks.

2. *Mortality* - Traditionally the first achievement of international comparisons have been in the field of deaths. At international level, well-established data sources and estimation methods exist for mortality. A significant problem, however, remains: only 110 countries out of 192 WHO Member States report mortality statistics thanks to the International Classification of Diseases (ICD) [1]. Remaining 82, on the other hand, fail to do so despite their death toll is five-fold of the 110 countries. This poses a huge "information paradox": we have the least information where we need the most to deal with the burden of deaths and disability.

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3. *Health and Disability* - The transition from death-related measures to actual health measures has been relatively recent, also confounded with the intrinsic difficulties of definition, measurement tools, analysis and interpretation. Given the advances in disease descriptions in epidemiology, assessment of daily activities of individuals in the context of their health conditions have culminated in better formulation and operationalizations of tools for measuring health and disability. The earlier International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980 [2] and the significantly revised version as International Classification of Functioning, Disability and Health (ICF) in 2001 [3] exemplify the international need and consensus in defining and measuring health and disability.

4. This paper will deal with the international aspects of measurement of health and disability within practical context of collaboration between WHO and UN-ECE.

II. INTERNATIONAL PERSPECTIVES

5. Dramatic increase in measuring and managing economy has greatly enhanced global economics. If only we could translate this into health!

6. Seeing the constellations of actors, institutions and practices as "health systems" require measurement of health as a *sine qua non* of the assessment of health system performance. We do need this for planning, benchmarking, targeting, monitoring, managing, research and evaluation with the overall aim of improving population health as a whole and reducing health inequities. Using a clear process and effective knowledge management and sharing approach countries may learn from each other.

7. International standards and norms are needed with a supporting set of tools and methods, as the key driver of globalization of health dictates. Given the global na ture of health problems ranging from HIV/AIDS to health information technology, international travel to intellectual property rights we do need standard legitimate and meaningful definitions of health.

8. Recognizing the need and key drivers in this field UN-ECE, Member States and WHO have been collaborating to foster the international consensus and knowledge sharing platform. A Joint ECE-WHO Meeting on Health Statistics (CES/AC.38/1998/3) was held 14-16 October 1998 in Rome. This meeting concluded (among other things):

- "... to further encourage international organizations involved in health statistics to increase their cooperation and coordination in those areas of health data collections and research which are not yet adequately coordinated.
- "... to encourage countries to intensify coordination and data comparability between different health sectors and data producers, ministries, statistical agencies, research institutes, etc.
- "... to give a higher priority to the area of health statistics, and that its work program focuses more on the conceptual issues of measurement, classifications, standardisation and harmonisation of data." (CES/AC.38/1998/3, 25 November, 1998, paragraphs 14 and 15)

9. Last Joint UN-ECE and WHO meeting was held in Ottawa Canada, 23- 25 October 2000 to discuss a common framework for health status assessment aiming comparability and review ongoing data collection efforts and instrumentation in the field. (CES/2001/28, 17 January 2001). This meeting concluded that enhancing cross-population comparability of health status is important. Indeed it raises important issues for the use of health status data within countries, especially those with ethnically or culturally diverse populations. Current approaches to cross-

population comparability need strengthening, and warrant further research and development. (CES/2001/28, 17 January 2001, paragraph 7)

10. The meeting also took certain practical steps and reviewed the candidate list of domains suggested by WHO to be used within its framework as a basis for a standardized health status description, and largely endorsed the content with two main adjustments (CES/2001/28, 17 January 2001, paragraph 9). Consequently WHO took action on these recommendations and included the suggested list as 'Suggested ICF Data Requirements for ideal and Minimal Health Information systems or Surveys" as part of the ICF which was unanimously approved by all Member States in 2001 in the World Health Assembly. (See Appendix 1).

11. The ICF and this short list is a parsimonious and comprehensive set of main domains provides a conceptually clear and operational basis for measuring health states. The list is generic and can be mapped onto various assessment instruments. In this way, it can form the basis of health or disability survey instruments. Various assessment strategies (e.g. anchored questions, vignettes etc.) or statistical methods (e.g. item response theory etc.) could be applied onto this list. Similarly various algorithms could be applied to generate an "overall health" score that can be dissected back to its components analytically. This list could be used to generate summary measures of population health or monitoring individual outcomes in response to health interventions.

III. A RE-ITERATION OF CONCEPTUAL CLARITY FOR DEFINITION OF HEALTH:

12. Given the WHO's definition of health as "a state of complete mental and social well-being and note merely the absence of disease or infirmity"; the concept of health has been seen:

- A part of well-being
- Different from disease or infirmity

13. ICF is in tune with this approach, and furthers the understanding and operationalization of the health:

- 1. Health is a part of general human well-being. Economics, environment, education can also be seen as other sectors that contribute to human well-being. For sake of clarity we need to differentiate boundaries of health from other well-being components. This differentiation is essential to study the interaction of health and human development.
- 2. Health is a complex, multifaceted phenomenon. There are multiple components that constitute a person's health. For example various body functions: seeing, hearing, energy, eating, digestion, sleeping ...or activities: walking, sports, working ... can all be seen as part of one's health. Consequently ICF has created an exhaustive list of various domains that cover the body functions, activities and participation domains that can jointly be seen to constitute health. Descriptions of health states using domains provide a profile of health or these can be algorithmically combined to form an index of overall health.
- 3. There may be differences between what a person "can do" and "does do". Different users may need to use either one or both, depending on their purpose. ICF basically refers to these as "capacity" and "performance" taking into account the environmental context and assistance.

4. Despite the fact that attempts to operationalize "health" measurement and "disability" measurement have taken different origins, the revision prœess of ICF has brought the two lines in consilience. Any domain in ICF could be used to assess health and capacity alike. For example domain of "vision" could be used to assess the visual capacity say for driving licence assessment, as well as assessment of blindness. Similarly they can be used to link health and disability surveys.

IV. INTERNATIONAL COMPARABILITY OF HEALTH DATA

14. Comparison is the basis of science and naturally one expects the outcome of any measurement be comparable if they are done in the same manner. The same goes for measurement of health when applying any ICF related instrument. Similar response on a domain should indicate the same level of health given the psychometric properties of the instrument (e.g. reliability, validity) and its implementation (translation, application, sampling etc) are appropriate.

15. The findings on the results of health interview surveys, however, posed significant problems of comparability. There have been systematic observations of implausible results which may indicate systematic biases between the man and women, rich and poor, as well as education, ethnic or geographical groups. Such probably artifactual differences exist also in results of similar standard surveys despite the systematic efforts towards harmonization [4 - 6]. These results are because of the self-report nature of the data and people may report their functioning in reference to different comparators (e.g. they may say that their walking is as good as their peers, or they may refer to it as worse or better comparing to their youth or expectations from themselves).

16. To ensure comparability basic methodological procedures (identical questions, response scales, translation protocols and application-mode) should be implemented and analytically the known confounders should be controlled for. Nevertheless, we may end up with differential item functioning (DIF) for various reasons. Statistical methods such as modern item response theory (IRT) [7] could assist in identifying the bias. These methods are successfully implemented in economics and education sectors to seek parity or equivalence. As IRT is an "internal validation" method, if DIF exists, then it is difficult to know in what way one should correct it. Best possible solution over arbitrary decisions is to develop an external validation such as an independent unidimensional indicator. Such indicators could be found in domains that avail themselves for physical measurement such as vision, mobility or even cognition. Where such measurements are not possible, external validation of some domains may not be viable, such as pain or affect.

17. Use of vignettes to anchor responses may provide a solution to the comparability problem. Vignettes have been used in social science research for long to calibrate responses. Vignettes are short case stories that provide concrete stimuli to respondents to choose their rating. For example, when you are asked about your mobility you may rate yourself as excellent to very bad; but if you are given options ranging from an olympic athlete to a quadriplegic person you have a "ruler" with fixed anchor in front of your eyes. Vignettes may provide a fix to the problem of comparability of self-report survey data if they are used properly. The World Health Survey has utilized the vignette approach as a cost-effective solution to the comparability problem [8]. This approach assumes that vignettes are fixing the ability on a given domain across countries and that any differences are due to response category cut-point shifts. This assumption, and whether people really view vignettes in an identical fashion to themselves, need to be questioned.

V. INTERNATIONAL USE OF ICF BASED HEALTH DATA

18. Given the nature of ICF as the international consensus and the possibility to use it as a "Rosetta stone" to map the assessment instruments to and anchoring extent of difficulty with operational definitions to known calibrators we have a first step to achieve better health and disability statistics. ICF can, and should, of course, be further developed. At this stage we cannot say that it has been used to its full potential to measure health states and related outcomes. WHO's World Health Survey has been a good model to implement ICF concepts in the health assessment in general population samples and this may form the basis of future research applications and population norms. Initial results indicate that you get finer detail data with better quality on population health and disability levels.

19. Comparability is an essential requirement for reporting on health internationally in addition to reliability and validity. WHO and the international organizations and research networks should use an explicit strategy to establish cross-population comparability which is incorporated into the common instrument design for each health domain.

ATTACHMENT 1:

Suggested ICF Data requirements for ideal and minimal health information systems or surveys

Body Functions and Structure	s Chapt	er and code	Classification block or category
Vision	2	b210-b220	Seeing and related functions
Hearing	2	b230-b240	Hearing and vestibular functions
Speech	3	b310-b340	Voice and speech functions
Digestion	5	b510-b535	Functions of the digestive system
Bodily excretion	6	b610-b630	Urinary functions
Fertility	6	b640-b670	Genital and reproductive functions
Sexual activity	6	b640	Genital and reproductive health
Skin and disfigurement	8	b810-b830	Skin and related structures
Breathing	4	b440-b460	Functions of the respiratory system
Pain*	2	b280	Pain
Affect*	1	b152-b180	Specific mental functions
Sleep	1	b134	Global mental functions
Energy/vitality	1	b130	Global mental functions
Cognition *	1	b140,b144,b164	Attention, memory and higher–level cognitive functions
Activities and Participation			
Communication	3	d310-d345	Communication receiving – producing
Mobility*	4	d450-d465	Walking and moving
Dexterity	4	d430-d445	Carrying, moving and handling objects
Self-care*	5	d510-d570	Self-care
Usual activities*	6 and 8	8	Domestic life; Major life areas
Interpersonal relations	7	d730-d770	Particular interpersonal relationships
Social functioning	9	d910-d930	Community social and civic life

^{*}Candidate items for a minimal list

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