

A blueprint for an internationally harmonised Summary Measure of Population Health

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EXECUTIVE SUMMARY

The Joint Action on Healthy Life Years is a European collaboration between the European Commission and almost all European Member States to develop a European Health and Life Expectancy Information System (EHLEIS).

One of the objectives of the Joint Action is to strengthen international harmonisation of Summary Measures of Population Health (SMPH) such as Healthy Life Years (HLY), a life expectancy without activity limitations, which the European Commission has been monitoring annually since 2005. The European Union already deployed many efforts to harmonize SMPH and in 2011 a working group on a Blueprint for SMPH was set up in order to extend these harmonisation efforts to OECD countries (including the US and Japan). Three annual seminars were organised. During the first seminar (April 2012), concepts and criteria behind SMPH were discussed and the need for a harmonised global measure of disability was expressed in the context of Health Expectancies. Based on a conceptual paper prepared by the EHLEIS team, needs, conceptual content, and criteria for a global measure of participation restriction in relation to a measure of functional limitation were discussed during the second seminar (April 2013). During the third seminar (April 2014), discussion was extended to technical aspects to consider in the development of a global instrument. This document, which results from the three seminars, provides guidelines for the development of a global measure of participation restriction (together with a measure of functional limitation) to be used as a basis for Health Expectancies across OECD countries.

INTRODUCTION

Over the last decades, Summary Measures of Population Health (SMPH) have gained popularity amongst countries and international organisations (Murray et al. 2002). However, the absence of a common framework for SMPH development and a lack of reliable cross-national data on disease and disability hamper comparison of SMPH between countries (Mont & Loeb 2010, van der Maas 2003). In this context, the European Joint Action EHLEIS¹ initiated an international discussion to further develop the conceptual basis of a SMPH with the objective to enhance comparability at global level. A working group on a blueprint for SMPH was established to extend European harmonisation efforts to OECD countries, including the US and Japan. Three annual seminars were organised in Paris between April 2012 and April 2014².

The working group focused on Health Expectancies in its attempt to characterize internationally comparable SMPH. Health Expectancies (sometimes also called Healthy Life Expectancies) have become a standard for measuring and monitoring population health at both international and national levels (Stiefel et al. 2010). They were first developed to address whether or not longer life is being accompanied by an increase in the time lived in good or in bad health, by dividing life expectancy into life spent in different states of health (e.g. in good or bad perceived health, with or without disability, with or without chronic disease). In this way Health Expectancies add a dimension of quality to the quantity of life lived.

Health Expectancies are appealing because they are easy to comprehend (i.e. measured in years) and easy to calculate (i.e. from a period life table and morbidity prevalence obtained from a population survey). They can be used for a variety of purposes, including comparing the health of one population with another, monitoring change in the health of populations, identifying and quantifying health inequalities, and comparing groups within a population (Mathers 2002). Other SMPHs such as Health-Adjusted Life Expectancy (HALE) or Disability-Adjusted Life Years (DALY) were also discussed during the first seminar, but not extensively reviewed.

During the first seminar, Health Expectancies which are currently monitored in Europe, the US and Japan were examined. In Europe, the Euro-REVES 2 project contributed to the harmonisation of the health measures used to calculate Health Expectancies by proposing a common set of indicators for introduction into European surveys (Robine et al. 2003). It further suggested a Minimum European Health Module (MEHM) containing three global health questions (the self-perceived health, the presence of chronic conditions and the Global Activity Limitation Indicator). The MEHM later became a major pillar of the Eurostat Health Survey System strategy which aims to introduce common health-related instruments in health and non-health surveys. Since 2005, three Health Expectancies are monitored annually across the European Union:

- Life Expectancy without activity limitation (“Healthy Life Years” indicator);
- Life Expectancy in good or very good health;
- Life Expectancy without chronic morbidity.

¹ EHLEIS stands for European Health and Life Expectancy Information System. www.eurohex.eu

² The list of participants to each seminar is provided in APPENDIX 1.

In the United States, “Healthy People 2020” tracks similar Health Expectancies, measured from slightly different health indicators (Healthy People 2020 2011):

- Expected years of life in good or better health;
- Expected years of life free of limitation of activity (from multiple survey items);
- Expected years of life free of chronic diseases (from a list of selected chronic diseases).

Interest has also been expressed in the measurement of health through functioning, which addresses major policy objectives. No single global measure of functioning has been proposed so far, although the Budapest Initiative developed potential approaches to measure functioning internationally.

Since the start of the EHLEIS project, Japan has shown interest in harmonisation efforts initiated in Europe and has recently replicated the three Health Expectancies monitored in the EU. For that purpose, Japanese researchers created conversion tables that allow health measures similar to those of the MEHM to be obtained.

Overall, Health Expectancies monitored in Europe, the US and Japan are based on fairly similar health measures. Yet, harmonisation efforts within the EU have found that a high level of data comparability is hard to reach (Eurostat 2008) and that international comparability could be better achieved based on clear conceptual specification of the health dimensions to measure and guidelines for the indicator measurement.

Following the Euro-REVES 2 project and discussion previously initiated during the 1995 REVES meeting, the working group focused on global health measures, sometimes also called “general” measures (Robine et al. 2003, Verbrugge et al. 1996). Global measures provide a first overview of the health situation and differences between or within countries. More specific instruments, conversely, are meant to provide a greater depth of understanding of differences observed through more detailed questions covering a health domain. A global indicator is obtained from one question (the preferred option) or a restricted number of survey questions – such as questions using a branch-and-stem format or several items combined. Global measures are designed to require little room and time, which makes their inclusion in various health and non-health surveys easier and, therefore, facilitate frequent measurement and better monitoring over time (Li et al. 2009, Robine et al. 2003, Sloan et al. 2002).

This document summarises discussions from the three seminars organised by the JA-EHLEIS including the justification for the measurement approach selected. It provides guidelines for the future development of a summary measure of population health to be used to calculate a comparable Health Expectancy across the European Union and OECD countries. After extensive discussion, the JA-EHLEIS decided to focus on developing a global summary measure of health based on participation restriction.

1. Rationale: main objectives of Health Expectancies

Health Expectancies as Summary Measures of Population Health may serve multiple purposes. In accordance with former international discussions (Mathers 2002), the working group identified four main purposes for Health Expectancies:

- Monitoring change in the health of a population;
- Comparing the health of one population with another;
- Identifying and quantifying health inequalities across measures of disadvantage;
- Comparing groups within population strata.

Health Expectancies are mainly used for domestic purposes and provide useful information for various policies (such as health, disability and social policies). Nevertheless, there is a long standing interest in making comparisons with other countries not only to see how one's own country ranks against others, but to benefit from the experience of others. In the context of the JA-EHLEIS, the main objective for Health Expectancies is to monitor population health and to allow comparisons across European Union and OECD countries. In order for these comparisons to be meaningful, the information itself – in particular the health information – must be comparable across countries, the indicators used must address the same constructs and the data collection process must not introduce differences that would affect the relevance and validity of the comparisons. Therefore, this document provides guidelines for the development of better harmonised Health Expectancies³.

2. Measurement priority: a summary measure that captures health-related restrictions in participation

Health is a complex concept that in the broadest sense includes a wide range of dimensions such as risk factors, disease, impairment, and disability. While health encompasses what is happening within the body (the bio-medical approach), it also encompasses the impact of pathology or abnormal functioning of organs and body structure on the individual's ability to participate in society. In order to calculate a summary measure of health, it is first necessary to identify the aspect of health to be captured and to be clear on the choices made. There is no one single summary measure of health but a range of measures that may tell inconsistent stories about the 'health' of the population. The working group discussed the many important dimensions of health that could be used to calculate Health Expectancies cross-nationally. Amongst these, disability, mental health and chronic morbidity received a high level of consideration both within the working group and amongst external experts consulted (by means of a survey). The working group selected disability as the key dimension for which a global measure is needed at the international level, allowing the

³ It should be mentioned that a better harmonisation of Health Expectancies is also likely to foster the use of the indicator for domestic purposes given that internationally accepted measures are more likely to be undertaken and included into national surveys and monitoring systems than other instruments. This may however not always be the case if validated and well-accepted indicators are already being used and monitored nationally. Legislation may in some cases constrain the use of new indicators (e.g. measurement requirements for disability policies).

calculation of comparable disability-free life expectancies. Disability was selected because it represents the consequence of injury and disease (within body health). As such it encompasses many other dimensions of health giving it an advantage over other more specific health dimensions such as chronic conditions or mental health. Disability may also be less problematic to measure in comparable ways than dimensions of health that are more closely related to the receipt of health care. Measures that are based on diagnosed conditions will vary based on access to health care whereas the report of disability, while challenging, can be obtained from population surveys.

However, disability, like health, is a complex and multifaceted concept making measurement comprehensively with a global indicator very challenging. To overcome this difficulty, the working group reviewed the different components of disability and selected a global measure of participation restriction as the goal for an internationally harmonized summary measure of health. In addition, a global measure of functional limitation (or limitation in action) was selected as a complementary dimension on which to build a summary measure.

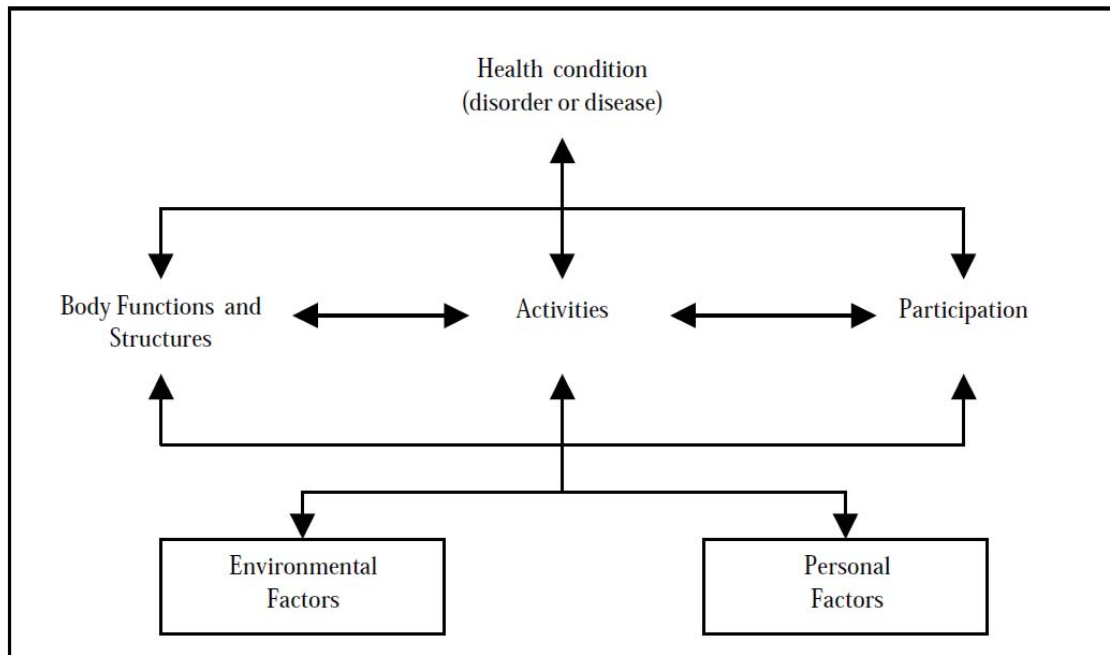
In this section, we present the conceptual framework used for disability and explain the rationale for the selection of participation restriction and functional limitation.

2.1. A conceptual perspective on disability

During the first seminar, the working group agreed to use the International Classification of Functioning, Disability and Health (ICF) as a guide for measurement development (WHO 2001, WHO 2002). In the ICF, disability is an umbrella term for impairments, activity limitations and participation restrictions⁴. It also denotes the negative aspects of the interaction between an individual's health condition(s) and that individual's environmental along with personal factors that can affect functioning. (Fig. 1).

⁴ The main terms of the ICF are reproduced in APPENDIX 2.

Fig. 1. Interactions between the components of ICF



As disability is a complex and multidimensional process, attempting to grasp its full complexity in one measure may not be feasible (Altman et al. 2006, Madans et al. 2011, Mont 2007b). Accordingly we decided to prioritize the measurement of one or more dimension(s) of the ICF (i.e. body function and structure, activity, participation). This approach required us to better specify the meaning of “activity” and “participation” as the ICF does not clearly differentiate them and proposes one classification system for the two dimensions.

The ICF defines activity as “the execution of a task or action by an individual” and participation as “involvement in a life situation”. These categories are not mutually exclusive, and the definition of participation fails to refer to the social dimension of participation (Dijkers 2010). Following Badley (Badley 2008), we distinguish actions (or acts) and tasks which differentiate activity from participation, which makes reference to societal involvement (see definitions in APPENDIX 2)⁵. Participation therefore represents the societal perspective of functioning, i.e. the performance of roles and social involvement in activities. Conceptually, we adopt a clear division between activity (action or task) and participation (Whiteneck & Dijkers 2009):

- Activity occurs at the person level while participation occurs at the societal level.
- Participation involves social role performance.
- Activities (tasks and actions) are the building blocks of social roles. Many alternative sets of activities might accomplish a role and many individual activities are part of several different roles.
- Activities are characteristics of people and can be assessed.. Participation is relational and takes place in a social setting.

⁵ The partitioning used is close to that of the Washington Group between wilful actions, specific tasks, organised activities and role participation (Madans et al. 2004).

In practice, this means that an activity can be done alone while participation gains its societal perspective by performance with or for others. It also means that participation is more influenced by environmental factors and social norms.

We further distinguish two types of activities: actions (or acts) and tasks. Limitation in action is very similar to the category of 'functional limitation' in Nagi and Verbrugge models (Verbrugge & Jette 1994) and 'wilful action' limitation in the Washington Group position paper (Madans et al. 2004) (or also 'basic activity' limitation in a former WHO framework). Actions reflect overall abilities of body and mind to carry out basic volitional bodily operations at the level of the organism (whole person). Examples include walking, climbing steps, reading, communication. Tasks, on the other hand, relate to the purposeful things that people do in daily life in a specific context. Tasks usually comprise coordinated, sequential and often synchronised actions (or other tasks). Tasks include most of what is covered by the terms 'activities of daily living' and 'instrumental activities of daily living'. They also include specific tasks that are carried out as part of work, leisure or social activities. Examples include bathing, dressing, and feeding.

2.2. Rationale for a global measure based on disability

2.2.1. Multiple uses of global disability indicators

In the context of the JA-EHLEIS, the main use of any global disability indicator is to calculate disability-free life expectancies by combining disability data with mortality data. As is the case for health, a range of disability-free life expectancies can be calculated depending on which aspects of disability are chosen for the metric. The ICF offers different ways in which disability can be measured and each could be used to develop an indicator of disability-free life expectancy. In addition to this descriptive use, global measures of disability may fulfil a variety of needs (Deeg et al. 2003, Leonardi 2010, Madans et al. 2004, Madans et al. 2011, Mont 2007a, Verbrugge 1997, Verbrugge et al. 1999), including:

- 1. Description:** Evaluation of the scope of disability (or level of functioning) in a population (prevalence estimation). This includes the comparison of subgroups or populations and the monitoring of trends in disability. Combined with mortality data it allows evaluation of whether we observe an expansion or compression of disability (cf. disability-free life expectancies)
- 2. Evaluation of interventions:** Assessment at the population level of the medium to long-term outcome of interventions. Several preventive (or intervention) strategies aim to sustain and restore functional capacity and to maximize a person's social involvement and independence (Verbrugge & Jette 1994). With the advent of civil rights legislation related to disability, equalisation of opportunities has been set as a major purpose for the measurement of disability.
- 3. Needs Assessment:** Identification of individuals with disabilities in order to provide services or resources (e.g. income support, housing, transportation, assistive technology, vocational or educational rehabilitation, long-term care). This need is better fulfilled with more detailed instruments than with a global approach.

4. **Screening** : Screening of persons with disabilities with a global question to ask them additional information about disability and follow them up longitudinally.
5. **Explanation**: Using a disability measure as a dependent/independent variable in research relating disability and other domains (e.g. life satisfaction, hospitalisation, institutionalisation). If included in multiple surveys, it can also be used to link information obtained in two different surveys, typically a health and a non-health survey.

A single global indicator may serve different needs. For instance, a global disability indicator developed for a descriptive use (prevalence estimation and disability-free life expectancy calculation) may also serve as a screener, or an explanatory variable. However, not all needs may be fulfilled with the same instrument.

2.2.2. Rationale for the disability dimensions selected

The choice of one or more dimension(s) is guided by the needs of research and public policies. The measurement of participation restriction - as a main indicator - and functional limitation - as a supplement - has a series of advantages:

1. Participation summarizes the interaction of functional limitation and the environment. In the last decade, there has been an important shift from the medical model to a “biopsychosocial” model of disability which integrates environmental factors and puts the emphasis on participation – the ultimate step in the disablement process. As a higher order functional dimension, participation encompasses and involves body functioning and structure, and activities (Madans et al. 2004, Mont 2007a).

A measure of participation would account for: 1) the impact of the prevention, treatment and rehabilitation on impairment and functional limitations; and 2) the impact of actions aiming to increase the participation of people with disabilities (accommodations and enabling environments). However, measuring participation restriction alone does not enable one to differentiate these two impacts. This is the reason why a global measure of functional limitations is seen as a useful supplement.

2. Measures of participation restriction and functional limitation are useful for public policies:

A. Disability and health policies. Disability policies from the European Union and the United Nations emphasise the role of participation restriction and the necessity to have adequate measures for it. The United Nations Convention on the Rights of People with Disabilities defines persons with disabilities as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (Article 1). At the EU level, the MHADIE project (Measuring Health and Disability in Europe: Supporting policy development) recently highlighted the “need for valid outcome measures for EU governments to monitor and evaluate the effectiveness of their disability policy, in terms of the primary ICF dimension of participation” (Leonardi 2010). A global measure of participation restriction is therefore likely to be helpful for disability policies.

The Washington Group on Disability Statistics and the Budapest Initiative have recently developed both global and extended survey instruments encompassing what we denote by functional limitation. The instruments were specifically developed for their public policy relevance. Objectives of the instruments were, respectively (i) to monitor the UN Convention on the Rights of Persons with Disabilities by indentifying a population at risk for restrictions in ability to fully participate in society due to functional limitations in key domains; (ii) to provide internationally comparable health state statistics (United Nations 2013, Madans et al. 2011). A global measure of functional limitation can therefore provide useful information for both health and disability policies.

B. Ageing policies. In most OECD countries, the ageing of the population is becoming one of the most pressing societal challenges. Fostering active and healthy ageing has become a public policy priority. Within the European Union, active and healthy ageing is seen as fundamental to the pursuit of smart, sustainable and inclusive growth and better jobs. Monitoring participation restriction is therefore particularly relevant in the context of ageing societies.

3. Desired conceptual characteristics of the global indicators

This section outlines the conceptual content of the disability dimensions selected, namely participation restriction and functional limitation. The desired global indicators should reflect the conceptual characteristics described for each dimension and meet the requirement of ascertainment through a single or limited number of questions.

3.1. Participation restriction

1. Measure of participation

The survey instrument should ask respondents about their functioning at the societal level. The instrument should make explicit or implicit reference to situations of societal involvement such as work and employment, leisure, parenting, community, social and civic life.

2. Measure of performance with current accommodation

In the ICF, Activity and Participation have two qualifiers: performance and capacity. The desired instrument should measure performance. Performance “describes what an individual does in his or her current environment. Because the current environment brings in a social context, performance as recorded by this qualifier can also be understood as “involvement in a life situation” or “the lived experience” of people in the actual context in which they live. This context includes the environmental factors – all aspects of the physical, social and attitudinal world.” (ICF, p123). A measure of performance enables the differences in the environment as a scene-setter to be taken into account (Badley 2008) and to inform on the extent to which an individual is adapted with current accommodation to his particular environment and vice-versa. The notion of performance therefore encompasses the use of assistive devices and / or personal assistance as well as the built environment, attitudes towards persons with functional limitations and laws that the rights of persons with disability. Note that the environment may vary greatly from country to country.

3. Health-relatedness

Our conceptual framework assumes that participation restriction has a health cause. We want to capture health-related participation problems only. Characteristics of what constitute a health problem or conditions are well accepted internationally. Ideally, the instrument should be understood to cover all health-related reasons, including physical health, mental health and emotional health. Consequences of ageing should also be included. In addition, ill-health caused by injuries/accidents, congenital conditions, birth defects, etc. should be included. It is irrelevant whether the health problem is diagnosed by a doctor or not.

4. Long-term duration of limitations

Although not unanimously accepted, most experts agreed that the purpose of the instrument is to measure the presence of long-standing limitations. This allows to obtain more stable estimations of the prevalence of persons with disabilities and to exclude acute limitations. Temporary, recurrent or seasonal limitations are therefore excluded. This may however be problematic if we want to capture mental health problems. A six month period is often used to define chronic or long-standing diseases in surveys. This is also suggested for the length of the limitation.

5. Comprehensive content

The instrument should encompass numerous domains of participation (i.e. work, school, parenting, community, leisure, housework, social and civic life). A difficulty is that the content of roles and social involvement varies by age, gender, culture and country.

6. Normative comparison

Following a normative model of disability, we would like respondents to assess their level of participation against population standards or norms which are relative to cultural and social expectations (Ziebland et al. 1993). These norms vary by gender, age group, culture, social status. Making an explicit reference to the norm enables a relative measure of disability (as opposed to an absolute measure) to be obtained and to assess if people are well adapted to their environment. Such a measure can be comparable cross-culturally. In practice, a comparison to peers or to the norm should be included in the instrument. Internal or habitual comparisons (“your usual activities”) are not desirable.

7. Severity of limitations

Instead of solely measuring the presence of a disability (YES/NO or limited/not limited), the severity (how much) of the limitation should be measured⁶. In accordance with the ICF, we believe that knowing the degree of severity (or difficulty) is desirable for reporting variations in population disability. It is essential for testing hypotheses about population trends (e.g. dynamic equilibrium hypothesis). A measure of severity with appropriate response options also makes the indicator more sensitive to change. The disadvantage of the measurement of severity is that it requires the definition of additional cut-off points on the disability scale, and these cut-off points may vary greatly between cultures, age groups, gender etc. (cf. vignette studies)⁷.

3.2. Functional limitation

1. Measure of functional limitation

The survey instrument should ask respondents about their limitations with basic actions such walking, climbing steps, reading, communication.

2. Measure of capacity : without assistive devices or personal assistance

Functioning should be measured within, on or near the skin. Functional limitation means something that is intrinsic to the individual (equivalent to “capacity” in the ICF). In other words, it is independent (to the extent possible) of external factors such as the physical or social environment. While aids like eyeglasses or pain medication can be considered to be essentially “within the skin”, wheelchairs and wheelchair accessible public transport are not. In that respect, we endorse the Budapest Initiative approach (United Nations 2013).

⁶ The importance (or centrality) of the domain in which a restriction/limitation is reported could also be measured.

⁷ Note that such cut-off points are already used to make a distinction between not limited and limited, which is not always evident.

3. Long-term duration of limitations

As for the participation dimension, the purpose of the instrument is to measure the presence of long-standing limitations which have more serious consequences than temporary or recurrent limitations.

4. Comprehensive content

The instrument must have a global scope. It should encompass numerous domains of functioning at the individual level (i.e. walking, climbing steps, reading, communication etc.)

5. Severity of limitations

As for the participation dimension, we want to measure the severity (or difficulty) of individual functional limitations.

4. Technical characteristics of a global indicator

To realise a global measure, the instrument selected or developed will have to meet a set of necessary criteria, labelled technical characteristics (Perenboom et al. 2002, Verbrugge et al. 1996, Verbrugge 1997, Verbrugge et al. 1999):

1. Conciseness of the instrument

The instrument should be as concise as possible. A global indicator is obtained from one question (the preferred option) or a restricted number of survey questions such as questions using a branch-and-stem format or several items combined. The instrument may be included in a short module such as the Minimum European Health Module. The conciseness of the instrument should be evaluated in terms of survey time required to answer to the instrument. Note that for the survey of the European Commission, the unit of interest is the “variable” and not the question. A variable usually refers to one concept or dimension to measure and can be composed by multiple questions.

2. Usability for general population surveys

The instrument should be relevant to the adult population targeted in (health and non-health) surveys, often individuals aged 15 years or older. This means that the domains covered by the question should apply to the whole adult population. The instrument will not allow measurement of disability in children (individuals younger than 15 years old) as it requires a different conceptual approach and a different measurement strategy. Further work, however, should specifically focus on the measurement of disability of children as otherwise assumptions about disability prevalence in children are required for the calculation of disability-free life expectancy at birth. The work of UNICEF and the Washington Group on the measuring child disability should be used as a starting point (UNICEF 2013).

3. Simplicity of the question(s)

The instrument has to be easily grasped and has to make sense to respondents. The cognitive burden on the respondent should be as low as possible. The simplicity (or complexity) of a question is best assessed qualitatively using cognitive and field tests. It can nevertheless be evaluated during

the design phase using best practice guidelines. The following characteristics can serve to evaluate the simplicity of a question (Lenzner et al. 2010, Yan & Tourangeau 2008): the number of clauses, the number of words per clause, the inclusion of low frequency words (i.e. words which are not often used in everyday life language, such as participation), the presence of vague or imprecise relative terms (e.g. “seldom”), the presence of vague or ambiguous noun-phrases (such as abstract nouns which have unclear or ambiguous referent), the syntax etc. In addition, the question(s) should be easily “transferable” to different languages. The grammar and concepts used in the language of reference (i.e. English) should have equivalent in other languages.

4. Amenability to multi-modes of collection

The instrument should be useable in self-administered surveys and applicable also to telephone and face-to-face interviews, with no intervention from the interviewer. Another requirement of the instrument would be its ability to be completed by a proxy respondent, i.e. when another person gives an answer on behalf of the selected respondent. The mode and proxy effect should be considered when crafting the instrument and assessed during the test phase.

5. Instrument selection and design

Following a non-systematic review of existing global instruments and in accordance with the results of the experts survey (APPENDIX 3), the working group approved that a generally accepted global measure of participation restriction has still to be developed. Whereas the GALI or Global Activity Limitation Indicator (Van Oyen et al. 2006) is conceptually close to what is envisaged, the GALI question lacks simplicity, which hampers its acceptability in an OECD context. Furthermore, the GALI question was developed within the EU and there is no guarantee that the content validity of the question can be extended to other OECD countries such as Japan.

As far as functional limitation is concerned, discussions revealed that a global approach is difficult to achieve without asking separate questions on different domains of functioning. We agreed to use the experience of the Washington Group to measure functional limitation. The Washington Group conducted extensive work on the global measure of functioning. Four of the six items in the Washington Group set could be used to measure functional limitation globally, each item referring to a different domain of functioning (Table 1). The working group agreed to use the Washington Group short set of questions as a starting point for the measure of functional limitation. Further work should evaluate whether the domains covered by the Washington Group instrument are the most relevant for OECD countries.. Discussion on the domains for inclusion in OECD relevant global measure of functional limitation is left for further work.

In this section, we describe the strategy suggested for the development of a global measure of participation restriction using conceptual and technical characteristics described in the preceding sections. Given the number of technical (4) and conceptual characteristics (8) defined for participation restriction, it appears difficult to find or develop an instrument including all the desired characteristics. In particular, the conciseness constraint seems difficult to follow if all conceptual characteristics are explicitly included into the instrument. Using pre-testing in English, we suggest a procedure for the instrument design:

1. Setting a technical constraint: The instrument should be as short as possible (in terms of survey time) while being simple. In the design phase, simplicity should be evaluated using recognised principles of question design. The simplicity constraint should not be violated by any means⁸.
2. Determining necessary conceptual characteristics: Comprehensiveness of the measure of participation, health-relatedness, and normative comparison form the core of the instrument pursued. These characteristics should be explicitly included in the instrument unless it can be proved that they can remain implicit. The later scenario would improve simplicity and conciseness without changing the conceptual content.
3. Evaluating the necessity of each conceptual characteristic: For each conceptual characteristic, it is suggested to evaluate whether explicitly including a question or clause making reference to the characteristic has an added value or not. For some characteristics (e.g. health-relatedness), there are different options for the inclusion of the information into the instrument. In such cases, evaluation should be made as to whether the extended options have an added value compared to more concise references to the characteristic (e.g. detailing all sorts of health causes vs. general reference to health problems). Possible means of implementations of each conceptual characteristic are presented in Table2. Note that in the table, there are 6 conceptual characteristics as the comprehensive content is evaluated together with the measure of participation. In Table 2, the core characteristics appear in the first positions as they should to be tested in priority.

Table 1 – The four core questions of the Washington Group Short Set of Questions on Disability

<p>The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.</p> <ol style="list-style-type: none"> 1. Do you have difficulty seeing, even if wearing glasses? <ol style="list-style-type: none"> a. No - no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all 2. Do you have difficulty hearing, even if using a hearing aid? <ol style="list-style-type: none"> a. No- no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all 3. Do you have difficulty walking or climbing steps? <ol style="list-style-type: none"> a. No- no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all 4. Do you have difficulty remembering or concentrating? <ol style="list-style-type: none"> a. No – no difficulty b. Yes – some difficulty c. Yes – a lot of difficulty d. Cannot do at all
--

⁸ Note that the other two technical characteristics (usability for general population surveys and amenability to multi-modes of collection) are not as constraining as conciseness and simplicity and should therefore be verified at a later stage, during the testing phase.

4. Finding a trade-off between conciseness and the conceptual characteristics: At the end of the pre-testing of different forms of the instrument, a trade-off should be found between optimising conciseness and including additional clauses or questions in the instrument. This should always be done under the simplicity constraint.

Table 2 Implementation of conceptual characteristics

Conceptual characteristic	Option 1	Option 2	Option 3
Comprehensive measure of participation	Reference to multiple domains of societal involvement	Reference to "usual activities"	
Normative comparison	Reference to the norm (people or people of the same age)	No reference to the norm if it can be shown that an explicitly clause does not enhance normative comparison	
Cause of limitation: a health problem	Reference to multiple health dimensions	General reference to health	No reference to health problems if it can be shown that the survey context or preceding questions guide the interpretation of the question as health-related
long-standing limitations	Question or clause on duration	No reference to long-standing limitations if it can be shown that the respondent interpret a health problem as long-standing	
with current accommodation	Question or clause on the use of assistive devices and/or personal assistance	No reference to assistance if it can be shown that respondents understand it that way without a clause	
level of severity	5 response categories	4 response categories	3 response categories

6. Translation, testing and validation

After the design phase, the selected instrument should be translated, tested and validated in order to make sure that the information measured is accurate and comparable across different countries.

Translation

The instrument should be translated from English into relevant languages using a strict protocol (to be defined) which clearly taps the conceptual basis of the measure. A good starting protocol is the Euro-REVES method. Eurostat and the European Social Survey also provide useful protocols for translation.

Testing

A testing protocol has to be defined and strictly followed in order to allow cross-country analysis. Testing protocols from the European Social Survey, SHARE or the Washington Group should serve as a basis for the specification of the protocol. Field and cognitive testing should be conducted in at least one country of each language group included in the EU and OECD countries. The main objectives of the tests will be to determine if: (i) the instrument is being interpreted as intended by the developers in that it covers participation restriction comprehensively; (ii) the instrument is interpreted consistently across countries; (iii) the instrument applies to the whole adult population and is useable across different survey modes.

Validation

Field testing should allow assessment of the validity of the instrument in particular content validity and face validity. In addition, reliability should be assessed in at least some countries based on a test-retest design. The sensitivity of the response scale should also be evaluated during the test phase. Validation should also investigate the impact of different implementation methods, such as the use of different modes of data collection, use of proxy interviews, the location of the instrument in the questionnaire and relation to other instruments, seasonality effect.

7. Recommendation for implementation

The instrument will be ready for use in population surveys after it has been shown to have validity and comparability in a sufficient number of countries. A high level of comparability of measured indicator is better achieved if the instrument is implemented in similar ways across the different countries. In order to minimise survey effects, we recommend all countries use comparable data collection method, sampling design, question order, survey types (health vs. non-health survey), sampling frames, use of proxy, and quality controls. Deviation from the recommended approach (which is to be further elaborated) should be carefully documented, and its impact on cross-country comparison evaluated.

8. Conclusion

This document results from three years of discussions on the international harmonisation of Summary Measures of Population Health at EU and OECD level. It puts forward the development of two global measures of health based on disability: a global measure of participation restriction (as a main measure) and a global measure of functional limitation (as a supplement). Such instruments are highly relevant for both research and policy purposes. Once designed, the two measures would form a short set of questions that could easily be introduced into population surveys of EU and OECD countries, allowing for the first time to calculate highly comparable Summary Measures of Population Health at EU and OECD level. The global measure of participation restriction, on the one hand, would have to be developed from scratch, using the conceptual characteristics and guidelines described in the document, together with the European experience with the GALI question. The global measure of functional limitation, on the other hand, is rather seen as an OECD adaptation of the Washington Group short set of questions on disability statistics.

This document intends to serve as a guide for the actual selection, design, testing and validation of the proposed global disability indicators. Further work is still needed. The series of seminars initiated by the European Union set the basis for subsequent international collaboration, having as a core group the EU, the US and Japan. We therefore recommend the EU, the US and Japan to share the leadership of further work and to invite OECD countries such as Canada and Australia to take part to this initiative.

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APPENDIX 1

List of seminar participants

List of seminar participants

Participant	Affiliation	Seminar 1	Seminar 2	Seminar 3
Jean-Marie Robine	(INSERM, France)	x	x	x
Herman Van Oyen	(Scientific Institute of Public Health, Belgium)	x	x	x
Emmanuelle Cambois	(INED, France)	x	x	x
Jürgen Thelen	(Robert Koch Institute, Germany)	x	x	x
Marten Lagergren	(Gerontology Research Center, Stockholm)	x	x	x
Carol Jagger	(Newcastle University, UK)	x		
Bernard Jeune	(University of Southern Denmark, Denmark)	x	x	x
Giorgos Ntoulos	(Hellenic Statistical Authority, Greece)	x	x	x
Viviana Egidi	(University la Sapienza, Italy)	x	x	x
Wilma Nusselder	(Erasmus MC, The Netherlands)	x	x	x
Henrik Bronnum-Hansen	(University of Copenhagen, Denmark)	x	x	x
Chris White	(Office for National Statistics, UK)	x	x	x
Jan-Willem Bruggink	(Statistical Office - CBS, Netherlands)	x	x	x
Pia Wohland	(Newcastle University, UK)		x	
Nicolas Berger	(Scientific Institute of Public Health, Belgium)	x	x	x
Xavier Briffault	(CNRS, France)	x		
Toshiyuki Ojima	(Hamamatsu University School of Medicine, Japan)	x	x	x
Gaetan Lafortune	(OECD)	x	x	x
Jennifer Madans	(NCHS, US)	x	x	x
Laurence G. Branch	(University of South Florida, US)	x		x
Richard Klein	(CDC, US)		x	
Rakovac Ivo	(WHO-Europe)		x	
Jakub Hral	(Eurostat)	x	x	x
Bart Denorre	(Eurostat)	x		
Pascal Wolff	(Eurostat)			x
Michele Zagordo	(European Commission)	x		
Marianne Van den Berg	(European Commission)		x	
Ana Villar	(City University, UK)			x

APPENDIX 2

Glossary of definitions

ICF GLOSSARY

Functioning - In the ICF, functioning is an umbrella term encompassing all body functions and structures, activities and participation. The term demotes positive aspects of the interaction between an individual (with a health condition) and that individual's contextual factors (environmental and personal factors) (ICF, p.3, 212).

Participation – A person's involvement in a life situation. It represents the societal perspective of functioning (ICF, p.14).

Impairment – Problem in body function or structure as a significant deviation or loss (ICF, p.12).

Environment - The external or extrinsic world that forms the context of an individual's life. Environmental factors make up the physical, social, and attitudinal environment in which people live and conduct their lives. These factors are external to the individual and can have a positive or negative influence on the individual's performance as a member of society, on the individual's capacity to execute actions or tasks, or on the individual's body function or structure (ICF, p.16).

Body functions – the physiological functions of body systems, including psychological functions. "Body" refers to the human organism as a whole, and this includes the brain. Hence, mental (or psychological) functions are subsumed under body functions. The standard for these functions is considered to be the statistical norm for humans. (ICF short version, p.190)

Body structures – the structural or anatomical parts of the body such as organs, limbs and their components classified according to body systems. The standard for these structures is considered to be the statistical norm for humans. (ICF short version, p.190)

Activity -the execution of a task or action by an individual. It represents the individual perspective of functioning. (ICF short version, p.190)

ADDITIONAL DEFINITIONS

Actions – Limitations in actions is similar to the category of ‘Functional Limitations’ in Nagi and Verbrugge models (Verbrugge & Jette 1994) and ‘Willful action’ limitations in the Washington Group position paper (Madans et al. 2004) (or also ‘basic activities’ limitations in a former WHO framework). Actions reflect overall abilities of body and mind to carry out basic volitional bodily operations at the level of the organism (whole person). Examples include walking, climbing steps, reading, communication.

Functional limitation – Difficulty to execute an action.

Tasks (Specific Tasks in Washington Group terminology) - Tasks relate to the purposeful things that people do in daily life in a specific context. Tasks usually comprise coordinated, sequence and often synchronised acts (or other tasks). Tasks include most of what is covered by the terms ‘activities of daily living’ and ‘instrumental activities of daily living’. They also include specific tasks that are carried out as part of work, leisure or social activities. Examples include bathing, dressing, and feeding etc.

Societal Involvement/participation (organised activity + role participation in Washington Group terminology) - “societal involvement concerns the individual as a player in socially or culturally recognized areas of human endeavour. The main feature of societal involvement is that it is defined by social role”. Societal involvement is likely to comprise a range of acts and tasks which take place in an appropriate setting. Examples include work and employment, leisure, parenting, community, social and civic life.

Persons with disabilities - “those who have long-term physical, mental intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” (United Nations Convention on the Rights of People with Disabilities, Article 1).

APPENDIX 3

Results of experts survey

Results of experts survey

Introduction

To enrich conceptual discussion on international harmonisation of Summary Measures of Population Health, the JA-EHLEIS sought additional input from international experts of the REVES network¹. For that purpose a questionnaire on Health Expectancies and disability measurement was developed and sent to all REVES members on 6 March 2014. Respondents were asked to complete the questionnaire and return it by 18 March 2014. The main results are presented below.

Survey population

Invited : 507 addresses from REVES mailing list².

Replies: 47

Response rate: 9%

Origin of respondents :

- European Union (31)
- North America: USA (5) + Canada (3)
- Japan, Australia, Egypt, Jordan, Palestine, Sudan

Respondents originated from 22 different countries.

¹ <http://reves.site.ined.fr/>

² Note: some addresses were incorrect and some experts have multiple addresses in the mailing list. The survey was therefore sent to less than 500 different experts.

Part 1: Health Expectancies

Q1 Indicate to what extent Health Expectancies should meet the following purposes (1 = not important at all; 5 = very important)

Purpose	Mean	Median	1st quartile	percentage (>=4)
Health monitoring (national or regional level)	4.5	5	4	93.6
Comparing populations	4.3	4	4	80.9
Understanding differences between populations	4.0	4	3	67.4
Health care / long-term care planning	3.7	4	3	61.7
Health care performance evaluation	3.1	3	2	38.3
Evaluation of health-related interventions	3.1	3	2	31.9
Monitoring health inequalities	4.3	4	4	87.2
Informing social policies	3.9	4	3	73.9
Informing pension policies	3.6	4	3	55.3
Informing disability policies	4.0	4	3	74.5
Informing health policies	4.1	4	4	76.6

Note that amongst non-EU respondents, “Understanding differences between population” received a high score. However, such a purpose is not realistic with Health Expectancies alone (i.e. without the use of decomposition or attribution methods).

Comments:

- need to improve data collection
- need comparable health data.

Q2. For each selected dimension (and sub-dimension) indicate how important it is to have/obtain an internationally comparable Health Expectancy (1 = not important at all; 5 = very important)

Dimension	Mean	1st quartile	percentage (>=4)
Health-Related Quality of Life	3.9	3	68.2
Self-rated health	3.8	3	69.6
Disability	4.3	4	87.2
Impairments	4.1	4	81.8
Basic activity limitations	4.3	4	93.5
Participation/higher order activity limitation	4.1	4	80.4
Self-care	4.0	3	71.7
Mobility	4.2	4	80.4
Work disability	4.1	4	78.3
Chronic morbidity	4.4	4	88.9
Mental health	4.2	4	80.4
Stress	3.5	3	47.8
Depression	3.9	3	65.2
Anxiety	3.5	3	52.2
Capability	3.5	3	54.8
Pain/discomfort	3.5	3	51.1

Note that for non-EU participants Health-Related Quality of Life also ranks high.

Q.2.B. In your opinion, which dimension of health/morbidity is likely to become a measurement priority during the 21st century?

Dimension	Frequency
Disability	9
Mental health	8
Chronic morbidity	5
Participation	4
HRQoL	3
Index of health	3
Activity limitation	2

Part 2: Disability and Disability-Free Life Expectancy

Purposes of Global disability indicators.

Our main purpose is to describe the scope of disability in a population

5 general purposes from the literature:

1. Description
2. Evaluation of Interventions – including equalization of opportunities
3. Needs Assessment
4. Screening
5. Explanation (as independent/dependent variable; link surveys)

Q3.A. Do you agree with this list? - 84% YES

Comments:

- Equalization of opportunity should be a purpose as such
- Evaluation: not realistic with a single item
- Needs assessment: not realistic with a single item
- Screening: might be difficult
- Explanation – link between surveys: not realistic as a same instrument included in health and non-health surveys leads to different results!

Q3.B. Could a global measure of disability fulfil multiple purposes? - 82% YES

Comments:

- Not all purposes with same instrument
- Same indicator for: prevalence estimation, screening and explanation
- Description: data comparability should be improved internationally

Q4. Participation Restriction

The JA-EHLEIS specified the following desirable characteristics of a global measure of participation: Comprehensive content; Health-relatedness; Duration of the limitation; and Severity of the limitation.

Q4.A. Evaluate and comment the relevance of each feature.

1.Health-relatedness - 83% relevant or very relevant

Comments:

- include ageing as health
- include injuries
- metrics will often pick up non-health factors
- health is so broadly defined nowadays that not so relevant anymore

2.Duration of the limitation - 80% relevant or very relevant [60% for non-EU]

Comments:

Attempting to define a duration cut-off is very problematic; people with restricted participation who have not yet reached the duration threshold may, or may not, eventually meet it but prognostication about expected duration is highly speculative.

3.Comprehensive content - 74% relevant or very relevant

Comments:

- not feasible with one indicator
- social aspects of disability are important especially for informing the barriers to participation
- domain relevance varies with age => problematic
- see GALI

4.Normative comparison - 67% relevant or very relevant

Comments (positive):

- it allows cultural adaptation
- it contextualizes the measure

Comments (negative):

- not important at all because it is all about how a person evaluates his or her own participation
- many norms in one country? Is there a population norm?
- introduces subjectivity
- unrealistic (with interview survey)
- difficult in international context; translation
- people should be of the same age
- individuals rather compare to peers, people of the same age or in a comparable situation. If a normative comparison is envisaged the norm should be clear.

8.Severity of the limitation - 87% relevant or very relevant [80% for non-EU]

Q4.B. Given the features you judge relevant to include, what is the minimum number of items necessary to achieve a global measure of participation restriction?

	%	% (non-EU)
1 item	8.9	7.1
2 or 3 items	35.6	21.4
more than 3 items	55.6	71.4

Q4.C. Indicate a good example of a global measure of participation restriction.

Most frequent answer: GALI

Q4.D. Is the GALI a good candidate in the pursuit of internationally comparable global measure of participation restriction? - 67% YES

Q5. Impairment / Functional Limitation

The JA-EHLEIS discussed the possibility to achieve a global indicator of impairment/functional limitation from a restricted number of items.

Q5.A. What is the best strategy to obtain a global measure of impairment?

	%	% (non-EU)
a global question	11.1	7.1
separate items for each dimension of impairment	71.1	57.1
a specific dimension as a proxy	11.1	21.4
other	6.7	14.3

Comments:

- too difficult; need more than one item
- need a list of impairment to prompt the respondent as to what sort of things should be considered
- People will self-define the scope of impairments in inconsistent ways
- less accurate than specific questions on domains
- Hard not to be context dependent
- It is a more efficient strategy... but is it viable?
- A starting point could be to use one big domain (like mobility)

Q5.B. When specifying the conceptual content of a global measure of impairment, the duration and the severity of the impairment were described as desirable characteristics.

1.Duration of the limitation: 80% relevant or very relevant [73% for non-EU]

2. Severity: 96% relevant or very relevant [80% for non-EU]

Comments:

- “Absolutely necessary”
- “Metric should also not capture relatively mild conditions”

Q5.D. Indicate a good example of a global measure of impairment.

- Washington Group
- Budapest Initiative
- EQ-5D-3L
- HUI3
- US American Community Survey (6 questions on disability)
- ONS harmonised standards for disability measurement
- “Are you able to walk stairs on your own?”
- Include cognitive and mental health: e.g. memory complaints



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