DSS/2015/Sept/04.3

## **Item 4.3**

Global Activity Limitation Indicator (GALI) as a core variable

MEETING OF THE EUROPEAN DIRECTORS OF SOCIAL STATISTICS

Luxembourg, 15-17 September 2015

BECH BUILDING, ROOM QUETELET

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#### 1. Introduction

This document presents Eurostat's proposal for disability-related variables, in particular the Global Activity Limitation Indicator (GALI) and the health variable on 'Self-perceived health' (SPH), to be included as core social variables into the EU Labour Force Survey (LFS) and other ESS social surveys in the context of the modernisation of social statistics.

It follows information provided to the Directors of Social Statistics (DSS) in November 2013 and April 2014, to the Labour Market Statistics Working Group (LAMAS WG) and to the Public Health Statistics Working Group in 2013-2014.

In November 2013, the DSS agreed that Eurostat initiates further methodological work to improve GALI with the help of a dedicated Task-Force and postponed the final decision on Eurostat's proposal to its September 2015 meeting.

The present document summarises in section 2 the background of this initiative, including related policy needs, recalls the current situation of collecting disability statistics in ESS surveys and the original Eurostat proposal for the modernisation of social statistics regarding GALI. Section 3 presents key findings of the GALI Task-Force and section 4 describes the consultations of the respective Working Groups. Section 5 includes Eurostat final proposal on the introduction and implementation of GALI and the health variable on 'Self-perceived health' (SPH) in all ESS surveys under the framework regulation on IESS (Integrated European Social Statistics). This proposal is for DSS discussion and adoption:

Eurostat agrees with the opinions and recommendations of the Task-Force on GALI and therefore invites the Directors of Social Statistics to:

- 1. Agree on the need to collect disability-related information in all ESS social surveys in order to answer to EU policy needs.
- 2. Adopt GALI as a core variable, which means to include GALI into LFS every two years and in other ESS surveys (those which do not yet include it). In addition, to include also the variable 'Self-perceived health' (SPH) as GALI cannot be asked alone in a questionnaire.
- 3. Endorse the GALI Task-Force report, comment on its recommendations (included in this document and in Annex 1) and ask the respective Working Groups to examine their technical implementation.

#### 2. BACKGROUND

## 2.1. Policy needs for disability statistics

This section recalls policy needs for disability statistics. Two main policy frameworks shape today's disability policies at international, European and national level. They are the <u>United Nations Convention on the Rights of Persons with Disabilities</u> and the <u>European Disability Strategy 2010-2020</u>.

#### United Nations Convention on the Rights of Person with Disabilities (UNCRPD)

The UNCRPD was adopted in December 2006, and entered into force on 3 May 2008. The EU is a party to the Convention since January 2011 together with 25 Member States, Norway and Switzerland. The three remaining Member States (Ireland, the Netherlands and Finland) and Iceland have signed the Convention and are in the process of ratifying it.

The UNCRPD puts clear obligations on State parties to ensure that persons with disabilities<sup>1</sup> can enjoy all human rights and fundamental freedoms and contains provisions addressing most aspects of the lives of persons with disabilities (access to health, employment, education, social participation, civil rights, etc.).

The UNCRPD lays down in its Article 31 on 'Statistics and data collection' that State parties undertake to collect appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the Convention. The data shall be used to help assess the implementation of the obligations resulting from the Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights. This means that the European Union should be able to produce comparable statistics on the situation of persons with disabilities in all aspects of their lives, which is currently largely not the case.

At the time of writing this document, the European Commission was preparing its position for a dialogue with the UN Committee on the Rights of Persons with Disabilities to be held in Geneva at the end of August 2015. The meeting is about the EU implementation of the UNCRPD as described in the EU report on the implementation of the UN Convention on the Rights of Persons with Disabilities and the follow-up response of the Commission to the subsequent list of issues raised by the Committee. The same procedure concerns all countries which ratified the UNCRPD.

#### **European Disability Strategy 2010-2020 (EDS)**

The EDS was adopted in 2010. It provides a framework for action - fully consistent with the UNCRPD - at European and national level to address the situation of persons with disabilities. It identifies a number of actions at EU level to supplement national ones according to eight priority areas: accessibility, participation, equality, employment, education and training, social protection, health, and external action.

'Statistics and data collection and monitoring' is a full section of the EDS where it is considered as an instrument that underpins the proposed actions. The aim is to streamline information collected on disability through the European Statistical System surveys. More specifically the EDS asks to produce indicators linked to the Europe 2020 targets for education, employment and poverty reduction depicting the situation of disabled people in Europe, and more generally to support Member States' efforts to collect statistics on the situation of disabled people.

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According to the Convention "persons with disabilities include 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."

#### 2.2. Current use of GALI and other disability variables in ESS surveys

The European Statistical System (ESS) already collects some statistical data which can be used to describe the situation of disabled people. Currently four population-based surveys provide some disability-related data within the ESS (only for the population living in private households and aged 15 or 16 and beyond). They are:

- The one-off European Health and Social Integration Survey (EHSIS) launched by Eurostat in 2012/2013. The DSS agreed to discontinue it.
- The European Health Interview Survey (EHIS), to be implemented every 5 years according to the current framework regulation on public health. The DSS agreed on the principle that the next 2019 wave should incorporate a module on disability.
- The annual EU Statistics on Income and Living Conditions (SILC) which collects since 2003 the so called Minimum European Health Module (MEHM)<sup>2</sup>, including data on long-standing activity limitation due to health problems (GALI variable).
- The Labour Force Survey (LFS) had specific ad-hoc modules in 2002 and 2011 as regards data on employment of disabled people. The adoption of GALI as a variable common to all ESS surveys would mean that these ad hoc modules will no longer be implemented.

In addition some non-harmonised data are available at national level (i.e. not requested by any ESS legislation or agreement) as most countries collect some data on the situation of disabled people either by extracting information from national registers or by managing national surveys or modules related to disabled people. They are usually based on different national definitions and therefore not usable at EU level.

#### 2.3. Eurostat proposal for the modernisation of social statistics (November 2013)

The current data availability at European level clearly does not allow for a regular, comprehensive and harmonised monitoring of the situation of the persons with disabilities. The need for such regular analysis of the situation of disabled people, regarding for instance the Europe 2020 targets, calls for the introduction of an identifier of people with disabilities in all ESS surveys. Therefore Eurostat, in the context of the modernisation of social statistics and because of this need for more EU-harmonized data on health and disability, recommended two improvements in this area: the introduction of GALI and self-perceived health (SPH) as core social variables and the further harmonisation and improvement of GALI.

## a. Introduction of GALI and self-perceived health as core social variables

Eurostat proposed to collect GALI in all ESS surveys because it is considered as a good proxy for measuring disability. Its introduction would cause only a minimal additional burden for countries and respondents as there is already a comprehensive experience with it in the ESS. As it is already implemented in SILC and EHIS, its introduction into other surveys would mean no (or limited) additional resources for development and implementation<sup>3</sup> and would open possibilities for statistical data matching and pooling

MEHM consists of three variables characterizing different concepts of health: self-perceived health, chronic morbidity and activity limitations.

This document no longer develops in depth arguments related to the burden on the ESS surveys resulting from the adoption of GALI as a variable common to all ESS surveys: as discussed in the document submitted to the DSS in April 2014, the inclusion of GALI as a core variable represents an increase of burden for surveys other than SILC and EHIS. However, the ad hoc EHSIS (2012-2013) is discontinued

across social surveys if implemented in all or some of them. The self-perceived health (SPH) variable was recommended to be collected together with GALI as an introductory question to the topic of health/disability is needed in any questionnaire. SPH is also used to measure health inequalities with a single question instrument developed by the World Health Organization.

It should be noted that GALI is only one of several ways of measuring disability. It uses a conceptual approach which is in fact different from the one recommended by the Washington Group on Disability Statistics, a UN initiative to develop instruments for measuring disability. The Washington Group uses the concept of functional limitations which implies a minimum of four or six variables (difficulties in seeing, hearing, walking, cognition, self-care and communication) and is therefore difficult to implement in non-specialised surveys with limited space for disability-related variables. For non-specialised surveys, Eurostat proposed to stick with the current approach in the ESS to use GALI (i.e. measuring restriction in participation instead of functional limitations). GALI is closer to the EU policy target (participation restriction) and provides several other advantages<sup>4</sup>. However, the set of variables on functional limitations constitutes a good complement to GALI and it is therefore already used in other ESS surveys such as EHIS and is proposed for collection every 3 years in the future SILC health module.

#### b. Harmonisation and improvement of GALI

Although it was scientifically developed and tested and is considered as a good proxy for measuring disability (as proven by different validation studies), GALI has been criticised in the past for different reasons:

- "Results are culturally biased as there are some differences across EU countries regarding judgements on health and personal activities". In addition, some concepts of GALI could be perceived as somewhat vague which may increase variation of results.
  - Comment: the conceptual framework for GALI is clear. Subjectivity or cultural influence cannot be avoided, and apply equally for many other survey questions. This fact should not prevent from collecting such data if they are valid and necessary for certain (national) contexts and if it does not make the interpretation of results impossible.
- "The operationalization of GALI is complex as it includes four concepts in one question". It is difficult for respondents to take all of them appropriately into account when evaluating their own situation.
  - Comment: according to current knowledge, the current GALI question is indeed somewhat complex and difficult to answer, at least for some respondents. However, different ways of operationalising it (for example splitting the question through routing) may have negative effects too, for example by decreasing the specificity. In addition, the fact that the GALI is a single item instrument measuring global activity limitation enables its introduction in general (non-health specific) surveys.
- "The instrument lacks some robustness and reliability, including when different collection methods are applied".

ad-hoc modules on the employment of disabled people. In addition, for LFS again, GALI is foreseen to be collected biennially.

<sup>&</sup>lt;sup>4</sup> For example, it enables measuring disability with a single item instrument and also to produce time series in surveys where it is currently implemented.

Comment: different studies showed that GALI is closely associated with more severe consequences of activity limiting illness such as mortality and the cost of and use of health care services; and also that the GALI has an acceptable reliability. As for many other variables, the method of data collection can obviously have an impact on results. It is therefore an argument for a closer harmonisation between countries in order to reduce the potential sources of systematic differences which contribute towards incomparability across countries.

These criticisms contributed to the reflection on the further improvement and harmonisation of GALI despite major progress reached in the past years in SILC. At the same time GALI is the source for the main health outcome indicator (Healthy Life Years) and many stakeholders, including national statistical institutes, are reluctant to introduce a new break in existing time series. Any new GALI instrument to be implemented in the short term should therefore take into account the two constraints, i.e. possible improvements in the GALI question as well as certain continuity in the operationalization of GALI to enable reliable trend measurement.

In this context, the DSS agreed in November 2013 that Eurostat initiates further methodological work to improve GALI with the help of a dedicated Task-Force and postponed the final decision on the proposal to its September 2015 meeting.

#### 3. TASK-FORCE ON GALI AND ITS RECOMMENDATIONS

The objective of the Task-Force on GALI was to propose ways to improve the acceptance and robustness of GALI, and to harmonise it further. The Task-Force met twice in September 2014 and May 2015 and the results of its work are summarized in the final report which reviews the state of art of the implementation of GALI at national level, reviews the quality of GALI from a general methodological and implementation point of view and from specific country experience, and finally provides recommendations for the improvement of GALI and on the measuring disability for (see annex 1 for the full report).

In addition, and based on a recommendation of the Task-Force to facilitate its work, Eurostat conducted a qualitative study on cognitive testing of different split (routed) versions of GALI in three languages. Main results of the study helped the formulation of the recommendations by the Task-Force.

#### The Task-Force proposed nine recommendations:

- 1. To keep unchanged the concepts underlying the GALI variable, i.e. 1) having 'restrictions' in activities, 2) 'activities people usually do', 3) 'because of a health problem', and 4) 'for at least the past 6 months'.
- 2. Any conceptual change to the GALI variable should be tested qualitatively and quantitatively.
- 3. To keep the current operationalization of GALI in SILC and EHIS (single-question instrument). However a routed version could facilitate the implementation of the variable in the LFS and other ESS surveys.
- 4. To adopt the proposed technical guidelines for GALI and implement them in all concerned data collections<sup>5</sup>.
- 5. To move in SILC and EHIS from output-harmonisation to input-harmonisation (standardization). Input-harmonisation is also recommended in all potential future

These guidelines were developed within the standardisation exercise for variables common to ESS surveys and subject to comments by the Task Force on GALI.

- data collections using GALI. In particular the Task-Force recommends a closer cooperation between countries, especially those using a common language.
- 6. To monitor and assess the implementation of GALI in all concerned data collections. It also includes more standardized approach for studies related to the validation of GALI.
- 7. To adopt GALI as a core variable to be included into LFS and other ESS surveys. As GALI cannot be asked alone in a questionnaire the Task-Force recommends that, in surveys beyond SILC and EHIS, it is included as part of the Minimum European Health Module or at least with its first variable named 'Self-perceived health'.

In addition, and according to its mandate, the Task-Force also made the following proposals regarding the measuring of disability for children:

- 8. To introduce a version of GALI adapted for children and in particular in 3yearly module on children and childcare in SILC.
- 9. The Technical Group HIS should investigate the possibility to introduce a module related to children into the future EHIS survey.

#### 4. CONSULTATIONS OF WORKING GROUPS

The decision to introduce GALI (and possible other health related variables such as SPH) as a core variable in all ESS surveys has to be finally taken by the DSS. However, consultation/information of most of the technical Working Groups took place.

## Working Group on Labour Market Statistics (LAMAS)

Eurostat's proposal to introduce health variables including GALI into the EU Labour Force Survey (LFS) every two years was presented to the LAMAS on 17-19 June 2015 (see annex 2). A slight majority of LAMAS members supported the proposal to introduce GALI and self-perceived health variables into the LFS. The principle of further testing of these variables in some countries was agreed upon.

## Working Group on Public Health Statistics (PH WG)

MEHM is included in the current EHIS and is supposed to be included in the future as well. The Working Group on Public Health Statistics was informed on 16-17 December 2014 about the plans to test and possibly improve the GALI instrument as well as to include it and related disability instruments in ESS surveys. These plans were supported by the PH WG.

#### Working Group on Living Conditions (LC WG)

Data on MEHM are collected annually in SILC and this will not change in the future according to the discussions in the LC WG (i.e. the MEHM will remain part of the core SILC). The Living Conditions Working Group has been regularly consulted about the changes in guidelines for MEHM. LC WG will further be contacted by the end of 2015 about the inclusion of GALI in the Household Budget Survey.

#### Working Group on Education and Training Statistics (ETS WG)

The ETS WG which took place on 16 and 17 June 2015 was informed on the process of standardisation of the variables used in more than one EU social survey and discussed the education variables.

## Working Groups on ICT and Time use survey

Discussion with these Working Groups will take place by the end of 2015.

It should be noted that once the agreement of the DSS is given on the introduction of GALI as a variable common to all ESS surveys, further technical work regarding the implementation

of these variables needs to be done through the Working Groups. This work will be based in particular on the report from the Task Force on GALI

#### 5. EUROSTAT PROPOSALS FOR THE DSS (SEPTEMBER 2015)

As a continuation of proposals made in November 2013 and in April 2014 and on the basis of the results of the Task-Force on GALI (including the methodological study) Eurostat is now proposing the following:

- 1. To adopt GALI as a core social variable to be included into LFS every two years and into other ESS surveys. In addition, to adopt the variable 'Self-perceived health' (SPH) as a core variable because GALI cannot be asked alone in a questionnaire. This proposal is already reflected in the draft framework regulation on IESS (Integrated European Social Statistics) which introduces "Health (including disability)" as one of the topics that are common to all ESS data collections.
- 2. To further discuss the technical implementation of GALI (as well as SPH) with all domain-specific Working Groups. The reason is to ensure that GALI is implemented in a harmonised way within each survey and across all ESS surveys.

According to the current state and plans GALI (and other health variables) are supposed to be implemented in the respective domains covered by IESS as follows<sup>6</sup>:

Domain	Health variables included	Periodicity of collection of health variables
Labour market	GALI and SPH	biennially <sup>7</sup>
Income and living conditions	MEHM	annually
Health	MEHM	every 6 years
Education and training	GALI and SPH	every 6 years
Use of ICT	GALI and SPH	annually(?) <sup>8</sup>
Time use	MEHM	every 10 years
Consumption	GALI and SPH	every 6 years

The initial year of the implementation of GALI in the respective domain will also be further discussed.

<sup>&</sup>lt;sup>7</sup> GALI and SPH could be collected alternately with the education module every 2 years in LFS.

The periodicity needs to be discussed by the respective Working Group.



DSS/2015/Sept/04.3/Annex 1

## Annex 1 of Document DSS/2015/Sept/04.3 Final report of the Task-Force on the Global Activity Limitation Indicator August 2015

MEETING OF THE EUROPEAN DIRECTORS OF SOCIAL STATISTICS

LUXEMBOURG, 15-17 SEPTEMBER 2015

BECH BUILDING, ROOM QUETELET

# Final report of the Task-Force on the Global Activity Limitation Indicator

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#### **EXECUTIVE SUMMARY**

In the context of the modernisation of social statistics and in view of the need for more and better EU-harmonized data on health and disability, Eurostat proposed to the Directors of Social Statistics (DSS) in November 2013 to include the Global Activity Limitation Indicator (GALI) together with the Self-Perceived Health variable (SPH) among the core social variables in the ESS population surveys.

In view of a final decision to be taken in September 2015 the DSS agreed to do further methodological work on the improvement of GALI within a dedicated Task-Force. The objective of the Task-Force was to propose ways to improve the acceptance and robustness of GALI, and to harmonise it further.

The present document is the final report of this Task-Force: section 1 presents the objective and mandate of the Task-Force, while section 2 introduces the background and policy needs for statistical information depicting the situation of people with disabilities. Section 3 takes stock of the current situation regarding the implementation of GALI across European Social Surveys. Section 4 looks at recent studies conducted either at EU or national level before Sections 5 and 6 introduces the recommendations of the Task-Force.

The report illustrates the important progress towards a better harmonization made in ESS surveys since the introduction of GALI. However some disparities still exist which may hamper the use of GALI – first of all with the Healthy Life Years indicator – in the public debate at EU level.

The Task-Force recognised the power of the GALI variable to address the challenges raised by disability policies, and acknowledged the need to keep the variable conceptually unchanged. In a pragmatic manner and in order to take into account in particular the prevalence of telephone interviews in some surveys, the Task-Force also proposed to keep GALI unchanged in SILC and EHIS – in order not to break time series – but to use a version of GALI which according to a recent study by Eurostat could be more easy to manage for both respondents and interviewers. Finally the Task-Force proposed to introduce in the 3-yearly child and childcare module of SILC a GALI variable adapted for children, while recognising the need for more detailed information on children with disabilities to be considered in the 2019 wave of EHIS

#### 1. OBJECTIVE AND MANDATE OF THE TASK-FORCE

The objective of the Task-Force was to propose ways to improve the acceptance and robustness of GALI, and to harmonise it further. More specifically, its mandate contained the following elements:

- Review the state of art of the implementation of GALI at national level, its difficulties and national plans for the future (see section 3);
- Review the quality of GALI from a general methodological and implementation point of view and from specific country experience (see section 3);
- Discuss possible ways for the improvement of GALI in the sense of its acceptability and harmonization and prepare a concrete proposal for the improvement of GALI (see sections 4 and 5);
- Consider how GALI or a variable with a similar objective could be administered for children (see section 6).

The Task-Force met twice in September 2014 and May 2015. Participants came from competent national administrations of Belgium, Germany, Estonia, France, Italy, Malta, the Netherlands, Norway, Austria, Slovenia, Finland and the United Kingdom, from Commission General-Directorates (besides Eurostat, DG SANTE and DG EMPL) and from the EU Agency for Fundamental Rights. Members of the team of researchers who developed GALI<sup>1</sup> also contributed to the Task-Force work. Eurostat provided the secretariat.

#### 2. BACKGROUND

## 2.1. Policy needs for disability statistics

This section recalls policy needs for disability statistics. Two main policy frameworks shape today's disability policies at European and national levels. They are the <u>United Nations Convention on the Rights of Persons with Disabilities</u> and the <u>European Disability Strategy 2010-2020</u>.

#### **United Nations Convention on the Rights of Person with Disabilities (UNCRPD)**

The UNCRPD was adopted in December 2006, and entered into force on 3 May 2008. The EU is a party to the Convention since January 2011 together with 25 Member States, Norway and Switzerland. The three remaining Member States (Ireland, the Netherlands and Finland) and Iceland have signed the Convention and are in the process of ratifying it.

The UNCRPD puts clear obligations on State parties to ensure that persons with disabilities<sup>2</sup> can enjoy all human rights and fundamental freedoms and contains provisions addressing most aspects of the lives of persons with disabilities (access to health, employment, education, social participation, civil rights, etc.).

The UNCRPD lays down in its Article 31 on 'Statistics and data collection' that State parties undertake to collect appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the Convention. The data shall be used to help assess the implementation of the obligations resulting from the Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights. This means that the European Union should be able to produce comparable statistics on the

See <u>Euro REVES II project</u> (1999-2002). It was followed by the EHEMU project (2002-2007) and the <u>EHLEIS</u> project (2007-2014).

<sup>&</sup>lt;sup>2</sup> According to the Convention "persons with disabilities include 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."

situation of persons with disabilities in all aspects of their lives, which is currently largely not the case.

At the time of writing this document, the European Commission was preparing itself for a dialogue with the UN Committee on the Rights of Persons with Disabilities to be held in Geneva at the end of August 2015. The meeting was about the EU implementation of the UNCRPD as described in the EU report on the implementation of the UN Convention on the Rights of Persons with Disabilities and the followed-up response of the Commission to the subsequent list of issues raised by the Committee. The same procedure concerns all countries which ratified the UNCRPD.

## **European Disability Strategy 2010-2020 (EDS)**

The EDS was adopted in 2010. It provides a framework for action - fully consistent with the UNCRPD - at European and national level to address the situation of persons with disabilities. It identifies a number of actions at EU level to supplement national ones according to eight priority areas: accessibility, participation, equality, employment, education and training, social protection, health, and external action.

'Statistics and data collection and monitoring' is a full section of the EDS where it is considered as an instrument that underpins the proposed actions. The aim is to streamline information collected on disability through the European Statistical System surveys. More specifically the EDS asks to produce indicators linked to the Europe 2020 targets for education, employment and poverty reduction depicting the situation of disabled people in Europe, and more generally to support Member States' efforts to collect statistics on the situation of disabled people.

## 2.2. The response from the European Statistical System so far<sup>3</sup>

The European Statistical System (ESS) already collects some statistical data which can be used to describe the situation of disabled people. Currently four population-based surveys provide some disability-related data within the ESS (only for the population living in private households and aged 15 or 16 and beyond). They are:

- The one-off European Health and Social Integration Survey (EHSIS) was launched by Eurostat in 2012/2013. The DSS agreed to discontinue it;
- The European Health Interview Survey (EHIS) which is currently running. The DSS agreed on the principle that the next 2019 wave should incorporate a module on disability;
- The Statistics on Income and Living Conditions (SILC) instrument annually in particular collects data on long-standing activity limitation due to health problems (GALI variable) since 2003;
- The Labour Force Survey (LFS) collected via specific ad-hoc modules in 2002 and 2011 data on employment of disabled people.

In addition some non-harmonised data are collected at national level (i.e. not requested by any ESS legislation or agreement) as most countries collect some data on the situation of disabled people either by extracting information from national registers or by managing national surveys or modules related to disabled people. They are usually based on different national definitions and therefore not usable at EU level

For more details see Doc. Eurostat/F/14/DSS/03/3.6 EN: "The future of disability statistics within the European Statistical System" (DSS of 3-4 April 2014).

#### 2.3. Eurostat proposal for the modernisation of social statistics

The current data availability at European level clearly does not allow for a regular and comprehensive monitoring of the situation of the persons with disabilities. The need for such regular analysis of the situation of disabled people, regarding for instance the Europe 2020 targets, calls for the introduction of an identifier of people with disabilities in all key ESS surveys. Therefore Eurostat, in the context of the modernisation of social statistics and because of this need for more EU-harmonized data on health and disability, recommended two improvements in this area: the introduction of SPH and GALI as core/common social variables and the further harmonisation and improvement of GALI.

#### Introduction of GALI and self-perceived health as core/common social variables

Eurostat proposed to collect GALI in all ESS surveys because it is considered as a good proxy for measuring disability. Its introduction would cause only a minimal additional burden for countries and respondents as there is already a comprehensive experience with it in the ESS. As it is already implemented in SILC and EHIS, its introduction into other surveys would mean no (or limited) additional resources for implementation and would open possibilities for statistical data matching and pooling across social surveys if implemented in all or some of them. In addition to GALI, the Self-Perceived Health variable was recommended to be collected together with GALI as it is seems that an introductory question to the topic of health/disability is needed in any questionnaire. SPH is also used to measure health inequalities with a single question instrument developed by the World Health Organization.

GALI is only one of several ways of measuring disability. It uses a conceptual approach which is different from the one recommended by the <u>Washington Group on Disability Statistics</u>, i.e. the concept of functional limitations which implies a minimum of four or six variables (difficulties in seeing, hearing, walking, cognition, self-care and communication) and is therefore difficult to implement in non-specialised surveys with limited space for additional variables. Eurostat proposed to stick to the approach currently used in the ESS (i.e. measuring directly restriction in participation) as it is closer to the EU policy definition and provides several advantages (see above). However, the set of variables on functional limitations constitutes a good complement to GALI and it is therefore proposed for collection every 3 years in the future SILC health module.

#### Harmonisation and improvement of GALI

Although it was scientifically developed and tested and is considered as a good proxy for measuring disability (as proven by different validation studies<sup>4</sup>), GALI has been criticised in the past for different reasons. It was useful for the Task-Force to review these criticisms which explain part of the reticence towards GALI:

• "Results are culturally biased as there are some differences across EU countries regarding judgements on health and personal activities". In addition, some concepts of GALI could be perceived as somewhat vague which may increase variation of results.

Comment: the conceptual framework for GALI is clear. Subjectivity or cultural influence cannot be avoided, and apply equally for many other topics. This fact should

<sup>&</sup>lt;sup>4</sup> See for example:

<sup>•</sup> C Jagger et al.: The Global Activity Limitation Index measured function and disability similarly across European countries. J Clin Epidemiol, 2010: 63 (8), 892-899.

<sup>•</sup> N Berger et al.: Assessing the validity of the Global Activity Limitation Indicator in fourteen European countries. BMC Medical Research Methodology 2015 15:1.

<sup>•</sup> JV d Heyden et al.: GALI validation studies in Belgium. EHLEIS Technical report 2014 7.1. 2014.

<sup>•</sup> B Cox et al.: The reliability of the Minimum European Health Module. Int J Public Health, 2009: 54 (1), 55-60.

not prevent from collecting such data if they are valid and necessary for certain (national) contexts and if it does not make the interpretation of results impossible.

• "The operationalization of GALI is complex as it includes four concepts in one question". It is difficult for respondents to take all of them appropriately into account when evaluating their own situation.

Comment: according to current knowledge, the current GALI question is indeed somewhat complex and difficult to answer at least for some respondents. However, different operationalization (for example splitting the question through routing) may have negative effects too, for example by decreasing the specificity. In addition, the fact that the GALI is a single item instrument measuring global activity limitation, enables its introduction in general (non-health specific) surveys.

• "The instrument lacks some robustness and reliability, including when different collection methods are applied".

Comment: different studies showed that GALI is closely associated with more severe consequences of activity limiting illness such as mortality and the cost of and use of health care services; and also that the GALI has an acceptable reliability. As for many other variables, the method of data collection can obviously have an impact on results. It is therefore an argument for a closer harmonisation between countries in order to reduce the potential sources of systematic differences which contribute towards incomparability across countries.

These criticisms contributed to the reflection on the further improvement and harmonisation of GALI despite major progress reached in the past years in SILC. At the same time GALI is the source for the main health outcome indicator (Healthy Life Years) and many stakeholders, including national statistical institutes, are reluctant to introduce a new break in existing time series. The solution is, therefore, to be found (if at all possible) in a trade-off between an improved measurement of GALI and a reliable and sustainable trend measurement.

#### 2.4. Previous DSS discussions

Eurostat presented to the DSS twice: in November 2013 as part of the package for the modernisation of health statistics; in April 2014 as part of the discussion about the future of disability statistics within the European Statistical System on different proposals regarding the improvement of disability statistics. Two of the proposals presented in those meetings concerned the Global Activity Limitation Indicator (GALI). The DSS agreed that Eurostat initiates further methodological work to improve GALI with the help of a dedicated Task-Force and postponed the final decision on the proposals until its September 2015 meeting.

It should also be noted that the recent high-level stakeholders meeting on health statistics with heads of some national statistical offices and high Commission representatives (Brussels, 8 July 2015) highlighted the need to identify the population of people with disabilities in all ESS surveys.

#### 3. CURRENT SITUATION REGARDING THE IMPLEMENTATION OF GALI

The standard GALI, which was developed within the Euro REVES II project, is a single question instrument designed for measuring long-term activity limitations<sup>5</sup>. As a part of the so-called Minimum European Health Module (MEHM)<sup>6</sup>, it was included in various surveys of the European

See <a href="http://eurpub.oxfordjournals.org/content/eurpub/13/suppl\_3/6.full.pdf">http://eurpub.oxfordjournals.org/content/eurpub/13/suppl\_3/6.full.pdf</a> (pages 10-12)

See <a href="http://ec.europa.eu/eurostat/statistics-explained/index.php/Glossary:Minimum\_European\_Health\_Module\_(MEHM)">http://ec.europa.eu/eurostat/statistics-explained/index.php/Glossary:Minimum\_European\_Health\_Module\_(MEHM)</a>

Statistical System (ESS) with a recommendation from Eurostat to use the same model question. Thus GALI has been collected so far:

- annually in SILC via the PH030 variable;
- every five years in the European Health Interview Survey (EHIS) via the HS3 variable
- and was also included in the one-off European Health and Social Integration Survey (EHSIS).

Previous analyses of the implementation of the GALI instrument performed by Eurostat and by EHLEIS experts confirmed that a close input harmonization – that is using the same model question and conceptual guidelines – would be necessary in order to produce more comparable data. This led to an agreement with Member States in order to improve SILC methodological guidelines and foster a closer collaboration between SILC and health statisticians since 2008.

Following this agreement a big improvement in the harmonisation of the GALI in SILC was observed across Member States. In 2012 Eurostat consulted the SILC delegates in order to get further information on the comparability across Europe as well as to better document the situation in Eurostat metadata information system.

The outcome of this consultation illustrated that some differences still existed in 10 countries (out of 31 countries conducting SILC which were evaluated) between the concepts used in the national SILC question and in the standard GALI question. At the end of 2012, Eurostat wrote to those 10 countries requesting them to consider moving towards the standard question (in particular to allow a full comparability between SILC and EHIS at national level) and recommending a closer cooperation with national EHIS experts. Eurostat targeted 2014 as the entry date for implementation for those countries as it is the year when a majority of EU Member States should conduct EHIS wave 2. As a follow-up of this initiative most of the 10 countries either introduced or worked on introducing changes for the PH030 variable in SILC.

#### 3.1. Method of assessment of GALI in SILC

The evaluation of the implementation of GALI in national  $SILC^7$  surveys was done in two ways:

- conceptual assessment: check if all the underlying concepts and answer categories are appropriately incorporated in national variables;
- technical assessment: check if the technical way of implementation (operationalization) of national questions follows the standard GALI question.

The evaluation was based on the available documentation, including results of previous assessments, analysis of national SILC questionnaires and quality reports and updates received from countries (mainly from those countries identified as deviating from the standard methodology in the previous evaluation conducted in 2012).

The conceptual evaluation consisted essentially of a linguistic comparison of the standard GALI question and national questions, i.e. if all terms and expressions were correctly and meaningfully translated. The following four concepts are included in the standard GALI question:

- a) Being limited (restriction in activities)
- b) In activities people usually do
- c) Because of a health problem
- d) For at least the past 6 months.

Evaluation of national implementation of GALI in EHIS was not conducted as EHIS wave 2was not finalized at the time of writing this paper.

The conceptual comparability is considered a prerequisite to ensure a high level of comparability of data.

The technical evaluation included a comparison of the operationalization (technical way of the implementation) of the national variable with GALI. The following technical features were taken into account:

- a) Number of model question(s) used for the implementation of the PH030 variable
- b) Filtering or not of the PH030 variable
- c) Order of the variables composing the MEHM
- d) Presence of other health questions before or in-between the MEHM questions.

It should be noted that there may exist a number of different ways of operationalising GALI that may bring comparable results.

Some other technical aspects - such as the location of the PH030 variable/MEHM in the national questionnaire, the order of the words/concepts in the PH030 question(s), when some aspects of the underlying concepts are not included in the question but explained by the interviewer after asking the question - were not considered in the evaluation. The evaluation also did not take into account the general survey characteristics (mode of data collection, response rate, use of proxy interviews, etc.) which could also impact the results<sup>8</sup>.

#### 3.2. Results of the assessment and further harmonization

#### Conceptual comparability:

Some deviations in wording from the standard GALI were detected in the national SILC questionnaires between 2004 and 2011. They are the following:

- referring to respondents' own activities ('your usual activities'),
- referring to 'normal / daily' 'work / tasks',
- referring to activities of 'people of the same age',
- introducing 'Because of: health / disability / impairment / handicap',
- using 'During / for the last / in the past 6 months or 'In the past 6 months limited for a longer time',
- using 'Being permanently limited / limited on long-term basis',
- using 'Usual/everyday activities' or 'activities of everyday life',
- and differences in the number and wording of response categories.

In the 2012 evaluation, eight countries used concepts of GALI in SILC which were considered as non-comparable to the standard GALI question. The progress in the respective countries was monitored and according to the last information available, it seems now that all 28 EU Members States, Norway, Iceland and Switzerland conceptually comply with the standard GALI question as from the 2015 wave.

## Technical comparability

Technical features were not systematically documented and discussed earlier. This section provides an overview on four technical features for the implementation of the PH030 variable in SILC.

Some of these aspects were subject of evaluation of French and Slovenian quantitative studies and Eurostat's qualitative study, all presented later.

<sup>&</sup>lt;sup>9</sup> In some cases there was also uncertainty if 6-month time period refers to the duration of activity limitation or duration of health problem.

## • Number of model questions used for implementation of PH030 variable

As of 2015<sup>10</sup>, the vast majority (26 out of 31) of countries use a single question instrument to collect data on PH030 variable. The following table presents different practical ways of implementation with more than one question and suggest possible impacts on survey results:

Table 1: Existing deviations and their potential impact on results, by deviation and country

Deviation	Potential impact on results
Duration asked in the 2 <sup>nd</sup> question (NL 2008-2014, UK 2012+ <sup>11</sup> )	Probably no effect on results <sup>12</sup>
Severity asked in the 2 <sup>nd</sup> question (IS 2008-2011 (and probably up to date), PT 2012-2013)	It is likely to provide lower prevalence of activity limitation <sup>13</sup>
Duration asked in the 2 <sup>nd</sup> question and Severity in the 3 <sup>rd</sup> question (NO 2011)	It is likely to provide lower prevalence of activity limitation (see above)
Severity in the 2 <sup>nd</sup> question and Duration in the 3 <sup>rd</sup> question (DE 2015+)	It is likely to provide lower prevalence of activity limitation because the severity is not asked in the first question (see above)
Reason of activity limitation (in the 2 <sup>nd</sup> question), Severity (3 <sup>rd</sup> question) and Duration (4 <sup>th</sup> question) (SE 2014)	It is likely to provide lower prevalence of activity limitation because the severity is not asked in the first question (see above).

Other ways of splitting PH030 into even more questions would be possible, such as asking for the reason of activity limitation or for activity limitations in specific subdomains of usual activities in separate questions. Such splitting would probably have major impact on results.

## Filtering of PH030 variable

Filtering of PH030 by PH020 variable, i.e. when PH030 is asked only to respondents with chronic (longstanding) illness or condition, was found to be used in two countries (UK and NO). It is likely to decrease the prevalence of activity limitation. Data shows that some respondents who answered 'no' in PH020 indicate then 'activity limitation because of a health problem' in PH030, and they would not be counted with a filtering question. A possible explanation is to be seen with the fact that they recognize the health problem only in connection to their activity limitation.

#### Order of MEHM variables

Two cases when PH030 question precedes PH020 question were identified in the available national questionnaires (CH in 2007 and SE until 2013). These deviations were corrected and no country seems anymore to deviate in such a way at the moment. This deviation has probably no significant effect on PH030 results but there may be a possible effect on PH020 values (see above: Filtering of PH030 variable).

#### Health questions included before or between MEHM variables

Taking into account incomplete information about national implementation of PH030 variable in SILC.

The UK asks about activity restriction and its extent from a routed questions asking initially about health problem and impairment type; a question on the duration follows.

The Netherlands started to use one-question instrument since 2015 and according to preliminary results this change seems to have no significant effect on the prevalence of activity limitation.

French quantitative study and also experience in some Member States proved that not asking about the severity of activity limitation in the first question provides lower prevalence of activity limitation.

Some countries included national health questions before MEHM module (IE, IS, NO) or between MEHM variables (CH, IT, LU, RO, SE, UK). It is difficult to assess the potential impact on PH030 and other MEHM variables results without testing of different options in the same survey but it is very likely for variables somehow connected with PH030. The question order effect can also play a role, like in the previous technical feature. The order of health questions and inclusion of national questions could be an explanation of some breaks in SILC time series which could not be explained by changes in concepts of PH030 variable or other technical features.

#### 4. REVIEW OF RECENT METHODOLOGICAL STUDIES RELATED TO GALI

In order to analyse possible options to be recommended for the improvement of GALI, the Task-Force had an in-depth look at recent studies made available at both national and EU level.

## 4.1. Qualitative study by Eurostat

Between March – July 2015, Eurostat conducted a cognitive study as part of the methodological work for improving GALI. The main purpose of the study was the testing of different versions of GALI. Five versions of GALI were tested: the current standard GALI used by Eurostat and four adapted (routed/simplified) versions. The four adapted versions were either chosen from existing national surveys or considered by Eurostat as potentially beneficial for the study. All four versions were derived from the standard GALI question by splitting it into two or three routed model questions (two versions use 2 model questions and two other ones use 3 model questions) and by adapting the wording. The wordings of adapted versions of GALI include all concepts included in the standard GALI.

In practice the main objectives of the study were to:

- undertake cognitive interviews in order to evaluate the quality of different versions of GALI in three languages (English, German and French);
- undertake cognitive interviews in order to evaluate the quality of different versions of GALI in different modes of data collection;
- undertake interviews with proxy interviewees to assess the impact of proxy on GALI results;
- formulate recommendations on how the current GALI could be improved and how the possible impact of different survey arrangements could be minimised.

The study was conducted in three languages (English, German and French) in order to enable broader analysis of functioning of GALI. English was chosen because the standard GALI question recommended by Eurostat is worded in English. French and German are languages used in more EU Member States where different wording and technical operationalization of GALI are implemented.

In addition to GALI, some other health questions selected from existing surveys were included in the questionnaire to complement GALI and enable its further validation.

The key findings of the Task-Force are <sup>14</sup>:

• Qualitative testing showed that all of the variants shared the same cognitive issues and there was no substantive difference between them in this regard. This applies to different data collection modes and in general also to tested languages.

Results of pseudo-quantitative analysis have to be treated with caution and only as indicative due to the (qualitative) design of the study.

- Two elements that could potentially be problematic are related to the comprehensive measure of health problem (mental and emotional aspects not usually considered but may be problematic to incorporate directly in the question) and to assessing, understanding and interpreting the expression "to what extent" (except for English)<sup>15</sup>.
- Some of the conceptual elements proved to be somewhat ambiguous, raising potential problems of interpretation in different languages: normative comparison, levels of severity (regarding the category 'limited but not severely', expressions 'activity' and 'limitation'.
- Pseudo-quantitative analysis of the easiness for respondents to understand and answer GALI did not reveal major differences between the routed variants, the originally GALI seemed to be just a bit more difficult for respondents compared to routed versions.
- External validity tests (i.e. comparing answers to GALI and detailed disability-related questions) revealed that there are no serious problems in any of the tested languages for any of the tested versions in face-to-face mode of data collection.
- Closeness between standard GALI and routed versions (measured by the level of association of validity performance) revealed that some routed versions are, as expected, closer to standard GALI than the other ones.
- Testing indicates that there could be some differences in how different versions of GALI
  perform in different data collection modes. Standard GALI performed worse compared to
  other modes and also compared to routed versions in telephone mode. Two routed
  versions selected for testing in different data collection modes performed similarly except
  for the face-to-face mode.
- Testing with proxy interviews revealed that for majority of proxy respondents GALI is not difficult to answer and that the majority of proxy respondents can reliably judge on the presence of any activity limitation (about 87 %) and that the correspondence of answers on different levels of limitation is still good (more than 70 %).
- The testing of proxy interviews revealed that answering of GALI is easier for proxies who live together with original respondents and the reliability of their answers is higher. If proxies are limited to those living together with original respondents the misclassification error could be reduced to around 5 %.
- The misclassification works in both directions (under- and over-reporting, but to a larger extent for under-reporting) and supported by results of cognitive interviews: although the GALI's classification of activity limitation is to some extent subjective in nature; in total it seems to lead only to minor underreporting. Similar to results of cognitive interviews, the answer category 'limited but not severely' is more ambiguous to interpret.
- Based on the overall results the choice between two routed versions (and having in mind limitations of the quantitative results) depends on the weight to be given to criteria of closeness to the standard version or validity. The recommendation of the study is to use routed version which seems to be closer to the standard GALI (see below under 5.2.1 the wording of the version).

#### 4.2. National studies

Germany introduced in the Task Force the work done at national level for improving the GALI question that is currently used in SILC. Different versions of GALI were tested and a routed version is going to be used first of all in EHIS in Germany.

The originally developed GALI did not include the expression "To what extent". It was included after cognitive testing (done only in English) to align the wording of the question with answer categories measuring severity gradient. Other similar instruments, such as the Washington Group, do not use the expression.

The Netherlands presented the use of GALI in their national SILC and EHIS surveys. Because of its complexity, two questions are used: the 1<sup>st</sup> one asking 3 dimensions of GALI, while the duration of the limitation is asked in a 2<sup>nd</sup> question. In 2012, similar results were obtained in both surveys despite some differences in survey methodology. Within EHIS, these 2 questions were adapted and used also for children.

Norway introduced the national experience with GALI. Because of the number of concepts, GALI was also split in Norway into 3 questions. In addition, it is filtered by questions about having a disease, health problem, disability or effect of injury. A study that was conducted on the 2011 SILC data showed a small change in the percentage with limitation when checking for duration of limitation and a small but significant difference in the likelihood to report limitation when GALI is filtered.

Belgium conducted several studies on the validity of the GALI (and self-rated health) using national Belgium data showing that self-rated health, resp. GALI are good predictors of mortality and closely associated with health care expenditures.

France presented results of a quantitative study for testing various versions of GALI. The results showed that the two routed versions of GALI reduced the prevalence of activity limitation which highlighted an impact of changing GALI. It also suggested that removing the second MEHM question on chronic morbidity can have impact on how respondents answer GALI.

Slovenia presented an analysis on a possible impact of the use of proxy and of mode of data collection on GALI. First results showed that there were only very small differences between CAPI and CATI modes. The overall differences between proxy and non-proxy interviews seem to be larger<sup>16</sup> but with no significant effect on total prevalence of activity limitation.

Finally the United Kingdom presented a comparison of disability measures based on SILC and EHIS data. The results showed significantly higher prevalence of activity limitation in EHIS which uses the standard GALI question (compared to SILC which uses a routed version). The impact of the instrument is difficult to quantify due to other differences between the two surveys.

## 5. RECOMMENDATIONS OF THE TASK-FORCE ON GALI<sup>17</sup>

## 5.1. Conceptual characteristics

The Task-Force is of the opinion that GALI has proven its robustness and therefore should remain conceptually unchanged.

The desire to avoid another break in time series, as a number of countries changed quite recently the question in order to adapt to Eurostat recommendation, was given high importance by several stakeholders, both producers and users of statistics.

**Recommendation 1:** the Task-Force recommends keeping unchanged the concepts underlying the GALI variable, i.e. 1) having 'restrictions' in activities, 2) 'activities people usually do', 3) 'because of a health problem', and 4) 'for at least the past 6 months'.

In a longer term perspective, a simplification of GALI by dropping some of its concepts (for instance, the reference to the duration or to the health problems) could be considered, in

According to additional calculation performed by Eurostat, age and sex standardized indicators do not differ between different data collection modes.

A German expert does not support recommendations 3, 4 and 5.

particular for the non-health surveys<sup>18</sup>. But such a critical change to the existing GALI would have to be qualitatively and quantitatively tested before any decision can be taken.

**Recommendation 2:** any conceptual change to the GALI variable should be tested qualitatively and quantitatively.

#### 5.2. Technical characteristics

#### 5.2.1. Three options for the operationalization of GALI

After having validated that GALI should remain unchanged at conceptual level the Task-Force considered possible options for the future of GALI in order to improve its acceptability and facilitate its implementation in European social surveys beyond SILC and EHIS. In this discussion a critical issue was the operationalization of the variables in terms of question(s).

Two out of the four concepts used in GALI (See Recommendation 1) were considered more problematic by the Task-Force. Firstly the concept of 'limitation or restriction in participation' was seen as complex and difficult to measure. Secondly it was acknowledged that the area of 'usual activities' could to some extent be understood differently in different countries as they are determined, among others, by the society/environment. However, this is in line with policy needs on measuring disability via participation as it represents the societal perspective of functioning (that is combining functional limitations and environment). The existence of such societal differences is important for analysing and interpreting the data but should not prevent international comparisons.

More information on how to develop a measure of disability is provided in the report "A blueprint for an internationally harmonised Summary Measure of Population Health".

The three main options considered by the Task-Force were the following:

- Keep GALI question unchanged with a single recommendation for all surveys;
- Keep GALI question unchanged only for SILC and EHIS (in order to keep comparability over time) but to propose a routed version of GALI (easier for respondents) for other surveys;
- Propose a routed version of GALI for all surveys (i.e. including SILC and EHIS).

Having in mind the relatively short experience with GALI (since 2003-2004 with SILC, so far only 1 wave of EHIS available) one should not under-estimate the importance given by a number of stakeholders to avoiding a new break in time series. This argument was decisive for rejecting the current Option 3 which could/should be the way in a medium-term future.

Based on the results of the Eurostat qualitative study and on results of other national studies and experience with the implementation of GALI in countries the recommended adaptation of GALI is as follows and presented together with the current version of GALI:

Current GALI	Adapted GALI proposed by the TF
For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do? Would you say you have been  1. severely limited  2. limited but not severely or  3. not limited at all?	<ul> <li>a. Are you limited because of a health problem in activities people usually do? Would you say you are</li> <li>1. severely limited</li> <li>2. limited but not severely, or</li> <li>3. not limited at all?</li> <li>b. Have you been limited for at least the past 6 months?</li> <li>1. Yes</li> <li>2. No</li> </ul>

The proposed adapted GALI uses two model questions and remove only the term 'to what extent' which could be problematic to use in some countries<sup>19</sup>. This version could make it easier for respondents to answer and performs well regarding validity. It is understood similarly to the current standard GALI<sup>20</sup> which would therefore ensure non-significant impact on results.

## 5.2.2. Pros and cons of each option

## Option 1: Keep GALI unchanged

The main advantage of this option would be the stability both for SILC and EHIS, which avoids any break in time series. The single-question option has been validated in a number of studies and surveys, including the LFS in several Member States, and does not require any further testing. On the other hand the length and complexity of the question is

According to available information, some countries do currently not include the expression 'to what extent' in national versions of GALI but use "have you". If a single question instrument is to be used in a survey, the Task-Force had the opinion that the expression "to what extent" could be removed and that the answer categories could be slightly amended (with Yes,.../No,...).

In addition, according to preliminary results from the Netherlands this routed version seems to provide similar results as the standard GALI.

not addressed, particularly in view of telephone interviews (which however already exist in some countries for both SILC and EHIS).

Option 2: Keep GALI question unchanged only for SILC and EHIS but use a routed version of GALI in other data collections<sup>21</sup>

This option keeps the same main advantage as Option 1 as regards the stability of results for SILC and EHIS. In addition, it introduces a set of questions easier for respondents to answer if implemented in other data collections, although Eurostat qualitative study has proved only a slight gain in easiness to understand the question compared with the standard GALI phrasing. However this solution would to some extent contradict the effort of standardisation of core variables; it would provide conceptually the same variable but adapted operationalization – splitting standard GALI question into more questions. In addition, despite the promising results of Eurostat qualitative study, the implementation of the routed version has not yet been tested on a significantly representative sample.

## Option 3: Propose a routed version of GALI for all surveys

The main advantage of this option would be to offer to respondents a set of questions which are easier to grasp. It would also respect the principle of standardisation of variables across surveys. However it could introduce a break in series for the main indicators and would be subject to a large-scale testing in different data collections before its adoption in all European surveys.

**Table 5:** Summary of pros and cons

	Criteria				Total
Option	Stability of results	Validation	Simplicity	Standar- disation	Total mark
Option 1	++	++	0	+	5+
Option 2	++	+	+	0	4+
Option 3	0	0	++	+	3+

This brief – and arbitrary – summary illustrates that the Task-Force mainly discussed about two options as Option 3 was perceived as too problematic and more expensive in the short-term.

This option envisages that only one operationalization of GALI within the same data collection is agreed by the respective working group in order to ensure full harmonisation within the data collection.

**Recommendation 3:** The Task-Force recommends not introducing any change in the operationalization of GALI in SILC and EHIS (single-question instrument). However a routed version could facilitate the implementation of the variable in the LFS and other ESS surveys.

#### 5.3. Technical guidelines

The Task Force is of opinion that improvement of the existing guidelines, especially by considering a better explanation of the concepts, could further increase the understanding, acceptability and harmonisation of GALI. Eurostat drafted technical guidelines for GALI (and SPH) in the standard format requested for the future core social variables which were commented by the Task Force. The current version can further be revised if needed.

**Recommendation 4:** The Task-Force recommends adopting the proposed technical guidelines for GALI and implementing them in all concerned data collections.

## **5.4.** Implementation issues

The successive assessments of the implementation of GALI in SILC as well as the results of different studies show that there is need for closer harmonisation in the implementation of GALI in order to ensure full harmonisation of results.

**Recommendation 5:** As regards GALI and other health variables, the Task-Force recommends moving in SILC and EHIS from output-harmonisation to input-harmonisation (standardization). Input-harmonisation is also recommended in all potential future data collections using GALI. In particular the Task-Force recommends a closer co-operation between countries, especially those using a common language.

**Recommendation 6:** The Task-Force recommends monitoring and assessing the implementation of GALI in all concerned data collections. It also includes more standardized approach for studies related to the validation of GALI.

#### 5.5. General recommendation

The Task-Force recognised the power of the GALI variable in order to address part of the needs for disability statistics. Its adoption as a core variable (i.e. in all European Social Surveys) is a necessary condition for fulfilling the EU commitments towards the UN Convention on the Rights of People with Disabilities.

**Recommendation 7:** The Task-Force recommends the adoption of GALI as a core variable to be included into LFS and other ESS surveys. As GALI cannot be asked alone in a questionnaire the Task-Force recommends that, in surveys beyond SILC and EHIS, it is included as part of the Minimum European Health Module or at least with its first variable named 'Self-perceived health'.

#### 6. RECOMMENDATIONS OF THE TASK-FORCE ON MEASURING DISABILITY FOR CHILDREN

According to the UN Convention on the Rights of Persons with Disabilities (in particular articles 7, 31 and 33) and the European Disability Strategy 2010-2020, there is a clear policy need for measuring disability among children. This need has for the time being not been addressed within the European Statistical System.

The UN city group dedicated to disability statistics, known as Washington Group and UNICEF are currently developing a module on child functioning and disability composed of a set of questions to

identify children that are at greater risk of participation restriction. However measuring disability among children is difficult as their situation is often 'filtered' by their parents and because they constantly develop and perform new activities. It is certainly difficult to address the issue with a single question, though it appears that, for example, 'difficulties in playing' has a strong correlation with the normal GALI question. The collaboration with Washington Group and UNICEF in this area would be important in order to take into account the work already done. Austria, Estonia, Germany, the Netherlands, Norway and the United Kingdom have already introduced in the past various national instruments related to child disability.

Following a recommendation from the Task-Force, the opportunity to introduce a slightly adapted version of GALI<sup>22</sup> into the future 2017 ad-hoc module of SILC was introduced by Eurostat and supported by the Living Conditions Working Group. The final decision on this module should be taken by the European Statistical System in September 2015. The solution to introduce GALI adapted for children which is supported by the Task-Force<sup>23</sup>, is recommended to be implemented into each child module foreseen with the SILC revision every 3 years.

Beyond the possible introduction of a GALI-like question for children in SILC every three years the Task-Force agreed upon the need to collect more detailed information on children, as recommended by the Washington Group and UNICEF. For this purpose the Task-Force suggested to investigate the possibility to integrate a module related to children into the future EHIS survey.

**Recommendation 8:** The Task-Force recommends the introduction of a version of GALI adapted for children and in particular in 3 yearly module on children and childcare in SILC.

**Recommendation 9:** The Task-Force recommends that the Technical Group HIS investigate the possibility to introduce a module related to children into the future EHIS survey.

1 ogether with a question on perceive
23 The Task-Force agreed on the conce

Together with a question on perceived health for children.

The Task-Force agreed on the conceptual content of GALI adapted for children but did not conclude on its exact operationalization as the final results of Eurostat study were not available at the time of the meeting. The Task-Force only agreed on the general principle that it should be aligned as much as possible with the version recommended for adult population.



DSS/2015/Sept/04.3/Annex 2

## Health/disability variables in the Labour Force Survey

(Document for item 2.10 of the agenda of the Working Group Labour Market Statistics meeting in June 2015

MEETING OF THE EUROPEAN DIRECTORS OF SOCIAL STATISTICS

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## WORKING GROUP LABOUR MARKET STATISTICS

Document for item 2.10 of the agenda

Health/disability variables in the Labour Force Survey

17-19 June 2015 JMO Building Room M2 Luxembourg

#### 1 Introduction

This document presents Eurostat's proposal for addressing the need for health and disability-related variables to be included into the Labour Force Survey (LFS) in the context of the modernisation of social statistics. It follows information provided to the Directors of Social Statistics (DSS) in November 2013 and April 2014, to the Labour Market Statistics Working Group (LAMAS WG) and to the Public Health Statistics Working Group in 2013-2014.

This proposal is for LAMAS opinion. The file will then be transmitted to the DSS for decision in the context of the overall discussion on the modernisation of social statistics.

The structure of the document is the following: section 2 describes the policy needs for information depicting in a comparable manner the participation in the labour market and in education systems of people with disabilities both at national and EU level. Section 3 introduces the information available in the European Statistical System so far, and why action is required. Section 4 explains Eurostat proposal. Section 5 concludes.

## 2 Policy needs regarding the situation of disabled persons in the EU

Two main policy frameworks shape today's disability policies at European and national levels. They are the <u>United Nations Convention on the Rights of Persons with Disabilities</u> and the <u>European Disability Strategy 2010-2020</u>.

## 2.1 United Nations Convention on the Rights of Person with Disabilities (UNCRPD)

The UNCRPD was adopted in December 2006, and entered into force on 3 May 2008. The EU is a party to the Convention since January 2011 together with 25 Member States, Norway and Switzerland. The three remaining Member States (Ireland, the Netherlands and Finland) and Iceland have signed the Convention and are in the process of ratifying it.

The UNCRPD puts clear obligations on State parties to ensure that persons with disabilities<sup>1</sup> can enjoy all human rights and fundamental freedoms and contains provisions addressing most aspects of the lives of persons with disabilities (access to health, employment, education, social participation, civil rights, etc.).

The UNCRPD lays down in its Article 31 on 'Statistics and data collection' that State parties undertake to collect appropriate information, including statistical and research data to enable them to formulate and implement policies to give effect to the Convention. The data shall be used to help assessing the implementation of the obligations resulting from the Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights. This means that the European Union should be able to produce comparable statistics on the situation of persons with disabilities in all aspects of their lives, which is currently largely not the case.

## 2.2 European Disability Strategy 2010-2020 (EDS)

The EDS was adopted in 2010. It provides a framework for action - fully consistent with the UNCRPD - at European and national level to address the situation of persons with disabilities. It identifies a number of actions at EU level to supplement national ones according to eight priority areas: accessibility, participation, equality, employment, education and training, social protection, health, and external action.

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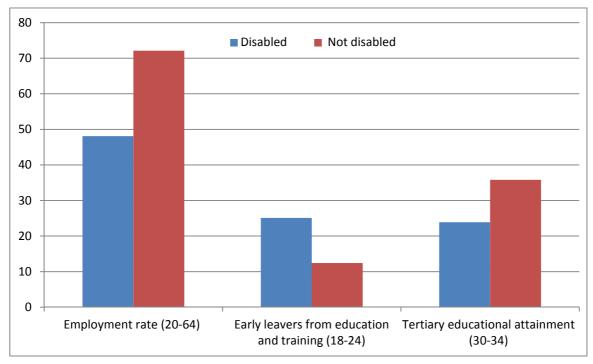
According to the Convention "persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others."

'Statistics and data collection and monitoring' is a full section of the EDS where it is considered as an instrument that underpins the proposed actions. The aim is to streamline information collected on disability through the European Statistical System surveys. More specifically the EDS asks to produce indicators linked to the Europe 2020 targets for education, employment and poverty reduction depicting the situation of disabled people in Europe, and more generally to support Member States' efforts to collect statistics on the situation of disabled people.

## 2.3 The situation of disabled people is part of the labour market analysis

A key objective of employment policies in the EU<sup>2</sup> is to increase labour market participation and to ensure the integration of people with disabilities and other vulnerable groups (Guideline 7). The objective is to ensure the economic independence of persons with disabilities in order to better protect them against poverty. A specific attention needs to be paid to young people with disabilities in their transition from education to employment. Guidelines 9 (education and training systems) and 10 (social inclusion) also refer to a full participation in society.

At statistical level, all the indicators related to the situation of disabled persons on the labour market and in education and training are derived from the LFS, and the results from the 2011 LFS ad-hoc module on the employment of disabled people illustrates the gap between people with and without disabilities. The following graph shows the gap for the three Europe 2020 headline indicators (both employment and education):



Graph 1 – LFS-based Europe 2020 indicators for EU-28 by disability status, 2011 (%)

In terms of access to the labour market, the employment rate of people with disabilities is 24 percentage points (pp) below the one of persons without disabilities (measured in terms of basic activity limitations). The gap exceeds 40% in Hungary (43 pp) and equals or exceeds 30% in 12 other countries (Netherlands, Romania, Slovakia, Bulgaria, Poland, the Czech Republic, Ireland, Denmark, Belgium, the United Kingdom, Cyprus and Lithuania). The gap

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See Council Decision 2010/707/EU of 21 October 2010 on guidelines for the employment policies of the Member States: <a href="http://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX:32010D0707">http://eur-lex.europa.eu/legal-content/EN/ALL/?uri=CELEX:32010D0707</a>

between disabled and non-disabled is respectively of 13 pp for early leavers from education and training and 12 pp for tertiary educational attainment.

## 3 The response from the European Statistical System so far

The European Statistical System (ESS) already collects some statistical data which can be used to describe the situation of disabled people. They are presented in the first section of this chapter. The availability of national disability data is described in the second section of this chapter. Most Member States also collect some disability-related statistics at the national level which are based usually on different national definitions and therefore not usable at EU level.

#### 3.1 Disability-related information in ESS surveys

The availability of data stemming from ESS sources to respond to the needs expressed by both the UNCRPD and the EDS is quite limited. Currently four population-based surveys provide some disability-related data within the ESS. These surveys collect health variables usually for the population living in private households<sup>3</sup> and aged 15 or 16 and above.

These ESS sources are respectively:

- The European Health and Social Integration Survey (EHSIS) was a one-shot exercise launched by Eurostat in 2012/2013 through calls for tenders (only five national statistical authorities were involved in data collection; contractors implemented the survey in the other countries). EHSIS is the most comprehensive source of data on the barriers to participation in different life areas for people having a health problem or a basic activity difficulty, but it does not allow computing for instance the main employment or education-related indicators.
- o The European Health Interview Survey (EHIS) is currently running. The next wave should be organised in 2019 and afterwards it should take place every 6 years according to the last DSS opinion. EHIS collects data on the level of functioning and activity limitations in the population and provides other information on health status, health determinants and health care use;
- o The Statistics on Income and Living Conditions (SILC) instrument collects annually data on long-standing activity limitation due to health problems (GALI variable) since 2003. GALI is considered as an appropriate proxy for disability (see below). The use of GALI allows building meaningful indicators related to income, social inclusion and living conditions (including the poverty-related Europe 2020 indicator).
- The Labour Force Survey (LFS) collected via specific ad-hoc modules in 2002 and 2011 data on employment of disabled people. This is the main source available at European level to assess the participation of disabled people in the labour market and in education and training.

In conclusion, the existing ESS data sources do not allow for a regular monitoring of the situation of disabled people in Europe according to the UNCRPD, in particular vis-à-vis the Europe 2020 targets.

#### 3.2 Additional data are available at national level

Eurostat collected in 2013-2014 information on the availability of disability data at national level (i.e. not requested by any ESS legislation or agreement). It appeared that most countries collect some data on the situation of disabled people either by extracting information from

This is an issue for disability statistics as a significant number of people with disabilities live in different kinds of institutions. The issue was addressed in the DSS paper of April 2014.

national registers or by managing national surveys or modules related to disabled people. Only Cyprus and Luxembourg did not report any source of information beyond the ESS surveys.

Among surveys the most frequent survey vehicle used for introducing national questions on disability was the LFS (used in 12 countries). Disability variables are collected quarterly (Belgium, Poland and Slovakia), annually (Bulgaria, France, the Netherlands, the United Kingdom, Norway and Switzerland) or less frequently (Germany, Denmark and Hungary). Those countries are in principle able to produce at some frequency the Europe 2020 indicators related to labour market from national data. Ten more countries responded that they are able to do it from other sources than the LFS. However such data can hardly be used for international comparisons due to the prevailing use of national definitions of disability. The use of such national data would restrict cross-country comparability and could even not be in line with the UNCRPD requirements.

35 30 25 20 ■ Non response ■ Not available 15 ■ Less than annually Annually 10 5 0 **Employment rate** Early leavers from Tertiary educational At risk of poverty or education and training attainment social exclusion

Graph 2 – Number of countries able to produce the social Europe 2020 indicators for disabled people

#### 4 Eurostat proposal for addressing this need

This section elaborates Eurostat proposal to answer the needs for disability statistics regarding the access to the labour market and to education. The option to do nothing does not really exist and in the current situation of a lack of data at EU level, stakeholders tend to extract data and indicators from inappropriate sources. This is illustrated for instance by a 2014 report from the European Commission "Report on the implementation of the UN Convention on the Rights of Persons with Disabilities (CRPD) by the European Union" where the authors use SILC microdata in order to compute indicators which should normally be based on the LFS:

"148. ......According to the latest EU-level data provided by EU-SILC 2011, the employment rate among people with disabilities is about 25 percentage points lower than that among people without disabilities (26 percentage points in 2010). These figures are very close to those provided by the Labour Force Survey ad hoc module on employment of disabled people in 2011, which indicate a difference of 24 percentage

points. About 47 % of persons with disabilities are employed, as compared with 72 % of persons without disabilities."......

Eurostat regularly opposes to such practice which is imposed by the obligation to report on the situation of disabled people in Europe. It happens that luckily the figures seem to converge between the LFS and EU-SILC based estimates at EU level, but this is not necessarily the case for each country.

In order to address this gap Eurostat proposes to adopt Self-perceived health and GALI as core social variables which would be collected in the LFS only every second year. The Global Activity Limitation Indicator (GALI) has the potential to become a core social variable, i.e. to be introduced into each ESS social survey, because of the need to identify the position of the sub-population of persons with disabilities in all aspects of life. Its introduction into non health-specialised surveys such as the LFS, the Adult Education Survey or the Household Budget Survey would in no way aim at measuring the prevalence of disability into the whole population but mainly at measuring the position of persons with disabilities as regards the relevant key indicators available from each survey (e.g. for the LFS the employment or unemployment rate of disabled people). Moreover, the use of GALI in these surveys would mean a common identification of disabled people across ESS surveys (standardisation across all social surveys as GALI is already used in SILC and EHIS). However GALI cannot be asked bluntly in a questionnaire and needs to be introduced by other variable(s). Although GALI was developed in the context of the Minimum European Health Module that Eurostat still recommends for implementation (see below), Eurostat proposes in order to reduce the respondents' burden that GALI could be introduced in the LFS only by the variable on selfperceived health, which is then also recommended as a core social variable.

If the DSS eventually did not agree on the introduction of Self-perceived health and GALI into the LFS, Eurostat would request to introduce a module on the employment of disabled persons in the list of topics to be measured through LFS regular modules. Currently, it is proposed that 6 topics would be regularly measured through LFS ad-hoc modules (see documents Eurostat/F3/LAMAS/40/14 and Eurostat/F3/LAMAS/06/15). LAMAS Supplemented by two non-regular modules, they constitute a cycle of 8 years of specific modules. This request would consist in adding a 7<sup>th</sup> regular module into the LFS, to specifically address the situation of disabled people on the labour market every 8 or 9 years. This solution would reduce either the periodicity of each regular module (from 8 to 9 years) or the number of supplementary modules from 2 to 1. It would also perpetuate an approach for disability statistics which is not consistent with the SILC one (which is the source in particular for the Europe 2020 target on poverty and social exclusion), which is an issue when the EU has to report on the UNCRPD and the EDS. Therefore Eurostat does not favour it in comparison with the GALI as a core variable solution.

#### 4.1 GALI within the Minimum European Health Module (MEHM)

The Global Activity Limitation Indicator (GALI), which was developed within the <u>Euro REVES II project</u>, is a standard question designed for measuring participation restriction through long-term activity limitations. It is recommended to be collected as part of the so-called Minimum European Health Module (MEHM). All three variables included in the MEHM should be asked in the recommended order with no inclusion of any other health status related variables before or between the MEHM questions as it could have an impact on results. In addition, none of the questions should be filtered by any other question. The MEHM should be introduced to respondents using a short introduction such as: "I would now like to talk to you about your health".

The MEHM is composed of:

- 1. Self-perceived general health, hereafter abbreviated as SPH (Recommended question: 'How is your health in general? Is it...')
- 2. Long-standing health problem (Recommended question: 'Do you have any longstanding illness or health problem?')
- 3. General activity limitation (Recommended question: 'For at least the past six months, to what extent have you been limited because of a health problem in activities people usually do? Would you say you have been ...').

Although Eurostat keeps on recommending collecting GALI as part of the MEHM, it is proposed to drop the second MEHM variable on long-standing health problems<sup>4</sup> in particular given the limited space in the LFS. It should be noted that it seems necessary to have at least two questions on a topic like health (in particular in order to introduce GALI) in a questionnaire which is not predominantly dealing with disability or health issues. Therefore, it is proposed to introduce the first and third MEHM variables into the LFS.

#### 4.2 GALI validation

GALI has been scientifically developed and tested and is considered as a good proxy for measuring disability. Validation studies have proven its reliability and validity in discriminating people with or without disabilities. However, some stakeholders still consider it difficult to implement for several reasons:

- Results could be culturally biased as there seem to exist some differences across EU countries regarding judgements on health and personal activities. In addition, some concepts of GALI could be perceived as somewhat vague which may increase variation of results.
  - Eurostat answer: subjectivity or cultural influence cannot be avoided for many topics. This fact should not prevent from collecting such data if they are valid for certain (national) context and if it does not disturb the interpretation of results.
- The operationalization of the GALI variable is complex as it includes four concepts in one question. It is difficult for respondents to take all of them appropriately into account when evaluating their own situation.
  - Eurostat answer: according to current knowledge, the question recommended by Eurostat is indeed complex and difficult to answer at least for some respondents. However, different operationalization (for example splitting the question) may have negative effects too, for example to decrease specificity.
- The instrument lacks some robustness and reliability, including when different collection methods are applied.
  - Eurostat answer: different studies showed that GALI is closely associated with mortality, cost of and use of health care services. As for many other variables, the method of data collection can obviously have an impact on outcomes. It is therefore an argument for a closer harmonisation between countries in order to reduce the potential sources of reduction of the comparability across countries.

In view of the possible adoption of GALI as a core variable, the Directors of Social Statistics agreed to set up a new Task-Force dedicated to GALI. It met twice, in September 2014 and lastly on 22 May 2015. In its first meeting the Task-Force strongly supported Eurostat views that the concepts into GALI should remain unchanged although some further work should be

The first and second MEHM question measure both the health status of the respondent but self-perceived health was selected as it enables more detailed stratification of respondents and is also less dependent on the organisation of health care services in countries. For example, respondents in countries with good screening

organisation of health care services in countries. For example, respondents in countries with good screening programmes or preventive services can be diagnosed with certain health problems (such as hypertension) more often and as such report more often prevalence of health problems (which do not necessarily have impact on their perception of health or limitations in daily life).

done in terms of operationalization. In its second meeting the Task-Force discussed possible ways to improve GALI, and in particular the outcomes of a recent study by Eurostat (see below) as well as similar studies run by the Robert Koch Institute (Germany) and the French Direction de la Recherche, des Études, de l'Évaluation et des Statistiques (DREES).

#### 4.3 Operationalization of GALI: Eurostat study

The various modalities of the variable are not at stake. They are presented in Annex 2. The discussion on the operationalization of the GALI variable which is presented in this section focuses on the question(s) to be recommended for use in the different surveys although ESS surveys use the concept of output-harmonization, i.e. leaving to each country the possibility to adapt the recommended question to national circumstances.

Eurostat launched in March 2015 a methodological study aiming at qualitative testing of different variants of GALI without changing the underlying concepts. The goal is to improve GALI so that it is easier for respondents to understand and easier to implement in a wide range of survey arrangements. The project includes the following three tasks:

- In Task 1, the current standard GALI and four variants were tested in three languages (English, German and French) with the aim of preselecting two alternative versions of the GALI.
- Task 2 consists of testing the standard version of the GALI, and the two alternative versions chosen in Task 1, with different modes of data collection. The focus is on the effect of the mode of data collection and on the response burden. As the face-to-face interview is less and less used by the Member States, the goal of Task 2 is to find the best version of the GALI to reduce the response burden and ensure that the impact of the data collection mode on the results of the survey is minimized.
- In Task 3, the versions selected in Task 1 plus the standard GALI will be tested in proxy interviews. This choice derived from the fact that some EU social surveys such as the LFS have a high share of proxy interviews.

Cognitive interviews were held in three countries / languages (the United Kingdom for English, Austria for German and France for French) in order to evaluate the quality of the proposed versions. The purpose of this study conducted among a sample of 150 persons (of which at least 50% were disabled) was not to produce any valid quantitative result but to assess the easiness of the question to be implemented (the response burden for both respondents and interviewers), its quality and validity, and the closeness to the current GALI version.

This study should be an essential input in the review of the operationalization of GALI which should be finalized after opinion of the GALI Task-Force and the Public Health Working Group. Therefore it is asked that the LAMAS WG takes a position of principle on the inclusion of GALI together with the first MEHM variable on self-perceived health while the documentation of the operationalization of GALI will be made available at a later stage<sup>5</sup>.

Eurostat is open to consider the further testing of SPH and GALI into the LFS although it is important to note that a number of countries already implement GALI or a variant of it in their national LFS. France and Switzerland implement all MEHM questions (including GALI) in their annual data collection. Another 10 countries collecting data on disability in LFS include either question(s) similar to GALI (BE, DK, HU, NL, UK and NO) or a question on official recognition of disability (BG, DE, SK, PL, but also FR).

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One of the objectives of the project on the modernisation of social variables is the standardisation of variables, which should be implemented in a similar way across EU surveys. This means in particular that SPH and GALI should – until further notice – be implemented in a way similar to SILC and EHIS.

#### 4.4 Strengths and weaknesses of the proposal

Confronted with a high demand for statistics on employment and education of disabled persons, Eurostat proposes to introduce SPH and GALI into the LFS every second year in the conditions described in Section 4.1. The following table lists the advantages and disadvantages of this approach:

Table 1: Pros and cons of SPH and GALI as core variables

Pros	<ul> <li>Allows for regular monitoring of the situation of disabled people according to UN convention and EU strategy (every two years)</li> <li>Robustness of GALI</li> <li>Harmonisation with SILC and EHIS (and possibly in other surveys if approved as core variable)</li> <li>Lower burden for countries and respondents (compared to introducing a module on employment of disabled people)</li> </ul>
Cons	<ul> <li>Less detailed information on different disability measures but sufficient for UN convention and EU strategy (only one variable)</li> <li>Need to test in LFS (apart from FR and CH). BE, DK, HU, NL, UK and NO may also not need to test GALI in LFS</li> </ul>

#### 5 Conclusions

This document presents Eurostat's proposal for addressing the need for disability-related statistics stemming from the Labour Force Survey in the context of the modernisation of social statistics. Boosting the participation of persons with disabilities in the labour market and in the education and training systems forms an integral part of the employment guidelines (7 and 9) and would support the EU in satisfying requirements of the UN convention and the EU strategy on disability. The introduction of relevant variables in the LFS would be an essential step towards the monitoring of the Europe 2020 targets on employment and education for people with disabilities.

With this aim Eurostat proposes to collect every second year the two following variables:

- Self-perceived general health;
- General activity limitation.

Countries are strongly encouraged to introduce as well the second variable of the MEHM, i.e. Long-standing health problem. Both SPH and GALI should be tested within the LFS before it is implemented.

#### LAMAS members are asked to:

- Agree on the need to collect disability-related information in the LFS;
- Agree on the solution proposed by Eurostat, i.e. to collect every second year at least the variables 'Self-perceived health' and 'Global activity limitation indicator'.

#### **Annexes:**

- Annex 1: description of the 'Self-perceived general health' variable

-	Annex 2. description of the Global activity limitation indicator variable

#### **Annex 1:** description of the 'Self-perceived general health' variable

#### Variable concept:

The concept of self-perceived health is, by its very nature, subjective. The notion is restricted to an assessment coming from the individual and as far as possible not from anyone else, whether an interviewer, healthcare professional or relative. Self-perceived health is influenced by impressions or opinions from others, but is the result after these impressions have been processed by the individual relative to their own beliefs and attitudes.

The reference is to health in general rather than the present state of health, as the question is not intended to measure temporary health problems. It is expected to include the different dimensions of health, i.e. physical, social and emotional functioning and biomedical signs and symptoms. It omits any reference to age as respondents are not specifically asked to compare their health with others of the same age or with their own previous or future health state.

#### Category concepts:

Five answers categories are proposed. Two (very good and good) are at the upper end of the scale and two (bad and very bad) are at the lower. It is also important to note that the intermediate category 'fair' should be translated into an appropriately neutral term (neither good, nor bad), as far as possible keeping in mind cultural interpretations, in the various languages .

## Standard concept system:

Standard answer categories for the variable are defined by LEVELS code list and are as following:

Name of the category	LEVELS
Total	<b>✓</b>
Very good	✓
Good	✓
Fair	✓
Bad	✓
Very bad	✓
Not stated	✓
Not applicable	<b>✓</b>

#### Implementation rules:

The variable is intended to be collected from individuals aged 15 years and more.

The model question for the variable should not to be filtered by any preceding question.

A proxy interview for the variable should be limited but is possible.

This variable is part of the Minimum European Health Module (MEHM). MEHM consists of two more variables on health status: Long-standing health problem and Global Activity Limitation Indicator. If the MEHM is implemented, all the questions should be asked in the recommended order (Self-perceived general health, Long-standing health problem, Limitation in activities because of health problems) and with no inclusion of any other health status related questions before or between MEHM questions as it could have impact on results.

MEHM could be introduced to respondents using a short introduction: "I would now like to talk to you about your health".

<u>Reference question</u>: How is your health in general? Is it... very good, good, fair, bad, very bad.

## Sources:

- 1. European Health Interview Survey (EHIS wave 2) Methodological manual, 2013 edition
- 2. Methodological guidelines and description of EU-SILC target variables, 2014 operation Version December 2013

#### **Annex 2:** description of the 'Global activity limitation indicator' variable

#### Variable concept:

The variable measures long-standing limitation (and its severity) in activities that people usually do because of health problems. It measures the respondent's self-assessment of whether he/she is restricted in "activities people usually do", by any on-going physical or mental health problem, illness or disability. Consequences of injuries/accidents, congenital conditions and birth defects, etc., are all also included.

An activity is defined as: 'the performance of a task or action by an individual' and thus activity limitations are defined as 'the difficulties the individual experience in performing an activity'.

Only the limitations directly caused by or related to one or more health problems are considered. Limitations due to financial, cultural or other none health-related causes should not be taken into account.

People with longstanding limitations due to health problems have passed through a process of adaptation which may have resulted in a reduction of their activities. To identify existing limitations a reference is necessary and therefore the activity limitations are assessed against a generally accepted population standard, relative to cultural and social expectations by referring only to 'activities people usually do'. The question should clearly show that the reference is to the activities people usually do and not to respondent's 'own activities'. Neither a list with examples of activities nor a reference to the age group of the subject is included in the question. This is a self-perceived question and gives no restrictions by culture, age, gender or the subjects own ambition. Specification of health concepts (e.g. physical and mental health) should be avoided.

The purpose of the variable is to measure the presence of long-standing limitations, as the consequences of such long-standing limitations (e.g. care, dependency) are more serious.

The period of at least the past 6 months is strictly related to the duration of the activity limitation and not to the duration of the health problem. The limitations must have started at least six months ago and still exist at the moment of the interview. This means that a positive answer ("severely limited" or "limited but not severely") should be recorded only if the person is currently limited and has been limited in activities for at least the past 6 months.

New limitations which have not yet lasted 6 months but are expected to continue for more than 6 months shall not be taken into consideration. The reason is that for long-standing diseases or health problems it is in general established from medical knowledge about diseases/illness whether they are longstanding or not. If a person is diagnosed having, e.g., diabetes, he/she knows from the first day that it is not curable (at least for diabetes type 1), so long-standing. At this stage he/she also knows that it may be controlled or not so it might have consequences or not but he/she doesn't know yet about it. Therefore, for the consequences it is a matter of experience from the individual, whether his or her diabetes will have disabling consequences. Only past experience can provide the answer.

#### Category concepts:

The response categories include 3 levels to better differentiate severity of activity limitations: severely limited, limited but not severely, not limited at all.

'Severely' means that performing or accomplish an activity – that people usually do – can hardly be done or only with extreme difficulty.

#### Standard concept system:

Standard answer categories for the variable are defined by LEV\_LIMIT code list and are as following:

Name of the category	LEV_LIMIT	
Total	✓	
severely limited	✓	
limited but not	1	
severely	V	
not limited at all	✓	
Not stated	✓	
Not applicable	✓	

#### <u>Implementation rules:</u>

The variable is intended to be collected from individuals aged 15 years and more.

The model question for the variable should not to be filtered by any preceding question.

A proxy interview for the variable should be limited but is possible.

This variable is part of the Minimum European Health Module (MEHM). MEHM consists of two more variables on health status: Self-perceived general health and Long-standing health problem. If the MEHM is implemented, all the questions should be asked in the recommended order (Self-perceived general health, Long-standing health problem, Limitation in activities because of health problems) and with no inclusion of any other health status related questions before or between MEHM questions as it could have impact on results. MEHM could be introduced to respondents using a short introduction: "I would now like to talk to you about your health".

## Reference question:

The model question was developed by the Euro-REVES project and is called Global Activity Limitation Indicator (GALI). The exact wording of the model question is as follows:

"For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do? Would you say you have been ...

- 1. severely limited
- 2. limited but not severely or
- 3. not limited at all?"

#### Sources:

- 1. European Health Interview Survey (EHIS wave 2) Methodological manual, 2013 edition
- 2. Methodological guidelines and description of EU-SILC target variables, 2014 operation Version December 2013