Harmonisation of Persistent Illness, Impairment and Disability data collection in social surveys

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What I’ll talk about today

Background to the disability harmonisation project

Concepts and definitions

Development and testing of questions for the 1°HStd.

Overview of results of the field testing

Final question set proposed at NSHG and GSS SPSC for approval
Background

**Review of Equality Data:**

ODI, GEO with ONS and DA’s were tasked to:

*improve data collection coordination and propagation of statistics by developing & applying a principled approach*

Develop conceptual definitions and questions to classify disability to standardised data inputs and outputs

*Health and Disability Harmonisation Sub-group*

*X-user workshops and consultations to determine core needs*

**Determine fitness for purpose by:**

*Cognitive testing (interpretability of the questions)*

*Field testing (cross-validation with other sources and the Census q)*

**Recommend an implementation across social survey sources**
Cross-sector Consultations

I. Feb 2008: x-govt. workshop discussed findings of the RED Report

II. Jun 2008: x-govt workshop on priorities for

   Question suite composition
   Classification of disability

III. Sept 2008 – Jan 2009: mail out 1st draft questions

   Gather views beyond govt (e.g. academia, third sector);
   Determine priorities for cog. testing

IV. Jun 2009 – Aug 2009:

   X-govt. workshop discuss cog. testing findings; produce 2nd draft Qs
   Mail out cog testing report; revised Qs for further comment pre field testing

V. Jan 2011 - final consultation on findings of field test and questions pre presentation to NSHG and SPSC in March and April
Findings from cross-govt. workshops

<table>
<thead>
<tr>
<th>Recommendation 4.3 of the RED approved for action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Standards should be sensitive to future EA legislation</td>
</tr>
<tr>
<td>Must balance national and European data needs</td>
</tr>
<tr>
<td>Definitions, questions, classification preferences varied x-govt</td>
</tr>
</tbody>
</table>

*Medical model v Social model v ICF biopsychosocial model*

**Key priorities agreed for the harmonised questions:**

*Monitoring core DDA population succinctly as possible*  
*Functionality to feed European data needs thru concept alignment*  
*Adequate level of continuity in outputs*  
*Relationship to Census 2011 question measured and known*  
*Develop secondary standard for capturing participation restriction and causes*
Concept of Disability

The disablement process used as conceptual framework

To derive a working definition

Develop questions to measure the definition

Adapted from Verbrugge & Jette, 1994
Definitions of disability

Concept is multi-faceted: definitions largely based on 2 models

SOCIAL MODEL: distinguishes disability from impairments
disability is the restriction of activity and participation, caused by aspects of society which take insufficient account of the needs of people with impairment

MEDICAL MODEL: abnormal attribute of the individual
which requires treatment or special services to help enable social inclusion and participation

ICFHD: presents disability as a process
Brings together medical, societal and individual factors and the interactions between them to define disability
includes traditional data on illness and activity restrictions, together with societal factors causing participation restrictions
Review of qs on LSI ‘Disability’ in surveys

**Life Opportunities Survey**
*Do you have any long-standing impairment, disability or illness lasting or expected to last for a period of 12 months or more?*

**General Lifestyle\English Housing\Health Survey for England**
*Do you/does (..) have any long-standing illness, disability or infirmity - by long-standing I mean anything that has troubled you over a period of time or that is likely to affect you/him/her over a period of time?*

**Family Resources Survey**
*Do you have any long standing illness, disability or infirmity lasting or expected to last for 12 months or more?*

**Annual Population Survey\Labour Force Survey**
*Do you have any health problems or disabilities that you expect will last for a year or more?*
Problems with these questions

Mix concepts of illness, impairment and disability

You can’t disentangle illness from disability or impairment
APS excludes the term illness
Conflicts with conceptual framework of the disablement process

Time frames differ

Past and/or expectation it will last 12 months or more
Vague period of time

Harmonise to conceptual framework and legislation

Consistent time frame 12 months or more - past or expectation classifies
Asks about physical or mental health conditions or illnesses only
Determine impact on prevalence excluding terms disability\impairment in testing
1° Harmonised standard question tested

Do you have a physical or mental health condition or illness/any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?

**Field test results:**

<table>
<thead>
<tr>
<th>Survey</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Harmonised question (opinions may-july 2010)</td>
<td>33.7%</td>
</tr>
<tr>
<td>Family Resources Survey 2008-09</td>
<td>29.2%</td>
</tr>
<tr>
<td>General Lifestyle Survey 2009</td>
<td>35.1%</td>
</tr>
<tr>
<td>Life Opportunities Survey 2009-10</td>
<td>35.1%</td>
</tr>
<tr>
<td>Annual Population Survey 2006-08</td>
<td>35.9%</td>
</tr>
</tbody>
</table>
Interviewer Instructions

Provide guidance regarding coverage of terms:

Includes impairments and developmental conditions such as:

- Sensory deficits
- Mobility difficulties
- Learning difficulties such as dyslexia
- Learning disabilities such as Down’s syndrome or cerebral palsy
- Autism and Asperger's syndrome
- Memory difficulties caused by dementia or injury

And health conditions such as:

- Depression
- Common illnesses such as asthma, diabetes, heart disease
- Seasonal conditions such as hay fever which recur
Review of type of impairment Qs to add detail to Q1

**Some focused more on impairment types e.g.:**

- Vision
- Hearing
- Breathing Problems (related to heart or respiratory disease)
- Learning disability

**Others focus more on capabilities (e.g. FRS DDA suite):**

- Manual dexterity (using hands to carry-out everyday tasks)
- Mobility (walking short distances and climbing stairs)
- Ability to concentrate learn and understand
- Continence
- Communication related to sensory impairment
Results of consultation with stakeholders

Useful to collect information on condition\impairment type

_Fits ICF framework and disablement process model_

_Provides context as to the nature of the functional impact of the illness_

Impairment affecting function preferred to health conditions

_Blindness or partial sight rather than glaucoma_

_Stamina or breathing rather than heart disease or COPD_

Format should be guided by testing:

_Open response recording up to six_

_Pre-defined independent category list with a show card_

Routeing – impact on prevalence balanced by cost savings

Take account of Equality Act guidelines
List agreed and tested at stage 2

Ask if has physical\mental health condition or illness

Does this condition or illness\do any of these conditions or illnesses affect you in any of the following areas?

Show card and code all that apply:

- **Vision** (for example blindness or partial sight)
- **Hearing** (for example deafness or partial hearing)
- **Mobility** (for example walking short distances, climbing stairs, lifting\carrying)
- **Learning or understanding or concentrating**
- **Memory**
- **Mental health**
- **Stamina or breathing**
- **Socially or behaviourally** (for example associated with Autistic Spectrum Conditions)
- **Other** (please specify)
Field test results - % Prevalence 16 years and above

<table>
<thead>
<tr>
<th>Impairment/Health condition (SCHCQ)</th>
<th>HQ %</th>
<th>LOS %</th>
<th>SCHCQ %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vision</td>
<td>4.0</td>
<td>3.0</td>
<td>3.4</td>
</tr>
<tr>
<td>Hearing</td>
<td>4.1</td>
<td>3.0</td>
<td>7.8</td>
</tr>
<tr>
<td>Mobility and Dexterity</td>
<td>16.6</td>
<td>14.0</td>
<td>9.4</td>
</tr>
<tr>
<td>Learning</td>
<td>2.7</td>
<td>2.0</td>
<td>2.8</td>
</tr>
<tr>
<td>Memory</td>
<td>2.9</td>
<td>3.0</td>
<td>*</td>
</tr>
<tr>
<td>Mental Health</td>
<td>3.9</td>
<td>4.0</td>
<td>3.2</td>
</tr>
<tr>
<td>Stamina or Breathing</td>
<td>9.0</td>
<td>3.0</td>
<td>*</td>
</tr>
<tr>
<td>Autistic Spectrum Cndts.</td>
<td>0.7</td>
<td>1.0</td>
<td>*</td>
</tr>
<tr>
<td>Other</td>
<td>3.5</td>
<td>1.0</td>
<td>6.9</td>
</tr>
<tr>
<td>Any Impairment</td>
<td>25.9</td>
<td>29.0</td>
<td>34.4</td>
</tr>
<tr>
<td>No Impairment</td>
<td>74.1</td>
<td>71.0</td>
<td>65.6</td>
</tr>
</tbody>
</table>
Sub-group decision on final list and routeing

Add term FATIGUE to stamina or breathing category

Expand mobility category:

**MOBILITY**: walk short distances and climb stairs

**MANUAL DEXTERITY**: lift and carry objects, use a keyboard

Routeing to link impairment to persistent condition

Alternative version for comprehensive sample coverage

Do you have any health conditions or illnesses which affect you in any of the following areas?
Review of activity restriction Qs to classify disability

**LOS\FRS** - *Does this\do these health problem(s) or disability(ies) mean that you have substantial difficulties with any of these areas of your life?*
Mobility; Lifting; Manual Dexterity; Continence; Communication; Memory\Ability to learn; Physical danger; Balance; Other

**GLF\EHS\HSE** - *Does this illness or disability (do any of these illnesses or disabilities) limit your activities in any way?*

**GLF only** - *Would you say your activities are limited or strongly limited?*

**APS\LFS** - *Do these health problems or disabilities, when taken singly or together, substantially limit your ability to carry out normal day to day activities? If you are receiving medication or treatment, please consider what the situation would be without the medication or treatment.*

**2011 Census** – *Are your day-to-day activities limited because of a health problem or disability which has lasted or is expected to last for 12 months or more?*
Issues with these questions

**EXTENT OF RESTRICTION** – variation in terms

- **Substantial difficulty** – used in DDA\EA legislation (FRS\LOS)
- **Substantially limit day-to-day activities** – used in LFS\APS
- **Limit activities in any way \\ strongly limited** GLF
- **Limited A Lot, A Little** – used in Census 2011

**TIME FRAMES** – none state a time frame

- EU-SILC REGULATION – *past 6 months or more*
- **EQUALITY ACT** – *past 12 months OR last 12 months or more\rest of life*

**MEDICATION OR TREATMENT**

*Whether activities would be limited without*
Findings of cognitive testing and consultations

**ROUTED** – Only asked of those reporting a health condition or illness

**INTERVIEWER INSTRUCTIONS** – standardise frames of reference

**ALTERNATIVE TERM TO LIMITED** - Difficulty / Reduced ability

**EXTENT SHOULD BE CAPTURED** -

- Relationship between terms must be tested (Substantial, Strongly, A Lot)
- Effect of extent on disability prevalence overall must be tested
- Preference for plain english terminology (a lot and a little)

**TIME FRAME** – meet DDA\EqA and EU-SILC guidelines

**QUESTION ELICITING RESTRICTION WITHOUT MEDICATION**

- Cumbersome, unlikely to deliver useful information
### Questions tested at stage 2

Routed from question capturing persistent illness

**Extent of activity restriction:**

> Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry-out day-to-day activities?

1. Yes, A Lot;
2. Yes, A Little; or
3. Not at all.

**Duration of activity restriction if yes a lot or yes a little:**

> For how long has your ability to carry-out day-to-day activities been reduced?

1. Less than 6 months;
2. Between 6 months and 12 months; or
3. 12 months or more.
# Field test results - % Prevalence 16 years and above

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Weighted percent of sample</th>
<th>95% confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Field test question – Opinions 2010</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes a lot or yes a little?</td>
<td>21.9</td>
<td>20.0 - 23.9</td>
</tr>
<tr>
<td>Yes, a lot</td>
<td>10.3</td>
<td>8.8 - 11.7</td>
</tr>
<tr>
<td>Yes, a little</td>
<td>11.7</td>
<td>10.1 - 13.2</td>
</tr>
<tr>
<td><strong>FRS question – 2008-09</strong></td>
<td>21.4</td>
<td></td>
</tr>
<tr>
<td><strong>LOS question 2009-10 interim results</strong></td>
<td>25.9</td>
<td></td>
</tr>
<tr>
<td><strong>GLF question 2008</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited or strongly limited</td>
<td>19.5</td>
<td></td>
</tr>
<tr>
<td>Strongly limited</td>
<td>8.5</td>
<td></td>
</tr>
<tr>
<td><strong>Field Test of 2011 Census question – Opinions 2010</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, limited a lot or yes limited a little</td>
<td>21.9</td>
<td>20.0 - 23.8</td>
</tr>
<tr>
<td>Yes, limited a lot</td>
<td>10.7</td>
<td>9.2 - 12.1</td>
</tr>
<tr>
<td>Yes, limited a little</td>
<td>11.2</td>
<td>9.7 - 12.7</td>
</tr>
</tbody>
</table>
Field test results – Impact of duration for EA and EU-SILC classification

<table>
<thead>
<tr>
<th>Field test question – Opinions 2010</th>
<th>%</th>
<th>95% confidence interval</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than six months or between 6 and 12 months or 12 months or more</td>
<td>21.9</td>
<td>20.0 - 23.9</td>
</tr>
<tr>
<td>Less than six months</td>
<td>1.3</td>
<td>0.7 - 1.8</td>
</tr>
<tr>
<td>Between 6 months and 12 months</td>
<td>1.8</td>
<td>1.2 - 2.5</td>
</tr>
<tr>
<td>12 months or more</td>
<td>18.8</td>
<td>17.0 - 20.7</td>
</tr>
<tr>
<td>Equality Act estimate taking account of duration</td>
<td>18.8</td>
<td>17.0 - 20.7</td>
</tr>
<tr>
<td>EU-SILC estimate taking account of duration</td>
<td>20.7</td>
<td>18.8 - 22.6</td>
</tr>
<tr>
<td>EU-SILC estimate of ‘Severely Hampered’ using the category Yes, a Lot</td>
<td>9.9</td>
<td>8.5-11.3</td>
</tr>
<tr>
<td>EU-SILC estimate of ‘Hampered to some extent’ using the category Yes, a little</td>
<td>10.8</td>
<td>9.3-12.2</td>
</tr>
<tr>
<td>EU-SILC 2008 estimate on Eurostat website – ‘Severely Hampered’</td>
<td>8.5</td>
<td></td>
</tr>
<tr>
<td>EU-SILC 2008 estimate on Eurostat website – ‘Hampered, but not severely’</td>
<td>11.0</td>
<td></td>
</tr>
</tbody>
</table>
Primary standard definition –

A disabled person is someone with a persistent (physical or mental) health condition or illness, which impairs their functioning and reduces their ability to carry-out day-to-day activities

Secondary standard definition –

A disabled person is someone with a persistent (physical or mental) health condition or illness. As a result, their participation in key areas of life is restricted relative to people without impairments, because of aspects of society which take inadequate account of the needs of people with impairments.
Question 1a. - establish whether has a physical or mental health condition or illness, long-lasting in nature

Ask all if >=16 years of age, ask by proxy if <16 or not fit to respond in person.

Do you have a physical or mental health condition or illness/any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?

1. Yes
2. No

Spontaneous only:
3. Don’t know
4. Refusal

Interviewer Instructions

Provide guidance on conditions or illnesses or impairments covered:

All impairments such as learning disabilities, ASC, sensory deficits, mobility problems, seasonal conditions which recur as well as general health conditions such as heart disease, diabetes and depression
Question 1b(i) (standard version): type of impairment

Ask if 1a = Yes

*Does this condition or illness\do any of these conditions or illnesses affect you in any of the following areas?*

**Show card and code all that apply:**

- Vision (for example blindness or partial sight)
- Hearing (for example deafness or partial hearing)
- Mobility (for example walking short distances or climbing stairs)
- Dexterity (for example lifting and carrying objects, using a keyboard)
- Learning or understanding or concentrating
- Memory
- Mental health
- Stamina or breathing or fatigue
- Socially or behaviourally (e.g. associated with Autistic Spectrum Conditions)
- Other (please specify)
Question 1b(ii) (optional version):

Whether any physical or mental health condition or illness affects functioning, irrespective of whether a positive answer was given to Question 1a.

Ask All

_Do you have any health conditions or illnesses which affect you in any of the following areas?

Continue as for Question 1b(i) same categories_
**Proposals to NSHG – March 2011**

**Question 2a - Whether a person with a persistent health condition or illness has activity restriction**

Ask if 1a = Yes

*Does your condition or illness/do any of your conditions or illnesses reduce your ability to carry-out day-to-day activities?*

Running prompt:

1. Yes, a lot
2. Yes, a little
3. Not at all

**Interviewer instructions:**

Typical day-to-day activities are washing and dressing, cleaning the living space, using transport, climbing stairs, paying bills, walking short distances, lifting and carrying objects.

Extent categories are determined by how much assistance is needed; a lot indicates largely reliant on another for daily activities, house bound.
Question 2b – duration of activity restriction

Ask if 2a = Yes, a lot or Yes, a little

For how long has your ability to carry-out day-to-day activities been reduced?

Running prompt:

1. Less than six months
2. Between six months and 12 months
3. 12 months or more
### Classification of disability in terms of the Equality Act

Question 1a = Yes AND Question 2a = Yes, a little OR Yes, a lot

### EU-SILC long-standing health condition or illness

Question 1a = Yes

### EU-SILC classification of disability by extent

#### Estimate of severely hampered in daily activities

Question 1a = Yes AND Question 2a = Yes, a lot AND Question 2b = Between 6 months and 12 months OR 12 months or more

#### Estimate of hampered to some extent in daily activities

Question 1a = Yes AND Question 2a = Yes, a little AND Question 2b = Between 6 months and 12 months OR 12 months or more
Next Steps

Implementation across surveys using face-to-face interview mode

Conduct further testing of qs to measure 2°harmonised def.

Continue work in 2011-12 on adaptation of these questions for other modes of survey administration, including presentations designed for people with specific types of impairments (Braille, easy read)

Develop questions for use in administrative sources