

The Matrix: as a framework for the development of the Extended Set(s)

The Matrix (refer to attached Excel document, Framework Blocks and Work plan) was originally designed as means to place the work of the WG in a larger context or perspective – both in terms of the development of extended question sets; and as a means of illustrating the commonalities among other initiatives that are in the process of questionnaire development. It has now been put to use as a tool for the development of the extended question sets, providing a framework on which these sets can be built.

The Matrix can be subdivided into 4 blocks:

1. Basic activity domains (columns) by Capacity and Performance (rows)
2. Complex activity domains (columns) by Capacity and Performance (rows)
3. All domains by Age at onset, Cause, Duration and Impact
4. Environmental factors (meso and macro).

The extended sets that will be presented fall under **Block 1**. Under **Block 2**, a single ADL question is included among the WG short set – but the development of extended questions under this domain, and the other domains included under Complex activities were determined to be beyond the scope of the Workgroup – and were in many cases often included in other sections of survey questionnaires. (Exceptions are self care and domestic activities and maybe that is something to be developed as well for a further extended set)

The items in **Block 3 - Age at onset, Cause and Duration** – might refer to the level of functional difficulty or the underlying (health) condition. Deliberations at the July meeting determined that these aspects of functioning should be measured with reference to the experience of difficulty in functioning under the domain and not the underlying (health) condition.

Questions would therefore be framed:

1. **Age at onset:** How old were you when you first starting having difficulty [*in this domain*]?
2. **Cause:** What condition or health problem is the reason for your difficulty [*with this domain*]?
3. **Duration:** How long have you had your current level of difficulty [*in this domain*]?

With respect to the measurement of **Impact** (green row) and three options were considered:

1. whether this was better captured as a Row item under specific domains. For example, “How does your difficulty walking affect your ability to: work & maintain a job, or get an education or make friends...?” – meaning impact of functional difficulty on education, employment, social activities etc.

2. whether it could be captured through measurements of outcome (columns as in Block 2). For example, as the impact of basic activity difficulties on complex activities and participation. “Considering the difficulties indicated under basic activities, how much difficulty do you have in participating in *life activities*?”
3. whether it could be derived through the analysis of existing data – as the impact of Assistive devices or other Environmental factors on functioning. This would involve asking questions about employment, education and social participation without asking about impact but measuring the impact through analysis with the responses on basic activities and to the questions about use of assistive devices and personal assistance and on other environmental factors.

In the first option, direct questions about impact are asked according to the domain- it is domain specific. In the second option, impact is treated as a more general outcome. In the third option, impact is not explicitly mentioned but is derived through data analyses.

Again, our discussions in July concluded that, as a question set, **Impact** would be best handled through the analysis of functional difficulties and outcome measures taking into account use of assistive devices, meso-environmental barriers – and also through qualitative case studies, that is, option 3 above.

Block 4 includes aspects of the meso- and macro-environment.

The **meso-environment** (blue, Row 9) comprises the environment beyond the person (e.g. services & service provision, transportation, infrastructure, accessibility, attitudes of others and feelings of stigmatization).

Meso-environmental factors have been conceptualized as NON-domain specific; the questions asked in general rather than for each domain. It may, however, be appropriate for some of these meso-environment factors to be examined within the specific domain.

Questions on service provision and use will necessarily be country specific (i.e. not cross-nationally comparable, but perhaps regionally) as service provision will vary in nature and extent across countries.

This is an area for which we do not have any set questions. There are some surveys that are starting to use questions on the meso-environment. The data from these surveys should be analyzed to determine if the questions used could be included in some extended sets.

Note: people’s experience of discrimination and feelings of stigma are considered here as **meso-environmental** factors and these can be collected in surveys.

Macro-environmental (yellow Row 10) factors include national policies, legislation and general societal attitudes and practices. These are better collected through other sources and were not suited to the format of population-based surveys or other personal survey data collections.

Further notes on the table are worth highlighting here:

1. **Note a** – Row 1 – indicates that two separate single questions on **Learning** would be developed: one for children and one for adults.
2. **Note b** – under **ADL**, it was thought that extended questions could be developed for ADL for special populations (e.g. the elderly) but that for general populations they were not required as prevalence estimates are usually very low and a person identified on this domain are usually also identified on more basic domains. It remained unclear whether extended questions should be developed to capture difficulty functioning (in terms of ADL) with assistance – hence the question mark (?). (Note: OECD is keen on the use of ADL questions as an indicator of health/social need.)
3. **Note c** – at this point the choice of questions and the exact wording of questions are yet to be decided; however, it was thought that extended questions on **Cognition** (including use of assistive devices) were needed.
4. **Note d** – it may be necessary to re-order the pattern of questions, compared to other domains, in order to capture performance: use of assistive devices and functioning with assistance (refer to: Proposed sets for measuring disability)