Mapping measures to the LifeCourse standard terminology

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Acknowledgements

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Contents

Executive summary

The LifeCourse platform aims to enable researchers to capitalise on the wealth of longitudinal cohort data available at the Melbourne Children's Campus to advance understanding of key health issues facing children and young people. Making these valuable cohort data findable and accessible for researchers is integral to achieving this goal. This requires a systematic approach to the way these metadata are described and organised.

As a first important step, LifeCourse standardised the terminology used to describe constructs captured across cohort data collections. Now, specific measures need to be aligned with the new terminology to generate a measures-to-terms map. Aligning measures to terms in a consistent and systematic way will allow: 1) auto-population of each measure's corresponding terms across the website; 2) significant reduction in human error and inconsistency; and 3) greater time efficiency in uploading new metadata to the website.

To assign relevant terminology to a measure, we drew on accompanying measure documentation, such as scoring guidelines and psychometric evaluations, which detail information about the key constructs assessed. We then took the following steps: 1) identified interpretable components of the measure (e.g., subscales), 2) determined the core constructs captured by the measure or component, 3) selected corresponding term/s describing the construct assessed from the LifeCourse standard terminology, and 4) documented this outcome.

The resulting measures-to-terms map is a living system that will develop further as new measures are encountered or issues with existing relationships identified. It should be noted that terms are not intended to provide an all-encompassing and granular description of the measures and constructs assessed. Rather, describing measures using a standard terminology provides an indication of relevant concepts captured to aid in browsing and searching during the high-level study design phase. Metadata collated on the LifeCourse website is not intended as a substitute for careful examination of detailed study documentation and codebooks.

As a next step, the resulting map of measures-to-terms will be uploaded to the LifeCourse website's back-end database, allowing for auto population. This move to auto population achieves a consistent and systematic approach, but does not allow for bespoke cohort-specific perspectives on measures. We are therefore also considering opportunities to clarify how terms and LifeCourse metadata should be understood on the LifeCourse website.

Background

The LifeCourse platform aims to enable researchers to capitalise on the wealth of longitudinal cohort data available at the Melbourne Children's Campus to advance understanding of key health issues facing children and young people. Making these valuable cohort data findable and accessible for researchers is an integral aspect of this initiative.

The LifeCourse website provides a bird's eye view of what data have been collected across our cohorts. Measures used within a study wave are described using a set of terms to capture the constructs assessed, which are then broadly summarised into a smaller number of domains, see example below in *Figure 1*. This enables easy and intuitive browsing and searching.

Figure 1. Labelled example of domains and terminology on the LifeCourse website

Historically, LifeCourse has used an in-house developed set of terms and domain groupings to describe measures, and applied these to measures in an ad hoc fashion each time a measure was encountered. This approach was flexible and allowed data custodians to describe data in a way that they preferred. However, with the scale that the platform has grown to, this is no longer tenable. Of particular concern is that the same measures have been described using different terms between studies. This makes comparison of data between cohorts more difficult. Additionally, this system requires a large investment of staff time, given that terms need to be assigned and receive data custodian sign-off every time a measure is encountered.

Standardising how we describe and organise data captured across LifeCourse cohorts will allow us to achieve a more streamlined, consistent, and intuitive format for browsing and searching of cohort data elements. LifeCourse made a first significant step towards this by standardising the terms used to describe and organise the data collected across the LifeCourse cohorts. For full details see *Describing data captured in the LifeCourse platform using a standardised terminology*. In summary, we proceeded term-by-term through the LifeCourse ad hoc developed system, identifying commensurate terms from SNOMED

that met pre-defined criteria. Where an appropriate SNOMED term could not be identified, we searched in the Medical Subject Headings (MeSH) as another widely utilised system, before turning to an in-house solution reached through discussion and consensus within the LifeCourse team. We found that 80% of concepts measured across LifeCourse cohorts could be described using SNOMED terminology, thereby achieving strong alignment to this international standard.

The next step required is to allocate these standardised terms to measures themselves. Rather than assigning these anew each time a measure is encountered, we aim to develop a measures-to-terms map with pre-defined term/s assigned for each measure, which will then auto populate to the website. Our previous approach when assigning LifeCourse terms to measures was ad hoc and often inconsistent. The process outlined in this report details a more systematic approach to assigning measures to the LifeCourse standard terminology, which is replicable and will lead to more consistent descriptions of the measures used across the LifeCourse cohorts.

Approach to assigning terms to measures

To assign relevant terminology to a measure, we drew on each measure's accompanying documentation, such as scoring guidelines, psychometric evaluations and publications, which detail information about the intended key constructs being assessed by the measure. To determine relevant terms for each measure, the following steps were taken: 1) identify interpretable components of the measure, 2) determine the core constructs captured by the measure or component, 3) select corresponding term/s describing construct from the LifeCourse standard terminology, and 4) document this outcome and integrate the relationship into a measures-to-terms map. This process was informed by discussions with the MCRI Data Group and MCRI Ontology Working Group.

LifeCourse team members worked through each measure, one at a time, in alignment with their content expertise. Initially, the process was piloted using one highly utilised measure (PedsQL 4.0), and then more broadly, using one wave of data collection for one cohort including a range of measures.

Assigned terms should be considered as 'relevant LifeCourse constructs' as identified through the process described and in line with the purpose of the LifeCourse website, rather than as a comprehensive description of a given measure.

What measures are being mapped?

The data collected by cohorts typically includes a range of established measures or instruments. Established measures have generally been published in the peer-reviewed or grey literature with corresponding data supporting their reliability and validity, along with guidelines for scoring and interpretation. There are some established measures that are used very widely across cohorts. For example, the PedsQL-4.0 is used by around 25% of cohorts.

Most cohort data collections also include a proportion of items or measures that were developed by the study itself, or another similar study in house, to meet their specific requirements or to assess constructs where no previously published measure is available. These study-devised measures are unlikely to have received extensive testing of reliability and validity, and less or no documentation may be available guiding their use.

While both established and study-devised measures need to be mapped, the process of assigning terms will sometimes differ given the different documentation and guidance available.

Relevant documentation to inform mapping

A range of sources of information are relevant to informing the mapping of measures to terms. Established measures will often be accompanied by a suite of documents to assist with understanding, interpretation and scoring, including:

1. The measure itself (name and complete instrument)
2. Publisher's instructions for scoring and interpretation
3. Publications in peer-reviewed journals describing development of the measure

For study-devised measures, less documentation is likely to be available but may still include:

1. The measure itself (name and complete instrument)
2. Descriptions prepared by the study who devised the measure

In addition, advice and guidance on the intended use of the measure may be available from the cohort team.

Criteria for assignment of terms

A set of pre-determined criteria was developed to define appropriate mapping of measures to terms in the LifeCourse context (*Box 1*). These criteria were used to guide the selection of terms for measures as outlined below.

> ## Box 1. Criteria for assigning terms to standard terminology
>
> The following criteria was used to define appropriate descriptions of measures according to LifeCourse standard terms:
>
> 1. Terms are assigned at the level of interpretable components of the measure, which typically includes:
>   a. The overarching measure (e.g., Strengths and Difficulties Questionnaire; SDQ) – *always assigned*
>   b. Subscales (e.g., Prosocial subscale of the SDQ) – *assigned where relevant*
>   c. Individual items (e.g., 'child volunteers' item of SDQ) – *rarely assigned*
>   o Individual items are rarely assigned because most items are not considered interpretable in isolation
>   o Exceptions arise where the individual item is intended as a complete measure, such as the Global rating of health
> 2. The term/s assigned should indicate the core construct being assessed by the measure / component.
> 3. Multiple terms can be assigned to a measure where it is designed to assess more than one construct.
> 4. Only the core construct/s assessed should be described by the assigned term/s (e.g., depression), and not other distinct but related constructs (e.g., risk factors for depression).
> 5. Terms are <u>not</u> intended as a comprehensive, granular description of the measure and do not indicate other critical properties such as informant or timing.
> 6. Terms should describe the construct/s assessed by the measure as commonly understood and within mainstream usage of that tool (i.e., not niche, theory-specific, or bespoke interpretations).

Steps in assignment of terms to individual measures

The following process was used to assign terms to measures while meeting the pre-specified criteria (Box 1), based on relevant measure documentation.

1. Determining what components of the measure need terms assigned

In accordance with the criteria outlined above in *Box 1,* team members identified the interpretable components of the measure that required terms to be assigned. When determining what the interpretable components were, consideration was placed in how the measure was scored (e.g., whether subscales are generated in standard scoring guidelines). This always included the overall measure, subscales where relevant, and more rarely individual items (such as for single-item measures like global ratings).

A conservative approach was taken, only defining interpretable components as commonly understood and within mainstream usage of that tool. Where multiple ways of scoring were available (e.g., in the Child Behaviour Checklist), prioritisation was given to the most granular level of scoring (e.g., subscales in the

Child Behaviour Checklist rather than broader internalizing and externalising scores). For study devised measures, advice was sought from the cohort team on intended usage where required.

2. Determining constructs captured by the measure

To determine the core construct/s being assessed by the measure or measure component, in the first instance, the measure name was examined for an indication of the core construct assessed. If the measure name did not identify the core construct as defined in Box 1 (e.g., 'Strengths and Difficulties Questionnaire'), the publisher's instructions for scoring and interpretation were examined.

For study-devised measures, formalised documentation on scoring and interpretation was rarely available. In this case, study descriptions of the measure in codebooks or other relevant documentation were prioritised.

If no published measure guidance or descriptions were found during a basic search (or not available for study-devised measures), individual items within the measure were examined and a construct identified on the basis of existing content knowledge.

If the core construct was still not clear, a discussion and review within the LifeCourse team occurred, with the aim of reaching a consensus for terms to assign. If no consensus was reached, external expertise was sought. For established measures, this included contacting an expert in that content area who was familiar with measure. In the case of study devised measures, this included contacting the project coordinator or data custodian for input.

3. Selecting term/s from LifeCourse standard terminology

Once the construct was identified, we searched for relevant construct names in the standard LifeCourse terminology. Content knowledge was used to filter on a domain and search for relevant constructs.

If required, the primary SNOMED term and its surrounding terms were reviewed within the SNOMED ontology to ensure alignment between the meaning of the term and the construct that we aimed to describe.

If no relevant terms existed to describe the construct, the process for incorporating a new term in to the LifeCourse terminology was undertaken, in alignment with the process and criteria outlined in _Describing data captured in the LifeCourse platform using a standardised terminology_.

4. Documenting measure-term relationships

Once terms were assigned for a corresponding measure, the outcomes were recorded. This formed the basis for the measures-to-terms map uploaded into the back-end database of the LifeCourse website.

Illustrative example

Initially, one measure was mapped to test the process outlined above. The process was carried out independently by two separate LifeCourse team members (Anna Duncan and Tehani Paiva) and the outcomes and deviations between the two results were discussed and any process issues resolved.

Below is the mapping outcome for the Pediatric Quality of Life Inventory – 4.0 Generic Core Scales, adult self report measure, providing an illustrative example.

Table 1. Example of recorded information when mapping measures to terminology

Measure abbr.	Measure name	Relating to whole measure or subscale	LifeCourse domain	LifeCourse standard term	SNOMED ID (if applicable)
PedsQL 4.0	Pediatric Quality of Life Inventory – 4.0 Generic Core Scales	Whole	Psychosocial wellbeing	Assessment of quality of life	709503007
PedsQL 4.0	Pediatric Quality of Life Inventory – 4.0 Generic Core Scales	Whole	Other health information	Activity of daily living	129025006
PedsQL 4.0	Pediatric Quality of Life Inventory – 4.0 Generic Core Scales	Whole	Mental health and behaviour problems	Emotional problems	386816005
PedsQL 4.0	Pediatric Quality of Life Inventory – 4.0 Generic Core Scales	Whole	Mental health and behaviour problems	Finding relating to psychosocial functioning	284465006
PedsQL 4.0	Pediatric Quality of Life Inventory – 4.0 Generic Core Scales	Whole	School functioning	School functioning	
PedsQL-4.0-PF	Pediatric Quality of Life Inventory – 4.0 Generic Core Scales – Physical functioning	Subscale	Other health information	Activity of daily living	129025006
PedsQL-4.0-EF	Pediatric Quality of Life Inventory – 4.0 Generic Core Scales – Emotional functioning	Subscale	Mental health and behaviour problems	Emotional problems	386816005
PedsQL-4.0-SoF	Pediatric Quality of Life Inventory – 4.0 Generic Core Scales – Social functioning	Subscale	Mental health and behaviour problems	Finding relating to psychosocial functioning	284465006
PedsQL-4.0-ScF	Pediatric Quality of Life Inventory – 4.0 Generic Core Scales – School functioning	Subscale	School functioning	School functioning	

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Outcomes of this mapping process

In undertaking this mapping process, we found that both established and study-devised measures could be mapped using the process described. The ease of mapping was highly dependent on the quality of the measure documentation, and required substantial content knowledge. In total, 233 of measures have been mapped to date, with the measures-to-terms map including 1515 relationships between these measures and their component subscales and terms. The number of terms assigned per measure currently ranges from 1 (e.g., Beck Anxiety Inventory) to 23 terms (e.g., Victorian Perinatal Data Collection). The average number of terms assigned per measure is 3.36, which span an average of 2 domains per measure across the LifeCourse terminology.

Future directions

Ongoing development and improvement

The LifeCourse measures-to-terms map is a living system. It is expected to develop further as new measures are encountered. As new measures are encountered, they will be mapped consistently with the process outlined herein, added to the measures-to-terms map, and uploaded to the LifeCourse website.

Issues may be identified that require re-review of measure-to-term relationships in the existing map; for example, where an error or misinterpretation is encountered. In such cases:

1. The measure of concern will be flagged by the relevant LifeCourse team member and a rationale provided as to why the existing mapping for this measure is inappropriate, in accordance with the mapping criteria described in this report.
2. The LifeCourse team will discuss and reach a consensus on whether any action is required (e.g., assigning a new term to measure or removing a term assigned to measure). A conservative approach will be taken, requiring clear justification that current terms are inappropriate or insufficient.
3. If no consensus is reached, expert input will be sought.
4. Changes will be recorded by LifeCourse team members in a change log and will be implemented onto the website as required.

Integration into LifeCourse website

The exhaustive list of mapped measures will be uploaded to the LifeCourse website's new back end database, allowing for auto population of measure terms on the LifeCourse website. There are currently ~480 measures featured in the LifeCourse measurement library, each of these will be mapped and integrated into this system.

Clarifying the role of terminology

This move to auto population achieves a consistent and systematic approach, but does not allow for bespoke cohort-specific perspectives on measures. Terms should not be interpreted as all-encompassing and granular descriptions of the measures and constructs assessed akin to a study codebook. Rather, terminology applied provides an indication of relevant concepts captured to aid in browsing and searching during the high-level study design phase. In the next steps, we are working to further clarify how these terms and other metadata should be understood on the LifeCourse website.

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