

RECAP preterm

Collaborative Research on Very Preterm Birth: Concepts and Methods – Working with the RECAP preterm Data Platform



WP9

- Sylvia van der Pal, TNO -

“Bridging the gap:
harmonizing the Quality of Life
outcomes of adults born very preterm”



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 733280.

Hello, I am Sylvia van der Pal and I work for TNO Child Health in the Netherlands. TNO is one of the RECAP partners that explores the QoL outcomes of adults born very preterm. In this short presentation I would like to tell you more about the “gap” we encountered when trying to harmonize the QoL outcomes and how we will “bridge this gap”.

Learning objectives



- Why use Quality of Life as an outcome measure in adulthood?
- How to harmonize QoL measures
- How to evaluate QoL if measures are different: 'bridging the gap'



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The learning objectives of this presentation are:

Why use Quality of Life as an outcome measure in adulthood?

And: How to best you harmonize QoL measures and 'bridge the gap' if measures are different

Why Quality of Life?



- 1 comprehensive outcome measure how people are doing
- Contains multiple domains
 - > both mental & physical functioning
- Create health profiles
- Use population-based preferences to obtain utility scores



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So why use Quality of Life as an outcome measure in adulthood?

QoL encompasses 1 comprehensive outcome measure that measures how people are doing

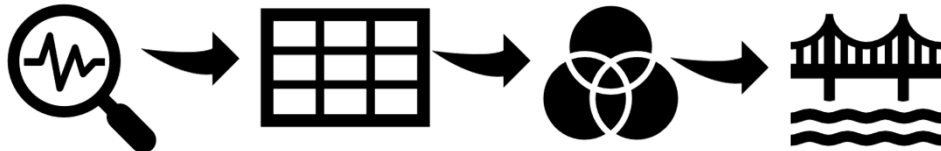
Which contains multiple domains

> And takes into account both mental & physical functioning

It allows you to create health profiles;

And you can use population-based preferences to obtain utility scores

Harmonization



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With regards to the harmonization I will discuss the way we explored, catalogued and harmonized the data and how we will bridge the gap that we encountered.

1. Explore & review



Quality of life of adults born very preterm or very low birth weight: A systematic review.
Van der Pal et al. (2020). Acta Paediatrica;
<https://doi.org/10.1111/apa.15249>

HUI;
Health Utilities
Index

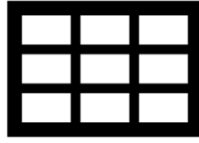
SF-36 > SF-12



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So, where to start? To get a clear picture of the literature and existing data we performed a systematic literature review. This showed that 2 measures were used most often: the Health Utility Index, or HUI, and the SF36 or the SF12, and all the 12 items of the SF12 are included in the SF36 questionnaire.

2. Catalogue





Cohort	HUI	SF12/36	Age (yrs)
1.BLS	Yes	Yes: SF12-v1-UK	26
2.VICS	Attribute scores only	Yes: SF12-v1-US	18
3.POPS	Yes (19 & 28y)	Yes: SF12-v1-UK (35y)	19, 28, 35
4.NTNU	NO	Yes: SF36-v1-US	19, 23
5.EPICURE	Yes	NO	19
6.New Zealand	NO	Yes: SF36-v2	22-23 & 26-30



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Next we catalogued all the available data and found 6 cohort that had Quality of Life data and were willing to share this within the RECAP-collaboration. Here you see the data they have obtained at different time-points or ages.

3a. Harmonize HUI





Cohort	HUI (15 items)
1.BLS	Yes
2.VICS	Yes; only attributes
3.POPS	Yes
4.NTNU	NO
5.EPICURE	Yes
6.New Zealand	NO

HUI harmonization dictionary

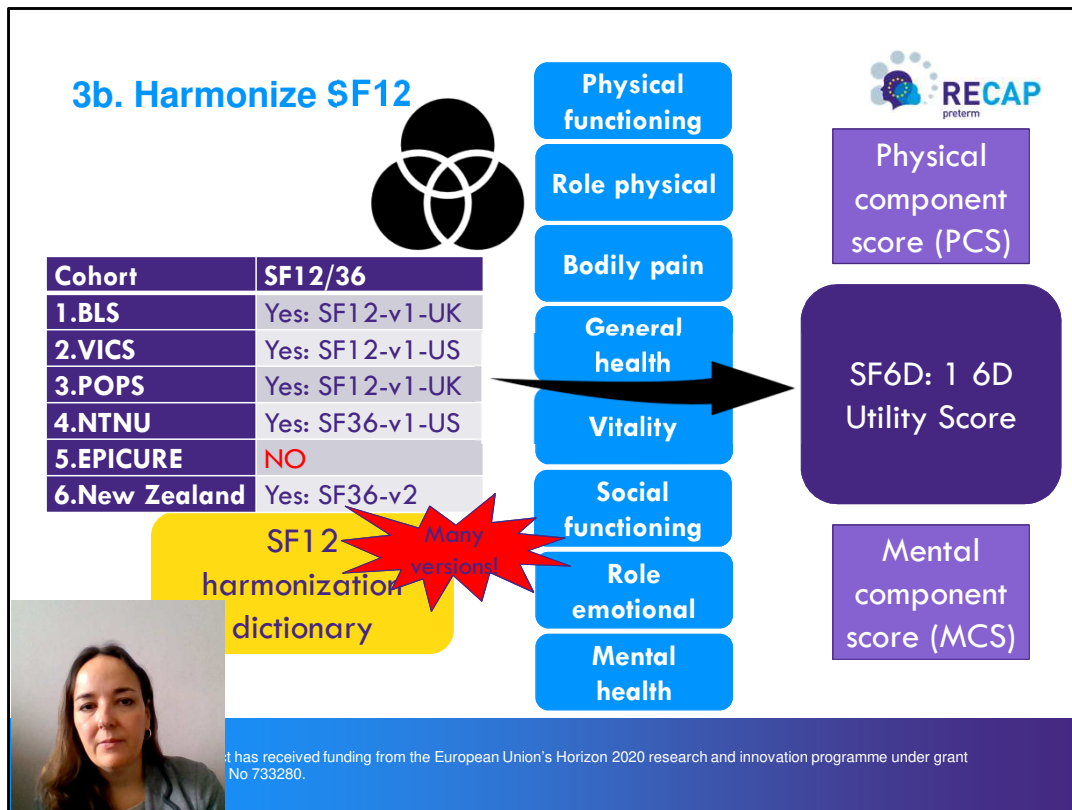
- Vision
- Hearing
- Speech
- Emotion
- Pain
- Ambulation
- Dexterity
- Cognition

MAU: 1 Multi-Attribute Utility Score



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We then started to harmonize the data per questionnaire. We first looked at the HUI questionnaire and created a HUI harmonization dictionaries that describes the harmonized variables and scale or utility scores which we wanted to obtain, in order to be compare the data between cohorts. The HUI is quite a straight forward questionnaire. The 15 items of HUI mark 3 can be rescored into 8 attributes. These 8 attributes are then transformed into one Multi Attribute Utility Score with the help of population-based preference scores.



Harmonizing the SF12 is less straight forward. The SF12 leads to 8 domains. All 8 domains contribute to 2 summary scores: the physical component score and the mental component score.

Several items of the SF12 can also be used to obtain 6 health domains to calculate one SF6D Utility Score.

With the harmonization of the SF12 we ran into a problem because we learned that many version were used.

The 5 cohorts that had SF12 or SF36 data used 4 different versions of the SF12 or SF36, with even different answer categories per item.

Luckily the University of Sheffield offers SPSS syntaxes to calculated the SF6D score with all these different versions, so we able to harmonize and calculate the SF6D utility score for all cohorts.

4. Bridging the gap



- Bridging, or filling up, the gaps by imputation from **“bridge cohorts”**

Cohort	HUI	SF12/36	Age (yrs)
1. BLS	Yes	Yes: SF12-v1-UK	26
2. VICS	Yes; only attributes	Yes: SF12-v1-US	18
3. POPS	Yes (19 & 28y)	Yes: SF12-v1-UK (35y)	19, 28, 35
4. NTNU	NO	Yes: SF36-v1-US	19, 23
5. EPICURE	Yes	NO	19
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innovation programme under grant

So now we have harmonized the 2 questionnaires and have utility scores for all cohorts. However, some cohorts have used the HUI questionnaire and some have used the SF12 or SF36.

These questionnaires and scores are not fully comparable.

Which already shows in the items and domains; the SF12 and SF36 for example includes more mental functioning items and domains.

Luckily two cohorts have administered both questionnaire at one time point.

This allows us to look at the relation between the questionnaires and make a more valid estimate of what the scores on the other questionnaire would have been.

In other words, with imputation techniques these two cohort can be used as bridge cohort to bridge the gaps in the other cohorts.

To RECAP:



- *Why use Quality of Life as an outcome measure in adulthood?*
 - One comprehensive measure of various domains how people are doing
- *How to harmonize different QoL measures and 'bridge the gap'*
 1. Explore and review what data is available
 2. Catalogue the data you have in store
 3. Harmonize each different measure, and versions (and time points)
 4. Bridge the gap by imputation; **“bridging cohorts”**



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So to RECAP:

Why should you use Quality of Life as an outcome measure of preterm birth in adulthood:

Because it gives you one comprehensive measure of various domain on how people are doing.

And how can you harmonize different Quality of Life measure and bridge the gap if not all cohorts have used the same measures?

You first need to explore and review what data is available

Next to can catalogue the data you have in store

Then thoroughly harmonize each measure and the different version, and time points (but that is another story)

And finally you can bridge the cap by using imputation techniques and bridging cohorts.



References

- van der Pal SM, Steinhof M, Grevinga M, Wolke D, Verrips E (2020). Quality of life of adults born very preterm or very low birth weight: A systematic review. Acta Paediatrica, <https://doi.org/10.1111/apa.15249>
- HUI: <http://www.healthutilities.com/hui3.htm>
- SF12: <https://www.qualitymetric.com/health-surveys/the-sf-12v2-health-survey/>

Thank you!

In case of questions, please feel free to contact:

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I would like to thank you for your attention and please contact me by email if you need any further information.