



EQ-5D

From cradle to grave: can we measure and value HRQoL consistently over the lifespan?

Elly Stolk

Scientific Director, EuroQol Research Foundation

EuroQol Group

Welcome from the organisers

Moderator: Elly Stolk

Speakers: Janine Verstraete, Mike Herdman, Nancy Devlin

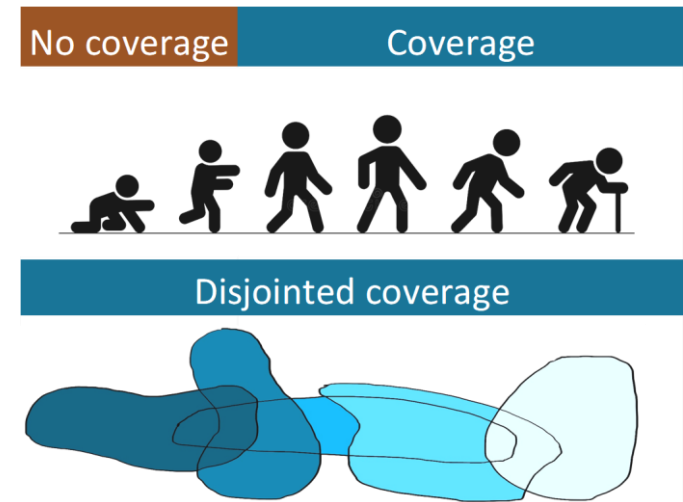


Introduction

- EuroQol introduced the EQ-5D in 1990. Today, EQ-5D is the most widely used measure of health
- EQ-5D was developed for use in **adults**, but accurate and reliable measurement of HRQoL is just as important for **children**
- Demand for a version that allowed children to self-report their health led to the development of a version of EQ-5D for use in children 8+: the EQ-5D-Y
- The recent development of new 'experimental' EuroQol instruments –EQ-TIPS and EQ-5D-Y-Adapted (for 2-4 yr olds) – opens up the possibility of having a suite of coherent, linked instruments that cover HRQoL 'from the cradle to the grave'
- The goal of this seminar is to report progress towards that emerging aim

The case for measuring 'From cradle to grave'

- Measurement and valuation of health across lifetime can support healthcare systems in achieving their objectives
- E.g. to support **public health surveillance** and by extending reach of **HTA frameworks**
- Inconsistent approaches over lifetime will hamper application; similarity of EuroQol instruments can help



Practical challenges in multiple areas

- There is a need to contemplate whether the practices from which EuroQol draws provide appropriate solutions for measurement and valuation of health in new target groups
- **Descriptively:** Children are not little adults – should we measure and value their health in the same way? Dimensions & wording need to be age-appropriate
- **Valuation:** Empirical questions around elicitation, and normative questions around what new values should reflect
- **Application:** how to use the obtained results?

Work in progress

- This is a relatively new direction for the EuroQol Group
- This symposium aims to provide a space for reflection on whether this idea of measuring health from cradle to grave is a good one and how it should be done



Aims of the symposium

- To introduce you to EuroQol's instrument portfolio, including experimental measures under development to fill gaps in age ranges covered
- To explain challenges that need to be addressed when pursuing the goal to measure and value health consistently across age groups
- To invite reflection on the case for measuring 'From cradle to grave'



EQ-5D

Measuring health over the lifespan: An overview of EuroQol measures

Dr Janine Verstraete, University of Cape Town

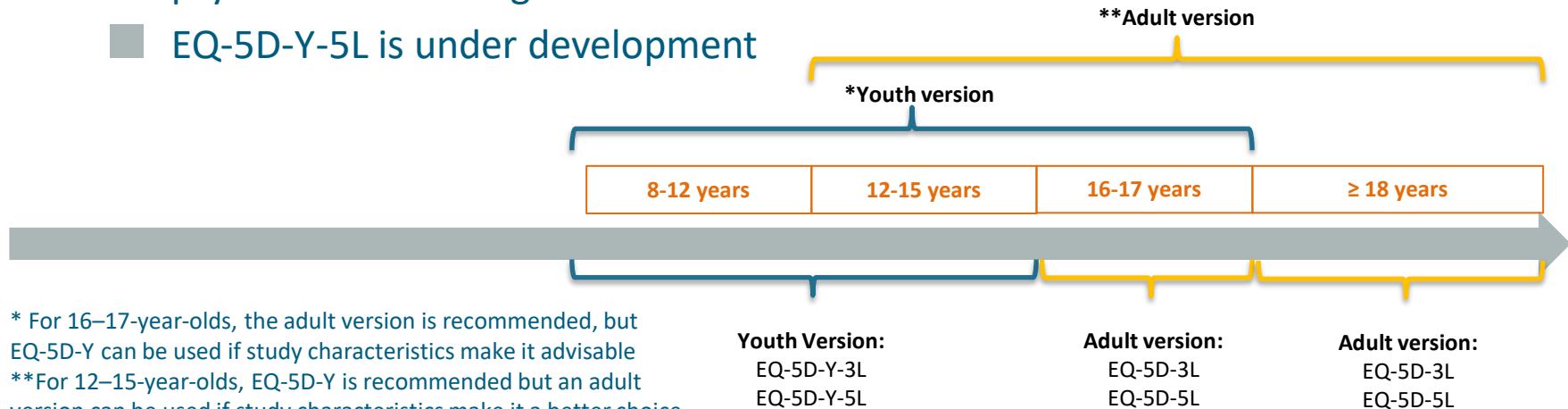
EQ-5D measures

- Generic questionnaire designed for use in a wide range of diseases and conditions, as well as in healthy populations to measure and value health
- Designed for self-completion by adults (≥ 18 years). Age range of EQ-5D extended to 16-17 years \Rightarrow Able to reliably self-complete
- Demand from HTA bodies and other healthcare decision makers to extend coverage to children



Development of EQ-5D-Y: based on EQ-5D-3L

- Dimension and level structure of EQ-5D maintained to ensure comparability
- Wording adapted with expert review, qualitative testing with children and psychometric testing
- EQ-5D-Y-5L is under development

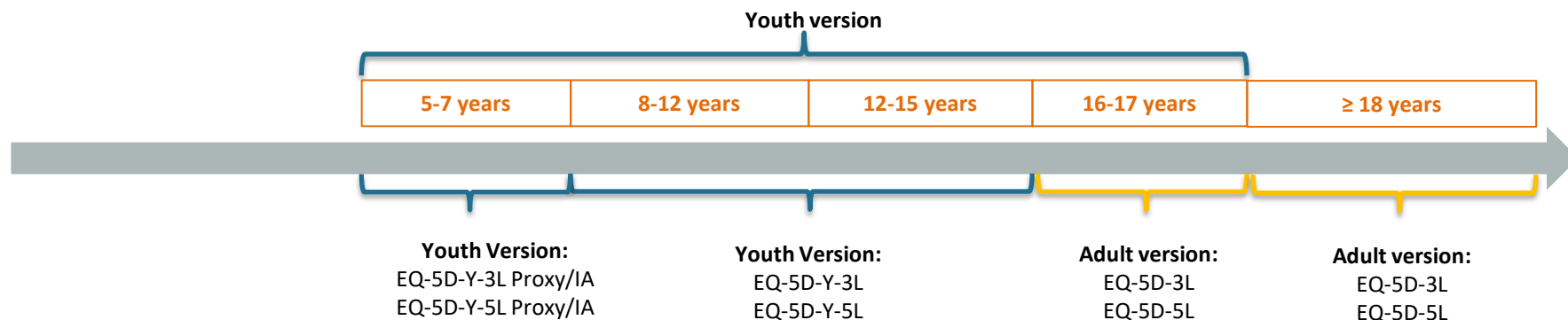


* For 16–17-year-olds, the adult version is recommended, but EQ-5D-Y can be used if study characteristics make it advisable

**For 12–15-year-olds, EQ-5D-Y is recommended but an adult version can be used if study characteristics make it a better choice

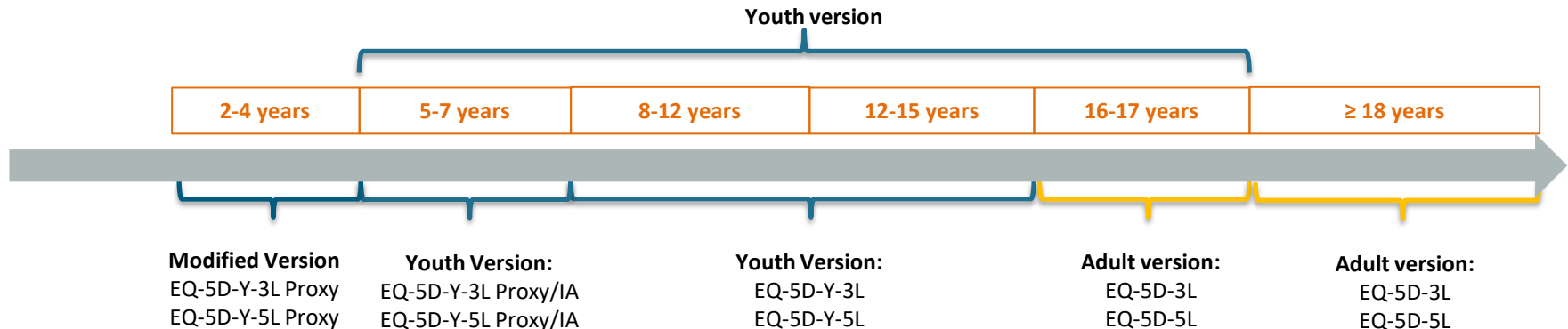
EQ-5D-Y alternatives: proxy and interviewer-administered (IA)

- Allows measurement of health in children who do not have the proficiency in reading and writing
- IA preferred over proxy reports – proxies may be less accurate
- IA version has shown promising results also in younger children aged 5-7 years



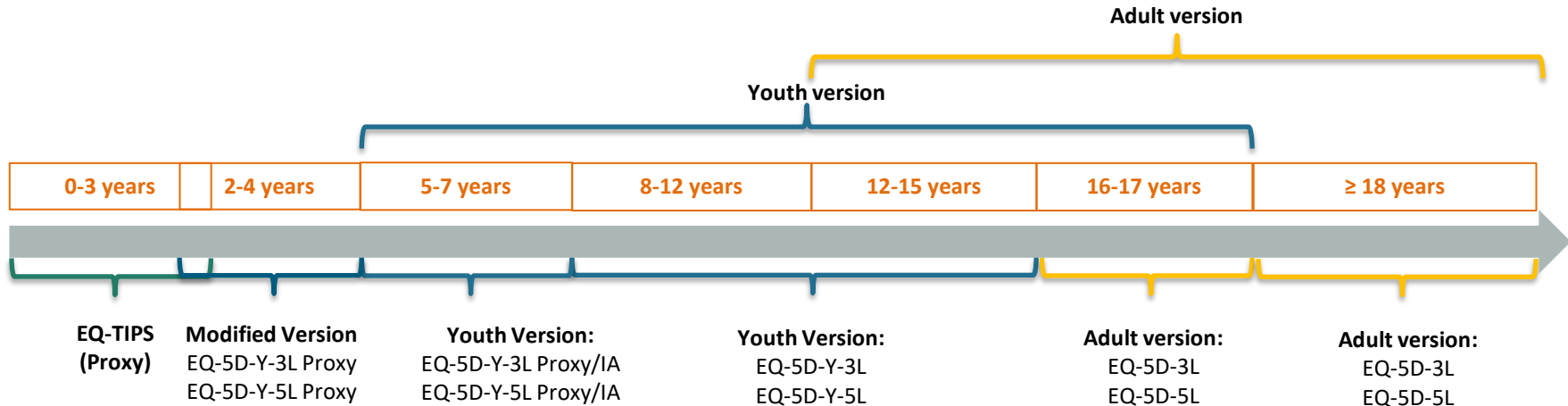
Measurement for younger children

- A modified EQ-5D-Y proxy version for 2 – 4 yr olds is tested in a large paediatric multi-instrument comparison in Australia (part of the QUOKKA study)
- Descriptive system adapted with expert review, qualitative testing with children & psychometric testing. Dimensions retained, wording amended



Measurement for even younger children

- EQ-Toddler and Infant Populations (EQ-TIPS) proxy version for 0-3 years
- Based on EQ model, but extra/different dimensions
- Current work focused on further development and testing globally



Status of Youth Instruments

- Approved: EQ-5D-Y-3L (all versions: self-report, proxy, IA)
 - Status implies: finalized product governed by same license policy as EQ-5D
- Experimental: EQ-5D-Y-5L, EQ-TIPS, modified proxy version for 2-4 year olds
 - Status implies: still under development and instrument may change. No value sets, no user guides etc. Not available for users: testing internally and by collaborators
- Beta status: EQ-5D-Y-5L is anticipated to move to beta status soon
 - Status implies: close to final product. Instrument may change, but major changes are not expected. No value sets, no user guides etc. Made available for external testing.

It's Time for a Poll!

Is the transition between age-specific instruments for measuring and/or valuing HRQoL of relevance to your work?

- **Yes, and I found a solution that works**
- **Yes, but further work is needed to address how to deal with the transition**
- **Not relevant to my work at present**

**Advance to next slide
for the poll**



EQ-5D

Measuring health over the lifespan: challenges, and solutions?

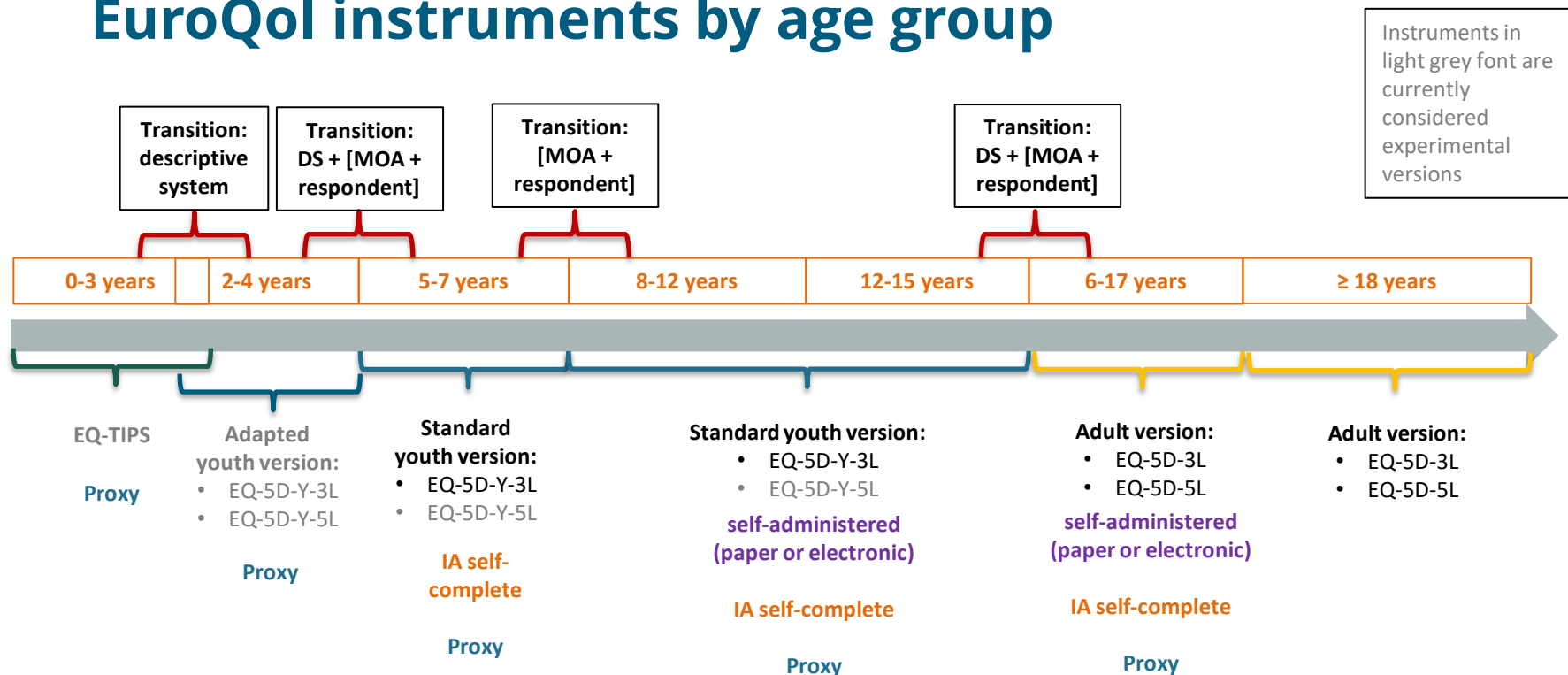
Mike Herdman, Chair of the EuroQol Younger
Populations Working Group

Background

- Being able to follow an individual's health trajectory from birth to death using one (set of) measurement instrument(s) is an appealing proposition
- EuroQol instruments may be able to approach that 'ideal'
- But several challenges...
-and some possible solutions



EuroQol instruments by age group



Lifespan measurement, principal challenges

- Different descriptive systems*
- Different respondents (self/proxy)
- Different modes of administration
- (Others? Response style/Response shift)

Differences in descriptive systems



EQ-TIPS™ EXPERIMENTAL VERSION, FOR 1 MONTH TO 3 YEARS

©EuroQol Research
Foundation.

MOVEMENT (Moves about at an age-appropriate level)

- No problems with movement ☐
- Some problems with movement ☐
- A lot of problems with movement ☐

PLAY (Enjoys playing with objects or toys at an age-appropriate level)

- No / Some / A lot of problems playing ☐

PAIN (Painful behavior includes: inconsolable crying, restless movement, grimacing)

- No / Some / A lot of pain ☐

SOCIAL INTERACTION (Engages with others in an age-appropriate manner)

- No / Some / A lot of problems interacting with others ☐

COMMUNICATION (Communicates at an age-appropriate level)

- No / Some / A lot of problems with communication ☐

EATING (Eats adequate available food in an age-appropriate manner)

- No / Some / A lot of problems with eating ☐



MOBILITY (walking about)

- I have no problems walking about ☐
- I have some problems walking about ☐
- I have a lot of problems walking about ☐

LOOKING AFTER MYSELF

- I have no problems washing or dressing myself ☐
- I have some problems washing or dressing myself ☐
- I have a lot of problems washing or dressing myself ☐

DOING USUAL ACTIVITIES (for example, going to school, hobbies, sports, playing, doing things with family or friends)

- I have no problems doing my usual activities ☐
- I have some problems doing my usual activities ☐
- I have a lot of problems doing my usual activities ☐

HAVING PAIN OR DISCOMFORT

- I have no pain or discomfort ☐
- I have some pain or discomfort ☐
- I have a lot of pain or discomfort ☐

FEELING WORRIED, SAD OR UNHAPPY

- I am not worried, sad or unhappy ☐
- I am a bit worried, sad or unhappy ☐
- I am very worried, sad or unhappy ☐

EQ-5D-Y™ Standard version, for ≥5 years

©EuroQol Research
Foundation.

Some key questions.....

- (How) Can we know whether a move from state 222113 on EQ-TIPS to state 22122 on EQ-5D-Y represents an improvement or a worsening in health, or if it represents no change?
- (How) Can we say whether state 112233 on EQ-TIPS is better, worse, or the same as state 12233 on EQ-5D-Y?
- Do we need to be able to 'say' that?

Similar health states?

EQ-TIPS - 222113

- ☐ Some problems with **movement**
- ☐ Some problems **playing**
- ☐ Some **pain**
- ☐ No problems **interacting** with others
- ☐ No problems with **communication**
- ☐ A lot of problems with **eating**

EQ-5D-Y - 22122

- ☐ Some problems **walking about**
- ☐ Some problems **washing or dressing**
- ☐ No problems with **usual activities**
- ☐ Some **pain/discomfort**
- ☐ A bit **worried, sad, or unhappy**

Different content, but comparable in other ways

■ While content likely can't be identical in instruments for toddlers and for older kids, they can be made consistent in other ways:

- Layout
- Identical response task
- Same time frame ('today')
- Same number/wording of response options
- Similarities in dimension content

Overlap in content: EQ-5D-Y and EQ-TIPS

EQ-TIPS
EXPERIMENTAL
VERSION, FOR 1
MONTH TO 3
YEARS

MOVEMENT (Moves about at an age-appropriate level)

- ☐ No problems with movement
- ☐ Some problems with movement
- ☐ A lot of problems with movement

PLAY (Enjoys playing with objects or toys at an age-appropriate level)

- ☐ No problems playing
- ☐ Some problems playing
- ☐ A lot of problems playing

PAIN (Painful behavior includes: inconsolable crying, restless movement, grimacing)

- ☐ No pain
- ☐ Some pain
- ☐ A lot of pain

SOCIAL INTERACTION (Engages with others in an age-appropriate manner)

- ☐ No problems interacting with others
- ☐ Some problems interacting with others
- ☐ A lot of problems interacting with others

COMMUNICATION (Communicates at an age-appropriate level)

- ☐ No problems with communication
- ☐ Some problems with communication
- ☐ A lot of problems with communication

EATING (Eats adequate available food in an age-appropriate manner)

- ☐ No problems with eating
- ☐ Some problems with eating
- ☐ A lot of problems with eating

MOBILITY (walking about)

- ☐ I have no problems walking about
- ☐ I have some problems walking about
- ☐ I have a lot of problems walking about

LOOKING AFTER MYSELF

- ☐ I have no problems washing or dressing myself
- ☐ I have some problems washing or dressing myself
- ☐ I have a lot of problems washing or dressing myself

DOING USUAL ACTIVITIES (for example, going to school, hobbies, sports, playing, doing things with family or friends)

- ☐ I have no problems doing my usual activities
- ☐ I have some problems doing my usual activities
- ☐ I have a lot of problems doing my usual activities

HAVING PAIN OR DISCOMFORT

- ☐ I have no pain or discomfort
- ☐ I have some pain or discomfort
- ☐ I have a lot of pain or discomfort

FEELING WORRIED, SAD OR UNHAPPY

- ☐ I am not worried, sad or unhappy
- ☐ I am a bit worried, sad or unhappy
- ☐ I am very worried, sad or unhappy

EQ-5D-Y
Standard
version, for 4
years and up

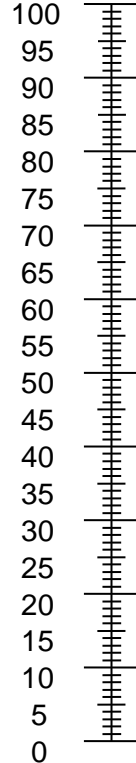
Methods to explore relationships between instruments

- Response mapping
- Factor analysis
- A 'secret weapon'....
- Preference weights

Secret weapon? EQ VAS

- ☐ Some problems with **movement**
- ☐ Some problems **playing**
- ☐ Some **pain**
- ☐ No problems **interacting** with others
- ☐ No problems with **communication**
- ☐ A lot of problems with **eating**

The **best** health
you can imagine



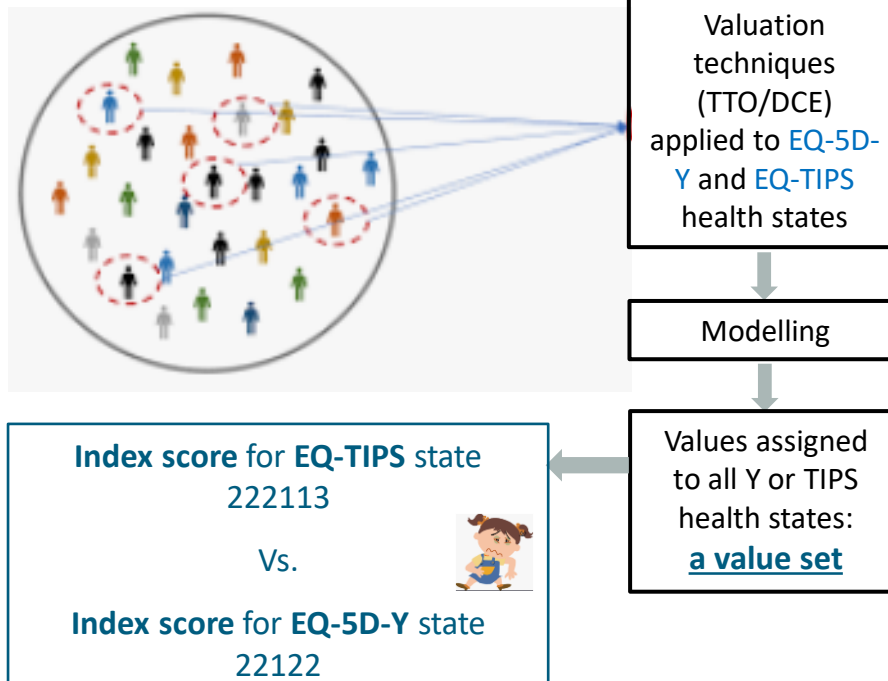
The **worst** health
you can imagine

- ☐ Some problems **walking about**
- ☐ Some problems **washing or dressing**
- ☐ No problems with **usual activities**
- ☐ Some **pain/discomfort**
- ☐ A bit **worried, sad, or unhappy**

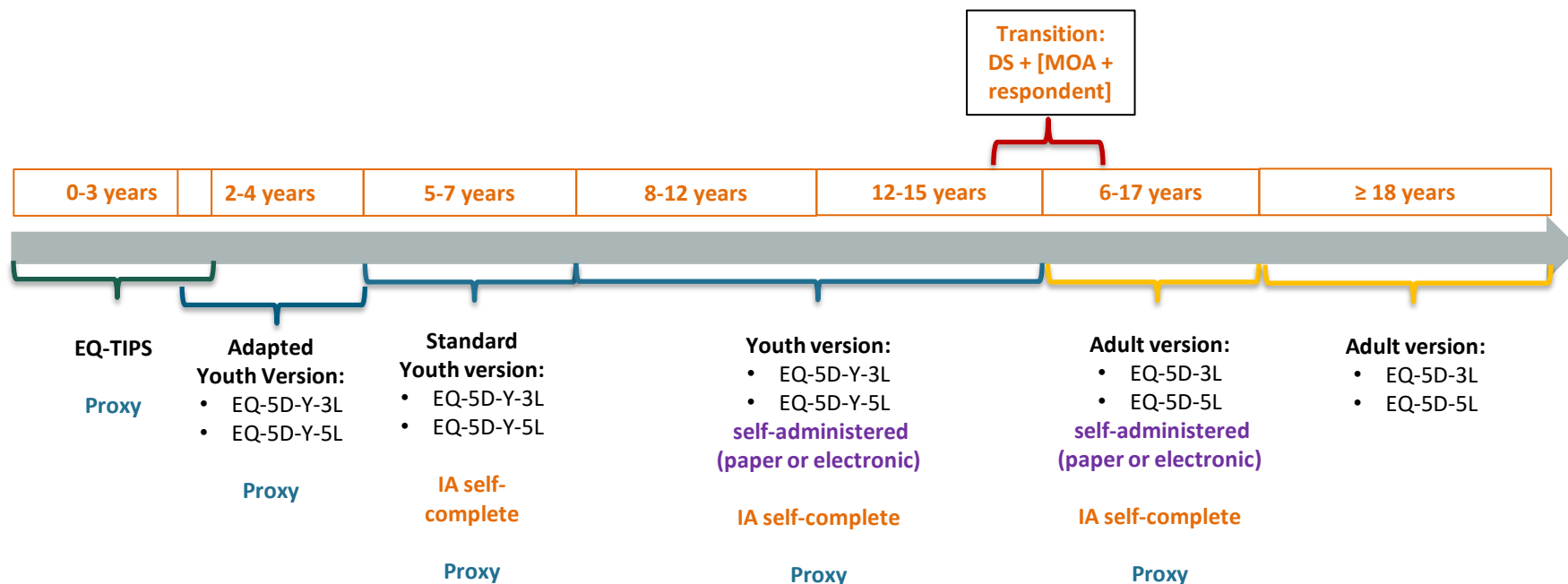
EQ VAS may provide a
common yardstick to help us
understand how health states
from different instruments
compare

Role for preference weights (utilities)?

- Preference weights obtained in general population valuation studies *may* inform about the relative severity of EQ-TIPS and EQ-5D-Y health states, but some caveats....



EuroQol instruments by age group



Differences in youth and adult (3L) descriptive systems

EQ-5D-Y-3L

MOBILITY (*walking about*)

- I have no problems walking about ☐
- I have some problems walking about ☐
- I have **a lot of problems walking about** ☐

HAVING PAIN OR DISCOMFORT

- I have no pain or discomfort ☐
- I have **some** pain or discomfort ☐
- I have **a lot of** pain or discomfort ☐

FEELING WORRIED, SAD OR UNHAPPY

- I am not worried, sad or unhappy ☐
- I am **a bit** worried, sad or unhappy ☐
- I am **very** worried, sad or unhappy ☐

EQ-5D-3L

MOBILITY

- I have no problems in walking about ☐
- I have some problems in walking about ☐
- I am **confined to bed** ☐

PAIN / DISCOMFORT

- I have no pain or discomfort ☐
- I have **moderate** pain or discomfort ☐
- I have **extreme** pain or discomfort ☐

ANXIETY / DEPRESSION

- I am not anxious or depressed ☐
- I am **moderately** anxious or depressed ☐
- I am **extremely** anxious or depressed ☐

EuroQol research focus – further harmonisation of instruments across age groups

- **Development of the EQ-5D-Y-5L:**
- expanded version of standard EQ-5D-Y
- 5 levels of severity in each dimension
- closer in content to the most used EQ version in adults, EQ-5D-5L
- measurement properties at least equal to those of the standard EQ-5D-Y and superior in some cases
- evidence that it is preferred by children over the standard version
- currently considered experimental, but will hopefully achieve ‘beta status’ this year

Youth and adult 5L descriptive systems

EQ-5D-Y-5L

MOBILITY (*walking about*)

- I have no problems walking about ☐
- I have **a little bit of a problem** walking about ☐
- I have **some problems** walking about ☐
- I have **a lot of problems** walking about ☐
- I **cannot** walk about ☐

HAVING PAIN OR DISCOMFORT

- I have no pain or discomfort ☐
- I have **a little bit** of pain or discomfort ☐
- I have **some** pain or discomfort ☐
- I have **a lot of** pain or discomfort ☐
- I have **extreme** pain or discomfort ☐

FEELING WORRIED, SAD OR UNHAPPY

- I am not worried, sad or unhappy ☐
- I am **a little bit** worried, sad or unhappy ☐
- I am **quite** worried, sad or unhappy ☐
- I am **really** worried, sad or unhappy ☐
- I am **extremely** worried, sad or unhappy ☐

EQ-5D-5L

MOBILITY

- I have no problems walking about ☐
- I have **slight problems** walking about ☐
- I have **moderate problems** walking about ☐
- I have **severe problems** walking about ☐
- I am **unable to** walk about ☐

PAIN / DISCOMFORT

- I have no pain or discomfort ☐
- I have **slight** pain or discomfort ☐
- I have **moderate** pain or discomfort ☐
- I have **severe** pain or discomfort ☐
- I have **extreme** pain or discomfort ☐

ANXIETY / DEPRESSION

- I am not anxious or depressed ☐
- I am **slightly** anxious or depressed ☐
- I am **moderately** anxious or depressed ☐
- I am **severely** anxious or depressed ☐
- I am **extremely** anxious or depressed ☐

Conclusions

- EuroQol Group now provides tools which can potentially trace a trajectory of health across the life-span
- Consistency in approach to instrument development potentially facilitates that task
- Consistency also required as far as possible in instrument selection (number of response levels, mode of administration, respondent – proxy/self)
- Important to note that some EQ tools still considered experimental, so use is restricted
- Currently funded and planned research will provide further insights into the feasibility of this life course approach to measuring health

Thanks for listening!



<https://www.youtube.com/watch?v=5FOTQtj5cjo>



michael.herdman@insightcr.com

It's Time for a Poll!

Is it (potentially) useful to have an integrated suite of preference-weighted PRO instruments which allow for consistent measurement and valuation of HRQoL across the lifespan?

- ☐ **Yes**
- ☐ **No**
- ☐ **Unsure**

**Advance to next slide
for the poll**



EQ-5D

Transitions between age-specific instruments in terms of value

Professor Nancy Devlin, University of Melbourne
Dr Bram Roudijk, EuroQol Research Foundation

Content

1. The state of play with EQ-5D-Y-3L value sets
2. Characteristics of values for adult vs child HRQoL
3. Methods for valuing EQ-5D-Y-3L
4. Why might characteristics of values for adult and child EQ-5D instruments differ?
5. Application of EQ-5D-Y values
6. A research agenda
7. Conclusions

1. The state of play with EQ-5D-Y values

- **Completed:** Japan, Slovenia, Spain, Germany, Belgium, Netherlands, Hungary, Indonesia, China
- **Underway:** Australia, Canada, UK, US, Hong Kong, Brazil, Singapore, Malaysia, Taiwan, Vietnam.

In the space of just 2 years since the protocol, close to 20 value sets will have either been produced or well underway

Devlin N et al (2022) [Valuing EQ-5D-Y: the current state of play](#). Health Qual Life Outcomes. 2022 Jul 6;20(1)

Valuation of 'experimental' age-specific instruments:

EQ-5D-Y-5L: new valuation protocol to be developed; mapping from Y-5L to Y-3L in interim

EQ-TIPs: conceptual work underway to provide foundations for values

2. Characteristics of adult vs child EQ-5D value sets -



- 8 countries with value sets for EQ-5D-Y-3L & EQ-5D-5L generated by EQ-VT protocols
- Europe: adult and Y value sets have similar distributions, but min value lower for adults (exception: Spain)
- Asia: marked differences between values for adult and child EQ-5D instruments
- Whether these patterns are generalisable remains to be seen

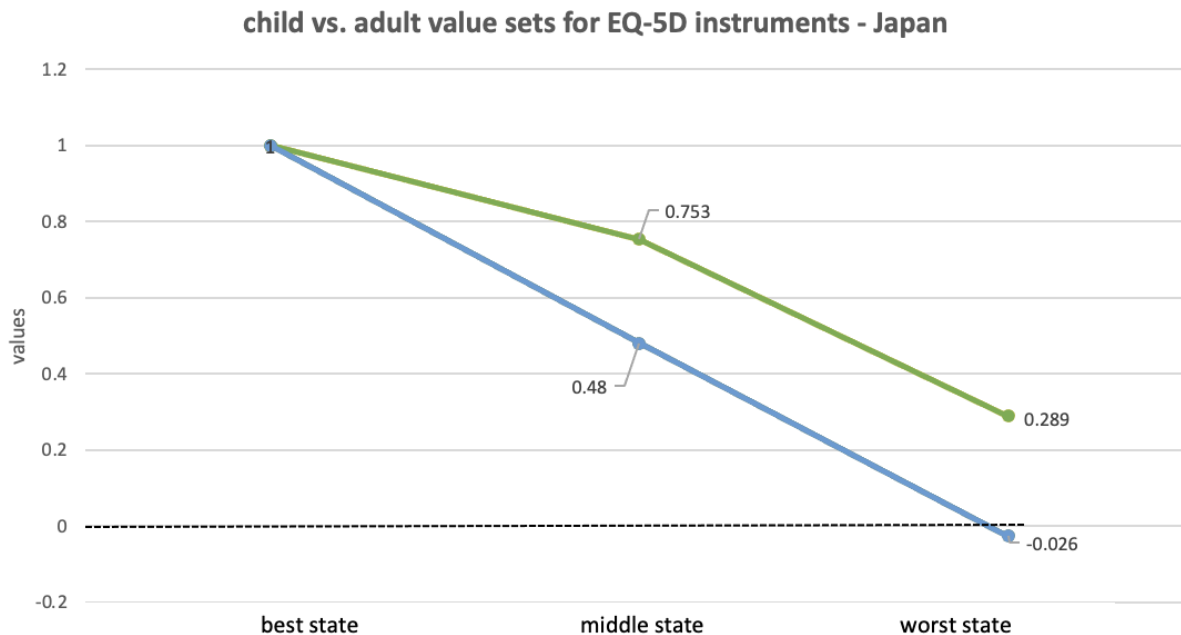
(b) Scale length: Values for the worst health state of each instrument

'worst state' in:	EQ-5D-Y-3L	EQ-5D-5L
Netherlands	-0.218	-0.446
Belgium	-0.4745	-0.533
Spain	-0.5392	-0.415
Germany	-0.2827	-0.661
China	0.057	-0.344
Japan	0.289	-0.026
Indonesia	-0.0861	-0.865
Hungary	-0.485	-0.848
Slovenia	-0.691	NA

(c) % values < 0 ('worse than dead') in child & adult EQ-5D instruments

Percentage negative	EQ-5D-Y-3L	EQ-5D-5L
Netherlands	3.30%	15.50%
Belgium	12.75%	15.10%
Spain	16.05%	8.26%
Germany	6.58%	15.07%
China	0%	10.21%
Japan	0%	0.10%
Indonesia	0.40%	35.46%
Hungary	12.35%	21.73%
Slovenia	20.57%	NA

(d) values for descriptively best, middle and worst states in child & adult EQ-5D instruments



- Differences are not just observed in values for the worst states (scale length)

— EQ-5D-Y-3L — Note: all such comparisons are complicated by the differences in the descriptive systems ('middle' is described differently)

— EQ-5D-5L

3. Methods for valuing EQ-5D-Y-3L

- Kreimeier et al (2018) compared adult's values for EQ-5D-3L and EQ-5D-Y-3L
- From both an 'own health' and child perspective
- Results of this multicountry study (Eng, Ge, Sp, NL) showed that the relative importance of the domains and levels differs by instrument (and perspective).
- Concluded that separate value sets for the EQ-5D-Y instrument are needed.

- EuroQol initiated a programme of research to explore methods to use for producing value sets specific to EQ-5D-Y

Kreimeier et al (2018) Valuation of EQ-5D-Y and EQ-5D-3L Health States: The Impact of Wording and Perspective Value Health;21(11):1291-98. 1

Methods used in EQ-5D-Y protocol

	DCE	TTO
Whose values are relevant?	Adult gen pop	
What perspective are adults asked to adopt?	Proxy 1 'given your views regarding a child'	
Age of child?	10-year-old	
Duration of states?	10 years	
Design & format	10 blocks; 15 pairwise choices per respondent	1 block of 10 states (<i>minimum</i>) valued using composite TTO
Sample size	1000	200
Mode of administration	online	CAPI

4. Why might characteristics of values for adult and child EQ-5D instruments differ?

(a) differences in methods

Methods used in the protocol to value EQ-5D-Y differ from those used to value adult EQ-5D instruments

- Respondents are valuing health in someone else – a child
- Role of DCE and cTTO data is different

4. Why might characteristics of values for adult and child EQ-5D instruments differ?

(b) Underlying preferences of adults with respect to children

- Observed unwillingness to trade off children's life years in TTO tasks
 - Higher importance of life years and survival in children vs adults
 - Higher values; shorter value scales
- Different order of dimension importance is apparent
 - pain/discomfort always worst dimension in 9 EQ-5D-Y value sets; self-care least important in all but one.
 - Intuitive explanations in adult views about child health?
- Transitions in values need to account for both differences in scale length & differences in value decrements by dimension

5. Application of EQ-5D-Y values

'QALY-related' applications	'non-QALY' applications
Values used to estimate QALYs	Values used to summarise profile data for statistical analysis
<ul style="list-style-type: none">• HTA• priority setting	<ul style="list-style-type: none">• routine outcomes measurement pediatric clinical settings• child population health surveys
Different HTA bodies and other stakeholders may have different views on normative methods questions – or may lack well defined views	Differences between adult and child values, and transitioning between them, arguably less relevant to non-QALY uses. Adolescent preferences may have a stronger rationale

6. A research agenda

- Continued exploration of the impact on EQ-5D-Y values of methods choices that entail normative positions. Evidence is rapidly building e.g. on age dependency, impact of perspectives
- ‘Nothing about me without me’: understanding characteristics of adolescents’ preferences, and how best to incorporate those
- Continued strengthening of preference elicitation methods, e.g. anchoring at 0
- Strengthening methods for stakeholder engagement
- *Valuation of ‘experimental’ age-specific instruments: EQ-5D-Y-5L:* new valuation protocol to be developed; mapping from Y-5L to Y-3L in interim. **EQ-TIPs:** conceptual work underway to provide foundations for values

7. Conclusions

- Need to consider how age-specific values are to be used in economic evaluation
- For decision making purposes, child HRQoL values and QALY estimates may need to be accepted as most relevant to comparisons between interventions aimed at children.
- The questions about valuation methods are relevant to all attempts to value child HRQoL instruments - not just EQ-5D-Y. But the *transitions* between child and adult values more apparent for EQ-5D instruments
- Stakeholder engagement methodological choices for valuing child HRQoL instruments is key: We need to intensify efforts and encourage and support HTA body reflections on the relevant social value judgements
- Remain open to different value sets and valuation methods being appropriate for different kinds of decisions e.g., PROMs vs. HTA

It's Time for a Poll!

In your view, should value sets for preference-weighted pediatric HRQoL instruments:

- **Be based on adult general public preferences regarding children's HRQoL**
- **Be based on adult's preferences for HRQoL states, valued from their own perspective, so values are unaffected by considerations about children**
- **Be based on the preferences of children in the general public, where feasible**
- **Be based on the preferences of children experiencing poor health, where feasible**
- **Other**