SONG
STANDARDISED OUTCOMES IN NEPHROLOGY

Establishing a core outcome measure for life participation in children with chronic kidney disease

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Australian and New Zealand Society of Nephrology Congress

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Life participation

The ability to participate in activities that are meaningful and important to patients.

Background

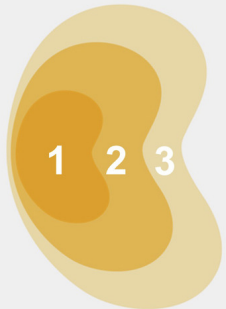
Poor school attendance

Reduced academic achievement/ employment

Low engagement in sport

Social difficulties

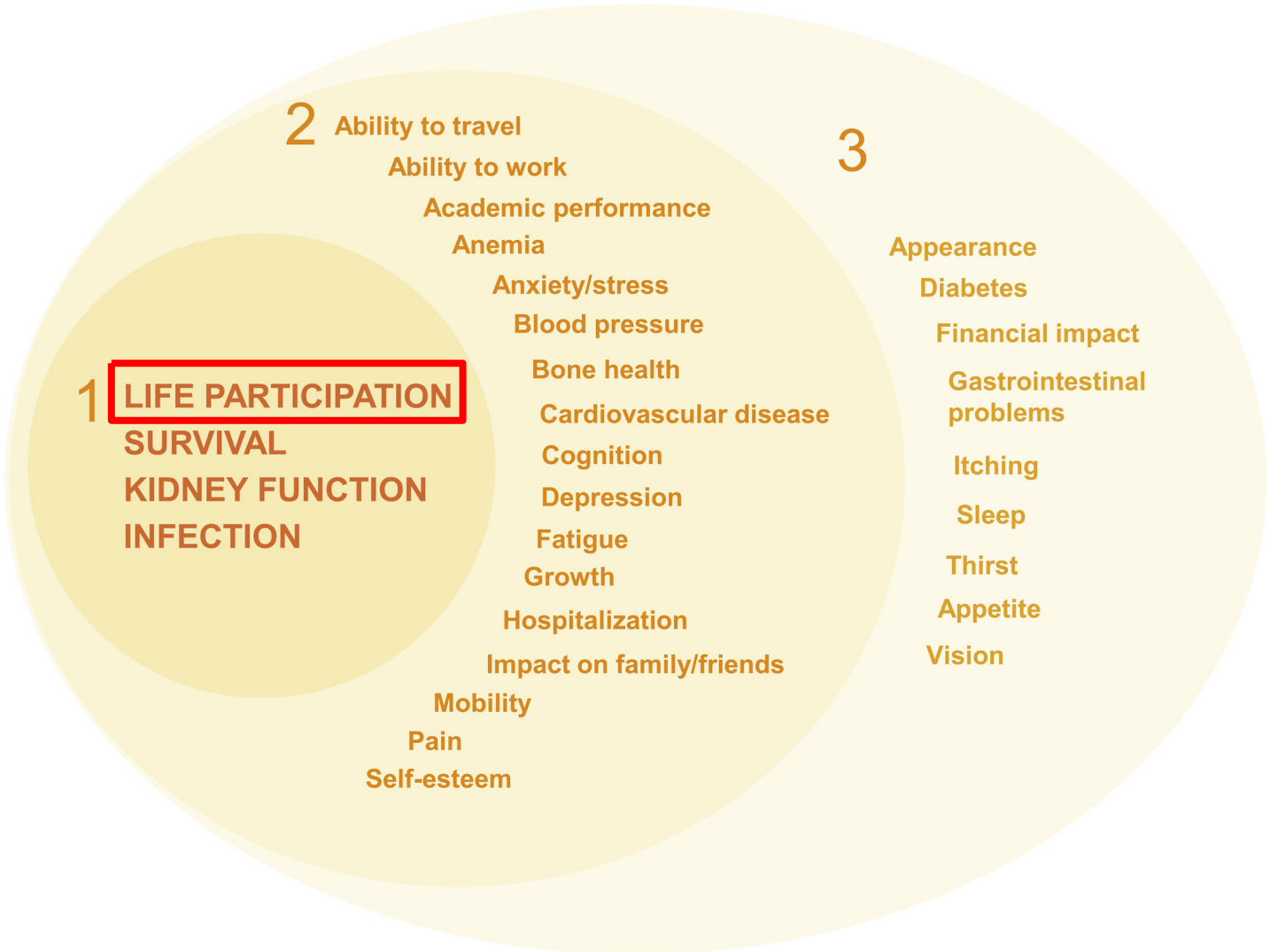
SONG-Kids



1 CORE OUTCOMES
Critically important
to all stakeholder groups
Report in all trials

2 MIDDLE TIER
Critically important to
some stakeholder groups
Report in some trials

3 OUTER TIER
Important to some or
all stakeholder groups
Consider for trials



Aim

To establish a core outcome measure for life participation in children with CKD.

Methods

Four workshops with patients, caregivers and health professionals.

- In-person (English language)
- Two online (English language)
- Online (Spanish language)

We analyzed the data.

SONG-LP instrument

SONG Life Participation Core Outcome Measure

Please respond to each item by marking one box per row.

During the past month…

	Never	Rarely	Sometimes	Usually	Always	N/A
I could do my leisure activities e.g. exercise, hobbies, travel	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐
I could do my family activities	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐
I could do my work e.g. employment, housework, study	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐
I could do my social activities with friends/others	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐

N/A, not applicable

Jaure, KI Reports, 2024

SONG-LP instrument

Please answer each question by ticking one box per row.

During the past month …

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	Does not apply to me
I could do my fun things like draw, sport, travel, games, read.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	❑
I could do things with my family like birthdays, going out.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	❑
I could do the things I need to do like school, study, helping out at home, job.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	❑
I could do things with my friends like go to parties.	❑ 1	❑ 2	❑ 3	❑ 4	❑ 5	❑

Methods

- Question 1: Should the SONG-LP measure be used as the core measure for life participation? Key domain, relevancy, recall period

- Question 2:
  - Considering the readability of the measure, are young children and up to 18 years able to complete this on their own?
  - Should proxy completion, for example completion by a parent, be considered?

Results

53 patients and caregivers

118 health professionals

16 countries

Encapsulating key domains of life participation

Recognizing varying degrees of achieving participation in a domain

Allowing individual interpretation and valuation of life participation

Reflecting the personal context and values

Emphasizing meaningful participation in activities

Acknowledging changes over time

“Not just doing but actually thriving or enjoying something. You can be there [at school], or you can really be attending” (Health professional, Australia).

Developing age-specific measures

Considering literacy

Establishing an appropriate recall period

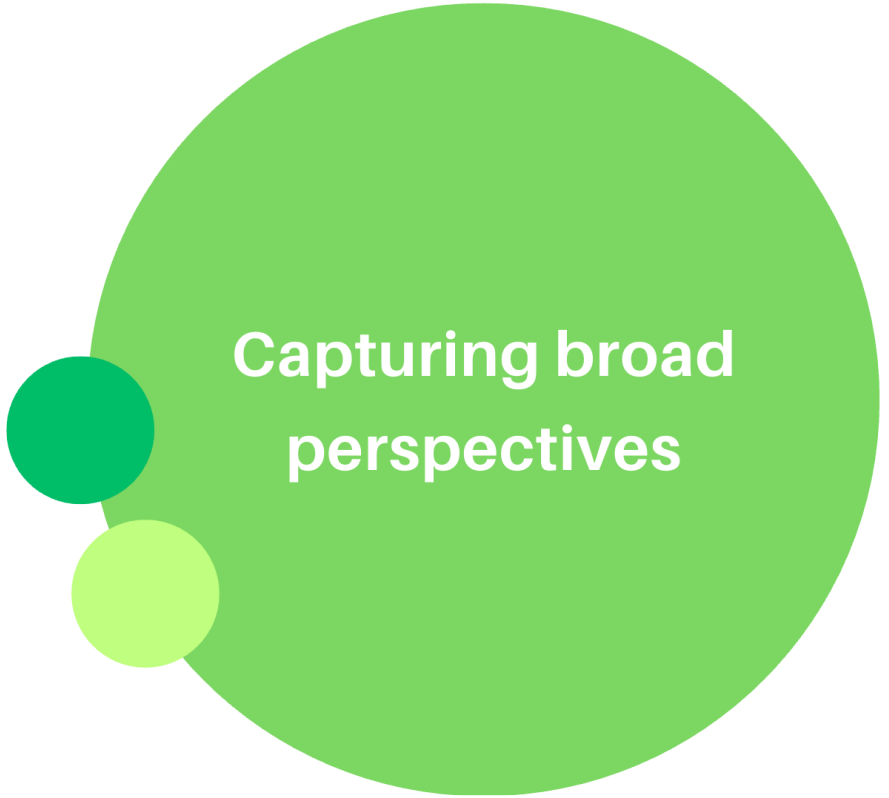
Utilizing relevant and clear language

Using engaging formats

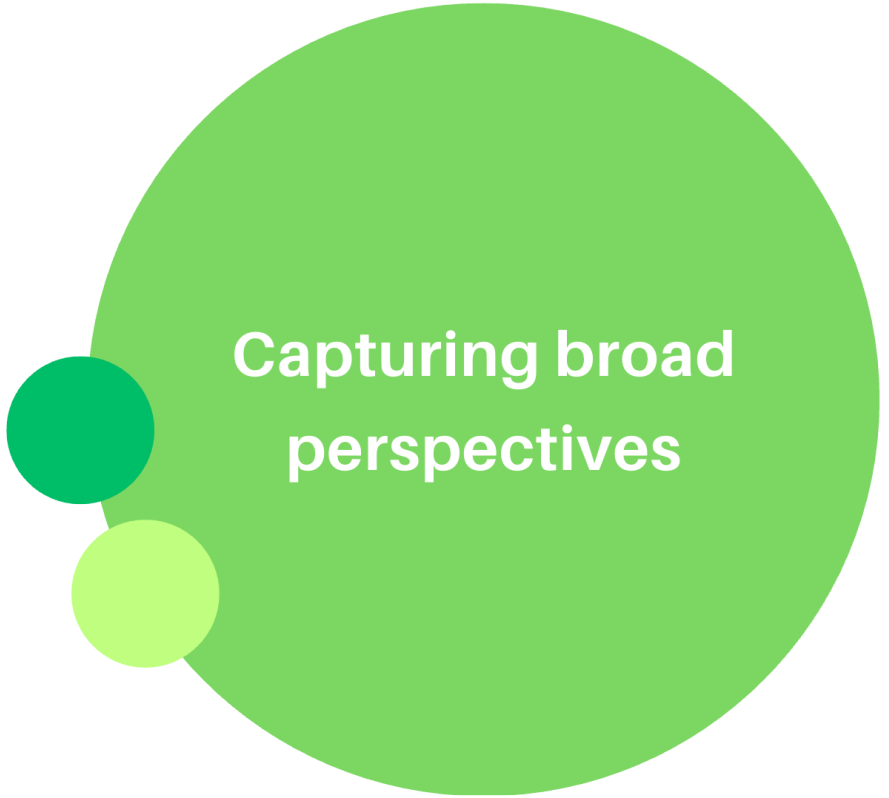
"Rephrasing 'work' to 'learning or school' and changing 'leisure activities' to 'things I want to do or things I enjoy doing'"
(Health professional, Australia).

Ensuring universal applicability across settings

Allowing for proxy completion and assistance



“If you've got an underlying intellectual disability or younger kids … otherwise you will miss out on capturing all that if you don't have a proxy filling it out” (Health professional, New Zealand).



Establishing widespread implementation

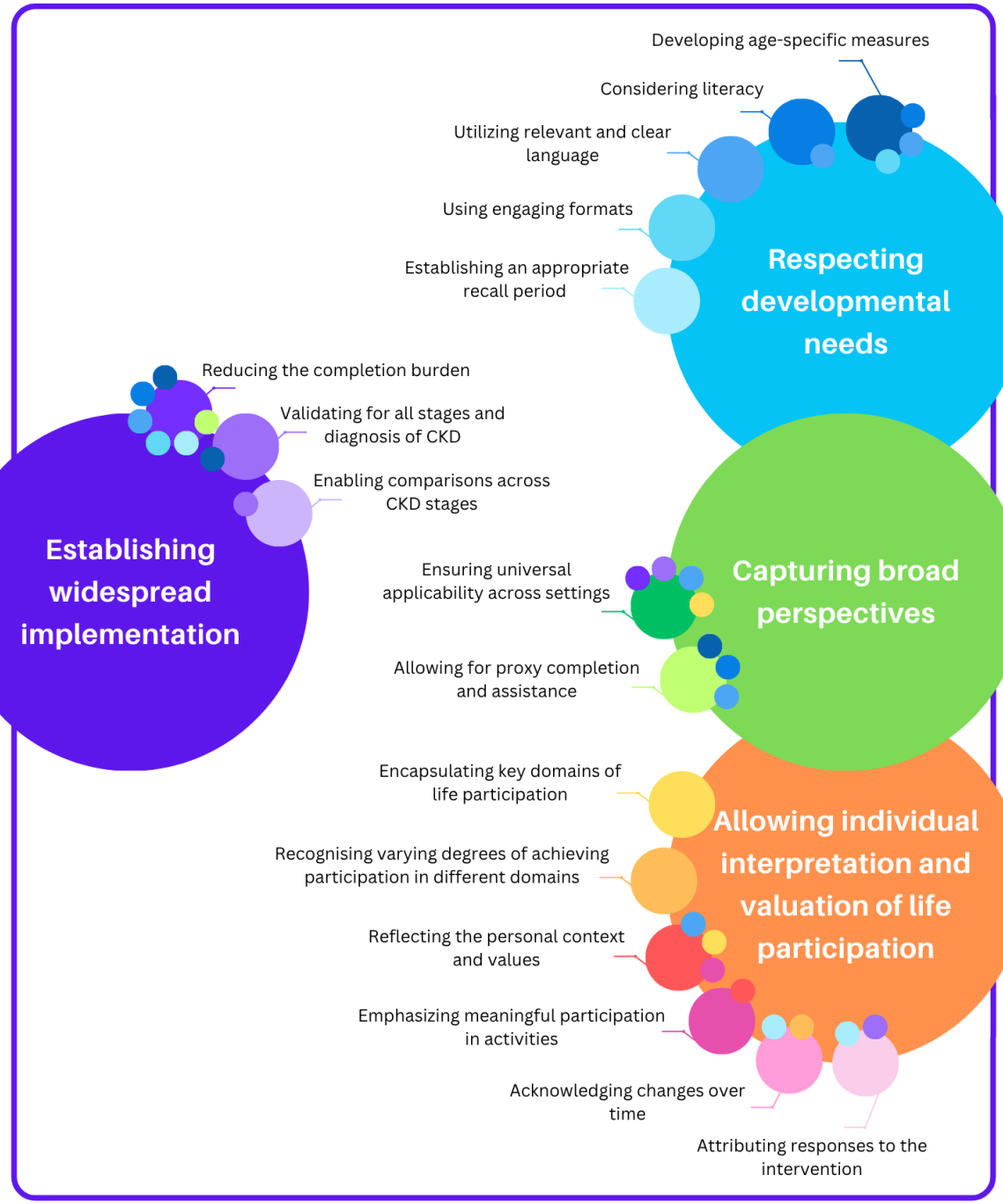
Reducing the completion burden

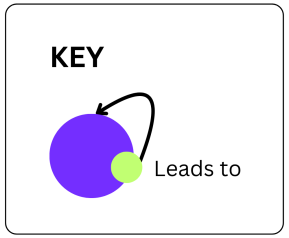
Validating for all stages and diagnosis of CKD

Enabling comparisons across CKD stages

“What we need is one questionnaire, easy to use for everybody” (Health professional, France).

Results


Developing age-specific measures
Considering literacy
Utilizing relevant and clear language
Using engaging formats
Establishing an appropriate recall period
Respecting developmental needs
Reducing the completion burden
Validating for all stages and diagnosis of CKD
Enabling comparisons across CKD stages
Establishing widespread implementation
Ensuring universal applicability across settings
Allowing for proxy completion and assistance
Capturing broad perspectives
Encapsulating key domains of life participation
Recognising varying degrees of achieving participation in different domains
Reflecting the personal context and values
Emphasizing meaningful participation in activities
Acknowledging changes over time
Attributing responses to the intervention
Allowing individual interpretation and valuation of life participation


KEY
Leads to

Conclusion

- Participants supported the use of a modified SONG-LP measure.
- Acknowledge many were from Australia and Chile.
- Pilot and validate to establish psychometric robustness and feasibility.
- Implementing a core outcome measure for life participation in trials will improve consistency of reporting.

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On behalf of the SONG-Kids Life participation Workshop Investigators

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