

Standardized outcomes in Nephrology – Hemodialysis (SONG-HD)

Jonathan C Craig and Allison Tong | Sydney School of Public Health | The University of Sydney

Core Outcomes in Effectiveness Trials (COMET) V Meeting May 20 – 21 2015

The University of Calgary, Calgary, Canada

SYDNEY MEDICAL SCHOOL



Executive Committee

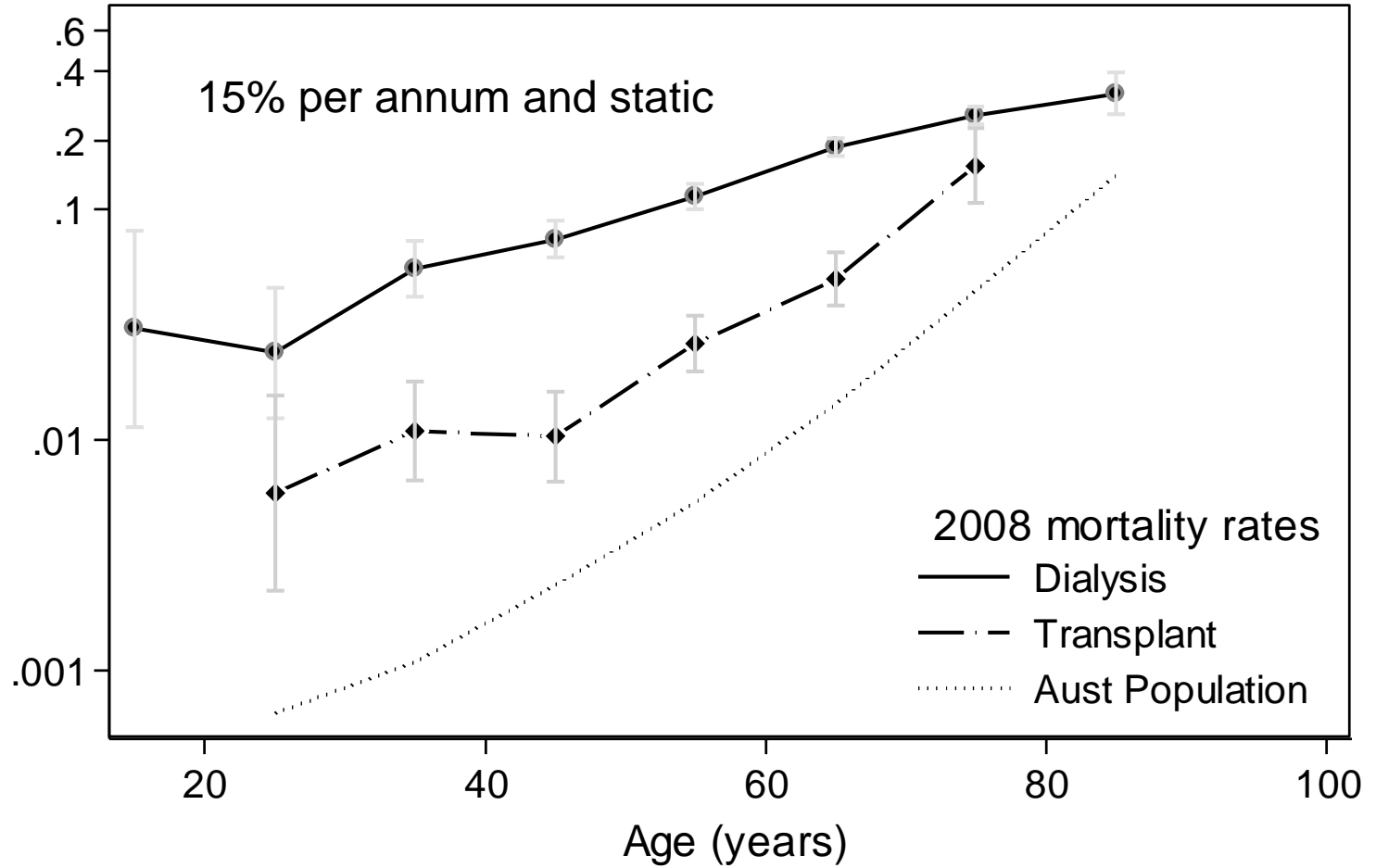
Jonathan C. Craig, Braden Manns, Brenda Hemmelgarn, David C. Wheeler, Peter Tugwell, Wim van Biesen, Wolfgang C. Winkelmayr, Allison Tong



1. Context and systematic review
2. Nominal group technique with patients/caregivers

1. Context and systematic review

High mortality rates for people with ESKD



Aust 2008 population rates from ABS

Nephrology gets the “wooden spoon” award

- lowest number/proportion of publications
- high risk of bias
- inequity of coverage

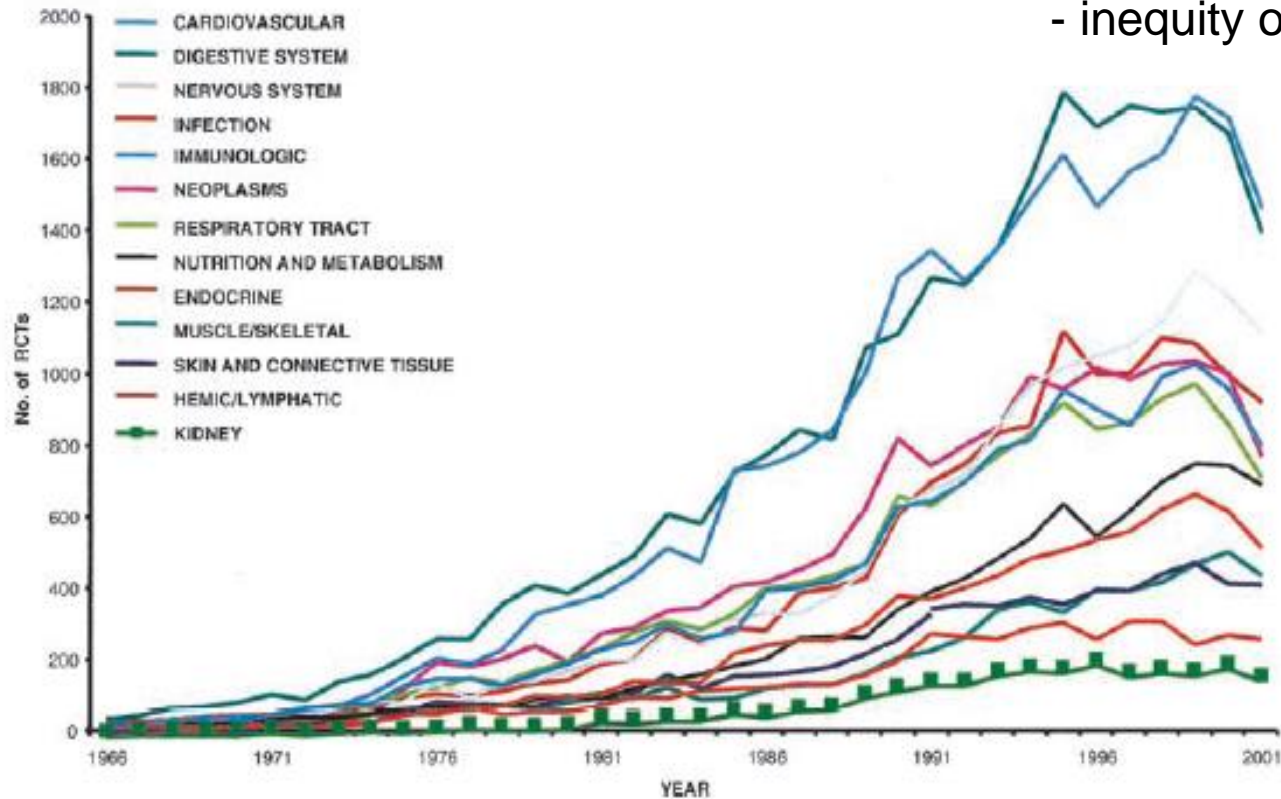


Figure 1. Number of randomized controlled trials (RCT) published in nephrology and 12 other specialties of internal medicine from 1966 to 2002.



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The **Australasian Kidney Trials Network** designs, conducts and supports high quality **clinical trials** focused on improving life for people with **kidney disease**.

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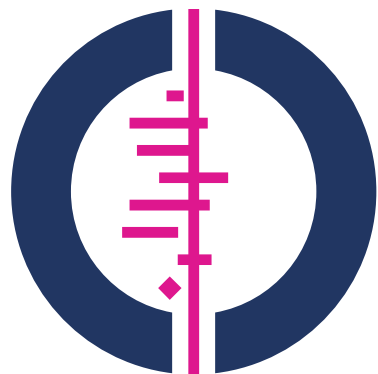
The Australasian Kidney Trials Network

The mission of the AKTN is to deliver high quality clinical trials to improve the health and wellbeing of people with kidney disease.

Clinical Research in Kidney Care

The Network's vision is to be an investigator-led clinical research organisation working with the kidney care community to achieve world class, innovative solutions that make meaningful differences to people with kidney disease.

To achieve this, the AKTN designs, conducts and supports clinical trials and fosters clinical trials expertise in Australia and New Zealand in conjunction with global collaborators.



Cochrane

Kidney and Transplant

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KIDNEY HEALTH AUSTRALIA **CARI GUIDELINES**



Welcome to KHA-CARI Guidelines

Caring for Australasians
with Renal Impairment

An Australian & New Zealand
Clinical Guidelines Initiative

Supported by KHA & ANZSN

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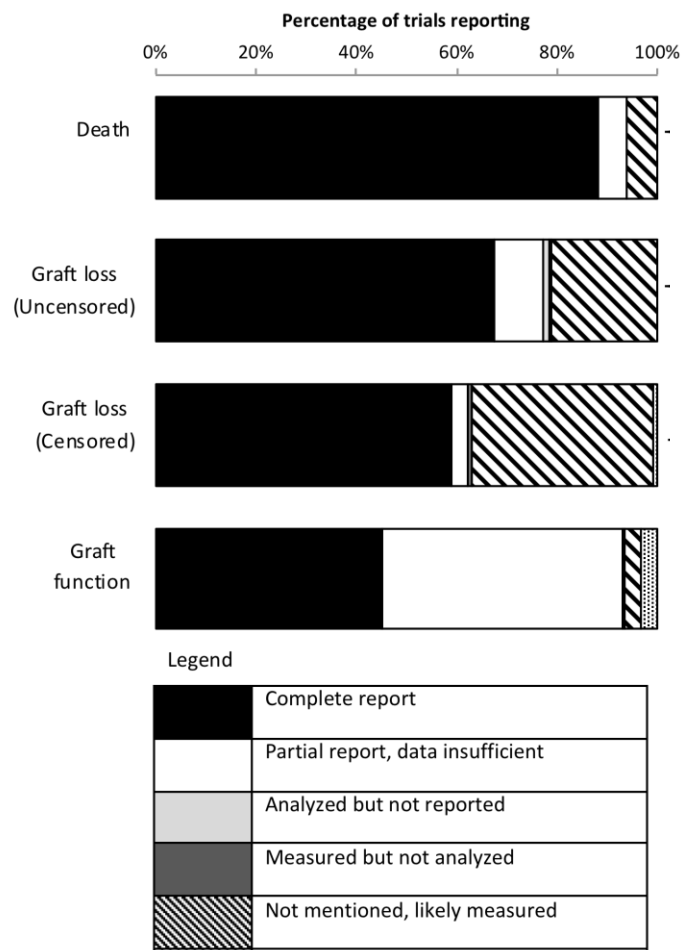
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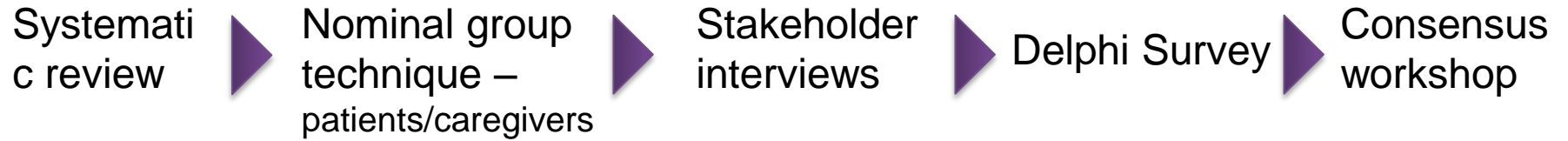
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Figure 2. Completeness of reporting of core outcomes amongst included trial reports



SONG-HD | A snapshot



2. Nominal group technique with patients/caregivers

Nominal group technique

- Generate ideas and priorities
- Minimize individual dominance
- Participants can raise views without fear of direct rejection
- Capture “think aloud” process

Corner et al 2007

Focus group

- Facilitated discussion: general experiences about hemodialysis / related treatment

Nominal group: identify outcomes

- Generate outcomes
- Augment with outcomes reported in the literature
- Define outcomes

Nominal group: rank outcomes

- Individual ranking of the outcomes in order of importance
- Discussion of reasons, consensus and differences in rankings`

- | | | |
|--|---|---|
| 1. Cardiovascular ²² | 13. dialysis freetime ² | 25. hospitalisation ³ |
| 2. Infection ³¹ | 14. Cramps ^X | 26. Calcium |
| 3. Vascular access ^{13^X} | 15. Fatigue | 27. Bone ^X |
| 4. Potassium ²¹² | 16. Sleep ³ | 28. Death ^{2XXXXX} |
| 5. Phosphate ³²³ | 17. Washed out | 29. Survival ¹³¹¹ |
| 6. Nausea/vomiting | 18. Blood pressure ² | 30. Parathyroid hormone |
| 7. Constipation | 19. ability to work ² | 31. Cancer ³ |
| 8. Interdialytic weight ¹¹ | 20. ability to travel ^{13^X} | 32. Knowledge ^{X^{XX}} |
| 9. Cognition | 21. itching | |
| 10. Depression | 22. Impact on family ³³ | |
| 11. Anxiety/stress ¹¹ | 23. Dry skin | |
| 12. Headache | 24. financial impact | |

Nominal group ranking

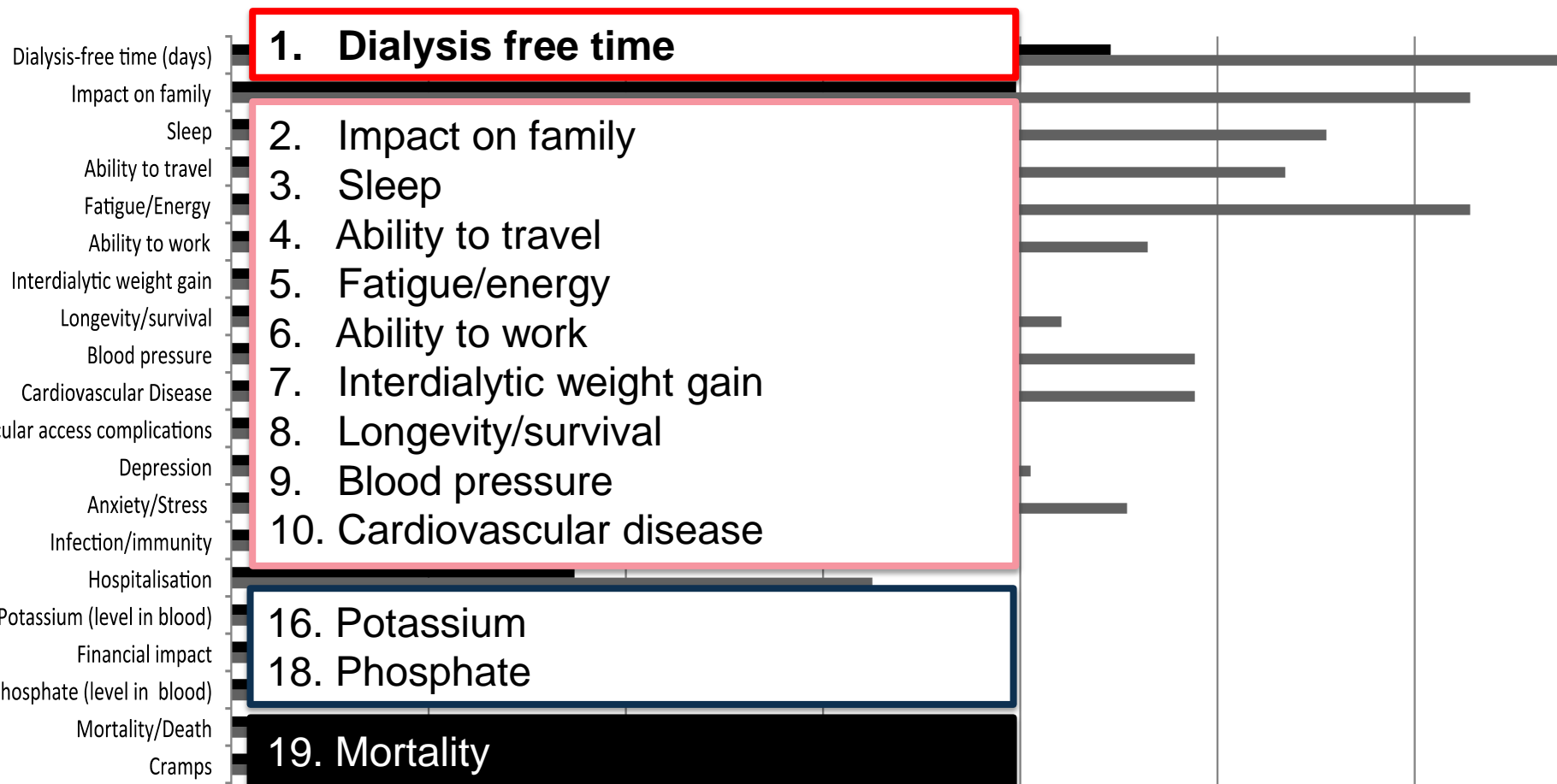
- Highest ranked outcome = 10
- Lowest ranked outcome = 1
- Not ranked = 0
- **Mean priority score** for each item was calculated by:

$$\frac{\text{Sum of ranking scores}}{\text{Maximum possible ranking score}}$$

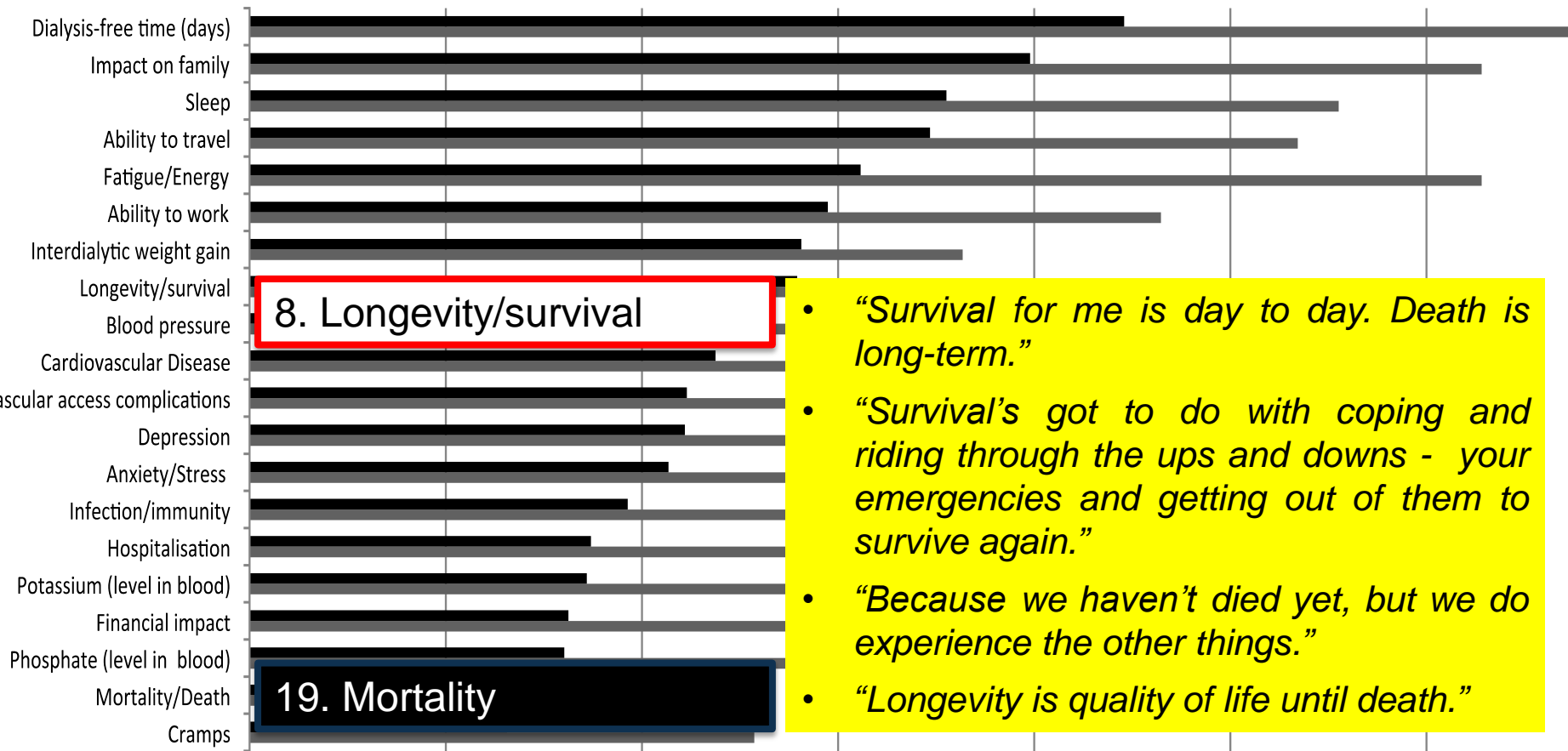
Qualitative analysis

- Thematic analysis – rationale, trade-off process

Preliminary results: top 20



Preliminary results: top 20



Preliminary themes

Tangible and experiential

“It’s hard for us to sit here and say, ‘Well, this blood level, or that blood level.’ The doctors tell you about it, it is objective. You don’t necessarily experience it.”

Ability to control

The reason vascular access, potassium and phosphate are not prioritised as highly is because we can’t control those. We depend on our doctors. The inter-dialytic weight gain is higher because it’s on us. We can control that.

Focusing on daily well-being

“You could have half a dozen measurements that hold important implications [phosphate, potassium, calcium], but they have no day to day implications... none whatsoever... for our physical or our experience of well-being.”

Inevitability of death

“I was given this graph about mortality that some doctor had made. I was supposed to read it and understand it. To me, it didn’t really matter. Death doesn’t really faze me. It’s out there but let’s just face what’s here.”

SONG-HD contributors (to date)

Peter Kerr, Kevan Polkinghorne, Kirsten Howard, Carol Pollock, Carmel Hawley, David Johnson, Stephen McDonald, Martin Gallagher, Rachel Urquhart-Secord, Gabrielle Williams, Rachel Urquhart-Secord, David Harris, Helen Tam, Stephanie Thompson, Kara Schick-Makaroff, Martin Howell, Madeleine King, Elaine Pascoe, Joe Ix, Dena Rifkin, Min Jun ...

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