From Childhood to Adulthood:
Navigating the lifelong Impact of Kidney Disease

Dr Melanie Wyld

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Conflicts of interest

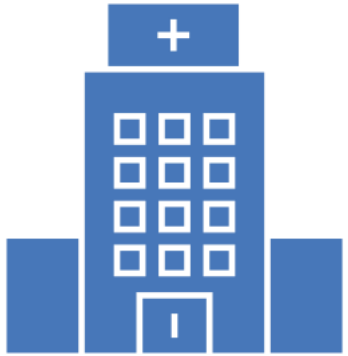
- Adult transplant nephrologist at Westmead Hospital (0.5FTE) and an academic at the University of Sydney (0.5FTE)
- At the end of training spent at Westmead Children's Hospital as a fellow
- Run a regular transition clinic
- I was diagnosed with kidney disease as a child and went on to dialysis and a transplant as a young adult

Children with kidney failure

- Incidence: 8 -13 children pmp
- Prevalence: 60-100 pmp
- Majority (>75-80%) treated with a functioning transplant (during childhood)

Sources: ANZDATA (2019). 42nd Report, Chapter 12: Paediatric Patients with End Stage Kidney Disease Requiring Renal Replacement Therapy, ERA-EDTA Registry (2017) Annual Report, USRDS (2019) . Annual Data Report: Epidemiology of Kidney Disease in the United States

Lifelong impact of kidney disease in childhood



Health

Social relationships

Educational
& employment

Financial

Quality of life

… and many others

Sources: Lopes M et al, Health-related quality of life of children and adolescents with CKD stages 4-5 and their caregivers Pediatr Nephrol. 2014;29(7):1239-47, Dharnidharka V et al, Kidney Transplantation in Children. NEJM. 2014;371(6):549-58, Moreira J et al, Anxiety, depression, resilience and quality of life in children and adolescents with pre-dialysis chronic kidney disease. Pediatr Nephrol. 2015;30(12):2153-62, Medway M et al. Parental Perspectives on the Financial Impact of Caring for a Child With CKD. AKJD. 2015;65(3):384-93, Wightman A et al, Health-related quality of life changes following renal transplantation in children. Pediatric Transplantation. 2019;23(2):e13333

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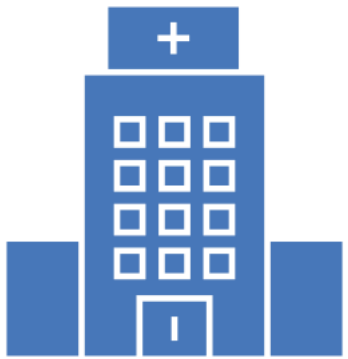

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What we know (and don’t know) currently

- Children and adolescents with kidney failure *treated with a transplant* have excellent 5 (99%) and 10 (90-97%) survival
- Focus of research is often treatment (transplant) specific and does not reflect the patient’s lived experience
- Despite survival being the primary priority, *we know little about the lifetime impact*
  - Hinders informed patient and parent counselling
  - Impacts policy makers who use expected length of life in conjunction with quality of life to inform funding and policy decisions
- Does lifetime impact vary by the sex of the child?

Source: Francis A, Johnson D, Melk A,C Foster B, Blazek K, Craig J, et al. Survival after Kidney Transplantation during Childhood and Adolescence. CJASN. 2020;15:392-400

CLINICAL EPIDEMIOLOGY www.jasn.org JASN

Life Years Lost in Children with Kidney Failure: A Binational Cohort Study with Multistate Probabilities of Death and Life Expectancy

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[2]Department of Renal and Transplant Medicine, Westmead Hospital, Westmead, New South Wales, Australia
[3]Centre for Kidney Research, Children's Hospital at, Westmead, Westmead, New South Wales, Australia

Aim

1. Ascertain mortality rates of children with kidney failure to determine life expectancy (by sex)
2. Estimate years of life lost from kidney failure in children by comparing their life expectancy to those in the general population (by sex)

Study design and setting

Patient data and inclusion criteria:

- **Binational population-based cohort study** of all people with treated kidney failure in Australia and New Zealand
- **Linked data** between ANZDATA and national death registries
- Inclusion criteria:
  - **Age ≤18 years**
  - Treated kidney failure in Australia (**1980 to 2019**) and in New Zealand (1988 to 2019)

ANZ DATA | AUSTRALIA & NEW ZEALAND DIALYSIS & TRANSPLANT REGISTRY

Mortality rates calculated by:

- Sex
- Age group (2-5yrs, 6-10yrs, 11-14yrs and 15+yrs)
- Time since kidney failure and time since transplant

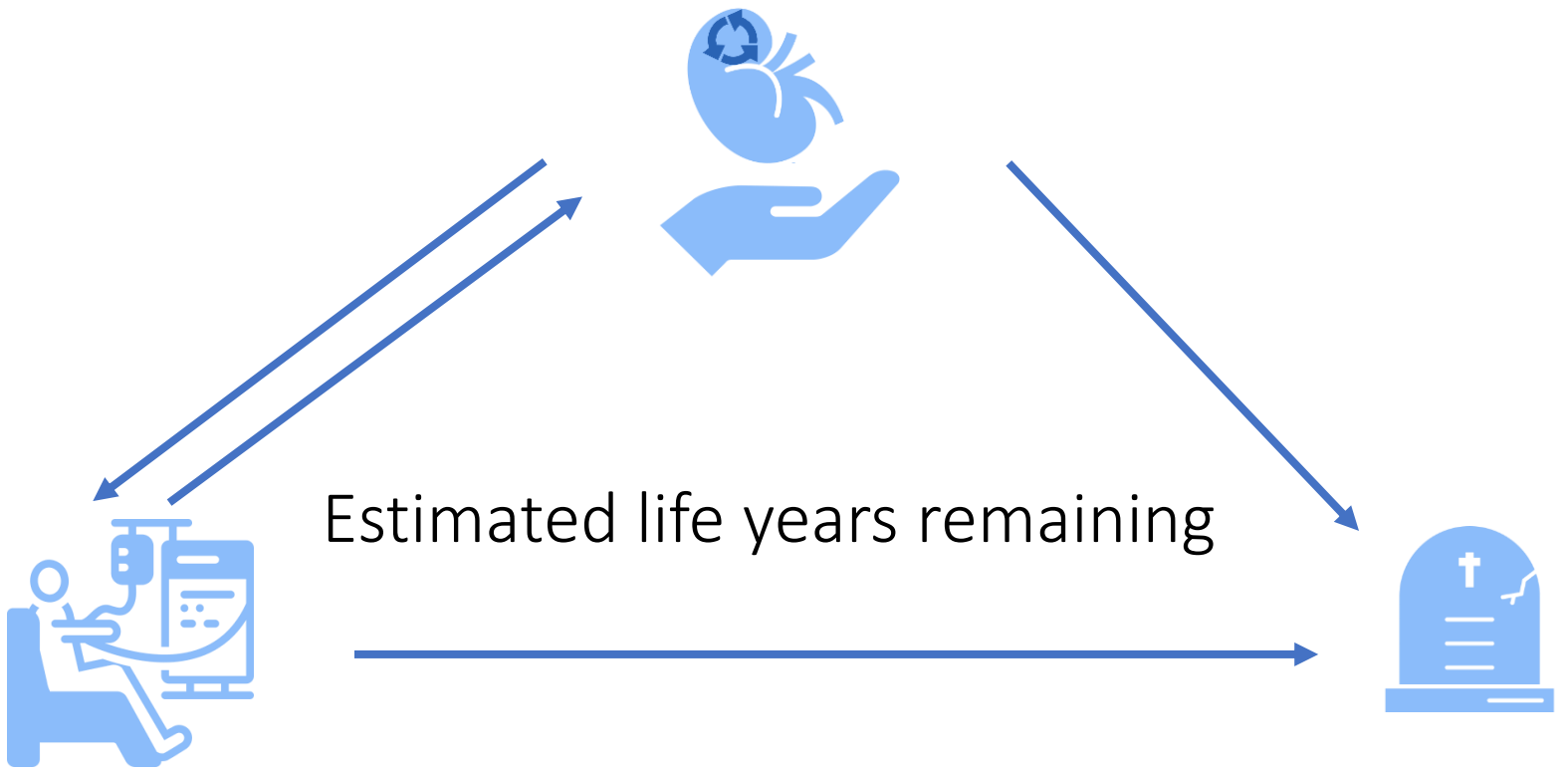
Standardised "excess" mortality rates calculated by:

- Calendar year period using *indirect standardisation* matching to gen. pop. death rates by
  - 5-year age band
  - Sex
  - Calendar year
  - Country

Australian Bureau of Statistics

MINISTRY OF HEALTH
MANATŪ HAUORA

Multistate modelling to mirror patient journey



We used multi-state models to estimate the expected life years remaining overall and in two living states, dialysis and transplant.

Characteristics of our cohort

2,013 children with kidney failure

30,082 person years of follow-up

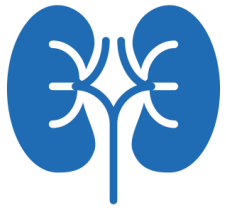
Median follow-up 13yrs (IQR 6-23yrs)

70% European
8% Maori & Pasifika
8% Asian
4% Aboriginal & Torres Strait Islander
4% African & Middle East
6% Other

1980s	1990s	2000s	2010s
19%	25%	27%	29%

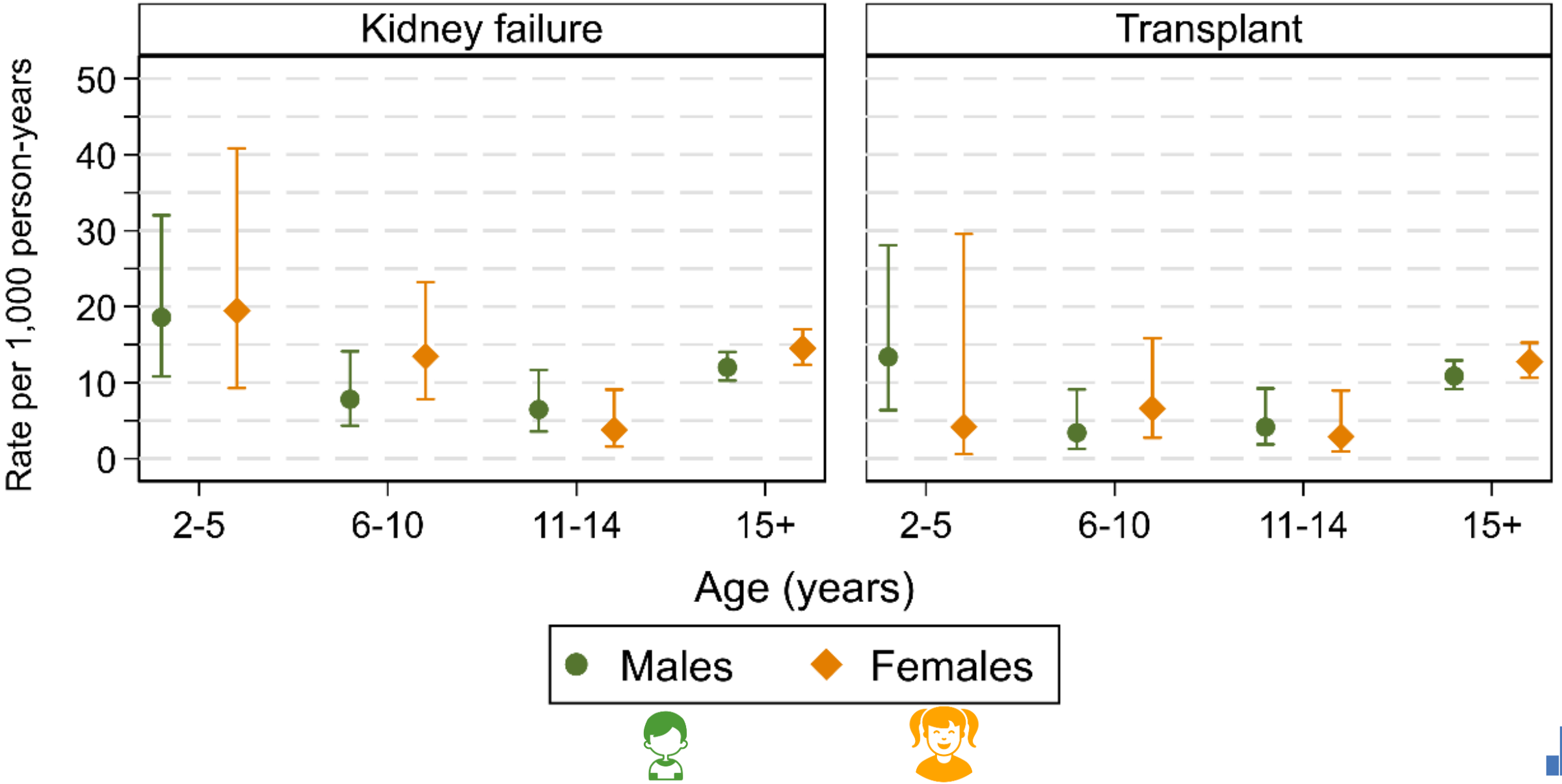
Median age 13yrs (IQR 7-16yrs)

Characteristics of our cohort

		42%	**58%**
	CAKUT	29%	46%
	GN	39%	30%
	Cystic diseases	15%	7%
	Other	18%	16%
	Pre-emptive	10%	18%
	Dialysis then transplant	77%	72%
	Never transplanted	13%	10%

What were the mortality rates of children with kidney failure?

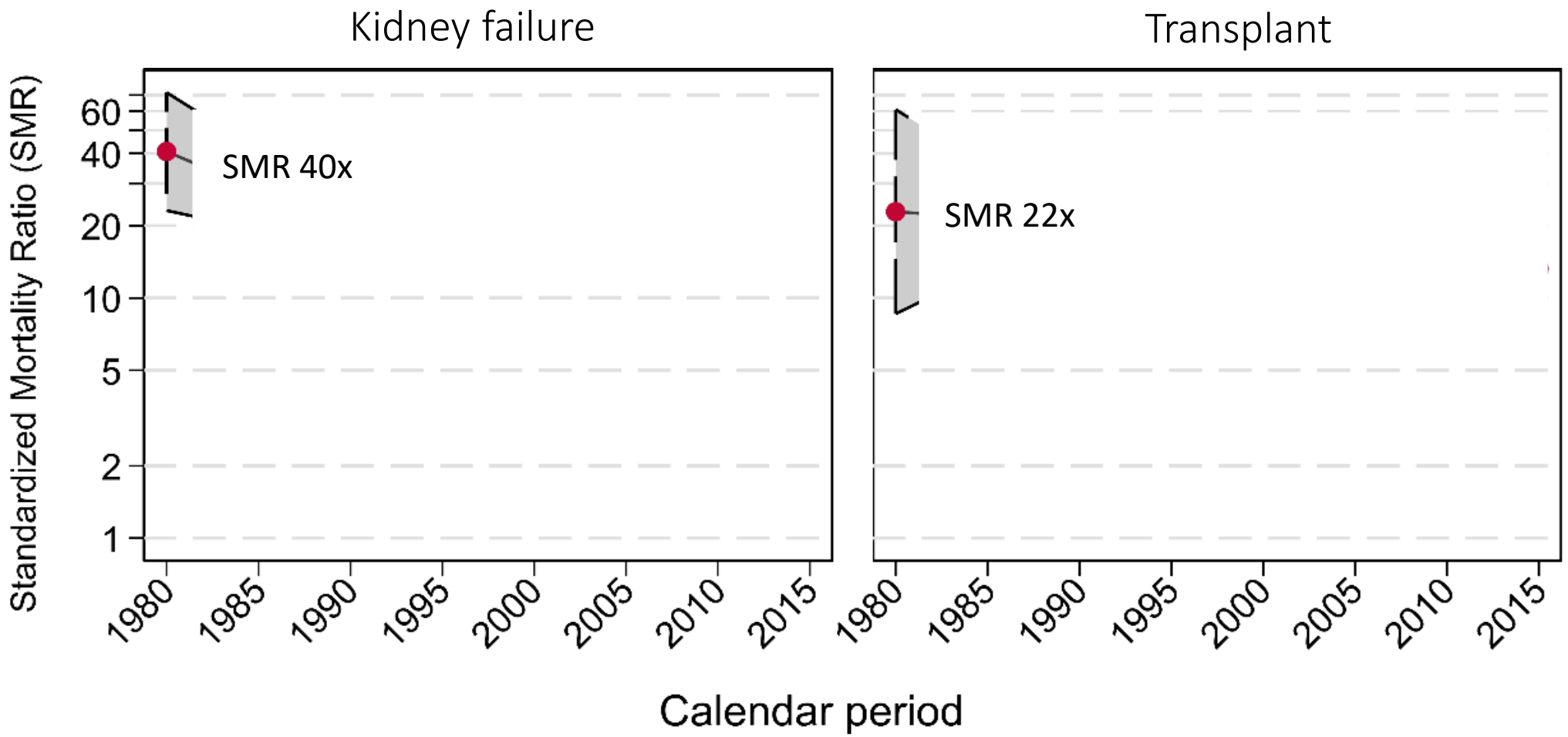
Mortality rates were not significantly different by sex



What about excess mortality?

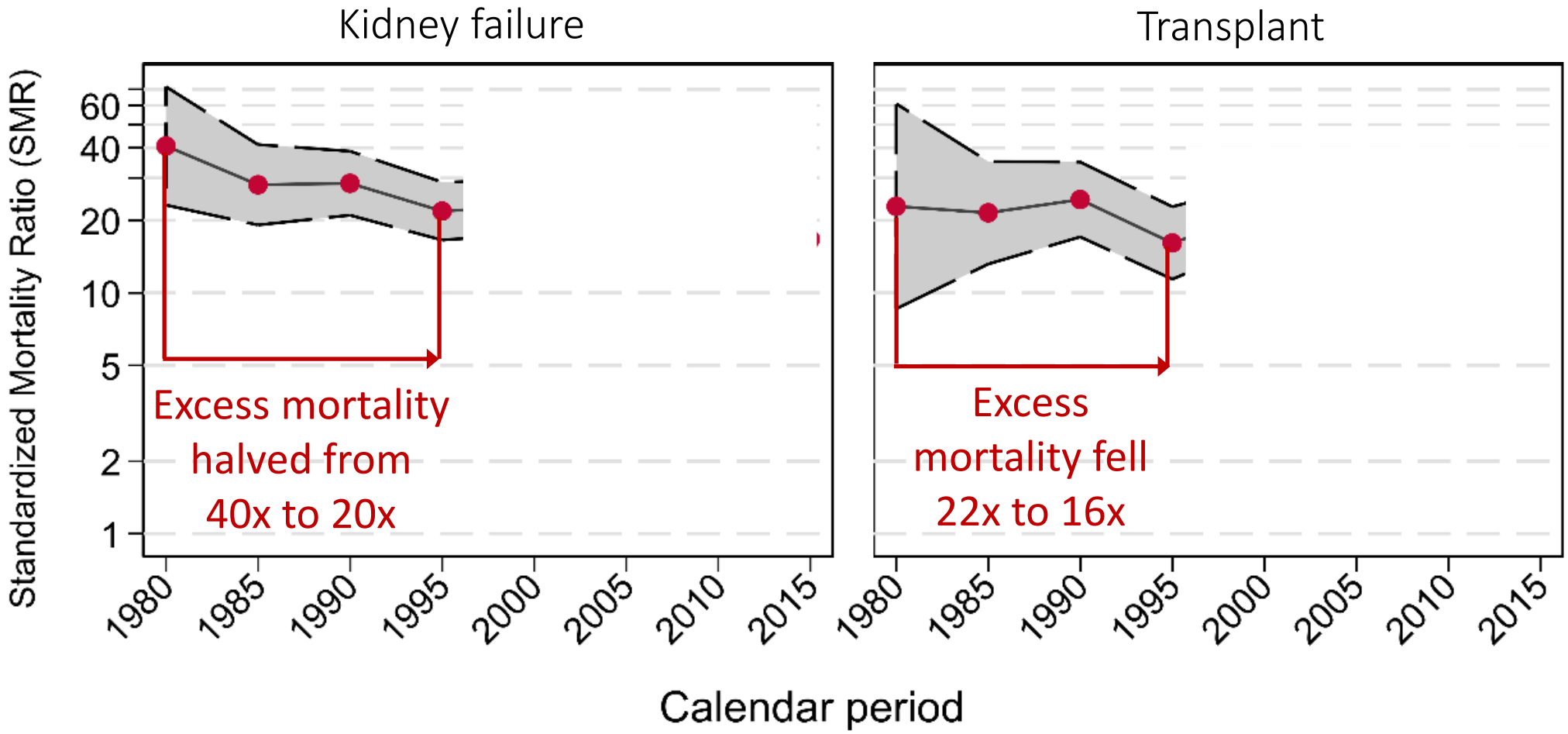
Excess mortality is (very) high

SMR “excess deaths” on log scale (with 95% CI) over time



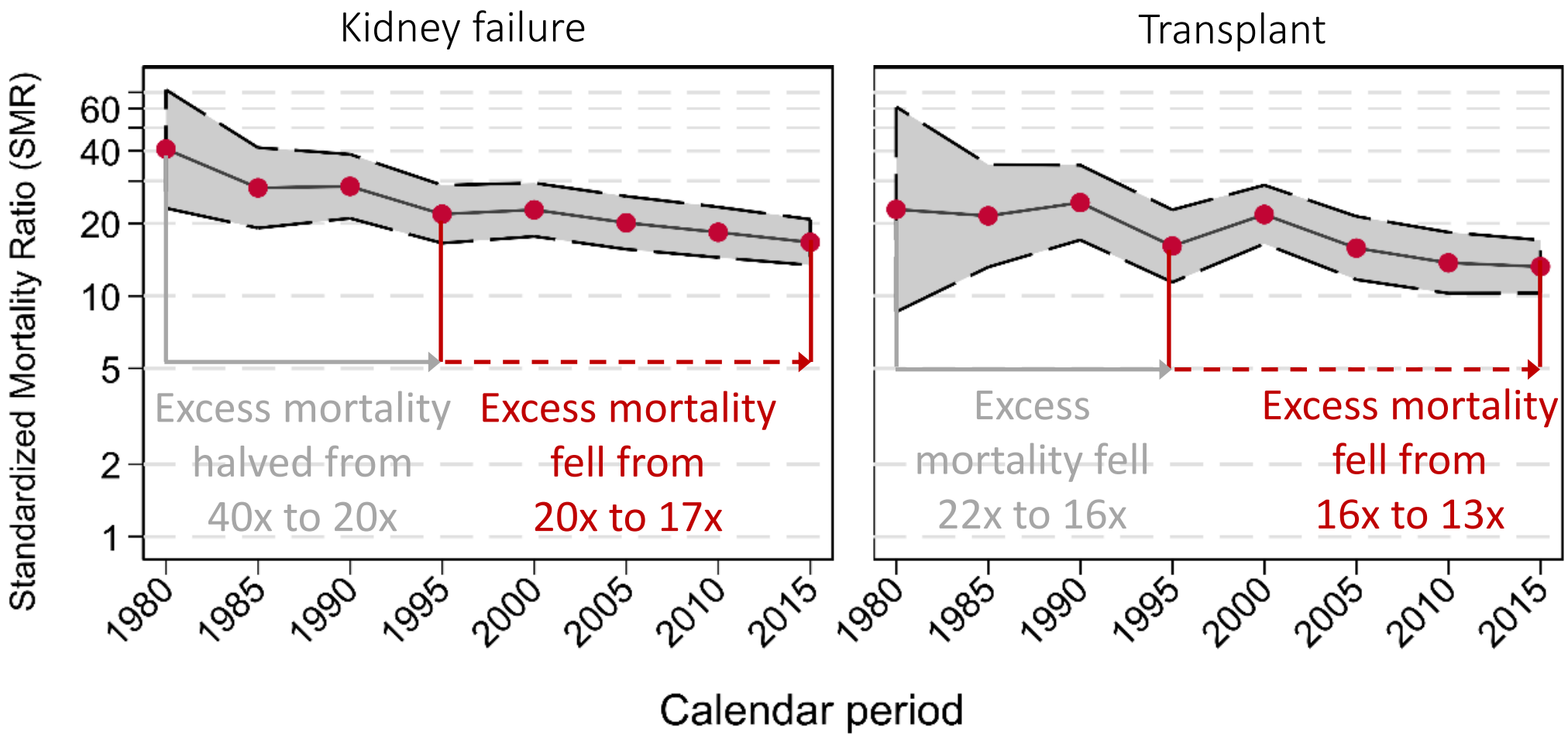
Excess mortality is high… but there were been sizable gains

SMR “excess deaths” on log scale (with 95% CI) over time



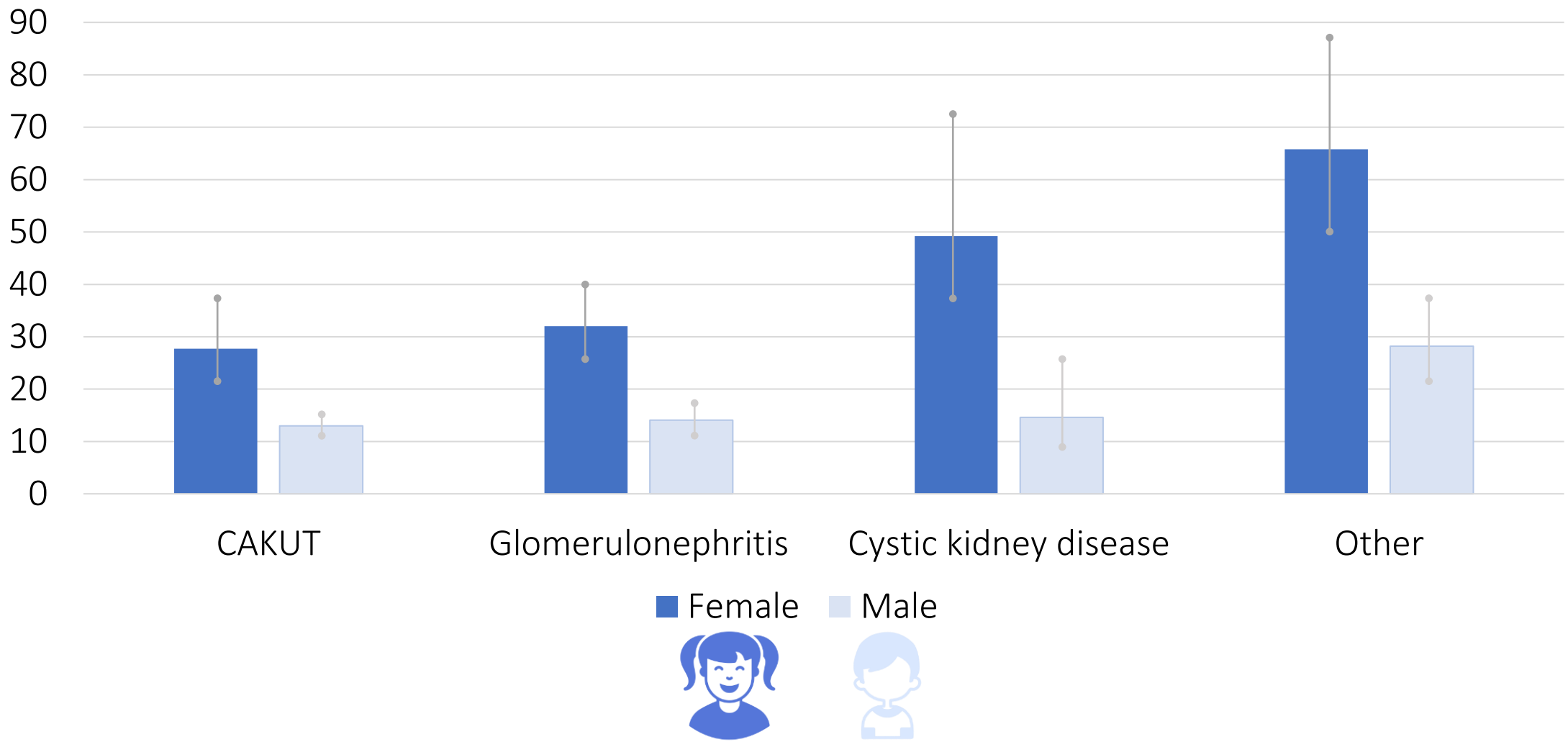
More recently the improvements have slowed

SMR “excess deaths” on log scale (with 95% CI) over time



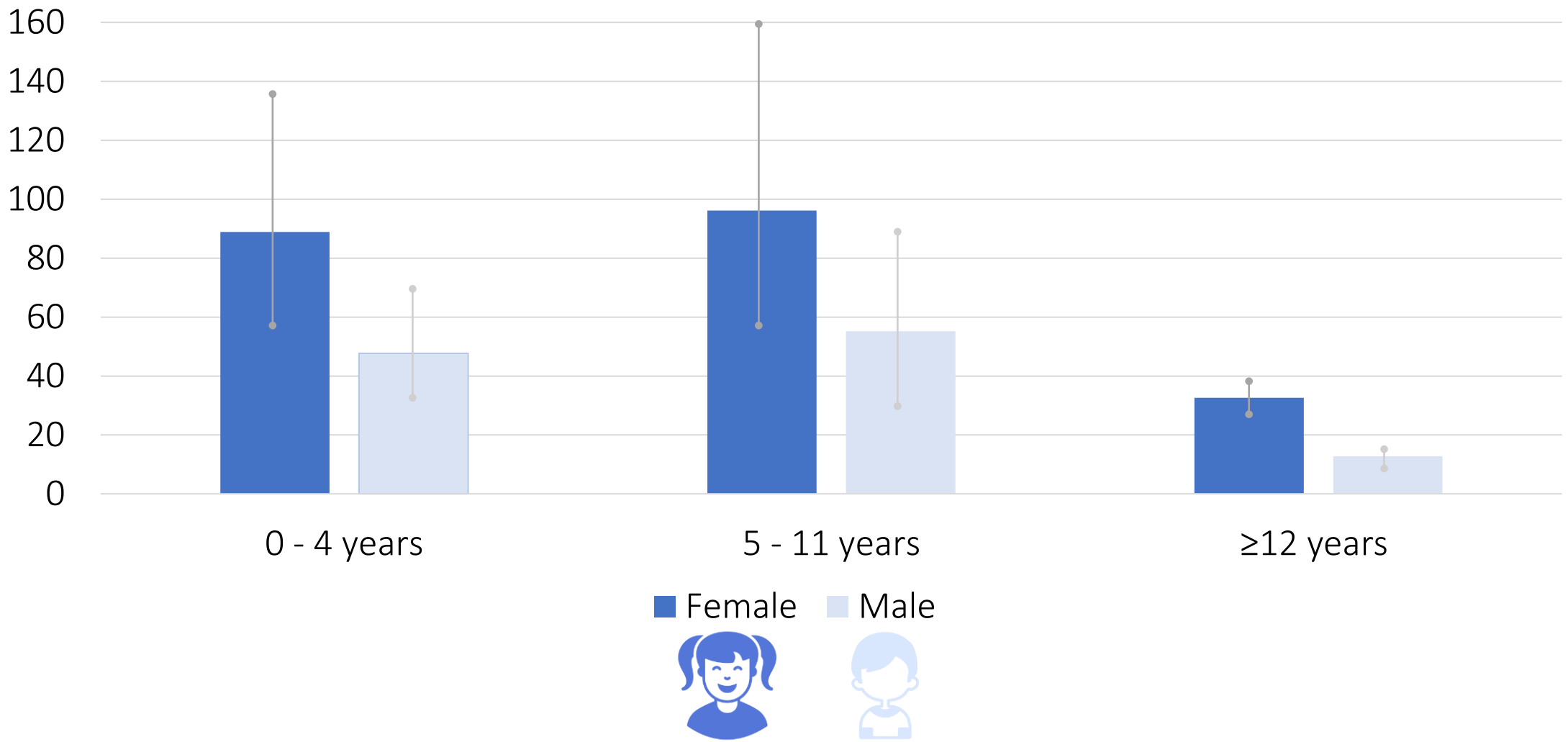
Females have higher excess mortality across all kidney disease types

SMR “excess deaths” (with 95% CI) by underlying kidney disease



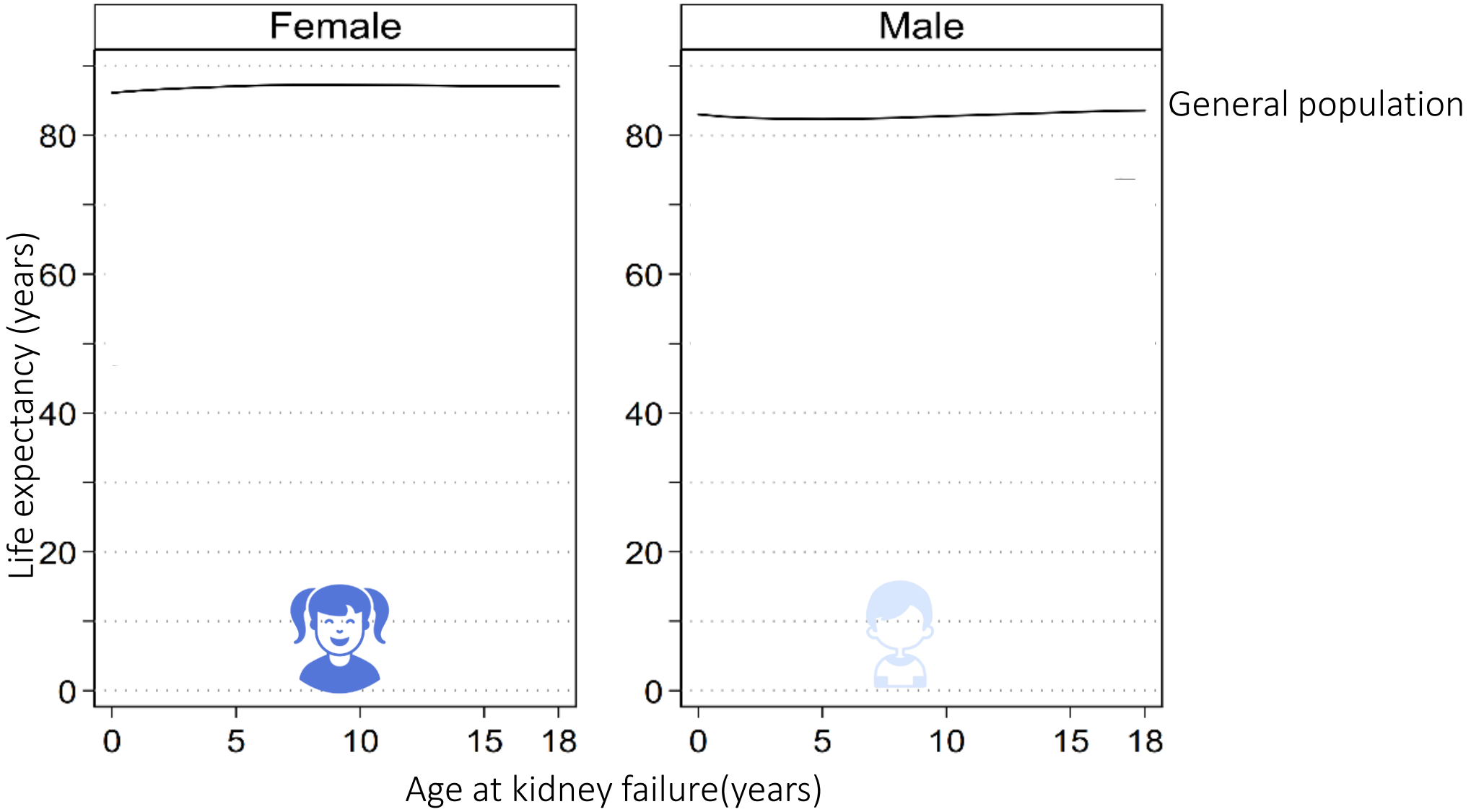
Females have higher SMRs across all age groups

SMR “excess deaths” (with 95% CI) by age group

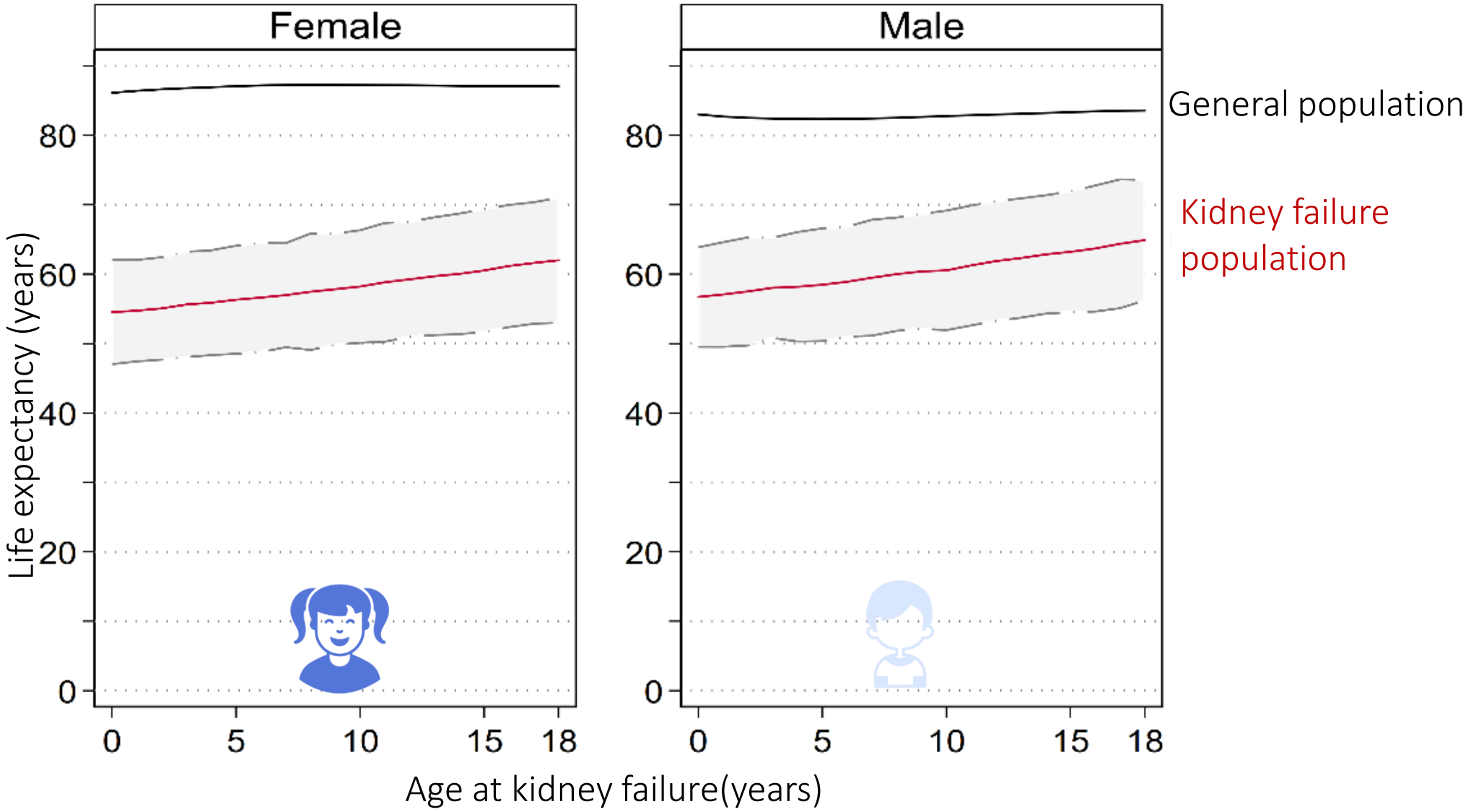


What is the impact of this high excess mortality in terms of life years lost?

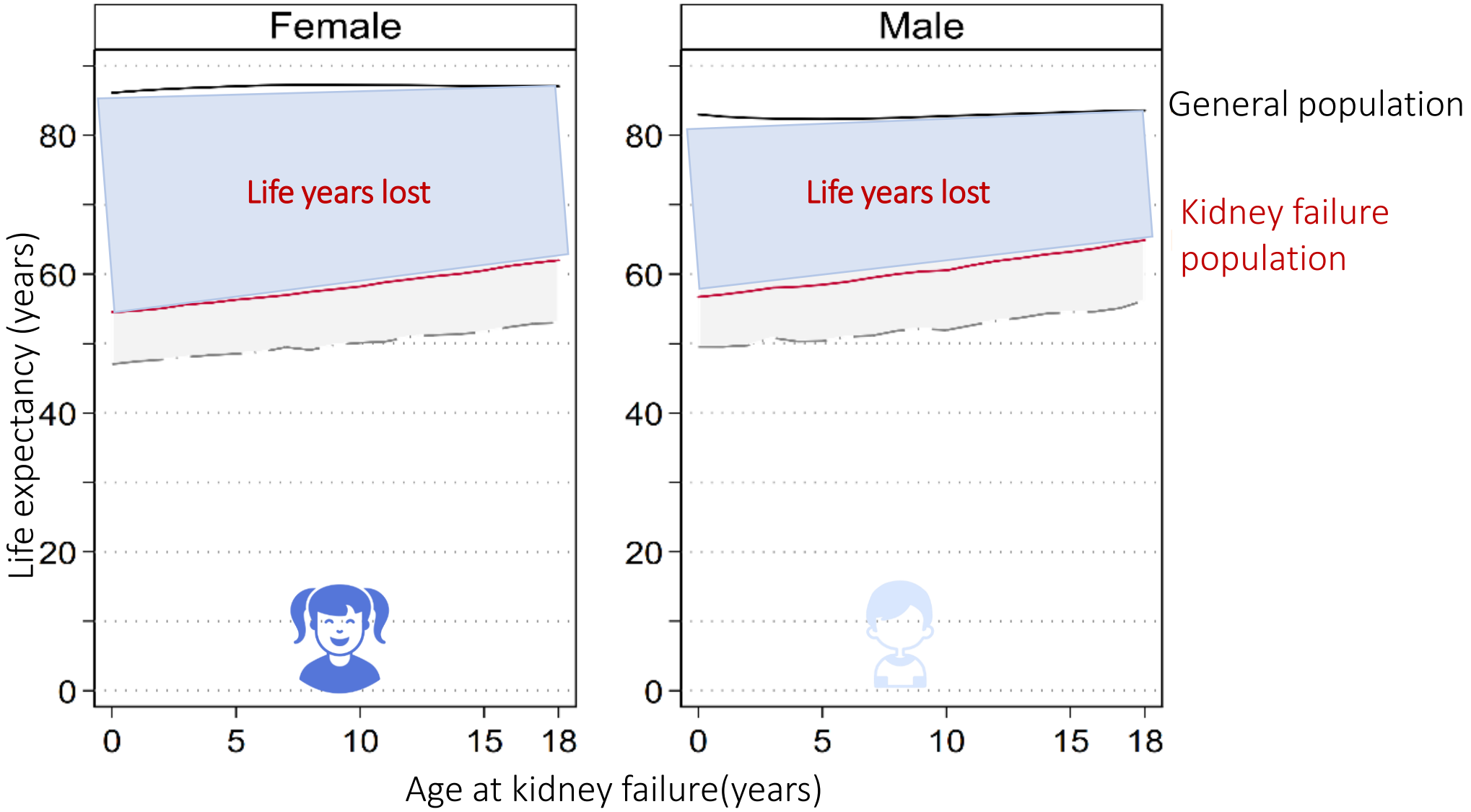
Life expectancy in the general population sits in the 80s, with females expected to live slightly longer than males



Regardless of age at kidney failure, life expectancy is substantially lower than peers



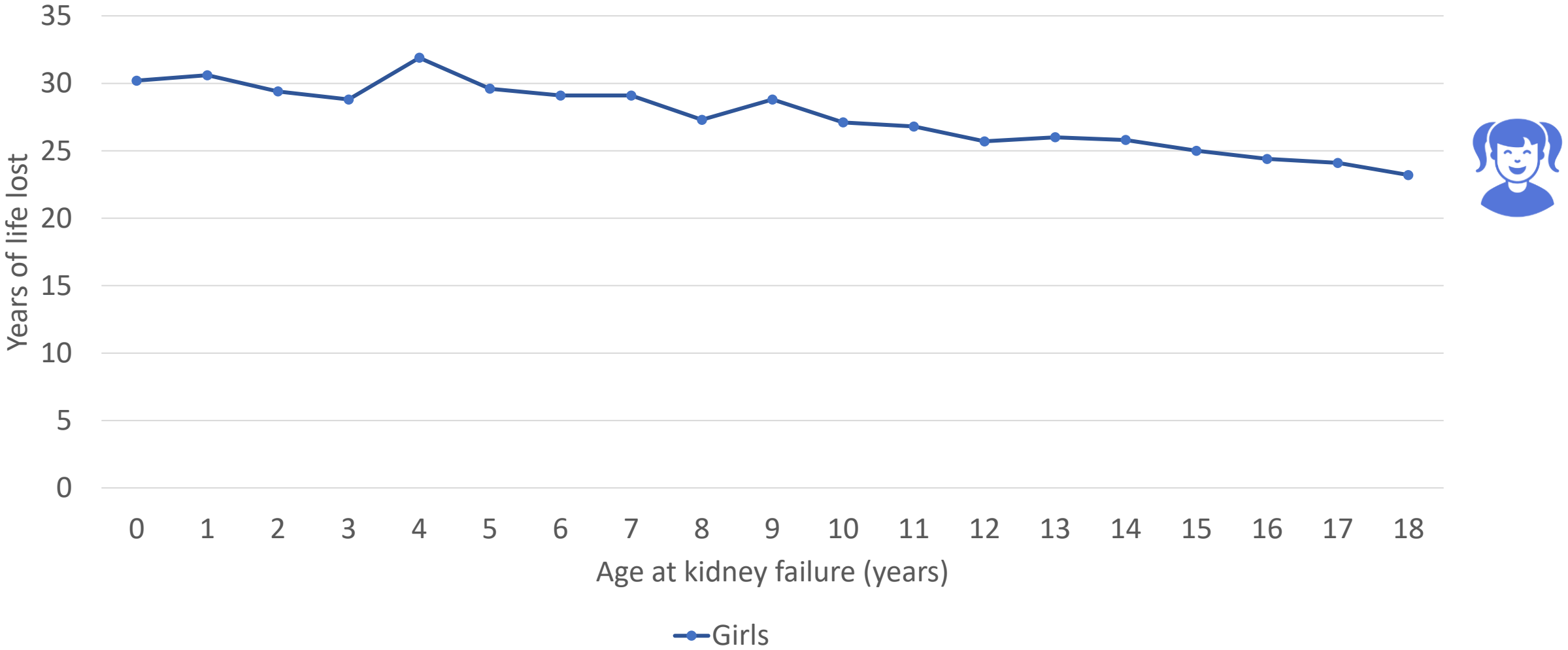
… resulting in 16-32 life years lost



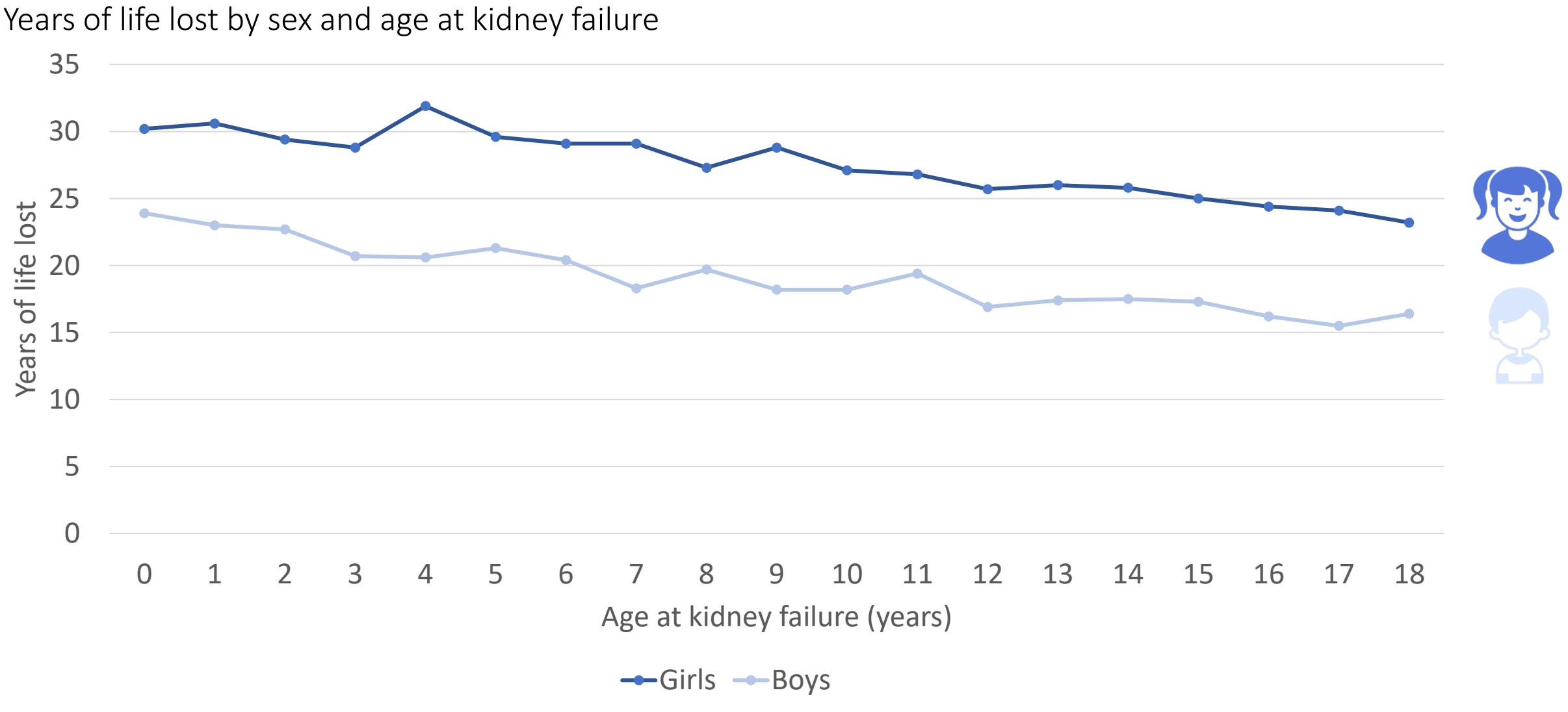
Are there sex differences in years of life lost?

Girls lose 32 years of life if diagnosed as toddlers or preschoolers, declining to 25 years for teens

Years of life lost by sex and age at kidney failure



Boys see a similar trend with life years lost falling from 23 years to 16 years as age at kidney failure increases



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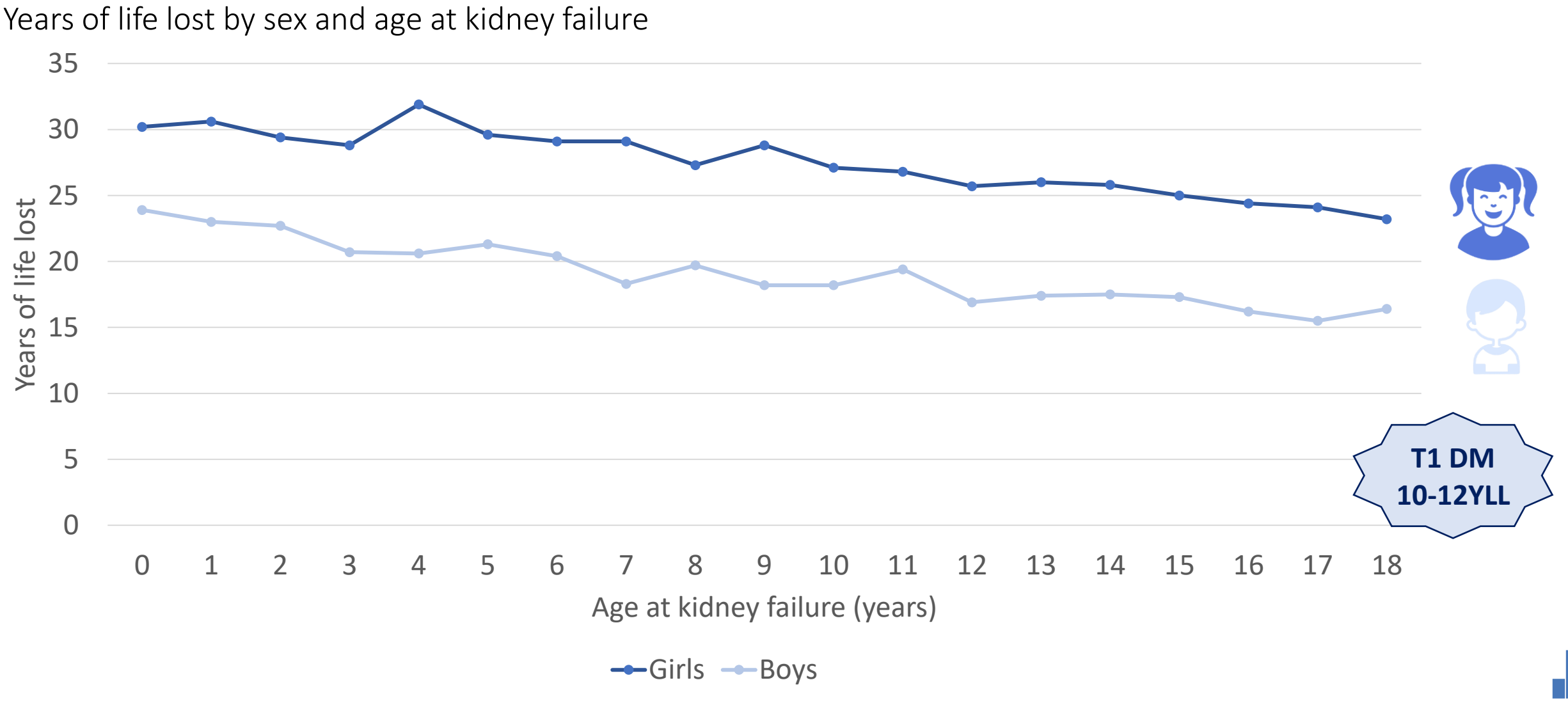
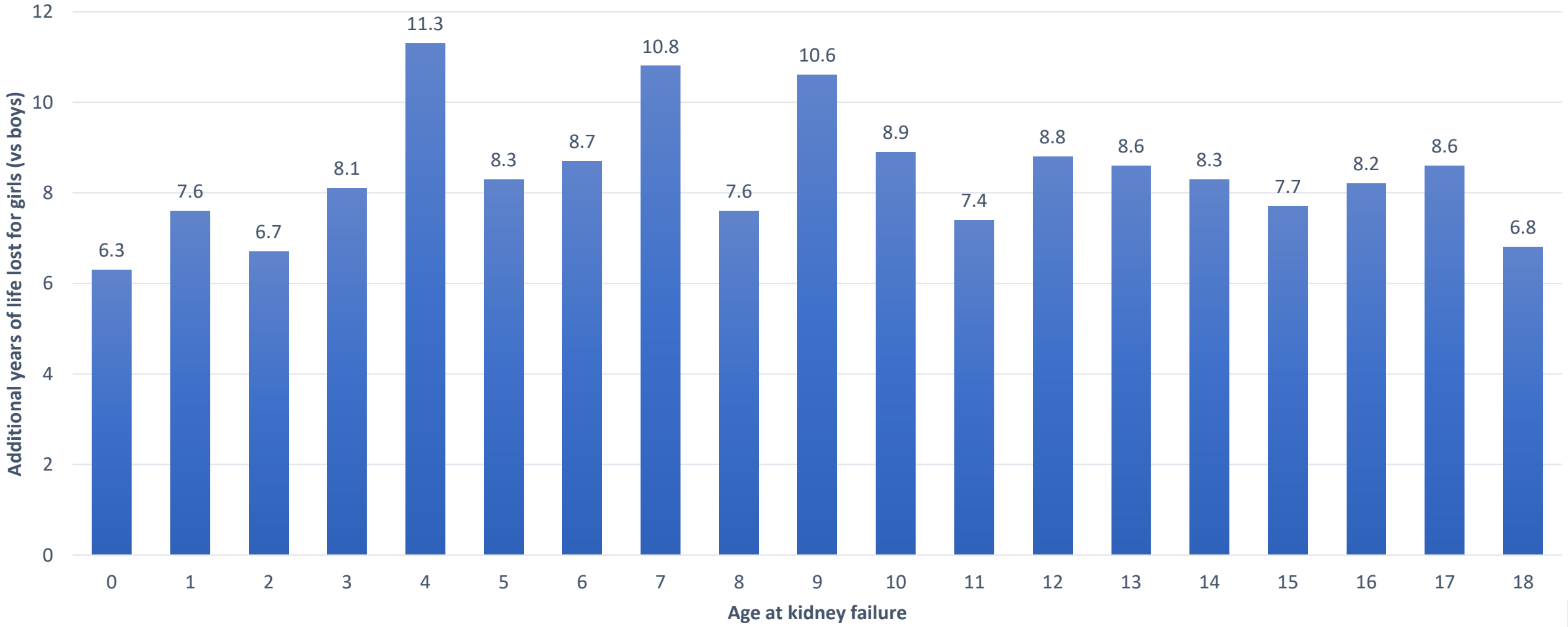


Girls lose 6 to 10 more life years than boys regardless of age at kidney failure

Additional years of life lost for girls (compared to boys) by age at kidney failure



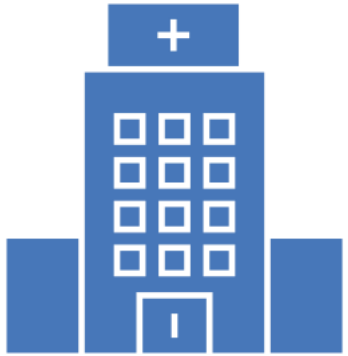
Key Findings

1. Children with kidney failure have extremely high excess mortality rates over their life course and while there initially substantial improvements, these have slowed

2. Females have higher rates of excess mortality across all kidney disease types and age groups

3. The years of life lost in our cohort ranges from 16-32 years depending on age at kidney failure diagnosis and sex. Girls lose 6-10 more life years at every age of diagnosis.

Lifelong impact of kidney disease in childhood



Health

Social relationships

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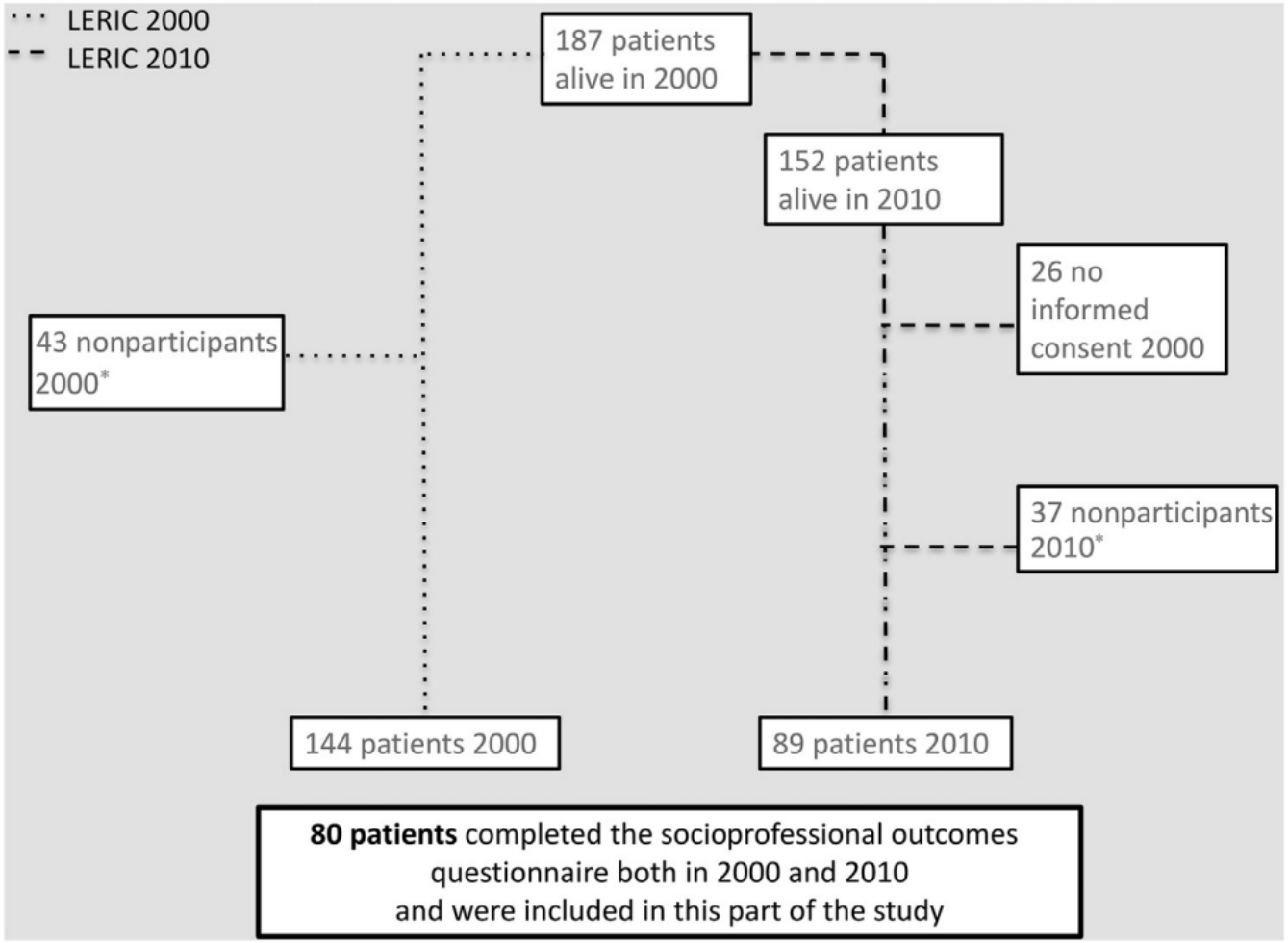
The LERIC cohort comprises all Dutch patients starting KRT at <15 years of age between 1972 and 1992 and born before 1979



Participants were more likely to be female and less likely to be on dialysis and/or disabled

Table I. Characteristics of the LERIC 2010 cohort

	Participants (N = 80)	Nonparticipants (N = 46)
Sex (female)	39 (48.8%)	19 (41.3%)
Mean age at start of RRT in y (range)	11.1 (1.9-14.9)	11.0 (2.7-15.0)
Mean age in 2010 in y (range)	40.6 (32.1-52.4)	40.2 (32.0-50.1)
Short stature (<2 SD)	47 (58.8%)	30 (65.2%)
Mean duration of RRT in y (range)	28.9 (18.1-39.6)	29.2 (19.1-37.1)
Median duration of dialysis in y (range)	2.5 (0.1-36.5)	4.2 (0.4-36.5)
Median duration of functioning renal graft in y (range)	23.5 (0.2-39.3)	21.8 (0.2-33.4)
On dialysis at time of investigations	13 (16.3%)	13 (28.3%)
Lifetime dialysis > transplantation	7 (8.8%)	8 (17.4%)
Disabilities*	16 (20.0%)	19 (41.3%)
Comorbidities	46 (57.5%)	20 (43.5%)

*Statistically significant difference between participants and nonparticipants ($P = .01$).

Sources: Tjaden, LA 'Impact of Renal Replacement Therapy in Childhood on Long-Term Socioprofessional Outcomes: A 30-year Follow-Up Study', Journal of Pediatrics,

There is a profound impact on the ability to develop and maintain social relationships and independence

	All patients (N = 80), % (95% CI)	Patients with a functioning transplant (N = 67), % (95% CI)	Patients on dialysis (N = 13), % (95% CI)	General Dutch population, 30-50 y* (N = 4 765 844)
Family life				
Married	50.0 (38.6-61.4)	52.2 (39.7-64.6)	38.5 (13.9-68.4)	57.1
Divorced	3.8 (0.1-10.6)	4.5 (0.1-12.5)	0†	9.7
Living with a partner	68.8 (57.4-78.8)	70.1 (57.7-80.7)	61.5 (31.6-86.1)	74.4
Single and living independently	18.8 (10.9-29.0)	20.9 (11.9-32.6)	7.7 (1.9-36.0)	21.2
Living with parents/institution	12.5 (6.2-21.8)†	8.9 (3.3-18.5)	30.8 (9.0-61.4)†	4.4
Children	28.8 (19.2-40.0)†	34.3 (23.2-46.9)†	0†	64.8

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In a French cohort study 12% had children, and the female fertility rate in their cohort was four times lower than in French general population

Sources: Tjaden, LA 'Impact of Renal Replacement Therapy in Childhood on Long-Term Socioprofessional Outcomes: A 30-year Follow-Up Study', Journal of Pediatrics,

Similar findings in a large French cohort

A French study of 374 adults (mean age 27) who had kidney transplant as a child (mean age 13, between 1985 and 2002) showed that they were more likely to be single and live with their parents – particularly for women.

	Observed, n (%)	Expected, n (%)	SIR	*P*
Familial life				
Living with a partner (n=373)	116 (31.1)	195 (52.2)	0.60	<0.01
Men	51 (26.7)	90 (46.9)	0.57	<0.01
Women	65 (35.7)	105 (57.8)	0.62	<0.01
Single and living independently (n=373)	103 (27.6)	76 (20.3)	1.36	<0.01
Men	60 (31.4)	36 (19.1)	1.65	<0.01
Women	43 (23.6)	39 (21.7)	1.09	0.62
Single and living with parents (n=373)	133 (35.7)	78 (21.0)	1.7	<0.01
Men	70 (36.6)	51 (26.5)	1.38	<0.01
Women	63 (34.6)	28 (15.2)	2.28	<0.01

Sources: Mellerio, H et al. 'Adult Social and Professional Outcomes of Pediatric Renal Transplant Recipients', Transplantation, 2014 97(2): 196-205

Quantitative Australian data

… is lacking.
Research is needed here!

Sources: Mellerio, H et al. ‘Adult Social and Professional Outcomes of Pediatric Renal Transplant Recipients’, Transplantation, 2014 97(2): 196-205

The profound impact on social relationships is clear from qualitative work

- *"I'd like to move out, but **if anything serious happens and I can't work**, I can't pay for the place anymore"*
  - Male, Age 22-25yrs

- *"It's three times a week, 5 or 6 hours each day. It's just ridiculous. So much time. And then when you get off, you feel so drained and I couldn't really socialise much"*
  - Female, Age 22-25yrs

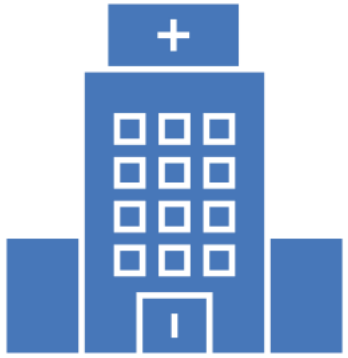
- *"I feel a bit socially awkward, I don't know if it's because of my **lack of social interactions when I younger**"*
  - Male, Age 22-25yrs

- *"You put yourself down and you start thinking, **would anyone ever love me because I have those problems**"*
  - Female, Age 22-25yrs

Professor Allison Jaure

Sources: Kerklaan, J 'Perspectives on life participation by young adults with CKD: an interview study', BMJ Open, 2020; 10(10): e037840.

Lifelong impact of kidney disease in childhood



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Quality of life

Children with CKD miss *a lot* of school

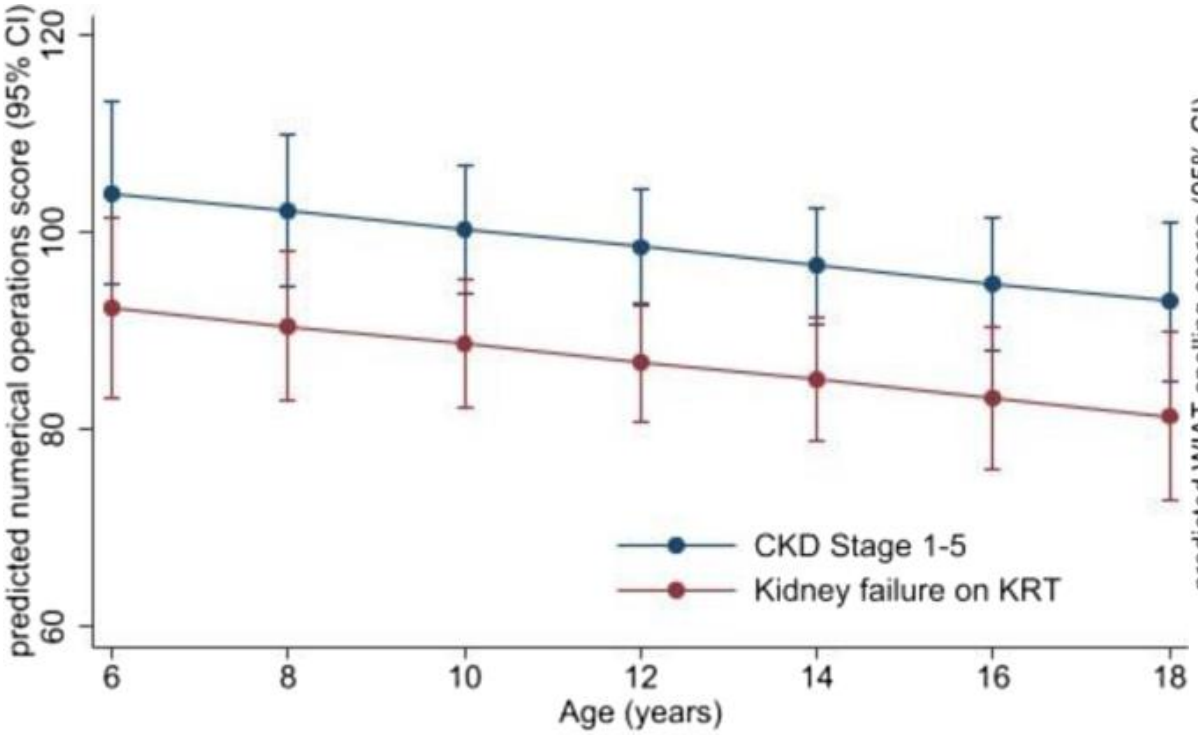
- School attendance is associated with both **social functioning and academic success**
- **Children with mild to moderate (eGFR 30-90) CKD have lower school attendance**
  - 17.3% of kids with CKD have chronic school absenteeism (>18 days of school in a year) compared to 2.7% in the general population, RR 6.2
  - Boys experienced less chronic absenteeism than girls (RR 0.65, 95% CI 0.46-0.91)
- Reasons given: doctors appointments (69%), feeling sick (60%), bullying (19%)
- School attendance is likely even poorer for those with more advanced CKD and kidney failure
  - **No Aus/NZ data, and no data on eGFR <30**

Sources: Richardson, KL 'Chronic school absenteeism of children with CKD', Journal of Pediatrics, 2018 199: 267-271; Craven, S et al 'Patient- and caregiver-reported factors associated with school absenteeism in children with chronic kidney disease'. Pediatr Nephrol 38, 1591–1598 (2023). https://doi.org/10.1007/s00467-022-05780-2

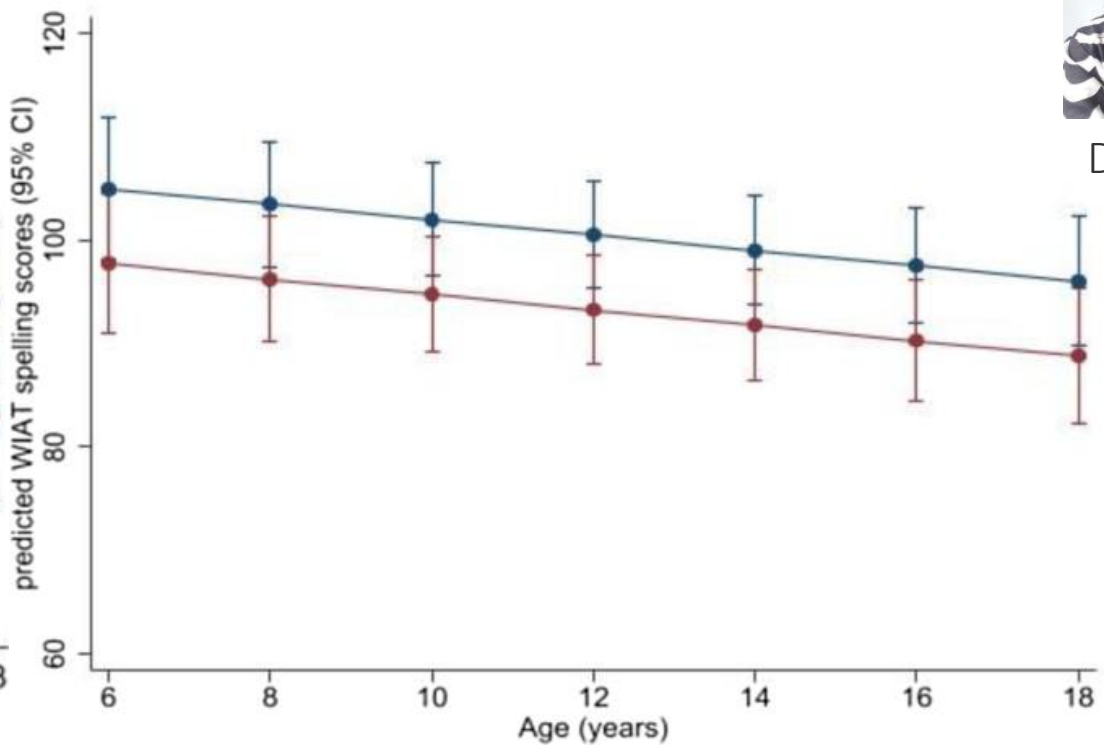
Children on kidney replacement therapy have lower academic performance

Dr Siah Kim

Numeracy



Spelling



Children treated with KRT have **low average cognitive abilities and lower academic performance** for numeracy and literacy compared to both children with CKD 1–5 and to the general population

Sources: Kim S, 'Cognitive and academic outcomes in children with chronic kidney disease', Pediatric Nephrology, (2022), 37: 2715-2724.

Children with kidney disease perform poorly in NAPLAN literacy and numeracy, especially in later school years.

Dr Anita Van Zwieten

Performance is below the NSW population across all domains

Domain	Grade 3	Grade 5	Grade 7	Grade 9
Reading	N=85	N=101	N=116	N=118
Mean (95% CI)	**-0.25 (-0.50 to 0.00)**	**-0.28 (-0.52 to -0.04)**	**-0.36 (-0.57 to -0.15)**	**-0.45 (-0.66 to -0.24)**
Writing*	N=64	N=75	N=93	N=114
Mean (95% CI)	**-0.31 (-0.61 to -0.00)**	**-0.13 (-0.35 to 0.09)**	**-0.26 (-0.50 to -0.02)**	**-0.42 (-0.64 to -0.19)**
Spelling	N=86	N=103	N=118	N=121
Mean (95% CI)	**-0.27 (-0.53 to -0.02)**	**-0.24 (-0.47 to -0.00)**	**-0.33 (-0.55 to -0.11)**	**-0.40 (-0.60 to -0.19)**
Grammar/Punct.	N=86	N=103	N=118	N=121
Mean (95% CI)	**-0.39 (-0.67 to -0.11)**	**-0.35 (-0.61 to -0.10)**	**-0.22 (-0.45 to 0.01)**	**-0.48 (-0.72 to -0.24)**
Numeracy	N=84	N=101	N=114	N=120
Mean (95% CI)	**-0.23 (-0.48 to 0.01)**	**-0.32 (-0.55 to -0.10)**	**-0.27 (-0.48 to -0.07)**	**-0.37 (-0.56 to -0.18)**

Effect size	ACARA guidance
-0.2 to 0	Close to
-0.2 to -0.5	Below
<-0.5	Substantially below

Sources: van Zwieten et al, 'Academic achievement among children with CKD in NAPLAN, Nephrology, 2022: 27,pp 24

The French cohort of paediatric kidney transplant recipients showed long term poor educational outcomes in adulthood

	Observed, n (%)	Expected, n (%)	SIR	*P*
Highest degree (n=308)				
None	63 (20.5)	38 (12.3)	1.66	<0.01
Primary school certificate[a] or secondary education general certificate[b]	23 (7.5)	17 (5.7)	1.32	0.23
Vocational training certificate	62 (20.1)	62 (20.1)	1	0.97
Professional or technical baccalaureate[c]	66 (21.4)	68 (22.2)	0.96	0.81
Second-year university degree	51 (16.6)	56 (18.2)	0.91	0.54
≥3-year university degree	43 (14.0)	66 (21.6)	0.65	<0.01
≥Baccalaureate[c]	160 (51.9)	191 (62.1)	0.84	0.03
Men (n=161)	93 (57.8)	93 (57.7)	1	0.97
Women (n=147)	67 (45.6)	98 (66.8)	0.68	<0.01

Sources: Mellerio, H et al. 'Adult Social and Professional Outcomes of Pediatric Renal Transplant Recipients', Transplantation, 2014 97(2): 196-205

The French cohort of paediatric kidney transplant recipients showed long term poor educational outcomes in adulthood… which translated to poorer professional outcomes

	Observed, n (%)	Expected, n (%)	SIR	*P*
Professional outcomes (students excluded)				
Unemployment (n=325)	60 (18.5)	34 (10.4)	1.77	<0.01
Employment contract (n=199)				
Apprenticeship contract	14 (7.0)	6 (3.1)	2.3	<0.01
Interim	10 (5.0)	6 (3.2)	1.59	0.21
Fixed-term contract	42 (21.1)	23 (11.8)	1.79	<0.01
Permanent contract	133 (66.8)	163 (81.8)	0.82	0.02
Half-time contract (n=184)	42 (22.8)	31 (16.7)	1.37	0.05

Half of the participants (47.6%) declared that they had suffered from discrimination (vs. 6.2%; *P*<0.01), mostly at school (60.8%) but also from employers (27.8%), work colleagues (19.9%), friends (19.3%), or family (15.3%).

Sources: Mellerio, H et al. 'Adult Social and Professional Outcomes of Pediatric Renal Transplant Recipients', Transplantation, 2014 97(2): 196-205

Poorer professional outcomes in those with childhood kidney failure

Table II. Familial life, education, and professional outcomes of the LERIC cohort in 2010 compared with the age-matched Dutch general population in 2010 (CBS)*

	All patients (N = 80), % (95% CI)	Patients with a functioning transplant (N = 67), % (95% CI)	Patients on dialysis (N = 13), % (95% CI)	General Dutch population, 30-50 y* (N = 4 765 844)
Educational attainment				
Primary school and low level	28.8 (19.2-40.0)	26.9 (16.8-39.1)	38.5 (13.9-68.4)	25.6
Intermediate level	48.8 (37.4-60.2)	50.7 (38.2-63.2)	38.5 (13.9-68.4)	42.6
High level	22.5 (13.9-33.2)	22.4 (13.1-34.2)	23.1 (5.0-53.8)	31.9
Professional outcomes				
Employed‡	62.5 (51.0-73.1)†	68.7 (56.2-79.4)†	30.8 (9.0-61.4)†	81.0
Medically rejected	36.3 (25.8-47.8)	34.3 (23.2-46.9)	46.2 (19.2-74.9)	NS
If currently employed				
≥50% FTE	82.0 (68.6-91.4)	82.2 (68.0-92.0)	100	NS
Income ≥ €2500/mo§	54.0 (39.3-68.2)	57.8 (42.1-72.3)	25.0 (0.6-80.6)	66.2
Employment contract				
Permanent contract	77.6 (63.4-88.2)	80.0 (65.4-90.4)	50.0 (6.8-93.2)	74.9
Interim/fixed term	12.2 (4.6-24.8)	11.1 (3.7-24.1)	25.0 (0.6-80.6)	10.1
Own enterprise	10.2 (3.4-22.2)	8.9 (2.5-21.2)	25.0 (0.6-80.6)	15.0
Unpaid work	8.8 (3.6-17.2)†	10.4 (4.3-20.3)†	0†	24.5
Social benefits	23.8 (14.9-34.6)†	19.4 (10.8-30.9)	46.2 (19.2-74.9)†	13.0

Sources: Tjaden, LA 'Impact of Renal Replacement Therapy in Childhood on Long-Term Socioprofessional Outcomes: A 30-year Follow-Up Study', Journal of Pediatrics,

Inability to fully participate in education and work has lifelong consequences

- *"**I missed out on a proper education. I feel like I've missed 3 years of my life**, I feel like a 17-year-old stuck in a 19-year-old body."*
  - Male aged 18-21 yrs

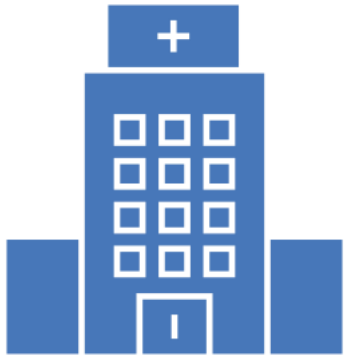
- *"I feel like **I'm dependent on either the government or my dad or even my fiancé sometimes, because I don't have the same education**. I don't have a degree in order for me to get a good job"*
  - Female, Age 22–25

Professor Allison Jaure

- *"I'm juggling school, it's just a big juggling act at the moment. And even then, **I'm still struggling cause sometimes I can't make it to school. Not because of my mental state. Just because I'm so tired.**"*
  - Male aged 18-21 yrs

Sources: Kerklaan, J 'Perspectives on life participation by young adults with CKD: an interview study', BMJ Open, 2020; 10(10): e037840.

Lifelong impact of kidney disease in childhood



Health

Social relationships

Educational
& employment

Financial

Quality of life

Those with childhood kidney failure had significantly lower income

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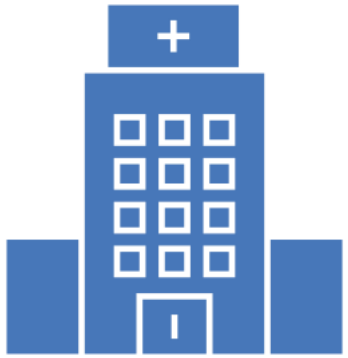
Lifelong impact of kidney disease in childhood



Health

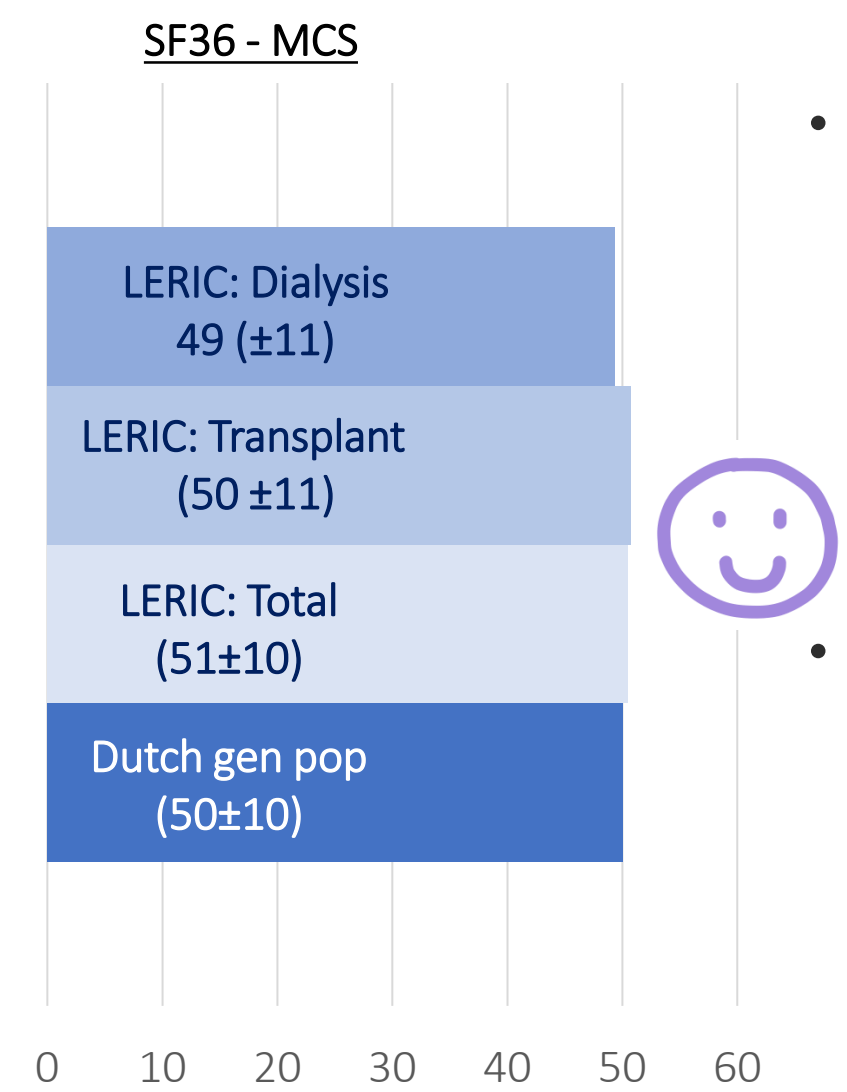
Social relationships

Educational
& employment

Financial

Quality of life

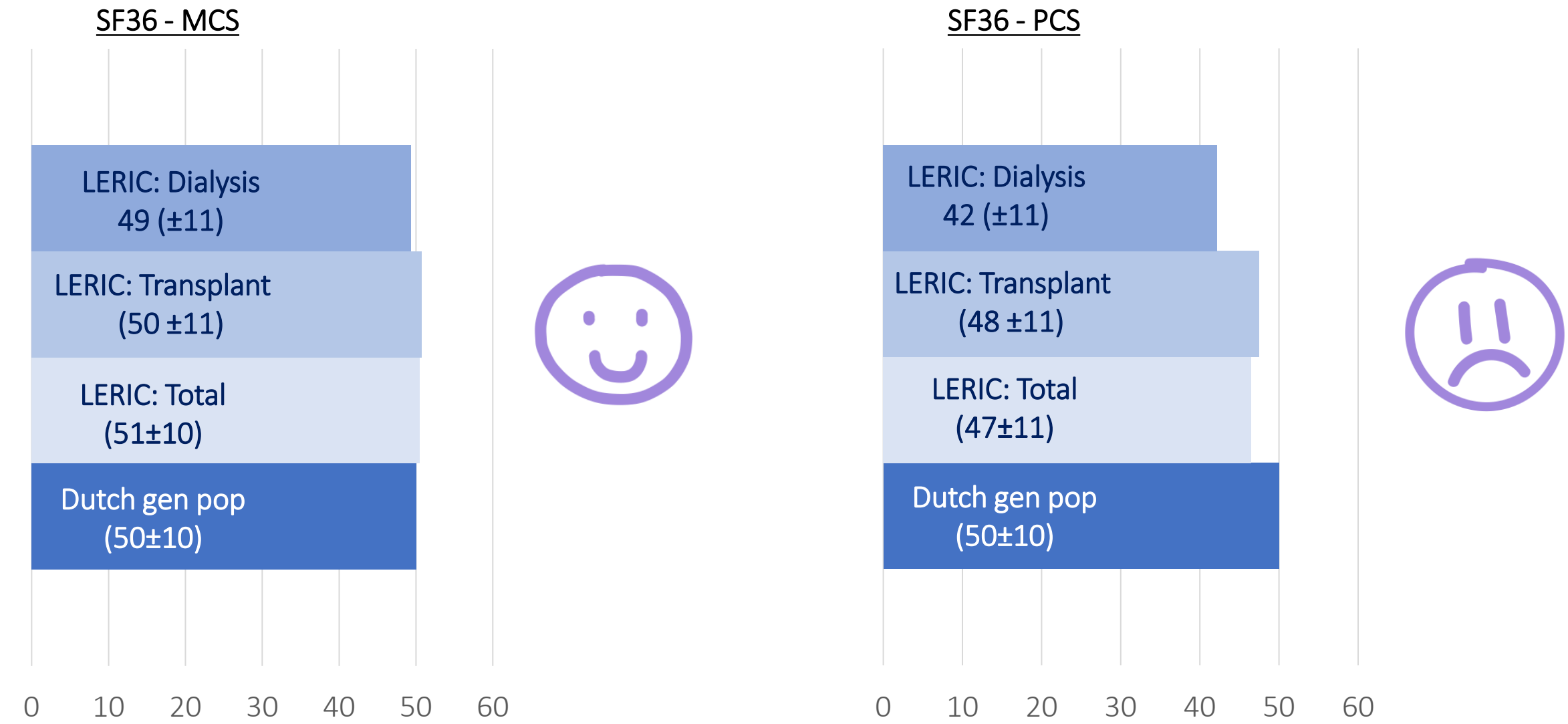
Middle-aged survivors of paediatric kidney failure have a good mental QoL even after 20-40 years of KRT



- Mental QoL scores in middle aged survivors of kidney failure were similar to gen pop
  - Authors hypothesised that this may be due to their ~life-long chronic disease status, and no recollection of life without kidney disease
- Nearly 75% of patients said their disease had brought them something positive in life. The perceived benefits of having kidney failure included more satisfaction with (small things in) life, and having developed a sense of perseverance.

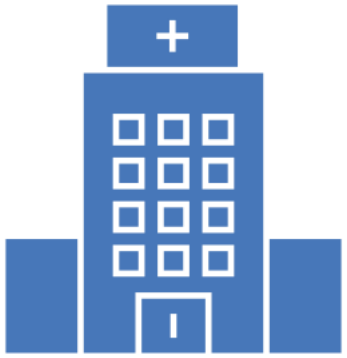
Sources: Tjaden, LA 'Long term Quality of Life and Social Outcome of Childhood End Stage Renal Disease', The Journal of Pediatrics, 2014 165(2): 336-342

Physical QoL faired more poorly, particularly for dialysis patients



Sources: Tjaden, LA 'Long term Quality of Life and Social Outcome of Childhood End Stage Renal Disease', The Journal of Pediatrics, 2014 165(2): 336-342

The lifelong impacts of childhood kidney disease are profound



Health

Social relationships

Educational
& employment

Financial

Physical
Quality of life

Transition is the nexus between childhood kidney disease and lifetime impact

Dr Angus Ritchie

- Transitioning from paediatric to adult services is an extremely high risk period for all patients with chronic illness
- Increased risk-taking behaviour and nonadherence in adolescents and young adults kidney failure -> poor outcomes
- The highest rates of KTx loss occur in patients aged 16–21 years
  - This holds across sexes, ethnicities, primary kidney disease, transplant donor type etc
- Graft failure in this age group is particularly disabling as it occurs when students are finishing high school, attending TAFE or Uni, entering the workforce and/or living independently for the first time.

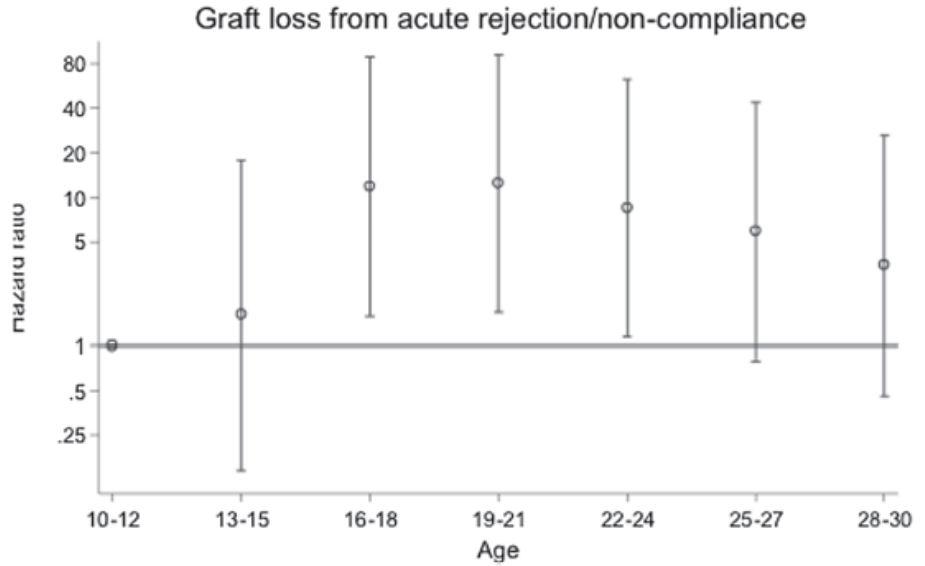


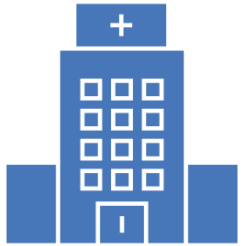
Fig. 2 Age-specific adjusted hazard ratios (with 95% confidence intervals) for graft loss due to late acute rejection or non-compliance.

Sources Matsuda-Abedini, M et al 'Transition of young adult kidney transplant recipients, Pediatric Nephrology, 2023 38: 383-390; Ritchie, A et all, 'Age specific graft loss from late acute rejection or non-compliance in the adolescent and young adult period. Nephrology, 2018 23: 585-591.

Transition is the nexus between childhood kidney disease and lifetime impact

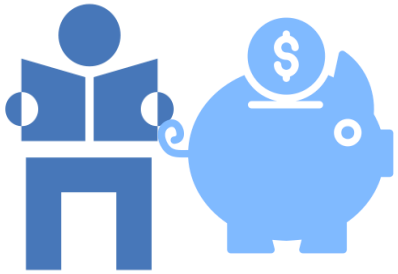
- Structured multi-disciplinary transition programmes may lead to improved outcomes but evidence is poor
- The transition from paediatric to adult care is often poorly organised and transition clinics are typically under resourced, particularly with key allied health
- Patients can slip through the cracks due to differences in models of care
- We need more research into what best in class transition programs look like, what interventions may be most efficacious, and the cost-effectiveness of these

What can we do?



Optimise medical care including investment into transition programs

Research the impact of childhood CKD on lifetime (adult) social functioning in an Australian context
Psychosocial support throughout childhood and adolescence
Awareness and advocacy to reduce stigma



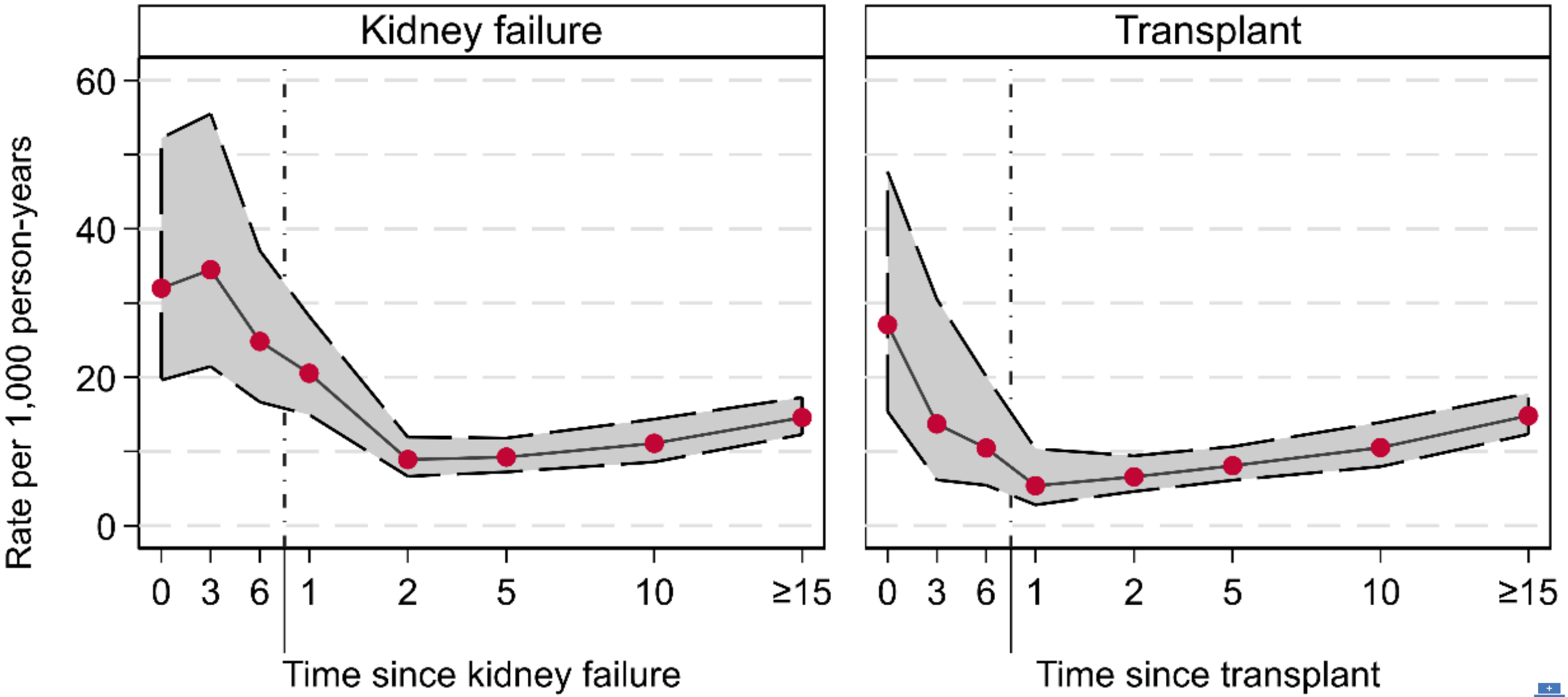
Research the impact of childhood CKD on lifetime educational, career and financial outcomes in an Australian context
Provide educational support

WESTMEAD HOSPITAL

THE UNIVERSITY OF SYDNEY

Thank you

Mortality rates were highest early on



Study strengths

- Long follow-up of >40 years & >30,000 person years
- Linkage with national death registries
- Inclusion of all paediatric kidney failure patients regardless of treatment type
- Patients modelled over their lifetime which includes periods of dialysis, transplant and re-transplant(s) - better reflecting the lived experience of paediatric patients with kidney failure
- Determining life years lost from developing kidney failure in childhood

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Dr Nicole De La Mata
A/Prof Patrick Kelly
Dr Philip Masson

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Dr Philip Clayton

University of Edinburgh
Dr Rustam Al-Shahi Salman

Australian Government
Australian Institute of Health and Welfare

Kidney Health Australia

MINISTRY OF HEALTH
MANATŪ HAUORA

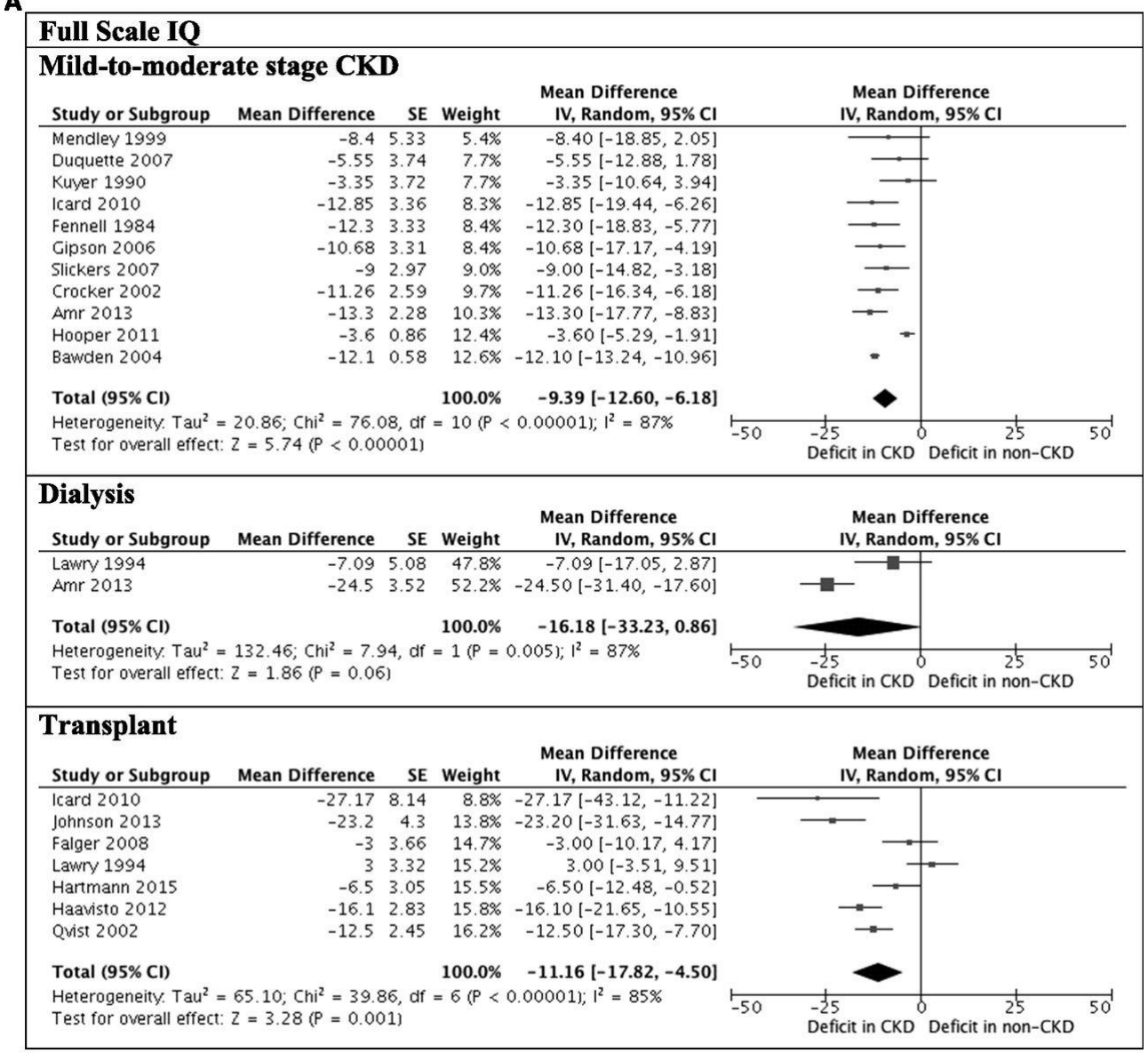
ANZ DATA
AUSTRALIA & NEW ZEALAND
DIALYSIS & TRANSPLANT REGISTRY

THE UNIVERSITY OF SYDNEY

Centre for Organ Donation Evidence

Systematic review

A

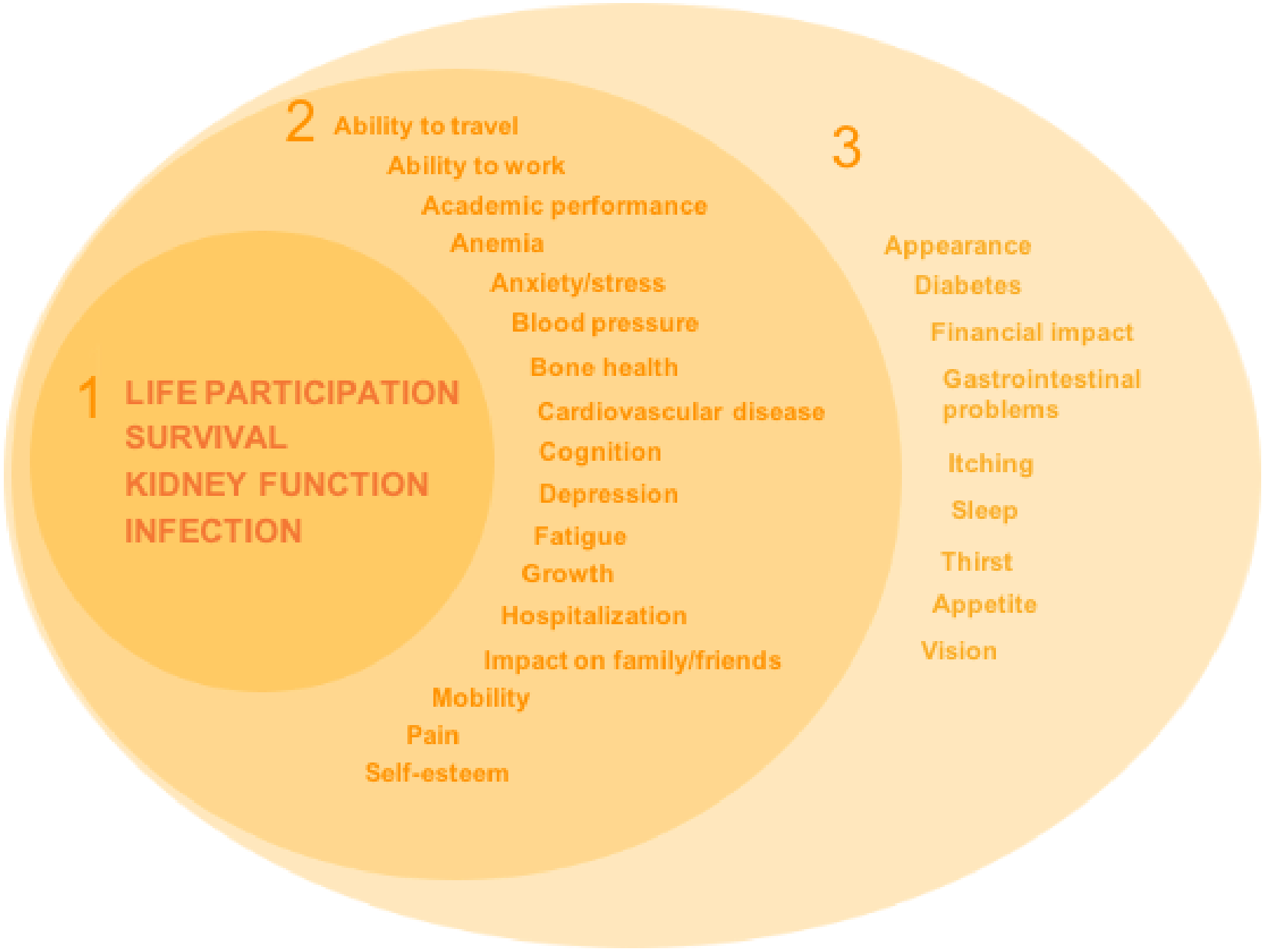


*SE: standard error; IV: inverse variance

Chen K et.al. CJASN 2018

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