

# North-West Kidney Network project

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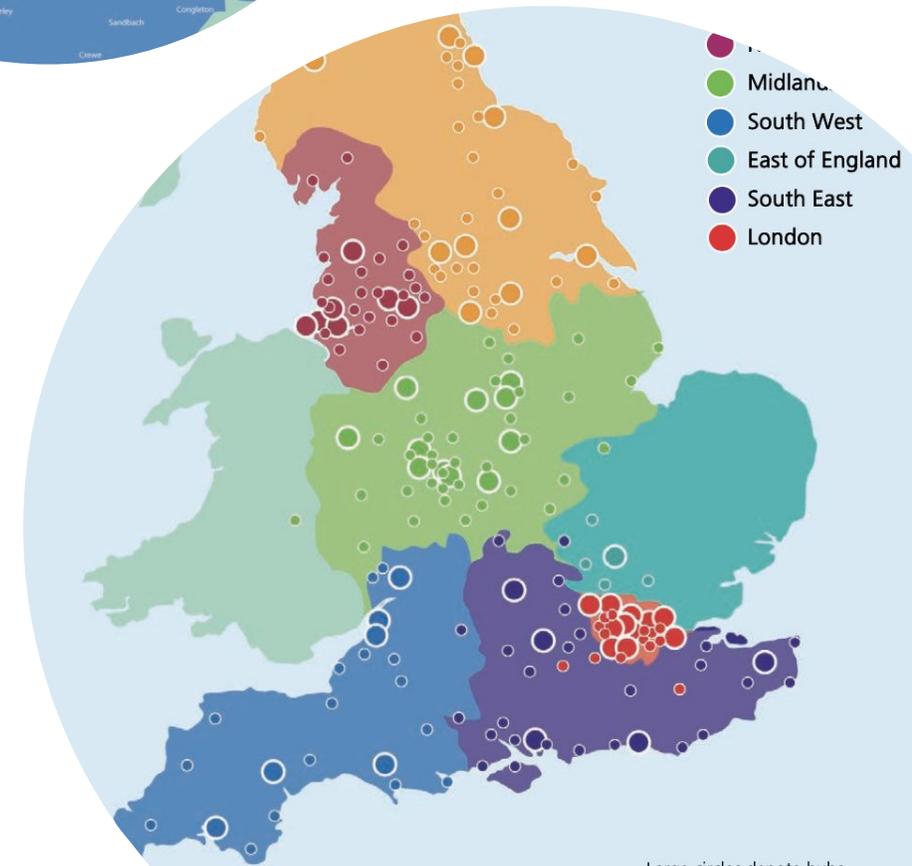
# Overview

- Paediatric nephrology services and NWKN
- Child health profiles for the northwest
- Outcomes in pupils with CKD
- Educating the educators of pupils with CKD



# North-West Kidney Network

- NWKN hosted by NHSE North-West Specialized Commissioning (2020-21)
- The Renal Medicine Getting It Right First Time (GIRFT) report found evidence of unwanted and widespread variation in key patient outcomes (and processes) across centres and modalities of kidney care



## Child health profiles NW

- High rates of child poverty
- High rates of hospital admissions and injuries
- High rates of obesity
- High rates of pupils with social, emotional and mental health needs
- Life expectancy (2018-20) boys 77.9 (79.4) and girls 81.7 (83.1)

**NOW ADD KIDNEY DISEASE...**



## Educational Outcomes

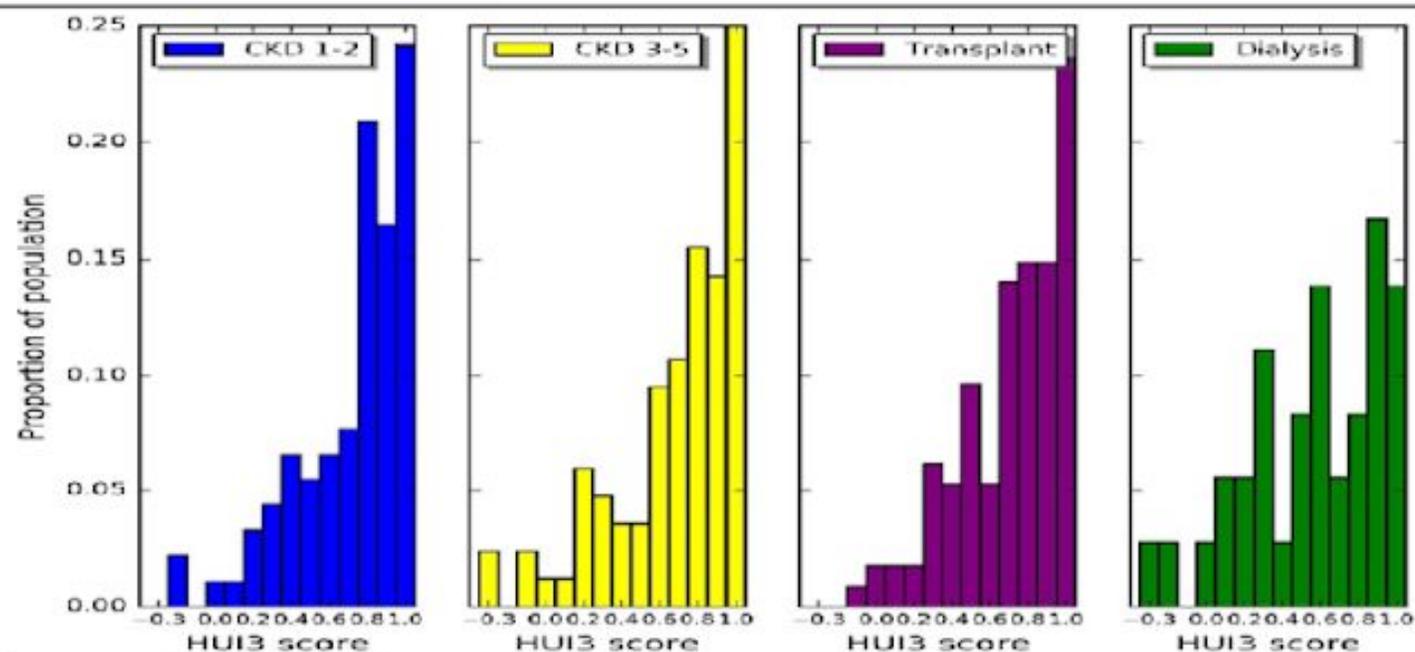
- Academic underachievement
- Low-average cognition (executive function, memory & attention)
- Poor school attendance
- Lower rates in sport participation
- Higher rates of specialised support needs



## Social and emotional outcomes

- Emotional distress
- Delayed independence
- Struggle with daily restrictions (symptoms, SE, activity, school/work, medicalised life)
- Body image and self-esteem issues
- Social isolation
- Disruption of family life
- Reorientation of plans/goals, little stability

**A** Distribution of quality of life score by stage of chronic kidney disease



**B** Summary QoL scores<sup>1</sup>

	CKD 1-2 n=106	CKD 3-5 n=91	Transplant n=135	Dialysis n=43
Median [IQR <sup>2</sup> ]	0.88 [0.63-0.96]	0.85 [0.60-0.98]	0.83 [0.59-0.97]	0.67 [0.39-0.92]
Mean (SD <sup>3</sup> )	0.76 (0.27)	0.72 (0.32)	0.76 (0.25)	0.61 (0.34)
p value <sup>4</sup>		0.28	0.30	0.01

<sup>1</sup>=50 missing data, <sup>2</sup>= interquartile range, <sup>3</sup>= standard deviation, <sup>4</sup>= compared to CKD 1-2 by Mann-Whitney *U* test

**Figure 1** Quality of life in children with chronic kidney disease. CKD, chronic kidney disease; HUI3, Health Utilities Index 3; QoL, quality of life.

# Chronic dialysis in children and adolescents: challenges and outcomes

Prof Lesley Rees, MD   • Prof Franz Schaefer, MD • Claus Peter Schmitt, MD • Rukshana Shroff, PhD • Prof Bradley A Warady, MD

- Long term CKD beginning in infancy had **delayed autonomy**, prolonged infantilization, **delayed social and psycho-sexual development**
- **More likely to live at home** in adolescence/early adulthood
- 68% had educational level similar to parents
- **UK**, Holland and Germany data showed **unemployment rates** for individuals who started RRT in Infancy to be **17%**, 20% and 14% respectively – **comparable to age matched controls.**

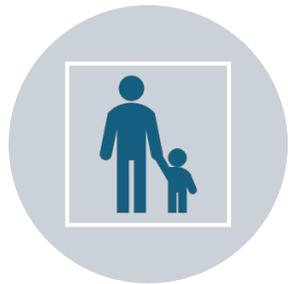
# Long term outcomes



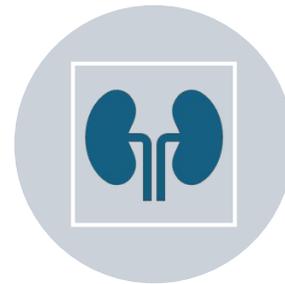
Employment difficulties (~58% employed, 20% not)



Barriers to higher education



Lower socioeconomic status in a child's family is strongly associated with poorer academic performance, which in turn affects future health and socioeconomic attainment.

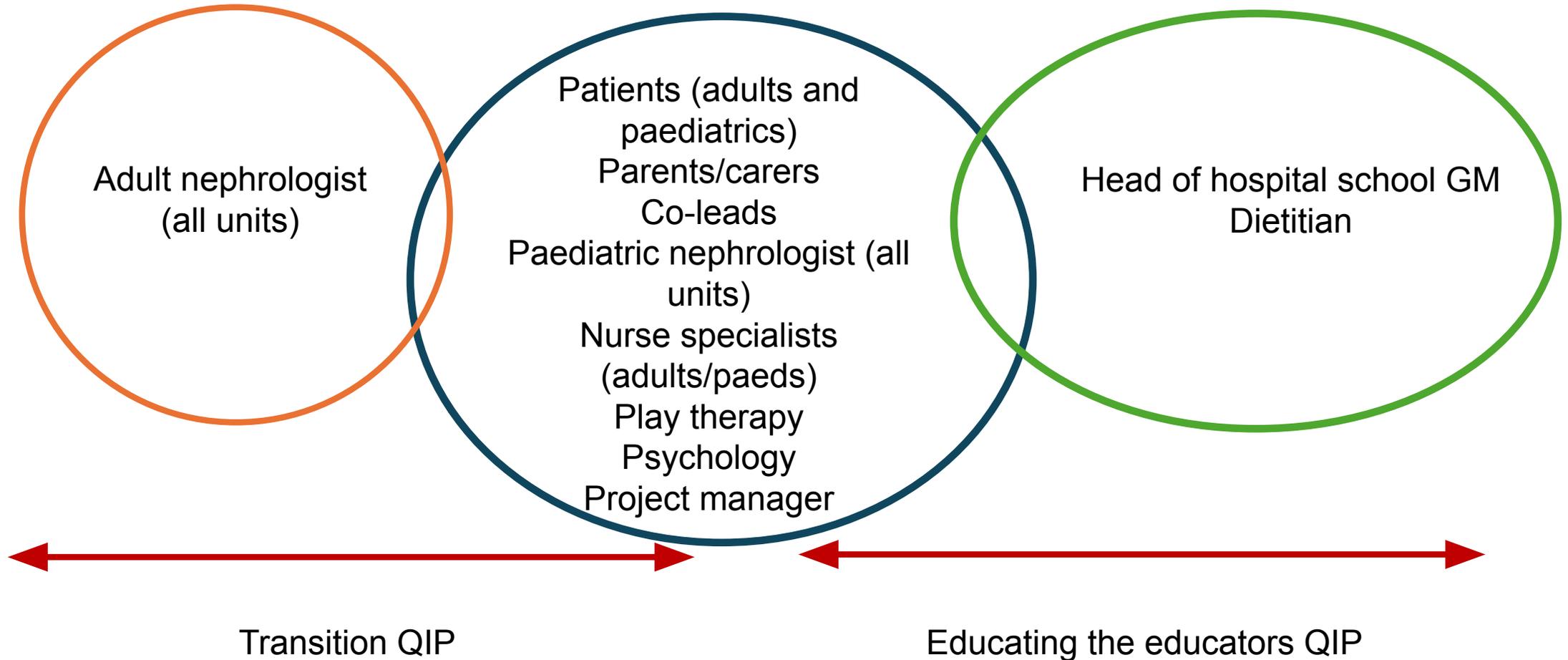


Individuals with lower education are more likely to experience complications, such as lower transplant graft survival

## Paediatric workstream (2023/2024)

- Brainstorm with co-leads (adult and paediatric nephrologist)
- 4 projects...
- Regional transition policy
- Educating the educators

# Working/focus groups



# Educating the educators of pupils with CKD

- Visual educational resources aimed at teachers & assistants in high school
- Key stages 3 & 4 (11-16 years)
- Public face of NWKN website, not hospital specific
- Simple registration
- Pre and post 'short' survey to assess prior knowledge/helpful resource
- Short videos < 10 minutes each
- Statutory guidance about the support that pupils with medical conditions should receive at school ([DOE.gov.uk](http://DOE.gov.uk))



## Our Work

### Chronic Kidney Disease (CKD)

- CKD CORE Kidney Project (Cheshire and Mersey ICB)
- CKD SPAN Project (Lancashire and South Cumbria ICB)
- CKD DREAM Project (Greater Manchester ICB)

### Acute Kidney Injury Network (AKI)

- Acute Kidney Injury - Think Fluids24

### Transplant

### Dialysis

### Workforce and Capacity

### Renal Nurse Education

### Incentre Haemodialysis Self-Travel Reimbursement

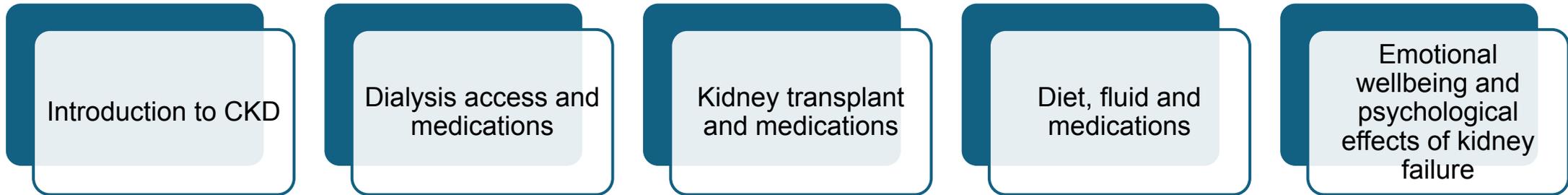
### Renal Genomics

### Paediatric and Transition Pathway

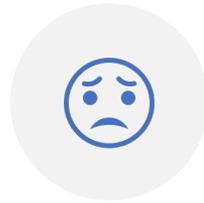
- Educational Videos for Schools

### Enhanced Supportive Kidney Care

# Educating the educators: Topics of 5 videos



# Example of dialysis video content : affect on learning



EXTREME TIREDNESS,  
POOR  
CONCENTRATION



RECOVERY TIME  
AFTER EACH SESSION



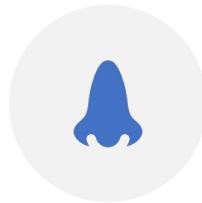
FISTULA/LINE  
AFFECTING  
DOMINANT ARM



IMPACT ON PHYSICAL  
LESSONS



OVERNIGHT DIALYSIS,  
DISTURBED  
SLEEP/ALARMS



PUNCTUALITY IN THE  
MORNINGS



UNPREDICTABILITY  
OF EXTRA  
SESSIONS/HOSPITAL  
VISITS

## Example of dialysis video content : next steps

- Completion of pupil's individual health care plan
- Identify where adaptations to curriculum may need to be made
- Consideration of type of dialysis access they have
- Current level of sleep
- Understanding of school attendance/punctuality
- Comfortable environment lessons/break



## Story so far...

- Went live early summer 2025
- 91 responses completed
- 29/91 viewed by school staff
- 49/91 based in NW
- Rate learning of CKD
  - 42% average
  - 31% very good
  - 21% excellent

# Next steps...

- Continue to raise awareness of resource
- Act on feedback
- Update contents as guidance changes
- Improve functionality and visual enjoyment of future versions

**Thank you for listening  
and  
teaching our children  
whilst they are having dialysis!**