The UK Kidney Ecosystem

The LifeArc-KRUK Centre for Rare Kidney Diseases

EMEESY meeting, Oct 2026

Professor Louise Oni

Professor in Paediatric Nephrology & Honorary consultant paediatric nephrologist

UCL Centre for Kidney and Bladder Health

Dept of Women's & Children's Health, University of Liverpool

Great Ormond Street Hospital, London

LifeArc Centre

Rare Kidney Diseases

In partnership with

Kidney Research UK

FIAT LUX

UCL

Centre for Kidney & Bladder Health

Aims of session

The healthcare crisis

What is ‘The UK Kidney Ecosystem’?

Why is this important?

How will it affect me & my patients?

A health care crisis



NHS Clinical teams → Manage crisis

NHS clinical academics

University academics → Improve the future



UNIVERSITY OF OXFORD

RECOVERY

GLOBAL CUMULATIVE TOTALS

48690 Participants

187 Active sites

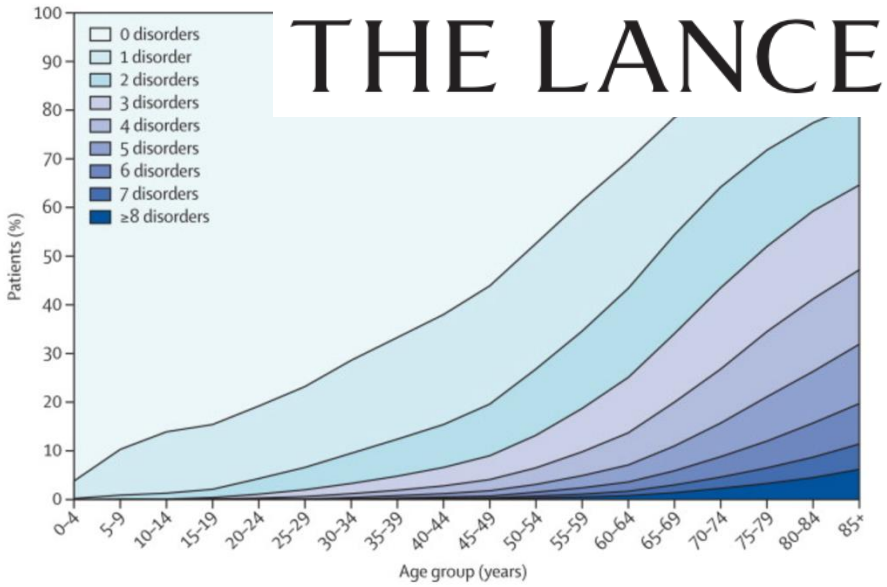
Complex systems, few people = challenging to bring change

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‘Rare’ diseases drive the crisis



THE LANCET

Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study

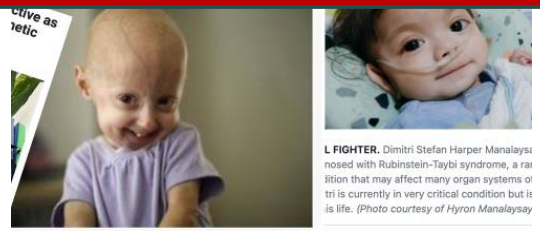
Karen Barnett, Stewart W Mercer, Michael Norbury, Graham Watt, Sally Wyke, Bruce Guthrie

Complex multi-morbidity

Article | Open access | Published: 05 May 2024

Novel therapeutic strategies for rare mutations in non-small cell lung cancer

Rare subtypes, non responders



L FIGHTER. Dimitri Stefan Harper Manalaysa
nosed with Rubinstein-Taybi syndrome, a ra
lition that may affect many organ systems o
tri is currently in very critical condition but i
is life. *(Photo courtesy of Hyron Manalaysay*

Medical Research Council | NIHR | National Institute for Health and Care Research

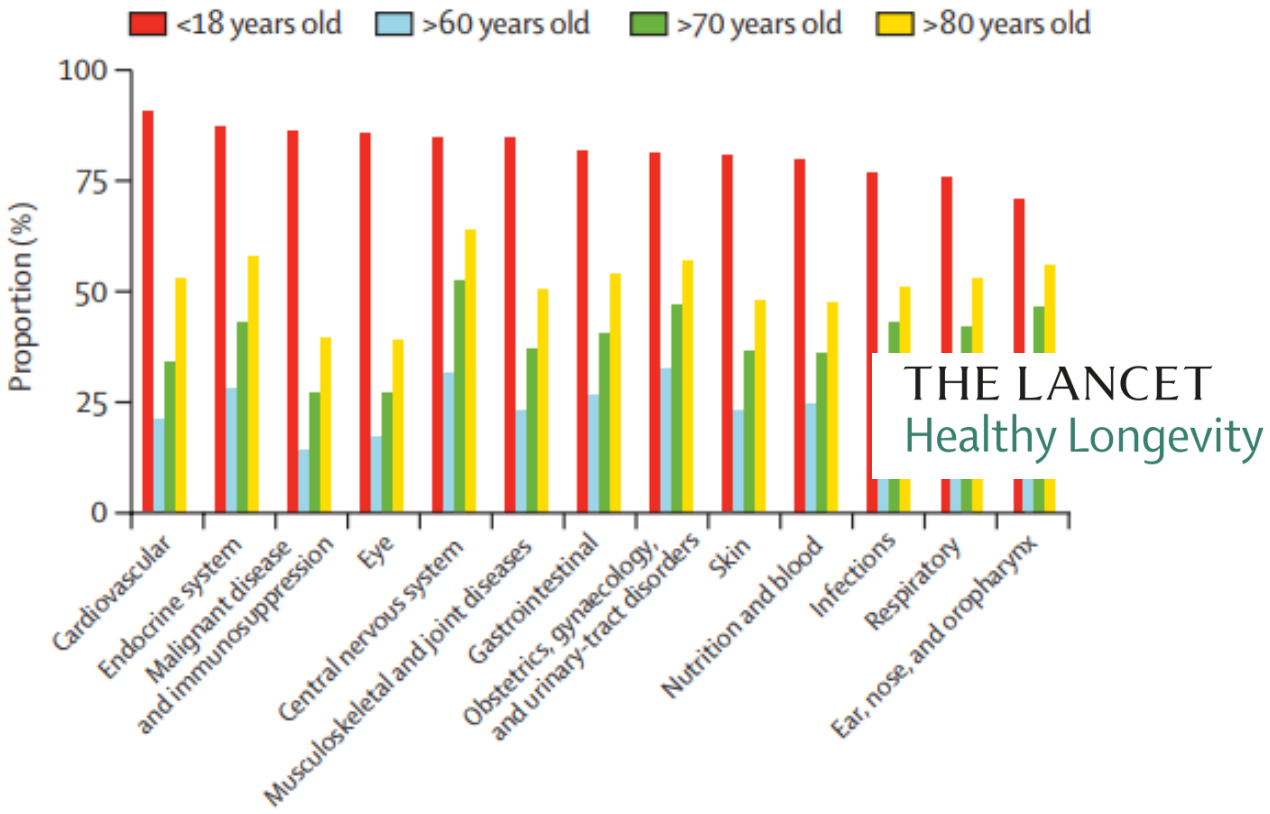
Rare Diseases Research Landscape Project Report

There are over 7,000 rare diseases. Around 95% of these lack an effective treatment. 75% of rare diseases affect children and more than 30% die before their 5th birthday*. There are an estimated 3.5 million people in the UK living with a rare disease.

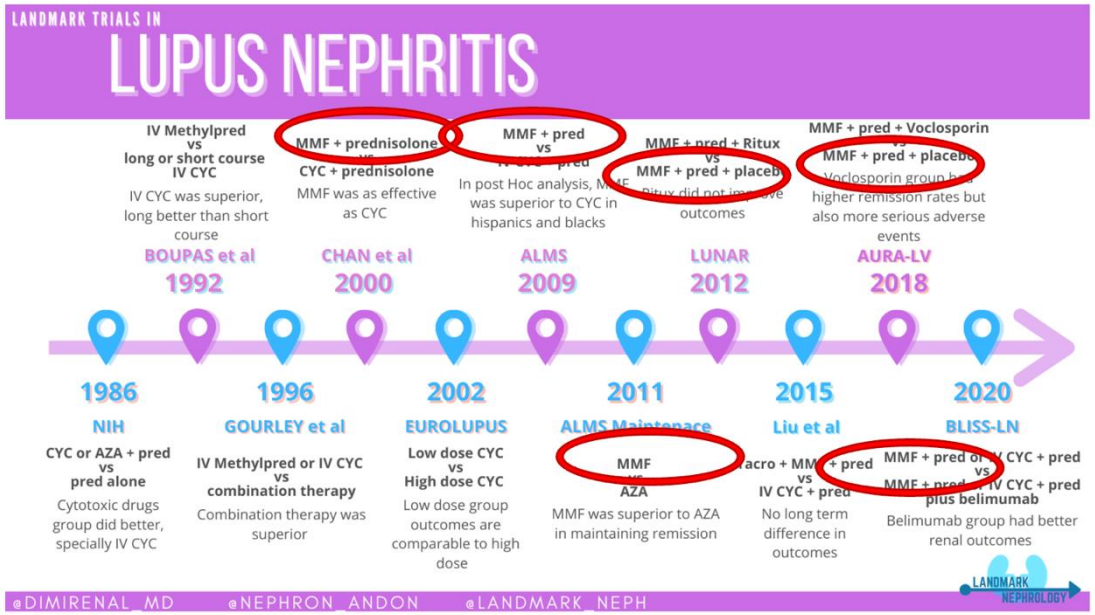
Primary rare diseases = young people

Research was not designed for ‘rare’

Exclusions



Inefficiencies



A unique opportunity for Nephrology

New £10.4M research centre will unlock new tests, treatments and cures for people living with rare kidney diseases

23 April 2024

Kidney Research UK

RaDaR
National Registry of Rare Kidney Diseases

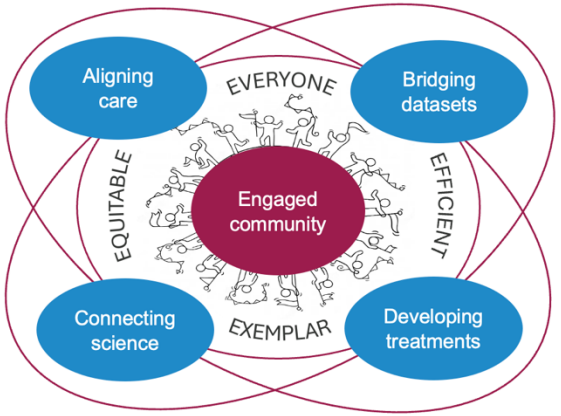
UK Kidney Ecosystem©

A translational, life course, rare kidney disease centre with research reimagined™

UKKA
UK Kidney Association

BAPN
British Association for Paediatric Nephrology

- Clinicians
- Scientists
- Small businesses
- Charity partners
- Industry
- Regulators



- Peer support
- Data scientists
- Academics
- Patient associations
- Universities
- Collaborators

A community united to stop kidney failure

Translational Rare Disease Centre (TRDC) Network

£40m investment

- Unblock the rare disease translational pipeline
- Scale translational expertise for rare disease
- Provide access to specialist expertise and Facilities.
- Leverage additional funding.

The RD research ecosystem



Centres:

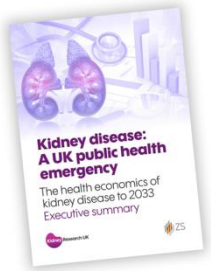
- Physical or virtual
- Challenge specific
- Build on existing landscape
- Synergise with MRC/NIHR Nodes and other funding initiatives.

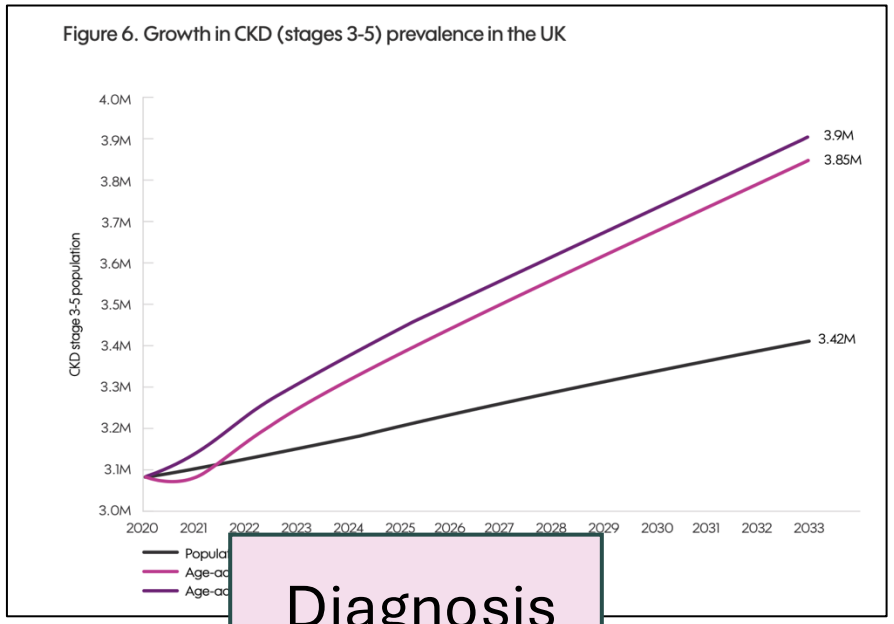
"Making research normal by 2030"

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A kidney failure crisis within 10 years





Diagnosis

Treatment

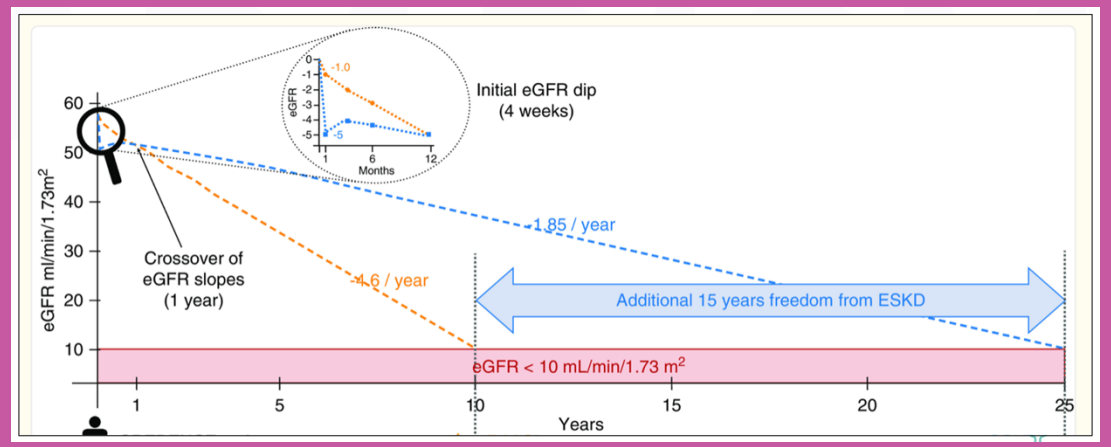
CKD

Kidney failure

Kidney transplant

Death

Common kidney disease = improved



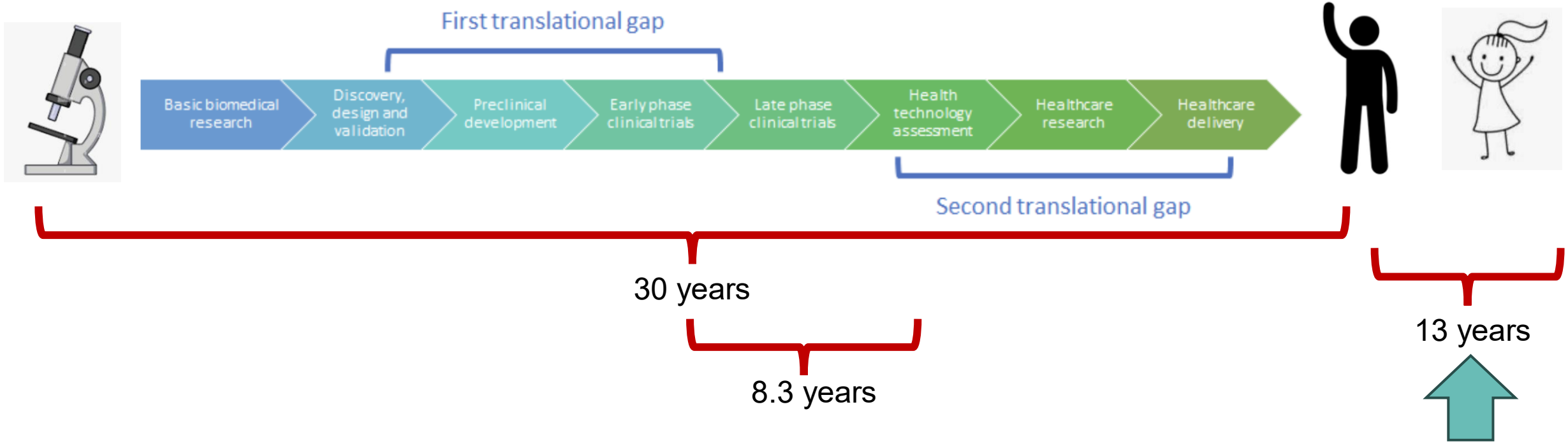
Rare kidney disease = no change

Age group (yrs)	2007-2011 N	2007-2011 pmarp	2012-2016 N	2012-2016 pmarp	2017-2021 N	2017-2021 pmarp
0-<2	94	12.0	118	15.0	93	12.6
2-<4	55	7.3	75	9.1	58	7.3
4-<8	89	6.4	119	7.5	90	5.5
8-<12	124	8.7	137	9.5	140	8.5
12-<16	217	14.2	181	12.7	181	11.8
<16 yrs	**579**	**9.8**	**630**	**10.4**	**562**	**8.9**

Rare Kidney

Children + Kidney = Ultra excluded

The translational pathway



PERSPECTIVE

Bridging the 13-Year Evidence Gap: A Time for Age-Inclusive Research

Oni, Louise[1,2]; Smith, Rona[3,4]; Salama, Alan D.[5]; Barratt, Jonathan[6]; Trachtman, Howard[7]; Saleem, Moin[8]

...a 13-year delay = 1,313 UK children reaching dialysis

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Co-designed transformation

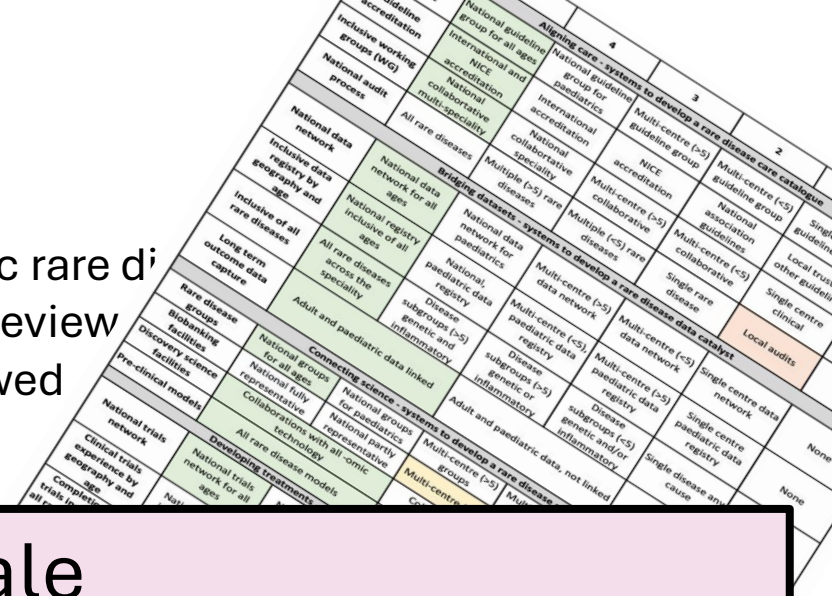
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RECOVERY

GLOBAL CUMULATIVE TOTALS

<u>Extensive scoping :</u>

- Deep understanding of paediatric rare di
- 9249 repurposing prescriptions review
- 232 papers systematically reviewed
- 104 meetings
- 68 questionnaires (52 patients)



<u>Rare disease change at scale</u>

Key themes: 1. systems & 2. people

<u>Strategic approach</u>: incremental, equitable, highly collaborative community

<u>Sustainability</u>: **Age-inclusive**

Research UK.

Renal Ciliopathies National Network - CILIAREN

Research UK.

Rare Early Onset Lower Urinary Tract Disorders - REOLUT

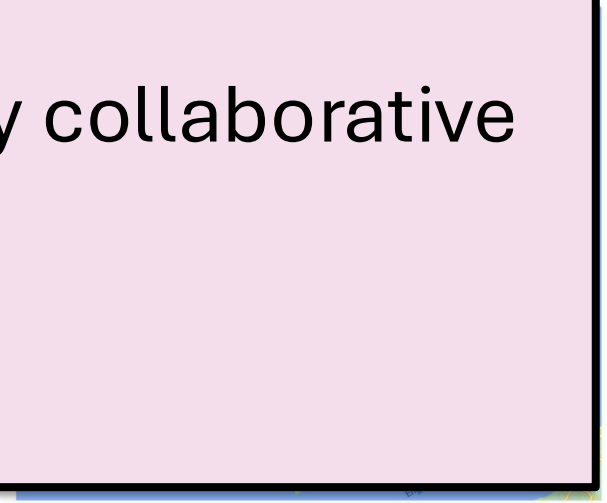


Fig 1: map of the UK showing the locations of the 13 BAPN sites.

Kidney Research UK

Unite people



NHS Clinical teams

NHS clinical academics

University clinical academics

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Unite systems

Kidney Research UK

LifeArc

Aligning care

UKKA UK Kidney Association Guidelines

Standard of care catalogue

Bridging datasets

RaDaR National Registry of Rare Kidney Diseases

Multi-purpose data catalyst

Connecting science

NURTURE National Unified Renal Translational Research Enterprise

Science accelerator pipeline

Developing treatments

Trial accelerator platform

Exemplar templates

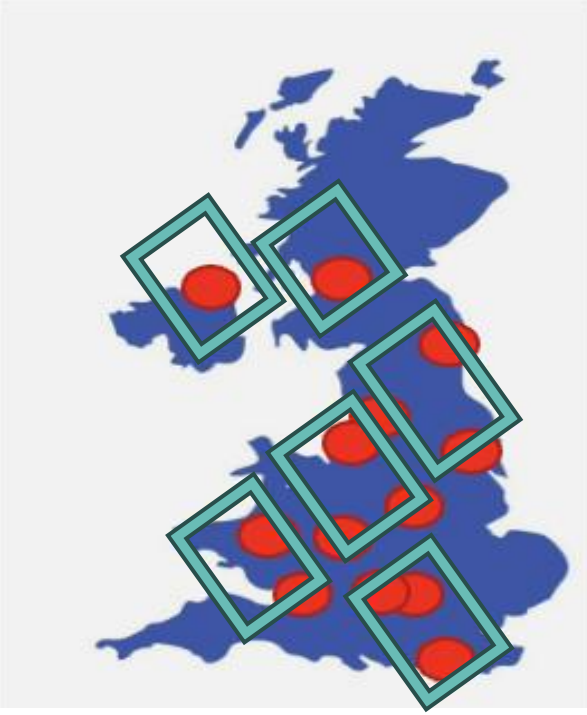
Prototype for replication

One goal – Stop kidney failure

‘Equitable national research delivery

for paediatric nephrology’

BAPN
British Association for Paediatric Nephrology



Data pipeline

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RaDaR — National Registry of Rare Kidney Diseases

University of BRISTOL

Health Economics and Decision Science

University of Sheffield

UCL

First translational gap

Basic biomedical research | Discovery, design and validation | Preclinical development | Early phase clinical trials | Late phase clinical trials | Health technology assessment | Healthcare research | Healthcare delivery

Second translational gap

NURTURE — National Unified Renal Translational Research Enterprise

UNIVERSITY OF LIVERPOOL

Newcastle University

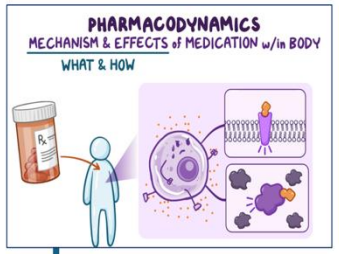
CBF — COMPUTATIONAL BIOLOGY FACILITY

Population Health Sciences Institute
Biostatistics Research Group

Science pipeline

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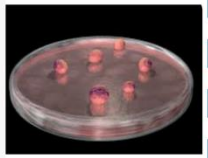


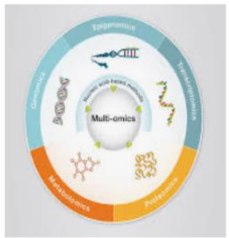
First translational gap

Basic biomedical research | Discovery, design and validation | Preclinical development | Early phase clinical trials | Late phase clinical trials | Health technology assessment | Healthcare research | Healthcare delivery

Second translational gap







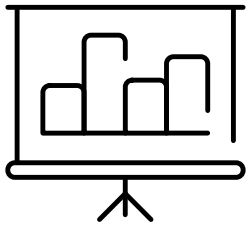
NURTURE — National Unified Renal Translational Research Enterprise

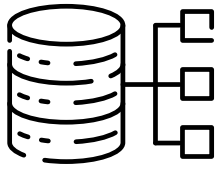
Incremental transformation

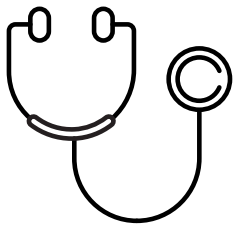
UCL Centre for Kidney & Bladder Health

Current phase 1: 2024-2029	*Future phase 2: 2026-2031*	*Future phase 3: 2027-2032*	*The vision: a global rare kidney ecosystem*
UK Kidney Ecosystem: Efficient systems for children	**UK Kidney Ecosystem: Efficient systems for adults**	**UK Rare Kidney MAMS Trial accelerator platform**	**Global linkage and efficiencies**







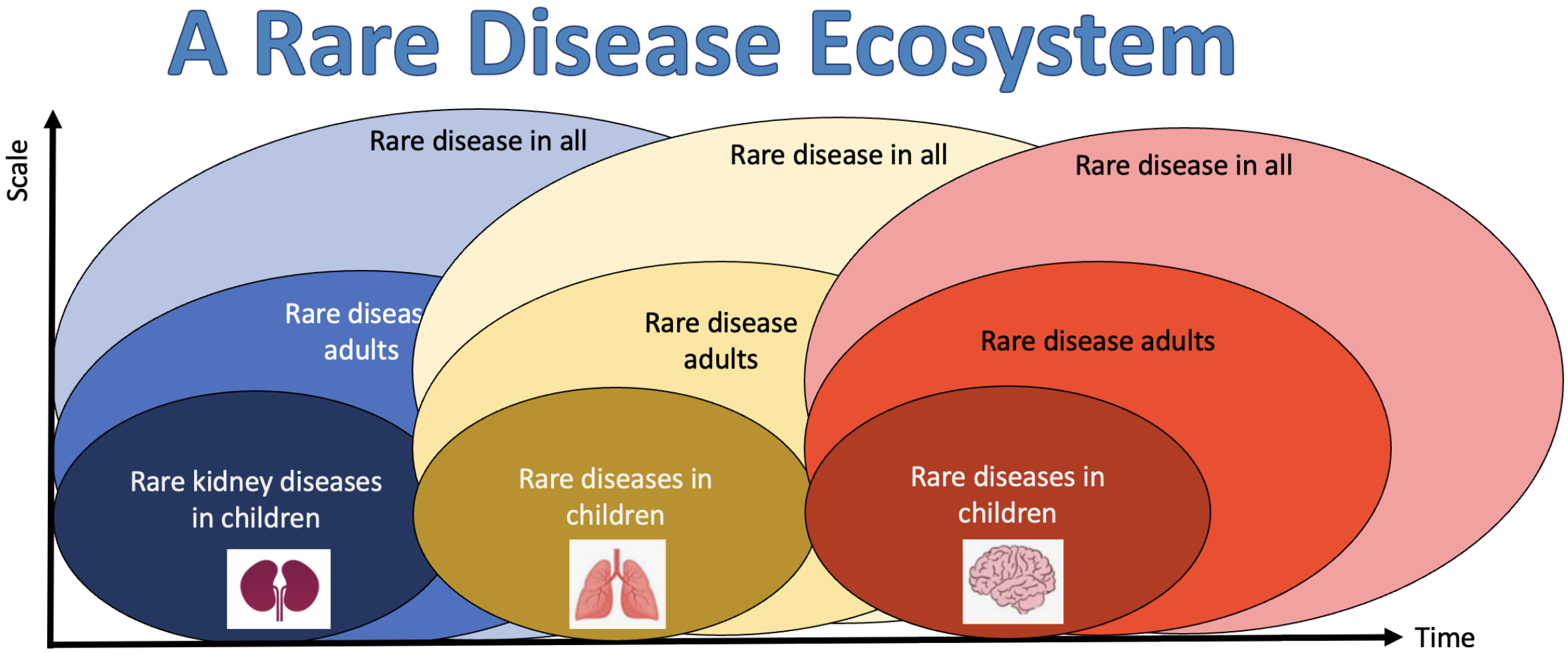


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The vision


A Rare Disease Ecosystem
Scale
Rare disease in all
Rare disease in all
Rare disease in all
Rare diseas
adults
Rare disease
adults
Rare disease adults
Rare kidney diseases
in children
Rare diseases in
children
Rare diseases in
children
Time

What does it mean for SPIN colleagues?

- Huge opportunity (for children) - needs everyone
- Getting an early diagnosis increasingly important
- Know your patients
- Connect patients to RaDaR – via BAPN or own site
- Be ‘research ready’ - aware of research in the network
- Keeping up to date with latest guidance
- Complex cases may need to be predominantly central

Acknowledgements

LifeArc Translational Centres for Rare Disease

Alder Hey Children's NHS Foundation Trust

Kidney Research UK

Experimental Arthritis Treatment Centre 4 Children

NHS Great Ormond Street Hospital for Children NHS Foundation Trust

UCL Centre for Kidney & Bladder Health