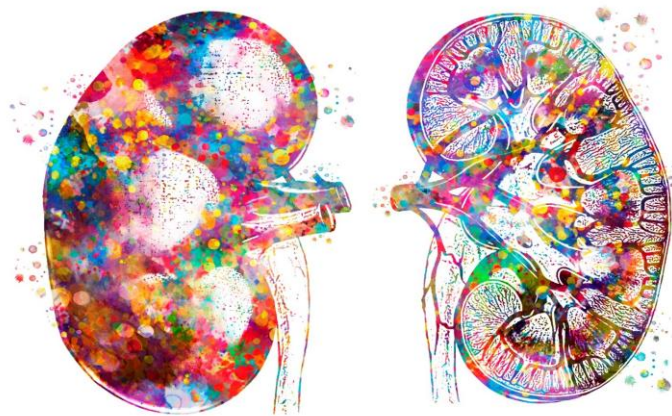


Using **data** to understand health inequalities in **early** kidney disease in Scotland



Audrey Hughes
PKD Charity
Patient Involvement and
Engagement Officer

KINDER study – Kidney Inequalities: Needs, Data, Experiences, Response

Audrey Hughes, Eilidh Cowan, Buse Keskindag,
Tom Blakeman, Magda Rzewuska Diaz, Simon Sawhney

Image Credit: © Valentyna Sokol



KINDER study – Kidney Inequalities:
Needs, Data, Experiences, Response

Statement of interest:

No interests to disclose

Overview



Where we are on
equity in Scotland



What we currently
measure in Scotland



What we did in
KINDER & why



What we found



KINDER study – Kidney Inequalities:
Needs, Data, Experiences, Response

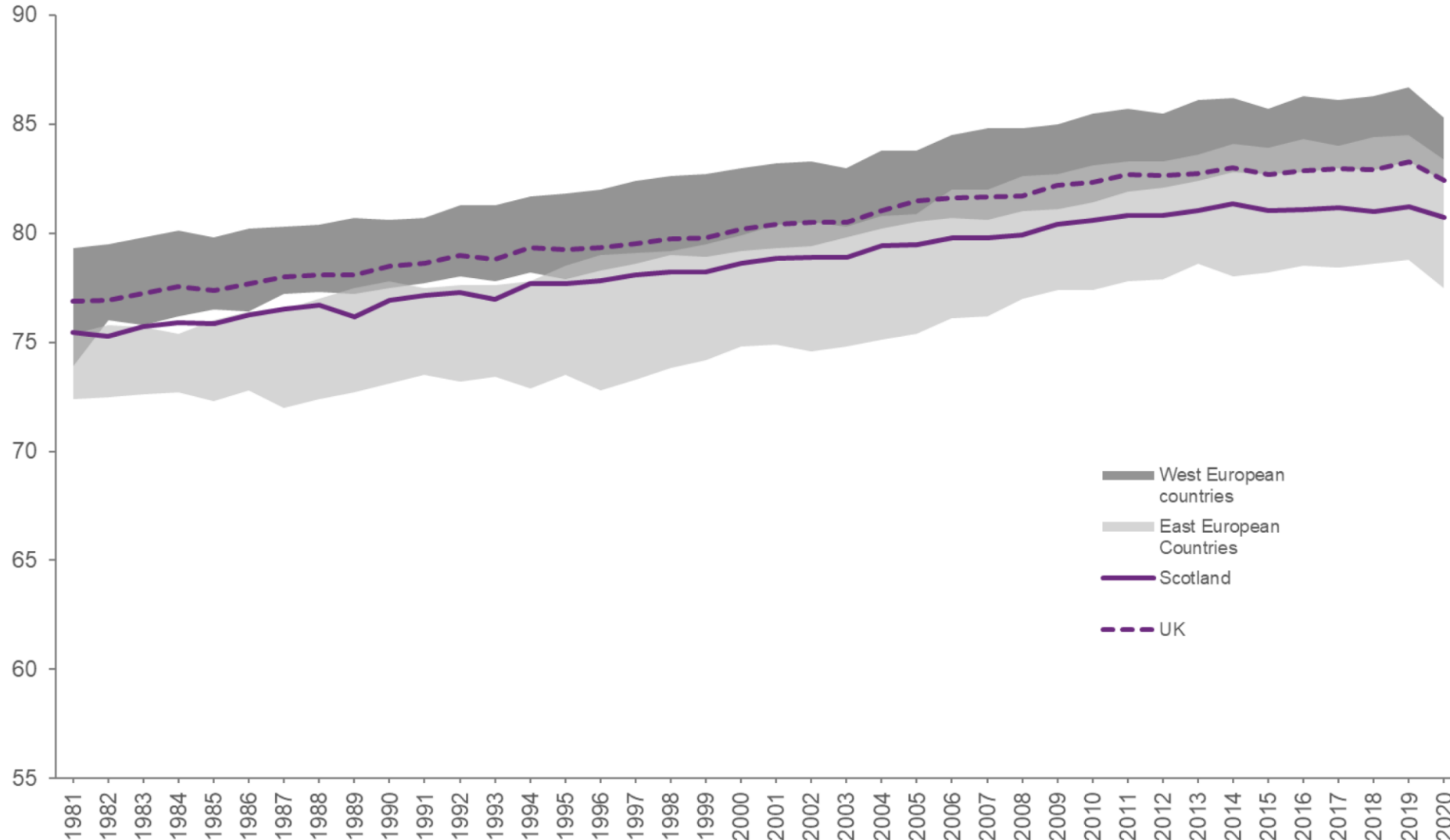
Life expectancy lags behind in Scotland

Public Health
Scotland

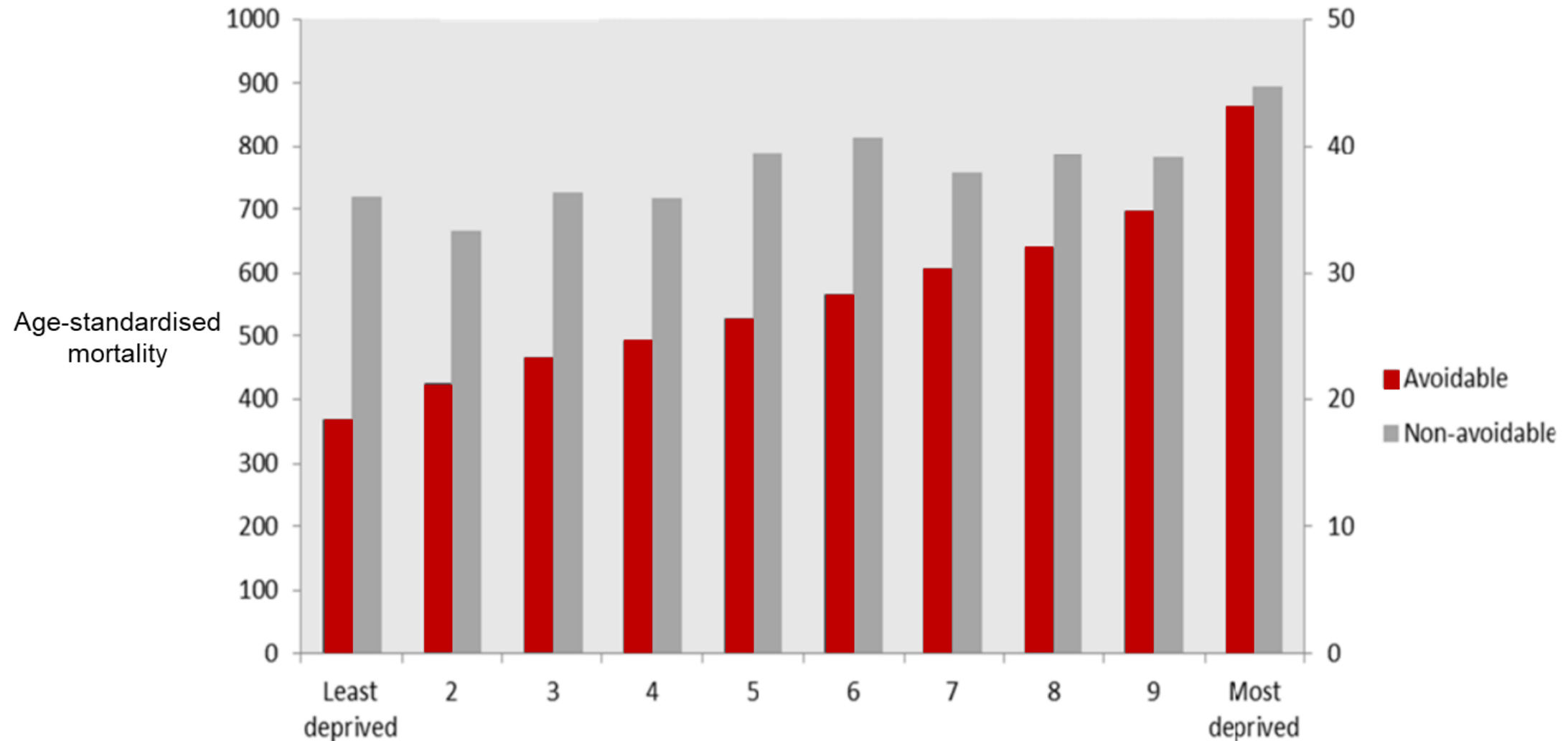


Related to:
Working ages
Men
Ethnic groups
Deprivation

Key concerns:
Healthy ageing
Mental Health
Long term conditions



More preventable = more unfair



THE NEW STATESMAN

16 July 2025

“During my three decades of service in the NHS,
my profession has been denigrated and devalued.”

“**What is the point of doctors** when so much
‘healthcare’ can be dished out cheaper?”

“**Far from being reducible to protocols,
medicine is inherently uncertain and complex**
– and individual patients even more so.”



Is there space for holistic care? (1/2)



58 female, multiple health conditions (arthritis, diabetes, and asthma)

Asked for repeat pain prescription from pharmacist

– *“you should not use that medication anymore because you have chronic kidney disease”*

GP practice pharmacist *“There is nothing to worry about”*

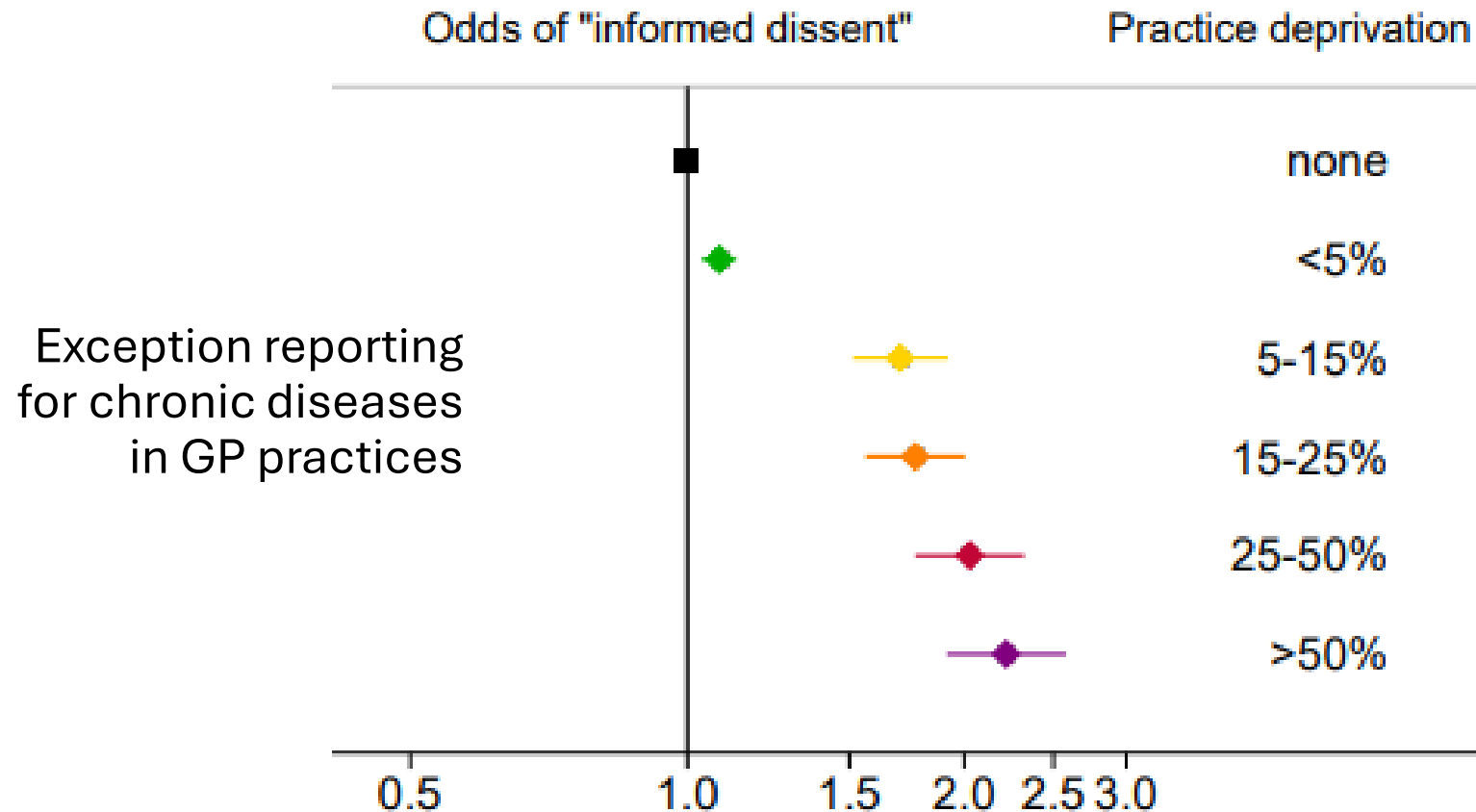
But she is worried.

Does not want to take more leave off work – job & financial worries

(the opportunity passes)

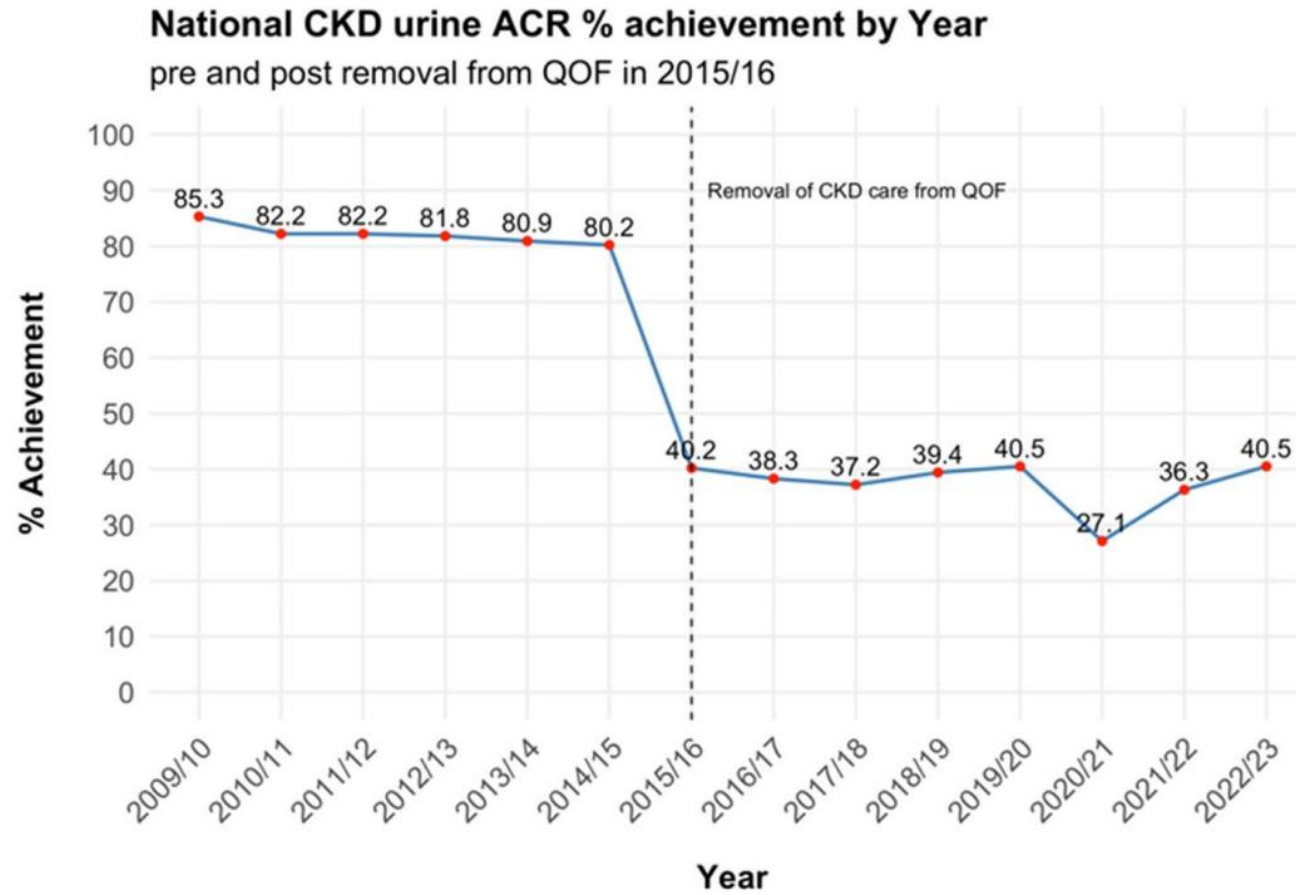


Space for equitable care?



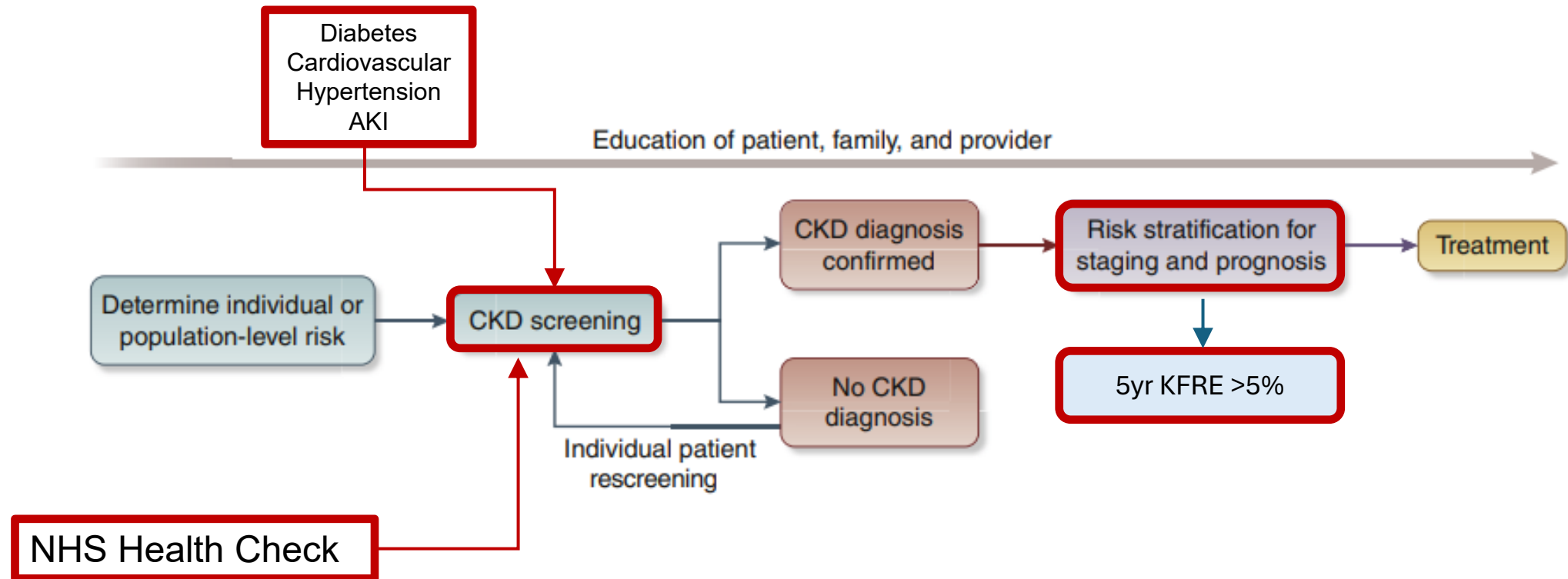
“This would imply that ‘hard to reach’ patients are receiving suboptimal care”

But what if we were to just stop?



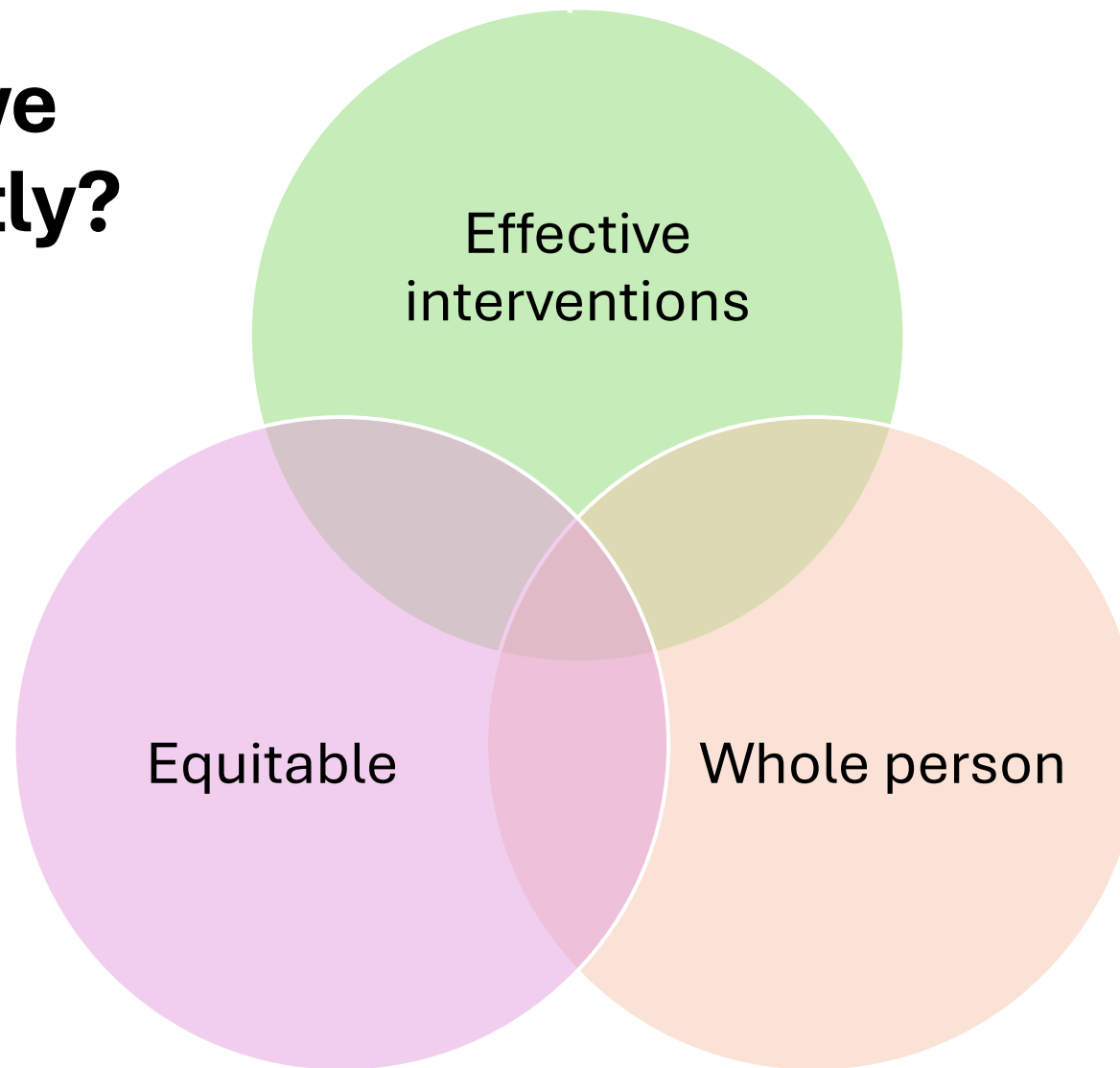
“If it’s not in QOF, it becomes a ‘nice to have’, not a ‘must do’”

This could happen again



“Individuals most likely to attend the Health Check programme included women, persons aged ≥ 60 years and those from more socioeconomically advantaged backgrounds”

What can we do differently?



More measurement



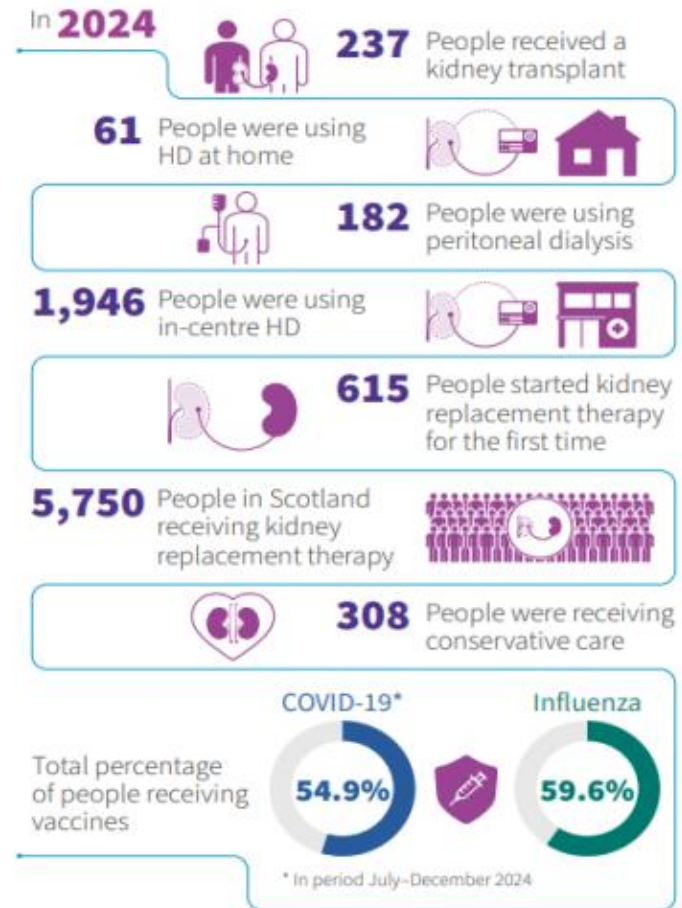
Less measurement

“We don’t always think about what patients need” Health Inequalities lead
NHS Grampian



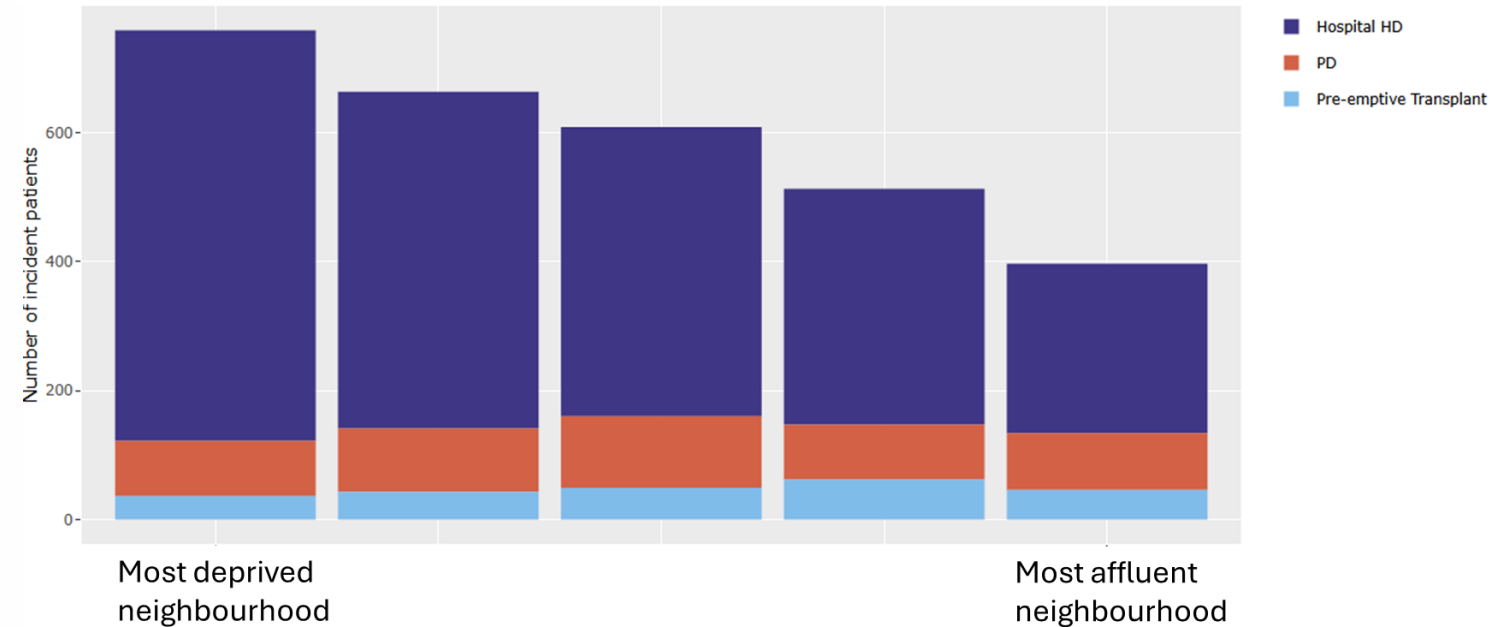
What do we measure in Scotland?

SNAP Scottish Renal Registry (SRR) Annual Report 2025



Public Health
Scotland

New KRT in Scotland



We don't measure or report the burden of CKD



Other specialties are ahead of us



SCI-DC
SCOTTISH CARE INFORMATION
DIABETES COLLABORATION

SCI-Diabetes

Home SCI-Diabetes Features & Benefits Our Vision Links »

Search...

Roll over a region to view diabetes statistics

Scotland
Population: 5,447,700
Number of people with diabetes: 353,088
Crude Prevalence: 6.50%

Orkney

Shetland

SCI-DIABETES

SCI-Diabetes is NHS Scotland's diabetes patient management system. It is used in every health board and holds data on all people with diabetes living in Scotland.

SCI-Diabetes provides a fully integrated shared electronic patient record to support the care and treatment of people with Diabetes. It provides functionality for both Primary and Secondary Care Clinicians and includes specialty modules for Paediatrics, Podiatry, Diabetes Specialist Nursing and Dietetics.

Its purpose is to ensure that patients receive the best possible care for their diabetes by providing authorised members of the healthcare team with the up-to-date information they require to effectively manage their patients.

The SCI-Diabetes Application is managed, developed and supported by the SCI-Diabetes Team, part of the NES Technology Service directorate of NHS Education for Scotland.

SCI-Diabetes is clinically led: clinicians across Scotland shape the 'Once for Scotland' approach and provide us the context to build the digital system which supports this.

SECURITY AND CONFIDENTIALITY

SCI-Diabetes is available to members of the NHS Scotland healthcare teams within the confines of the SWAN network. SCI-Diabetes can only be accessed via a secure connection and data are never shared with any unauthorised third-parties.

Diabetes Managed Clinical Networks have been set up in all NHS Scotland health boards and they have the responsibility for managing access to SCI-Diabetes.

Statistics are taken from the [Scottish Diabetes Survey 2023](#)

Roll over a region to view diabetes statistics

Scotland
Population: 5,447,700
Number of people with diabetes: 353,088
Crude Prevalence: 6.50%

Orkney

Shetland

Other specialties are ahead of us



SCI-Diabetes

Dashboard

Step 2: Select Criteria - Data view: Latest Cohort: Type 2 & Other 18+ Main domain: S0100 - Grampian

Comparator domain: S0000 - Scotland

Step 3: View Selected Dashboard:

Dashboard

Diabetes Care

Change

Data View

Latest

Change

Patient Cohort

Type 2 & Other 18+

Change

Region - Population

42 patients

Compared with

Scotland
as at 09-Jul-2022 11:41

620 patients

Pathways of Care

Click on a measure below to view details

Measures of Care

Scotland

Measure

Trend

Measure

Trend

Standards of Care

Red

Amber

Green

1. Glycaemic Control

1.1

HbA1c Recorded

83.3%

0.5%

< 75%

75-85%

> 85%

1.2

HbA1c < 58mmol/mol 1 year post diagnosis

-

-

< 70%

70-75%

> 75%

1.3

HbA1c < 58 mmol/mol

45.7%

33.3%

< 50%

50-55%

> 55%

1.4

HbA1c > 75 mmol/mol

22.9%

33.3%

> 25%

20-25%

< 20%

2. Cardiovascular Health

2.1

BP Recorded

88.1%

0.2%

< 75%

75-85%

> 85%

2.2

BP <= 130/80mmHg

29.7%

100%

< 60%

60-75%

> 75%

2.3

Cholesterol Measured

71.4%

0.2%

< 75%

75-85%

> 85%

2.4

Statin use in > 50

43.2%

0%

< 60%

60-75%

> 75%

3. Kidney Health

3.1

Albuminuria Screened

38.1%

0%

< 75%

75-85%

> 85%

3.2

eGFR Measured

88.1%

0.2%

< 75%

75-85%

> 85%

3.3

Albuminuria on AT2 Inhibitors

66.7%

-

< 60%

60-75%

> 75%

3.4

Albuminuria and SBP > 130mmHg

66.7%

-

> 40%

30-40%

< 30%

3.5

Albuminuria and HbA1c > 75mmol/mol

33.3%

-

> 40%

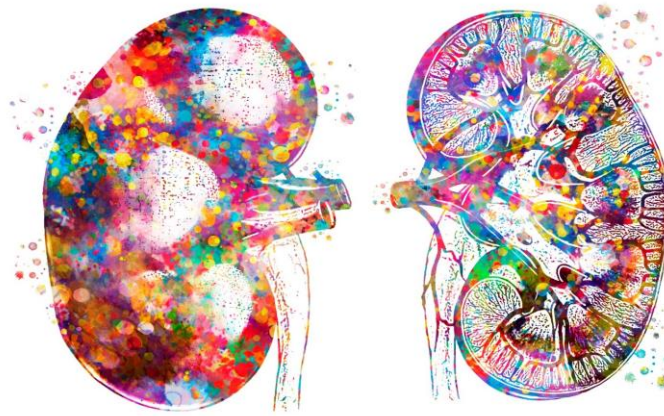
30-40%

< 30%

We can't report equity in kidney care



Using **data** to understand health inequalities in **early** kidney disease in Scotland



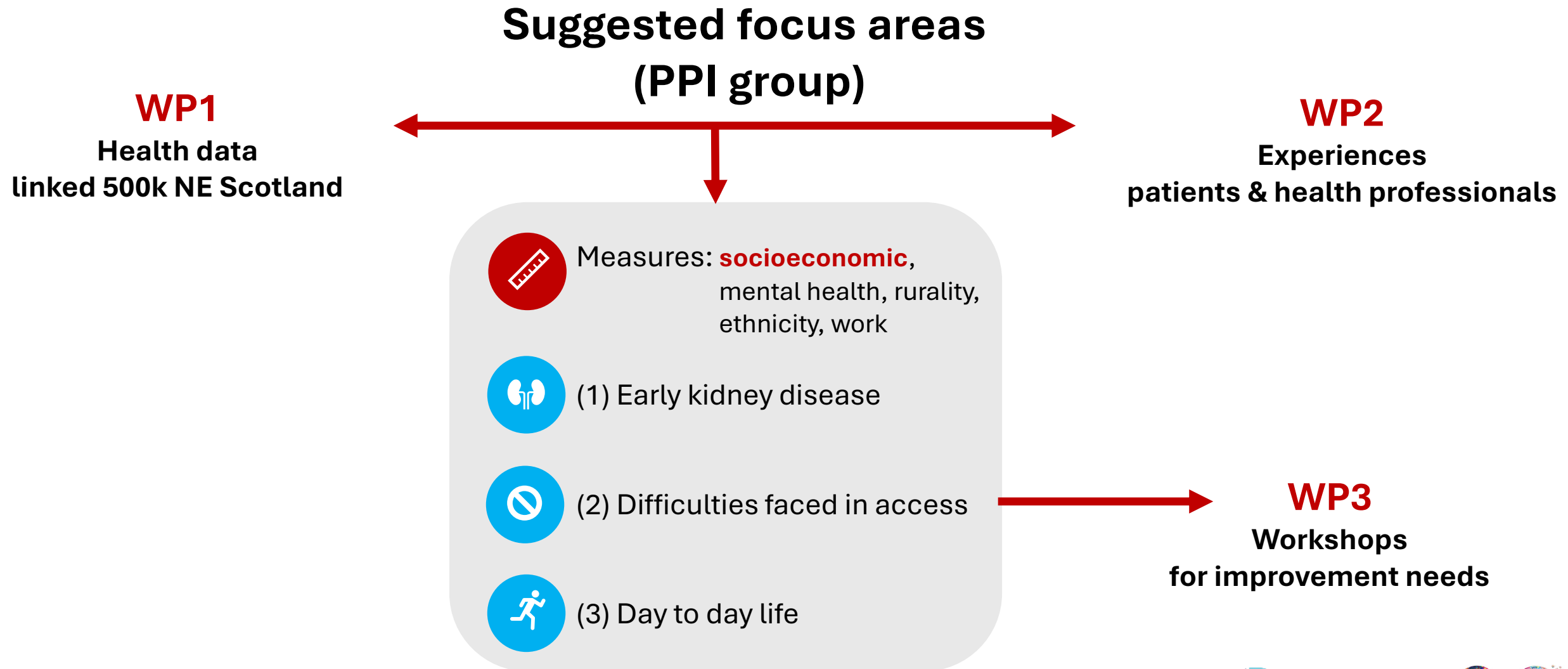
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KINDER study – Kidney Inequalities:
Needs, Data, Experiences, Response



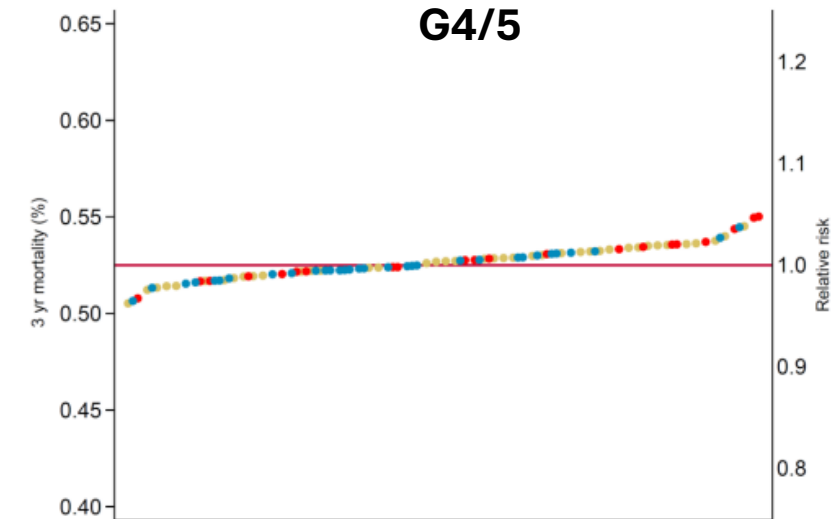
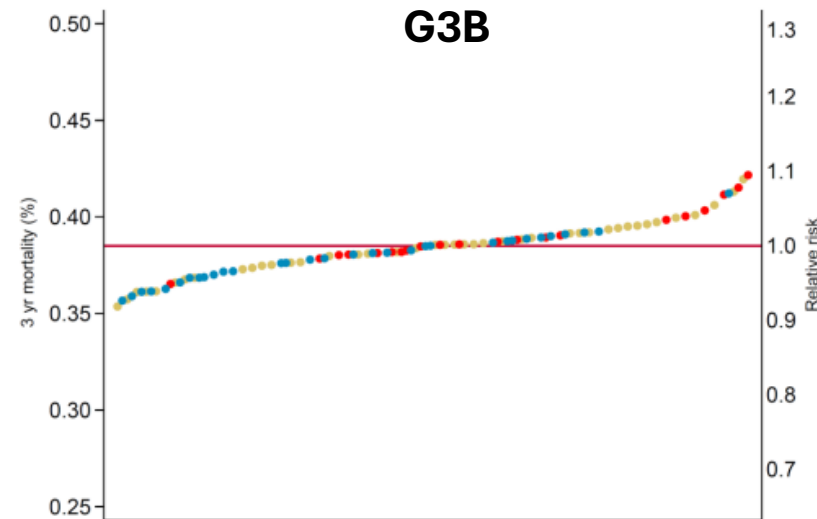
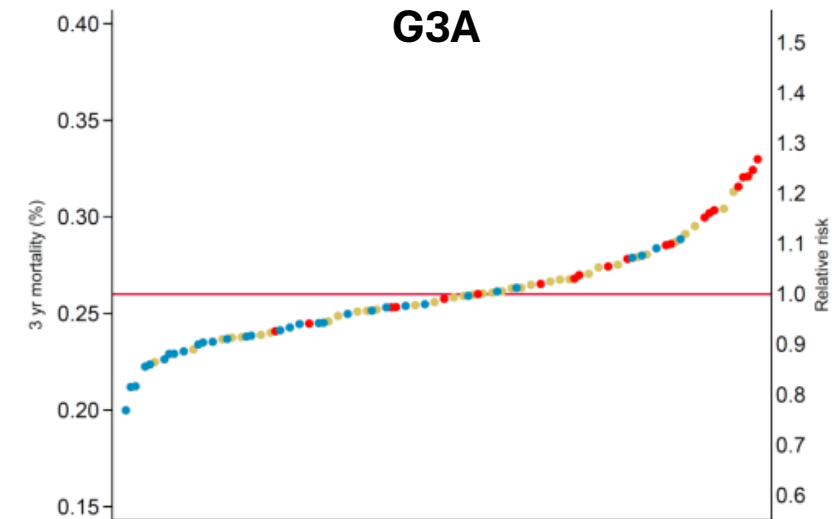
Why (1) early kidney disease?

3-year standardised mortality across neighbourhoods
50k incident kidney disease in NE Scotland

Deprived

Intermediate

Affluent



Why (2) difficulties with access and (3) daily life?

“When you live with the issues every day it is very frustrating to be dismissed and not **acknowledge the difficulties we face.**”



Audrey Hughes
PKD Charity
Patient Involvement and
Engagement Officer

“**We are way more than our disease.**”



Nicki Scholes-Robertson
Kidney Patient Advocate
SONG working group

Measures within local context: neighbourhoods change

Aberdeen set to lose another 5,500 jobs through oil downturn



Oil price



Mike Melvin
Aberdeen Council of Voluntary
Organisations (ACVO)



BBC News: “Homelessness applications on the rise”

P&J: “Aberdeen’s hidden homelessness crisis as ‘extreme’ gap between rich and poor widens”

“A tale of two cities”



Mike Melvin
Aberdeen Council of Voluntary
Organisations (ACVO)

Three challenges from our PPI group

Are we covering **relevant** people?

Do the numbers tell the story of their **difficulties**?

Are we measuring **what matters** to them?



Audrey Hughes
PKD Charity
Patient Involvement and
Engagement Officer



Nicki Scholes-Robertson
Kidney Patient Advocate
SONG working group



Mike Melvin
Aberdeen Council of Voluntary
Organisations (ACVO)

Linking health and census data

“The most expensive single statistical undertaking - getting it right matters... to base decisions on trusted and high-quality data... in all areas of society” [foreword]

Household socioeconomic; living circumstances; self reported health wellbeing

Whole population

Outside of a health context

Extensive validation and stakeholder work

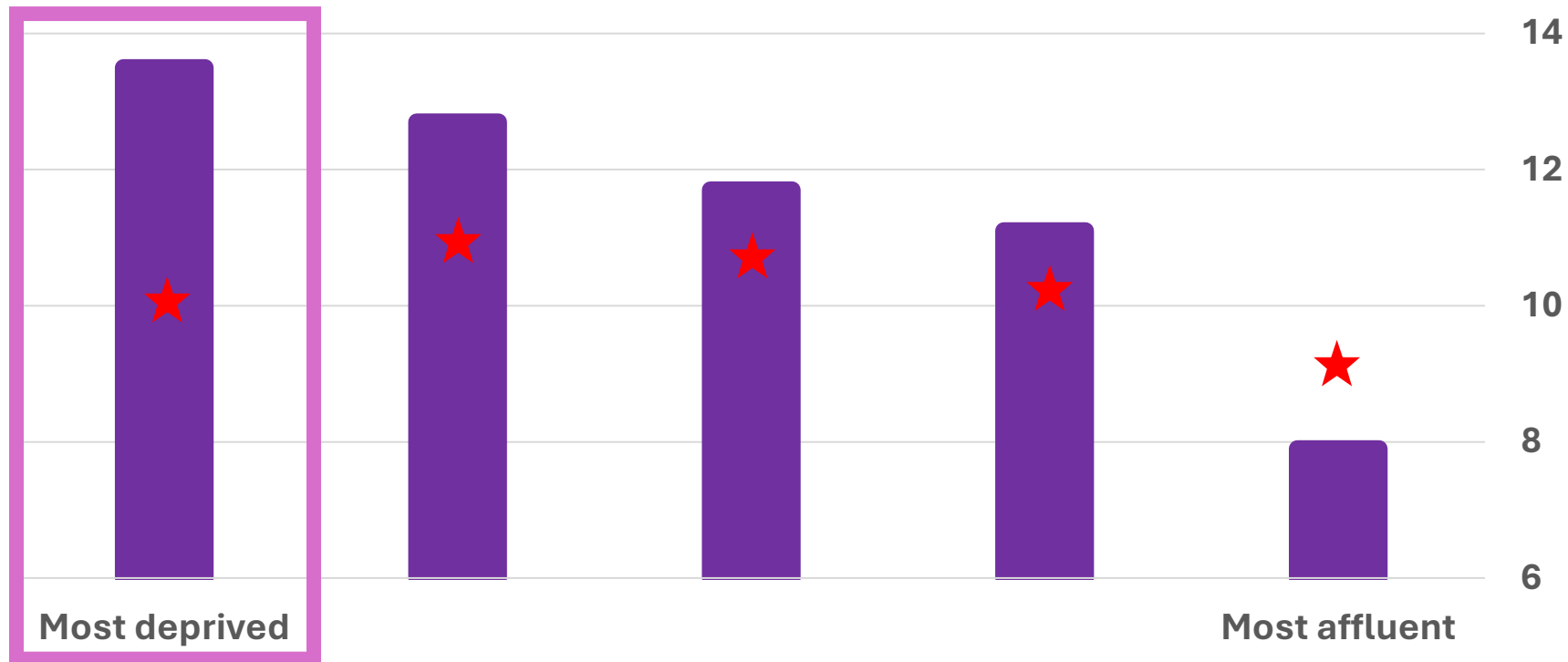


Office for
National Statistics

Cohort profile

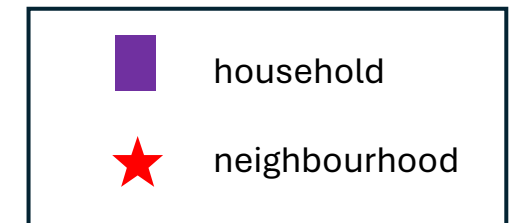


People with new kidney disease, 2011-2021 (%)



Linked Kidney +
Census data for 500k

50k developed
reduced eGFRs



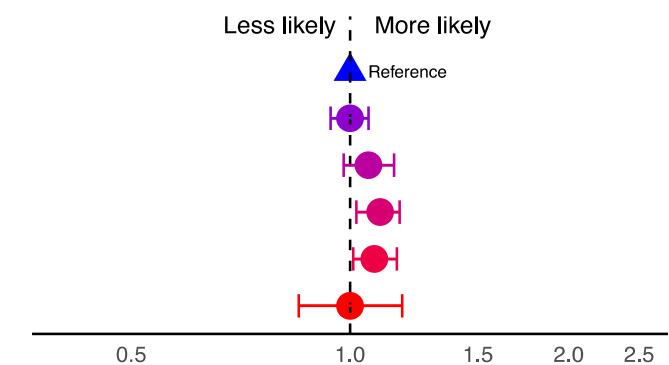
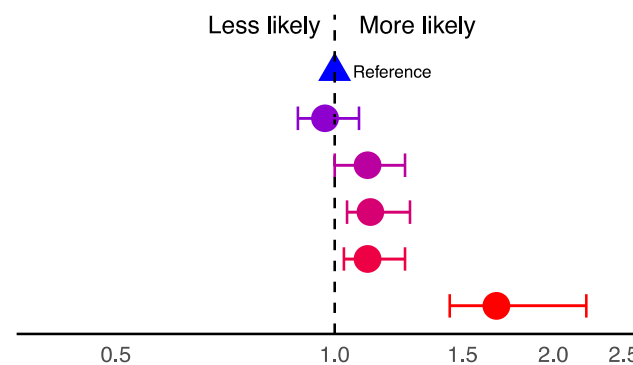
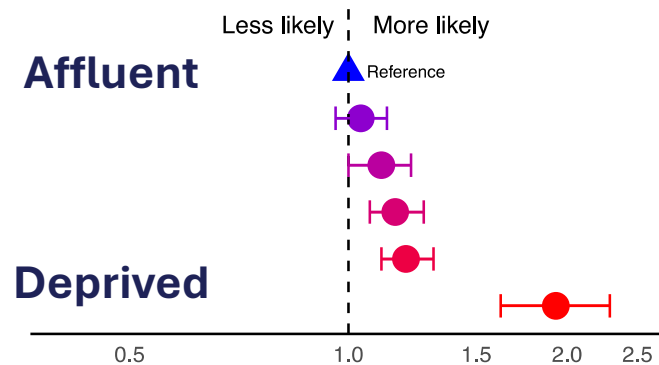
KINDER study – Kidney Inequalities:
Needs, Data, Experiences, Response

(1) Early kidney care

**Present (too) “late”
(15%)**

**A&E utilisation
(16%)**

**Immediate next monitoring steps
(68% blood, 25% ACR)**



Appear late after eGFR already < 30

Present in hospital setting, and use A&E more

Monitoring similarly poor (but this may change)



KINDER study – Kidney Inequalities:
Needs, Data, Experiences, Response

(1) Early kidney mortality

two dimensions of deprivation

Household socioeconomic position	Neighbourhood deprivation quintile				
	5 (affluent)	4	3	2	1 (deprived)
managers/professionals	1.00	1.06	1.18	1.14	1.31
intermediate/small employer	1.16	1.16	1.11	1.26	1.39
lower supervisory/technical	1.23	1.23	1.24	1.29	1.91
semi-skilled	1.29	1.24	1.27	1.36	1.65
unskilled	1.36	1.29	1.37	1.41	1.70
never worked/unemployed	1.98	1.89	1.87	2.04	2.06

(1) Early kidney mortality

two dimensions of deprivation

“All we have time for is fire-fighting”

Household socioeconomic position	Neighbourhood deprivation quintile				
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never worked/unemployed	1.98	1.89	1.87	2.04	2.06

**25% of all Grampian residents
They would be missed
by targeted interventions**



KINDER study – Kidney Inequalities:
Needs, Data, Experiences, Response

(2) Difficulties faced

50k people with early CKD	Affluent household	Deprived household	Adjusted OR
Prior mental health condition	3%	12%	4.04
Learning difficulty	3%	15%	5.28
Language difficulty	3%	14%	5.17
Living alone	22%	56%	4.45
No access to a car	11%	62%	13.3

Navigating appointments?

Two buses to get to a 9am clinic?



KINDER study – Kidney Inequalities: Needs, Data, Experiences, Response

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Navigating appointments?

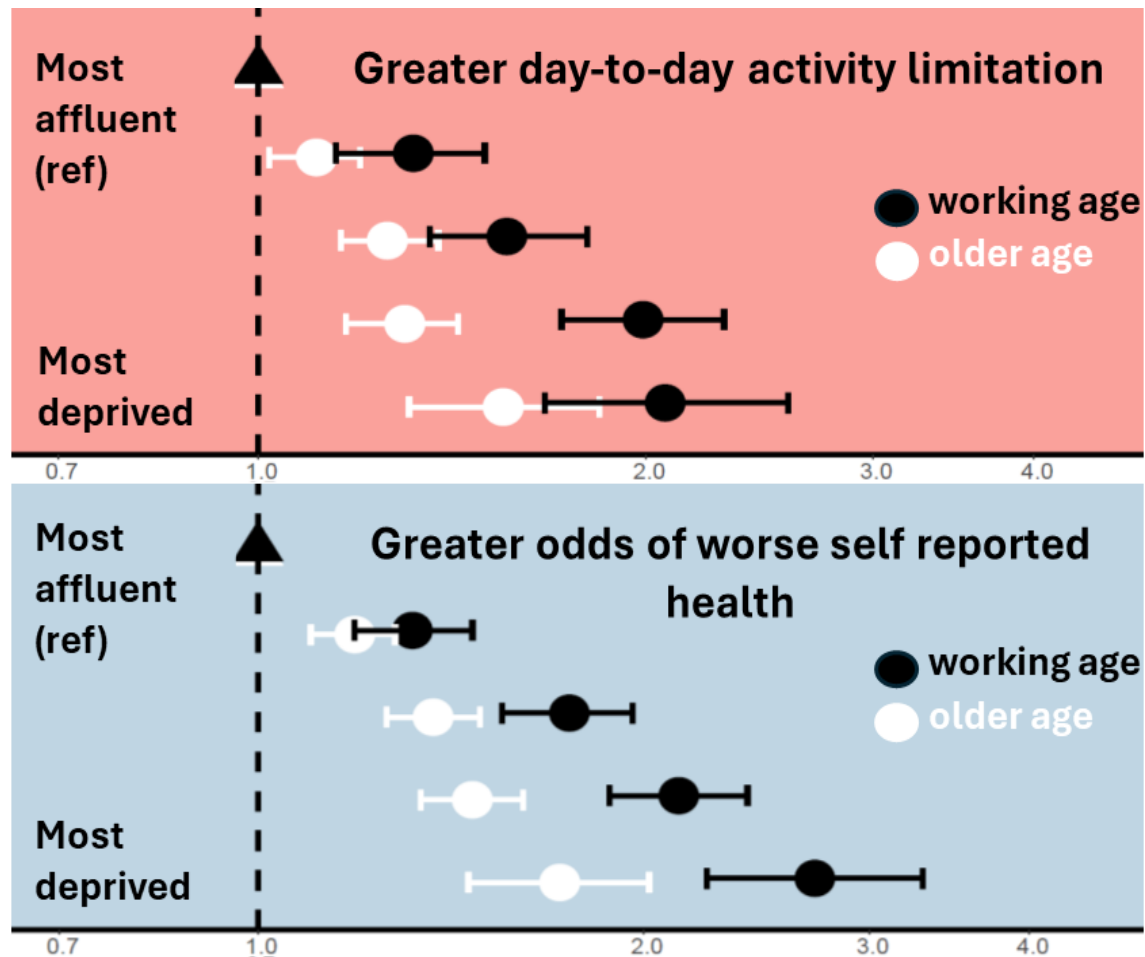
Two buses to get to a 9am clinic?

“Sometimes the car is low in petrol and ***I dinna hae the money*** to put petrol in” (Female, 60-65)

“I would come into work and my own manager would tell me things like, ‘***I need to quit because they are sick of paying an invalid***’...” (Male, 30-35)

“***They are nae worrying about it... so I just think, well what’s the point in asking?***”
(Female, 60-65)

(3) Day to day life from first presentation



(1) “Are your **day-to-day activities limited?**”
(Not limited | Limited | Limited a lot)

(2) “How is your **health in general?**”
(Very good | Good | Fair | Bad | Very bad)



Nicki Scholes-Robertson
Kidney Patient Advocate
SONG working group

“We are way more than our disease”



50F deprived household



80F affluent household



Limited a lot

Limited

Not limited

50F deprived household



80F affluent household



Limited a lot

Limited

Not limited

*“I was nervous. I didn’t feel I could go to my primary care to talk about it. **I was worried I’d be wasting their time.**”*
(Female, 50-55)

*“**You can’t discuss it with them** because you are just there to have those tests that are taken”* (Male, 50-55)

Work, health and daily life (2/2)



52M presented “late” in hospital

“There was no-one saying you’d better look after your kidneys... my late father had kidney disease and I never really looked into why...”

“In the past eight months, I have lost my job, I have split up from my wife and family... all these things just happened and crashed from underneath me in that short period ... initially I was homeless. When I was at my lowest, I was suicidal. I didn’t know where to turn.”

Three stakeholder improvement needs

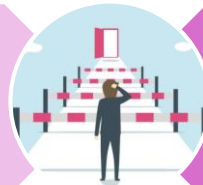
A data blind spot for early kidney care in Scotland with stark inequalities

- (1) Late presenting (invisible early stage)
Mixed messages or none



Improve kidney health messaging:
trusted, consistent, usable

- (2) Complex domains deprivation & difficulty
associated with poor outcomes



Reduce barriers to access
(improve kidney/social data?)

- (3) Limitations in day-to-day life
Concerns: work, finances, mental health



Provide a whole-person approach to care

