

Using data to understand health inequalities

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This is a very old problem

“A terrible screeching filled the air and the contents of the box burst out, flinging the lid from her hands. Pandora watched helplessly as hundreds of writhing, horrible things billowed into the air. They were things that people had never experienced before - **war and disease, poverty, hatred, malice and jealousy.** Pandora was unable to move, **numb with despair** at what she had done.

Then, as she watched, one last little thing fluttered out. It was pretty and delicate, leaving a trail of light behind it. Pandora watched it fly away and, despite herself, she felt her heart lift. The very last thing that had come out of the box was **hope.**”



Original Article

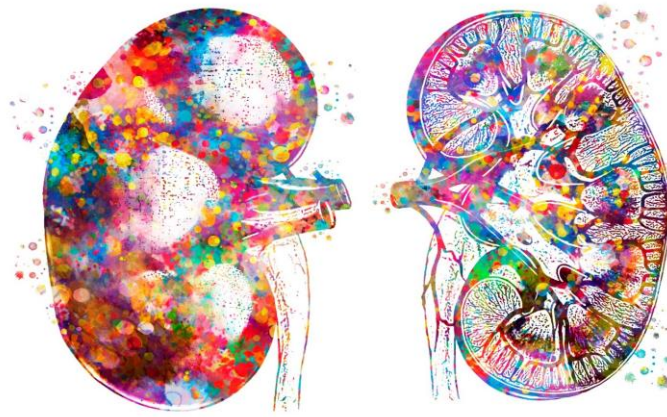
Fantasy paradigms of health inequalities: Utopian thinking?

Alex Scott-Samuel^{a,*} and Katherine Elizabeth Smith^b
Social Theory & Health Vol. 13, 3/4, 418–436

“Well-meaning policymakers, practitioners, researchers and members of the public collude in a cult of health behaviourism”

1. “Crude optimism” – individuals should try harder change behaviours
2. “**Hopeful pessimism**” – strive to mitigate harms
3. “Resignation” – politics is too broken to be able to fix society

Understanding and reducing inequalities in **early** kidney health care and outcomes in Scotland



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

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



Why **early** kidney care?

People in lower socioeconomic and minority groups
more likely to get kidney failure

Access to dialysis and transplantation

“So long as we continue to fight the battle downstream...we are doomed to frustration, repeated failure, and perhaps ultimately to a sicker society”

McKinlay JB. A case for refocusing upstream: the political economy of illness.
American Heart Association 1975



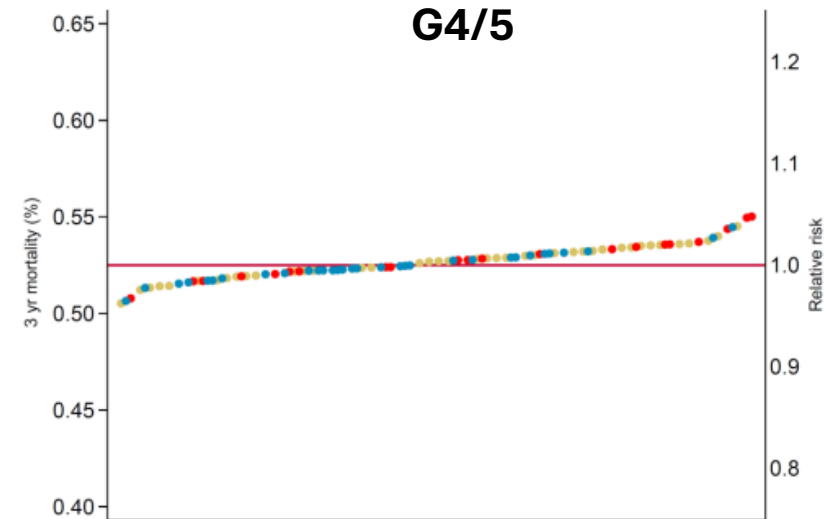
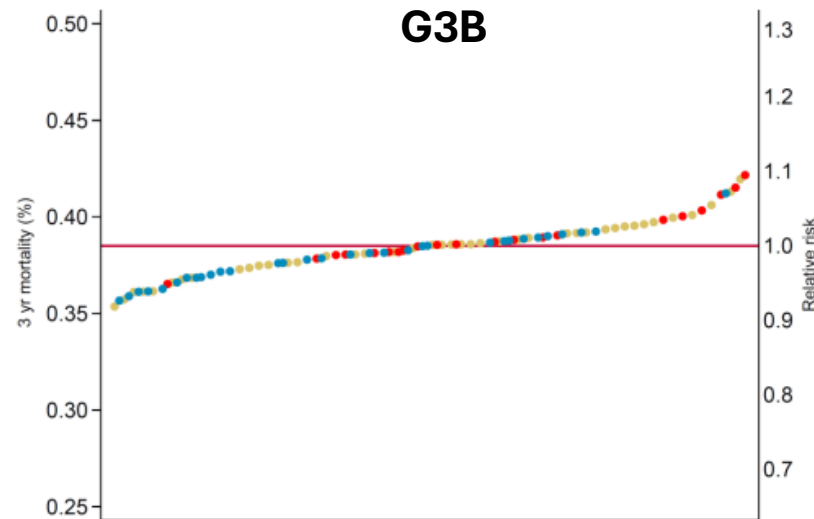
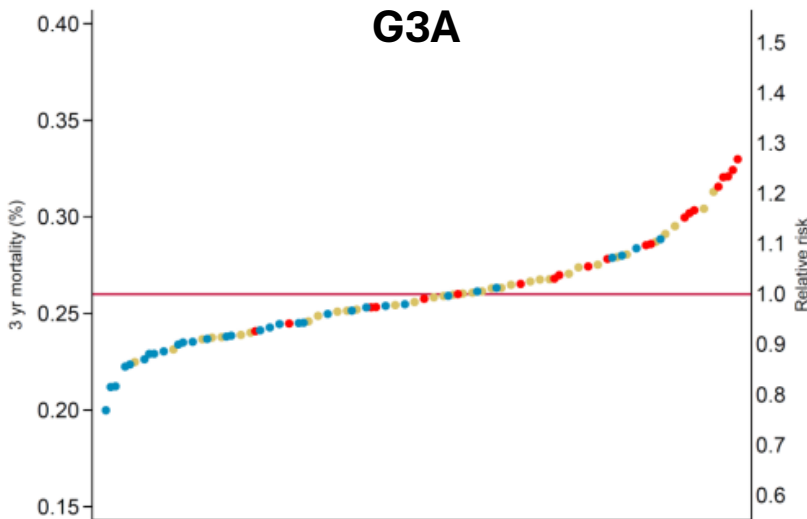
Health inequity most evident **early**

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

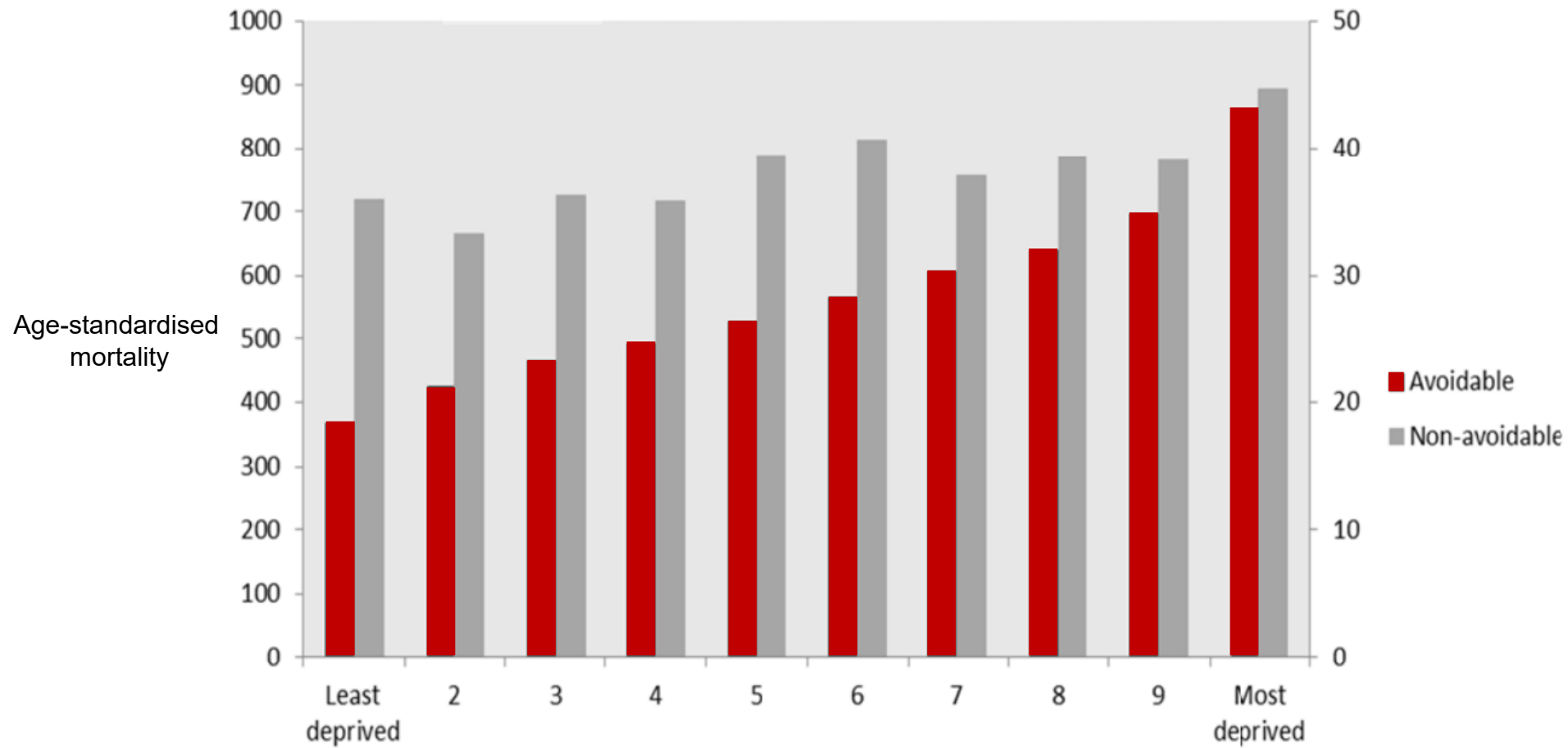
Deprived

Intermediate

Affluent



Avoidable?



Input from our stakeholders

“Sometimes the most useful action you can take is to *improve the data*... beware of data that is *relevant but inaccurate*, or *accurate but irrelevant*.”

Hans Rosling, global health perspective

People – kidney disease ?

Exposure – deprivation ?

Outcomes – mortality ?

Meaning – trust ?



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)

RESEARCH ARTICLE

Science

ECONOMICS

Dissecting racial bias in an algorithm used to manage the health of populationsZiad Obermeyer^{1,2*}, Brian Powers³, Christine Vogeli⁴, Sendhil Mullainathan^{5*†}

“Bias occurs because the **algorithm uses health costs as a proxy for health needs**. The algorithm thus falsely concludes that Black patients are healthier than equally sick White patients”

Commentary – “Artificial Intelligence is not the problem. It is the wrong metric.”

Improve the data – census linkage?



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

Extensive validation and stakeholder work for every question

Whole population

Self-reported

Outside of a health context



Office for
National Statistics

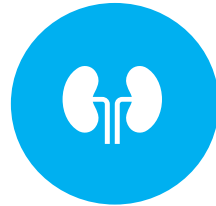
WP1

health data



WP2

experiences



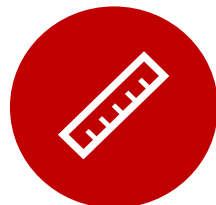
Health Outcomes



Clinical Care



Day-to-day activities



Measures: **socioeconomic**, mental health, rurality, social isolation, work

Cohort profile: population and exposure

New cohort formation (GLOMMS-CORE):

Linkage of kidney records
and a census of 458,897
North Scotland residents



Incident kidney disease
presentations

eGFR <60	n= 48,546
eGFR <45	n= 29,081
eGFR <30	n= 16,116
AKD	n= 28,097

% residents presenting with early disease (eGFR <60):

By household:

Professionals (lawyers)	7.9 %
Unskilled (cleaners)	13.4 %
Unemployed (no job)	13.5 %

By neighbourhood quintile:

Most affluent	8.9 %
Most deprived	10.0 %

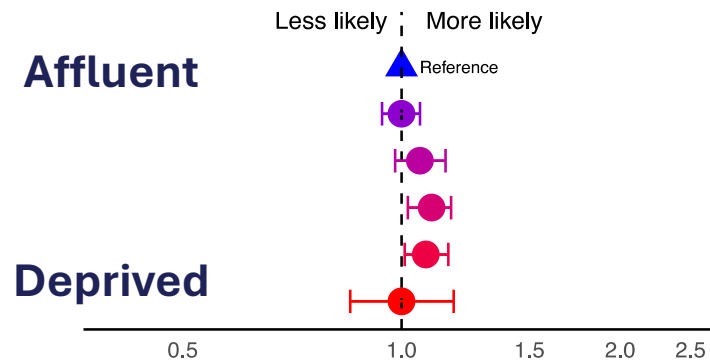
Followed up 2011-2021

Inequity of mortality outcomes – separate dimensions of deprivation

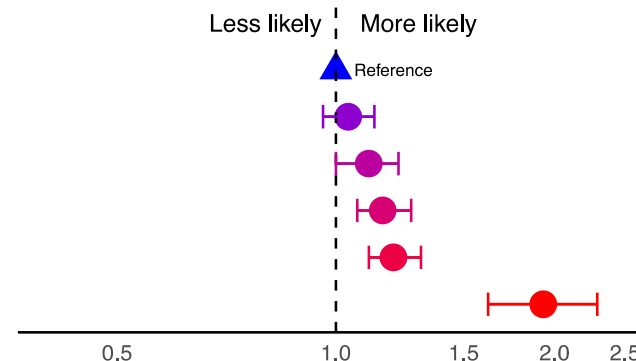
<u>Household socioeconomic status</u>	<u>Neighbourhood deprivation quintile</u>				
	5 (affluent)	4	3	2	1 (deprived)
managers/professionals	1.00	1.06	1.18	1.14	1.31
intermediate/small employer	1.16	1.16	1.11	1.26	1.39
lower supervisory/technical	1.23	1.23	1.24	1.29	1.91
semi-skilled	1.29	1.24	1.27	1.36	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

Inequity of clinical care – “permeability”

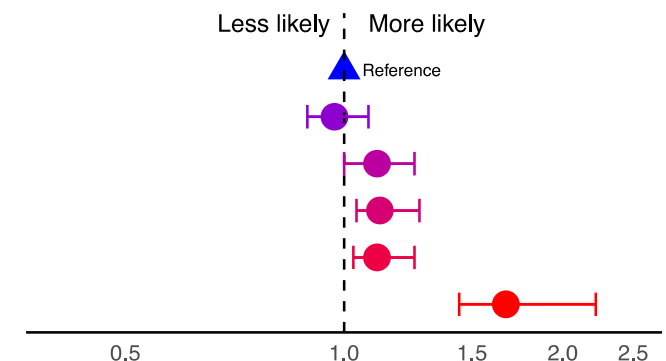
Tested for chronicity / monitoring
(68% blood)
(25% ACR)



Presented “late” (skipped CKD 3A)
(15%)



Attended A&E
(16%)



A struggle to access care

50k people with early CKD	Professional	Low skill job	Unemployed
Mental health condition	3%	5%	12%
Living alone	22%	30%	56%
No access to a car	11%	33%	62%
Learning difficulty	3%	6%	15%
Language difficulty	3%	10%	14%
Hearing difficulty	15%	18%	21%

A struggle to access care

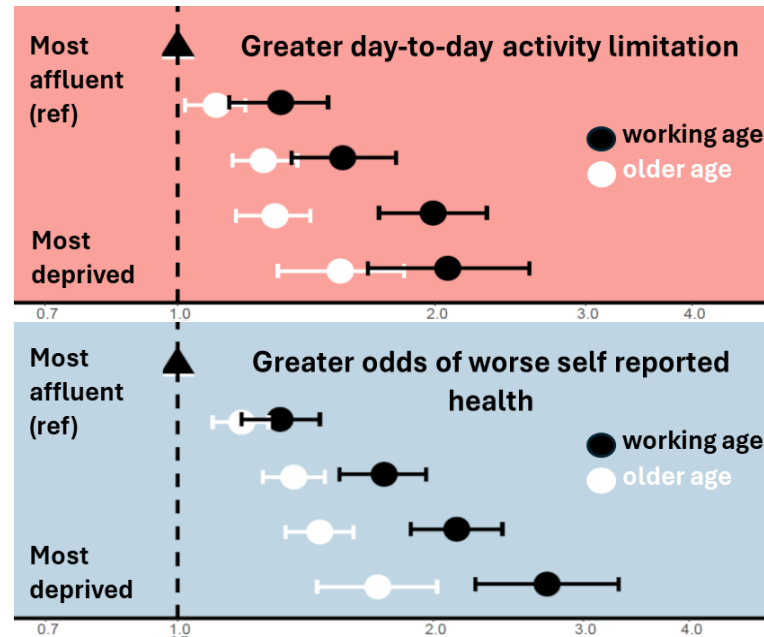
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“Sometimes the car is low in petrol and ***I dinna hae the money*** to put petrol in” (Female, 60-65)

“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)

Inequity in day-to-day activities



(1) “Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?”

(2) “How is your health in general?”

“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)

“Kidney disease **doesn’t fall into that category**” (Male, 30-35)

Reflections

Kidney disease is inequitable and increasingly preventable

“Hopeful pessimist” would need better data to avoid unintended consequences

- Population: Kidney data footprint
- Exposure: Deprivation metrics
- Outcomes: Relevant and interpreted with patients

