



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



AIMS

The KINDER study aimed to improve understanding of unfair differences in kidney care and outcomes in Scotland. Rather than simply describing these differences, we sought to understand why they occur and identify practical actions that could reduce them. The study focused particularly on people of working age living in socioeconomically deprived communities who had chronic kidney disease (CKD).



KEY FINDINGS

- The study brought together innovative health data and Scottish Census linkages; patient and health professional lived experiences from across Scotland; and workshops with patients and experts.
- Unfair differences in kidney care (i.e. “inequities”) were present across all stages of kidney disease. However, they were most marked in the earliest stages of disease, among people of



working age and among men. Disadvantages in care were greatest when neighbourhood, home circumstances, and personal circumstances all occurred together. Mortality was two-fold higher when household and neighbourhood deprivation occurred together. People in deprived households were twice as likely to present late and miss opportunities to start helpful treatments in good time.

- Our interviews showed that in deprived communities, kidney care that should happen “early” often ended up happening “late”. People often discovered their diagnosis by accident and at an already advanced stage. Messages from clinicians typically signalled to them a problem of low urgency, meaning that CKD rarely became a priority for them amid other pressing health and life problems. People struggled to navigate a pressured primary-care system with limited understanding of what CKD is, limited resources to adjust, and difficulties accessing community social and psychological support.
- Stakeholder workshops identified three priority areas for narrowing kidney inequities in Scotland:
 - **(1) improve messaging**
 - **(2) reduce practical barriers**
 - **(3) whole-person care (care that addresses health practical and emotional needs)**



WHAT DID THE STUDY INVOLVE?

Approach

The study idea initially came from our patient partners from Grampian Kidney Patient Association. Each element of study design was developed with careful discussions between qualitative and quantitative analysts, study leads (primary care, nephrology, and counselling practitioners), methods experts, clinical stakeholders, and public and patient partners. Our interpretation of the findings drew from the insights of patients and primary care professionals to understand social contexts and potential mechanisms.



Health and census data

This was a groundbreaking linkage of health and social data for 80,000 people newly presenting with kidney disease in Scotland over a ten-year period. By linking health records to the 2011 and 2022 Scottish Censuses, the study examined how socioeconomic deprivation affected diagnosis, self-reported health, access to care, and health outcomes. This was an entirely new way to evaluate equity in kidney care.

Interviews and focus groups with patients and professionals

We interviewed 38 working-age adults with kidney disease from deprived urban and rural communities across Scotland and held focus groups with 23 primary care professionals working in disadvantaged areas of Scotland to explore experiences and challenges in early-stage kidney care.

Workshops

We organised workshops with professional groups from Scotland and England, including NHS Education for Scotland education leads, general practitioners, public health specialists, social prescribing services, nurses, pharmacists, and patients. The process identified seven improvement opportunities for issues affecting early kidney care, drawn from quantitative data, interviews and focus groups. These were consolidated into three overarching themes, with 18 specific activities to address them.



WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

Health and census data: consequences of socioeconomic deprivation for early kidney care

We found that both deprived households and neighbourhoods were independently associated with greater mortality risk: up to two-fold for people in both deprived households and deprived neighbourhoods (figure below). Deprived households also more frequently faced additional risks to health outcomes of adverse mental health, living alone, basic accommodation, lack of car, language,



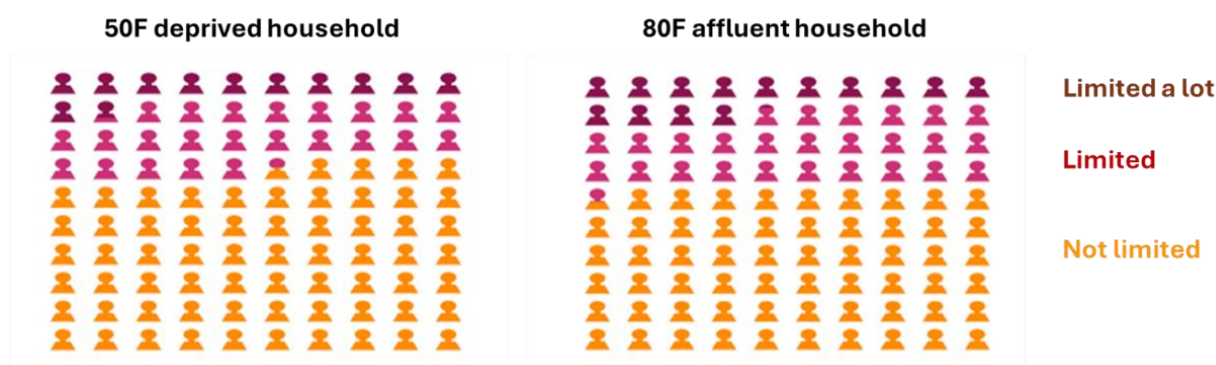
visual and hearing difficulties.

The heat map below shows that people in less affluent households living in deprived areas had the worst outcomes if they developed kidney disease. They were approximately twice as likely to die compared to affluent professionals living in affluent areas, who had the best outcomes. However people in deprived households living in affluent areas, and people in affluent households living in deprived areas also fared less well, and these are groups that may be less visible or targeted by interventions.

Household socioeconomic status	Neighborhood deprivation quintile					Color key
	5 (affluent)	4	3	2	1 (deprived)	
Managers/professionals	1.00	1.06	1.18	1.14	1.31	1.0
Intermediate/small employer	1.16	1.16	1.11	1.26	1.39	1.1
Lower supervisory/technical	1.23	1.23	1.24	1.29	1.91	1.2
Semi-skilled	1.29	1.24	1.27	1.36	1.65	1.3
Unskilled	1.36	1.29	1.37	1.41	1.70	1.4
Never worked/unemployed	1.98	1.89	1.87	2.04	2.06	1.5

When we systematically evaluated all the key aspects of good early kidney care we found that the greatest gaps between deprived and affluent communities were in (1) the timeliness of first presentation and (2) their ability to navigate care and avoid need for unscheduled care. People in deprived households were twice as likely to present late, leading to worse health outcomes.

They were also twice as likely to report that their health was holding them back in their day-to-day life. In fact, in the graphic below based on our study, if we were to compare 100 females aged 50 living in a deprived household, a similar number would be expected to report being limited in their daily life (35, shaded light/dark red), to females aged 80 living in an affluent household (40).





Interviews with patients and professionals: “Triple Invisibility” of kidney disease in Scotland

38 patient and 23 primary care health professional participants were drawn from the most deprived areas of Scottish health boards. We found that early kidney care for working-age adults in deprived communities was often delayed. Kidney disease was detected late with patients’ resources - time, money, and support - already stretched. Diagnosis was typically explained briefly, if explained at all, leading to uncertainty about its significance and next steps. We found communication and care to vary widely, with many patients relying on personal persistence to navigate fragmented healthcare systems, and professionals needing to go above and beyond to bridge gaps in care.

In group discussions with patients and professionals this was described as a “**triple invisibility**” at the levels of populations, systems, and individual symptoms. At a population level, early stages of kidney disease have limited public health visibility in Scotland, reflected in a relative absence from national dashboards and reports. At a system level, kidney disease lacks the enhanced services and incentives that exist for conditions such as diabetes and cardiovascular disease in primary care. At an individual level, early CKD often has few or no specific symptoms, further limiting recognition while there is time to treat. The effects of this triple invisibility are hardest to overcome for people who already have limited time, money, support, or flexibility in their daily lives.

Workshops: Co-designing solutions for early entry points to kidney care

The workshops identified seven improvement opportunities for issues affecting early kidney care, drawn from the data, interviews and focus groups. These were consolidated into three priority themes. The three priority themes are listed below and expanded in the figure overleaf:

1. Improve kidney health messaging that is trusted, consistent, and usable by patients
2. Reduce the practical barriers to early access to care
3. “Whole-person” (holistic) care, including lay support, social prescribing, and resourced counselling

During initial discussions about CKD, typically with pharmacists and practice nurses, trusted and consistent messaging was considered important. Participants felt that there was a need for support from peers and social prescribing services including care navigators. Such support should happen in



genuine, predictable ways and be embedded in the NHS pathway. They also agreed that improving primary care appointment flexibility and coordination would reduce barriers for disadvantaged individuals. Participants emphasised the importance of early mental health interventions in CKD as key to sustaining their wellbeing and ability to participate in day-to-day life.



WHAT IMPACT COULD THE FINDINGS HAVE?

The KINDER study comes at a critical time as Scotland responds to evidence from an independent review into health inequalities, has a life expectancy falling further behind the rest of Europe, and develops a new Long Term Conditions Framework to cut across long term conditions including kidney disease. Beyond Scotland, the kidney community is increasingly aware of the potential of inequitable organisation of care as health services act to rapidly implement prescription of new effective treatments for kidney disease. KINDER highlights constraints within current community care models that limit the ability to deliver flexible, holistic, equitable care at the earliest and most treatable stages of kidney disease.

Our real-world data analyses, interviews and focus groups both illustrate and explain a recurring concern across patients and professionals: kidney disease is often "invisible". We described this as a triple invisibility operating at population, health-system and symptom levels. This provides a new way of understanding why inequities emerge despite the availability of effective treatments and preventive care – the concern is not one of a lack of treatments, but a need for more careful implementation.

The seven improvement opportunities under three themes in the figure below represent the carefully selected and worded priorities that were felt to be important and potentially achievable to reduce kidney inequalities in Scotland if sufficiently resourced. Improvement opportunities that were of high importance to patients in the study included improving the consistency of messaging and embedding psychosocial support early in the kidney care pathway.

The research team is part of a kidney working group informing the Scottish Government for the long-term conditions framework and presented the key findings of the KINDER study to the Cabinet Secretary for Health and Social Care at a Cross Parliamentary CKD Summit. This has helped to ensure that the specific needs of those with kidney disease have been understood by policymakers.



The KINDER research team includes a Counselling Psychologist and Psychotherapist who is working with the policy lead for Kidney Research UK to consider available funding routes to design tailored and resourced psychosocial interventions to support people living with early kidney disease. Kidney disease also represents an exemplar condition for the need to improve currently inequitable models of care cutting across cardiovascular-kidney-metabolic conditions – as highlighted by a Presidential Advisory from the American Heart Association.

Three priority areas with seven improvement opportunities to address inequities in kidney care in Scotland



Messaging:

1. Provide clear, consistent, trusted information on kidney health.
2. Support clinicians with communication tools and guidelines.



Barriers:

3. Improve access to monitoring and practical support.
4. Offer flexible appointment formats and timings.



Whole-person:

5. Strengthen guidance for navigating biopsychosocial challenges.
6. Integrate psychosocial support across services.
7. Ensure continuity to build trusted, relational care for complex needs.



HOW WILL THE OUTCOMES BE DISSEMINATED?

Findings have been presented nationally and internationally to researchers, clinicians, policymakers and patient organisations. They have informed discussions on future kidney care and health inequalities within Scotland and beyond. These have included Kidney Diseases Improving Global Outcomes (KDIGO); the World Congress of Nephrology; and the Scottish Government.

An invited lecture about the KINDER study to the Royal Society of Medicine (2025) provided an opportunity to highlight the value improving the quality, relevance and interpretation of health and social care data in Scotland together to address underserved communities and traditional data “blind spots”.

Findings from the KINDER study have been published in Kidney International, BMC Nephrology,





and Clinical Kidney Journal with two papers currently being finalised. Further information about the KINDER study is available here: <https://tinyurl.com/bdh457s5>.

We are very grateful for the regular contact we have had with Kidney Research UK, Kidney Care UK, and the UK Kidney Association to ensure that findings can be used to inform models of care within the Scottish and UK kidney communities, including the 2026 Voices to Vision listening exercise for co-designing a national kidney disease strategy for the UK.



CONCLUSION

Inequities in care for people living with kidney disease in Scotland are substantial, most evidence in the early stages of disease, associated with overlapping sources of social disadvantage, and most evident among people of work ages. The consequences include increased mortality, worse kidney outcomes, and greater limitations in day-to-day life.

People from deprived communities report uncertainty and mixed messaging about the meaning of kidney disease. They first present late amid competing life circumstances, and experience practical barriers to navigating and accessing fragmented care, including a lack of psychological and social support.

Patient and expert participants in the KINDER study recognized that underserved communities with kidney disease face an added challenge of a “triple invisibility” of kidney disease at population, system, and individual levels. We identified improvement activities that are proportionate or target underserved communities. They were all considered to be feasible, with potential to mitigate inequities if implemented.

Implication: Early, equitable CKD care in deprived communities may be more achievable when embedded within cardiovascular-metabolic pathways and delivered through community-linked primary care, achieved through a series of incremental improvements. Our findings identify specific, equitable, and doable actions to support those improvements.



RESEARCH TEAM & CONTACT



**Dr Simon Sawhney, Dr Magda
Rzewuska Diaz**

**Professor Tom Blakeman, Mrs
Audrey Hughes**

**The Universities of Aberdeen and
Manchester**



simon.sawhney@abdn.ac.uk

magdalena.rzewuska@abdn.ac.uk

Additional Information

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