

UK Kidney Association organisational submission to - Change NHS: A health service fit for the future

Authors

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The questions relate to 3 'shifts' – big changes to the way health and care services work – that doctors, nurses, patient charities, academics and politicians from all parties broadly agree are necessary to improve health and care services in England:

- Shift 1: moving more care from hospitals to communities
- Shift 2: making better use of technology in health and care
- Shift 3: focussing on preventing sickness, not just treating it

Q1: What does your organisation want to see included in the 10-year health plan and why?

Background

The UK Kidney Association (UKKA) is the leading representative organisation in the UK for all healthcare professionals caring for patients with kidney disease.

1 in 7 of the entire UK population are affected by chronic kidney disease (CKD) which is a major independent risk for early death and disability.

At least 3.9 million people in the UK are affected by early CKD where they have underlying kidney damage (usually identified through a urinary leak of protein from the kidneys) and normal or close to normal kidney function. Those with early CKD have a major increased risk of cardiovascular disease events and mortality compared to those without CKD. There is also a high risk for progression from early CKD to more advanced CKD (low kidney function), where risk of cardiovascular disease and early death is higher still. At least 3.25 million people in the UK are living with more advanced kidney disease.

The foundations of CKD include poor diet, obesity, high blood pressure, and diabetes. Globally, the proportion of the population who are exposed to these risk factors is increasing; for the UK these risk factors are increasing more than any other high-income country other than the USA. Kidney disease is projected to become the 5th commonest cause of death world-wide by 2040. In the UK increasing rates of CKD are contributing to the increase in compound annual growth rate of 5% in long-term condition prevalence since 2017. The failure to deal with this is likely to be one of the major causes of increased urgent and emergency care demand. As outcomes from cancer improve year on year, CKD and other circulatory diseases and long-term conditions will dominate direct health care needs, individual and population-based quality of life, disability associated lifestyle years and will be the major healthcare drag on sustainable economic growth.

Patients with CKD should be benefiting from both established and innovative new prevention therapies, which have compelling evidence for primary prevention, such as decreasing risk of cardiovascular events and cardiovascular mortality, and secondary prevention such as decreasing

risk of progression of CKD to kidney failure requiring kidney replacement therapies, such as kidney transplantation or long-term dialysis treatment.

However, despite the benefits that should accrue from accurate identification and implementation of treatment, only a small proportion of those with CKD currently derive this. For patients to benefit from preventative therapies, they require identification of clinical risk factors, regular blood and urine tests, and care systems that are supporting the development of a workforce that can deliver this care.

Whilst many patients develop kidney disease as a result of risk factors shared with other circulatory disease, for those with more advanced kidney disease where there is a high risk of progression to kidney failure, there is an over-representation of those with genetic or immunological kidney diseases.

Approximately 70,000 people in the UK have progressed to kidney failure such that they rely on either artificial kidney replacement treatment through dialysis care or have a functioning kidney transplant. Without these treatments these patients would die within a few weeks. These patients have high disease and high treatment burden, are often unable to work, and have high rates of hospital usage. Dialysis costs approximately £34,000 per patient per year.

A further consideration is acute kidney injury (AKI), where there is a sudden drop in kidney function; this is always a serious illness. This affects one in 7 people requiring non-elective hospitalisation and has a 30-day mortality risk of around 20%. Acute kidney injury should be seen as equivalent to sepsis; in some patients it is avoidable and when it occurs, delays in treatment are associated with an increased risk of death. AKI contributes to CKD both through causing CKD and through causing pre-existing CKD to progress.

Kidney care in the UK is currently estimated to cost approximately 3.2% of total NHS spending across the four nations. The absolute cost of kidney care is in excess of £7 billion per year across the UK NHS and at a population level the costs are higher still.

The provision of kidney care in this country presents a major sustainability challenge. The carbon footprint of haemodialysis alone in this country is equivalent to that of 50,000 additional houses.

Intervening at earlier stages in kidney disease as suggested throughout this submission will require investment but has the potential to significantly improve clinical care, reduce current and future cost in this area, and reduce the carbon footprint of kidney disease.

UKKA would like to see:

A. Transparent population-based modelling of future disease patterns including those affecting kidney health together with their full economic costing to ensure that each health care system (commissioning entity; regional; national specialty) is able to identify current provision and the gap to the workforce, estate, and digital infrastructure required to provide optimal current and future care. Such modelling will enable:

- 1. Greater public and political awareness of key disease areas** (organ failure, chronic and acute, circulatory diseases, rare diseases) relating to kidney disease and clear identification of the resource required to deliver the care and the gap between this and the current provision. An honest debate about what we can provide is required but the

starting point is understanding the current position, which is unclear because of opaque funding and lack of data from systems around workforce, estates, and digital capability.

- 2. A clear case for funding for the early identification and prevention of diseases affecting the cardiovascular system including kidney disease.** This should include a reduction in risk factors such as hypertension, obesity (leading to Type 2 Diabetes), and dyslipidaemia, and increased use of medications that reduce cardiovascular mortality and slow progression of chronic kidney disease (CKD).
 - 3. Planning for capacity building including the provision of new dialysis units** and modelling of estate requirements for integrating neighbourhood care (a primary care network footprint) for circulatory long-term conditions for population areas that map on to neighbourhoods (primary care network footprints).
 - 4. Planning for capacity in clinics and infusion suites to allow for implementation of new therapeutics for rare renal diseases,** many of which have not had treatment options to date. This requires funding of multi-disciplinary team input and time alongside clinician time for such clinics.
 - 5. Accurate Workforce planning:** Optimal modelling of the whole medical and multi-professional workforce by speciality against population requirements to allow the correct training and recruitment of our future workforce.
 - 6. Integrated cross speciality working with broadening of the workforce to include new roles** (e.g. more specialist pharmacist, clinical nurse specialist and therapist roles) working across the cardio-renal-metabolic interface and spanning primary, community, and secondary care. Such roles will require appropriate training and support from multi-professional senior colleagues and medical consultants for whom training and support time must be clearly funded and structured within job plans. A clear operational framework across providers is required to ensure that colleagues can work in multiple systems and are job planned at a system level and not at a provider level. Radical changes are required to integrate finance and HR at system levels. This should be fast-tracked.
 - 7. Digital integration and rapid utilisation of tools for identification of and digital support for patients with kidney disease and related medical conditions.** This should be supported by the development of an evidence base to ensure that digital interventions do not reinforce inequalities.
 - 8. Co-design of services with patients, carers, and community leaders,** focusing on addressing inequalities and ensuring that local communities can input into their care models to ensure that differential health literacy, belief frameworks, and variable access to care are addressed.
- B. Provision of adequate adult and paediatric dialysis capacity now and in the near future to enable kidney teams to move from permanent crisis management into prevention-based care.**

1. **Tools such as the London Kidney Network dialysis occupancy measure** (assessing current dialysis capacity versus need) should be combined with data from the UK Renal Registry (which will predict immediate future dialysis capacity need).

C. Integrated information technology to enable:

1. **Seamless patient care across sectors** through a single shared clinical record accessible across primary and secondary care where possible, with optimal connectivity between systems where a single record is not possible.
2. **Optimal access to and visibility of medication information** to ensure all patients will benefit from systematic introduction of new prevention and treatment therapies.
3. **Integration of secondary care into primary and community care** to ensure that specialists and generalists are working together in clinical teams that are scaled to population footprints; this requires cross organisational support of virtual and hybrid models of care. The pharmacological and lifestyle interventions currently available would have a substantial impact on a range of outcomes from non-elective hospitalisation through to disability associated life years. However, these require integration and use of risk assessment tools and digital pathways into primary care systems and integration of work. Such integrated IT will also require a framework for co-evaluation by patients and healthcare professionals for any digital tools to support patient management.
4. **Facilitation of data linkage to allow:**
 - a. Optimisation of medical therapies such as whole system provision of vaccination for patients with kidney disease and use of preventative drugs such as SGLT2 inhibitors and statins.
 - b. Full understanding of the relationship between renal and cardiovascular outcomes and the development of digital care plans that are individualised for the patient based on their risk profiles and evidence base for best management of those risk profiles.

D. Investment in artificial intelligence (AI) development and piloting projects to optimise use - an example from kidney medicine would be developing the use of AI in the interpretation of kidney biopsy samples.

E. The further optimisation of a renal rare disease strategy enabled by further development of the renal rare disease registry to allow:

In renal medicine the earlier systematic introduction of preventative therapies for rare kidney diseases would realise disproportionate benefit. Whilst rare diseases account for only 5-10% of those with chronic kidney disease, they represent 30% of those receiving high-cost renal replacement therapy with kidney transplantation and/or dialysis treatment.

1. Identification of all patients with rare diseases including those outside specialist centres.
2. Equitable access to pharmacogenomic testing to allow targeted therapies.
3. Equitable adoption of new therapeutics regardless of geography or local expertise.

4. Longitudinal understanding of disease progression and the effect of new medication in diseases seen in small numbers in any individual treating centre.

F. Age inclusive kidney care allowing a continuum of kidney healthcare services from conception to grave including:

Optimal paediatric care:

1. **Adequate dialysis capacity** - current levels of crisis have necessitated discussions with NHS Blood and Transplant to increase the prioritisation of deceased donor kidneys to children.
2. **Consistent access to medicines and medical devices** (often not the case for paediatric supply chains).
3. **Removal of geographical inequity** where lack of expertise in small infant transplantation in some centres necessitates elongated time on dialysis compared to infants cared for in centres who hold this expertise.
4. **Age-appropriate educational materials** and adequate provision of youth workers and young adult workers.
5. **Adequately resourced adolescent and transition care** enabling children with complex needs to move to adult care whilst maintaining optimal outcomes.
6. **Integration of paediatric and adult nephrology services including integration of research** to allow early inclusion of children in clinical trials so that the benefits of new therapies are not delayed in this population. This should include a review of pharmaceutical sponsored trials where those under 18 are often excluded when they could have been included in the clinical trials.

Better investment in provision of care for older and or frailer patients and those reaching the end of their lives:

1. **Investment in more geriatricians/frailty practitioners/therapists and education of renal specialists** to ensure older frailer patients receive holistic care to improve function and quality of life as well as renal replacement therapy where beneficial, and supportive care where renal replacement therapy would not be beneficial.
2. **Investment in a fully NHS funded hospice, community and hospital based palliative care workforce.** This will enable movement of patients from acute care settings that are unable to provide for their full needs at the end of life to a more appropriate, compassionate and better value community setting.

G. Integration of health policy with policy on housing, welfare and education to allow those with the greatest wider needs to derive equal benefit from newer therapies. This will reduce inequalities in patient care across socioeconomic boundaries.

Shift 1: Moving more care from hospitals to communities

A. A Primary Care Chronic Kidney Disease prevention strategy integrated with a wider cardiovascular disease prevention strategy to include:

1. **Standardisation of approaches across primary care** to address huge variations in care provision.

2. **Supporting the development of integrated neighbourhood models of care for CKD** and related long-term conditions.
 3. **Investment in primary care information technology and support** to ensure optimal identification of CKD through use of blood and urine tests in those with CKD or at high risk of CKD with optimal coding, regular auditing of progress and reduction in unwarranted variation across providers.
 4. **Greater use of primary care pharmacists, specialist and primary care nurses together with dieticians and therapists** to accurately manage risk factors for chronic kidney disease (such as high blood pressure and diabetes) and to support all health care professionals to promote healthy behaviours to reduce disease likelihood and progression. The fundamentals of health behaviours are shared across long term conditions.
 5. **Creation of an integrated circulatory long-term condition team** including the development of renal expertise in primary care pharmacists, nurse specialist teams, and the integration of the nephrologist workforce into neighbourhood teams to optimise preventative medicine uptake in patients with CKD.
 6. **Clear specifications for CKD management** so that patients who are currently seen in hospital-based clinics but who should receive integrated long-term conditions care (with diabetes, hypertension, obesity, and heart failure) are supported to transition to community care. This will require cross-provider job planning and contracts.
 7. **The creation of community-based cardio-renal metabolic clinics** run with the community renal workforce and primary care to optimise timely use of medications to prevent CKD progression and minimise cardiovascular risk.
- B. Optimisation of community-delivered but specialist linked diagnostic testing (including drug levels for patients with transplants and immune mediated diseases and haematinics and monitoring of appropriate frequency for kidney anaemia management) to allow patients to have their treatment monitored close to home but with specialist oversight.**
- C. Increased use of home dialysis therapies through better education and support for patients and staff, better provision of assisted home dialysis and where cost effective change or alteration to accommodation to enable home treatment.**
- D. Full NHS funding for hospital, community and hospice based palliative care teams.**
1. The current lack of investment with significant reliance on the charity sector in this area necessitates use of acute hospital beds to deliver care which is neither focused to the true needs of these patients nor delivered in the most compassionate setting.

Q2. What does your organisation see as the biggest challenges and enablers to moving care from hospitals to communities (in renal medicine)?

Challenges

1. Lack of primary care incentivisation schemes to measure urinary albumin to creatinine ratio.
2. Lack of an adequate community-based workforce with cumulative inadequate investment in primary care and community-based roles.
3. Inadequate investment in capacity for diagnostics mapped to patient need.

4. Inadequately linked IT systems preventing cross sector visibility of blood results, radiology, medications and progress notes.
5. Inadequate and poor-quality housing stock currently limits the number of patients able to undertake home dialysis, limiting patient independence and adding to economic cost.
6. Lack of NHS funding for palliative care often results in poorer quality end of life care delivered in a less suitable more expensive acute setting.

Enablers

1. Integration of secondary care and primary care workforce including education and support for workforce transformation in delivering prevention therapy for those with or at risk of early CKD and other long-term conditions and for high quality secondary prevention for those with established disease.
2. The creation of community based renal expertise by the:
 - a. Development of integrated pharmacist services across primary, community and secondary care with specific expertise in circulatory long term conditions including CKD.
 - b. Inclusion of community sessions in hospital nephrologists' job plans and piloting of community-based nephrology posts.

Shift 2: Analogue to digital

- A. Optimal data linkage as described in response to Q1.**
- B. Use of automated real time data collection by specialist disease registries to provide a national dataset which can:**
 1. Optimise performance and reduce unwarranted variation in key performance indicators across providers.
 2. Aid planning of future service provision.
 3. Describe key inequalities in specific disease areas.
- C. Joined up information technology where patients have a single medical record that can be seen by all providers, including blood results, letters, allergy status and medications together with patient access for results.**
- D. Creation and use of digitally provided patient education materials.**
- E. Consistent implementation of the Kidney Failure Risk Equation to allow the identification of patients for whom targeted resource should be prioritised. Further development and evaluation of remote digital monitoring of blood pressure, diabetic control and home dialysis therapies with ongoing research to ensure increased use of digital technology does not widen health inequalities.**
- F. Increased use of virtual appointments for appropriate patients linked with availability of local blood testing and ability to deliver medications or GPs to provide medications.**
- G. Optimal availability of digital self-management tools such as physiotherapy, exercise, weight management and AHP delivered symptom control classes.**

Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology and healthcare?

Challenges:

1. Poor public understanding of value of data analysis and data linkage may be hampering progress.
2. Inability of IT systems to integrate and share data.
3. Poor quality outdated IT infrastructure.

Enablers:

1. Development of a unified single IT medical record.
2. Clear specification documents for each individual speciality with minimum data sets and configurations which can be used in commissioning new IT providers to the NHS.
3. Education of public and NHS staff about value of data and adequate support to allow full clinician use of full dataset without raising public concern.

Shift 3: Sickness to prevention

- A. Better investment in public health education with strong emphasis on healthy diet, obesity, diabetes, BP, smoking and alcohol.**
- B. Full public health legislation, e.g. year on year reduction in salt, high glycaemic, and ultra-processed constituents of diet. Progressive taxation of foods deleterious to population health invested in ensuring that healthy foodstuffs are accessible and affordable.**
- C. Facilitation of optimal preventive therapies through:**
 - 1. Use of IT to track systematic introduction of prevention drugs** in high-risk populations such as SGLT2 inhibitors in chronic kidney disease populations.
 - 2. Delivery of preventative therapies in non-traditional** but more patient accessible settings (such as vaccination in dialysis units) through financial incentivisation.
 - 3. Investment in the rehabilitation and wellbeing workforce** to support pre-rehabilitation programs for kidney patients as well as to assist them to live well, reduce symptom burden and make reasonable adjustments to support a return to work.

- D. Greater direct involvement of patients in their own care through:**

[Note: Optimising outcomes for those with established kidney disease relies heavily on high levels of self-management (healthy eating and exercise, medication concordance, dietary and fluid modifications, regular dialysis attendance)].

- 1. Optimising co-management in kidney patients** - this will require:
 - a. Greater investment in education and activation of patients with dedicated digital AND clinician resource to enable true patient self-management and shared care.

- b. Greater involvement of patients and public, including ensuring representation of the demography that are differentially affected by kidney disease in the design of the health service and the creation of patient education.
- c. Greater investment in ensuring hospital and primary care kidney teams have adequate provision of social workers, counsellors, mental health liaison teams, dieticians and therapists to ensure supported uptake of all kidney preventative and treatment therapies.

E. Optimisation of kidney transplantation through:

- a. Patient and public education to optimise deceased donor rates.
- b. Optimisation of live kidney donor rates through:
 - i. Investment in cultural peer support to increase donor rates in ethnic minority population.
 - ii. Easy to access financial compensation for lost earnings for kidney transplant donors.
- c. Widening of access to transplantation through funding of local weight management clinics and weight loss therapeutics (high BMI currently precludes transplantation due to safety issues).
- d. Precision medicine approaches to transplantation, with integration of basic science and translational advances into NHS care (including genetic, epigenetic, pharmacogenetic, biomarker and artificial intelligence and machine learning tools to individualise and optimise patient care).

F. Investment in clinical and basic science research as an integrated strand of clinical care, by:

[Note: Basic science drives innovation, which in turn underpins the development of novel and refined therapies for adoption into existing care pathways to improve kidney patient outcomes. This will not be possible without a commitment from UK Government to support the creation of tenured positions in UK universities for basic scientists and clinical academics who will work, in close collaboration with NHS colleagues, to realise these innovations and their consequent health benefits].

Academic nephrology in the UK is severely compromised by lack of funding. In paediatric academic nephrology, there are only 5 funded university posts for the whole of England. Without improvements in this situation UK kidney medicine cannot realise the potential to develop new therapies for kidney patients and to increase preventative strategies.]

1. Investment in basic science, translational and clinical workforce and infrastructure.
2. Investment in research for all members of the multi-professional team.
3. Productive collaboration with industry to ensure flexible career paths and optimal training for scientists and clinicians contributing to basic science research.
4. Integration of adult nephrology with paediatric nephrology to improve patient care throughout the life course of kidney disease. Current limitations on the inclusion of children and young people in clinical trials results in an average 13-year delay between the implementation of proven therapies in children compared to adults. Projects such as the LifeArc research project are working to address this inequity. They will begin by focusing on a paediatric cohort where the majority of kidney diseases are rare and aim

to strategically unite paediatric services into a translational platform to stop kidney failure onset in childhood. The project will then be up scaled across the speciality into adult services using rare diseases and then expanded into common kidney diseases.

5. Partnered research with cardiology, endocrinology and public health to address comorbidities such as diabetes and hypertension.

G. Reducing barriers to introducing new medications.

Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Challenges:

1. GP and non-medical prescriber confidence, understanding and capacity currently severely limit optimal delivery of preventative kidney care by primary care teams such as allowing proactive identification of patients and prescribing/optimisation of preventative medications.
2. Lack of political and public understanding kidney disease, its risk factors, patient impact and economic burden.
3. Inequitable up-take of preventative therapies with discrepancy by ethnicity, age, levels of deprivation and geography.
4. Complexity of accessing preventive and treatment medications due to:
 - a. Cost of prescription charges disproportionately affecting more deprived communities.
 - b. Disproportionate delays in approving primary care prescribing of newer therapies and the creation of overly complex shared care guidance.
 - c. Complexity and capacity issues surrounding the continued prescribing of medications requiring safety blood checks.
 - d. Over-complex primary care guidelines with disproportionate focus on drug side effects severely limiting implementation of proven prevention strategies.
5. Limited integrated clinical and operational leadership, and provider organisations working in silos with no clear system approaches to integration.
6. Lack of workforce planning, quality assurance frameworks, clinical specifications and transparency of funding for kidney care within block contracts.

Enablers:

1. Creation of short, practical and easy to use GP guidelines on management of chronic kidney disease with **proportionate** balance of benefit versus risk for medications highlighted.
2. Integration of expert specialist clinicians in ICB leadership and sufficient allocated time for clinical and operational leadership.
3. Full economic costing models of preventive strategies.
4. Ensuring single system employment frameworks.
5. Financial transparency.
6. Quality assurance frameworks supported by peer review programmes.

7. More utilisation of existing and extended scope community roles such as community pharmacists, therapists and dieticians to promote healthy behaviour such as monitoring blood pressure and early kidney disease detection. Funding of cross sector posts to allow training of the team by specialist pharmacists in secondary care.
8. Enhanced recruitment to clinical and academic nephrology including recruitment from diverse communities over-represented in the kidney patient community.
9. Use of expert patient peer support programmes to optimise education and concordance amongst kidney patients.
10. Increased investment in academic early career investigators and physician scientists.
11. The creation and expansion of mentorship and leadership training for early career research nephrologists and the wider multi-professional team.
12. Increased flexibility within academic nephrology including the removal of barriers to career paths which span both the NHS and the commercial pharmaceutical sector.
13. Increased flexibility with the multi-professional team including removal of barriers to career paths which include research and span primary and secondary care.

Q5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in:

Quick to do, that is in the next year or so:

1. Improved primary care detection of kidney disease through increased testing of high-risk groups with blood and urine tests including the restoration of primary care incentivisation for urinary testing of albumin to creatinine ratios.
2. Roll out of simple practical chronic kidney disease guidelines to primary care such as those developed by the London Kidney Network. <https://londonkidneynetwork.nhs.uk/preventing-ckd-progression/> and the North East Health Innovation: <https://healthinnovationenc.org.uk/what-we-do/improving-population-health/cardiovascular-disease-prevention/chronic-kidney-disease/> [Chronic Kidney Disease - Health Innovation NENC.](#)
3. Full linkage of the UK Renal Registry with the Open Safely database to allow improved understanding and optimisation of medication prescribing in those at high risk of kidney disease.
4. Consistent introduction of the Kidney failure Risk equation into primary and secondary care to enable the identification of those at highest risk of progression to end stage kidney failure. [The Kidney Failure Risk Equation.](#)
5. Utilisation of primary care systems as developed during a project in the Northeast Health Innovation to identify patients with CKD. [Resources - Clinical Digital Resource Collaborative.](#)
6. More consistent introduction of evaluated tools and clinics to support lifestyle changes in patients with kidney disease such as the KIDNEY BEAM exercise tool and renal weight reduction services to allow kidney transplantation for those whose BMI is currently too high as described in:

MacLaughlin HL, et al Nonrandomized trial of weight loss with orlistat, nutrition education, diet, and exercise in obese patients with CKD: 2-year follow-up. Am J Kidney Dis. 2010 Jan;55(1):69-76. doi: 10.1053/j.ajkd.2009.09.011. Epub 2009 Nov 17. PMID: 19926371. [https://pubmed.ncbi.nlm.nih.gov/19926371/.](https://pubmed.ncbi.nlm.nih.gov/19926371/)

Sharlene A Cook et al A structured weight management programme can achieve improved functional ability and significant weight loss in obese patients with chronic kidney disease. *Nephrol Dial Transplant*. 2008 Jan;23(1):263-8. doi: 10.1093/ndt/gfm511. Epub 2007 Oct 31. <https://pubmed.ncbi.nlm.nih.gov/17977872/>.

In the middle, that is in the next 2 to 5 years:

1. Use of tools such as the Dialysis Occupancy Measure to assess the supply of adequate dialysis provision for our current population. The London Kidney Network dialysis occupancy measure as seen below can identify critical pressures on current dialysis capacity in the 7 London renal units to enable shared capacity where possible, and to identify where there is an urgent need for new capacity. The table below describes the situation in London, which is replicated in many areas of the country.

		Sep-24	IMP	RFH	Barts	SGH	ESTH	GSTT	KCH	LDN
Slots / Patients	Patients % Max Estates Capacity		85.4%	103.9%	112.4%	84.5%	77.1%	59.6%	97.0%	87.6%
	Patients % of staffed capacity		103.1%	99.8%	107.2%	95.4%	88.0%	82.7%	94.8%	96.5%
Sessions	Sessions % of staffed sessions		99.8%	94.7%	92.9%	89.1%	86.0%	77.8%	87.8%	89.9%
	Sessions % of staffed sessions (inc DNA)		94.8%	92.8%	91.1%	88.8%	84.9%	77.8%	87.8%	88.9%

2. Improved raising public awareness of kidney disease through the provision of a public health campaign.
3. The provision of more widely available culturally appropriate peer support for kidney patients to support better understanding of disease, improved concordance with therapy and enhanced support for possible live kidney donation in harder to reach communities (peer support, GOLD). <https://www.giftoflivingdonation.co.uk/book/pilot-project-report-2024>.

Systematic review showing that peer support improves well being, self-efficacy, and engagement: Longley RM, Harnedy LE, Ghanime PM, Arroyo-Ariza D, Deary EC, Daskalakis E, Sadang KG, West J, Huffman JC, Celano CM, Amonoo HL. Peer support interventions in patients with kidney failure: A systematic review. *J Psychosom Res*. 2023 Aug;171:111379. doi: 10.1016/j.jpsychores.2023.111379. Epub 2023 May 20. PMID: 37270909; PMCID: PMC10340538.

4. Co-working of primary care and specialist renal services to create further education and support to primary care to deliver community based preventative kidney medicine as exemplified in the Leicestershire based LUCID programme. This will be assisted by optimal data linkage to link chronic kidney disease coding with medication data to ensure optimal and audited uptake of prevention medications. Link to project summary below with publications in preparation. <https://leicesterleicestershireandrutland.icb.nhs.uk/pilot-programme-for-patients-with-chronic-kidney-disease-will-be-expanded-following-its-success/>.

5. Further development of the RADAR kidney rare disease database to allow universal coverage with additional use to enable provision of highly specialist rare disease drugs to local patients regardless of local expertise through national support from specialist centres.

Long term change that will take more than 5 years

1. Reinvestment in understanding and rebuilding the academic infrastructure for academic nephrology as exemplified in the Life ARC project.
https://journals.lww.com/jasn/fulltext/2024/04000/bridging_the_13_year_evidence_gap_a_time_for.14.aspx.
2. Increased flexibility of academic career paths as exemplified in the Goodfellow Mathieson report.
<https://acmedsci.ac.uk/file-download/23875189>.

Subject Experts

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