Research recommendations from the 2024 Kidney Research UK, Diabetes UK, and Breakthrough T1D diabetes and kidney disease expert workshop.

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Novelty statement

- Kidney Research UK, Diabetes UK and Breakthrough T1D held a research workshop that brought together healthcare professionals, academics, charity representatives, and experts by experience living with diabetes and/or kidney disease to identify key research priorities and recommendations in diabetic kidney disease
- Six priority areas were identified, and research recommendations were developed:
    - Understanding causal mechanisms in diabetic kidney disease
    - Prevention of diabetic kidney disease

- Addressing health inequalities
- Improving diagnosis
- Improving care
- Supporting self-management

Conflicts of interest: JK reports honoraria for delivering educational meetings and/or attending advisory boards Astra Zeneca, Boehringer Ingelheim, Lilly, Daiichi Sankyo. MKR reports receiving consultancy payments from Eli Lilly, unrelated to the current work

Abstract

Aims

To develop a position statement which identifies research priorities in diabetic kidney disease and provides recommendations to researchers and research funders on how best to address them.

Methods

A one-day research workshop was conducted, bringing together research experts in diabetes and kidney disease, healthcare professionals and people living with diabetes, to identify and prioritise research recommendations.

Results

The following key areas were identified as needing increased focus:

- Understanding causal mechanisms in diabetic kidney disease
- Prevention of diabetic kidney disease
- Addressing health inequalities
- Improving diagnosis
- Improving care
- Supporting self-management

Conclusions

This position statement outlines recommendations to address the urgent need to tackle diabetic kidney disease and calls on the diabetes and kidney research communities to act upon these recommendations to ensure future research works to eliminate unfair and avoidable disparities in health.

Introduction

Diabetes is the leading cause of kidney disease in the UK. It occurs in up to 50% of those living with diabetes, is a major cause of end-stage kidney disease that requires treatment with dialysis or renal transplantation and is associated with significantly increased cardiovascular morbidity and mortality. There is limited funding for kidney research with only 1% of the UK non-commercial research spend invested in this general area and much less for diabetic kidney disease (DKD) specifically. From a lived experience perspective, people with diabetes often receive little information about the causes and prevention of DKD, even though around 1 in 3 will develop the condition during their lifetime[1,2].

Diabetes UK, Breakthrough T1D (formerly JDRF) and Kidney Research UK share common interests in preventing people living with diabetes from developing kidney disease, finding ways to protect kidney health for people living with kidney disease and developing treatments to reduce the damage caused by kidney disease/ to kidneys.

Following an initial review of funding in this area, the charities highlighted the need for a workshop bringing together the diabetes and kidney communities to build consensus on evidence gaps and identify areas where additional research is needed.

Methods

In February 2024, Diabetes UK, Breakthrough T1D and Kidney Research UK brought together clinicians, academics, and people with lived experience for a 1-day workshop to identify key gaps in the evidence and best practice around DKD. In total, there were 38 participants, including 6 people living with or affected by diabetes, 14 researchers, 14 healthcare professionals (including GPs, consultants, nurses, a psychologist, pharmacists, and dietitians), 2 charity and advocacy organisations, 2 health economists, and 11 Diabetes UK, Kidney Research UK and Breakthrough T1D staff who facilitated the workshop. Participants are listed in Appendix A.

When determining the scope and format of the workshop, an expert advisory group made up of 1 researcher, 1 healthcare professional, and 2 people living with diabetes was convened to guide the design of the workshop. A survey was also conducted amongst people with lived experience to help design the workshop. Insights gathered were clustered into six thematic areas (see below), which were used to direct roundtable discussions at the workshop.

Thematic areas

1. Causes
2. Diagnosis
3. Prevention
4. Treatments
5. Day-to-day management
6. Improved care

The workshop commenced with presentations from experts in the field (listed in Appendix B), followed by a fireside chat where people living with diabetes and kidney disease shared their experiences. Following these presentations, all workshop participants self-selected into small groups divided into the thematic areas and were asked to discuss the following questions:

- What do we already know about this area, where is there good evidence?
- Where are the gaps in knowledge and where is further evidence needed?
- From your lived experience, what would you say are the common questions or issues you face that go unanswered when visiting clinic?
- From what you are hearing, are there any areas you think researchers/clinicians are not addressing that are important to you?
- What are the burning questions?

Responses to these questions were collated and themed by the facilitators. Participants were then invited to self-select a theme they would like to discuss in more detail. Each group was then asked to refine the research questions relative to their topic, answering the following questions:

- What is the specific research question(s)?
- What are the opportunities?
- What approaches should be taken?
- What are the barriers? Any dependencies? How could they be overcome?
- Who needs to be involved?
- What scale of investment is needed?
- How could this be funded?

This report summarises the outputs from those discussions and outlines key recommendations to address DKD through research. An overview of key recommendations can be found in Table 1.

Findings

Theme 1: Understanding causal mechanisms in diabetic kidney disease

Context

DKD is the clinical manifestation of multiple pathologies in people with diabetes and therefore, we need to think broadly about underlying causes. The pathogenesis of DKD involves modifiable and non-modifiable risk factors such as glucose levels and familial factors. What makes the topic more complex, is that variation in the onset and progression of DKD, and variability in the associated clinical outcomes, depends on factors specific to individuals including ethnicity, deprivation, and other multiple long-term conditions. Therefore, the field would benefit from an individualised approach to the causes of DKD, alongside tackling the social determinants of ill health, which could lead to development of more personalised interventions.

Several burning research questions highlight important gaps in our understanding of the pathogenesis of DKD and its progression[3]. Which molecular processes determine faster compared to slower DKD progression? How do pathological processes differ by diabetes type and how do these processes compare to chronic kidney disease (CKD) in people without diabetes? How do genetic and environmental factors interact in individuals to cause DKD progression[4,5]? How can we best stratify people with DKD based on underlying causal pathways to better guide personalised intervention?[6] Can we identify biomarkers early in disease progression to help stratify people for specific interventions?[7] How do other organs contribute to the development of, or are affected, by DKD? How do sodium-glucose cotransporter 2 (SGLT-2) inhibitors modulate inter-organ communication, particularly between the kidneys, pancreas, liver, eyes and adipose tissue, and what insights can be gained from understanding these effects in relation to mechanisms of DKD progression[8-11]? Can the study of drugs targeting specific pathways in organs such as the pancreas (e.g., glucagon-like peptide-1 (GLP-1) receptor agonists, liver (e.g., PPAR agonists), or the cardiovascular system (e.g., angiotensin-converting enzyme (ACE) inhibitors, SGLT2i, GLP-1 receptor agonists) provide insights into the interconnected mechanisms underlying DKD pathogenesis[12]?

Research recommendations

(1)

A. Improve understanding of DKD pathogenesis
- *i.* through the integration of data at multiple levels: molecular, cellular, organ, person, and societal.
- *ii.* through developing research in large diverse populations including the creation of a UK-wide DKD longitudinal biorepository/registry. These approaches would make use of prospectively collected electronic health records NHS data, histological and tissue level data, multi-omics data, and analysis using machine learning and AI techniques to help untangle the network of complex causal pathways.
- *iii.* through developing an international platform for knowledge/data sharing
- *iv.* through developing better animal models of human DKD, kidney organoids derived from patient cells and improved *in vivo* imaging technologies.
- *v.* by identifying shared molecular mechanisms underlying DKD and other diabetes-related complications.

vi. through studying medication with beneficial effects on DKD progression.

B. Find effective ways to improve engagement of diverse populations in the co-design and participation in interventional trials targeting novel molecular pathways.

C. Research and identify the most appropriate way of communicating DKD risk, its causes and prevention, with people living and working with diabetes.

Theme 2: Prevention of diabetic kidney disease

Context

DKD is a complex condition influenced by non-modifiable risk factors such as chronological age, age at onset of diabetes, duration of diabetes, and inherited genetic phenotype[13]. It is also influenced by risk factors that are amenable to prevention strategies such as smoking, hyperglycaemia, hypertension, dyslipidaemia, overweight and obesity, diet, physical activity, drugs such as steroids and diuretics, and environmental impacts[14].

There are personal health and economic drivers to prevent diabetes and the subsequent development of kidney disease. Intensive management of modifiable risk factors decreases the cumulative incidence of kidney disease in many, but not all, people with diabetes. We are yet to understand why some people who meet glucose targets develop DKD, while others whose glucose levels are not well controlled are protected from developing DKD.

For people with diabetes, cost-effective screening strategies for kidney disease should be routinely employed, but implementation is sub-optimal[14]. While improved biomarkers for the earlier detection of kidney disease are required, best use is not being made of those that are well established. There is a need to develop personalised prediction and prevention tools that help identify people at increased risk to enable earlier therapeutic interventions. An effective prevention strategy for DKD includes consideration of environmental exposures across the life course, community engagement, understanding of biological mechanisms underlying disease risks and interventions that increase resilience to DKD, alongside sustained, evidence-based public health messages.

Significant investment has been made to raise awareness of diabetes and complications of diabetes, for example training days for health and social care professionals, presentations at workshops, conferences and annual meetings, embedding screening guidelines and diagnostic tools in undergraduate curricula, and continuing professional development training, but significant knowledge gaps remain. Investing in education and intensive intervention strategies reduces the prevalence of diabetes and associated complications, particularly when implemented shortly after a timely diagnosis[15-18]. Leveraging digital innovations such as clinical decisional support tools, online platforms, social media, wearable technology, self-management apps, community groups, and remote / virtual healthcare delivery supports people on their diabetes journey and can facilitate diabetes management and DKD prevention strategies. More research is required to maximise awareness of diabetes and improve education strategies that optimise the management of diabetes, ultimately reducing the onset and progression of DKD.

Research recommendations
(2)

A. Development of cohorts sampled across their life course with biomarkers linked to comprehensive exposure data, health and social care systems, residential, and occupational information.

B. Research to increase mechanistic understanding of how different risk factors and external exposures interact at an individual level.

C. Multidisciplinary research considering social determinants of health to co-create interventions that address underlying health inequalities.

D. Research exploring the barriers to routine urine testing for kidney disease in people with diabetes and how to overcome these barriers (Early identification of kidney damage is a key aspect of prevention, particularly with new and emerging therapies becoming available.)
E. Review of Polypharmacy and drugs available to support prevention of DKD.
F. Exploring how best to encourage patients and families to take a more active role in their care, considering health behaviour models when co-designing strategies that promote adherence to medicines, healthy behaviours including weight management, and appropriate physical activity.
G. Development, evaluation, and implementation of age-appropriate digital tools and peer / community support strategies that support people living with diabetes to develop and maintain a lifestyle that optimises healthy kidneys.

Theme 3: Addressing health inequalities

Context

A 2024 cross-sectional analysis of a large primary care database highlighted inequalities in DKD management in the UK[19]. This study highlighted inequalities with respect to socio-economic factors, ethnicity, age and sex. For example, females were less likely to have: biochemical measures recorded in the previous year, blood pressure or cholesterol measures at or better-than target levels and be prescribed statins or renin-angiotensin-aldosterone system (RAAS) inhibitors. Phillips et al. reported reduced biochemical and health measurements in individuals with lower socio-economic status (defined by the Townsend deprivation score (based on the participants postcode)), as well as different prescribing patterns depending on ethnicity. Intriguingly, the study reported that ethnicity data was missing for 46% of individuals and socio-economic data missing for 27% of individuals, reflecting the often observed 'data-gap' that makes research on such inequalities challenging[19].

Ozaki et al. investigated the prescribing patterns of (SGLT2) inhibitors in 208,303 individuals from Canada with concomitant type 2 diabetes (T2D) and atherosclerotic cardiovascular disease (CVD)[20]. Female sex, aged 75 years or older, having history of heart failure and kidney disease, and low income were independent factors predicting lower SGLT2 inhibitor prescribing. For example, prescribing of SGLT2 inhibitors was 47.3% higher in those without CKD compared to those with CKD[20].

A 2023 UK Kidney Association (UKKA) report highlighted that adults whose ethnicity was Other, Black, Asian or Mixed were more likely to experience kidney failure, and develop kidney failure at a younger age, compared to adults whose ethnicity was White[21]. This report also highlighted that a high proportion (65-81%) of adults whose ethnicity was Other, Black, Asian or Mixed were living in regions of above average deprivation; only 53% of individuals of white ethnicity lived in such regions. Diabetes was the leading cause of kidney disease across ethnicities, but the proportion of individuals experiencing DKD was higher in adults whose ethnicity was Other (31%), Black (35%), Asian (46%) or Mixed (33%) compared to individuals of White ethnicity (25%).

Prevention strategies minimise the risk of type 2 diabetes and the onset of micro and macrovascular complications associated with diabetes. Risk factors for poorer patient outcomes include being from a Black, Asian, or minority ethnic group, older age, socioeconomic deprivation, and BMI >30 – all features where individuals may be less engaged with national healthcare services and yet who would benefit from tailored protective strategies[19,22]. Exacerbating such inequalities, is the fact that most biomarkers identified for

DKD are based on research in White Caucasian individuals. There are known genetic differences affecting the progression of kidney disease in certain ethnicities[23].

Additional multi-ethnic research is required so that health, social, and biological data is representative of communities living with diabetes, enabling them to benefit from data-driven digital health improvements[24]. Emerging strategies to engage with underserved communities include the Diabetes Prevention Program for underserved populations[25], group clinics for young adults in ethnically diverse and socioeconomically deprived communities[26], and partnering with faith-based organizations, schools, workplaces, community development groups, and social service organisations to reach socially disadvantaged communities and positively influence health behaviours[27].However, there remains a significant knowledge gap as to how these are best implemented.

More research is needed to understand the fundamental causes of health inequalities, so that adequate interventions can be developed to overcome them. Research must first fill the 'data gap', ensuring that high quality data is available to carry out high-powered investigations to explore the impact of ethnicity, sex, age and socio-economic factors across kidney disease stages[28].

Research recommendations
(3)

A. Establish links with underserved communities, exploring how best to empower people living with diabetes to advocate for optimised, coordinated care, and shared decision-making.
B. Conduct participatory action research [29] engaging individuals who have lived experience, researchers and HCPs, to design and refine public health prevention strategies, medication adherence, and care delivery models for diabetes.
C. Explore enablers and barriers to implementing and accessing structured educational intervention programmes, to help inform how future programmes should be co-designed, co-created, and implemented for underserved communities.
D. Deliver a scoping review for digital exclusion, with a focus on attitudes to digital tools supporting those with, or at risk of, diabetes alongside barriers to digital participation.
E. Audit of implementation of agreed and optimal diabetes care pathways [30-33], exploring the real time impact of prevention strategies for patient outcomes across diverse groups.
F. Identify barriers to recording ethnicity in general practice and which methods could be used to improve this.
G. Identify which groups of people are currently under-diagnosed, or experience poorer disease management, with respect to DKD and determine to what degree health inequalities are responsible for the under-representation or under-management of these groups.
    i. Obtain information about these under-represented or under-managed groups, such as key demographics and outcomes.
    ii. Understand how interventions can be implemented to increase diagnosis and management in these groups.
H. Utilise the advanced knowledge gained via the points above to update expected prevalence models of DKD.

Theme 4: Improving diagnosis

Developing better biomarkers/tools for the early detection of diabetic kidney disease

Context

DKD is usually diagnosed if patients with diabetes develop albuminuria or a persistent reduction in glomerular filtration rate. Kidney biopsies to confirm the presence of diabetic nephropathy are not routinely carried out, meaning a DKD diagnosis is often given based on presence of CKD in patients with diabetes[34-35].
The biggest barrier to early diagnosis is failure to recognise albuminuria and not using established markers of DKD earlier. Current mechanisms of measuring albuminuria (a reliable and validated marker of DKD detection and progression) have been problematic with variable penetrance into routine practice.

However, the course of kidney disease in patients with type 1 diabetes, and many with type 2 diabetes, is heterogeneous; not always following the classic CKD pathway of progressive hyperfiltration (increasing levels of albuminuria) and then progressive kidney function decline leading to end stage kidney disease (ESKD) [34,36]. Studies have shown a large proportion of individuals with diabetes and reduced estimated glomerular filtration rate, who do not have significant albuminuria[37-40]. Moreover, inequalities have been observed in how well patients with diabetes are monitored and managed based on sex, socio-economic factors, CKD stage, age and ethnicity[19,37], putting particular groups of patients at increased risk of more rapid kidney function decline.

Work is needed to improve and standardise the monitoring and management of diabetes, to reduce the risk of kidney function decline. Moreover, novel methods to detect kidney function decline at an earlier stage and predict those who may decline at a faster rate, are needed. This is particularly important to identify DKD in patients who may not present with the earlier albuminuria marker and might otherwise be overlooked. Effective interventions and medications are available upon DKD diagnosis[41], emphasising the importance of early detection.

Research recommendations
(4)

A. Identify interventions which increase the use of albuminuria testing in routine care
B. Identify new biomarkers for DKD diagnosis and risk stratification.
    i. Embrace innovative approaches, including basic research, data science, machine learning, advanced genomics, such as long-read DNA sequencing, to uncover novel patterns and associations.
    ii. Explore common underlying mechanisms of diabetes and learn from shared mechanisms of disease to better understand potential biomarkers i.e. hypertension.
C. Identify and understand the underlying heterogeneous subtypes of kidney disease to enable personalised treatment and monitoring.
D. Embrace a multi-ethnic perspective to capture diverse genetic and environmental factors.
E. Engage with patient communities to understand various disease subtypes/endotypes and their experiences.
F. Utilise longitudinal- and cohort-based studies, ensuring these studies are representative of the wider population.
G. Expand data-driven studies, establishing robust registries, and enhancing population-based research initiatives.
H. Build collaborations between research centres, data repositories, industry partners, healthcare services and universities.

Improving rates of diabetic kidney disease diagnosis

Context
NICE guidelines recommend estimated glomerular filtration rate (eGFR) and urine albumin: creatinine ratio (uACR) testing for patients with diabetes, and in the UK, this is to be included

in an annual diabetes review[42,43]. Early screening for albuminuria is a crucial step in the identification of kidney damage[44] and for monitoring kidney function[45]. However, the UK National Diabetes Audit (2019/2020) reported that whilst 94.4% of patients diagnosed with type 2 diabetes had a measurement of serum creatinine (sCrea), only 61.1% had a measurement of urine albumin. These values decreased to 85.7% and 52.7%, respectively, after the COVID-19 pandemic[46,47]. Phillips et al. reported similar results via a cross-sectional analysis of the IQVIA Medical Research Data in the UK. They reported that for patients with diabetes (type 1 or type 2) and CKD, 92.7% had sCrea and 59.7% had albumin: creatinine ratio (ACR) measured within the previous year[19]. This study highlighted inequalities in testing with people aged 81 years and older and 18–30 years, 9% and 69%, less likely to have ACR measured respectively[19]. Female patients were less likely to have sCrea and ACR measurements compared to male patients (sCrea - Male: 93%, Female: 92%; ACR - Male: 62%, Female: 58%)[19]. Patients with type 1 diabetes, compared to type 2 diabetes, were also less likely to have sCrea and ACR measurements (sCrea - T1D: 88 %, T2D: 93%; ACR - T1D: 46%, T2D: 61%)[19].

Unfortunately, there is evidence that lack of timely identification of CKD is a longstanding problem. A 2015 analysis among just under 13,000 people with incident CKD stages 3-5 in the south of England identified that only about a third had uACR testing over a three-year period[48]. Among people with diabetes at study entry, only 18.8% were registered as having CKD within a year of it being identified from eGFR values.

Further research is needed to understand why clinicians may not request urine samples and/or why patients may not provide them. Obtaining urine samples for testing can be difficult, leading to frustration and challenges in diagnosis. Sex-specific factors may also exist with regards to uptake of urine testing. Informational needs for females have been explored in the context of urinary tract infections[49] but have not yet been investigated in the context of DKD. Research into novel diagnostic approaches that do not rely on urine samples may improve DKD detection and accessibility for certain patient populations. There may be health system factors that impose significant barriers to diagnosis, such as lack of time in primary care, care structured around single-condition paradigms and education of the healthcare workforce[50].

While patients are often aware of diabetes, they may lack understanding about CKD and its implications. ‘Think Kidneys’ is an NHS England programme, and in partnership with the UK Renal Registry and Ipsos MORI, they released the report ‘Understanding what the public know about their kidneys and what they do’ in 2015[51,52]. This report, surveying 2,005 residents of Great Britain (older than 15), highlighted a clear knowledge gap in this area. Only 51% of respondents were aware that the kidneys made urine, with 10% of respondents aware that the kidneys help to control blood pressure. Moreover, only 0.3% of respondents reported diabetes as one of the ‘biggest danger(s) to the health of your kidneys’[51].

Effective communication strategies are required to convey the implications of CKD diagnoses to patients and to support health care providers in this endeavour. Additionally, risk assessment tools such as the Kidney Failure Risk Equation (KFRE) can aid in discussing diagnoses, particularly for older individuals without proteinuria, and can assist general practitioners in their referral strategy[52]. Improvements in health service organisation are also needed to ensure that urine sample collection is facilitated in practice to reduce barriers for patients and clinicians.

Research recommendations
(4)
Healthcare provider engagement:

I. Determine what interventions are needed in primary care and beyond to improve diagnosis of kidney disease in people living with diabetes.

i. Identify opportunities to expand beyond primary care, harnessing already available infrastructure.
ii. Investigate the feasibility of 'one-stop shop' opportunities for diagnosis.
iii. Explore alternatives for current diagnostic tests
iv. Establish the health economic benefits of such interventions.

J. Explore incentivisation of health care providers and other system-level methods designed to encourage wider uACR testing and determine whether paying for or providing vouchers for patients would encourage them to seek and take up testing.
K. Explore methods to enhance education among general practitioners regarding CKD management in diabetes, including awareness of proteinuria and updated diagnostic criteria, such as Kidney Disease Improving Global Outcomes (KDIGO) guidelines [41] and implementing the Kidney Failure Risk Equation (KRFE) in practice [52].

Patient engagement:

L. Ask those living with diabetes how access to and uptake of testing could be improved including:
i. Speaking to different communities to understand the variation in approaches needed.
ii. Modeling these different approaches in health economic evaluations.
iii. Utilise the knowledge of people with lived expertise to understand the best way to communicate the need for testing, as well as understanding the psychological impact of diagnosis and the associated burden or offset by long-term reduced progression.
iv. Working with community leaders to increase the visibility of people taking tests.

M. Explore the potential benefits of providing patients with their KDIGO chart and determine its impact on understanding and management.

Research institute engagement:

N. Develop 'better biomarkers/tools for the early detection of diabetic kidney disease', as outlined in the research prevention and diagnosis themes above.
O. Determine who should undergo screening for DKD based on risk factors and population characteristics.
i. Include an awareness of current inequalities, as outlined in the 'Understanding and addressing inequalities' theme above.
P. Considering genetic variations and rare forms of kidney disease in diagnostic processes is necessary for comprehensive care.

Theme 5: Improving care

Context

Extensive guidelines are in place for the management of DKD [53,54], but they are not implemented effectively. It is important to understand and investigate both the barriers and enablers of improved care so that effective service transformation can focus on the early development of DKD. An important question is to understand the impact of removing uACR from the Quality and Outcomes Framework (QoF) evaluation in England on the early identification of those with DKD, and what opportunities exist for ensuring early screening and prevention in primary care[55].
Philip et al[19] identified inequalities in outcomes for people with diabetes and CKD among different socioeconomic groups, sex, and ethnicities. Particular attention needs to be paid to investigating how to engage these at-risk groups and to understand what novel interventions can be employed to prevent worse outcomes in this cohort. The work needs to evaluate the

impact of low health literacy, multiple long-term conditions, ethnicity, and socioeconomic groups on novel interventions so that outcomes for those with the worst outcomes can be improved.

Models of care for this cohort need to be holistic, with a particular focus on healthcare settings so that people living with DKD experience integration of the interactions they need to improve outcomes[56]. Co-production or evidence-based co-design is a method of engaging with communities through partnership and power-sharing between professionals and communities to collaboratively create models of care, solutions, and decisions. The aim is to improve healthcare delivery and outcomes in the long term[57].
Screening for diabetes distress and depression in those with DKD is important and can inform about how low mood impacts engagement, outcomes, and well-being.

Research recommendations:
(5)

A. Evaluate the most effective strategies to improve the implementation of existing guidelines for DKD management with identification of barriers to early screening and prevention of DKD in primary care, and how these can be overcome.
B. Assessment of whether the removal of uACR from the QoF evaluation in England affects the early identification of DKD, and identification of alternative markers that could be used for early detection.
C. Develop novel interventions to prevent worse outcomes in patients at high risk of DKD, considering factors such as low health literacy, multiple long-term conditions, ethnicity, and socioeconomic status.
D. Identify the most effective methods for screening and managing distress and depression in patients with DKD, and how these impact engagement, outcomes, and well-being.
E. Assessment of the long-term outcomes of various interventions for DKD, including medication, lifestyle changes, and surgical interventions.
F. Explore the role genetic factors play in the development and progression of DKD, and development of approaches which use this knowledge to personalise treatment and prevention strategies.
G. Explore how digital health technologies can be leveraged to improve self-management and monitoring of DKD.
H. Identify the most effective models of care for DKD, and how these can be implemented across healthcare settings to ensure equitable access and outcomes for all patients.
I. Evaluation of the safety, feasibility, acceptability and efficacy of using Hybrid Closed Loop in people with diabetes on dialysis.

Theme 6: Supporting self-management

Context
Self-management is an integral part of living with chronic disease. It encompasses making behavioural choices (exercise, diet), taking medication, and use of medical technology. In young people, there is a known challenge of moving from paediatric to adult care, which often impacts on the management of chronic conditions including diabetes and kidney disease[58].

Research has shown that most patients in weight loss clinics regain weight, and that maintaining weight loss with the conventional approaches is very difficult, if not impossible[59]. Unfortunately, the societal approach with regards to blaming overweight/obesity on

individuals has caused untold damage with patients struggling to lose weight or maintain weight being unfairly stigmatised and demotivated.

By the time a patient with diabetes has been diagnosed with DKD, they typically have a long-standing history of having received conflicting information by a range of health professionals, potentially feeling stigmatised/blamed for not having managed their diabetes, weight or blood sugar well enough, and struggling to access relevant appropriately targeted information. For example, many patients with DKD find it hard to get meaningful life-style advice: available nutritional information for DKD is primarily written for pre-dialysis patients who need to restrict potassium and/or phosphate, whilst for the majority of patients with less severe DKD and diabetes, a healthy Mediterranean diet with reduced salt and red meat intake would be appropriate[60]. Many health professionals engaging with these patients do not have an overview or understanding of which self-management choices are appropriate for multiple long-term conditions. There is a wide differential in knowledge and health literacy which further aggravates existing population health inequalities.

Research recommendations
(6)

A. Development and evaluation of healthcare professional educational interventions to raise awareness of evidence based self-management resulting in improved care for people with DKD.
B. Development and evaluation of a structured education programme for people living with DKD.
C. Explore the use of patient reported outcome measures (PROMs) in routine clinical management/ engagement to monitor and support self-management

Conclusion

This research workshop was an important step in understanding the actions needed to help tackle diabetic kidney disease through research. Whilst these recommendations are designed by UK stakeholders with a focus on the UK health system, there is broader international relevance for the majority of recommendations.
Diabetes UK, Breakthrough T1D and Kidney Research UK call on researchers, funders, health services, and people living with or affected by Diabetes and/or Diabetic Kidney Disease to act upon the recommendations set out within this paper.

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