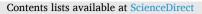
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A conceptual framework to assess the health, socioeconomic and environmental burden of chronic kidney disease

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ABSTRACT

Chronic kidney disease (CKD) is a global health challenge that affects patients, caregivers, healthcare systems, the environment and national economies. Despite its far-reaching impact, there is no framework to systematically evaluate national CKD prevention and management programmes or evaluate the societal burden of disease. This paper has two objectives: first, to introduce a comprehensive framework to assess national programmes, which recognises gaps and weaknesses and identifies feasible policy interventions to reduce overall CKD burden; second, to present some key challenges and success stories in delivering CKD services delivered in eight different country settings.

A literature review informed an initial version of the framework, which was further developed and refined via collaboration with a panel of UK experts across relevant disciplines. This framework was then presented to seven other country expert panels (Australia, Brazil, China, Germany, the Netherlands, Spain and the USA) that made further refinements based on their country perspective. The resultant framework covers all health system levels, from preventive public health measures to primary, secondary and tertiary care, including dialysis, transplantation and palliative care. Furthermore, it evaluates the disease burden from economic, social and environmental perspectives. Each panel also discussed challenges regarding providing CKD services in their country and provided success stories, generating valuable insights into areas where policy initiatives could have positive impact on the various components of burden of disease.

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1. Background

The growing burden of chronic kidney disease (CKD) demands urgent attention from health systems, policymakers and researchers. CKD stands out as one of the most prevalent non-communicable diseases globally. The estimated global prevalence is approximately 10 % [1], affecting >850 million individuals [2]. In the period from 1990 to 2017, there was a notable 29.3 % increase in the global all-age prevalence of CKD and a staggering 41.5 % rise in mortality. These alarming statistics translate to CKD being responsible for approximately 1.2 million deaths in 2017 alone [3]. In 2019, the WHO listed CKD as the 10th most common cause of death [4]. Deaths from CKD are likely underestimated due to the lack of renal registries in many countries and misattribution to other causes, such as cardiovascular disease (CVD). A positive correlation exists between CKD and age, meaning the increasing prevalence will likely worsen as populations age. In many countries, the rising prevalence of obesity, metabolic syndrome and CVD may further drive increases in CKD. Almost two-thirds of CKD cases co-occur with diabetes and hypertension [5,6], both of which are projected to increase significantly over the coming years [7–9]. There exists a significant disparity in CKD rates both within and between countries, with a disproportionate burden often affecting socio-economically disadvantaged populations [9,10]. This inequality can be partially attributed to advancements in treating related and predisposing conditions as age-adjusted prevalence is presently not rising in many high- and middle-income nations [3]. Nonetheless, the absolute number of individuals afflicted by CKD has been surging globally, primarily owing to demographic shifts [10], particularly in low- and middle-income countries. Rapid urbanisation and lifestyle alterations in these regions are additional catalysts for the increasing prevalence of non-communicable diseases [11]. Moreover, low- and middle-income countries often face significant barriers to accessing effective treatment, compounding the issue.

The implications of CKD for patients and their families are considerable. Patients receiving dialysis require a significant amount of care, including transport to and from dialysis units or assistance with peritoneal dialysis. The impact on quality of life, particularly once kidney failure occurs, is devastating. Patients with CKD also frequently experience multiple comorbidities such as CVD, diabetes and hypertension. As a result, a multidisciplinary care approach involving multiple professionals is often necessary to improve outcomes [11].

The rising burden of CKD has serious economic consequences. In high- and middle-income settings, CKD is among the costliest conditions to treat. The International Society of Nephrology estimates that in many developed countries, approximately 2-3 % of annual healthcare spending is attributable to treating kidney failure [12]. A recent report from the UK estimated that spending on kidney disease amounts to 3.2 % of the National Health Service's (NHS) total annual budget [13]. In the USA in 2020, spending on individuals with CKD was more than US\$75 billion, corresponding to approximately 25 % of total Medicare fee-for-service spending, despite patients 66 years of age or older with CKD representing only 13.9 % of Medicare fee-for-service enrolees [14]. In Brazil, between 2013 and 2015, 13 % of total healthcare expenditure was related to kidney disease and related diseases, and kidney replacement therapy accounted for 5 % of the costs to the Unified Healthcare System for medium- and high-complexity treatments [15]. Additionally, CKD is recognised as being one of the leading causes of catastrophic household spending on healthcare globally [16-18]. This is particularly notable in low- and middle-income countries, where universal health coverage is often inadequate, and many costs may be borne 100 % out-of-pocket [19].

The management of CKD has considerable environmental implications, particularly regarding dialysis treatment [20]. Patient transport, the production, transportation and disposal of dialysis-related waste, and the energy and water consumption associated with the process contribute to the disease's environmental footprint. Given that health systems account for as much as 10 % of total emissions in some countries, action should be taken to reduce their carbon footprint [21], with CKD considered an essential contributor to this [22].

A broad understanding of the clinical progression of CKD is essential to the context of this paper. Fig. 1 provides a high-level overview of CKD progression and management. CKD is clinically staged from 1 (normal kidney function) to 5 (severe impairment or kidney failure). Wellintegrated interdisciplinary care is vital, particularly as CKD progresses and clinical needs rise. For this reason, Fig. 1 does not attempt to divide the pathway by health-system level. However, in most settings, primary care practitioners will manage the bulk of patients with earlystage CKD, advising on lifestyle, adequately managing cardiovascular risk factors and comorbidities such as diabetes and hypertension, and prescribing medications that reduce renal and cardiovascular risk. As CKD progresses, referral to nephrology is necessary, and management of the disease will increasingly sit within secondary (and tertiary) care. Primary care will remain involved throughout the pathway, for monitoring, prescribing and providing support for other conditions. For patients who progress to more severe kidney damage/failure, decisions will be made regarding the appropriateness of kidney replacement therapy (dialysis or transplant). In elderly, frail and multimorbid patients, a palliative/conservative care plan may be favoured instead [23].

The health, socioeconomic and environmental costs of CKD escalate significantly as the disease progresses, and the insidious nature of CKD means that many patients are unaware of their illness until it has progressed considerably. The US Centers for Disease Control and Prevention estimates that 9 in 10 adults with CKD are unaware of their condition [24]. Modelling indicates that the societal, economic and environmental costs linked to CKD could be significantly reduced through the early identification of more individuals and the prompt initiation of treatment [18]. The need for early identification through targeted screening is evident, but has not been prioritised by the majority of healthcare systems. A report from the International Society of Nephrology in 2023 revealed that merely 25 % of countries have established national CKD detection programmes [1]. Routine testing of urine albumin-to-creatinine ratio (UACR) in at-risk patients is not widely practised, even in many high-income countries. However, it is crucial when determining prognosis and the downstream risk of cardiovascular complications. Together, poor awareness and insufficient efforts to educate policymakers, the public and other stakeholders have led to CKD being a relatively neglected disease, the impact of which is underestimated by many [25].

Conceptual frameworks are essential tools for guiding health systems research and policy, providing a structured approach to understanding complex problems and identifying potential interventions [26]. However, to our knowledge, no comprehensive framework has been developed for the interaction between CKD-focused policy and the societal burden of disease. A more holistic view of the burden of CKD could drive more efficient policy interventions and improve outcomes for patients and healthcare systems globally. The project described in this paper drew on the knowledge and experience of panels of experts from eight countries, representative of different health system archetypes and demographics. The first objective was to build a comprehensive conceptual framework for CKD that could guide the assessment of health system policies and approaches to the prevention, treatment and management of CKD, and to understand its health, socioeconomic and environmental costs. The second objective was to gain insights regarding any gaps, challenges and successes in the CKD pathway and describe emerging common themes that could be valuable lessons to policymakers and those responsible for planning and delivering health services.

2. Methods

A four-stage modular approach was used to develop the CKD framework and gather the qualitative data required for a thematic analysis of the gaps, challenges and successes in CKD service delivery. The process started with a narrative review of the literature to identify

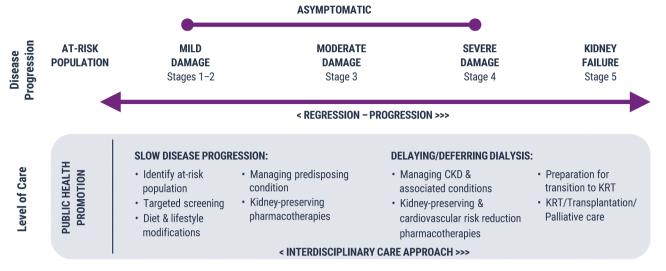


Fig. 1. Complete CKD patient pathway encompassing prevention and screening to treatment and management. *CKD, chronic kidney disease; KRT, kidney replacement therapy.*

the most salient elements of CKD and its impact on individuals and the broader health system (Supplementary Fig. 1).

2.1. Stage one – narrative literature review

The objective of the literature review was to inform the building of a preliminary version of the CKD framework (see stage two) which was to be used as a starting point in the subsequent panel discussions (see stages three and four). It therefore had two focal points. The first identified sources outlining the ideal components for the prevention, detection and management of CKD. For pragmatic reasons, this focused initially on the current UK guidelines for CKD [27]. Documents discussing internationally recognised CKD management guidelines were also incorporated [28-30] to account for national variations in the CKD pathway and capture the nuances in care across different country health systems. This drew on documents such as those detailed in Supplementary Table 1 to support the conceptualisation of the various components and perspectives of the CKD pathway. The second component of the search aimed to identify relevant literature describing existing frameworks addressing the management of chronic diseases, including CKD. The purpose was to identify and build on work already performed in the field, identify similarities in management and treatment between CKD and other chronic diseases, and inform the development of the CKD framework. Keywords and phrases were added to the search terms, including conceptual model, chronic kidney disease, management, treatment of CKD, disease model, healthcare access and disparities in healthcare access.

The search generated the keywords and phrases listed in Supplementary Table 2. We used these to retrieve additional publications from databases, including MEDLINE, PubMed and EMBASE. We also used Internet search engines, such as Google Scholar, to retrieve further articles and additional grey literature, such as international reports and surveys. Searches were limited by publication date from March 2012 to March 2022 and restricted to articles written in English. One of the researchers was responsible for screening titles and abstracts, and selection was made based on relevance to the identified CKD pathway components. Overall, 78 items were retrieved and thoroughly assessed, resulting in a final 38 items of relevance (Fig. 2).

2.2. Stage two – building the preliminary framework

Having reviewed the materials retrieved from the literature review, a first version of the framework was developed via collaborative

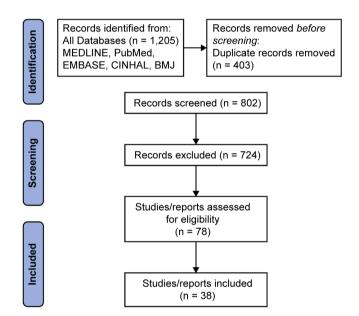


Fig. 2. Prisma diagram summarising the results of the narrative literature review.

discussions to identify the main components of the framework and the critical elements within these components. The process resulted in overarching domains reflecting disease progression, elements in CKD service delivery and underpinning principles of care. Components were divided between system-level and patient-level burden of disease. This preliminary version endeavoured to encompass all aspects of the CKD pathway and all possible health, socioeconomic and environmental impacts (see Appendix 1).

2.3. Stage three – validating the preliminary framework using the UK as the pilot country

The preliminary framework was presented to a panel of 10 UK CKD experts, based on purposive sampling [31], and drawn from relevant disciplines, including public health, primary care, nephrology, transplant surgery, sustainable healthcare and health economics (see Appendix 3 for panel composition).

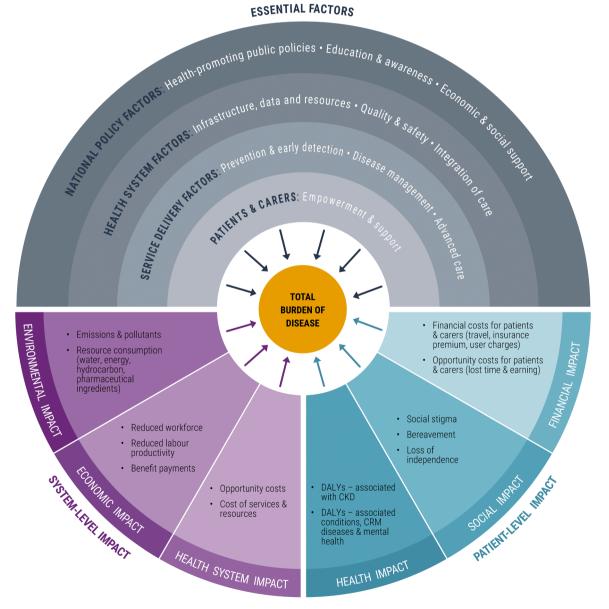
A virtual 90-minute recorded meeting was convened to discuss the

framework and its application to the UK context. Guided by a set of 11 predetermined questions (Appendix 2), the panel advised on whether the framework was comprehensive and accurately captured the representation of best practice. The questions attempted to capture the overarching elements of the framework's structure and its ability to reflect key components in CKD service delivery. The framework was then compared with existing clinical practice in the UK to identify missing elements. The discussion concluded with identifying potential gaps from a system-level perspective at which policy recommendations could be targeted at a health-system, environmental and individual patient level. The panel were encouraged to consider any challenges or barriers to providing CKD care in the UK setting, and how these might be overcome. The expert panel members were also encouraged to email any further thoughts or questions. After the meeting, the framework underwent revisions to incorporate the key points discussed and a technical report summarising the expert feedback was drafted to guide the modifications made. The revised framework, alongside the technical report, was sent via email to the UK panel members for additional

feedback, which was then integrated into the second iteration of the framework.

2.4. Stage four – further refinement of the framework via multi-country expert panels

The final stage convened seven expert panels, which attempted to expand and contextualise the framework to a broader set of country health system archetypes (Australia, Brazil, China, Germany, the Netherlands, Spain and the USA) (see Appendix 3 for panel composition). These panels advised on the adaptability of the framework to their country setting, and how it would encompass various health system archetypes. The meetings were guided by the same set of 11 predetermined questions as the UK meeting (Appendix 2). As before, the framework was compared with existing in-country clinical practice to identify missing elements and identify potential gaps from a systemlevel perspective that could be addressed via policy change. The panels were asked to consider any challenges and barriers to providing



ESSENTIAL FACTORS

Fig. 3. CKD framework. The top half of the framework represents essential factors to consider in the appraisal of national CKD services, and the bottom half represents the different components of the societal burden of disease. CKMS, Cardiovascular-Kidney-Metabolic Syndrome; DALY, disability-adjusted life year.

Table 1

Factors to consider in the appraisal of national CKD services.

Essential factors for assessing national ser	rvices	Factors specific to CKD Food and nutrition policies
National policy factors	Health-promoting public policies	
		Environmental and urban health policies
		Action on social and commercial determinants of health
	Education and awareness	Public health campaigns
		School-based health education
	Provide and assistances	Media engagement for CKD awareness
	Economic and social support	Workplace accommodations
		Fair financing and financial risk protection Social security for CKD patients and carers
Health system factors	Infrastructure, data and resources	Equity in resource allocation
Health System factors	illiastructure, data and resources	Workforce planning and development
		Investment in medicines and technologies
		Health economics and technology assessment
		Comprehensive digital health infrastructure and disease registries
	Quality and safety	Patient safety initiatives
	Quality and safety	Evidence-based clinical guidelines
		Continuous professional development
		Monitoring and improvement of care processes
		Performance-based incentives for healthcare providers
	Integration of care	Multidisciplinary care teams
	integration of care	Care transition management
		Defined referral processes and consultation mechanisms
		Interagency collaboration and multi-system interfacing
CKD service delivery factors	Prevention and early detection	Risk factor screening programmes
Skill service derivery factors		Data analytics for risk stratification
		Targeted interventions for high-risk groups
		Regular kidney function monitoring
		Genetic screening and counselling
	Disease management	Comorbidity management
		Personalised treatment plans
		Lifestyle modification programmes
		Nutritional support and counselling
		Telemedicine and remote monitoring
		Medication management and adherence support
	Advanced CKD care	Timely initiation of kidney replacement therapy
		Access to various dialysis modalities
		Kidney transplantation programmes
		Conservative care options
		Palliative and end-of-life care
		Ethical guidelines for complex cases and advanced care planning
Patients and carers	Empowerment and support	Health literacy and self-management support
		Psychosocial support services
		Peer support networks
		Shared decision-making processes
		Culturally sensitive and inclusive practices

the highest standard of CKD care in their country setting and to proffer any potential solutions to these. The choice of countries was intended to provide a range of diverse health systems and economic contexts, but was also partly pragmatic, based on existing contacts of the author team in those jurisdictions. Each panel included at least one public health expert, one primary care expert, one nephrologist, one expert on sustainable healthcare, one health economist and one patient representative (Appendix 3).

These expert panels were presented with the second iteration of the CKD framework. The meetings were guided by the same questions used for the UK expert panel meeting. All 90-minute sessions were recorded, and a technical report that captured the discussion points and expert feedback was drafted and subsequently shared with the participants. Experts were encouraged to provide any further input via email. These reports formed the basis of the thematic analysis conducted by the research team to capture nuances in CKD service delivery in the different settings and the resulting impact at a system and individual patient level. After concluding all expert meetings, the framework underwent additional updates to encompass any further suggestions. This iteration was subsequently circulated among all expert panel members leading to final refinements, and an approved version of the framework endorsed by all experts involved.

3. Results

3.1. Overview of the CKD framework

Here we present the CKD framework (Fig. 3) and explore the key themes that arose from the expert panel meetings, illustrated by examples of challenges and successes in the eight countries.

In the top half, the concentric layers depict the various systemic levels impacting service delivery. Table 1 uses this part of the framework to consider the various elements necessary for good practice in delivering CKD care. The elements in the layers are interdependent, mutually exclusive and collectively exhaustive, intending to demonstrate the necessity for a holistic approach.

The bottom half represents the multiple societal burdens attributable to the disease. System-level impacts are shown on the left (in purple). The effects on patients and carers are shown on the right (in blue).

The relationships between the essential factors in the top half and the societal burden of disease in the bottom half are multiple and complex and are not represented in the framework. Instead, we can extrapolate the relationships and hypothesise how improvements to the CKD pathway would positively impact on the societal burden of disease. For example, where user charges apply, what impact would removing these

Table 2

Prominent themes that arose during the expert panel meetings.

Framework factor	Theme	Possible solutions discussed by the expert panels
	Public health programmes and primary care capacity	
National Policy	Few public health programmes focus on kidney health.	 Implement programmes to mitigate population's risk factors for CKD. Improve kidney health literacy.
		 Deploy culturally sensitive educational campaigns.
Service Delivery	Comprehensive population screening programmes for CKD are rare.	Implement screening programmes targeting high-risk groups.Deploy strategies to reach marginalised communities.
National Policy / Financial Impact	Financial incentive programmes are needed to increase CKD screening and enhance follow-up.	• Ensure services are adequately reimbursed and incentivised throughout the care pathway.
Service Delivery	Primary care service provision is overstretched.	Provide clear screening guidelines.Provide financial incentives for primary care to promote adherence to
		guidance.Increase workforce capacity to deliver holistic follow-up and patient education.
	Care quality and responsiveness	
Health System	There is a need for improved cultural awareness and programmes for marginalised groups.	 Designate funding for outreach services in marginalised communities. Engage community and faith leaders when developing policy.
Service Delivery	Conservative care should be considered over dialysis for frail multimorbid patients.	 Ensure guidance is in place to support conservative care. Facilitate candid discussions between patients and caregivers about treatment options.
Service Delivery	There are persistent inconsistencies in the implementation of guidelines across regions. Access to care	• Promote consistent implementation of screening and treatment guidelines through national financial incentives.
Service Delivery	There are significant disparities in access to CKD services due to geographic distribution of care.	Enhance follow-up and review through telemedicine services/virtual clinics.
		 Deploy mobile dialysis units to remote communities.
National Policy / Financial Impact	Financial barriers to screening and treatment persist in some countries.	Review national user charge policies to mitigate delayed diagnoses and foregone care.
		Enhance patient/carer benefits to support any costs associated with accessing care.
	Digital health technologies	0
Health System	There is a need to bridge health data gaps and facilitate linkage	 Improve Health IT and databases for data collection.
	between health operating systems. Environmental burden of disease	Facilitate interoperability among healthcare operating systems.
Environmental Impact	There is poor investment in green technologies to mitigate the environmental impact of dialysis.	Adopt practices minimising water, energy and material consumption.Enable waste recycling and water reuse strategies.

have on diagnosis rates and slowing progression of disease?

3.2. Prominent themes arising from the country expert panels

The framework's components and various themes were developed interactively during the eight country expert panel meetings. The meetings covered many topics, some specific to individual country contexts. Recurring themes emerged, shared by several or all countries, exhibiting a high level of consensus. Table 2 provides a summary of the key themes, arranged according to the corresponding factors of the framework.

3.2.1. Public health programmes and primary care capacity Few public health programmes have a focus on kidney health.

All our country panels agreed that national CKD programmes should include public health initiatives to mitigate population risk factors. Evidence from the literature has also demonstrated that socioeconomically disadvantaged groups face higher CKD risks [32-34], and several country-level surveys have reported limited public awareness regarding kidney function and disease risk factors [35-37]. However, the expert panels highlighted shortfalls in targeted public health interventions for CKD in their countries. Problems discussed included relatively poor public health funding and the fact that preventative care often lost out in the competition for funding with curative services and the prioritisation of other disease areas. Additionally, the expert panels reported a lack of initiatives to improve health literacy around kidney disease or efforts to educate the public regarding lifestyle modifications that may mitigate risk. It was highlighted that for educational campaigns to be effective, they must be consistently conducted over time, emphasising the necessity for continual commitment and sustained efforts.

Nevertheless, some positive examples do exist. For instance, in 2014, the NHS in England launched the 'Think Kidneys' campaign [38], an

initiative led by the renal community and supported by NHS England and the UK Renal Registry. Its objectives were 'raising awareness of our kidneys, their importance for life and health and how to look after them'. The campaign attempted to reach as many people as possible through NHS units and the media, and won an award at the Health Business Awards in 2016.

Early detection and assertive intervention may slow disease progression and mitigate the need for dialysis or transplantation. However, population screening programmes for CKD are rare.

Evidence from the literature on the utility of routine population-wide screening for CKD has been equivocal, and guidance generally recommends that only high-risk populations be targeted [39,40]. However, even in high-income settings, the prevalence of undiagnosed stage 3 CKD is high [41]. It has been suggested that the advent of new, effective treatments for CKD may dramatically improve long-term outcomes, thus making population-wide screening cost-effective, provided treatment is initiated promptly and assertively [42]. The primary care physicians and nephrologists contributing to the expert panels highlighted that, with timely and appropriate intervention, progression to kidney failure is not inevitable, and that some patients may even experience a modest improvement in kidney function. In all the panel meetings, experts emphasised the importance of public health interventions to prevent kidney disease and primary care's key role in early detection and management. While specific population-wide screening for CKD isn't conducted in the countries covered in this paper, instances of preventive health checks, such as those in Germany, were provided as examples. The adult health check in Germany is offered free of charge to all adults covered by statutory insurance older than 18 years [43]. Between the ages of 18 and 35, adults can attend once, but after the age of 35, the check can be performed every three years. It helps detect type 2 diabetes (T2D) and CVD but could also help to identify those at risk of CKD. Patients are asked questions about lifestyle, medical history and family

illnesses. A physical examination, including blood pressure, is carried out, and blood samples are taken for glucose and lipids. A urine dipstick is also carried out to check for protein, glucose and blood, which may help identify those with kidney disease.

A lack of appropriate incentives leads to insufficient screening, even in high-risk populations.

All of our country panels, except China, reported that national guidelines were in place for detecting and managing CKD. Most expert panels reported routine population screening programmes for diabetes and hypertension. In some countries, such as the UK, incentives were in place to encourage adherence to guidelines [44,45]. However, specific screening for CKD was not included in these programmes (although it was often recommended for high-risk groups), and the UK, Spanish and Chinese panels all commented on the fact that UACR measurements were not routinely performed, even in patients with known risk factors. The UK expert panel highlighted that in 2018, the measurement of UACR in patients with diabetes had been removed from the Quality Outcomes Framework, the UK's incentive reward scheme for primary care physicians [46]. Other essential factors discussed included the accuracy of available screening options, cost, laboratory infrastructure, clinical time and patient acceptability. Additionally, the German expert panel described how reimbursement schemes are poorly designed to encourage physicians to order screening tests for CKD.

Nevertheless, certain countries have initiated efforts to improve population screening. For example, in the Netherlands, the pilot SALINE study (Screening for Albuminuria at the first LINE primary care) [47] is trialling screening for albuminuria in targeted groups – patients with diabetes, hypertension, hypercholesterolaemia, CVD or obesity. The aims are to estimate the prevalence of elevated albuminuria in high-risk individuals and evaluate which screening approach delivered via primary care (including pharmacies) is most effective, based on costs per identified patient with elevated albuminuria.

Primary care is overstretched, and provision is patchy in some countries, leading to scattered access and delayed diagnosis.

All the country panels discussed at length the crucial role of primary care in the prevention, screening, detection and early management of CKD. However, they also described significant challenges facing primary care services in providing adequate services for CKD. Primary care services were frequently described as overstretched, presenting general challenges to service provision. Some countries, such as Germany and Australia, reported that short contact times impede the provision of complete information regarding diagnosis or lifestyle advice. Others, such as China and Brazil, noted that primary care provision is patchy and concentrated in urban areas. The German and Brazilian expert panels also highlighted problems in providing adequate training to primary care physicians, given their broad remit and the many treatment guidelines they must adhere to.

However, there have been efforts to improve access to lifestyle modification programmes in the Netherlands. The Dutch Combined Lifestyle Intervention Scheme is primarily aimed at overweight or obese individuals, a group at high risk of developing CKD [48]. This scheme is a reimbursable programme that primary care physicians can refer individuals to. The aim is to prevent or mitigate the risk of chronic lifestyle-related diseases such as T2D. Advice and interventions are provided to help individuals manage their weight, including referral to a lifestyle coach, physiotherapist, remedial therapist or dietitian. Although the programme is not designed explicitly with CKD in mind, it could help to reduce the incidence of CKD in high-risk individuals.

3.2.2. Care quality and responsiveness

There is a need for tailored programmes for marginalised groups and greater cultural awareness in the design of services for patients with CKD.

The expert panels discussed marginalised groups in their countries who have high rates of CKD and poor outcomes. The need for culturally sensitive services was frequently discussed, as was the need to implement deliberate efforts to engage marginalised groups. All felt that consultation with community members in designing and implementing engagement strategies was necessary. The Australian and US expert panels discussed challenges associated with engaging indigenous Australians and Native Americans with services owing to historical trauma and resultant mistrust of the healthcare system. The Brazilian panel spoke of how disparities in provision, predominantly affecting rural areas, disproportionately affected marginalised groups. All the panels advocated for improved programmes and incentives to provide care to these communities.

Despite these challenges, the USA has had success in engaging Native Americans through the Indian Health Service (IHS) [49]. Native Americans have high rates of T2D, almost twice the national average diagnosis rate. This often leads to complications, including kidney failure. However, over the past two decades, a public health model initiated by the IHS, an agency of the US Public Health Service, has led to a 54 % reduction in kidney failure due to diabetes. Health staff and community health workers were trained at many health facilities run by the IHS or the Native American tribes themselves. Workshops and early intervention strategies were implemented to promote evidence-based interventions with proven efficacy.

Additionally, a highly successful and innovative telenephrology clinic has helped to deliver care to isolated and remote communities in New Mexico. This has mainly been aimed at patients with advanced kidney failure, delivering ongoing multidisciplinary care from a nephrologist and other professionals in a highly collaborative model [50].

Another related and frequently discussed topic was the need to engage the whole population in national screening programmes, and how achieving this goal hinges on the population's level of trust in the system. Developing approaches that are culturally appropriate and acceptable was considered essential. The panels discussed how cultural interpretations of illness, and any stigma attached, may determine whether people will present for screening and treatment. There are specific instances in which cultural interpretations are widespread and problematic, as advised by our Chinese expert panel. In traditional Chinese medicine, kidneys are closely associated with sexual function [51]. Therefore, a diagnosis of CKD may be misunderstood and seen as potentially adversely affecting sexual function and fertility. This results in significant stigma being associated with kidney disease, which could affect many aspects of an individual's life, including their relationships, marital status and even their work. The Chinese expert panel reflected that sensitive and thoughtful solutions are required to overcome this barrier and fully implement effective screening programmes.

Conservative care should be considered for very elderly, multimorbid and frail patients as an alternative to dialysis.

The expert panels, most notably those of the UK and Australia, discussed how, in some circumstances, conservative/palliative care is more appropriate than dialysis [52]. They were keen to emphasise that in very elderly, frail and multimorbid patients, the decision to start dialysis should not be taken lightly, and that the balance between prolonging life and maximising quality of life should be considered very carefully. The experts highlighted the fact that with ageing populations globally, an increasing proportion of individuals with kidney failure will also be very elderly and multimorbid. In such cases, initiating dialysis is often inappropriate and renal supportive care is a more acceptable pathway for patients and their families. For example, our Australian panel pointed us towards the clear and regularly reviewed guidance for renal supportive care [53] in New South Wales. The approach is nurse-led and involves collaboration between renal medicine and palliative care, supporting patients with advanced CKD and kidney failure who are making decisions regarding whether to continue or pursue kidney replacement therapies. The model aims to ensure a consistent approach to renal supportive care across New South Wales and to enable patients and their carers to live as well as possible via symptom management, advanced care planning and end-of-life care.

There are unwarranted variations in the implementation of guidelines across different regions.

All the expert panels agreed that clinical guidelines and protocols must be in place to clearly lay out expectations for screening, diagnosis, treatment and onward referral. All the countries in scope had guidelines in place; however, it was often reported that these were not consistently followed. Regional differences were particularly pronounced in countries with a decentralised structure, such as Brazil, China, Spain and the USA.

This problem was linked to a lack of incentives to follow guidance and poor data collection and reporting, thus hampering benchmarking and comparison between regions and healthcare providers. Our Spanish panel shared two initiatives in Spain aimed at encouraging consistency in the management of CKD across Spain's autonomous regions. Spain has a highly decentralised political structure comprising 17 autonomous communities and two autonomous cities in North Africa, resulting in high variability in implementing national guidelines around the detection and management of CKD. This has been identified as an issue that needs attention and was addressed by a 2016 Sistema Nacional de Salud (SNS) clinical practice guideline and a national consensus among 10 scientific societies for managing CKD, which was updated in 2022 [54,55].

3.2.3. Access to care

Geographical challenges lead to inequities in the provision of services for all stages.

Across most of the countries, there was a mismatch in terms of the distribution of services and level of need, and concerns were raised regarding equitable access to care. This often entailed a concentration of services in urban areas, typically favouring wealthier regions, leading to waiting lists for accessing specific treatments and specialities. These challenges were more pronounced for the geographically larger countries in our sample (Australia, Brazil, China and the USA), where many patients must travel several hours to access dialysis and other forms of clinical care.

Rolling out telehealth services to more remote communities was frequently discussed as one effective strategy to alleviate these challenges. However, the experts also highlighted barriers to telehealth, for example, poor IT literacy, limited internet access in remote communities and limited health IT development in low-income settings. The experts were keen to emphasise that these issues significantly impact on the most vulnerable populations, and that care must be taken to prevent widening health inequalities. Additionally, significant challenges of delivering dialysis to remote regions were emphasised. For example, the Australian panel discussed how many indigenous Australians live in remote communities far from centres providing dialysis despite this population having higher rates of CKD and kidney failure than nonindigenous Australians [56]. They told us about the Purple House, a service established and funded by indigenous Australian artists, which provides dialysis to remote Aboriginal communities in Western Australia [57]. It has established 10 dialysis units with 22 dialysis machines in remote locations, providing care to individuals who would otherwise have to move away from their families and communities to receive the needed treatment. Additionally, the Purple Truck, a two-chair dialysis unit, travels around Central Australia, visiting remote communities and allowing patients to take a break from lengthy journeys to access care.

Financial barriers to screening and treatment are a challenge in some countries.

Most services are covered either fully or partially by public insurance and statutory benefits packages in most of the countries in our sample. However, access to care was sometimes hampered by co-payments. The expert panels all discussed at length how effective screening and detection are dependent on universal health coverage and equitable access to services. They highlighted that financial impediments result in foregone screening and/or treatment, resulting in late-stage detection of CKD and inadequate treatment. In some countries, out-of-pocket expenses may be incurred in accessing screening, attending office visits, acquiring essential medicines (also for predisposing conditions) and other interventions, including dialysis.

In addition, our expert panels raised other indirect expenses for patients and carers. These included the cost of travel, which is often substantial and not always subsidised. Those of employable age, particularly in the later stages of CKD, are likely to have to reduce their working hours or give up working. Associated mental health conditions may also have an impact on the ability to work full-time. Furthermore, as previously mentioned, the experts underlined that the risk of CKD is positively correlated with pre-existing socioeconomic deprivation, and that these combined factors may lead to significant financial hardship for patients, carers and their families. Our panel members suggested that financial benefits given to patients and carers should be reviewed to ensure they did not fall into poverty or be impoverished by the costs of accessing care. The Chinese panel told us how, in China, co-payments have an impact on access to screening and treatment, and that disparities in reimbursement policies between regions cause inequities in access to care. The Chinese experts reported that although there have been improvements in achieving universal health coverage in China over recent years, coverage for non-communicable diseases remains challenging [58,59]. The US panel outlined how out-of-pocket maximums and co-payments at the point of care or for medicines cause delays in seeking screening, diagnosis and treatment [60]. They also reported that co-payments for the treatment of predisposing or comorbid conditions have an impact on outcomes.

3.2.4. Digital health technologies

Data are inconsistent and patchy, with poor linkage between subsystems and providers.

The great potential of sophisticated IT and data systems to improve the detection and management of CKD was a key theme raised by all our country panels. They advocated for national registers of patients with CKD, ideally disaggregated by stage, with linked records to other conditions, and inclusive of demographic and socioeconomic data. They discussed how these would be a value-add in terms of planning and evaluation of services and the development of targeted national public health initiatives and screening programmes. However, such comprehensive systems did not exist in our country sample. A common thread was insufficient data collection and poor linkage of IT systems. The experts reflected that this was partly symptomatic of a broader issue around health IT fragmentation; however, it was particularly marked in countries with a federalised structure, such as Spain and Brazil, where regional databases were not always linked to a national database. The panels agreed that significant improvements to care could be realised through improved IT systems, and this related to improving clinical pathways, providing better-integrated care and supporting the planning of services. The UK and Australian expert panels shared how national registers of CKD patients have been established in their countries, providing examples of ways to improve data consistency on a countrywide scale. The Quality and Outcomes Framework, the UK's incentive scheme for primary care, stipulates that primary care physicians must keep a register of all patients diagnosed with CKD stage 3 or above. However, no records are required for patients with CKD stages 1 or 2. Additionally, the data are not necessarily linked to records on related conditions such as diabetes or CVD [61]. In Australia, the ANZDATA Registry [62] has complete capture of all patients undergoing maintenance dialysis or living with a kidney transplant; however, ANZDATA does not capture the vast majority of people with CKD who have not undergone transplantation or are undergoing dialysis.

3.2.5. Environmental impact

Dialysis greatly impacts the environment, but there is poor investment in green technologies to mitigate this.

It is well known that dialysis, particularly haemodialysis, has a significant environmental impact, using large quantities of water and energy and generating high volumes of clinical waste [63]. Our country expert panels advised that although there is an increasing awareness of the need to find more environmentally friendly kidney care strategies, much remains to be done to address this matter. Some of the panels, notably Australia and Brazil, discussed the implications in terms of water usage. Dialysis requires high volumes of purified water, and each haemodialysis session uses approximately 500 litres [64]. Globally, it is estimated that over 150 billion litres of water are used annually for dialysis; however, two-thirds of this is reverse osmosis water discarded before dialysis [65,66]. In most locations, this water is thrown away; however, it could have many different uses in the hospital setting, including the generation of steam for sterilisation of equipment and use in laundry, sanitation services and landscaping. The Brazilian and Australian panels advised that water reuse projects have been implemented in some regions to try to combat this problem.

4. Discussion

This paper presents a framework intended to serve as a tool to assess national care pathways for CKD and its associated impacts. It also explores the challenges, barriers and success stories from eight different country contexts regarding their experience in providing services for this complex condition. The framework is deliberately broad in scope and aims to facilitate an analysis of national systems for the prevention, detection and management of CKD, encompassing various levels of the health system and related sectors. To our knowledge, it is the first attempt to synthesise the multiple societal burdens presented by CKD, encompassing the health and economic impacts and the societal and environmental implications. It is interesting to reflect that, although the framework was initially built from the results of a narrative literature review and the views of the UK expert panel, only minor modifications were suggested when presented to the other seven country expert panels. There was a high degree of concordance between all our experts regarding the key components of the framework, despite markedly different cultural and geographical contexts between countries.

The panel discussions revealed many challenges and success stories peculiar to each country's circumstances. These stories serve well to illustrate the themes of our analysis, and to highlight both the commonalities and differences between different jurisdictions. Some of the themes, such as capacity in primary care and the stage of health IT development, were issues that all our country panels described as challenging. However, other issues had greater relevance for certain jurisdictions depending on underlying factors such as geography, health system structure, climate and culture. For example, the geographic distribution of services and outreach to remote communities was far more relevant to Australia, China, Brazil and the USA than smaller European countries. Cultural interpretations of health and sickness had particular significance for China; water availability for dialysis was especially important to Australia and Brazil, and financial barriers to care were particularly evident in China and the USA.

One key point, discussed extensively by all our country panels, is that although effective screening tools and treatment strategies are available for CKD, and most high-income countries have detailed policies and guidelines in place, these are not consistently implemented. This is relevant to many of the themes of the analysis and leads to problems in providing access to equitable and effective care. Our experts were unanimous in their view that proper implementation of existing CKD guidelines was key to mitigating some of the impacts of CKD. They were clear that full implementation of national and international guidelines would enhance screening and diagnosis, slow disease progression and prevent a proportion of individuals from progressing to end-stage disease. However, policymakers must be cognisant of the fact that in order to facilitate proper adherence to CKD guidelines, it is necessary to take a holistic, systems-based approach as laid out in our framework. This approach will require attention to many different factors, including public health and primary care, digital capacity, reimbursement mechanisms, workforce, education, training and provision of adequate resources and infrastructure.

A strength of our project is that it was developed with the input of 50 experts from the field of CKD and other fields affected by CKD, drawn from across relevant disciplines, and from eight different countries. From the outset, there was a high degree of concordance in terms of the contents of the framework and the importance of the various domains. However, we acknowledge that despite the number of experts consulted, there is inevitably a degree of subjectivity regarding the selection of the key components of the framework and the factors which emerged as the dominant themes during the panel meetings. Given the high degree of concordance on the components of the framework, we hope that it should be adaptable to other contexts and settings, generating further exploration of the barriers to implementing gold-standard CKD care, and helpful examples of overcoming these. However, we are mindful that the countries chosen for this project were all high- or middle-income, and that the framework might need considerable adjustment for more resource-constrained settings. Additionally, when it comes to utilising the framework for assessing the impact of disease, poor or inconsistent data availability may be a challenge in many countries.

5. Conclusion

Without significant policy interventions, CKD will present an increasing burden to health systems, society and the environment globally over the coming decades. We hope that this paper, through the provision of a comprehensive adaptable framework and the rich insights from several different country contexts, will add to the compelling evidence that CKD is an area of healthcare that warrants more attention and investment from governments and health systems. More work is needed to determine what specific policies could drive improvements in the care pathway, and how these might be adapted to different country settings. This will require elevating CKD in the health policy agenda globally; as such, efforts are currently under way to leverage the insights gathered through this work in order to develop a set of recommendations that will be effectively positioned to drive improvements across the CKD care pathway.

Disclaimer

The expert panel members consulted for this paper are not liable or responsible for its contents.

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CRediT authorship contribution statement

Charlotte Johnston-Webber: Writing – review & editing, Writing – original draft, Project administration, Conceptualization. Isaac Bencomo-Bermudez: Writing – review & editing, Writing – original draft, Project administration, Conceptualization. George Wharton: Writing – review & editing, Writing – original draft, Project administration, Conceptualization. Robin van Kessel: Writing – review & editing. Salvatore Barone: Writing – review & editing. Francisco Brotons Muntó: Writing – review & editing. Steven Chadban: Writing – review & editing. Juan Jose Garcia Sanchez: Writing – review & editing, Conceptualization. Janwillem W.H. Kocks: Writing – review & editing. Kyra Obolensky: Writing – review & editing. Petra Sandow: Writing – review & editing. Neil Skolnik: Writing – review & editing. Ming-Hui Zhao: Writing – review & editing. Alexei Volaco: Writing – review & editing. David C. Wheeler: Writing – review & editing. Alistair McGuire: Writing – review & editing, Supervision. Elias Mossialos: Writing – review & editing, Supervision.

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Supplementary materials

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