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# A national survey of current rehabilitation service provisions for people living with chronic kidney disease in the UK: implications for policy and practice

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## Abstract

**Background** National guidance recognises the key role of rehabilitation in improving outcomes for people living with chronic kidney disease. Implementation of this guidance is reliant upon an adequate and skilled rehabilitation workforce. Data relating to this is currently lacking within the UK. This survey aimed to identify variations and good practices in kidney physiotherapy (PT), occupational therapy (OT) and clinical exercise physiologist (CEP) provision; and to understand barriers to implementation.

**Methods** An online survey was sent to all 87 UK kidney units between June 2022 and January 2023. Data was collected on the provision of therapy services, barriers to service provision and responses to the COVID-19 pandemic. The quantitative survey was analysed using descriptive statistics. Free-text responses were explored using reflexive thematic analysis.

**Results** Forty-five units (52%) responded. Seventeen (38%) units reported having a PT and 15 (33%) an OT with a specialist kidney role; one unit (7%) had access to a CEP. Thirty units (67%) offered inpatient therapy services, ten (22%) outpatient therapy clinics, six (13%) intradialytic exercise, six (13%) symptom management and three (7%) outpatient rehabilitation. Qualitative data revealed lack of money/funding and time (both  $n = 35$ , 85% and  $n = 34$ , 83% respectively) were the main barriers to delivering kidney-specific therapy. Responders saw an increase in the complexity of their caseload, a reduction in staffing levels and consequently, service provision during the COVID-19 pandemic. Exemplars of innovative service delivery, including hybrid digital and remote services, were viewed as positive responses to the COVID-19 pandemic.

**Conclusion** Despite clear evidence of the benefits of rehabilitation, across the UK, there remains limited and variable access to kidney-specific therapy services. Equitable access to kidney-specific rehabilitation services is urgently required to support people to 'live well' with kidney disease.

**Keywords** Allied health professional, Chronic kidney disease, Exercise, Rehabilitation, Well-being, Physiotherapy, Occupational therapy, Clinical exercise physiologist, Workforce

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## Introduction

There are approximately 3.5 million people in the United Kingdom (UK) living with chronic kidney disease (CKD) [1]. Advanced CKD is associated with a higher prevalence of multimorbidity and frailty [2–4], functional deterioration, increased symptom burden, anxiety, depression and cognitive decline [5–10]. These factors contribute to elevated levels of treatment burden, healthcare utilisation, and negatively impact on quality of life [5, 11].

Given the complex needs of people with CKD, the importance of a holistic and person-centred approach to care, which moves beyond the traditional medico-pharmacological approach, is being increasingly recognised [12]. This focus is also important to people with CKD and their caregivers, who identify life participation as the outcome of primary importance to them [13]. Access to timely and appropriate rehabilitation, defined as ‘a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environment’ [14], is a key element of this holistic approach. Over the last 10–15 years increasing evidence has emerged regarding the benefits of exercise in the management of CKD [15]. Many papers report that regular exercise can have a positive impact on physical function, muscle and bone strength, depression, and quality of life [16–18]. Others show that it can be beneficial on blood pressure, inflammatory markers, peak oxygen uptake, estimated glomerular filtration rate (eGFR) and mortality [19–21]. Finally, exercise has been shown to improve the experience of distressing symptoms such as restless legs, cramping and fatigue as well as poor sleep quality [21–23]. Increasingly the idea of rehabilitation is expanding beyond just exercise to include a broader range of interventions such as cognitive screening, symptom management and relaxation techniques that can support an individual to live well with kidney disease [8, 24, 25]. For example, Farragher et al. showed a positive response to a fatigue management programme in a dialysis population across multiple measures of fatigue and life participation and an improvement in ability to complete daily activities [26].

The UK Renal Medicine ‘Getting It Right First Time’ (GIRFT) report [27] and the Renal Services Transformation Plan (RSTP) [28] both recognise the need for holistic kidney care, including the commissioning of a suitable multi-professional workforce required to effectively deliver a holistic approach to care [27–29]. In addition, national [30, 31] and international guidelines [32–34] highlight the importance of exercise rehabilitation as integral to holistic kidney care. The World Health Organisation has recognised the importance of rehabilitation in its Rehabilitation 2030 initiative as a ‘critical health strategy’ and identifies the lack of access to appropriately

trained professionals as a major issue [35]. Rehabilitation as a core intervention in the management of kidney disease has a growing international profile, with organisations such as the Global Renal Exercise Program (GREX) and the European Association of Rehabilitation in CKD highlighting the importance of education and research in the field [36, 37].

Within the UK, rehabilitation is typically provided by physiotherapists (PTs), occupational therapists (OTs), and increasingly, clinical exercise physiologists (CEPS) [24, 38]. Despite evidence for both the benefit and importance of rehabilitation for people with CKD, a 2014 UK survey of existing practices found that encouragement for exercise from healthcare professionals and access to rehabilitation programmes was limited, with great national variation [39]. Almost ten years after this survey, a contemporaneous understanding of the provision of rehabilitation for people with CKD within the UK, which moves beyond a focus on exercise-based programmes to include more holistic interventions across the UK, is essential to ensure services are both developed in line with the needs and priorities of people with CKD, and meet workforce guidance recommendations [40].

Here, we describe the results of a survey which aimed to (i) describe the current provision of rehabilitation to people with CKD across the UK; (ii) identify areas of regional variance in rehabilitation provision; and (iii) understand current perceptions of barriers to kidney rehabilitation within the UK.

## Methods

A bespoke online survey was created to capture the current provision of therapy services across UK kidney units as described previously [41]. Data was collected for PT, OT, and CEP staff across all bandings. As per the NHS Agenda for Change [42], contract staff are employed to a banding based on skill level and years of experience. See Supplementary Material 1 for an explanation of these bandings [40]. Data was collected from June 2022 to March 2023. Ethical approval was not required (see Supplementary Material 2) and the study was registered as a service evaluation at the University Hospitals of Leicester NHS Trust (audit number: 12007). Completion of the survey was considered indicative of willingness to participate and implied consent.

## Participants and settings

All 87 kidney hub units in the UK, as identified using the UK Kidney Association (UKKA) database were invited to participate in the survey; this included both adult and paediatric centres [43]. Units were grouped into 13 geographical areas (see Supplementary Material 3).

### Survey development

A bespoke online survey was developed using Jisc Online Surveys (Bristol) by a team of academic and clinical specialists in kidney rehabilitation. The survey consisted of four core sections: (1) information on kidney units and staffing; (2) outpatient services (including intradialytic exercise, kidney rehabilitation programmes, and therapy-led clinics); (3) inpatient services; and (4) perceptions of barriers to rehabilitation. Definitions for interventions were provided to ensure consistency of responses. The survey primarily used closed questions to improve speed and ease of completion, with the option for free text comments if respondents wanted to provide additional detail. The concluding section related to perceived barriers to rehabilitation was based on a survey conducted by Greenwood et al. [39]. Responses to questions within this section used a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). A draft of the survey was piloted by therapists from King's College Hospital NHS Foundation Trust, Guy's and St Thomas' NHS Foundation Trust, and University Hospitals of Leicester NHS Trust. Following this, modifications were made to reduce the questionnaire length and improve clarity. The definitive version of the survey is included in Supplementary Material 4. The initial rollout of the survey was delayed due to the outbreak of the COVID-19 pandemic. In 2022, the survey was reviewed and modified to capture how kidney rehabilitation services responded to the pandemic and how they had recovered, prior to beginning data collection.

### Data collection

All UK kidney units [43] were divided into regions, with England split into ten regions. Wales, Scotland, and Northern Ireland were treated as single regions. National professional networks were used to identify regional representatives. The representatives constituted therapy professionals either working specifically or with an interest in kidney care. These representatives helped to identify therapy leads at kidney units and sent invitations via email to complete the survey with personalised follow-up emails at agreed time points. Further invitations were sent to the Clinical Directors of the units who did not initially respond. The survey was advertised via the UKKA. Units that did not complete the survey but responded to say they had no therapy input were included in the analysis.

### Data analysis

Data on the workforce, service provision, and barriers to delivery are presented descriptively as frequency and percentage of the sites responding. All 'free text' box question responses were anonymised and exported to NVIVO version 12 for PC (QSR International). Thematic

analysis was used to determine patterns and descriptive themes across the survey responders [44]. This involved reading and re-reading all 'free text' responses, performing line-by-line coding to summarise key concepts, looking for patterns across the responses and grouping these as themes. A researcher (EC) with extensive qualitative research experience conducted this analysis. Themes were discussed and agreed with all authors.

### Results

Responses were received from 45 units out of a possible 87 (52%). Forty sites were from England, two from Scotland, two from Wales and one from Northern Ireland (see Supplementary Material 5 for a map of unit responses).

#### Access to therapy and staffing provision

Twenty-eight units (62%) reported having access to PT with seventeen (38%) having a majority caseload in kidney care. Seven units (15%) reported having no PT on-site and two units (4%) provided no data. Twenty-eight units (62%) reported having access to OT with fifteen (33%) having a majority caseload in kidney care. Nine units (20%) reported having no OT (see Supplementary Material 6 for the distribution of OT and PT staffing across the UK).

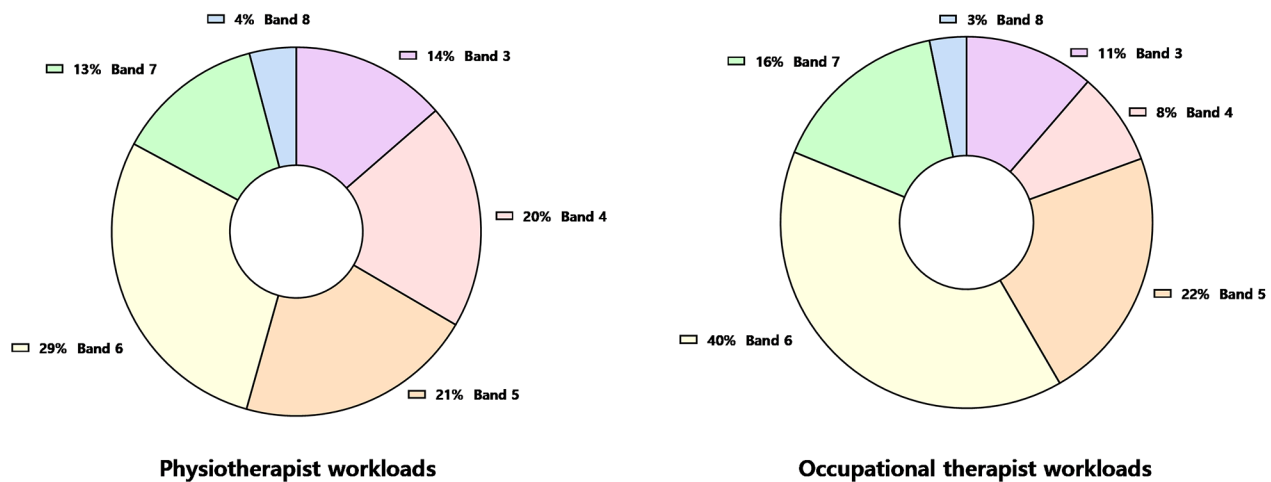
As a proportion of whole time equivalent (WTE), fifty per cent of PTs working in kidney care were Band 5 or 6 (i.e., junior rotational staff) and 34% were Band 3 or Band 4 (i.e., unqualified assistants). For OT, 62% were Band 5 or 6 and 19% were Band 3 or Band 4 (see Fig. 1).

Fourteen units (31%) reported having additional staff to facilitate therapy services in the unit. One site (2%) had an exercise specialist; ten (22%) a dietician; five (11%) a nurse; and four (9%) utilised other staff (psychologist and generic assistant practitioners).

#### Outpatient rehabilitation services

Only three units (7%) provided outpatient kidney-specific rehabilitation services. All three accepted participants with CKD stages 1–5 (non-dialysis), or who had received a transplant or were receiving haemodialysis (HD) or peritoneal dialysis (PD). One site also offered input to kidney donors and another site to people on conservative management pathways. Programme durations ranged from 10 to 12 weeks. Two units offered two classes a week and one offered six. All units provided combined aerobic and resistance exercise programmes with one additionally offering balance exercises. Two units offered a hybrid programme of in-person and virtual delivery and one provided only in-person classes.

Six units (13%) referred people to generic acute or community PT programmes; two (4%) referred to cardiac/pulmonary rehabilitation programmes. Three units (7%) reported signposting people to the Kidney BEAM



**Fig. 1** Staffing quotas of physiotherapists and occupational therapists. Data shown as frequency (percentage) for each banding

[45] digital health intervention. Two units (4%) additionally offered behaviour change support for physical activity, education and symptom management programmes. One unit (2%) offered relaxation sessions.

#### Outpatient therapy clinics

Ten units (22%) offered outpatient therapy-specific kidney clinics. Four units (9%) offered these clinics to people with pre-dialysis CKD, three (7%) for transplant recipients, three (7%) for people receiving HD, three (7%) for people receiving PD, and three (7%) for people receiving conservative management. Units offered a variety of different therapy-specific services during kidney outpatient clinics. Six units (13%) offered mobility assessments, six (13%) offered symptom management, six (13%) provided individualised exercise and physical activity prescriptions, six (13%) offered weight management, four (9%) ran relaxation sessions, three (7%) assessed cognition, three (7%) offered services on an ad hoc basis, two (4%) provided vocational rehabilitation, and one (2%) offered anxiety management. Four units (9%) facilitated meaningful activity. Meaningful activity is defined as having a social quality such as community interaction or a caring role, with purpose and motivation, facilitating feelings of satisfaction, and experiences relating to personal values and belief structures, and thus is closely related to life participation [46].

#### Access to clinical exercise physiologists and associated professionals

Only three units (7%) reported access to any form of CEP, Accredited Exercise Referral Scheme, or Accredited Personal Trainer. Services accessed included diet and exercise assistant practitioners and exercise on referral schemes via community services or the individual's General Practitioner. One unit offered lifestyle support

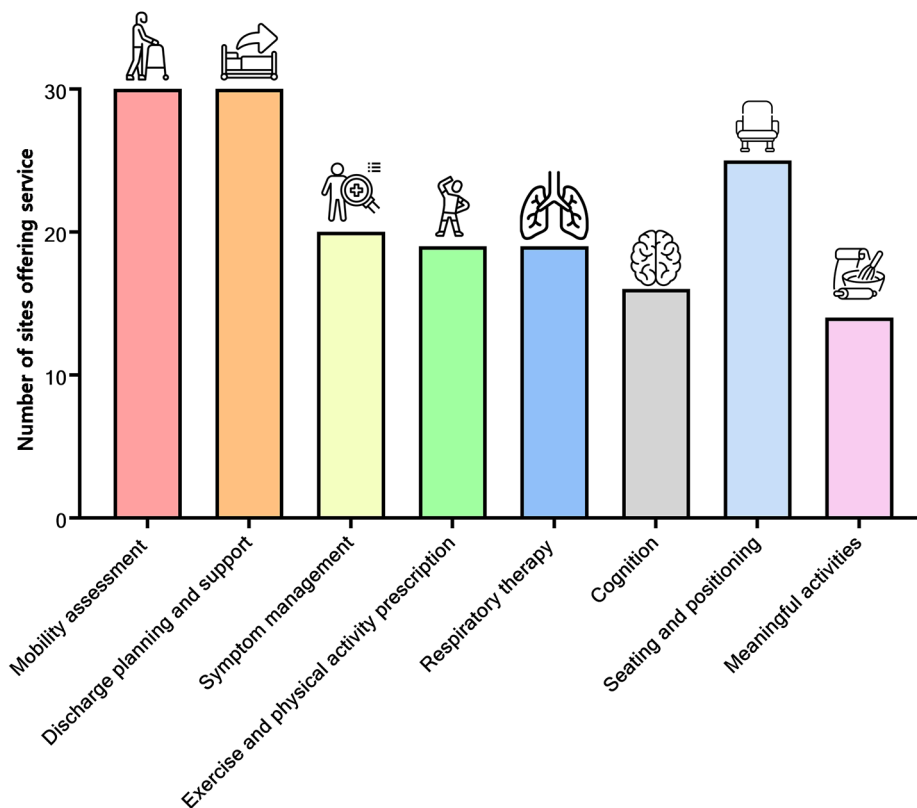
including physical activity advice and body composition assessments.

#### Intradialytic therapy provision

Six units (13%) offered intradialytic exercise with three providing aerobic exercise (cycling) and three a combination of aerobic and resistance exercise. Ten units (22%) offered some form of symptom management. The majority of this was provided by OTs but in some units by PTs and nurses. Interventions included pacing strategies, fatigue, breathlessness or pain management and advice on improving sleep. Four units (9%) facilitated meaningful activities during dialysis, including art therapy, relaxation sessions, reading or activities of daily living (e.g., washing and dressing). Two units (4%) offered another form of meaningful activity such as vocational rehabilitation, mindfulness, schoolwork, or games.

#### Inpatient services

Thirty units (67%) provided inpatient therapy services across pre-dialysis/CKD, transplant, HD, PD and supportive care. One unit also covered acute kidney injury (AKI) caseloads. Services covered on average 34.5 general or low dependency care beds (range 4–70) and on average 5.5 high dependency care beds (range 0–15). High dependency beds are for those requiring enhanced care including more intensive observation, intervention, and nursing support than more stable patients in a low dependency bed. All 30 units provided mobility assessments and discharge planning support (see Fig. 2). In summary, 25 units (56%) assessed for seating and positioning, 20 (44%) provided symptom management, 19 (42%) offered exercise and physical activity prescriptions and respiratory therapy respectively, 16 (36%) supported cognition, and 14 (31%) facilitated meaningful activities. Additionally, some units offered mental capacity



**Fig. 2** Types of inpatient therapy services offered

assessments, OT access visits, breakfast food preparation practice and chair-based yoga classes.

### Barriers to the delivery of kidney therapy

Only 15 units surveyed (35%) had read or were aware of the UKKA clinical practice guideline for exercise and lifestyle in CKD [31]. Responses relating to barriers to the delivery of kidney therapy were gathered from 41 individuals from the 37 units who completed the survey. Figure 3 shows the frequency of responses across each barrier. Thirty-five respondents (85%) either 'agreed' or 'strongly agreed' that 'lack of money/funding' was a primary barrier to services. Other barriers included 'lack of time' (34, 83% either 'agreed' or 'strongly agreed'), 'prioritisation of other services' (31, 76%) and 'lack of qualified personnel for this role' (25, 61%). 'Lack of hard research evidence' was the least frequently reported barrier.

Many services described using charity grants to provide short-term funding for therapy services. Consequently, services were established but then struggled to secure ongoing financial support in the longer term. Other commonly raised barriers were difficulty successfully influencing financial decision-makers who were not familiar with the benefits of therapy provision within the CKD population and selecting outcome measures which would provide compelling evidence of benefits to these

individuals. See Table 1 for illustrative quotes pertaining to barriers.

### Adaptation of services in response to the Covid-19 pandemic

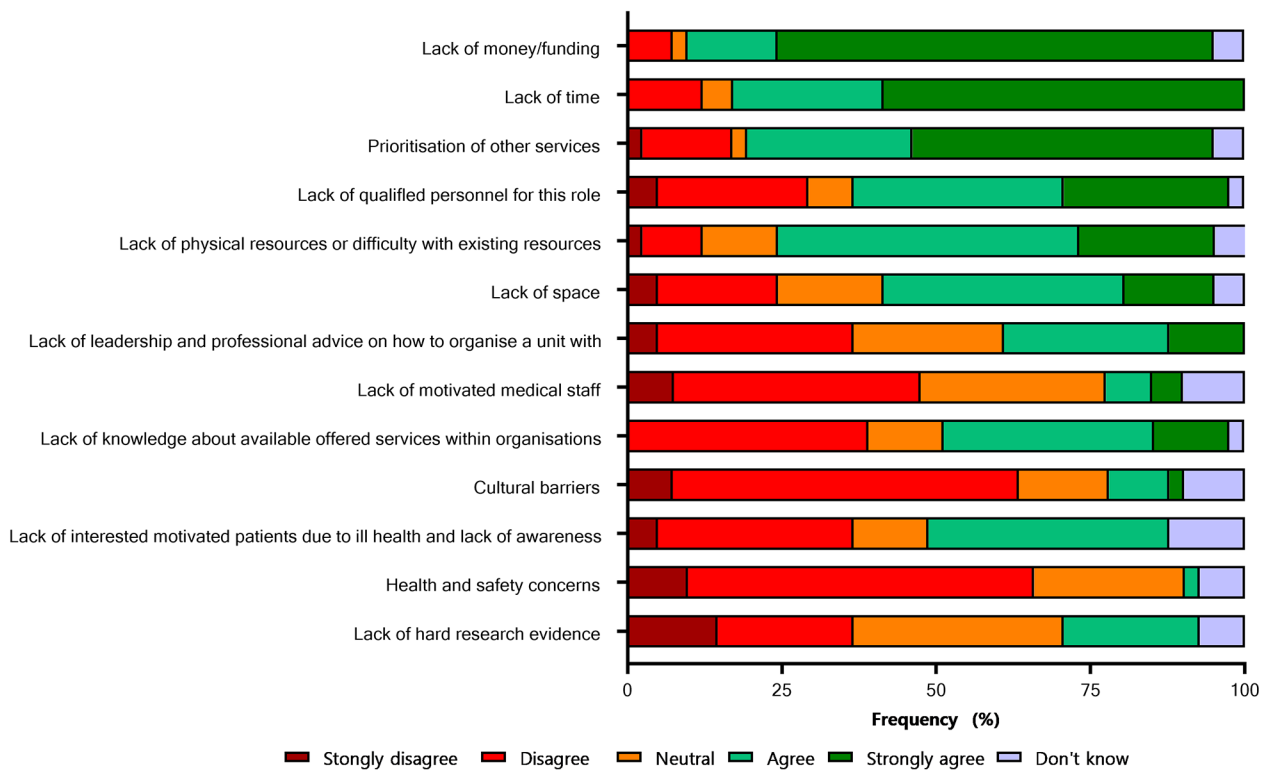
Responses to the impact of the COVID-19 pandemic on kidney therapy and kidney therapy provision are summarised in Table 2. Thematic analysis revealed four key themes: (1) the increase in complexity of the caseload; (2) the impact on staffing and therapy services; (3) the impact on care, and (4) the recovery of therapy services.

#### The increase in complexity of the caseload

Whilst one responder reported no significant change in patient acuity, most responders felt that the pandemic had increased the caseload and the complexity of care required. Patients were more deconditioned, and discharge planning, and social care needs also increased. Overall, the workload increased, and the already scant therapy resources available were further affected (see Table 2).

#### The impact on staffing and therapy services

COVID-19 had a considerable impact on staffing and service provision. Staff were redeployed, and priority was given to acute care rather than rehabilitation. In many



**Fig. 3** Barriers to the delivery of kidney therapy. Data is shown as frequency (percentage) of 42 responders from 37 sites. Barriers are ordered with the highest frequency in those who responded 'Strongly agree'

cases, in-person services ceased, and the delivery of rehabilitation changed. Staffing was also reduced due to sickness and an increase in vacancies, reducing the provision of kidney-specific therapy further.

#### The impact on care

Respondents highlighted a significant impact on the quality of patient care because of the pandemic. In addition to an increase in patient acuity, and a reduction in staffing, barriers relating to COVID-19 appeared to impact therapy services for people living with CKD (See Table 2). These barriers include challenges locating patients due to bed moves, the additional time for donning and doffing Personal Protective Equipment (PPE), balancing infection control, timing rehabilitation around HD treatment, the inability to take patients off the ward for functional assessments, and reduced patient morale due to a lack of visitors.

#### The recovery of therapy services

Whilst there were unique challenges during the COVID-19 pandemic, there were also examples of innovation. Some responders reported a shift to telephone or digital interventions. Reassuringly, all existing services reported having resumed their in-person services, with some continuing to offer people with CKD a hybrid approach to

care, combining in-person, digital and telephone support (see Table 2).

#### Discussion

This survey captured the current provision of therapy services to people with CKD across the UK and demonstrated regional variation in access to services provided by a predominantly rotational workforce. Despite areas of excellent practice, no kidney units are currently meeting therapy workforce guidelines across inpatient and outpatient services for OT, PT and CEP [40]. Current barriers to provision were similar to those reported in 2014 [39]. Overall, despite improvements in access to national [10, 11, 27–31, 40] and international [32–34] guidance supporting the importance of physical activity and the specialist role of therapists in kidney care, this survey has shown limited real-world evidence of this widely being translated into practice.

#### Current provision of rehabilitation to people with CKD across the UK

Results showed that over half of kidney units that responded to the survey had access to OT or PT and just over half of these were specialist kidney therapists. Between 15 and 20% of units had no access to any therapy. Limited access to CEPs was also evident. British

**Table 1** Example free text responses to the barriers to the delivery of kidney therapy

Theme	Illustrative Quotes
Funding	<p>"We ran an exercise on dialysis (static bikes) pilot a few years ago funded by the _ however when the funding for the pilot ran out there was no money from the NHS to continue service." [Responder 1, from large teaching hospital]</p> <p>"Finding funding, creating a new role which kidney services don't always understand." [Responder 2, from a large teaching hospital]</p> <p>"Funding for my post was initially via charitable sources." [Responder 3, from a large teaching hospital]</p>
Understanding of AHP roles	<p>"Resources and time is a big barrier for OT, complex discharge planning, also understanding of our role." [Responder 4, from specialist tertiary service]</p> <p>"No guidelines to assist with knowing how the service should be set up- that's now improved, but also that meant no back-up when trying to justify having renal physio." [Responder 3, from a large teaching hospital]</p>
Resources	<p>"Perceived health and safety concerns mainly from staff, tackled by education and support from consultants. Lack of suitable equipment e.g. dialysis cycles- tried working with industry to shape what's needed and what's available; worked with our technicians to adapt what was available." [Responder 3, from a large teaching hospital]</p>
Impact	<p>"Being able to quantify impact to non-therapy decision makers and importance of quality of life and 'soft outcomes'" [Responder 5, from a large teaching hospital]</p>

Abbreviations AHP, Allied Health Professional; NHS, National Health Service; OT, Occupational Therapy

Renal Society (BRS) workforce guidance [40] recommends 1.0 WTE PT per 25 inpatient beds and 2.0 WTE PT (band 6 and 7–8) to cover kidney rehabilitation classes, intradialytic exercise, weight management clinics and transplant clinics. For OT, recommendations are 1.0 WTE (band 6–7) per 27 inpatient beds and 1.0 WTE for outpatient services covering dialysis units and specialist clinics. Based on our results, despite good practice within several of the units surveyed, no kidney unit is currently meeting all these recommended levels [40]. This leaves most people with CKD reliant on generic community therapy services that can be difficult to access due to time lost to appointments and treatments. Community therapy teams may also lack confidence in meeting the specialist needs of people with CKD and in adapting interventions around kidney replacement treatments [47]. GIRFT advocates that its recommendations along with the BRS workforce guidance are used to inform service development and the adaptation of the workforce to meet the needs of people living with kidney disease. This includes having an appropriately skilled multiprofessional workforce that can support the psychosocial and physical requirements across kidney pathways [27, 40]. As part of the RSTP, consensus was gained on the need for holistic

wellbeing assessments as part of standard care with the use of validated outcome measures and digital resources to allow people to live well with kidney disease [29]. With the reported therapy staffing levels identified within this survey, it will be difficult for kidney units to implement the mandates set out in both the Renal Medicine GIRFT [27] and RSTP [28, 29] guidance. Most of the staffing in kidney-specific OT and PT roles were Band 5 and 6 or unqualified assistant roles. In most hospital trusts, Band 5 and 6 therapists are rotational posts remaining approximately 4–9 months in the role before moving on. Services provided predominantly by rotational staff may have reduced opportunities for service development and quality improvement, and for championing the crucial role of therapy in the management of kidney disease.

Professional recognition of CEPs in the UK has increased [48, 49]. They provide a complementary role to therapists and offer an additional workforce proficient in exercise testing, prescription and delivery [16, 38, 48–52]. Our survey reveals that, like therapists, this workforce is currently underutilised in kidney care [53]. Kidney services should include CEPs who, in partnership with PT and OT input, can support the development of individualised, effective and sustainable physical activity programmes. In particular, CEPs may support the transition from acute rehabilitation services to community-based programmes [38]. Clearer referral pathways to appropriately trained CEPs would further enhance access to sustainable, safe and effective exercise services.

#### Areas of regional variance in rehabilitation provision

Access to specialist kidney therapy services was highly variable across the UK. The Care Quality Commission (CQC), the independent regulator of health and social care in England, found that one in five people aged over 65 years were currently waiting for rehabilitation services including PT and two in five reported their physical function had deteriorated whilst they waited, with people living in more deprived areas reporting lower levels of satisfaction with access to rehabilitation services [54]. A recent report from Kidney Research UK identified geographical location can contribute to health inequalities in kidney care across the UK [55]. Investment in kidney therapy services may help to reduce health inequalities and optimise function, so that people can be supported to live well with their condition, increasing life participation and reducing their need for social care and services both now and in the future [56–59].

#### Barriers to kidney rehabilitation within the UK

In 2014, Greenwood et al. identified the main barriers to rehabilitation as lack of funding, time, and knowledgeable personnel [39]. Almost 10 years later, these barriers remain the same. Given the limited investment in therapy

**Table 2** Example free text responses regarding Covid-19 activity

Theme	ILLUSTRATIVE Quotes
Increased complexity of caseload	"Increased acuity of patients." [Responder 6, from an acute general hospital]
	"Staffing levels remain the same however we are finding the patients we are treating are sicker and more complex so taking more time." [Responder 1, from large teaching hospital]
	"Difficult to comment on but increased dependency and social support." [Responder 7, from major teaching hospital]
The impact on care	"No significant change but due to general therapy staffing across all areas there has been a reduction in acute rehab of patients and an increase in deconditioning." [Responder 8, from an acute general hospital]
	"Had to reduce numbers from 12 to 8 [in exercise group] to allow for distancing. Used to be circuit-based, now having patients in individual 'pods' with their own equipment." [Responder 9, from specialist tertiary service]
	"Reduced staffing at times impacting on provision and quality of service." [Responder 4, from specialist tertiary service]
	"Access to patients more difficult depending on ward reallocations and isolation." [Responder 10, from large teaching hospital]
	"COVID positive patients have had to be left to the end of the day, if this clashes with HD timings some patients have had less therapy input." [Responder 11, from an acute general hospital]
	"Lack of visitors has had an impact on patient motivation and morale at times." [Responder 6, from an acute general hospital]
	"Availability of outpatient isolation dialysis slots has had an impact on discharge from acute hospital." [Responder 11, from an acute general hospital]
	"Renal wards became cohorted COVID wards, donning and doffing of scrubs and PPE was time consuming and therefore, impacted clinical time." [Responder 12, from an acute general hospital]
	"Assessments were limited as we were not allowed to take patients to kitchen or stairs and therefore had to adapt assessments." [Responder 12, from an acute general hospital]
	"The level of therapeutic intervention provided was reduced due to patients either being too unwell to participate, or limitations and restrictions on movement on the wards." [Responder 9, from a large teaching hospital]
Recovery of kidney therapy services	"The service was stopped for about 18 months as our priority was the in-patient wards. We started back permanently in April 2021." [Responder 13 from a large teaching hospital]
	"Changed from face-to-face to virtual. Now face to face has resumed." [Responder 14, from large teaching hospital]
	"Yes, outpatient services for dietitians transitioned to telephone clinics, now returned to mixture of telephone and face-to-face." [Responder 6, from acute general hospital]
	"We did move to virtual appointments but have now returned to face-to-face." [Responder 15, from large teaching hospital]
The impact on staffing and therapy services	"Therapists now see patients who are medically fit therefore no rehabilitation happens anymore." [Responder 2, from a large teaching hospital]
	"We provide cycles on dialysis in most units, but no physiotherapy time to educate or supervise." [Responder 10, from a large teaching hospital]
	"Diet and exercise assistant practitioner provides some support, which was stopped during COVID due to redeployment." [Responder 10, from a large teaching hospital]
	"Yes - we did not visit the dialysis units in person on a regular basis - provided telephone service and face to face for urgent issues only." [Responder 16 from a large teaching hospital]
	"During COVID we stopped doing face to face sessions and classes and developed Kidney BEAM to offer exercise online." [Responder 14 from a large teaching hospital]
	"Staff were redeployed, outpatient service started up again April 2022." [Responder 16, from a large teaching hospital]
	"No. this is a new service being provided as a trial and is only funded until June 2023." [Responder 17, from a large teaching hospital]
	"Services have not been affected to the inpatient renal ward due to COVID19." [Responder 18, from general hospital]
	"Introduction of telephone reviews which as less effective for certain groups of patients especially [older people]/[people who are] frail/hearing impaired/visually impaired." [Responder 19, from an acute general hospital]
	"Impacted on community services available to support with discharge issues with supply of equipment however multifactorial reasons for this." [Responder 4, from specialist tertiary service]
"Reduction in staffing due to increased vacancies, and in particular reduction in OT provision, meaning patients may not be seen until medically optimised for discharge." [Responder 20, from general hospital]	
"The OT and physio teamwork across the entirety of Medicine and Oncology and therefore have to go where the priorities are across all specialities. There has been less therapy presence on the wards due to this and staff sickness/ shortages." [Responder 17, from a large teaching hospital]	

Abbreviations OT, Occupational Therapy

services, despite established evidence and guidelines for the benefits of physical activity for people with CKD, this is perhaps unsurprising. Future research should focus on strategies to improve the implementation of evidenced-based rehabilitation, supported by appropriate financial investment in therapy services.

### Response to pandemic

Approximately 70,000 people with CKD in the UK were in the extremely vulnerable group and advised to shield [60]. Physical activity levels, well-being, mental health, and quality of life were all negatively impacted [60, 61]. It was recognised early on that rehabilitation played a key role in recovery, and the amelioration of deconditioning as a result of both the illness itself and the impact of shielding [62–64]. The results of the current survey



indicated that inpatient kidney therapists saw increased caseloads of more complex patients. Outpatient services saw the biggest impact with services switching to remote clinics or ceasing altogether. The World Health Organisation reports that rehabilitation services were consistently among the health services most severely disrupted by the pandemic [65]. Our survey indicates that the COVID-19 pandemic may have had a further negative impact on the provision of an already limited rehabilitation provision for people with CKD.

Respondents reported feeling the strain of having reduced resources and only being able to provide limited therapy input, but also seeing the benefits of new ways of working and the development of additional resources such as Kidney BEAM [45, 66]. With limited investment in rehabilitation services, and challenges retaining staff across the NHS [67], specialist kidney rehabilitation may need to adopt innovative and hybrid in-person and digital models of care, which address digital exclusion to maximise the reach of a highly limited resource.

### **Current global perspectives on kidney rehabilitation**

Globally there has been a shift towards bringing together specialist and interested healthcare professionals to promote the role of rehabilitation in kidney care [36, 37]. This has resulted in increasing recognition of kidney rehabilitation as a core intervention. Despite this, the sustained and widespread implementation of kidney rehabilitation within clinical practice has been slow. One exemplar of where practice has changed is the introduction of a certification program to become a Registered Instructor of Renal Rehabilitation (RIRR) in Japan. This has resulted in kidney rehabilitation being recognised as a core treatment intervention and eligible for National Health Insurance Reimbursement [15]. A nationwide survey looking at exercise provision post adoption of the national reimbursement scheme in Japan found that within a year of bringing in the new tariff the number of units providing exercise for dialysis patients almost doubled. Most exercise programs were provided by nurses (74%) with less than half the units utilising OT/PTs and CEPS (48%) [68]. Although more focussed on access to the reimbursement scheme rather than detailed workforce and service details this data further highlights gaps in kidney specific therapy led rehabilitation but does show the role national mandates and support can play in creating investment in a kidney rehabilitation service.

### **Learning from other long-term conditions**

Physical activity has been shown to have an impact on many health outcomes across a range of other long-term conditions [69]. The adoption and implementation of rehabilitation within routine practice for many of these

conditions appears to be further advanced than kidney care. Cardiac rehabilitation has a strong evidence base behind it and has been shown to be a cost-effective treatment in the long-term management of cardiac disease [70–72]. The British Association for Cardiovascular Prevention and Rehabilitation with endorsement from the British Heart Foundation has recognised the importance of interventions that support both physical and mental wellbeing. They have published national standards and core competencies for cardiac rehabilitation that sets out evidence for practice, standards for multiprofessional staffing and key components to include in program delivery [73]. Pulmonary rehabilitation in the UK has high level support with associated NICE guidance and quality standards and an NHS Service Specification [74]. It is acknowledged that pulmonary rehabilitation is an essential element of standard care and is cost effective as well as being shown to improve quality of life for people suffering with respiratory conditions [74, 75]. Stroke guidelines have long been held as a gold standard for therapy interventions; recommendations state that people who've had a stroke should receive 45 min each from appropriate rehabilitation professionals of a duration as long as they are engaged and making progress [76]. These recommendations are strengthened by a national audit program; the Sentinel Stroke National Audit Programme (SSNAP) mandates that all NHS stroke teams report data including access to acute and community therapy and rehabilitation services [76]. Although data suggests patients are not currently receiving the full recommended 45 min of therapy input, such robust monitoring of services allows for demand and capacity to be reviewed against this benchmark. Without the full integration of rehabilitation services into standard practice kidney care guidelines and with limited ability to capture real time data on workforce and service capacity it remains a challenge to promote the role of rehabilitation in kidney care and compare patient needs to existing services.

### **The future of kidney rehabilitation services**

The data provided within this survey will allow kidney units to compare their services to the data collected and against the areas of good practice identified. When benchmarked against national mandates and guidelines [27–29, 31, 40] this could aid in the submission of business cases for increased therapy staffing and service development. In the interim, units should ensure current staffing is being used effectively to meet the needs of their cohort locally. Using the findings of this survey, we provide an outline of ways in which kidney rehabilitation service might be enhanced, and identified barriers overcome, within Table 3. Data from this survey will inform future updates of the UKKA workforce guidance and support ongoing recommendations for therapy provision.

**Table 3** Key challenges to the provision of kidney rehabilitation in the UK and potential strategies to overcome these

Issue identified by the survey	Potential strategies
<ul style="list-style-type: none"> <li>• Lack of funding.</li> </ul>	<ul style="list-style-type: none"> <li>• Understand local kidney rehabilitation needs via audit and service evaluation. Target services and service development to areas of greatest need initially</li> <li>• Utilise Quality Improvement (QI) methodology and data from a wide range of sources (process data, healthcare utilisation, patient reported outcomes and experience) to demonstrate the impact of kidney rehabilitation.</li> <li>• Learn from and utilise the experiences of established services to support the development of the workforce and targeted service improvement.</li> <li>• Use needs and QI data together with supporting national [10, 11, 27, 28, 29, 30, 31, 40] and international guidance [32, 33, 34], national workforce planning guidance [40, 77] and recommendations to develop local business cases for therapy services.</li> </ul>
<ul style="list-style-type: none"> <li>• Lack of kidney specialism in 39–46% of responding units.</li> <li>• Majority of input provided by rotation or unqualified staff.</li> <li>• Lack of qualified and knowledgeable personnel identified as a barrier.</li> <li>• Lack of awareness of UKKA clinical practice guidance for exercise and lifestyle in CKD.</li> </ul>	<ul style="list-style-type: none"> <li>• Prioritise the development of specialist roles for rehabilitation in kidney units to provide leadership and promote the development and retention of skills and knowledge.</li> <li>• Utilisation of available training programmes to upskill existing work force (e.g. Global Renal Exercise (GREX) exercise in CKD course [36], and MOVE programme [78]).</li> </ul>
<ul style="list-style-type: none"> <li>• Underutilisation of existing rehabilitation programmes (in person and digital).</li> </ul>	<ul style="list-style-type: none"> <li>• Strengthen links and relationships with pre-existing local rehabilitation providers who deliver services which may be suitable for people with CKD.</li> <li>• Understand and work collaboratively with providers to overcome barriers to accessing these services for people with CKD.</li> <li>• Identify local champions to promote evidenced-based CKD specific digital health interventions such as Kidney BEAM [45].</li> </ul>
<ul style="list-style-type: none"> <li>• Underutilisation of clinical exercise physiologists to provide physical activity support.</li> </ul>	<ul style="list-style-type: none"> <li>• Explore routes to accessing CEP support via university placement links and GP exercise referral schemes.</li> </ul>
<ul style="list-style-type: none"> <li>• Predominance of inpatient therapy programmes for discharge support over outpatient therapy/ rehabilitation input.</li> </ul>	<ul style="list-style-type: none"> <li>• Focus service evaluation and development work on establishing and integrating rehabilitation services and pathways within outpatient settings where provision is lowest.</li> </ul>

### Strengths and limitations

Building on the 2014 survey [39] this is the first survey in the UK to more comprehensively review the kidney therapy workforce and service provision. Our findings clearly demonstrate marked variances in staffing and service

provision in rehabilitation for people with CKD, driving inequitable care nationally, and in comparison, with other long-term conditions. As part of the survey, we were able to collect data exploring kidney therapy services' responses to the COVID-19 pandemic. A key limitation is our failure to meet the a priori response rate of 65% [41, 44]. Despite this, a meta-analysis of online surveys concluded that studies with a sample size of less than 500 require a 20–25% response rate to be confident in results [79], indicating that this survey had an adequate response rate. This survey was completed by interested individuals as part of a national service evaluation and therefore we were unable to provide financial incentives which may have increased the response rates. Future surveys may seek to provide an incentive, and additionally, Freedom of Information requests could be used as per other workforce mapping surveys [80]; or response items relating to kidney therapy workforce could be incorporated into the UK Renal Registry [81] data return.

### Conclusion

Despite clear evidence of the benefits of rehabilitation, across the UK, there remains limited and variable access to kidney-specific therapy services. Compared to other long-term conditions, kidney care appears to under invest and underutilise PTs, OTs and CEPS to support holistic care. Consequently, the recommendations from national initiatives such as GIRFT [27] and the RSTP [28] may be hard to realise. Whilst there are areas of excellent provision which can act as exemplars, more must be done to improve equity of access to kidney-specific therapies to ensure that all may be supported to 'live well' with kidney disease.

### Abbreviations

CEP	Clinical exercise physiologist
CKD	Chronic kidney disease
CQC	Care quality commission
GIRFT	Getting it Right First Time
GREX	Global renal exercise network
HD	Haemodialysis
NHS	national health service
OT	Occupational therapy/ therapist
PC	Personal computer
PD	Peritoneal dialysis
PPE	Personal protective equipment
QI	Quality improvement
RSTP	Renal service transformation programme
UK	United Kingdom
UKKA	United Kingdom Kidney Association

### Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12882-024-03742-4>.

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

Supplementary Material 4

Supplementary Material 5

Supplementary Material 6

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### Author contributions

Authorship followed ICMJE guidelines. LA EC TW and HMLY were responsible for the inception and design of the project and prepared the manuscript. LA EC TW and HMLY contributed to the design of the study, and provided methodological input. LA wrote the manuscript text, tables and supplementary materials. TW prepared the figures. All authors reviewed and approved the manuscript.

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### Data availability

Data available from corresponding author upon request; lisa.ancliffe@nhs.net.

### Declarations

#### Ethics approval and consent to participate

Ethical approval was not required (see Supplementary Material 3) and upon guidance from local governance, the study was registered as a service evaluation at the University Hospitals of Leicester NHS Trust (audit number: 12007). Completion of the survey was considered indicative of willingness to participate and implied consent.

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare no competing interests.

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