

Project Title: KidnEy olDer person Assessment (EDNA) study development: understanding what matters to older people living with frailty and chronic kidney disease, their caregivers and healthcare professionals

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Plain English Summary

Aims and objectives

- 1) To understand whether a health assessment called 'Comprehensive Geriatric Assessment (CGA)' can be adapted for older people with advanced chronic kidney disease (CKD);
- 2) To understand what is important for kidney patients, carers, and health professionals, and use the information to develop a new approach to CGA in UK kidney centres.

Background

CGA is already used for other health conditions to assess an older person's health needs, but it is still rarely used in kidney care. This study explored whether it can be adapted for older people with advanced CKD.

Methods

A survey of all 67 kidney centres in the UK and eight focus groups with 16 patients, 17 carers and 17 health professionals.

Key findings

Forty-seven kidney centres responded to the survey (70%). Support for older people varied considerably and only eight centres were using CGA. Barriers included time pressures (49%), training (36%), funding (33%), access to relevant services (33%) and staff engagement (15%). Within the focus groups, priorities for older people with advanced CKD included: enjoying independence, being treated as an individual, receiving timely information, sharing decisions, having 'joined up' care and support for carers.

Dissemination, outputs and impacts

Findings will be shared with patients, carers, kidney teams and managers and presented at conferences and in journals.

Patient and public involvement

Kidney patients and carers were involved throughout the project, with one patient and one carer in the project team and 13 patients and carers forming an advisory group. They helped to design the study, including questions for the survey and focus groups.

Conclusions and future plans

CGA can be adapted for use in kidney units. A follow-up study is planned to develop an effective Kidney-CGA for older people with advanced CKD.

Summary of research findings

Background

The overall aim of this development grant was to provide relevant information for a programme grant for applied research (PGfAR) application to evaluate the effectiveness of CGA in the advanced kidney care clinic. We aimed to understand current practices across the UK by completing a detailed survey of UK kidney units. The survey captured the assessments that are currently performed and by whom, and how kidney units address problems identified. This information enabled us to adapt CGA to the outpatient nephrology, ensuring that it is practical for clinical care and can be implemented with fidelity. We also completed focus groups to develop a core set of outcomes important to older people and their carers living with advanced chronic kidney (CKD) disease and frailty. This information was used to select outcome measures to evaluate the effectiveness of Kidney-CGA.

Why is this work important?

In the United Kingdom (UK), 3,474 people aged >65 years old started kidney replacement therapy (includes dialysis and pre-emptive transplantation) in 2020 (5), representing 47% of all people starting kidney replacement therapy. The prevalence of frailty, the state of increased vulnerability to stressor events (6), is 39% in chronic kidney disease (CKD), with the risk of mortality increased by 94% compared to non-frail individuals (7). The prevalence of frailty is as high as 46% in the dialysis population, with older age being associated with greater frailty risk (8).

Comprehensive Geriatric Assessment (CGA) is considered the 'Gold Standard' care of older adults (9). CGA is 'a multidimensional, multidisciplinary process which identifies medical, social and functional needs, and the development of an integrated/co-ordinated care plan to meet those needs' (4). It has mainly been studied in general populations, during acute hospitalisations, by geriatric medicine multidisciplinary teams (MDT) (4, 9, 10). Toolkits aimed at enhancing delivery of CGA by non-specialists exist, though still require geriatrician and implementation support (11), and are variably effective (12). The James Lind Alliance Multiple Conditions in Later Life Priority Setting Partnership (13) highlighted the need for research that answers the question "How can CGA be optimally delivered in different populations experiencing multiple conditions in older age?". Research is needed to inform the development of CGA for populations with advanced CKD (10), which have high healthcare utilisation (14), high symptom-burden (15), marked multimorbidity and associated complex healthcare needs (16). Older people with advanced CKD are also presented with life-changing treatment decisions, choosing between dialysis and conservative kidney management. This is especially challenging for those with multimorbidity and frailty, as dialysis has the potential to prolong life but the burden of treatment is high and may not always improve wellbeing (3). A previous survey of conservative kidney management demonstrated variability in care provided at UK kidney units (17). A survey of care provided to older people with advanced CKD is needed to understand variations in practice at UK kidney units. This will subsequently inform adaptation of CGA to facilitate implementation across UK kidney units.

Priorities and outcomes important to older people with advanced CKD are not well understood. Most studies report outcomes such as mortality, hospitalisation and healthcare utilisation (18). Within our scoping review work (18) we identified few studies exploring patient and carer perspectives, including outcomes that matter most to people with advanced CKD. Research is therefore needed that better understands what matters most for older people living with frailty and advanced CKD. This evidence will inform selection of the most appropriate outcome measure for a study of CGA in older adults living with advanced CKD.

We hypothesise that CGA, adapted to the advanced kidney care context, will lead to improvements in health and well-being for older people and their caregivers. The overall aim of the Programme Development Grant was to develop a research study that evaluates CGA adapted to the outpatient nephrology setting. Key objectives to achieve this were to: (1) understand assessments and care of older people living with advanced CKD at UK Kidney units, and (2) determine important outcomes for older people with advanced CKD. Ethical approval was obtained for this research (Rec Ref 24/PR/0003).

Work package 1

Work package 1 involved a national survey of assessment and care of older people (>65 years old) receiving advanced kidney care at UK kidney units.

Methods

A survey was developed in collaboration with the team and the PPI advisory group (PAG). Cognitive interviews were conducted with five health care professionals (HCP). After further refinement, the survey was piloted at one centre to determine the time required for completion and identify any additional corrections or clarifications needed. Appropriate HCPs from all UK kidney units were identified and invited to complete the survey. The survey was published on Qualtrics and open between October 2024 and February 2025. It was widely shared at UK events and through newsletters via the UK Kidney Association (UKKA) and the Association of Nephrology Nurses (ANN UK). Responses that included name, role, kidney unit and at least an answer to the first survey question (“is frailty assessed in the advanced kidney care clinic?”) were included for analysis. Index responders were identified from each kidney unit, with responses from clinical leads given priority. Data were analysed using descriptive statistics. Selected units were invited to participate in a semi-structured interview with research team members to provide additional context to survey responses, including whether CGA or component parts were completed at their unit.

Results

A total of 103 HCPs responded to the survey from 47 (70%) UK kidney units. Figure 1 illustrates the location of responses, which included representation from all 4 home countries.

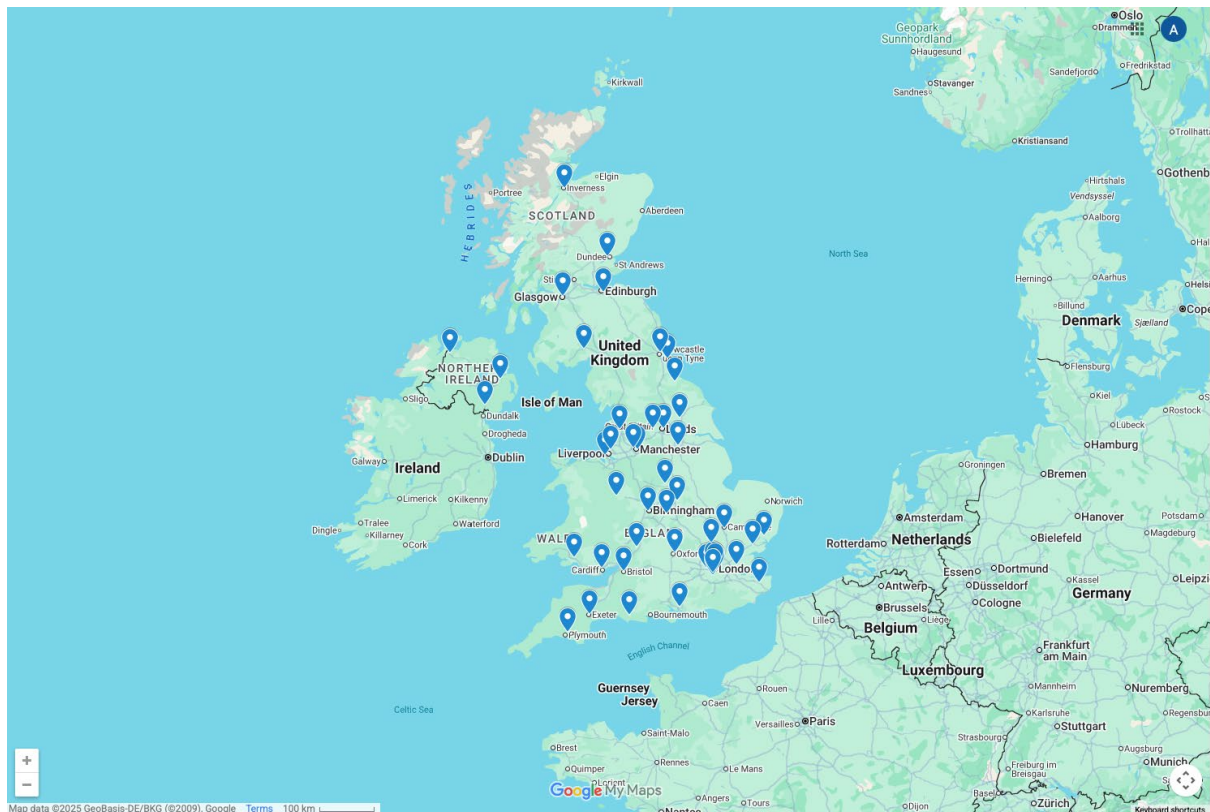


Figure 1. Map demonstrating location of survey responses.

Map data ©2025 GeoBasis-DE/BKG (©2009), Google

Most responders were consultant nephrologists (n=48) or kidney clinical nurse specialists (n=24). Index responder roles included consultant nephrologists (n=38), kidney clinical nurse specialists (N=7), a consultant nurse (1) and an associate specialist (1). Sixteen responses were from a kidney unit clinical director/lead or advanced kidney care lead.

Assessments of geriatric impairments sometimes, usually or always help kidney treatment decision making with patients for 84% (66/79) of responders. Frailty (58%), functional status (57%) and comorbidity (57%) were the three most reported geriatric impairments that help kidney treatment decision-making (Figure 2).

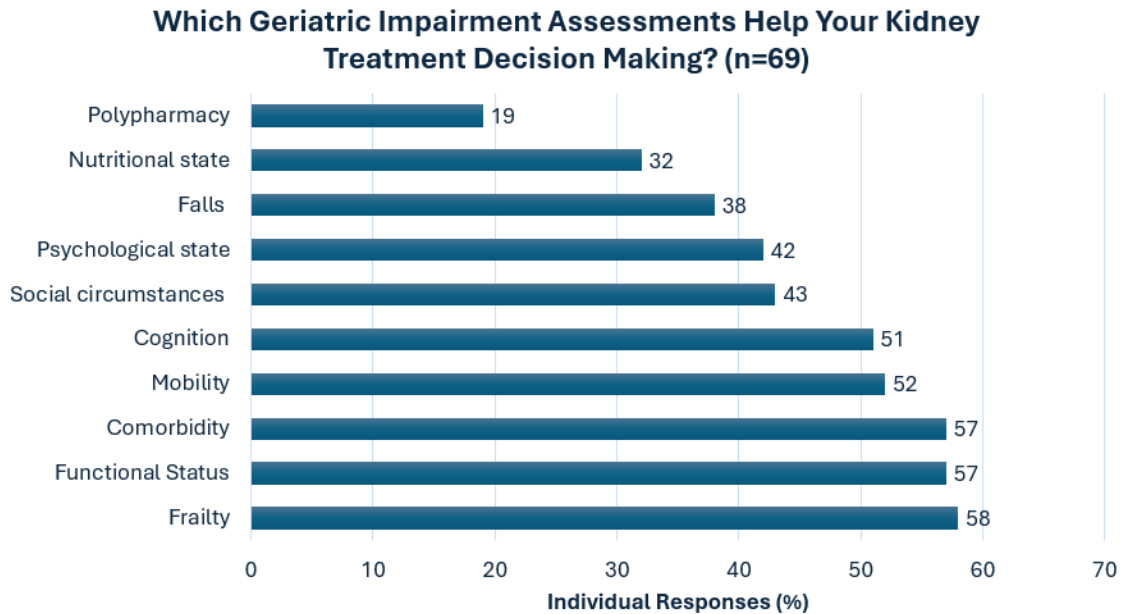


Figure 2. Geriatric impairments and kidney treatment decision-making.

Figure 3 illustrates the proportion of responders who performed assessments of specific domains (e.g. frailty, activities of daily living, mobility) in older people, including use of recognised assessment tools (as opposed to clinical judgement). Notably, 58% of responders used a validated frailty tool.

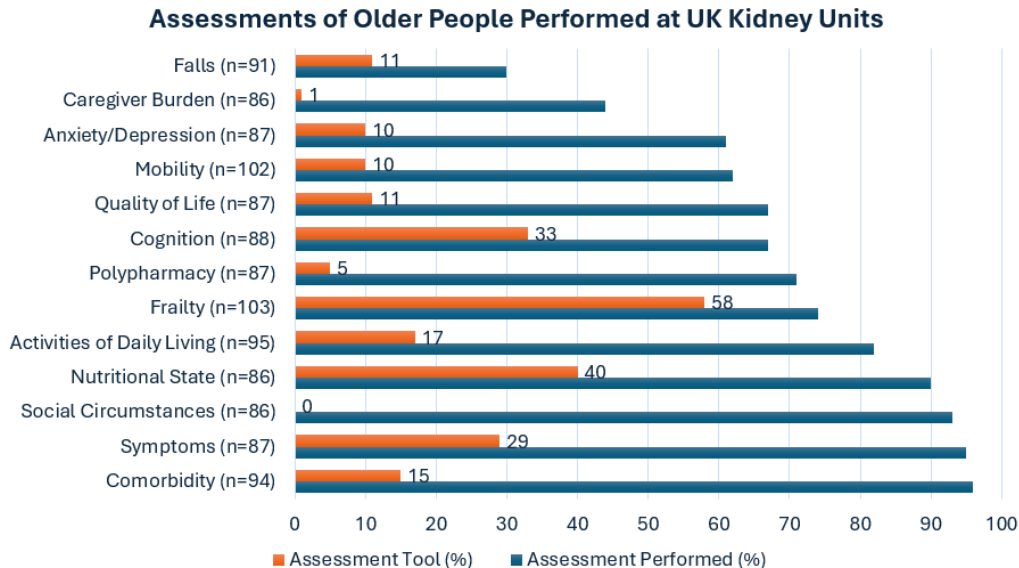


Figure 3. Assessments performed in older people living with advanced CKD.

Only 13% of responders reported that geriatricians were involved in frailty assessment; this proportion was even lower for other assessment domains included within the survey. Figure 4 illustrates MDT members involved in the assessment of older people with advanced CKD.

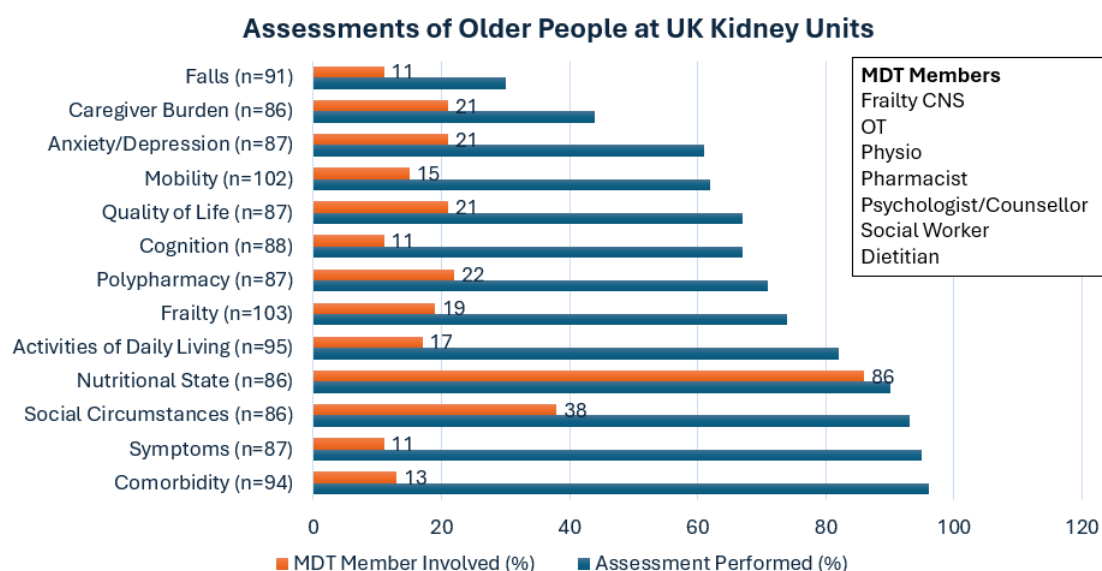


Figure 4. Multidisciplinary team members involved in the assessment of older people with advanced CKD.

Table 1 details where older people living with advanced CKD can be reviewed by frailty HCPs, geriatricians, occupational therapists and physiotherapists.

Table 1. Appointment setting with healthcare professionals involved in the care of older people.

Where can patients see a frailty HCP?	Unit Response (%)
Renal Medicine Service	20
Hospital Geriatric Medicine Clinic	59
Hospital Frailty Service	46
Community Frailty Service	33
Where can patients see a geriatrician?	Unit Response (%)
Renal Medicine Service	13
Hospital Geriatric Medicine Clinic	89
Community Geriatric Medicine Service	28
Where can patients see an occupational therapist?	Unit Response (%)
Renal Medicine Service	11
Hospital Occupational Therapy Service	41
Community Occupational Therapy Service	67
Where can patients see a physiotherapist?	Unit Response (%)
Renal Medicine Service	11
Hospital Physiotherapy Service	37
Community Physiotherapy Service	78

Percentages total >100% as multiple response options possible.

Figure 5 illustrates the proportion of kidney units that can refer patients directly to other services, rather than requesting primary care teams to refer patients on their behalf.

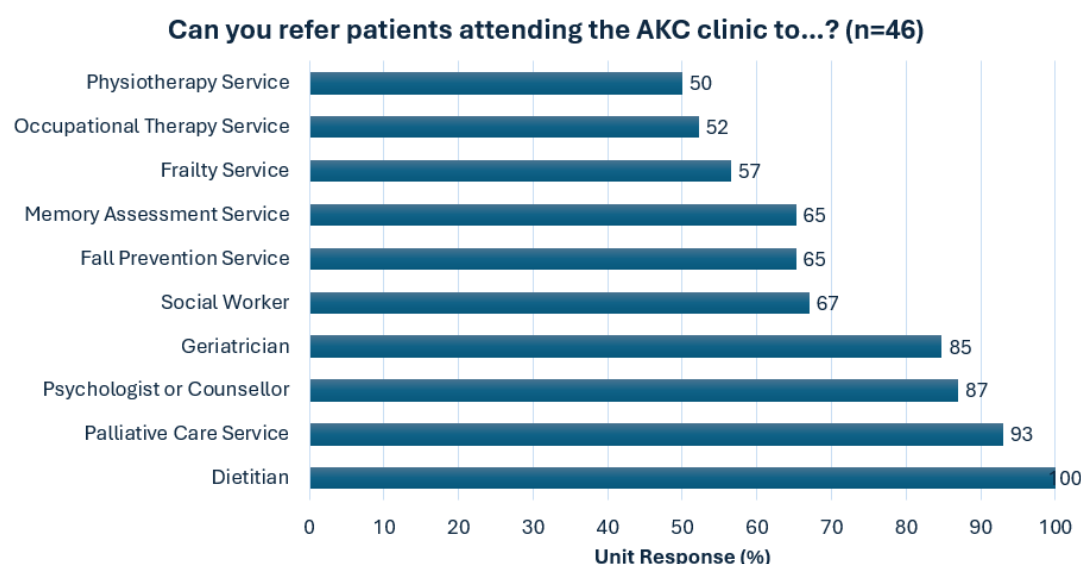


Figure 5. Direct referrals to other healthcare professionals and services.

CGA was performed in 17% (8/46) of kidney units. Five units reported performing modified CGA, i.e. only one HCP involved in performing a multidomain assessment. Three units reported performing true CGA, although only one of these three units involved more than one HCP. Table 2 details HCP involved in delivering CGA.

Table 2. HCPs involved in delivering CGA at UK Kidney Units.

Who is involved in the delivery of CGA/mCGA?	Frequency
Geriatrician	5
Nephrologist	4
Kidney Clinical Nurse Specialist	4
Advanced Clinical Practitioner	3
Frailty Clinical Nurse Specialist	3
Psychologist/Counsellor	1
Kidney Staff Nurse	1
Palliative Care Clinical Nurse Specialist	1
Renal Medicine Registrar Doctor	1
Dietitian/Social Worker/Pharmacist/OT/Physio	0

Barriers to implementing CGA within advanced kidney care were time (49%), training (36%), funding (33%), access to relevant services (33%) and staff engagement (15%).

Semi-structured interviews have been conducted with 9 kidney units (Glasgow, King's College London, Leeds, Lister, Portsmouth, Preston, Royal Free London, St George's London and Wirral) to provide additional context for survey responses, including how CGA or component

parts have been implemented. These interviews also provided an opportunity to obtain feedback on the proposed Kidney-CGA intervention and trial.

Work package 2

The primary aim was to define a core set of outcomes, through stakeholder engagement, for a study evaluating CGA for older people living with frailty and advanced CKD.

Methods

Focus groups were chosen as the most appropriate method. Additional telephone interviews were offered for participants who could not attend and for non-English speaking participants. These focus groups were designed to capture the perspectives of patients, carers, and HCPs on the most important outcomes in this setting.

Before conducting the focus groups, meetings with the PAG were held to help inform the design and execution of the groups. Special care was taken to ensure that the language and understanding of frailty and CGA were accessible to older individuals and their carers. This preparatory work, involving the PAG, was invaluable in shaping the design and content of the focus groups.

Patient and Carer Focus Groups

The patient and carer focus groups were held in person across three units with two facilitators leading each session. A video of a patient and carer describing their experiences was shown, along with slides co-designed by the PAG, to help contextualize the discussion and highlight key topics. The focus group topics included:

- Experiences of kidney and other health problems
- Daily living and activities
- Life as we age
- Planning current and future care
- Family and carer relationships

Participants were given time to write down important outcomes for each topic, followed by a group discussion. The groups were recorded and transcribed for analysis. Interviews were conducted over the phone with non-English speaking participants using language specific researchers.

Health Care Professionals (HCPs) Focus Groups

Two online focus groups were conducted with HCPs. Like the patient and carer groups, slides were used to set the context. HCPs were asked to consider how the effectiveness of CGA should be assessed in practice and research, and to reflect on the outcomes that should be prioritised for a study evaluating CGA. Participants independently provided lists of important outcomes, which were then discussed in the group.

After the focus groups and interviews, the framework analysis approach (19) was used for analysis, which follows five clear steps:

1. Familiarisation
2. Thematic framework-coding index
3. Indexing and sorting
4. Data summary and display
5. Mapping and interpretation

Two team members (HH and CS) conducted the analysis. A final online focus group with representatives from patients, carers, and HCPs was then held to present findings from this analysis. The group ranked the themes in order of importance using a nominal group methodology.

Results

In total, 50 participants were involved in the focus groups: 16 patients (median age 80 years [IQR 76-84]), 17 carers, and 17 HCPs from various disciplines, including nephrologists, nurses, social workers, physiotherapists, occupational therapists, geriatricians, and primary care professionals. Participants were recruited from three kidney centres (two in the northwest and one in the south) for patients and carers, while healthcare professionals were recruited nationally as these were held online. Three focus groups were conducted for patients and three for carers in each unit, and additional interviews were conducted by phone for those who could not attend in person. Interviews were arranged separately for non-English speaking participants with language specific researchers. Age and ethnicity of the focus groups and interviews were collected. A full record of screening was collected at each site and reasons for declining.

Analysis of Focus Groups and Interviews

The focus group and interview transcripts were coded independently by two team members (HH and CS). An initial framework was developed based on the aims and objectives of the focus groups. Identification of patient, carer and HCP was used within the coding just as letter and number so anonymised data could be used for direct quotes. The analysis led to the identification of several key themes by mapping and interpreting the coded groups:

- Enabling meaningful life participation
- Carer experience and support
- Timely, tailored information and education
- Patient/carer-centred planning and choices
- Flow of care and joined-up working
- Future care and choices

These themes were refined through consultation with other focus group facilitators to ensure they reflected the discussions in the focus groups and interviews. Additional analysis for the non-English speaking participants was conducted following translation and quality assurance. These were compared and mapped to the findings to explore any differences or culturally specific findings.

Final Focus Group

A final consensus focus group was held with a representative group of patients (n=2), carers (n=4), and HCPs (n=5). The themes identified earlier were presented to the group for ranking by importance (nominal group technique). The final priority list, in order of importance, was as follows:

1. Enabling meaningful life participation
2. Patient/carer-centred planning and choices
3. Timely, tailored information and education
4. Flow of care and joined-up working
5. Future care and choices
6. Carer experience and support

While all the identified outcomes were considered relevant for a future study, "enabling meaningful life participation" was ranked as the most important priority. These findings were

presented to the programme planning committee and the PPI advisory group to inform the development of outcome measures for the larger study.

Findings Discussion

Both work packages have provided important findings that will inform a future study evaluating the effectiveness of CGA adapted to the outpatient nephrology setting. Most UK kidney HCPs reported that assessments of geriatric impairments helped kidney treatment decision-making. However, assessments were not often performed using recognised assessment tools; this is especially important for frailty screening and assessment given clinical impression poorly correlates with measured frailty (20). There was a low representation of geriatricians and MDT HCPs in advanced kidney care services, and a need for better integration with primary and secondary care services in the care of older people with advanced CKD. CGA is feasible within advanced kidney care, although performed in few UK kidney units and with varied approaches. Lack of time was reported as the most significant barrier to CGA implementation. Survey findings have informed the development of Kidney-CGA, CGA adapted to the nephrology setting, with the aim that it be implemented with fidelity across all kidney units. Research determining clinical and cost-effectiveness of CGA adapted to the outpatient nephrology setting is needed to advance its implementation within routine clinical practice.

Recruitment for the focus groups was challenging due to the specific inclusion criteria (older adults aged 65+ living with frailty attending advanced kidney care clinics). Target recruitment was not achieved for non-English speaking participants mainly due to time constraints caused by delays in set up time. Despite challenges in recruitment, the focus groups provided valuable insights into the most important outcomes for older patients with advanced CKD. These findings have allowed selection of outcome measures that will be used to evaluate the effectiveness of Kidney-CGA for older people living with advanced CKD and frailty.

Conclusion

In conclusion, the programme development work has provided valuable information on current UK practices when it comes to the care of older people with advanced CKD. This has allowed the development of a practical and feasible intervention, Kidney-CGA, for UK kidney units. Furthermore, better understanding important perspectives of patients, carers and HCPs has informed selection of outcome measures that will be used to evaluate the effectiveness of Kidney-CGA in the outpatient nephrology setting.

Data sharing statement - See link

[\[https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253\]](https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253) for the NIHR position of the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

Disclaimer

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been peer-reviewed. The report was examined by the Programme at the time of submission to assess completeness against the stated aims. These reports do not undergo a peer review process.

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