



ORIGINAL ARTICLE

Achieving consensus on psychosocial and physical rehabilitation management for people living with kidney disease

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ABSTRACT

Background. People living with chronic kidney disease (CKD) need to be able to live well with their condition. The provision of psychosocial interventions (psychological, psychiatric and social care) and physical rehabilitation management is variable across England, as well as the rest of the UK. There is a need for clear recommendations for standards of psychosocial and physical rehabilitation care for people living with CKD, and guidance for the commissioning and measurement of these services. The National Health Service (NHS) England Renal Services Transformation Programme (RSTP) supported a programme of work and modified Delphi process to address the management of psychosocial and physical rehabilitation care as part of a larger body of work to formulate a comprehensive commissioning toolkit for renal care services across England. We sought to achieve expert consensus

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regarding the psychosocial and physical rehabilitation management of people living with CKD in England and the rest of the UK.

Methods. A Delphi consensus method was used to gather and refine expert opinions of senior members of the kidney multi-disciplinary team (MDT) and other key stakeholders in the UK. An agreement was sought on 16 statements reflecting aspects of psychosocial and physical rehabilitation management for people living with CKD.

Results. Twenty-six expert practitioners and other key stakeholders, including lived experience representatives, participated in the process. The consensus (>80% affirmative votes) amongst the respondents for all 16 statements was high. Nine recommendation statements were discussed and refined further to be included in the final iteration of the 'Systems' section of the NHS England RSTP commissioning toolkit. These priority recommendations reflect pragmatic solutions that can be implemented in renal care and include recommendations for a holistic wellbeing assessment for all people living with CKD who are approaching dialysis, or who are at listing for kidney transplantation, which includes the use of validated measurement tools to assess the need for further intervention in psychosocial and physical rehabilitation management. It is recommended that the scores from these measurement tools be included in the NHS England Renal Data Dashboard. There was also a recommendation for referral as appropriate to NHS Talking Therapies, psychology, counselling or psychotherapy, social work or liaison psychiatry for those with identified psychosocial needs. The use of digital resources was recommended to be used in addition to face-to-face care to provide physical rehabilitation, and all healthcare professionals should be educated to recognize psychosocial and physical rehabilitation needs and refer/sign-post people with CKD to appropriate services.

Conclusion. There was high consensus amongst senior members of the kidney MDT and other key stakeholders, including those with lived experience, in the UK on all aspects of the psychosocial and physical rehabilitation management of people living with CKD. The results of this process will be used by NHS England to inform the 'Systems' section of the commissioning toolkit and data dashboard and to inform the National Standards of Care for people living with CKD.

LAY SUMMARY

This paper presents the process for achieving consensus for the psychosocial and physical rehabilitation management of people living with chronic kidney disease. A modified Delphi process was used to achieve consensus and make recommendations about the changes that can be made to renal care. Nine final recommendations will be used to guide and ensure that people living with chronic kidney disease can live well with their condition.

Keywords: CKD, exercise, physical activity, psychosocial, rehabilitation

INTRODUCTION

A diagnosis of kidney failure is very challenging, impacting every aspect of a person's wellbeing—physical and mental health, finance, employment and relationships. This level of adversity can significantly impact an individual and their family's quality of life. It can influence their self-respect and esteem, and prevent them from taking more control of their lives, becoming a partner in their own healthcare, or adopting life enhancing and self-management behaviours [1]. People living with chronic kidney disease (CKD) should have equity of access to the holistic care provision they need to live their lives well [2, 3]. Supporting people to live well with CKD includes promotion of good mental health, social provision, education and physical rehabilitation, all of which have a significant impact on emotional, social and physical health, creating a greater focus on shared responsibility for health and reducing time spent in care settings.

Psychosocial issues in people with CKD include psychological, psychiatric and social care needs, and these can impact physical health and treatment outcomes. Depression in early-stage kidney disease increases the risk of progressing to late-stage kidney disease, leading to the need for dialysis or a kidney transplant. Depression increases the risk of hospitalization [4, 5]; in addition, depression in people receiving dialysis and in people living with kidney transplants increases the risk of dying by approximately 50% and 65%, respectively. People living with severe mental illness make up 7% of the UK kidney population

[6–8], receive suboptimal kidney care and can die up to 15 years younger than their peers. Dementia-like conditions are common in kidney patients but significantly under-diagnosed, leading to suboptimal care for both dementia and kidney disease [9]. There are also significant barriers for people with CKD and intellectual disabilities. These conditions are likely to decline more quickly in dialysis patients and have a negative impact on their ability to make decisions about their treatment [10]. Very high levels of social need are reported and the need for social care intervention must not be underestimated, particularly as this in turn often has a significant impact on a person's emotional wellbeing [11].

Despite a large body of research evidence supporting the clinical effectiveness (improved psychological wellbeing, quality of life and physical health outcomes) and cost-effectiveness of psychosocial interventions in physical healthcare which has been published over the last 50 years [12], there remains wide variation in the provision of specialist psychosocial care and access to renal specialist psychosocial practitioners [13, 14]. Individuals living with CKD report high levels of physical inactivity and poor emotional and social wellbeing [15]. Despite disease-specific guidelines promoting physical activity participation [16], people living with CKD do not routinely receive physical activity, or social or emotional wellbeing support as part of their clinical care [16].

National Health Service (NHS) England has been running a multi-agency programme that aims to transform delivery of kidney specialized services across England. The Renal Services

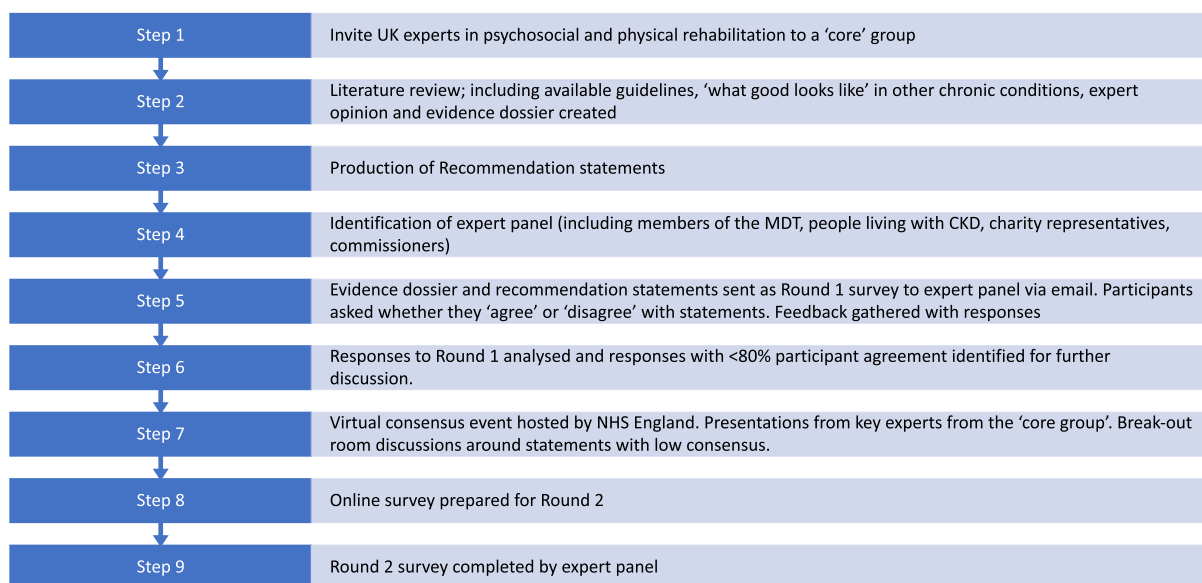


Figure 1: Methodology of modified Delphi process.

Transformation Programme (RSTP) has five workstreams; four are clinical and the fifth, Systems Working, aims to unpick cross-cutting themes that will enable commissioning on the principles of a whole person, whole care pathway approach. One of the cross-cutting themes within the programme explores how people could live well with CKD, especially those who develop additional long-term conditions. The purpose of this process was to identify best practices that support patient care by specifically focusing on their psychosocial and physical rehabilitation needs. We also wanted to identify some key recommendations for interventions that would be feasible to implement and deliver in the short term. It was acknowledged that there would be some recommendations that would require considerable resources to deliver and would need commitment from major stakeholders and commissioners to develop further. We aimed to develop consensus by having clinicians, people living with CKD and other subject matter experts engage in a conversation on what good psychosocial provision and physical rehabilitation for people with CKD should look like.

MATERIALS AND METHODS

Figure 1 describes the methodology utilized for the modified Delphi process.

Recruitment of the core expert group and the expert panel

Ten multidisciplinary specialist kidney healthcare professionals ($n = 4$ physiotherapists, $n = 1$ occupational therapists, $n = 4$ exercise scientists/physiologists, $n = 1$ nephrologist) and six specialist kidney psychosocial healthcare professionals ($n = 2$ clinical and health psychologists, $n = 2$ counsellor, $n = 1$ psychiatrist, social worker, $n = 1$ specialist nurse) were convened by the NHS England RSTP committee as a core healthcare professional group. NHS England RSTP worked together with the UK Kidney Association (UKKA) Living Well with Kidney Disease special interest group (SIG) and the National Renal Psychosocial Group

to identify and formally invite experts in the field to take part in this modified Delphi process. To the best of our knowledge, members of this core group represented the specialist centres who offer kidney-specific psychosocial health or physical rehabilitation management within the UK. All members were well recognized as having many years of experience and expertise in psychosocial and physical rehabilitation care for people living with CKD. In addition to the healthcare professional experts, an invitation was extended to the UK kidney patient charities and to the patient representatives from the UKKA Living Well with Kidney Disease SIG and the UK Renal Psychosocial group to join the core group. This included people living with kidney disease ($n = 4$) and patient charity representatives ($n = 4$). This core group were involved in the development of the statements.

Purposive sampling was utilized to select an expert panel for the modified Delphi survey who met the inclusion criteria and had the necessary expertise to be on the panel. All participants were required to be 18 years or above, actively conducting research or clinical practice in kidney-specific psychosocial or physical rehabilitation fields, and affiliated with one of the national groups. The invited participants were either members of the multi-professional kidney team ($n = 3$ nephrologists, $n = 3$ nurses, $n = 3$ physiotherapists; $n = 1$ occupational therapist, $n = 2$ social workers, $n = 3$ counsellors, $n = 2$ psychologists), people living with CKD or their representatives ($n = 2$ charity representatives, $n = 4$ patients) or kidney care commissioners ($n = 2$), and also a member from the NHS England team ($n = 1$). All participants were formally invited to participate, and consent to take part in the modified Delphi process was collected by the NHS England RSTP. All participant information and responses to both online surveys were confidential, and responses were collected anonymously. Twenty-two participants responded to Round 1 and 26 of the expert panel attended Round 2 and were involved in revision of the remaining statements and online voting. Four of the people living with kidney disease chose to not respond to the online survey in Round 1 but wished to be included in the subsequent group discussions and second online survey.

Survey development

The core group of experts were invited to express opinions and formulate statements, based on their knowledge and experience and a thorough review of the available literature (including guidelines and what 'good' psychosocial and physical rehabilitation looks like in other chronic disease populations), of psychosocial care provision and physical rehabilitation management for people living with CKD. This core group met a number of times in advance of the consensus workshop to prepare the discussion rounds, inform the statements and ensure a full and clear view of the needs of people with kidney disease would be covered by them. A total of 16 statements across five domains were included in the survey: identification of need; addressing provision of interventions at all levels of need; addressing integrated care; addressing workforce needs; and accountability and reporting (see Table 1). The survey statements were constructed to highlight the key challenges and opportunities relating to each domain, and to agree effective approaches to address these challenges. The survey was piloted with three clinicians who had psychosocial and physical rehabilitation experience. An iterative process of feedback was undertaken to improve the readability of statements, and to determine whether any additional statements were needed.

Conducting the survey

The statements were circulated to the expert panel as an online survey. The expert panel were asked to score whether they 'agree' or 'do not agree' with each statement in the questionnaire. Level of participant agreement for each statement was ranked on a scale of 0%–100%, with 0 being total participant disagreement and 100% being total participant agreement. Scores between 75% and 100% participant agreement were considered to represent good agreement with each statement [17]. When more than 80% of participants scored 'agree' on any statement, this was regarded as an acceptable level of consensus. This threshold was agreed in advance by the group. Any statements with a consensus level of >50% but <80% were explored further in Round 2. The written responses from Round 1 were also collated to explore the degree of individual experts' agreement with each statement. All responses to the online survey were anonymous. Round 2 was executed during an online consensus workshop hosted by NHS England. The consensus workshop took place on Friday 13 May 2022 and included a range of representatives from the expert group. The consensus day included presentations and breakout sessions, where participants were asked to consider all the consensus statements (Table 1). This was in relation to:

- gaining consensus on the pathway to identify, assess, monitor and support the psychosocial and physical wellbeing of people with CKD to help them live longer in better health;
- co-developing a set of recommendations for further consideration as part of RSTP.

The summarized results were presented to all members of the expert panel along with the identical set of statements from Round 1. Participants were offered the opportunity to view the results, discuss any changes to statements with below 70% participant agreement during break-out sessions with members of the core group, and to help formulate a final set of statements. At the end of Round 2, the modified statements were presented to the expert group and participants were asked to respond to an online survey asking if they 'agreed' or 'did not agree' with

each of the revised consensus statements. A range of evidence-based outcome measures to identify the need for psychosocial and physical rehabilitation were also discussed by the expert panel during the group discussion and four outcome measures were voted for at the end of Round 2.

Following on from the consensus event, all 16 statements were circulated to the NHS England Renal Clinical Networks, the NHS England RSTP Clinical Director and the four RSTP work-stream leads for consideration to be included in the RSTP commissioning toolkit. Following this feedback and further discussion with the core group, a total of nine priority statements were selected to be included in the commissioning toolkit (see Table 2 and 3).

Data analysis

The online surveys were conducted in Microsoft Forms (2021) and results were collated, analysed by two independent members of the NHS England RSTP team using Microsoft Excel (2021). Descriptive statistics were used to describe participants' demographic characteristics and group responses to each statement in both rounds. An acceptable level of consensus was reached when more than 80% of participants scored 'agree' on any statement [17].

RESULTS

Agreement levels for Rounds 1 and 2 are displayed in Table 4. At the end of Round 1, acceptable levels (>80%) of consensus were obtained for 15/16 statements. The only statement with <80% consensus at the end of Round 1 (77%) stated: 'All people with advanced kidney disease (Stage 4+) should be assessed at diagnosis (or when they reach this stage) to understand their psychological, social, and physical care needs. (Assessment to include depression, anxiety, social needs, nutrition, frailty, physical activity levels, physical function and cognitive impairment)' (Statement 1a). Five people did not agree with this statement. They felt that there should be priority given to people approaching dialysis therapy or at listing for kidney transplantation. The issues relating to this statement were explored further at the online consensus workshop during the breakout sessions facilitated by representatives from NHS England and prior to the Round 2 online survey at the end of the workshop. During these discussions, there was acknowledgement that this recommendation should remain inclusive of all people with CKD at stage 4+ to allow for preventative therapeutic approaches. However, a priority for the resource required for measurement of intervention need should be targeted at those people with CKD approaching dialysis, or at listing for kidney transplantation. At the end of Round 2, all 16 statements reached high levels of consensus (>90%). The Patient Health Questionnaire (PHQ-4) [18], Distress Thermometer [19], the sit to stand 5 (STSS) physical function outcome [20] and The Single-item Score physical activity measure [16] were unanimously selected by the expert panel to be included in the RSTP commissioning toolkit.

DISCUSSION

Findings from this modified Delphi process suggested a high level of consensus [21] on all statements reflecting the expert opinion of key members of the kidney MDT, people living with CKD, and other key stakeholders. The results are therefore likely to be a fair representation of general practice and expert opinion

Table 1: Consensus statements.**Identification of needs**

1a: All people with advanced kidney disease (Stage 4+) should be assessed at diagnosis (or when they reach this stage) to understand their psychosocial and physical care needs. (Assessment to include depression, anxiety, social needs, nutrition, frailty, physical activity levels, physical function and cognitive impairment.)

1b: All people with advanced kidney disease should receive annual screening to identify holistic care needs (including psychosocial and physical rehabilitation) and at key points in their pathway when their treatment needs change, e.g. start of active RRT, change of treatment modality, after hospitalization, transition to adult services, conservative management, or end of life care.

1c: All people who are at risk pre-transplantation should have a psychosocial and physical health assessment (as per NICE guideline NG107). All donors (altruistic, living related and directed) should have a pre-donation psychosocial assessment [as per BTS Guidelines for Living Donor Kidney Transplantation (2018) and for Directed Altruistic Donation (2018); and KDIGO Clinical Practice Guideline on the Evaluation and Care of Living Kidney Donors (2017)].

Addressing provision of interventions at all levels of need

2a: Routine screening for psychosocial distress and physical rehabilitation needs should be undertaken by the renal MDT and follow-up interventions determined by the traffic light system or rehabilitation care model. This should link to interventions which will increase in relation to identified need (e.g. for psychosocial the NICE Level 1–4 stepped care should be applied, and for physical rehabilitation the NHS commissioning rehabilitation model should be applied).

2b: Enhanced renal psychosocial and physical rehabilitation pathways should be identified for groups of people living with CKD who are at increased risk of poor health outcomes due to health inequalities. This includes ethnicity and social deprivation, comorbidity (e.g. severe mental illness, dementia, intellectual disability, frailty), challenges with access (e.g. due to digital and health literacy, digital exclusion, English not being the first language, other communication challenges) and challenges engaging with the care plan due to treatment non-adherence.

2c: A face-to-face annual review should be offered where clinically indicated, where people living with CKD choose it or where there is no access to digital care. It is anticipated that at least one in-person assessment will be required for the majority of people living with CKD.

2d: Pre-emptive psychosocial and physical rehabilitation interventions should be available to improve outcomes for people living with CKD at specific points in the care pathway, e.g. preparation for dialysis, pre-transplant rehabilitation, preparation for conservative care.

2e: People with advanced kidney disease (Stage 4+) should have care plans which include physical and psychosocial health and recognize the support needs of informal carers and family members. These should link to primary care social prescribing and promote shared decision making and patient activation.

Addressing integrated care

3a: Integrated mental health pathways need to be commissioned within local areas to enable stepped care which includes primary care, third sector providers, NHS Talking Therapies, community mental health provision, crisis mental health care, hospital liaison psychiatry, adult social care working with specialist Renal Psychosocial care teams. Community integrated rehabilitation should be commissioned in the context of the whole system. This should include access for people living with kidney disease for bed-based care, home based, group rehabilitation and home-based community rehabilitation, and include kidney-specific psychosocial and physical rehabilitation.

3b: Psychosocial provision and rehabilitation services for people living with advanced kidney disease should be delivered by a specialist renal MDT which includes all the professionals required to meet local population need (including renal psychosocial and renal physical rehabilitation practitioners).

3c: The renal MDT should tailor psychosocial and physical rehabilitation interventions for the person to enable:

- The development of individual care plans for physical, psychological, mental and social needs which may include supporting people through a virtual rehabilitation platform.
- Access to clinical review and more specialist advice or rehabilitation when needed.
- Care co-ordination for streamlined care.
- Provision of education resources for people living with CKD.

3d: Advanced kidney outpatient preparation (to support dialysis, conservative care and transplant decision making) for multidisciplinary care should include access to Renal Psychosocial Practitioners and health and exercise rehabilitation practitioners.

3e: Specialist renal MDTs should provide system wide consultation, liaison and training of other staff across the pathway (CNSs, AHPs, GPs and practice nurses, MDT colleagues, NHS Talking Therapies workers, community rehabilitation services) to enhance renal-informed care and develop the skills of other professionals seen by the person with kidney disease.

Addressing workforce needs

4a: All people with advanced kidney disease should have equality of access to renal psychosocial and physical rehabilitation services. The recommended staffing levels for psychosocial and therapies renal staff have been published in the Renal Workforce Plan (2020). There should be adequate renal workforce to support psychosocial and physical rehabilitation needs in all outpatient settings.

4b: All renal staff must receive training in the psychosocial and physical rehabilitation needs of people living with CKD so they are able to act as 'first responders' and know who and where to refer. In cancer and diabetes services, specialist nurses are trained to provide lower-level psychosocial provision (Level 2) with specialist supervision (from Level 3/4 practitioners).

Table 1: Continued

4c: Capability and competency analysis should be undertaken for MDTs to ensure that professionals are being supported to develop skills that are aligned to the needs of the population.

4d: Services should use digital health interventions (digital/apps/technology) to equip people and staff with skills to use new technology to maximize access to provision and enable access to specialist renal psychosocial and physical rehabilitation within their home environment. Services should also support people living with CKD to overcome barriers to access new technology and improve digital literacy, e.g. cognitive and language impairments.

Accountability and reporting

5a: To ensure there is equity of care (no postcode lotteries), national standards, audits of psychosocial and physical rehabilitation care should be introduced and monitored. The renal dashboard should include measures of psychosocial and physical wellbeing/rehabilitation and monitor the number of people with advanced kidney disease receiving a holistic assessment.

RRT, renal replacement therapy; NICE, National Institute for Health and Care Excellence; BTS, British Transplantation Society; CNS, clinical nurse specialist; AHP, allied health professional; GP, general practitioner.

Table 2: Key psychosocial health recommendations.

We recommend the introduction of the PHQ-4 and the Distress Thermometer to allow for identification need for psychosocial assessment and intervention. This should be undertaken and recorded annually for all those expecting or on dialysis, or at listing for transplantation.

We recommend people living with CKD who are at-risk, and are identified using the above tools are reviewed and where necessary referred as appropriate to NHS Talking Therapies, psychology, counselling or psychotherapy, or liaison psychiatry. The results of assessments should be linked to (with people's assent) and shared with other care providers (ideally in a care plan) to include primary care and enable local social prescribing.

Mental health provider collaboratives must ensure the education and training of staff to enhance renal-informed care, including referral routes for people with CKD into their local IAPT provider. We note that kidney disease is not covered in the long-term conditions training for IAPT staff, and believe this should be remedied.

Renal staff must receive training in the psychosocial needs of people living with CKD, and be able to act as 'first responders', knowing who and where to refer. Renal specialist nurses can be trained (a national Level 2 course for renal staff could be developed in conjunction with ANN-UK and UKKA) to provide lower-level psychosocial provision (Level 2) with specialist supervision.

All people who are at risk pre-transplantation should have a psychosocial and physical health assessment (as per NICE guideline NG107). All donors (altruistic, living related and directed) should have a pre-donation psychosocial assessment [as per BTS Guidelines for Living Donor Kidney Transplantation (2018) and for Directed Altruistic Donation (2018); and KDIGO Clinical Practice Guideline on the Evaluation and Care of Living Kidney Donors (2017)].

IAPT, improving access to psychological therapies; ANN-UK, Association of Nephrology Nurses UK; NICE, National Institute for Health and Care Excellence; BTS, British Transplantation Society.

on the key areas surrounding the provision of psychosocial and physical rehabilitation for people living with CKD.

When planning for an optimal pathway that delivers good kidney-specific psychosocial and physical rehabilitation management for all people living with CKD, the extent to which experts agree on the management can be synthesized using consensus methodology. It was essential that as many of the key expert healthcare professionals, people living with CKD and essential stakeholders were involved, so that the key recommendations resulting from this process had credibility and were a fair reflection of current opinion and practice.

The single contentious issue exposed by the process related to the statement recommending that all people with advanced CKD (stage 4+) be assessed to understand their psychosocial and physical care needs. Concerns about whether this type of assessment should be prioritized only for those people approaching end-stage CKD, rather than the whole of stage 4+, were raised in response to this statement in Round 1. Extended discussion at the consensus workshop reflecting the importance of preventative therapeutic approaches [22] resulted in subsequent high consensus with this statement (92%).

There was a high level of consensus for all other statements (>92%) at the end of Round 2, a strong show of support for the integration of psychosocial and physical rehabilitation management within the care and commissioning pathway for people living with CKD. Five statements reached 100% consensus by the end of Round 2. It was recommended for people who are at risk pre-transplantation, including recipients and donors, to have a psychosocial and physical health assessment (Statement 1c). It was also recommended that enhanced kidney psychosocial and physical rehabilitation pathways should be identified for groups of people living with CKD at increased risk of poor health outcomes due to health inequalities (Statement 2b). Pre-emptive psychosocial and physical rehabilitation interventions were recommended to be available to improve outcomes for people living with CKD at specific points in the patient pathway, e.g. preparation for dialysis, pre-transplant rehabilitation and preparation for conservative care (Statement 2d). It was recommended that the kidney MDT should tailor psychosocial and physical rehabilitation interventions for the person to enable the development of individual care plans for physical mental and social needs which may include supporting people through a virtual rehabilitation

Table 3: Key physical health recommendations.

All people expecting or on dialysis, or at listing for transplantation, should receive a holistic physical health review at diagnosis or annually, that includes a physical function, nutritional and frailty assessment (Clinical Frailty Score). Care plans must include physical rehabilitation, linking to primary care social prescribing.

We recommend that all people living with CKD expecting or on dialysis, or at listing for transplantation, should be assessed with the validated 'Sit to Stand 5 (STS5) functional assessment measure' and the physical activity vital scale. This should be recorded annually as the physical function and physical activity measures that allow for identification of those in need of physical rehabilitation assessment and intervention.

We recommend the inclusion of digital health interventions to equip people living with CKD and the staff caring for them to maximize access to care. Services should support people living with CKD to overcome barriers to accessing new technology and improve digital literacy. Free NHS-developed web-based self-management programmes (that offer live and on-demand movement classes, and behaviour change support tools to increase physical activity) for people living with CKD exist and should be adopted wherever possible.

Renal staff must receive training in recognizing frailty and renal-informed physical rehabilitation care. They should link to integrated community rehabilitation teams, and where needed to specialist physiotherapists and occupational therapists for renal-specific care.

Table 4: Consensus results for Round 1 and Round 2.

Consensus statement	Round 1: participant responses 'Yes', n (%)	Round 1: participant responses 'No', n (%)	Round 2: participant responses 'Yes', n (%)	Round 2: participant responses 'No', n (%)
1a	17 (77)	5 (23)	24 (92)	2 (8)
1b	19 (86)	3 (14)	25 (96)	1 (4)
1c	22 (100)	0 (0)	26 (100)	0 (0)
2a	20 (91)	2 (9)	25 (96)	1 (4)
2b	21 (95)	1 (5)	26 (100)	0 (0)
2c	18 (82)	4 (8)	25 (96)	1 (4)
2d	22 (100)	0 (0)	26 (100)	0 (0)
2e	19 (86)	3 (14)	25 (96)	1 (4)
3a	21 (95)	1 (5)	25 (96)	1 (4)
3b	19 (86)	3 (14)	24 (92)	2 (8)
3c	22 (100)	0 (0)	26 (100)	0 (0)
3d	21 (95)	1 (5)	25 (96)	1 (4)
3e	19 (86)	3 (14)	25 (96)	1 (4)
4a	20 (91)	2 (9)	25 (96)	1 (4)
4b	20 (91)	2 (9)	25 (96)	1 (4)
4c	22 (100)	0 (0)	25 (96)	1 (4)
4d	22 (100)	0 (0)	24 (92)	2 (8)
5	21 (95)	1 (5)	26 (100)	0 (0)

There were n = 22 respondents in Round 1 and n = 26 respondents in Round 2.

platform, access to clinical review and more specialist advice or rehabilitation when needed, care co-ordination for streamlined care and the provision of education resources for people living with CKD (Statement 3c). Finally, there was also a recommendation to ensure that the kidney dashboard includes measures of psychosocial and physical health so there is equity of care (Statement 5). The key recommendations for the RSTP toolkit (Table 2 and 3), and also the recommendation for the RSTP dashboard to include a record that a holistic needs assessment has been completed at diagnosis, change of modality and otherwise annually, reflect these identified priority areas.

In brief, from an outcome measure perspective, the PHQ-4 was recommended as an ultra-brief valid and reliable self-report questionnaire that measures depression and anxiety scale [18]. The Distress Thermometer is a simple tool used to screen for symptoms of distress and empowers the clinician to facilitate appropriate psychosocial support and referrals [19]. The STS5 outcome measure was suggested as a measure of physical function. The STS5 is a reliable [20] and commonly used assessment

of frailty, lower body strength, muscle power and balance in CKD, and is associated with progression to dialysis and mortality [23]. The Single-item Score physical activity measure, a self-report single-question outcome measure to determine weekly physical activity levels, was also recommended to screen for low levels of physical activity. This measure was recently recommended in the UKKA exercise and lifestyle clinical practice guidelines [16]. All these measures were deemed to be simple, easy to complete by the patient and simple to score by the healthcare professional, and therefore to have an increased likelihood of being adopted into clinical practice.

The consensus statements and priority statements we report for the commissioning of psychosocial and physical rehabilitation kidney care offer a unique and comprehensive, evidence-based approach to prioritize and deliver clinically implementable care for people living with CKD. The statements, which are based on the current evidence that includes published guidelines, also benefits from the collation of expert opinions, including those of people living with CKD, that the Del-

phi methodology affords. In contrast, guidelines are often based on published studies of randomized controlled trials only. It is anticipated that these statements will be utilized alongside other published guidelines to offer people living with CKD an opportunity to live well with their kidney disease. The additional cost resource to provide this care is acknowledged. The increased inequality in provision of this type of care for people living with CKD, when compared with other long-term conditions, and potential cost-saving of proposed preventative measures should entice kidney care providers to commission these services.

The modified Delphi process has very few geographical limitations as it primarily uses online questionnaires. This enabled many experts throughout the UK to take part at relatively little cost. This methodology also allows a degree of anonymity, which helps to avoid domination by an individual with strong opinions or vested interests. The process of 'rounds' also allows individuals to view the distribution of the group's response and to change their own response considering this. Criticisms of the Delphi process include the absence of accountability afforded to panel members by the anonymity of the process and the lack of open discussion on issues relating to each statement. However, our consensus workshop allowed for open discussion during revision of statements for Round 2, giving the opportunity for each expert panel member to clarify and expand on their opinions. There is no standard threshold for consensus, however previous Delphi studies have accepted consensus levels of between 50% and 80% [17].

CONCLUSION

The Delphi process proved successful in finding consensus on the most appropriate kidney-specific psychosocial and physical rehabilitation management for people living with CKD. The final 16 statements generated during this process will form the basis of key recommendations for the short- and longer-term, which will be included in the RSTP commissioning toolkit for kidney care. The process has provided recognition that kidney-specific psychosocial provision and physical rehabilitation management should be a component of any optimal care pathway for people living with CKD.

DATA AVAILABILITY STATEMENT

The data underlying this article are available in the article.

CONFLICT OF INTEREST STATEMENT

The results presented in this article have not been published previously in whole or part. There are no reported conflicts of interest for any authors.

REFERENCES

- Kalantar-Zadeh K, Li PK, Tantisattamo E et al. Living well with kidney disease by patient and care-partner empowerment: kidney health for everyone everywhere. *Am J Nephrol* 2021;52:1–7. <https://doi.org/10.1159/000513952>
- Fraser S, Taal M. Helping people to live well with chronic kidney disease. *Br J Hosp Med* 2020;81:1–10. <https://doi.org/10.12968/hmed.2020.0069>
- Kidney Care UK. National Psychosocial Working Group. Psychosocial Health – a manifesto for action. Alton 2022. <https://www.kidneycareuk.org/about-kidney-health/living-kidney-disease/mental-health/manifesto/> (14 February 2023, date last accessed)
- Hedayati SS, Minhajuddin AT, Afshar M et al. Association between major depressive episodes in patients with chronic kidney disease and initiation of dialysis, hospitalization, or death. *JAMA* 2010;303:1946–53. <https://doi.org/10.1001/jama.2010.619>
- Lopes AA, Bragg J, Young E et al. Depression as a predictor of mortality and hospitalization among hemodialysis patients in the United States and Europe. *Kidney Int* 2002;62:199–207. <https://doi.org/10.1046/j.1523-1755.2002.00411.x>
- Wilk AS, Hu JC, Chehal P et al. National estimates of mental health needs among adults with self-reported CKD in the United States. *Kidney Int Rep* 2022;7:1630–42. <https://doi.org/10.1016/j.ekir.2022.04.088>
- Cogley C, Carswell C, Bramham K et al. Chronic kidney disease and severe mental illness: addressing disparities in access to health care and health outcomes. *Clin J Am Soc Nephrol* 2022;17:1413–7. <https://doi.org/10.2215/CJN.15691221>
- Chang CK, Hayes RD, Perera G et al. Life expectancy at birth for people with serious mental illness and other major disorders from a secondary mental health care case register in London. *PLoS One* 2011;6:e19590. <https://doi.org/10.1371/journal.pone.0019590>
- Banerjee G, Karia S, Varley J et al. Cognitive impairment in elderly renal inpatients: an under-identified phenomenon. *Nephron Clin Pract* 2014;126:19–23. <https://doi.org/10.1159/000357778>
- Iyasere O, Okai D, Brown E. Cognitive function and advanced kidney disease: longitudinal trends and impact on decision-making. *Clin Kidney J* 2017;10:89–94. <https://doi.org/10.1093/ckj/sfw128>
- Seekles ML, Ormandy P. Exploring the role of the UK renal social worker: the nexus between health and social care for renal patients. *PLoS One* 2022;17:e0275007. <https://doi.org/10.1371/journal.pone.0275007>
- Psychological Professions Network. Maximising the impact of psychological practice in physical healthcare: discussion paper. 2020. Available from: <https://www.ppn.nhs.uk/resources/ppn-publications/34-maximising-the-impact-of-psychological-practice-in-physical-healthcare-discussion-paper/file> (14 February 2023, date last accessed)
- Seekles ML, Ormandy P, Coyne E. Mapping the UK renal psychosocial workforce: the first comprehensive workforce survey. *BMC Nephrol* 2019;20:100. <https://doi.org/10.1186/s12882-019-1287-0>
- Seekles M, Ormandy P, Kameråde D. Examining patient distress and unmet need for support across UK renal units with varying models of psychosocial care delivery: a cross-sectional survey study. *BMJ Open* 2020;10:e036931. <https://doi.org/10.1136/bmjopen-2020-036931>
- Wilkinson TJ, Clarke AL, Nixon DGD et al. Prevalence and correlates of physical activity across kidney disease stages: an observational multicentre study. *Nephrol Dial Transplant* 2021;36:641–9. <https://doi.org/10.1093/ndt/gfz235> [published Online First: 2019/11/15].
- Baker LA, March DS, Wilkinson TJ et al. Clinical practice guideline exercise and lifestyle in chronic kidney disease. *BMC Nephrol* 2022;23:75. <https://doi.org/10.1186/s12882-021-02618-1>
- Sumsion T. The Delphi technique: an adaptive research tool. *Br J Occup Ther* 1998;61:153–6. <https://doi.org/10.1177/030802269806100403>

18. Löwe B, Wahl I, Rose M et al. A 4-item measure of depression and anxiety: validation and standardization of the Patient Health Questionnaire-4 (PHQ-4) in the general population. *J Affect Disord* 2010;**122**:86–95. <https://doi.org/10.1016/j.jad.2009.06.019>
19. Ownby KK. Use of the distress thermometer in clinical practice. *J Adv Pract Oncol* 2019;**10**:175–9.
20. Huang KS, O'Connor E, Tuffnell R et al. Reliability and validity of the five-repetition sit-to-stand test in adult kidney transplant recipients. *Int J Ther Rehabil* 2018;**25**:158–66. <https://doi.org/10.12968/ijtr.2018.25.4.158>
21. Barrios M, Guilera G, Nuño L et al. Consensus in the delphi method: what makes a decision change? *Technol Forecast Soc Change* 2021;**163**:120484. <https://doi.org/10.1016/j.techfore.2020.120484>
22. Tsai YC, Chiu YW, Hung CC et al. Association of symptoms of depression with progression of CKD. *Am J Kidney Dis* 2012;**60**:54–61. <https://doi.org/10.1053/j.ajkd.2012.02.325>
23. Rampersad C, Darcel J, Harasemiw O et al. Change in physical activity and function in patients with baseline advanced nondialysis CKD. *Clin J Am Soc Nephrol* 2021;**16**:1805–12. <https://doi.org/10.2215/cjn.07050521>