# ORIGINAL RESEARCH



Check for updates

# The identification and management of depression in UK Kidney Care: Results from the Mood Maps Study

Joseph Chilcot PhD<sup>1</sup> | Christina J. Pearce PhD<sup>1</sup> | Natalie Hall MSc<sup>2</sup> | Amanda D. Busby MSc<sup>2</sup> | Janine Hawkins PhD<sup>2</sup> | Balvinder Vraitch<sup>3</sup> | Mandy Rathjen<sup>4</sup> | Alexander Hamilton PhD<sup>5,6</sup> | Amanda Bevin PGDip<sup>7</sup> | Lucy Mackintosh MSc<sup>2</sup> | Joanna L. Hudson PhD<sup>1</sup> | David Wellsted PhD<sup>2</sup> | Julia Jones PhD<sup>8</sup> | Shivani Sharma PhD<sup>2</sup> | Sam Norton PhD<sup>1</sup> | Paula Ormandy PhD<sup>9</sup> | Nick Palmer BSc<sup>10</sup> | Ken Farrington MD<sup>2,11</sup> |

#### Correspondence

Dr. Joseph Chilcot, PhD, Health Psychology Section, Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College London, 5th floor Bermondsey Wing, Guy's Campus, London Bridge, London SE1 9RT, UK.

Email: joseph.chilcot@kcl.ac.uk

#### **Funding information**

Kidney Care UK; Kidney Research UK; British Renal Society

### Abstract

**Background:** Depression is common in people with chronic kidney disease, yet little is known about how depression is identified and managed as part of routine kidney care.

**Objectives:** The primary objective was to survey all UK adult kidney centres to understand how depression is identified and managed. A secondary objective was to broadly describe the variability in psychosocial care.

Design: Online survey.

**Methods:** The survey comprised of three sections: (1) general kidney care, (2) psychological provision and (3) social work provision.

**Results:** 48/68 (71%) of centres responded to the general survey with 20 and 13 responses from psychological and social work module respectively. Only 31.4% reported having both in centre psychological and social work practitioners. Three

J Ren Care. 2024;1–10. wileyonlinelibrary.com/journal/jorc

<sup>&</sup>lt;sup>1</sup>Department of Psychology, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

<sup>&</sup>lt;sup>2</sup>Centre for Health Services and Clinical Research, School of Life and Medical Sciences, University of Hertfordshire, College Lane Campus, Hatfield, UK

<sup>&</sup>lt;sup>3</sup>Renal Department, University Hospitals Coventry & Warwickshire NHS Trust, Coventry, United Kingdom, United Kingdom

<sup>&</sup>lt;sup>4</sup>Renal Department, Edinburgh Royal Infirmary, Edinburgh, United Kingdom, United Kingdom

<sup>&</sup>lt;sup>5</sup>Exeter Kidney Unit, Royal Devon and Exeter NHS Foundation Trust, Barrack Road, Exeter, Devon, UK

<sup>&</sup>lt;sup>6</sup>Exeter Medical School, University of Exeter, Exeter, United Kingdom

<sup>&</sup>lt;sup>7</sup>Kent & Canterbury Kidney Care Centre, Kent & Canterbury Hospital, Canterbury, UK

<sup>&</sup>lt;sup>8</sup>Centre for Research in Public Health and Community Care, School of Health and Social Work, University of Hertfordshire, Hatfield, UK

<sup>&</sup>lt;sup>9</sup>School of Health and Society, University of Salford, Salford, UK

<sup>&</sup>lt;sup>10</sup>Kidney Care UK, Alton, UK

<sup>&</sup>lt;sup>11</sup>Renal Medicine, Lister Hospital, Stevenage, UK

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

<sup>© 2024</sup> The Authors. Journal of Renal Care published by John Wiley & Sons Ltd on behalf of European Dialysis & Transplant Nurses Association/European Renal Care Association.

centres reported no access to psychosocial provision. Of the 25 centres who reported on pathways, 36.0% reported having internal pathways for the identification and management of depression. Within services with psychological provision, screening for depression varied across modality/group (e.g., 7.1% in mild/moderate chronic kidney disease vs. 62.5% in kidney donors). Cognitive Behavioural Therapy and Acceptance and Commitment Therapy were the most common interventions offered. Most psychosocial services were aware of the National Institute for Health and Care Excellence guidelines for managing depression in long-term conditions (n = 18, 94.7%) yet few fully utilised (n = 6, 33.3%). Limited workforce capacity was evident.

**Conclusions:** There is considerable variability in approaches taken to identify and treat depression across UK kidney services, with few services having specific pathways designed to detect and manage depression. Workforce capacity remains a significant issue.

#### KEYWORDS

chronic kidney disease, depression, kidney care, psychological services, psychosocial care

# INTRODUCTION

In 2023, approximately 7.19 million people in the United Kingdom are estimated to have chronic kidney disease (CKD) which represents more than 10% of the UK population (KRUK, 2023). Globally CKD is estimated to effect 13% of the population and by 2040 is predicted to be the fifth leading cause of lost life years (Kovesdy, 2022; Wen et al., 2022). The management of kidney disease is complex and varied depending on the degree of kidney failure. Those with moderately severe CKD require management of the underlying disease, treatment to reduce disease progression and ultimately, preparation for kidney replacement therapy (KRT). KRT is required when kidney failure is advanced. It consists of dialysis (haemodialysis or peritoneal dialysis) or transplantation. These all impose significant, though distinct, burdens on people with CKD, their families, and carers (Belasco & Sesso, 2002; Mcclellan et al., 2010; Mehrotra et al., 2023; Picariello et al., 2020).

# LITERATURE REVIEW

Across the international kidney community, the psychosocial impact of CKD is significant, notably effecting mental health and well-being (Cukor, 2021; Mehrotra et al., 2023; Weisbord et al., 2007; Yang et al., 2015). Depression contributes to poorer quality of life, worse clinical outcomes, and higher healthcare costs (Chilcot, Almond, et al., 2018; Chilcot, Guirguis, et al., 2018, Farrokhi et al., 2014; Lopes et al., 2002; Tsai et al., 2012; Weisbord et al., 2014). The prevalence of depression in people with CKD is estimated to be between 26.5% and 39.3% depending on the assessment method

used (Palmer et al., 2013). The identification and diagnosis of depression in people with a long-term condition (LTC) can also be complicated by overlapping physical symptoms. In kidney disease, common symptoms such as fatigue, changes in appetite and concentration can therefore create diagnostic overshadowing of underlying depressive disorder making the diagnosis of depression more challenging (Chilcot et al., 2008). Further, there is evidence that identification and management is more complex in multiethnic settings (Sharma et al., 2011, 2023).

In 2009, the National Institute for Health and Care Excellence (NICE¹) published guidelines in England on depression in people with chronic physical health problems, recognising the link between physical and mental health, advising a stepped care model based primarily on symptom severity (NICE, 2009). Although not specific to the complexities and needs of people with CKD, these general guidelines advise that the choice of intervention should be influenced by, among other things, the likelihood of adherence to treatment and any potential adverse effects. This may be particularly relevant when considering antidepressant use in those with CKD (Guirguis et al., 2020) especially given the paucity of evidence relating to the management of depression in this population and the increased propensity for adverse drug reactions (Chilcot & Hudson, 2019; Natale et al., 2019; Pearce et al., 2023).

More recently in England, NICE published implementation guidance documenting how evidence-based talk therapy for depression and anxiety in the context of LTCs could be delivered with the support of the NHS Talking Therapies, for anxiety and depression service (formerly known as Improving Access to

<sup>&</sup>lt;sup>1</sup>In England, NICE is a national body which provides evidence-based practice guidelines to practitioners and commissioners.

Psychological Therapy services, IAPT) (NHS, 2018). This service provides evidence-based psychological treatments at step 2 and step 3 of the stepped care model. However, clear evidence for the implementation of NICE evidence-based treatments for the management of depression in the CKD population is lacking. Currently, little is known about how these NICE guidelines are adhered to as part of UK kidney care. Past work has identified variability in the psychosocial workforce and models of service provision related to psychosocial care (Seekles et al., 2019), yet no specific data exists regarding approaches to the identification and management of depression in UK kidney care. Accordingly, our primary objective was to survey all UK adult kidney care centres to understand how depression is identified and managed. This survey forms part of a larger national study to identify centres with different levels of psychosocial provision to understand more about local and national practice patterns, as well as barriers and facilitators towards the management of depression. The data here serves as a national landscaping exercise to understand how depression is recognised and managed at a macro level and was used to inform selection of six case study sites, with different levels of psychosocial provision being studied in the next study phase of the MOODMAPS study. Therefore, details of specific guideline implementation at a micro level, remains the focus of subsequent work. Our secondary objective was to ascertain variability in psychosocial care more broadly given its potential impact on depression management, including the use of alternative clinical guidelines used in the devolved nations of the United Kingdom.

# **METHODS**

# Design

The study used an online survey design of all 68 UK kidney centres. Primary data was collected between December 2021-April 2022. The Mood Maps kidney centre survey was merged with a British Renal Society and Kidney Care UK funded, COVID-19 focussed questionnaire due to parallel data collection periods and participants. This reduced research burden on the NHS staff during the Omicron COVID-19 wave and prevented confusion regarding the differences between the surveys. This paper focusses on data regarding the services and the psychosocial provision. The impact of COVID-19 is reported separately (Mackintosh et al., 2023). Ethical approval was granted by the University of Hertfordshire research ethics committee.

# **Participants**

All UK kidney centres were invited to participant by email, containing a link to the survey. There were no exclusion criteria. The UK Kidney Association provided a list of centre CDs and the Association of Nephrology Nurses UK a list of lead nurse contacts, which were used to approach centres across the United Kingdom. Leads for social work and psychological provision in the centre (if applicable), were identified by the CD or lead nurse.

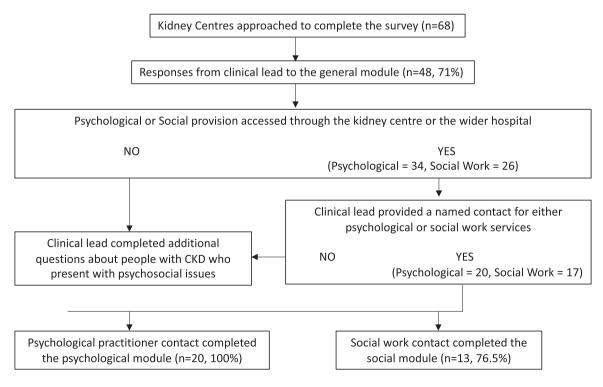


FIGURE 1 Overview of the survey structure and navigation.



# **Materials**

The survey comprised of three modules (Figure 1), outlined below. The survey was developed by the study team in collaboration with the study patient and public involvement group (PPI) comprising of 11 members. The PPI group comprised of people living with kidney disease and carers, with various experience of kidney replacement therapies and transplantation. It was then piloted by a nephrologist (AH), chair of the Mood Maps steering group and a counsellor, also a steering group member (AB). Amendments (such as item rewording, and suggestions for additional items) were implemented based on their feedback and shared with the PPI group. The survey was designed to be completed in approximately 30 minutes, collecting descriptive, categorical, continuous and free text data in each module. The online survey was hosted via the University of Hertfordshire's REDCap site, a secure web application for building and managing online surveys and databases.

# General module

The general module was completed by the clinical directors (CDs) and was designed to capture data on the centre characteristics and patient profile. There were 61 questions in total, collecting data on service provision, staffing structure, patient and staff profiles, the impact of the COVID-19 pandemic and a small number of questions about psychosocial provision. CDs were asked to forward specific questions pertaining to nursing provision to the lead nurse. Due to initial low completion on questions pertaining to nursing provision, we sent these relevant questions separately to lead nurses through the Association of Nephrology Nurses UK in December 2022. Their responses were combined with centre clinical CDs responses collected earlier. Email addresses for the social work and psychological leads (if applicable) were captured from the CD, which would then automatically send the named individual the relevant module.

# Psychological module

The psychological module comprised of 30 questions, focusing predominantly on questions regarding the identification (i.e., screening protocols) and management of depression (treatments offered), use of guidelines, referral pathways and assessment, alongside other questions about the types of services offered, modes of delivery and staffing levels. Participants were given a free-text option to identify gaps in psychological service provision.

# Social work module

The social work module comprised of 23 questions focusing on staffing levels, roles, need assessments and interventions offered,

and guideline use. Participants were given a free-text option to identify gaps in social work provision.

# Data analysis

Scoring was embedded into the REDCap data file so that coded data could be extracted from the website once data collection had closed. Data cleaning and checks were conducted by NH, CP and ADB initially in Microsoft Excel and then within Stata/IC 15.1. This included the removal of records from centres who opened and immediately closed the survey without inputting any data (n = 15) and missing data analysis. Due to the relatively small number of kidney centres across the United Kingdom (n = 68), descriptive statistics are predominantly utilised for this analysis.

# Results

Forty-two of the 68 adult kidney centres responded to the general module (see Figure 1). Forty-one were analysable (60% of centres). One entry included only the psychological module with no accompanying centre identifier. The later abbreviated nursing questionnaire provided an additional seven novel responses, making a total response from 48 (71%) individual centres. There were 20 valid responses for the psychological module and 13 for the social work module (out of a possible 16, 81.2%). At least one centre from each of England, Scotland, Wales and Northern Ireland participated (see Supporting Information File S1: Figure 1). The number of responses varied across survey questions, so percentages are reported throughout as a proportion of those centres providing answers (e.g., up to 41 or 48, 20 and 13).

# Clinical leads perspectives on the identification and management of depression

Of the 25 centres who answered questions on pathways, nine (36%) reported having a specific local pathway for the identification and management of depression. One-third of centres (16 centres) reported awareness of the NICE guidelines 'Depression in adults with a chronic physical health problem: recognition and management' (NICE, 2009) or National equivalents (n = 14, 29.2%). Thirty of 48 centres (62.5%) responded to questions about antidepressant policies, with most reporting that these were typically prescribed (n = 29, 96.7%) and monitored (n = 27, 90.0%) by General Practitioners (GPs). Twenty-nine centres responded when asked for an approximation of the numbers of people with CKD taking antidepressants across different modalities. The majority from these 29 centres (between 72.4% and 89.7% across the modalities) selected the response 'I don't know'.

# Service provision and access to support depression and other psychosocial needs

Forty-four centres responded to questions about psychosocial provision, with 34 (77.3%) reporting patient access to a psychologist, psychiatrist or counsellor, and/or a social worker as part of the kidney service. Thirty of 44 responding centres (68.2%) reported having access to both psychological practitioners (e.g., Psychologist, Psychiatrist or Counsellor/Psychotherapist) and social workers, either as part of the wider hospital community, within the kidney centre or a mixture of both. Three centres (8.1%) reported having no access these practitioners. Thirty centres (68.2%) reported access to a psychiatrist within the general hospital.

# Staff education and training about depression in CKD

Twenty-eight centres responded to questions about education and training for medical staff. Only four centres (14.3%) reported having specific training on identification and management of depression/and or anxiety. Twenty-two centres responded to questions about education and training for nursing staff, with six reporting specific training, typically delivered in a multidisciplinary team (MDT) setting.

# Psychological module

Thirty-four centres reported having in-kidney centre or inhospital psychological teams. Twenty centres provided contact information (58.8%) and all 20 responded to the survey (see Supporting Information File S1: Figure 2), although one centre was not identifiable.

# Screening for depression

Within services with psychological provisions, proactive screening varied according to modality. For example, only four services (20%) proactively screened people CKD stages 3b-5, while 10 of 16 transplanting centres (62.5%) screened living kidney donors (Table 1).

The most common screening tools were the Patient Health Questionanire-9 (PHQ-9, n = 6, 46.2%) and the Generalised Anxiety Disorder-7 scale (for anxiety GAD-7, n = 7, 53.8%). Others included the distress thermometer (n = 3, 23.1%), Hospital Anxiety and Depression Scale (HADS, n = 3, 23.1%) and the PHQ-Anxiety and Depression Scale (PHQ-ADS, n = 1, 7.7%).

Screening frequency varied from 6 to 12 months, but most occurred 'at key points' in kidney care. The majority of screening was usually conducted by a psychological practitioner.

TABLE 1 Percentage of centres who proactively screening for depression in each modality for people with Chronic Kidney Disease

(CKD), n = 20.

(61,5), 11 26.		
Service	Number of centres providing that service	Number of centres who proactively screen within the service
Mild/moderate CKD	14	1 (7.1%)
Advanced/low clearance (stages 3b-5)	20	4 (20.0%)
Transition to adult services	11	1 (9.1%)
In-Centre haemodialysis	19	6 (31.6%)
In-satellite haemodialysis	17	5 (29.4%)
Home haemodialysis/ peritoneal dialysis	19	3 (15.8%)
Assisted peritoneal dialysis	19	2 (10.5%)
Immunosuppressed	19	3 (15.8%)
Living donors	16	10 (62.5%)
Transplant surgery	14	5 (35.7%)
Transplant follow up	18	4 (22.2%)
Conservative management	18	4 (22.2%)
End of life care	16	2 (12.5%)

# Guideline awareness and implementation

Nineteen services responded to questions about guidelines. Most (n = 18, 94.7%) were aware of the NICE guideline [CG91] but only seven respondents felt the guidance was very relevant to people with CKD (38.9%), with six fully utilising the guidance in their service (n = 6, 31.6%). Other national or professional guidelines informing psychosocial provision were reported. These were usually generic, not necessarily mental health focused and not tailored specifically to kidney care or longterm conditions (see Supporting Information File S1: Table S1).

#### Antidepressant prescription

When asked who might consider the suitability and prescription of medication as an intervention (e.g., antidepressants), the most likely health professional identified were GPs (n = 18, 94.7%), followed by nephrologists (n = 14, 73.7%), mental health services (n = 13, 68.4%) and others MDT members (n = 5, 26.3%).

# Psychosocial staffing

Most respondents reported having one or more psychologist whole time equivalent (WTE) in post and more than one social worker



(see Supporting Information File S1: Table S2). Vacancies were notable with an average of 1.1 WTE for psychologists, 0.8 WTE for counsellors and 0.2 WTE for social workers.

# Psychological referral pathways

From the 20 centres between 90% and 100% of their referrals came from outpatient clinics (n = 11, 55%). Half had formal (n = 10, 50.0%) or both formal and informal referral pathways (n = 7, 35.0%). Numbers of new referrals to kidney psychological services varied between 1 and 15 weekly, along with four to 100 follow-up appointments. Fifteen centres (78.9%) reported having a waiting list for referrals, with 9 offering interventions or signposting to wait-listed people.

# Psychological assessment and intervention

A wide range of psychological assessments, services and interventions were reported as being offered (Table 2). Cognitive Behavioural Therapy (CBT) and Acceptance & Commitment Therapy (ACT) were the most common psychological interventions provided (n = 17, 85.0% and n = 15, 75% respectively). Counselling was also provided in 11 (55.5%) of responding centres. Most centres reported that their service offered 16 or more therapy sessions (n = 8, 42.0%) per person with no maximum number (n = 14, 73.7%). The frequency of sessions was usually fortnightly (n = 12, 66.7%).

# Gaps in service provision

Centres were asked to identify the most important gaps in their services for people with CKD and/or carers. All 20 reported gaps, the most common being limited capacity due to funding issues, staff vacancies and waiting times (see Supporting Information File S1: Table S3 for more examples.)

#### Social work module

Twenty-six centres indicated that people with CKD had access to a social worker either as part of the kidney team or as part of a broader general hospital social work team working across different services. Of these, nine centres relied on general hospital provision. Seventeen centres provided a named contact for the social work module of which 16 responded and started the survey. However, three responders reported that they had no social workers, with no vacancies, so were excluded from future questions, leaving 13 analysable responses from centres (see Supporting Information File S1: Figure 3).

# Social work staffing

Of the 13 social worker teams surveyed, 12 stated that the social work provision was a dedicated part of the kidney service (92.3%).

**TABLE 2** Psychological services offered by psychological practitioners, *n* = 20.

Psychological service	n	%
Signposting	19	95.0
Screening for distress	18	90.0
Low intensity intervention	17	85.0
Complex assessment, formulation, intervention	16	80.0
One-one counselling	15	75.0
Patient Leaflets	12	60.0
Support for carers	10	50.0
Peer support groups	10	50.0
Online support	9	45.0
Bereavement counselling	8	40.0
Cognitive screening/neuropsychological assessments	3	15.0
Other	3	15.0
Emergency hotlines	1	5.0

Most centres reported having one or more qualified social worker (see Supporting Information File S1: Table S4).

# Referral routes and delivery of care

Given differences in centre size and the size of patient population, between 2 and 20 new referrals and 3 to 55 follow-ups each week were reported, with many describing significant variability depending upon staffing levels. The main referral source was the MDT (n = 11, 84.6%), followed by the medical/surgical team (n = 10, 76.9%) or self-referral (n = 10, 76.9%). Waiting times for most services was between 0 and 2 weeks (n = 10, 83.3%). Six (54.5%) indicated that information and/or support was offered while waiting. This included signposting to the Kidney Care UK website and other community support agencies, supplying information packs and leaflets, and phone calls or email support if needed. All reported service delivery on an individual basis. For summary of models of service delivery practices see Supporting Information File S1: Table S5. Social workers offered a variety of services and interventions (Table 3).

# Guidelines and roles

Reported guidelines most informing centre social work practice included NICE, Social Work England, the Mental Capacity Act (2005), Scottish Social Services Council and Social Services and Wellbeing Act (Wales) 2014. In total, 34 guidelines were reported (unique n = 23, see Supporting Information File S1: Table S6) with nearly all described as 'very useful' (n = 29, 87.9%) for patients with CKD. Key social worker roles in this setting were reported as

**TABLE 3** Services and interventions offered by social workers.

TABLE 6 Services and interventions	, , , , , , , , , , , , , , , , , , , ,	
Social work service	n	%
Need identification	11	91.7
Referral to agency	11	91.7
Low level support	11	91.7
Welfare/benefits advice/support	11	91.7
Informal counselling	9	75.0
Information provision	11	91.7
Emotional support	11	91.7
Carer bereavement support	6	50.0
Care needs assessment	7	58.3
Supporting grant applications	10	83.3
Pre-dialysis assessment/education	7	58.3
Conservative management	6	50.0
Supportive/Palliative Care	6	50.0
Carer Assessments	5	41.7
Risk assessments	6	50.0
Discharge planning	6	50.0
Other	4	33.3

needs identification, facilitate hospital discharges, safe-guarding, crisis management, referral to agencies, low level support, welfare and benefits advice and support, information provision and emotional support (each n=11, 91.7%). External agencies engaged with (Table 4) included adult social care (n=11, 100%) and psychological and mental health services (n=9, 81.8%), adult care (n=8, 72.7%) and Money Advice Unit (n=5, 45.5%) for carers.

# Gaps in service provision

Centres also highlighted the main gaps in social provisions for their services, with staffing being highlighted as a common concern (see Supporting Information File S1: Table S7 for more examples).

# DISCUSSION

This national survey aimed to understand how depression is identified and managed across UK kidney care. Depression remains a significant burden to people living with CKD, yet the nature of practice patterns implemented to detect and treat depression across UK kidney centres is not known. Our study therefore serves as a national landscaping exercise to further understand these issues. Our secondary aim was to ascertain variability in psychosocial care more broadly focusing on psychological practitioner and social work provisions, and relevant national guidelines used in the devolved nations.

**TABLE 4** External services engaged with for both people with CKD and carers. *n* = 11.

CRD and carers, II - 11.		
External services	People with CKD	Carers
NHS Talking Therapies, for anxiety and depression (formerly IAPT)	2 (18.2%)	1 (9.1%)
Palliative care	6 (54.5%)	3 (27.3%)
Community mental health	8 (72.7%)	2 (18.2%)
Adult care	11 (100.0%)	8 (72.7%)
Citizens' Advice Bureau	9 (81.8%)	4 (36.4%)
Psychiatry	7 (63.6%)	1 (9.1%)
Primary care (GPs)	8 (72.7%)	2 (18.2%)
Psychology services	9 (81.8%)	3 (27.3%)
Counselling	6 (54.5%)	4 (36.4%)
Self-help online services	2 (18.2%)	2 (18.2%)
Kidney Care UK online counselling	3 (27.3%)	2 (18.2%)
Welfare officer	7 (63.6%)	3 (27.3%)
Youth workers	2 (18.2%)	1 (9.1%)
Money Advice Unit (MAU)	7 (63.6%)	5 (45.5%)
Carers UK	4 (36.4%)	3 (27.3%)
Age UK	6 (54.5%)	2 (18.2%)
Cruise (bereavement)	3 (27.3%)	3 (27.3%)
Chaplin/Spiritual	8 (72.7%)	4 (36.4%)
Other	0 (0.0%)	1 (9.1%)

Over 30% of responding centres reported having no access to both psychological and social care practitioners either as part of the wider hospital community or within the kidney unit, although the size of these provisions was variable. Where centres had these provisions, around a third were in-centre. It is concerning that three centres responded that they have no access to psychosocial provision, either within the kidney service or the wider hospital. Given the high rates of depression found in people with CKD, it is concerning that psychosocial teams are not more accessible to kidney patients. In other settings, for example cancer care, psychooncology units have been widely established (Seekles, 2021). Two recent national reports call for an integrated model of psychosocial provision as part of routine kidney care (KCUK, 2022; Wilton, 2023), adapted from an existing cancer psychosocial support pathway (Coyne and Fretwell, 2022). This would include a kidney psychosocial team (including psychology, counselling, social work) embedded within the kidney service.

A third of centre leads were aware of the NICE guidelines (Nice, 2009) or national equivalents, and there was disparity between additional training offered to doctors and nurses on assessment and treatment of depression. Insufficient training may act as a barrier to appropriate identification and management (Combes et al., 2019;

Damery et al., 2019). Regular education and training on the complex interplay between mental health and kidney disease is an essential part of integrated psychosocial care, in combination with a sense of shared responsibility and confidence by all members of the MDT. This extends to communication with GPs, who appear to manage the prescription and monitoring of antidepressants according to centres. Since evidence for antidepressants in people with CKD is inconclusive and adverse events are common, continued monitoring is vital (Chilcot & Farrington, 2019; Friedli et al., 2017; Hedayati et al., 2017; Pearce et al., 2023). Integrated psychosocial pathways should therefore incorporate GPs, navigating care to kidney psychosocial teams and general hospital liaison psychiatry (Coyne & Fretwell, 2022).

Half of the respondents to the psychology module reported having formal referral pathways in their service. Although most psychological staff were aware of NICE guidelines, only one-third utilised them in full. Proactive screening for depression varied across centre and modality type, with living kidney donors being the most proactively screened group. Given the commonality of depression in CKD it is likely that current levels of screening are insufficient. The most utilised screening tools were the PHQ-9 (Kroenke et al., 2001; Spitzer et al., 1999) GAD-7 (for anxiety) (Spitzer et al., 2006). The HADS (Zigmond & Snaith, 1983) and the PHQ-ADS (Chilcot et al., 2018c; Kroenke et al., 2016) were also used but less commonly. The model of screening delivery (digital, in person, assisted) was not clear, however. Although NICE guidelines do not specify an assessment tool (NICE, 2009), they do specify use of a validated measure (for symptoms, functions and/or disability) to inform and evaluate treatment. The most common forms of intervention reported were complex assessments, formulation, low and high intensity interventions. CBT, ACT and counselling were commonly offered by psychological practitioners. The use of CBT aligns with NICE guidelines for depression and long-term conditions and has shown promise in people with CKD, particularly in randomised controlled trials in people undergoing haemodialysis (Pearce et al., 2023).

Most respondents to the social provision module (*n* = 13) reported that social work provision was dedicated to the kidney service, though this could reflect selection bias. Social work provisions and care were informed by various guidelines including Social Work England, the Mental Capacity Act (2005), Scottish Social Services Council and Social Services and Wellbeing Act (Wales) 2014. With regard to the identification and management of depression, the role of social workers in the NICE guidelines for depression in LTCs is not clear. Due to the vital, context-specific role the kidney social worker plays within the MDT (Holman, 2011; Seekles & Ormandy, 2022) they have a significant role in supporting and intervening with factors known to impact upon well-being and mental health.

There is a lack of comparable data internationally regarding psychosocial provision. While there is evidence showing that variability in health professional staffing levels is associated with poorer clinical outcomes (Chen et al., 2019; Hand et al., 2018), less is

known about the size and nature of psychosocial care kidney patients receive globally and how this effects psychosocial outcomes. Data from the United States suggest variability in social work provision across dialysis centres with an average of 0.84 full time equivalents across centres (Yoder et al., 2013). While international data on psychosocial provision is lacking, the global burden of symptoms (including mental health) experienced by people with CKD is clear and substantial (Mehrotra et al., 2023). However, improvements in symptom assessment and management are dependent on contextual factors related to local resources and needs (Mehrotra et al., 2023), so further research is needed to identify what these are.

While our study provides novel insights to the nature of psychosocial provisions across UK kidney care, with good geographical representation, our findings are limited by the overall response rate and the varied item level response rate. Therefore, some of our results may be limited by selection bias. As part of ongoing work, the variability evidenced in this survey has supported the selection of six case study sites, with different levels of psychosocial provision being studied in the broader MOOD MAPS project. Our aims are to better understand barriers and facilitators of service delivery, document areas of good practice and make future recommendations for improved psychosocial care while also identifying research priorities. We also acknowledge that while this study has a particular focus on depression, there is much more work that is needed to understand the complex interplay and management of other serious mental health conditions (Carswell et al., 2023; Cogley et al., 2022).

# Implications for clinical practice

Although depression is common in people living with CKD, services for this group are hampered by a shortage of suitably trained staff and lack of consensus on management pathways. While there remain challenges to identify and implement evidence-based practice relevant for people with CKD, the development of screening protocols and enhanced staff training regarding mental health and psychosocial issues are practical recommendations. National clinical pathways need to be developed and piloted, codesigned by the kidney MDT and people with CKD. The integrated model of psychosocial provision (KCUK, 2022; Wilton, 2023) would seem to be a suitable foundation.

# CONCLUSIONS

Practices for the identification and management of depression across UK kidney care are variable with resource and staffing being a significant barrier to service provision. More broadly, psychosocial provision and support across UK kidney care is insufficient given the complex needs of people with kidney disease. This work supports prepandemic findings mapping the psychosocial workforce (Seekles et al., 2019) and recent calls for a more integrated pathway for psychosocial provision within kidney services.

# **AUTHORS CONTRIBUTIONS**

The study aims, design, and procedure was designed by all authors. Christina J. Pearce, Janine Hawkins and Natalie Hall led the survey programming and data collection. Christina J. Pearce, Natalie Hall, Joseph Chilcot, Amanda Busby and Sam Norton designed the analysis plan and completed the data analysis. Data interpretation involved all authors who also reviewed the paper and approved the submission. Nick Palmer and Julia Jones led the PPI work related to the MOODMAPS modules.

# **ACKNOWLEDGEMENTS**

Thank you to the steering group who reviewed and supported the development of the survey and to our patient and public involvement group for their guidance. Thanks to Rebecca Flanagan for initial exploratory work related to the survey data. Finally, thank you to all the participating centres and staff. This survey was funded from two project grants: 'Centre characteristics, practice patterns and the experience of kidney patients during the COVID-19 pandemic'—funded by British Renal Society/Kidney Care UK (grant number 20-002 BRS/KCUK) and 'A national study of practice patterns in renal services in the identification and management of depression in people with chronic kidney disease'—funded by Kidney Research UK and the Stoneygate Trust (grant number KS\_RP\_006\_20190919).

#### CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

# DATA AVAILABILITY STATEMENT

Research data are not shared. The data are not publicly available due to privacy or ethical restrictions.

#### ORCID

Joseph Chilcot http://orcid.org/0000-0001-6427-4690
Alexander Hamilton http://orcid.org/0000-0002-0730-4897
Lucy Mackintosh http://orcid.org/0000-0001-6327-3522
Julia Jones http://orcid.org/0000-0003-3221-7362
Ken Farrington http://orcid.org/0000-0001-8862-6056

### REFERENCES

- Belasco, A.G. & Sesso, R. (2002) Burden and quality of life of caregivers for hemodialysis patients. *American Journal of Kidney Diseases*, 39, 805–812.
- Carswell, C., Cogley, C., Bramham, K., Chilcot, J., Noble, H. & Siddiqi, N. (2023) Chronic kidney disease and severe mental illness: a scoping review. *Journal of Nephrology*, 36, 1519–1547.
- Chen, Y., Rhee, C., Senturk, D., Kurum, E., Campos, L., Ll, Y. et al. (2019) Association of US dialysis facility staffing with profiling of hospitalwide 30-day unplanned readmission. *Kidney Diseases*, 5, 153–162.
- Chilcot, J., Almond, M.K., Guirguis, A., Friedli, K., Day, C., Davenport, A. et al. (2018) Self-reported depression symptoms in haemodialysis patients: Bi-factor structures of two common measures and their association with clinical factors. *General Hospital Psychiatry*, 54, 31–36.
- Chilcot, J. & Farrington, K. (2019) The case for selective withdrawal of antidepressants in patients with advanced kidney disease. *Journal of the American Society of Nephrology*, 30, 1339–1340.

- Chilcot, J., Guirguis, A., Friedli, K., Almond, M., Day, C., Silva-Gane, D.A. et al. (2018) Depression symptoms in haemodialysis patients predict all-cause mortality but not kidney transplantation: a cause-specific outcome analysis. *Annals of Behavioral Medicine*, 52, 1–8.
- Chilcot, J., Hudson, J.L., Moss-Morris, R., Carroll, A., Game, D., Simpson, A. et al. (2018c) Screening for psychological distress using the patient health questionnaire anxiety and depression scale (PHQ-ADS): initial validation of structural validity in dialysis patients. *General Hospital Psychiatry*, 50, 15–19.
- Chilcot, J. & Hudson, J.L. (2019) Is successful treatment of depression in dialysis patients an achievable goal? Seminars in Dialysis, 32, 210–214.
- Chilcot, J., Wellsted, D., Da Silva-Gane, M. & Farrington, K. (2008) Depression on dialysis. Nephron Clinical Practice, 108, c256-c264.
- Cogley, C., Carswell, C., Bramham, K. & Chilcot, J. (2022) Chronic kidney disease and severe mental illness: addressing disparities in access to health care and health outcomes. Clinical Journal of the American Society of Nephrology, 17, 1413–1417.
- Combes, G., Damery, S., Sein, K., Allen, K., Nicholas, J. & Baharani, J. (2019) Distress in patients with end-stage renal disease: staff perceptions of barriers to the identification of mild-moderate distress and the provision of emotional support. PLoS One, 14, e0225269.
- Coyne, E. & Fretwell, N. (2022) What is psychosocial care and why is it important for renal patients? *Journal of Kidney Care*, 7, 288–292.
- Cukor, D. (2021) Introduction: psychosocial issues in kidney disease. Seminars in Nephrology, 41, 485-486.
- Damery, S., Sein, K., Nicholas, J., Baharani, J. & Combes, G. (2019) The challenge of managing mild to moderate distress in patients with end stage renal disease: results from a multi-centre, mixed methods research study and the implications for renal service organisation. BMC Health Services Research, 19, 989.
- Farrokhi, F., Abedi, N., Beyene, J., Kurdyak, P. & Jassal, S.V. (2014) Association between depression and mortality in patients receiving long-term dialysis: a systematic review and meta-analysis. *American Journal of Kidney Diseases*, 63, 623–635.
- Friedli, K., Guirguis, A., Almond, M., Day, C., Chilcot, J., Da silva-Gane, M. et al. (2017) Sertraline versus placebo in patients with major depressive disorder undergoing hemodialysis: a randomized, controlled feasibility trial. Clinical Journal of the American Society of Nephrology, 12, 280–286.
- Guirguis, A., Chilcot, J., Almond, M., Davenport, A., Wellsted, D. & Farrington, K. (2020) Antidepressant usage in haemodialysis patients: evidence of sub-optimal practice patterns. *Journal of Renal Care*, 46, 124–132.
- Hand, R.K., Albert, J.M. & Sehgal, A.R. (2018) Structural equation modeling to explore patient to staff ratios as an explanatory factor for variation in dialysis facility outcomes. *Journal of Renal Nutrition*, 28, 309–316.
- Hedayati, S.S., Gregg, L.P., Carmody, T., Jain, N., Toups, M., Rush, A.J. et al. (2017) Effect of sertraline on depressive symptoms in patients with chronic kidney disease without dialysis dependence: the CAST randomized clinical trial. *Journal of the American Medical Association*, 318, 1876–1890.
- Holman, C. (2011) A day in the life of a renal social worker, *Professional Social Work*. Birmingham: The British Association of Social Workers.
- KCUK. (2022) Caring for people with kidney disease: psychosocial health—a manifesto for action. In: Group, N. P. W. (ed.). Kidney Care UK.
- Kovesdy, C.P. (2022) Epidemiology of chronic kidney disease: an update 2022. Kidney International Supplements, 12, 7–11.
- Kroenke, K., Spitzer, R.L. & Williams, J.B.W. (2001) The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16, 606–613.
- Kroenke, K., WU, J., YU, Z., Bair, M.J., Kean, J., Stump, T. et al. (2016) Patient health questionnaire anxiety and depression scale: initial

- validation in three clinical trials. Psychosomatic Medicine, 78, 716-727.
- KRUK. (2023) Kidney disease: A UK public health emergency. The health economics of kidney disease to 2033. Kidney Research UK &
- Lopes, A.A., Bragg, J., Young, E., Goodkin, D., Mapes, D., Combe, C. et al. (2002) Depression as a predictor of mortality and hospitalization among hemodialysis patients in the United States and Europe. Kidney International, 62, 199-207.
- Mackintosh, L., Busby, A., Farrington, K., Hawkins, J., Afuwape, S., Bristow, P. et al. (2023) Impact of the COVID-19 pandemic on services for patients with chronic kidney disease: findings of a national survey of UK kidney centres. BMC Nephrology, 24, 356.
- Mcclellan, W.M., Abramson, J., Newsome, B., Temple, E., Wadley, V.G., Audhya, P. et al. (2010) Physical and psychological burden of chronic kidney disease among older adults. American Journal of Nephrology, 31 309-317
- Mehrotra, R., Davison, S.N., Farrington, K., Flythe, J.E., Foo, M., Madero, M. et al. (2023) Managing the symptom burden associated with maintenance dialysis: conclusions from a kidney disease: improving global outcomes (KDIGO) controversies conference. Kidney International, 104, 441-454.
- Natale, P., Palmer, S.C., Ruospo, M., Saglimbene, V.M., Rabindranath, K.S. & Strippoli, G.F. (2019) Psychosocial interventions for preventing and treating depression in dialysis patients. Cochrane Database of Systematic Reviews, 12, CD004542.
- NHS. (2018) The Improving Access to Psychological Therapies (IAPT) pathway for people with long-term physical health conditions and medically unexplained symptoms. Full Implementation Guidance. London: National Collaborating Centre for Mental Health. NHS England.
- NICE. (2009) Clinical guideline CG91: depression in adults with a chronic physical health problem: treatment and management. National Institute for Health and Care Excellence.
- Palmer, S., Vecchio, M., Craig, J.C., Tonelli, M., Johnson, D.W., Nicolucci, A. et al. (2013) Prevalence of depression in chronic kidney disease: systematic review and meta-analysis of observational studies. Kidney International, 84, 179-191.
- Pearce, C.J., Hall, N., Hudson, J.L., Farrington, K., Tucker, M.J.R., Wellsted, D. et al. (2023) Approaches to the identification and management of depression in people living with chronic kidney disease: A scoping review of 860 papers. Journal of Renal Care.
- Picariello, F., Norton, S., Moss-Morris, R., Macdougall, I.C. & Chilcot, J. (2020) A prospective study of fatigue trajectories among in-centre haemodialysis patients. British Journal of Health Psychology, 25, 61-88.
- Seekles, M.L. (2021) Investigating UK renal psychosocial service provision. PhD, University of Salford.
- Seekles, M.L. & Ormandy, P. (2022) Exploring the role of the UK renal social worker: the nexus between health and social care for renal patients. PLoS One, 17, e0275007.
- Seekles, M.L., Ormandy, P. & Coyne, E. (2019) Mapping the UK renal psychosocial workforce: the first comprehensive workforce survey. BMC Nephrology, 20, 100.
- Sharma, S., Bhui, K., Chilcot, J., Wellsted, D. & Farrington, K. (2011) Identifying depression in south asian patients with end-stage renal disease: considerations for practice. Nephron Extra, 1, 262-271.
- Sharma, S., Norton, S., Bhui, K., Mooney, R., Caton, E., Bansal, T. et al. (2023) The use of culturally adapted and translated depression screening questionnaires with South Asian haemodialysis patients in england. PLoS One, 18, e0284090.
- Spitzer, R.L. (1999) Validation and utility of a self-report version of PRIME-MD. The PHQ primary care study. Journal of the American Medical Association, 282, 1737-1744.

- Spitzer, R.L., Kroenke, K., Williams, J.B.W. & Löwe, B. (2006) A brief measure for assessing generalized anxiety disorder: the GAD-7. Archives of Internal Medicine, 166, 1092-1097.
- Tsai, Y.-C., Chiu, Y.-W., Hung, C.-C., Hwang, S.-J., Tsai, J.-C., Wang, S.-L. et al. (2012) Association of symptoms of depression with progression of CKD. American Journal of Kidney Diseases, 60, 54-61.
- Weisbord, S.D., Mcgill, J.B. & Kimmel, P.L. (2007) Psychosocial factors in patients with chronic kidney disease. Advances in Chronic Kidney Disease, 14, 316-318.
- Weisbord, S.D., Mor, M.K., Sevick, M.A., Shields, A.M., Rollman, B.L., Palevsky, P.M. et al. (2014) Associations of depressive symptoms and pain with dialysis adherence, health resource utilization, and mortality in patients receiving chronic hemodialysis. Clinical Journal of the American Society of Nephrology, 9, 1594-1602.
- Wen, H., Yang, D., Xie, C., Shi, F., Liu, Y., Zhang, J. et al. (2022) Comparison of trend in chronic kidney disease burden between China, Japan, the United Kingdom, and the United States. Frontiers in Public Health, 10, 999848
- Wilton, J. (2023) Addressing the mental health challenges of life with kidney disease: the case for change. Centre for Mental Health & Kidney research UK.
- Yang, F., Griva, K., Lau, T., Vathsala, A., Lee, E., NG, H.J. et al. (2015) Health-related quality of life of Asian patients with end-stage renal disease (ESRD) in Singapore. Quality of Life Research, 24, 2163-2171
- Yoder, L.A.G., Xin, W., Norris, K.C. & Yan, G. (2013) Patient care staffing levels and facility characteristics in US hemodialysis facilities. American Journal of Kidney Diseases, 62, 1130-1140.
- Zigmond, A.S. & Snaith, R.P. (1983) The hospital anxiety and depression scale. Acta Psychiatrica Scandinavica, 67, 361-370.

# **AUTHOR BIOGRAPHY**



Dr. Joseph Chilcot is a Reader in Health Psychology and Head of the Health Psychology Section. at the Institute of Psychiatry, Psychology & Neuroscience, King's College London. His research is focused on the psychological aspects associated with long-term conditions (LTCs),

particularly advanced kidney disease. Joe is interested in the role cognitive and behavioural factors have upon symptoms and their trajectories (including distress and fatigue) and how these relate to clinical outcomes. He is also interested in the detection, management and treatment of depression among individuals living with kidney disease and other LTCs.

# SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Chilcot, J., Pearce, C.J., Hall, N., Busby, A.D., Hawkins, J., Vraitch, B. et al. (2024) The identification and management of depression in UK Kidney Care: results from the Mood Maps Study. Journal of Renal Care, 1-10. https://doi.org/10.1111/jorc.12489