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The UK renal psychosocial workforce : a mapping exercise

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THE UK RENAL PSYCHOSOCIAL WORKFORCE

A mapping exercise

M.L. Seekles, E. Coyne, P. Ormandy, L. Wells, A. Bevin & A. Danbury-Lee



University of
Salford
MANCHESTER



THE BRITISH ASSOCIATION OF SOCIAL WORKERS
RENAL SPECIAL INTEREST GROUP



The
British
Psychological
Society



Foreword

The British Renal Society and Kidney Care UK are pleased to present the first comprehensive report on the workforce providing psychological and social work support to patients with kidney disease in the United Kingdom. Chronic kidney disease is a long-term condition that has a major impact on a person’s sense of well-being as well as really significant implications for their family. In the context of the major effort and resources required to provide high quality renal replacement therapy, psychological and social issues are frequently neglected. Psychological and social work services are too often regarded as an optional extra, though those struggling to cope with the personal pressures of a treatment that dominates their lives may identify these services as their most important need.

It has been clear for some time that the provision of psychology and social work support to patients with kidney disease is generally inadequate and varies considerably across the NHS. Kidney Care UK (previously The British Kidney Patient Association) has played a leading role in advocating for the provision of these services as well as funding the establishment of services at many centres and providing practical and financial support to patients. It is clear, however, that in order to make progress towards universal inclusion of psychology and social work services in kidney care, comprehensive data on current provision and trends over time is vital.

Prof Ormandy and her team are therefore to be congratulated for producing this detailed and comprehensive report. The report shows a welcome increase in psychology services over the past 16 years, though this remains variable and well below recommended levels. Worryingly, the provision of social work support appears to have decreased. We hope that this report will encourage providers to review their provision of services. We further hope they use the evidence gathered in the report to demonstrate the inequitable access to psychosocial care across the country in order to support the case for new and increased services.



Maarten Taal
President of the British
Renal Society



Paddy Tabor
Chief Executive of Kidney
Care UK

The aim has got to be to promote expansion of psychology and social work support for people with kidney disease so that all patients in the NHS are able to access the services they need.

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Executive Lay Summary

This report describes the provision of psychosocial care to kidney patients in all 84 renal units across the UK. It presents a snapshot of the renal psychosocial workforce (in July 2017) and compares this to results of a similar report written in 2002. Psychosocial care is support for psychological or social problems usually provided by professionals such as psychologists, social workers, counsellors, youth workers and welfare advisors. Studies show that kidney patients face many problems, for which these professionals provide much needed help.

The current report shows the following findings:

- Renal units employ different combinations of psychosocial staff. For example, in some units a social worker and psychologist work together, whereas in other units this would be a counsellor and a psychologist.
- There are inequalities and large variations in the number of psychosocial staff available to help patients within units. 12 units (14%) have no psychosocial staff dedicated to kidney patients, 34 units (40%) have one or two dedicated staff, and 38 units (46%) provide three or more psychosocial staff to care for their patients.
- The number of psychologists (in adult services) has increased over the past 15 years but the number of social workers has decreased. Overall, these adult psychosocial services have increased with 25%, but this is not as much as the increase in number of patients of about 50%.
- In paediatric services, psychology and social work services overall have decreased with 21% compared to 2002.
- None of the 84 units employ the recommended number of social workers (proposed in 2002).
- Only 4 units (5%) employ the recommended number of psychologists (proposed in 2002).
- These results suggest that there are not enough psychosocial staff to provide care to all renal patients.

The provision of renal psychosocial care is patchy and appears to be inadequate. Further research into the psychosocial needs of kidney patients is necessary, to develop innovative solutions to provide equitable care and evidence based psychosocial clinical guidelines.

Acknowledgements

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- British Psychological Society (BPS) renal members for their support in data collection.
- Renal Psychological Services Group (RPSG) for their support in data collection.

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Introduction

The following report shows the results of a mapping exercise to investigate the staffing levels of psychosocial staff in renal healthcare in the United Kingdom.

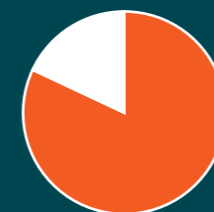
This report covers the whole range of specialist renal services including the provision of children's renal services and renal transplantation. The last report on the complete multi-professional renal workforce dates back to 2002, written by a national renal workforce planning group, established by the British Renal Society (BRS).

This report identified gaps in the provision of psychosocial services and provided recommendations about future workforce requirements. In 2016, the BRS decided to send out a new survey, based on the Scottish Renal Registry Survey, to update the data on the renal workforce. This survey was sent out to all renal units in England, Wales and Northern Ireland. Unfortunately, the response rate to this survey was low and in some cases the questionnaire was poorly completed.

To obtain more detailed information about psychosocial staff, a psychosocial survey was designed jointly by the British Psychological Society Renal Network (BPS Renal Network), the Renal Psychological Services Group (RPSG) and the British Association of Social Workers renal Special Interest Group (BASW -rSIG).

This survey was distributed via networks of psychosocial staff late 2016. In 2017, Kidney Care UK started a collaboration with Salford University, to investigate the renal psychosocial service provision in the UK. As part of that project, the data from the BRS survey and the psychosocial survey has been collated and this data was completed with Freedom of Information requests. It was hoped that the different surveys would corroborate findings, but instead, many units provided conflicting information.

Therefore, all clinical directors were asked to confirm the found data. Ultimately, 82% of the units confirmed their data and all units replied to at least one of the surveys. It was decided that when conflicting data was found for units that had not confirmed, the results of the Freedom of Information requests would be used as decisive.



82%

of the units confirmed their data and all units replied to at least one of the surveys

Context


Chronic Kidney Disease

Chronic Kidney Disease (CKD) is a worldwide public health problem, with increasing incidence and prevalence, high costs, and poor outcomes (Eknoyan et al., 2004). CKD is defined as kidney damage or decreased level of kidney function for three months or longer and the disease typically is progressive. It is mainly caused by diabetes, hypertension and other kidney disorders like glomerulonephritis and polycystic kidney disease (NICE, 2014).

It can be divided into five stages of increasing severity, with treatments based on these stages. For a small, but significant percentage of people, CKD progresses to end-stage renal disease (ESRD), which is reached in stage 5. At this stage, which is irreversible, the kidneys are no longer able to function, and renal replacement therapy (RRT) - dialysis or transplantation - becomes necessary to maintain life (Jansen, 2012; NICE, 2014). CKD has many comorbidities and the care for CKD patients is complex, multifaceted and often fragmented among different specialties (Bayliss et al., 2011).

Patients need to adhere to medication regimes and dietary restrictions and especially those on dialysis experience significant lifestyle changes from the disease (Browne, 2011). Since the first stages of CKD are largely asymptomatic, CKD is often not diagnosed, or diagnosed at an advanced stage (NICE, 2014). The most recent population prevalence of CKD in England was reported by Barron (2014) using data from the nationally representative Health Surveys for England (HSEs) 2009, 2010 and 2011.

It is expected that 2.6 million people aged 16 and older in England have CKD stage 3-5. This equates to 6.1% of the population of this age group. The prevalence of CKD stage 3-5 is higher in women than in men, 7.4% versus 4.7%. There is a clear association between increasing age and higher CKD stage 3-5 prevalence; with 1.9% of people aged 64 and under estimated to have CKD stage 3-5, 13.5% of people aged 65-74 and 32.7% of people aged 75 and over (Barron, 2014).


61,256

According to the latest UK Renal Registry report, 61,256 adults received RRT in the UK on the 31st of December 2015 (MacNeill & Ford, 2017).


941

In addition, a total of 941 children and young people aged below 18 years with established renal failure (ERF) were receiving treatment at paediatric nephrology centres in 2015 (Hamilton et al., 2017).

CKD in the NHS

The UK population is aging and with it, the prevalence of CKD and its impact on the health systems grows. It is estimated that there will be a 48.9% increase of people aged over 65 and a 113.9% increase of people aged over 85 in England in 2035/6 compared to 2015/6 (Age UK, 2017).

Already, the number of people receiving RRT has grown with 3.9% between 2014 and 2015 (MacNeill & Ford, 2017) and with almost 50% over the past decade (Kerr et al., 2012). CKD has proven to be a major and growing challenge for the NHS, with an estimated 1.3% of annual health service spending in 2009-10 spend on the disease. In particular, RRT poses a high burden on the health care budget.

It is estimated that more than half of the total expenditure on CKD is for RRT, although the RRT population only comprises 2% of the total diagnosed CKD population (Kerr et al., 2012).

The NHS, however, has come under unprecedented financial pressure in recent years, with funding falling in 2010/11 and only making a slow recovery since. The period of funding restraint has coincided with a collapse in social care spending and rapid rise in demand.

It is expected that in an attempt to minimize the financial gap between NHS funding and demand, more dramatic reductions in social care will follow. Together with the funding restraints, there has also been relatively little growth in the bulk of the NHS workforce since 2010/11 (Age UK, 2017).



Psychosocial factors in CKD

Living with renal failure provides many ongoing challenges throughout an individual's renal journey, not only for patients, but also for families and carers. The impact of these challenges should be understood within the context of the individual's development (age related issues) and disease development (renal-specific issues) (Coyne, 2013). These challenges, or stressors, could cause patients to experience stress. Psychosocial stressors identified as most frequently experienced are fluid and food restrictions; frequent and time-consuming hospitalisation; unemployment; sexual problems; changes in body appearance; limitations in leisure activities and vacations; increased dependence; sleep disturbances; and uncertainties about the future (Harwood et al., 2009; Gerogianni & Babatsikou, 2013).

Key stages during which patients experience stress are the time around diagnosis, the transition to adult care, change in treatment modality, and the transition to end-of-life care (Coyne, 2013). Each patient deals with stress in different ways, through coping (Cukor et al., 2007). If a patient's coping is unsuccessful, heightened levels of stress can cause a patient to develop psychological disorders and/or social issues, which are said to negatively affect health outcomes (Thompson et al., 2010; Marlow et al., 2016).

Research into psychosocial factors, quality of life and psychological disorders in CKD has developed rapidly over the last 30 years. The most frequently reported psychological disorders in CKD patients are depression, anxiety and adjustment disorders (Chan et al., 2011; McKercher et al., 2013; Cukor et al., 2015). Several recent, large and well-conducted studies have confirmed markedly raised rates of clinical depression amongst those with CKD, with meta-analysis suggesting the prevalence of interview-defined depression to be approximately 20% (Bautovich, 2014). Clinician and self-reported levels of psychological distress are found to be higher generally and in those patients undertaking dialysis the prevalence of depressive symptoms is approximately 40% (Palmer et al., 2013a).

Depressive symptoms in transplant patients have been shown to increase the relative risk (RR) of mortality by 65% in transplant patients (Dew et al. 2015). In CKD patients, they were found to be independent predictors of adverse clinical outcomes, including faster progression to ESRD, increased mortality and hospitalization (Tsai et al., 2013; Palmer et al., 2013b). More specifically, Tsai et al, (2013) found that patients with CKD with high depressive symptoms seem to have a faster decrease in kidney function and are more likely to start dialysis therapy at a higher eGFR.



The most frequently reported psychological disorders in CKD patients are depression, anxiety and adjustment disorders

65%

Depressive symptoms in transplant patients have been shown to increase the relative risk (RR) of mortality by 65% in transplant patients

However, it has been demonstrated that CKD patients who participate in renal multidisciplinary care which includes psychosocial support show slower renal function declines in advanced stage CKD and achieve greater improvement of clinical outcomes, timing initiation of dialysis with functional vascular access and reduced mortality (Chen et al., 2013).

Not only is there clinical evidence to support psychosocial intervention, studies in the fields of other chronic diseases have also identified a possible economic value. Naylor et al. (2012) state that international research shows that co-morbid mental health problems are associated with a 45-75% increase in service costs per patient, because of increased hospital admissions and other health service costs. Importantly, these estimates are based on costs increases observed after adjusting for severity of physical disease. It is suggested that the bulk of these excess costs will be associated with the most complex patients whose long-term conditions are most severe or who have multiple co-morbidities. In addition, wider economic costs have been identified, with good evidence of decreased employment or productivity in those with chronic conditions and mental health problems (Naylor et al., 2012). In cancer care there is a limited, but emerging number of studies, which suggest that offering information, emotional support and psychological care to cancer patients and survivors can be cost-effective (Carlson & Bultz, 2004; Dieng et al., 2016). The evidence indicates that psychological treatments can be cost-effective forms of treatment and have the potential to reduce health care costs, as successfully treated patients typically reduce their utilisation of other health care services (Chiles, Lambert & Hatch, 1999).

Even though the evidence of psychosocial problems and the potential impact support can have in CKD patients is still emerging, it is leading to an acceptance that a focus on the emotional and psychosocial needs of the patient should be included in the provision of comprehensive medical care to the CKD patient (Cukor et al., 2015).

45-75%

International research shows that co-morbid mental health problems are associated with a 45-75% increase in service costs per patient



Renal Psychosocial Support Staff

While all members of staff within the Renal Unit have a role in providing general psychosocial care to meet these psychosocial needs, the core specialist psychosocial renal professionals generally include a Psychologist (Clinical, Counselling or Health), a Counsellor or a Psychotherapist, and a Social Worker. There are differences in the training and expertise of these professionals (e.g. a Psychologist will have undertaken a minimum of 6 years of training to doctorate level; a Counsellor or Psychotherapist will have a minimum of an undergraduate diploma but may have degree or post-graduate qualifications; a Social Worker will have a degree in social work and/or a post-graduate social work qualification). It is also important to recognise that these roles are not interchangeable and each professional uses different approaches to support patients and /or alleviate psychological distress (e.g. advice, education, support, psychological therapy, staff consultation, indirect service intervention).

Dependent on the needs of the specific service, psychosocial professionals are proficient in working with children, families and adults and with people presenting with a range of clinical severity. They deliver care in all renal settings including outpatients, inpatients, community and residential care. The advantage of specialist services based within the renal team is that they are in a better position to offer intervention which considers the impact of CKD, work jointly within the team and combine appointments to reduce treatment burden (Coyne, 2013).



Policy for psychosocial support in the UK

Over the past 10 years, different national guidelines and policy documents have highlighted the importance of meeting CKD patients' psychosocial needs. Support for these needs is also integral to the recommended management of all long-term conditions in the NHS. In addition, policy emphasizes that mental health should have parity with physical health and be integrated into care pathways (Taylor & Combes, 2014; Taylor et al., 2016).

References are made to the psychological and social aspects of CKD in the first two standards of The National Service Framework for Renal Disease (Department of Health, DH 2004, 2005). Standard One aims to optimize the role that people with CKD can play in the management of their own care and recognizes that patients can meet physical, psychological and socio-economic problems. It states that people need information, advice, education, and support if they are to be full partners in care and that this could positively improve psychological and social outcomes. It highlights the importance of a multi-skilled renal team and an agreed care plan to identify health and social care needs. The standard specifically mentions how the care plan 'can set out the social work support required to help patients with problems relating to benefits, work, and family matters, and can highlight the need for psychological support and recognition and management of depression' (DH, 2004: p19). Standard Two aims 'to provide coordinated care to patients approaching established renal failure which is responsive to their individual needs and personal preferences', to timely inform the patient about RRT. In this standard, 'referral to a multi-skilled renal team, where possible at least one year before the anticipated start of dialysis treatment, for appropriate clinical and psychological preparation', is a marker of good practice (DH, 2004).

The current NHS England service specification for assessment and preparation for renal replacement therapy (including establishing dialysis access) (2017) base their specification on the NSF standards. It states that 'patients with progressive CKD shall have access to a multidisciplinary team which will include trained nephrologists, specialist renal nurses, specialist renal dieticians ... and transplant coordinators. The provider shall also provide access to other support including (but not limited to) clinical psychology, counsellors and social workers/welfare officers with specific expertise in the problems encountered by patients with kidney disease. Where these services are not available at the provider's facility, information should be provided about how, and/or arrangements should be made, to access them' (NHS England, 2017a). In addition, the service specification for in centre haemodialysis patients (2017) states that 'the provider will offer patients access to social work advice/psychological services as required' (NHS England, 2017b).

The National Institute for Health and Clinical Excellence (NICE) Chronic Kidney Disease quality standard (2014) is currently being updated. Now it includes quality statement 10, which states that:

"People with established renal failure have access to psychosocial support (which may include support with personal, family, financial, employment and/or social needs) appropriate to their circumstances." **Quality Statement NICE 2014**

Although not yet published, it is suspected that the revised 2017 quality statements will no longer prioritise access to psychosocial support for people with renal failure. The Kidney Health Advisory Group (2013) recommends that all people with advanced kidney disease should have access to timely psychological and social support and that they should be made aware of the benefits of specialised allied health professionals. They highlight that patients with a diagnosis of CKD may also experience difficulties that are both practical and psychological, at a less advanced stage.

Finally, the importance of support for psychosocial needs of patients is emphasized in several government policy documents. It is integral to the Department of Health’s guidance on support for patients with any physical long-term condition (DH, 2012) and its mental health strategy ‘Closing the Gap: Priorities for essential change in mental health’ (DH, 2014). This strategy emphasizes that mental health should have parity with physical health and be integrated into the care pathways (DH, 2014).

Workforce planning 2002

The previous BRS renal workforce survey, executed by the National Renal Workforce Planning Group, stems from 2002. The findings from this survey have been published in a workforce plan, together with recommendations for establishments and staffing levels across each professional group involved in renal healthcare (National Renal Workforce Planning Group, 2002).

The report outlined the personnel that should constitute the multi-professional renal team. It showed variability in the availability of the recommended types of professionals between units, with few having the full complement. Notably lacking were social workers, psychologists and counsellors, suggesting that formal emotional and psychological support were often seen as a relatively low priority, especially in a financially constrained, medically driven environment (Ahmad et al., 2006). In the current report, the data on psychosocial services from the 2002 publication will be compared to recent findings, where possible.

Psychosocial services are psychological and/or social care which is provided by psychosocial staff to meet patients’ informational and emotional needs. Even though nurses often also provide this type of care, the focus of this report is only on staff that has been specifically hired to provide psychosocial support.



Results

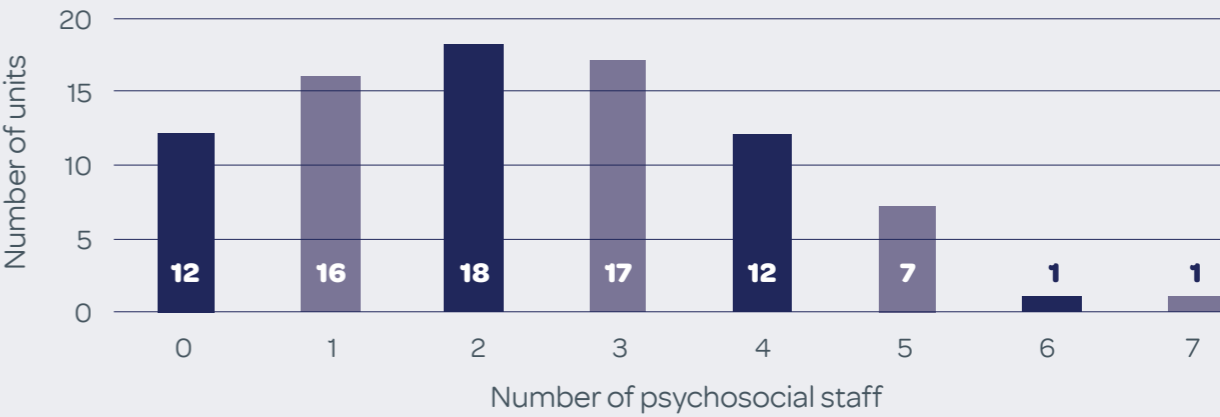
The following data has been collated from all the different sources and has been confirmed by 69 out of 84 (82%) of the units. It provides an overview of the staffing levels in July 2017. All units provided some form of information about psychosocial staffing levels, even though for a few members of staff no WTE was given. To be able to calculate a total WTE, the average WTE was allocated to these members of staff. Nursing staff (such as mental health nurses or pre-dialysis/supportive nurses) has not been included.

Models of service provision

The results show that 72 out of 84 (85.7%) UK renal units have some form of psychosocial service, provided by at least one member of psychosocial staff, in place. Twelve units stated they had no psychosocial staff available for their patients: “Although we’d love to have people with these skills, we unfortunately don’t have any of this very important staff here....”- Renal Consultant. In many of these units there was a general psychology or social work service available to renal patients, however, these members of staff do not have allocated renal time. In Scotland, the number of units without a dedicated renal psychosocial service (6 out of 10) was relatively high.

There appear to be many different models of psychosocial service provision across renal units, with members of different psychosocial professions working together in different combinations. The numbers of psychosocial staff available to renal patients in a unit vary from zero to seven (Figure 1). A higher number of staff does not necessarily equate to a higher number of sessions available to patients. In the units that offer a psychosocial service, the lowest number of sessions reported is 1 session per two weeks (0.05 WTE) provided by one member of staff; the highest number reported is 40 sessions (4.0 WTE) per week in a unit with 5 members of psychosocial staff.

Figure 1. Number of units with a certain number of renal psychosocial staff available



Number and Whole Time Equivalent (WTE) of psychosocial staff

The total number of psychosocial staff and the total of WTE that has been identified in this 2017 workforce audit are presented in Table 1, with Tables 2 and 3 providing a more detailed overview for both adult and paediatric units respectively. It was observed that some of the units employed non-traditional members of psychosocial staff, and three units contracted external companies (Auriga and Citizens Advise Bureau) to provide patients with welfare and benefits advise (Table 1).

Table 1. Number and WTE of psychosocial staff 2017

Profession	Number of staff	Whole Time Equivalent (WTE)
Psychologist	65	32.9
Social worker	68	52.0
Counsellor/psychotherapist	29	15.7
Youth/young adult worker	10	6.75
Play therapist	4	4.0
Welfare officer	3	2.2
Psychiatrist	2	Not known
Psychology assistant	2	Not known
Play worker (unqualified)	2	2.0
Music therapist	1	0.2
Social care practitioner	1	1
Assessment and support coordinator	1	0.85
Trainee CB specialist	1	0.4
Cultural and Health liaison officer	1	0.8
External companies	3	Not known

Table 2. Number and WTE of psychosocial staff in adult units in 2017

Profession	Number of staff	Whole Time Equivalent
Psychologist	51	27.2
Social worker	58	44.6
Counsellor	28	15.2
Welfare officer	3	2.2
Youth worker	9	6.5
Psychiatrist	2	0.8
Psychology assistant	2	1.2
Social care practitioner	1	1.0
CAB	2	Not known
Assessment and support coordinator	1	0.85
Trainee CB specialist	1	0.4
Cultural and Health liaison officer	1	0.8

Table 3. Number and WTE of psychosocial staff working in paediatric units in 2017

Profession	Number of staff	Whole Time Equivalent
Psychologist	14	5.7
Social worker	10	7.4
Play Therapist	2	2
Counsellor/psychotherapist	1	0.5
Music Therapist	1	0.2
Youth worker	1	0.25
Play worker (unqualified)	2	2

In addition, one unit reported having a play specialist team. However, this team does not have allocated renal time.

Psychologists, social workers, counsellors and youth workers have been identified as the main four providers of psychosocial services in the nephrology setting. In total, for these four professions:



Staff to patient ratios

Adult services

The staff to patient ratios were calculated for dialysis patients and all RRT patients, using the latest patient number data from the UK Renal Registry Report (MacNeill & Ford, 2017). Table 4 shows the average, minimum, maximum and median number of adult patients per 1 WTE staff, for psychologists, social workers, counsellors and youth workers.

The ratios were only calculated for the units that have a certain member of staff employed and provided information on WTE of staff. Workforce recommendations from 2002 for social workers are 1 WTE per 70 dialysis patients, or 140 RRT patients.

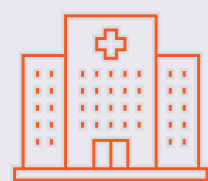
If these requirements are met, then the recommendation for psychologists is 1 WTE per 1000 RRT patients, or 1 WTE psychologist per 500 RRT patients if such support is not provided. No recommendations were found for renal counsellors and renal youth workers.

Table 4. Number of adult patients per 1 WTE staff

	Renal Psychology (33 units)		Renal Social Work (32 units)		Renal Counselling (15 units)		Renal Youth Work (7 units)	
	Dialysis	RRT	Dialysis	RRT	Dialysis	RRT	Dialysis	RRT
Average	1044	2240	355	761	1054	2287	2520	6248
Minimum	165	303	104	185	171	285	388	845
Maximum	4330	8570	1895	4150	7390	16710	11640	29540
Median	675	1393	311	613	591	1358	867	2088

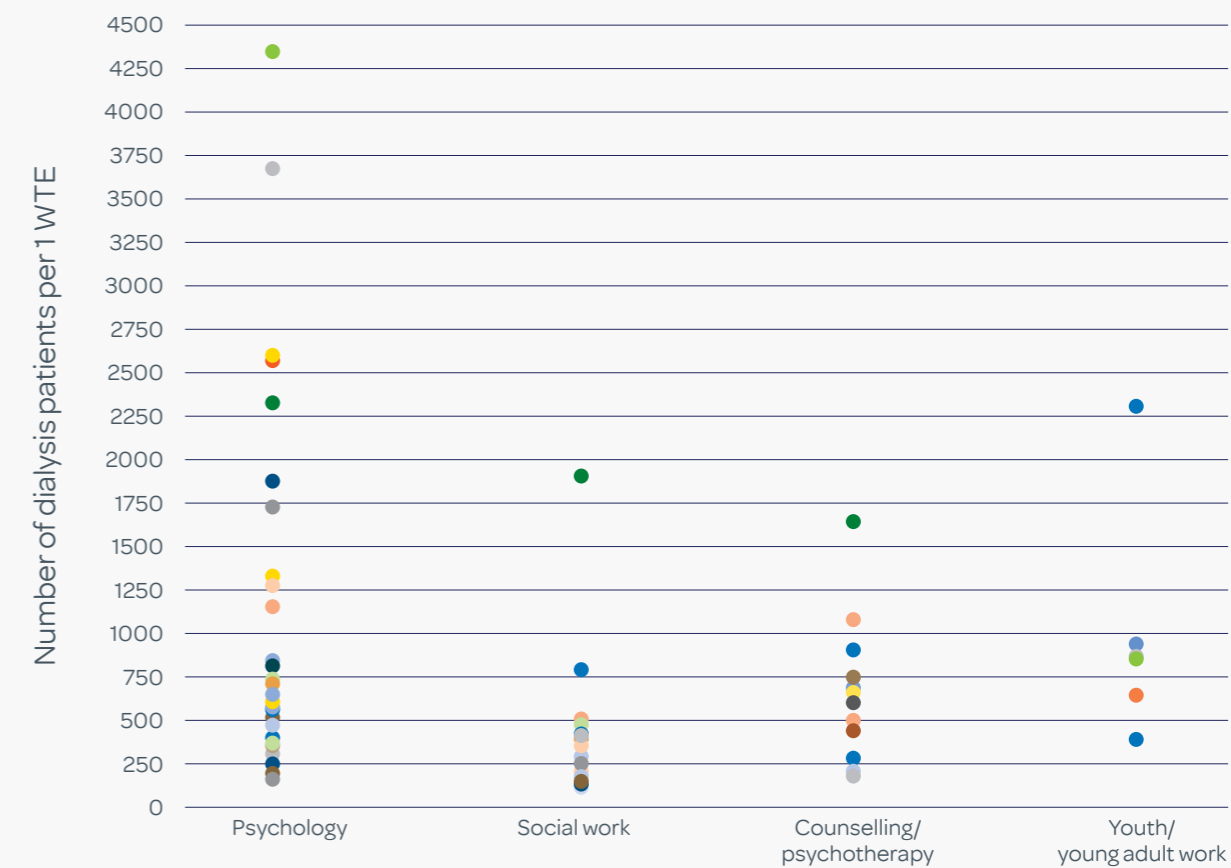
Significant variations exist between the staff to patient ratios across different units, which can be seen by the considerable differences in minimum and maximum number of patients per 1 WTE staff (Figure 2). Four units meet the psychology requirement of 1 WTE per 500 RRT patients and five units have 1 WTE psychologist for less than 1000 RRT patients.

However, these five units would still be classed as having insufficient psychological services, since there is not one unit that meets the social work recommendations. There is only one unit that has a ratio of 1 WTE social worker per less than 200 RRT patients (Figure 3).



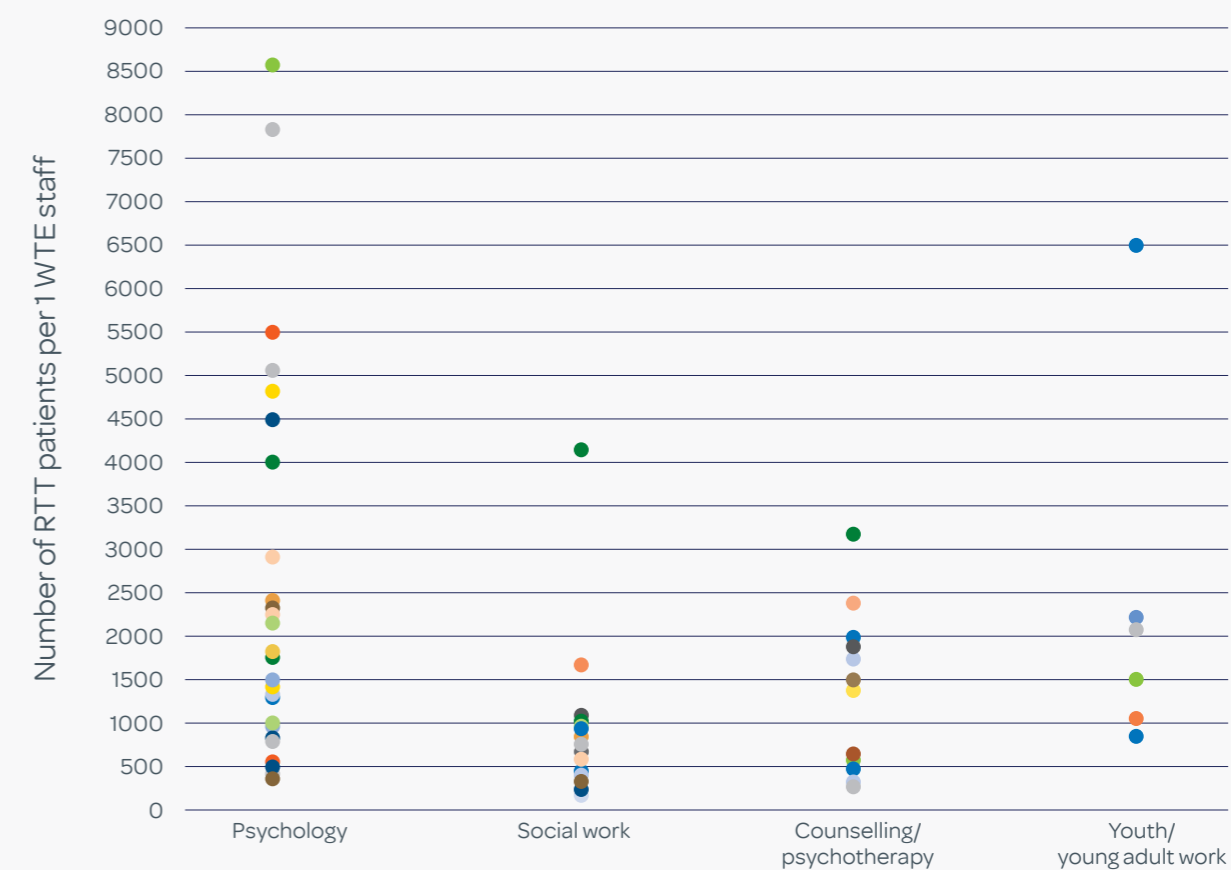
No units meet the social work recommendations of 1 WTE per 140 RRT patients and only four units meet the psychology requirement of 1 WTE per 500 RRT patients.

Figure 2. Variance in dialysis patient-to-staff ratio per profession



*Please note outliers of 7390 for counselling and 11640 for youth work have been removed, to increase visibility of smaller values.

Figure 3. Variance in RRT patient-to-staff ratio



Please note outliers of 16710 for counselling and 29540 for youth work have been removed, to increase visibility of smaller values.

It appears that smaller units have relatively more psychosocial provision than bigger units (Table 5). The median ratios are quite similar in the units who have place for up to 800 dialysis patients, but then appear to greatly increase in the bigger units with more than 800 dialysis patients. It should be noted, however, that the number of units without any provision is highest in the units with the lowest number of dialysis patients.

Table 5. Differences in staff-to-patient ratios according to size of adult renal unit

Number of dialysis patients per unit	0-200 (n=20)	201-400 (n=21)	401-600 (n=17)	601-800 (n=6)	801-1000 (n=2)	>1000 (n=4)
Number of units without psychosocial staff	6 (30%) 2 unknown	4 (19%) 2 unknown	1 (5.9%)	1 (16.6%)	0	0 2 unknown
Minimum ratio	65	109	111	135	216	656
First quartile	92	117	147	150	673	1065
Median ratio	161	225	186	185	1129	1474
Third quartile	392	353	276	191	1586	1884
Maximum ratio	905	1140	1453	6670	1586	2293

In addition, differences in ratios across the four countries have been observed. Firstly, as previously mentioned, most renal units in Scotland (6 out of 10) do not have any renal dedicated psychosocial staff. Secondly, it appears that Scottish renal units do not employ any renal psychologists, counsellors or youth workers. However, the RRT patient to social worker ratio is lower in Scotland and Wales, compared to Northern Ireland and England.

Overall, it seems that compared to the other UK countries, Wales offers a larger renal psychosocial service provision. Even though there are no renal counsellors employed in Wales, all the units in Wales employ more than one member of psychosocial staff, and the patient to staff ratios are relatively low for psychologists and social workers.

Paediatric services

For paediatric services, UK Renal Registry data provided information on patients below 18 years with Established Renal Failure (ERF). These numbers have been used to calculate the staff to patient ratios for renal psychologists, social workers and play therapists (Table 6). The ratios for paediatric patients per 1 WTE staff are substantially lower than for adult patients.

The latest workforce recommendations for paediatric renal psychosocial services have been described in the 2002 workforce report. These recommendations are based on WTE staff per million population. The population used in this calculation is that of the entire region that a hospital may serve, and is not based on the paediatric renal population in that hospital. Workforce recommendations for staff per number of renal patients in paediatric services have however not been identified.

Table 6. Number of paediatric patients per 1 WTE staff

	Renal Psychology (11 units)	Renal Social Work (8 units)	Renal Play Therapy (2 units)
	ERF patients	ERF patients	ERF patients
Average	294	81	60
Minimum	30	36	32
Median	93	71	60
Maximum	1820	179	87

Number of sessions

The number of sessions worked by the members of staff varied from less than 1 per week to 10 sessions per week. On average, the psychosocial staff worked a little over 6 sessions per week on renal services. Table 7 show the averages of sessions per week; how these are distributed is shown in Figure 4.

Table 7. Average number of sessions per profession

Profession	Average number of renal sessions per week
Psychologist	5.1 sessions
Social Worker	7.8 sessions
Youth/Young Adult Worker	6.8 sessions
Counsellor/Psychotherapist	5.8 sessions

Figure 4 shows the percentage of full time posts for the main professions. Even though many staff work part-time, this is predominantly the case for psychologists and counsellors/psychotherapists (Figure 5). Moreover, 42% of psychologists, 8% of social workers, 32% of counsellors and 20% of youth workers work less than 20 hours per week on renal services.



Figure 4. Distribution of sessions across staff

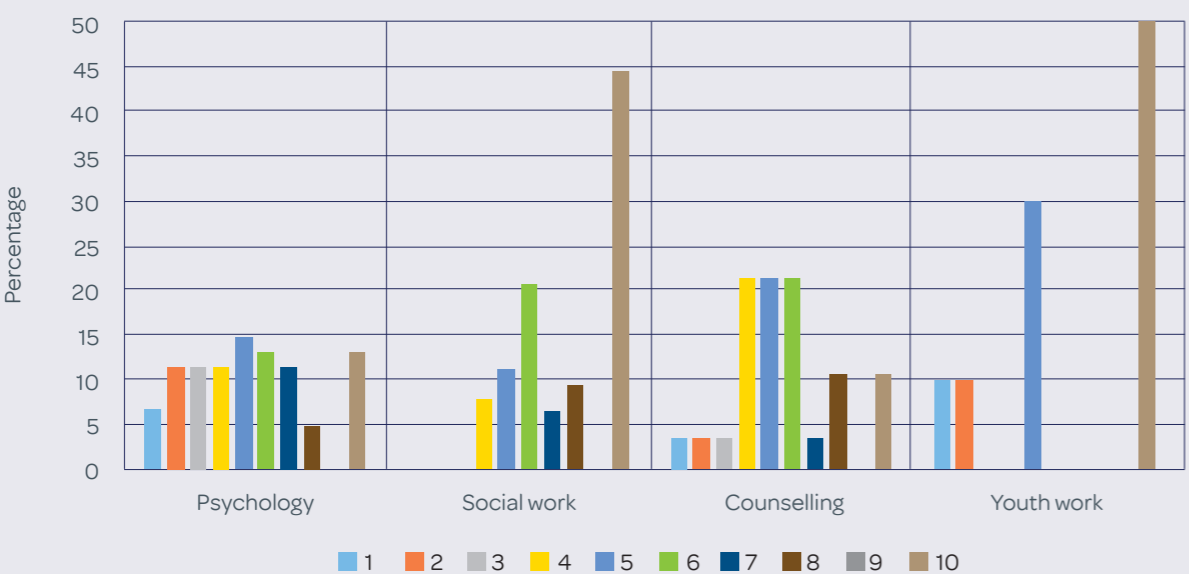
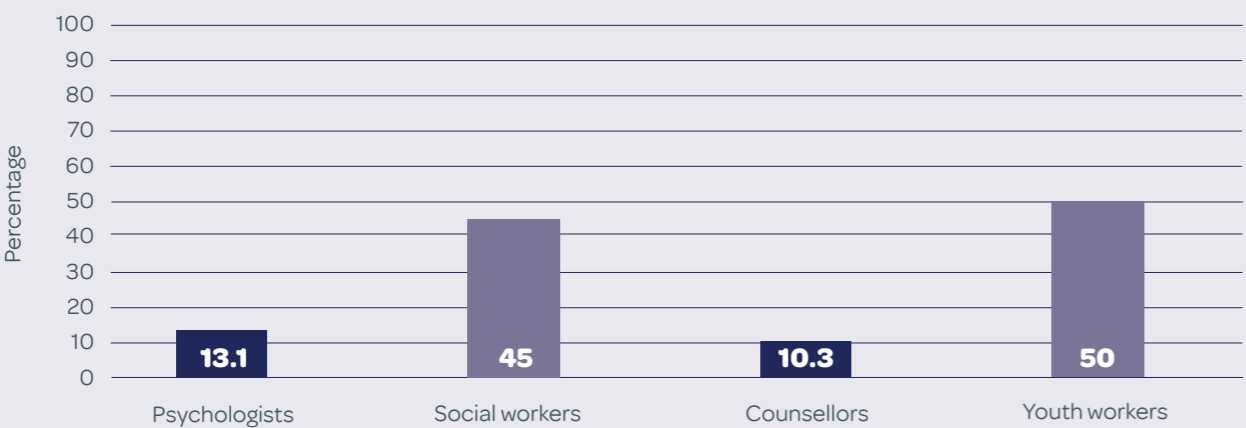


Figure 5. Percentage of psychosocial staff working full-time



Comparisons to the 2002 workforce report

In 2002, the National Renal Workforce Planning Group reported on workforce data for renal social workers and psychologists. In addition, they made recommendations about the requirements in 2001 and projected requirements in 2006 and 2010. Apart from counsellors and play therapists, other psychosocial professions were not mentioned in the document. It is unclear if these professions did not exist in nephrology at that time, or that they have not been identified. Table 8 provides an overview of the 2001 establishment, the 2010 projected requirements and the current establishment for adult renal social workers and psychologists.

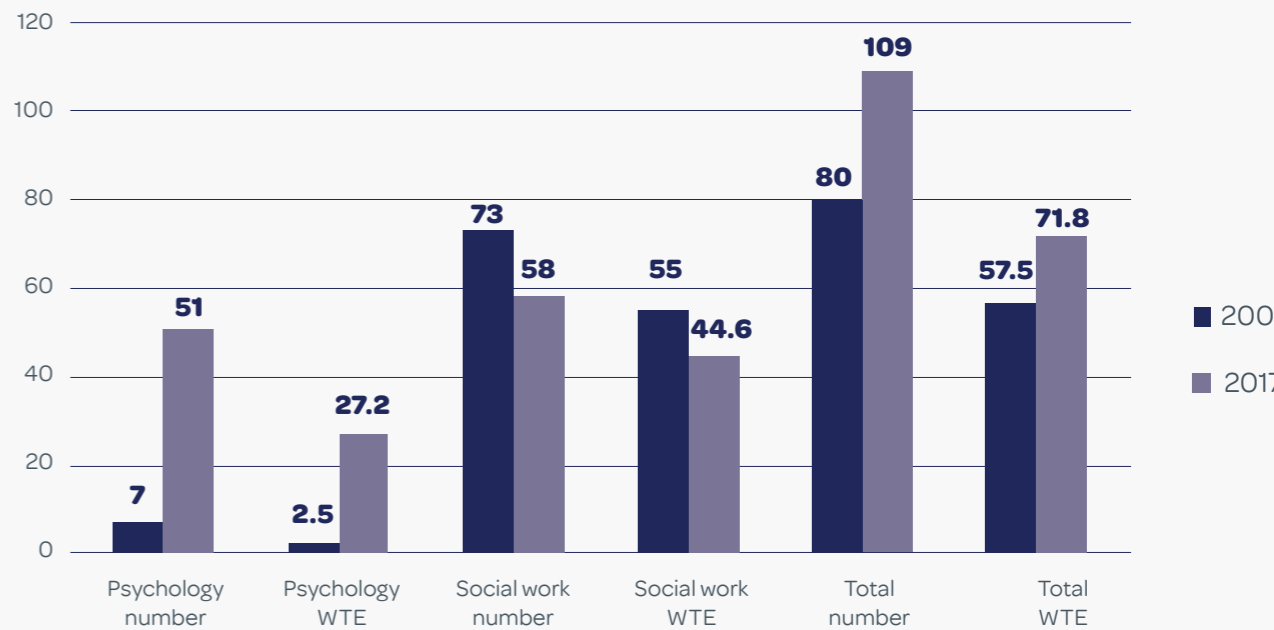
As can be seen in figure 5, the WTE of adult renal psychologists have increased tenfold, from 2.5 WTE to 27.2 WTE. The adult renal social worker WTE has decreased with 19%, from 55 WTE to 44.6 WTE. Taken together, the adult workforce of these psychosocial professions has increased with almost 25% over the past 15 years.

However, over the same time, the RRT population has increased with over 50% and the current numbers are nowhere near meeting the projected requirements (Table 8). In addition, in 2001, 14% of adult renal units did not have renal social work input. This number has now increased to 49.3% of adult renal units having no social worker support; 29.6% of units have no psychology and/or social work staff available.

Table 8. Comparison of adult renal psychologist and social worker workforce establishments

	2001 establishment		2010 projected		2017 establishment	
	Number	WTE	Number	WTE	Number	WTE
Renal Psychologists	7	2.5	168	60	51	27.2
Renal Social Workers	73	55	555	427	58	44.6

Figure 6. Comparison of adult renal psychology and social worker workforce 2001 to 2017



As previously mentioned, the report recommended psychology needs of patients would be met by a minimum of 1 WTE psychologist per 1000 RRT patients in units with adequate renal social work and renal counselling workforce. In the absence of such support, requirements would increase to 1 WTE per 500 RRT patients.

An adequate renal social work service was indicated to be 1 WTE social work post per 140 RRT patients. The 2002 report provided general staff to RRT patient ratios for psychology and social work by dividing the total number of adult RRT patients by the WTE of staff. Table 9 shows a comparison of 2001 data, current data, and recommendations.

Table 9. WTE adult staff to RRT patient ratios

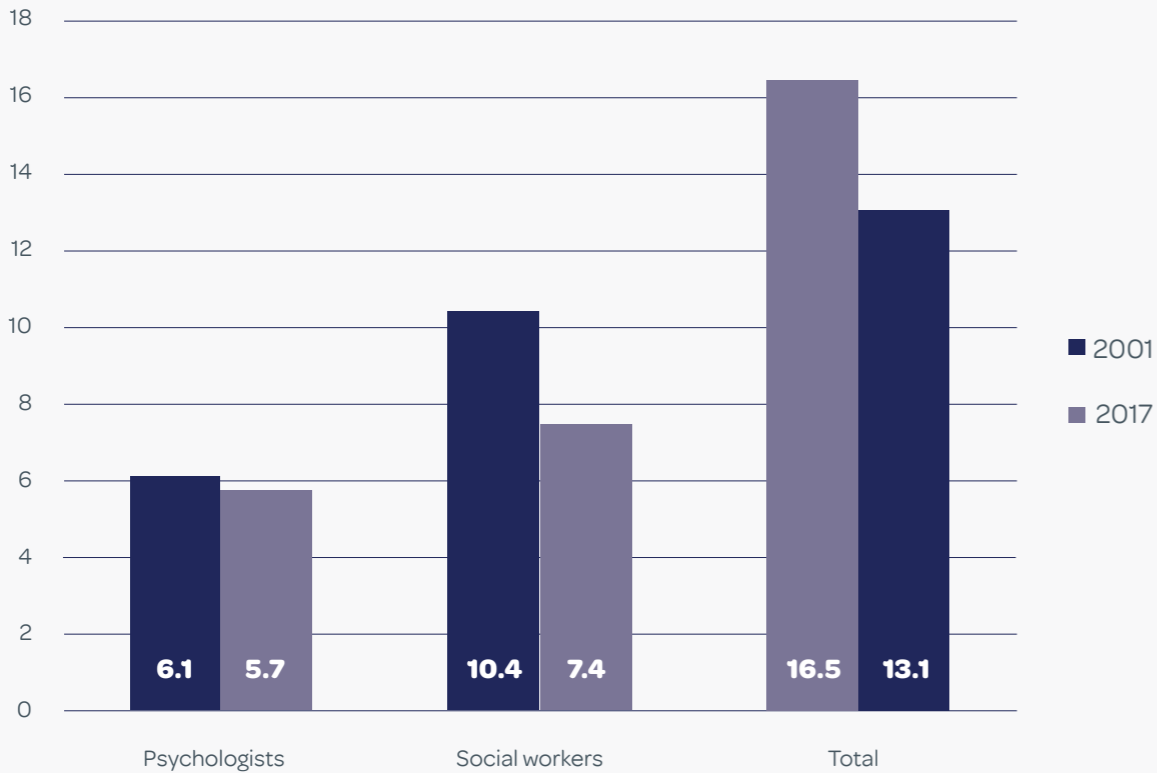
	2001: 1 WTE per	2017: 1 WTE per	Recommendations: 1 WTE per
Renal Psychologists	15233	2252	1000/500
Renal Social Workers	693	1373	140

The 2001 establishment, 2010 projected requirement and current establishment of WTE of paediatric renal psychologists and social workers can be seen in Table 10. Renal paediatric psychologist WTEs have decreased with 6.5% and the social workers have decreased with 28.8% (Figure 7).

Table 10. Comparison of paediatric renal psychologist and social worker workforce establishments

	2001 establishment	2010 Projected	2017 establishment
Renal Psychologists	6.1	12.5	5.7
Renal Social Workers	10.4	25.1	7.4

Figure 7. Comparison of paediatric renal psychology and social worker WTEs 2001 to 2017



Overall, a decrease of 20.6% is observed for both professions and the projected requirements have not been met (Table 10). In 2002, it was reported that three paediatric units (21.4%) did not have social work input and six units (43%) had no psychology input. Now, a change in these numbers is observed: five paediatric units (35.7%) have no social work input and two units (14.2%) have no psychology input. All paediatric units have at least one social worker or psychologist present, even though in one of the units the psychosocial service is made up of a psychologist who works less than 0.1 WTE on renal services.

Funding arrangements

The 2002 report raised concerns about funding arrangements for renal social workers. It was stated that funding responsibilities for social worker posts needed to be urgently addressed on a national basis, since it was observed that 38% of these posts depended on charitable funding. Less social work posts (5.6%) today are funded by charities; the majority (44.4%) funded from the renal budget. It is important to note that funding arrangements derived from the psychosocial workforce survey (Table 11), reflects an overall response rate of 65% for the four main professions and 53% for just the social workers.

Table 11. Funding arrangements per profession

Profession	Funding body	Number	Percentage %
Psychologists	Acute hospital budget	19	35.8
	Renal budget	22	41.5
	Externally funded by CCG	3	5.7
	Mental health services	2	5.7
	Charity	3	3.8
	Other	4	7.5
Social Workers	Acute hospital budget	9	25.0
	Renal budget	16	44.4
	Local Authority	4	11.1
	Joint funding: renal budget + local authority	3	8.3
	Charity	2	5.6
	Other	2	5.6
Counsellors/ psychotherapists	Acute hospital budget	4	25
	Renal budget	10	62.5
	Charity	2	12.5
Youth/Young adult workers	Acute hospital budget	2	25
	Renal budget	2	25
	Charity	3	37.5
	Other	1	12.5

Preliminary data from Kidney Care UK (KCUK), a charity that has been the main funder of psychosocial posts, highlighted that approximately 75% of posts, formerly funded by KCUK, have since 2010 been taken over by the local trusts. The sustained funding of these posts by the trusts reinforces the demand for such professional roles within the multi-disciplinary team.

Concerns

As part of the psychosocial survey, psychosocial staff was asked whether they had any concerns about their post or service. More than half of participants expressed worries about the future of their post. 9.7% stated they have concerns about their post since it is temporary; 26.2% of the participants worried about the future funding of their post or service and 9.7% stated there was a risk of their service being decommissioned. 33.3% of the respondent stated that the staffing levels are too low whereas others are concerned about long waiting lists (2.9% over 18 weeks, 9.7 per cent over 12 weeks). When asked if they had any other concerns about psychosocial support for renal patients, 63.1% of the respondents commented. The following quotes are a few of the many concerns expressed by psychosocial staff:

'At a local level the renal patients here in my hospital would be better served by a full-time psychologist who could be more embedded on the unit. The model of choice and partnership does not fit for renal patients; and although we have a 'pathway' for dialysis and transplant patients, in practice this doesn't work particularly well because there just isn't enough dedicated renal psychology staff to cover all the days that these patients might be attending the hospital.' – **Renal Psychologist**

'On a National level - Great concern and have had since I started in renal 25 years ago! The national picture has not changed over that time despite various professional groups raising the profile and concern. There is not any national renal criteria or agreement of the resources, professional skill mix or funding required to have provide a service fit for purpose. The cover has always been patchy nationally and has relied too heavily on charitable funds for the provision of SW, Psychology and Counselling posts. Locally - I have worked over the last 25 years to build a robust and skilled team.

The majority of the posts, including mine, were initially funded externally and the need and value had to be evidenced for the posts to continue. One post was funded externally for 9 years in various ways before it was given the appropriate funding. I have had and still have an extremely supportive Clinical Director and line manager who is the Director of Medicine over the years, but it has still taken a huge amount of energy, determination and commitment to secure these posts and the team.'

Renal Counsellor

'Our department is currently being reviewed and one major concern, which has been highlighted as a result of meetings relating to the review, is that the trust do not understand the nature of our work. Additionally, although the Renal Department do see the value of psychological support for renal patients, they do not contribute to the costs of supplying this service. So we are understandably nervous about the impact of the findings of the review and potential funding implications for posts.' –

Renal Psychologist

'I worry that I cannot provide as much support as my patients need, and there is always the risk that the funding for my post may not be continued. I am part of the renal social work group and I am aware that since I joined 7 years ago the numbers are now lower than they were. I am also very aware that most of the services which we might have referred patients and their families to no longer exist.' –

Renal Social Worker



'My concerns are significant as recent members of RPSG have vacated their posts and are either not being replaced or there has been delay in filling vacancy with discussions with other psychosocial practitioners - funding being cut and services not commissioned. Uncertainty in my service as jumping through hoops to get KCUK funded post substantiated ahead of funding ending next year.' –

Renal Counsellor

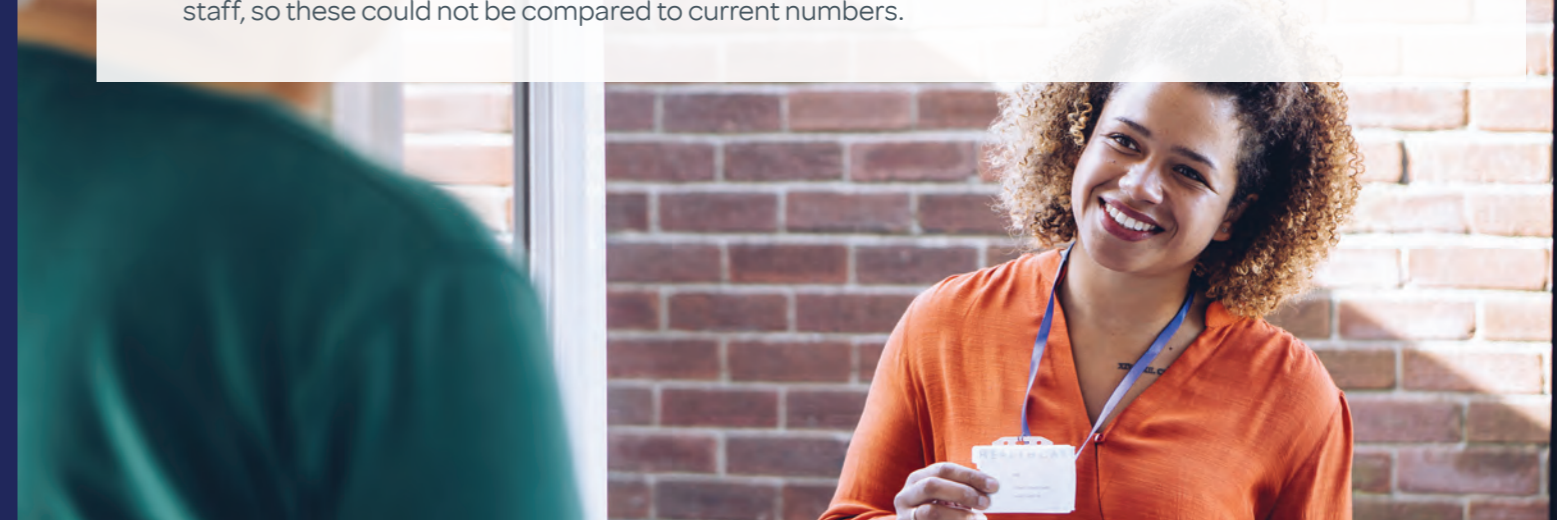
Limitations

Collecting data for this report has proved to be a complicated, and at times, a strenuous task. Response rates for the BRS workforce questionnaire and the following psychosocial questionnaires were low, but using researcher telephone follow-up and freedom of information requests, eventually all units provided information that could be used in this report. In some cases, the responses to the different questionnaires were inconsistent and conflicting, with several units reporting incomplete data for different members of staff and WTE.

The reason for this remains unclear, but may be attributable to a lack of clarity or understanding job titles, qualifications and job descriptions of psychosocial staff. Where this occurred units were asked to confirm and agree one data set. Not all units provided data regarding WTE of staff. For this reason, patient to staff ratios could not be calculated for all units. In addition, the total WTE of staff for psychologists and social workers had to be estimated, based on total numbers and average number of sessions. Recent numbers of paediatric patients on RRT were not available; instead numbers of patients with ERF were used to calculate the ratios for paediatric services.

With every attempt to extrapolate an accurate and reliable workforce data set, overcoming inconsistent and non-responses for data items, the researchers achieved 100% response rate from listed renal units and 82% of units confirmed that their data was correct, given this the reported data can be considered highly accurate.

When comparing the current data to the 2002 workforce report, uncertainties in that document arose. Firstly, the number and WTE of adult social workers was reported, separate of that of the paediatric social workers. However, a social work audit from 2007 suggests that the number of adult social workers reported in the 2002 document, is the total number of social workers, paediatrics included. The original document on which the 2002 report was based could not be found, so this remains unclear. In addition, the 2002 document lacked data about WTE of counsellors and the number of paediatric psychosocial staff, so these could not be compared to current numbers.



Alternative models of Renal Psychosocial Workforce planning

Psychosocial workforce planning has evolved in many physical health specialities and it is useful to compare their recommended levels of provision. In paediatric and adult cystic fibrosis, the care standards require 1 FTE psychologist and 1 FTE social worker per 150 patients (The Cystic Fibrosis Trust, 2011). This model involves providing all patients with routine psychosocial care and not stratifying on the basis of psychosocial need (e.g. assuming only part of the population will require input). The recommended levels for social work provision are broadly similar in both CF and CKD which suggests the recommended staffing levels for social work is based on a model of all CKD patients receiving social work input.

In cancer care, a stratified model for psychological provision has developed. Psychological support is separated into two distinct categories; that provided by those who have had some training in assessment and frontline intervention of psychological problems but who are not mental health or psychological support professionals (level 1 e.g. all staff and level 2 e.g. specialist nurse); and that which is provided by trained mental health / psychological support professionals (level 3 Counsellor/ Psychologist and level 4 Psychologist/Psychiatrist). Nice (2004) estimates 15% of cancer patients will need level 3 support and 10% will need level 4 intervention.

This model has been applied to cancer care across London to benchmark and develop psychological services in cancer (London Cancer Alliance, 2014).

Applying this model to a RRT population of 61,256 adult patients would suggest 9188 patients would require level 3 intervention (Counsellor or Psychologist) and a further 6126 patients would need intervention at level 4 (Psychologist and or Psychiatrist). The cancer care model suggests a maximum yearly caseload of 150 patients per full-time level 3/4 worker. This would suggest a requirement nationally for at least 102 WTE Psychological therapists to meet the projected need for psychological intervention. This would enable us to use an acuity model so for every 600 RRT patients; 150 patients would require level 3/4 psychological intervention and lead to a recommendation of 1WTE for every 600 RRT patients. It should be noted that this is a model for psychological intervention only and not social work provision (general psychosocial support and specific benefit support is available for all Cancer patients via a number of support organisations e.g. Macmillan Cancer Support and Maggie's Centres). It also assumes that all workers at level 1 and level 2 have received additional training and are receiving specialist supervision from level 3/4 workers.

This comparison suggests that the renal recommended staffing levels from the 2002 report are in line with a social work provision model of providing support to all RRT patients; and a psychological provision model of providing support to approximately 25% of the RRT population. This would lead to a recommendation based on an acuity model of 1WTE (0.6 WTE at Level 3/ 0.4WTE at Level 4) for every 600 RRT patients. Sharing of psychosocial provision across other long-term conditions such as diabetes and oncology, may be a way this would be operationalised for smaller units, indeed in some areas this is already established practice.

This would lead to a recommendation for psychological provision based on an acuity model of:

0.6 WTE
at level 3

0.4 WTE
at level 4

for every
600 RRT
patients

Conclusion

This document reports the findings from a renal psychosocial workforce audit across 84 renal units in the UK. It was observed that psychologists and social workers were the main providers of psychosocial support, followed by counsellors/psychotherapists and youth/young adult workers. In addition to these traditional professions, some non-traditional professions and external companies were found to provide psychosocial patient services. Psychology has seen a significant tenfold increase over the past 15 years, but social work input has decreased. Overall, the psychosocial workforce has increased, but when taking the increase in patients over this period into account, the increment is relatively low. The 2002 recommendations for renal psychosocial care are based upon a model of all RRT patients receiving social work input and up to a quarter of RRT patients requiring specialist psychological intervention.

These recommendations are not dissimilar to other specialist areas in physical health. The results from this mapping exercise show these are far from being met and low staff to patient ratios do not meet recommendations in any of the adult renal units. Psychosocial services for paediatric services have seen an overall decrease, even though they are generally better staffed than adult services. It is unclear whether this apparent lack of psychosocial services has consequences for the psychosocial wellbeing of patients, and what these consequences are.

In units that provide psychosocial services, many models of psychosocial service provision have been found. Different members of staff work together in different combinations and huge variations between staff to patient ratios across units and even countries exist. It seems that smaller units have relatively more psychosocial staff available to their patients than larger units. It is unclear whether patients in larger units have access to general psychosocial staff or other forms of psychosocial support. Further research into models of psychosocial service provision is required; to investigate and share good practice of how best to address the psychosocial needs of patients; to examine if patients' needs are different across units with different models of service provision; and explore where and how patients may access psychosocial services or support if not available within their unit. The decisions made by units to employ certain members of psychosocial staff or not, requires clearer understanding, although it may be that there is no substantive evidence to support these decisions. Evidence based guidelines or consensus quality standards for managing psychosocial distress in kidney patients are lacking, present within other physical health conditions.

While there are clear limits to our current knowledge, what is evident from the research literature is that there is a high level of psychological issues which may cause distress within the CKD population and that this distress has both a significant clinical and economic impact on patient care. There are unanswered questions as to the optimal way to deliver renal psychosocial care. Much needed research into the psychosocial needs of renal patients lies at the heart of the answer to these questions.

References

Age UK. (2017). *Briefing: Health and Care of Older people in England 2017*. Retrieved from http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/The_Health_and_Care_of_Older_People_in_England_2016.pdf

Ahmad, A., Roderick, P., Ward, M., Steenkamp, R., Burden, R., O'donoghue, D., ... & Feest, T. (2006). Current chronic kidney disease practice patterns in the UK: a national survey. *Journal of the Association of Physicians*, 99(4), 245-251. Doi: 10.1093/qjmed/hcl029

Bautovich, A., Katz, I., Smith, M., Loo, C., & Harvey, S. (2014). Depression and chronic kidney disease: A review for clinicians. *Australian & New Zealand Journal of Psychiatry*, 48(6), 530-541. Doi: 10.1177/0004867414528589

Bayliss, E. A., Bhardwaja, B., Ross, C., Beck, A. & Lanese, D. M. (2011). Multidisciplinary Team Care May Slow the Rate of Decline in Renal Function. *Clinical Journal of the American Society of Nephrology*, 6, 704-710. Doi: 10.2215/CJN.06610810

Barron, E. (2014). *Chronic Kidney Disease Prevalence Model*. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/612303/ChronickidneydiseaseCKDprevalencemodelbriefing.pdf

Browne, T. (2011) Nephrology Social Work. In: Gehlert, S. & Browne, T. (Eds) *Handbook of Health Social Work* (pp. 468-497).

Carlson, L. E., & Bultz, B.D. (2004). Efficacy and medical cost offset of psychosocial interventions in cancer care: Making the case for economic analyses. *Psycho-Oncology*, 13(12), <http://dx.doi.org/10.1002/pon.832>

Chan, R., Brooks, R., Steel, Z., Heung, T., Erlich, J., Chow, J., Suranyi, M. (2011). The psychosocial correlates of Quality of Life in the dialysis population: a Systematic Review and Meta-Regression Analysis. *Quality of Life Research*, 21, 563-580. DOI 10.1007/s11136-011-9973-9

Chen, Y.R., Yang, Y., Wang, S.C., Chiu, P.F., Chou, W.Y., Lin, C.Y., Chang, J.M., Chen, T.W., Feng, S.H., & Lin, C.L. (2013). Effectiveness of multidisciplinary care for chronic kidney disease in Taiwan: a 3-year prospective cohort study. *Nephrology Dialysis Transplantation*, 28,(3), 671-682, <https://doi.org/10.1093/ndt/gfs469>

Chiles, J. A., Lambert, M. J. and Hatch, A. L. (1999). The Impact of Psychological Interventions on Medical Cost Offset: A Meta-analytic Review. *Clinical Psychology: Science and Practice*, 6: 204-220. doi:10.1093/clipsy.6.2.204

Cohen, S., Patel, S., Khetpal, P., Peterson, R. & Kimmel, P. (2007). Pain, Sleep Disturbance, and Quality of Life in Patients with Chronic Kidney Disease. *Clinical Journal of the American Society of Nephrology*, 2, 919-925

Coyne, E. (2013). Psychosocial aspects of living with chronic kidney disease. In Lewis, R. & Noble, H. (Eds) *Kidney Disease Management: A practical approach for the non-specialist healthcare practitioner*. Wiley-Blackwell.

Cukor, D., Cohen, S.D., Peterson, R.A., & Kimmel, P.L. (2007). Psychosocial Aspects of Chronic Disease: ESRD as a Paradigmatic Illness. *Journal of the American Society of Nephrology*, 18, 3042-3055

Cukor, D., Ver Halen, N., Fruchter, Y. & Kimmel, P. L. (2015). Psychosocial Issues in Chronic Kidney Disease Patients. In: Kimmel, P.L. & Rosenberg, M. (Eds.) *Chronic Renal Disease* (pp 229-236). Doi: 10.1016/B978-0-12-411602-3.00019-6

Cystic Fibrosis Trust (2011) *Standards for the Clinical Care of Children and Adults with cystic fibrosis in the UK*. Retrieved from <https://www.cysticfibrosis.org.uk/~media/documents/the-work-we-do/care/consensus-docs-with-new-address/cystic-fibrosis-trust-standards-of-care.ashx?la=en>

Department of Health [DH]. (2004). *The National Service Framework for Renal Services Part 1: Dialysis and transplantation*. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199001/National_Service_Framework_for_Renal_Services_Part_One_-_Dialysis_and_Transplantation.pdf

Department of Health [DH]. (2005). *The National Service Framework for Renal Services Part 2: Chronic Kidney Disease, Acute Renal Failure and End of life Care*. Retrieved from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199002/National_Service_Framework_for_Renal_Services_Part_Two_Chronic_Kidney_Disease_-_Acute_Renal_Failure_and_End_of_Life_Care.pdf

Department of Health [DH]. (2014). *Closing the gap: priorities for essential change in mental health*. Retrieved from: <https://www.gov.uk/government/publications/mental-health-priorities-for-change>

Dew, M. A., Rosenberger, E. M., Myaskovsky, L., DiMartini, A. F., DeVito Dabbs, A. J., Posluszny, D. M., ... Greenhouse, J. B. (2015). Depression and Anxiety as Risk Factors for Morbidity and Mortality after Organ Transplantation: A Systematic Review and Meta-Analysis. *Transplantation*, 100(5), 988-1003. <http://doi.org/10.1097/TP.0000000000000901>

Dieng, M., Cust, A., Kasparian, N., Mann, G., & Morton, R. (2016). Economic evaluations of psychosocial interventions in cancer: A systematic review. *Psycho Oncology*, 25(12), 1380-1392.

Eknoyan, G., Lameire, N., Barsoum, R., Eckardt, K-U., Levin, A., Levin, N., ... Wang, H. (2004). The burden of kidney disease: Improving global outcomes. *Kidney International*, 66(4), 1310-1314. doi:10.1111/j.1523-1755.2004.00894.x

Gerogianni, G. G. & Babatsikou, F. P. (2013). Identification of stress in chronic haemodialysis. *Health Science Journal*, 7 (2), 169-176.

Hamilton, A.J., Braddon, F., Casula, A., Lewis, M., Mallet, T., Marks, S.D., Shenoy, M., Sinha, M.D., Tse, Y., & Maxwel, H. (2017). UK Renal Registry 19th Annual Report: Chapter 4 Demography of the UK Paediatric Renal Replacement Therapy Population in 2015. *Nephron*, 137(1), 103-166, DOI: 10.1159/000481366

Harwood, L., Wilson, B., Locking-Cusolito, H., Sontrop, J., & Spittal, J. (2009). Stressors and coping in individuals with chronic kidney disease. *Nephrology Nursing Journal*, 36(3), 265-301.

Jansen, D. L. (2012). Living with chronic kidney disease: *The role of illness perceptions, treatment perceptions and social support* (Doctoral dissertation). Retrieved from <https://dspace.library.uu.nl/handle/1874/236030>.

Kerr, M., Bray, B., Medcalf, J., O'Donoghue, D. J. & Matthews, B. (2012). Estimating the Financial Cost of Chronic Kidney Disease to the NHS in England. *Nephrology Dialysis Transplantation*, 27(3), 73-80. doi:10.1093/ndt/gfs269

London Cancer Alliance (2014). *Developing a pathway for mental health and psychological support services for adults*. Retrieved from <http://www.londoncanceralliance.nhs.uk/media/83191/developing-a-pathway-for-mental-health.pdf>

MacNeill, S.J. & Ford, D. (2017). UK Renal Registry 19th Annual Report: Chapter 2 UK Renal Replacement Therapy Prevalence in 2015: National and Centre-specific Analyses. *Nephron*, 137(1), 45-72. DOI: 10.1159/000481364

Marlow, N. M., Simpson, K. N., Kazley, A. S., Balliet, W. E., Chavin, K. D., & Baliga, P. K. (2016). Variations in coping stages for individuals with chronic kidney disease: Results from an exploratory study with patient navigators. *Journal of health psychology*, 21(7), 1299-1310. Doi: 10.1177/1359105314551776

McKercher, C. M., Venn, A.J., Blizzard, L., Nelson, M.R., Palmer, A. J., Ashby, M. A., Scott, J. L. & Jose, M.D. (2013). Psychosocial Factors in Adults with Chronic Kidney Disease: Characteristics of Pilot Participants in the Tasmanian Chronic Kidney Disease study. *BMC Nephrology*, 14(83), 1-9. Doi:10.1186/1471-2369-14-83

National Institute for Health and Care Excellence (NICE) (2004). *Improving Supportive and Palliative Care for Adults with Cancer*. Cancer Service Guideline. Retrieved from <https://www.nice.org.uk/guidance/csg4>

National Institute for Health and Care Excellence (NICE). (2014). *Chronic Kidney Disease in Adults: Assessment and Management. Clinical Guideline*. Retrieved from <https://www.nice.org.uk/guidance/cg182/resources/chronic-kidney-disease-in-adults-assessment-and-management-pdf-35109809343205>

Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M. & Galea, A. *Long-term conditions and mental health: The cost of co-morbidities. The Kings Fund*. Retrieved from: <https://www.kingsfund.org.uk/projects/mental-health-and-long-term-conditions-cost-co-morbidity>

NHS England. (2017a). *Service specifications: assessment and preparation for renal replacement therapy (including establishing dialysis access)*. Retrieved from: <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/a06-spec-renal-asses-ad.pdf>

NHS England. (2017b). Service specifications: In centre *Haemodialysis (ICHD). Main and satellite units*. Retrieved from: <https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/a06-serv-spec-haemodialysis-ichd.pdf>

Palmer, S.C., Vecchio, M., Craig, J.C., Tonelli, M., Johnson, D.W., Nicolucci, A., Pellegrini, F., Saglimbene, V., Logroscino, G., Hedayati, S.S., & Strippoli, G.F. (2013). Prevalence of depression in chronic kidney disease: Systematic review and meta-analysis of observational studies. *Kidney International*, 84(1), 179-191. doi: 10.1038/ki.2013.77.

Palmer, S.C., Vecchio, M., Craig, J.C., Tonelli, M., Johnson, D.W., Nicolucci, A., Pellegrini, F., Saglimbene, V., Logroscino, G., Hedayati, S.S., & Strippoli, G.F. (2013b). Association between depression and death in people with CKD: a meta-analysis of cohort studies. *American Journal Kidney Disease*.62(3), 493-505. doi: 10.1053/j.ajkd.2013.02.369.

Tallis, K. (2005). *How to improve quality of life in patients living with end stage renal failure. Renal Society of Australasia Journal*, 1, (1), 18-24.

Taylor, F., Combes, G. (2014). *Supporting the emotional and psychological needs of end-stage renal disease patients. Study report. Appedix 6: literature review*. Retrieved from http://www2.warwick.ac.uk/fac/med/about/centres/clahrc/research/theme4-integrated-holistic-care-chronic/disease/publications/supporting_the_emotional_and_psychological_needs_of_esrd_appendix.pdf

Taylor, F., Taylor C., Baharani, J., Nicholas, J. & Combes, G. (2016). Integrating emotional and psychological support into the end-stage renal disease pathway: a protocol for mixed methods research to identify patients' lower-level support needs and how these can most effectively be addressed. *BMC Nephrology*, 17(111), 1-12. DOI: 10.1186/s12882-016-0327-2

The Kidney Health Advisory Group. (2013). *Kidney Health: Delivering Excellence. A kidney health report*. Retrieved from: <http://www.kidneyresearchuk.org/file/media/Kidney-Health-Delivering-Excellence-1709-15-Oct.pdf>.

The National Renal Workforce Planning Group. (2002). *The Renal Team. A multi-professional renal workforce plan for adults and children with renal disease. Recommendations of the National Renal Workforce Planning Group*. Retrieved from http://www.britishrenal.org/getattachment/Workforce-Planning/WFP_Renal_Book1.pdf.aspx.

Thompson, R. J., Mata, J., Jaeggi, S. M., Buschkuhl, M., Jonides, J., & Gotlib, I. H. (2010). Maladaptive coping, adaptive coping, and depressive symptoms: Variations across age and depressive state. *Behaviour research and therapy*, 48(6), 459-466. Doi:10.1016/j.brat.2010.01.007.

Tsai, Y.C., Chiu, Y.W., Hung, C.C., Hwang, S.J., Tsai, J.C., Wang, S.L., Lin, M.Y., & Chen, H.C. (2012). *Association of Symptoms of Depression With Progression of CKD*. American Journal of Kidney Diseases, 60(1), 54-61. doi: 10.1053/j.ajkd.2012.02.325.

Appendix A

Psychosocial Provision per Renal Unit July 2017 – **Confirmed data in bold.**

Units in England

Name of renal unit	Staff available	Number of sessions on renal services
Addenbrooks	2 counsellor/psychotherapist 1 Social Care Practitioner	5 + 4 sessions 10 sessions
Aintree University Hospital	3 psychologists + 1 assistant	2.5 sessions
Alder Hey Children's Hospital	1 psychologist	3 sessions
Arrowe Park Hospital	1 social worker	10 sessions
Barts & The London Hospital	1 assistant psychologist 1 psychiatrist Recruiting 1 psychologist CAB	6 sessions unknown
Basildon University Hospital	1 counsellor/psychotherapist	4 sessions
Birmingham Children's Hospital	1 psychologist 1 social worker 2 play workers (Not qualified)	5 sessions 10 sessions 20 sessions
Bristol Royal Hospital for Children	1 psychologist 1 social worker	6 sessions 10 sessions
Broomfield Hospital	2 counsellor/psychotherapist	4 + 6 sessions
Churchill Hospital	1 psychologist 1 social worker 1 youth worker	7 sessions 10 sessions 10 sessions
Colchester General Hospital	No renal psychosocial staff available	-
Cumberland Infirmary	1 social worker	4 sessions
Derriford Hospital	1 psychologist 1 Youth/Young adult worker	1 session 2 sessions
Doncaster Royal Infirmary	No renal psychosocial staff available. Patients who are also receiving care from Northern General (mostly transplant patients) are seen by the psychosocial team of Northern General.	-
Dorset County Hospital	2 social workers 2 counsellor/psychotherapist 1 assessment & support coordinator	8 + 5 sessions 5 sessions 8.5 sessions
Evelina Children's Hospital	1 social worker 1 music therapist 2 psychologists Play specialist team	10 sessions 2 sessions 14 sessions
Freeman Hospital	3 social workers 1 youth/young adult worker	6+6+6 sessions 10 sessions

Name of renal unit	Staff available	Number of sessions on renal services
Gloucestershire Royal Hospital	1 psychologist	2 sessions
Great North Children's Hospital	2 psychologists 1 social worker	5+7 sessions 10 sessions
Great Ormond Street Hospital	1 psychologist 1 counsellor/psychotherapist 2 social workers	4 sessions 5 sessions 5+5 sessions
Guy's and St Thomas's Hospital	2 psychologists 2 social workers 1 youth/young adult worker	10 + 10 sessions 10 + 10 sessions 5 sessions
Heartlands Hospital	1 social worker	6 sessions
Hull Royal Infirmary	1 psychologist 2 social workers	1 session 10+4 sessions
Ipswich Hospital	1 counsellor/psychotherapist	2 sessions
James Cook University Hospital	1 psychologist 1 social worker (on sick leave for the past 6 months)	2 sessions 8 sessions
Kent & Canterbury Hospital	2 counsellors/psychotherapists 1 welfare officer	6 + 10 sessions 10 sessions
King's College Hospital	2 social workers 3 counsellors/psychotherapists	10 + 10 sessions 10 +7 + 5 sessions
Leeds Children's Hospital	1 psychologist	5 sessions
Leicester General Hospital	1 psychologist (only main unit)	4 sessions
Lister Hospital	1 psychologist 2 social workers 2 counsellors	10 sessions 10 +8 sessions 8 + 4 sessions
Manchester Royal Infirmary	1 psychologist 2 social workers 1 counsellor	8 sessions 10+8 sessions 10 sessions
New Cross Hospital	2 psychologists 1 welfare officer	3 + 4 sessions 2 sessions
Norfolk & Norwich University Hospital	1 social worker 1 counsellor	10 sessions 5 sessions
Northern General Hospital (Sheffield Kidney Institute)	2 psychologists 1 Trainee CB therapist 3 Social workers	4 + 4 sessions 4 sessions 20 sessions
Nottingham Children's Hospital	2 Social workers 1 play therapist	5 + 5 sessions 10 sessions
Nottingham City Hospital	1 psychologist 1 youth worker	8 sessions 5 sessions
Queen Alexandra Hospital	1 counsellor/psychotherapist	1 session

Name of renal unit	Staff available	Number of sessions on renal services
Queen Elizabeth Hospital	2 psychologists 2 counsellors/psychotherapists 3 welfare officers	5 + 5 sessions 3 + 4 sessions Company
Royal Berkshire Hospital	1 psychologist 2 social workers	1 session 10 + 10 sessions
Royal Cornwall Hospital	No renal dedicated psychosocial staff	
Royal Derby Hospital	1 Youth/young adult worker	5 sessions
Royal Devon and Exeter Hospital	1 psychologist CAB welfare advice (funded by PA)	2 sessions 1 session
Royal Free Hospital	3 psychologists 1 youth/young adult worker	10 + 8 + 5 sessions 10 sessions
Royal Liverpool University hospital	1 psychologist 2 social workers	6 sessions 10 + 10 sessions
Royal Manchester Children's Hospital	1 psychologist	<1 session
Royal Preston Hospital	1 psychologist 2 social workers (should be full time, but 1 on 12 month maternity leave, 1 post half filled)	10 sessions 10+10 sessions
Royal Shrewsbury Hospital	1 psychologist	7 sessions
Royal Sussex county Hospital	4 counsellors 1 welfare officer	6 + 6 + 6 + 5 sessions 10
Russells Hall Hospital	3 psychologists	unknown
Salford Royal Hospital	3 psychologists 1 social worker	10 + 10 + 6 sessions 10 sessions
Southampton Children's Hospital	1 renal psychologist Play therapist Currently aiming to get a youth worker	4 sessions 10 sessions
Southend University Hospital	1 social worker	4 sessions
Southmead Hospital	2 psychologists (1 of them is on maternity leave, not covered) 1 youth worker	6 + 2 sessions 0,5 session
St George's Hospital	1 psychologist 1 social worker 1 youth worker	10 sessions 10 sessions 10 sessions
St Helier Hospital	1 psychotherapist In the process of hiring a social worker	4 sessions
St James's University Hospital	2 psychologists 3 social workers	7 + 5 sessions 10 + 6 + 6 sessions
St Luke's Hospital	1 psychologist 1 Cultural and health Liaison officer	2 sessions 8 sessions

Name of renal unit	Staff available	Number of sessions on renal services
Sunderland Royal Hospital	No renal psychosocial staff available. Sunderland has a large psychology department but has no specified sessions allocated. Also Psych Liason.	-
The York Hospital	2 psychologists 2 social workers	3 + 3 sessions 7 + 7 sessions
University Hospital Coventry & Warwickshire	1 psychologist 2 social workers	7 sessions 5 + 5 sessions
University Hospital of North Staffordshire	No renal psychosocial staff available	-
West London Renal & Transplant Centre	1 social worker 2 counsellors/psychotherapists	8 sessions 8 + 6 sessions

Units in Northern Ireland

Name of renal unit	Staff available	Number of sessions on renal services
Altnagelvin Area Hospital	1 psychologist 1 social worker	2 sessions 7 sessions
Antrim Area Hospital	1 counsellor/psychotherapist 1 social worker	8 sessions 4 sessions
Belfast City Hospital	No renal dedicated staff available. Hospital psychologists (3) and social work team.	-
Daisy Hill Hospital	2 social workers	unknown
Royal Belfast Hospital for sick children	1 psychologist 1 social worker	6 sessions 6 sessions
Ulster Hospital	1 social worker The dedicated social worker has been drafted in to ease crisis in unscheduled care	As required.



Units in Wales

Name of renal unit	Staff available	Number of sessions on renal services
Children’s Hospital for Wales	1 social worker 1 youth/young adult worker (shared)	8 sessions 2.5 sessions
Morrison Hospital	1 social worker 1 youth worker (shared)	10 sessions 5 sessions
University Hospital of Wales	3 psychologists 1 youth worker (same person as at Morrison)	5 + 5 + 6 sessions 2.5 sessions
Wrexham Maelor Hospital	1 psychologist 2 social workers	6 sessions 6 + 6 sessions
Ysbyty Glan Clwyd	2 psychologists 1 social worker	3 + 3 sessions 10 sessions
Ysbyty Gwynedd	1 psychologist 1 social worker	6 sessions 7 sessions

Units in Scotland


Name of renal unit	Staff available	Number of sessions on renal services
Aberdeen Royal Infirmary	No renal psychosocial staff available	-
Inverness- Raigmore Hospital	No renal psychosocial staff available	-
Dundee- Ninewells	1 social worker (shared with oncology)	-
Airdrie – Monklands Hospital	2 social workers	10+ 6 sessions
Glasgow- Yorkhill	2 psychologists	3 + 4 sessions
Glasgow Renal and transplant unit	No renal psychosocial staff available	-
Dumfries & Galloway Royal infirmary	No dedicated renal service. Clinical Health Psychology team has four full time members of staff. Operates a general medical model and this includes renal medicine, but it has no allocated renal time.	-
Crosshouse Hospital	No renal psychosocial staff available. (General psychology and social work service)	-
Edinburgh Royal Infirmary	1 psychiatrist 3 social workers	4 sessions 10 +6+6 sessions
Kirkcaldy	No renal psychosocial staff available	-






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