**UKKW programme workstream 3**

**28/11/22**

**Attendees:** Lisa Ancliffe, Winnie Chan, Christy Walklin, Anna Winterbottom, Caroline Anderson, Bethan Pettifer, Sarah Crimp

**Session proposal notes and actions:**

**Understanding the link between mental health and kidney disease and the impact on the lives of patients**

No/Maybe

More informationneeded on session structure and proposed speakers before a final decision is made.

**Action: Caroline to write to session proposer**

**'We don't have enough psychosocial staff to meet patient need': developing integrated patient pathways for psychosocial support and therapy**

Yes.

Will need to ensure perspective from more than one unit.

Caroline to lead.

**Plant-Based Diets for Renal Health & Beyond**

No. All medics from USA. Will need more local input/UK dietitians. Session on plant-based last year so not felt to be of value this year. Other nutrition topics covered in other proposals.

**Launch Event: a new skills-based resource for kidney health professionals talking with people about kidney failure, end of life and advance care planning**

Yes.

Diversify speakers.

Anna to lead

**Enhanced Supportive Care - understanding the need ; identifying the resource**

Yes.

Compliments Difficult Conversations session well.

Anna to lead.

**Moving on Up Together: The joys and tribulations of working with young adults. Relevant from cradle to old age**

Yes.

MDT representation needed.

Manish to lead

**Addressing Frailty in Chronic Kidney Disease**

Yes.

MDT representation needed.

Winnie to lead – Caroline to help with psychosocial input

**Physical activity, rehabilitation, and exercise in kidney disease: 5 years later, where are we now?**

Yes.

Lisa and Christy to lead

**The impact of food processing and diet quality on nutrition therapy for adults living with kidney disease**

No/maybe.

Look at combining with the low potassium session in workstream 4.

**Action: Winnie to liaise with RNG chair re merging sessions**

**A Multicultural Diet Dietitian’s Handbook to support culturally appropriate dietary advice for patients from ethnic minority background.**

Yes.

More info needed on how the session will be structured, may be a 60 min or mini symposium. Consider a patient voice

**Action: Winnie to discuss with RNG chair**

**AOB**

**Action: Caroline and Lisa to liaise with Nicki re Wales Peer Support session, could be merged with NKF’s session on peer support and bring in a national perspective.**

**Action: Lisa to put together a session on non-pharmacological management of symptoms**

**Action: Manish to look at paeds sessions**

**Action: Bethan to chase up social workers group for session ideas or ways in which social work could be added to existing sessions.**

Keep in mind: Welsh report on well-being post-COVID and the cost of living crisis.

Proposals for mini symposia will open in Jan 2023.

Consider session structure standardisation – review session development guidelines.

**Understanding the link between mental health and kidney disease and the impact on the lives of patients**

**Theme:** ["Behavioural, psychological and quality of life","Rehabilitation, exercise and lifestyle"]

**Session length:** 90 Minute Session

**Speakers proposed**

**Rationale/Importance**

People with kidney disease are at greater risk of having poor mental health and this has multiple causes, unique to every individual. The consequences are serious and potentially life-threatening. Poor mental health makes it less likely that people will adhere to their treatment plan and when this includes life-preserving medication or dialysis not taking treatment, this has immediate and serious implications. Equally people with a serious mental health condition are at a greater risk of developing kidney disease.

**Additional comments**

**Session proposers/organisers**

**Submitted by**

Jo Pywell

**'We don't have enough psychosocial staff to meet patient need': developing integrated patient pathways for psychosocial support and therapy**

**Theme:** ["Behavioural, psychological and quality of life"]

**Session length:** 90 Minute Session

**Speakers proposed**

(1) Hayley Matthews, Programme Manager – IAPT, Mental Health Team, NHS England & NHS Improvement

(2) Professor Paul Farrand Professor of Evidence-Based Psychological Practice and Research and/or Dr Alex Hamilton Consultant Nephrologist

(3) Dr Emma Coyne Consultant Clinical Psychologist and/or Dr Alex Baille Clinical Psychologist

**Rationale/Importance**

There is a gap between the need for specialist psychological provision for renal patients and the availability of provision. This is further complicated by funding limitations and historical differences in service provision which has led to inequalities of provision across the UK. (1,2)

Psychological (and psychosocial support) is based on a stepped care model with 4 levels of provision. Within England the Improving Access to psychological therapy programme (IAPT) has started to develop specialist long term condition pathways to offer support at step 2 and 3. Renal specialist psychosocial staff work at step 3 and 4 and support the training and supervision of staff at step 2.The original long term conditions work did not include renal as one of their core conditions. Recent work following on from the Renal Psychosocial Manifesto (3) and work within the renal services transformation programme (RSTP) has identified the need for joined up systems and patient pathways between the different levels of psychological interventions including developing specialist training for IAPT staff and for renal staff linking generic metal health services into specialist renal psychosocial services.

The aim of this symposium is the share the learnings about the opportunities and challenges of developing integrated patient pathways focusing on presenting information and practical examples applicable to different renal units.

We are proposing 3 x 20 mins speakers:

Speaker 1: The national context of IAPT/ long-term conditions and integrated care pathways

Speaker 2: A project that aimed to develop pathways in a service with very limited psychological provision using an innovative model of screening and signposting (this pilot project has just completed)

Speaker 3: A case study exploring the development of an integrated pathway where the renal service already has specialist provision but wanted to refer out lower level care because of service demand. In this example they aimed to develop an integrated stepped care pathway in conjunction with another health condition (Cancer).

We are aware that a number of renal networks are currently looking to develop these integrated pathways and feel the opportunity to explore what the potential pathways can look like, the opportunities, the pitfalls (and lessons learned) would be helpful to renal services looking to develop similar services.

(1) Seekles ML, Coyne E, Ormandy P et al. The UK renal psychosocial workforce - a mapping exercise. 2018. https:// www.kidneycareuk.org/documents/206/The\_UK\_Renal\_ Psychosocial\_Workforce\_-\_A\_mapping\_exercise.pdf (accessed 6 November 2022)

(2) Seekles ML, Ormandy P, Coyne E. Mapping the UK renal psychosocial workforce: the first comprehensive workforce survey. BMC nephrology. 2019;20(1):100. https://doi. org/10.1186/s12882-019-1287-0

(3) Kidney Care UK, National Psychosocial Working Group. Psychosocial Health - a manifesto for action. Alton: Kidney Care UK; 2022

**Additional comments**

We would need costs for speaker’s attendance

This session proposal has been developed in conjunction with the Renal National Psychosocial Working Group and Kidney Care UK who would be willing to co-badge it alongside the psychosocial affiliate organisations within UKKA.

**Session proposers/organisers**

All potential speakers have been approached to discuss the potential idea and have confirmed their interest and willingness to be involved in a symposium if this proposal is successful.

The session is being proposed by Emma Coyne, Consultant Clinical Psy

**Submitted by**

Emma Coyne

**Plant-Based Diets for Renal Health & Beyond**

**Theme:** ["CKD","Patient education","Rehabilitation, exercise and lifestyle","Renal nutrition"]

**Session length:** 90 Minute Session

**Speakers proposed**

Shivam Joshi, MD

Michelle McMacken, MD

Kam Kalantar-Zadeh, MD, MPH, PhD

**Rationale/Importance**

In recent years, a growing body of evidence has emerged on the benefits of plant-based diets for the prevention and treatment of lifestyle diseases. In parallel, data now exist regarding the application of plant-based diets for the prevention and treatment of chronic kidney disease and its most common complications. Improving the nutrient quality of foods consumed by patients by including a higher proportion of plant-based foods while reducing total and animal protein intake may reduce the need for or complement nephroprotective medications, improve kidney disease complications, and perhaps favorably affect disease progression and patient survival. In this presentation, Dr. McMacken will review the benefits or this diet for general health, including obesity, diabetes, hypertension, cancer, and cardiovascular disease. Then, Dr. Joshi will the available evidence on plant-dominant fiber-rich diet as it relates to kidney disease prevention, chronic kidney disease incidence and progression, metabolic acidosis, hyperphosphatemia, uremic toxins, and concerns of hyperkalemia. Finally, Dr. Kalantar-Zadeh will review how these concepts are coalescing to form the renal diet of the 21st century: the PLADO diet. He will review protein requirements and the benefits of modulating protein intake. In conclusion, the risk to benefit ratio of plant-based diets appears to be tilting in favor of their use for patients with and at-risk for kidney disease.

**Additional comments**

none

**Session proposers/organisers**

1. Shivam Joshi, MD

New York University

Veterans Affairs

2. Michelle McMacken, MD

New York University

New York City Health and Hospitals

3. Kam Kalantar-Zadeh, MD, MPH, PhD

University of California, Irvine

**Submitted by**

Shivam Joshi

**Launch Event: a new skills-based resource for kidney health professionals talking with people about kidney failure, end of life and advance care planning:**

**Theme:** ["End of life and palliative care","Patient outcome and experience","Staff education and workforce"]

**Session length:** 90 Minute CPD/CME Session

**Speakers proposed**

1. Anna Winterbottom, project lead, Health Services Research, St James University Hospital, Leeds

Working title: ‘A brief introduction to the development of the Difficult Conversations booklet’

5-minute introductory presentation to discuss the background and rationale and development of the ‘Difficult Conversations: talking with people about kidney failure, end of life and advance care planning, a guide for kidney health professionals’

 1. Keith Bucknall, PPI study lead and transplant patient (presentation will be pre-recorded)

Working title: ‘Thinking about future treatment and care: what matters to me’

15-minute talk presented by a person with kidney disease talking about their views, perception, and experiences of discussing end of life treatment and care.

 1. Anna Winterbottom

Working title: ‘Experiences of end-of-life care planning for people with kidney failure and their families’

10-minute talk describing interview data from 27 people with kidney failure, their family members and bereaved family members, which informed the content and structure of the resource

 1. Helen Hurst – Professor of Nursing, University of Salfo5rfrd

Working title: ‘Integrating the booklet into practice, some initial thoughts, and experiences’

15-minute talk discussing how the booklet can support routine kidney care management consultations

30-minute panel discussion: Chaired by Anna Winterbottom, with panel members: Barny Hole, Andrew Mooney and Helen Hurst.

An interactive session involving audience members to discuss issues around discussing end of life treatment and care, use of the resource in practice, suggestions for further dissemination and training.30-minute panel discussion: Chaired by Anna Winterbottom, with panel members: Barny Hole, Andrew Mooney and Helen Hurst. An interactive session involving audience members to discuss issues around discussing end of life treatment and care, use of the resource in practice, suggestions for further dissemination and training.

**Rationale/Importance**

Our research team have developed and designed a ‘Difficult Conversations’ guide to support kidney health professionals talking with people with kidney failure, their family members and/or carers, about treatment and care towards the end of life. We would like to launch our new, open access resource at UKKW 2023. Dissemination activities such as these are crucial to ensuring the booklet has maximum impact and that is able to support health professional delivery and improve patients experiences of care, at a national level.

The research leading to the development of the resource was co-funded by the British Renal Society (now UKKA) and Kidney Care UK (KCUK). We are working in collaboration with KCUK to disseminate this resource via their website and national networks.

We have had considerable interest from (inter)national stakeholders during the development phase of this research. The UKKW conference would provide a valuable opportunity to share details about the booklet’s development, availability, and some initial accessibility and pilot data, with interested parties.

**Additional comments**

The session is affiliated to the UKKA supportive care SIG. Two members of the study team, Anna Winterbottom and Andrew Mooney, are members of this special interest group.

**Session proposers/organisers**

Anna Winterbottom1, Andrew Mooney1, Barny Hole2, Hilary L Bekker3, Fliss Murtagh4, Helen Hurst5, Keith Bucknall6 on behalf of the Difficult Conversations Study Team.

1Leeds Teaching Hospitals Trust, 2North Bristol NHS Foundation Trust, 3University of Lee

**Submitted by**

Anna Winterbottom

**Enhanced Supportive Care - understanding the need ; identifying the resource**

**Theme:** ["End of life and palliative care"]

**Session length:** 90 Minute Session

**Speakers proposed**

Enhanced Supportive Care - what matters to you - led by Andy Nixon and Katharine Parker in discussion with people living with kidney disease.

Providing Enhanced Supportive Care - A workforce challenge - Barny Hole and Ben Reynolds.

Enhanced Supportive Care - An optimal service - priorities for implementation with tools to assist - Jyoti Baharani and Karen Jenkins.

**Rationale/Importance**

Supportive kidney care is increasingly recognised as a crucial component of care for people with kidney disease – both those who start kidney replacement therapy, and those who opt for conservative kidney management. It has recently been identified as a key priority by the Chronic Kidney Disease (CKD) workstream of the Renal Service Transformation Programme (RSTP) and the Getting It Right First Time (GIRFT) review for renal medicine. This session examines why supportive care is needed and, from patients’ perspective, why delivery of is so important. It describes the work of the RSTP in defining ‘enhanced’ supportive kidney care, and the priorities and resources required for implementation. Providing a workforce that can deliver all aspects of kidney care is challenging, and the services and staff available to patients are known to influence their understanding and attitudes to treatment options. Results from surveys of adult and paediatric kidney services will be shared and provide a platform for discussion.

**Additional comments**

**Session proposers/organisers**

Karen Jenkins, Consultant Nurse, Kent Kidney Centre

Katie Vinen, Consultant Nephrologist , King's Kidney Care

on behalf of the Supportive Care Special Interest Group.

**Submitted by**

katie vinen

**Moving on Up Together: The joys and tribulations of working with young adults. Relevant from cradle to old age**

**Theme:** ["Genetic and rare diseases","Paediatrics","Transitional and young adult care","Behavioural, psychological and quality of life","Patient outcome and experience","Patient and public involvement","Rehabilitation, exercise and lifestyle","Renal nutrition","S

**Session length:** 90 Minute Session

**Speakers proposed**

\* Partnership, shared decision making and patient/peer support

 \* Sex, contraception and body image (AV Fistula for all?)

 \* Extending dietary choice for all including vegans, religious beliefs, vegetarians, foodie fads

 \* Clinicians and Young adult experience of transition and serious kidney disease (abstracts)

 \* Glomerulonephritis for young adults - managing those at high renal risk.

Speakers:

Patient voice

Dr Arvind Nagra +Jonathan Berry NHSE Shared decision making lead

Professor Neil Turner, Professor Liz Lightstone

Dr Kate Wiles

Caroline Anderson

Young Adult Kidney Group- Holly Loughton

**Rationale/Importance**

The ‘Moving on Up Together’ MDT meeting that has been held annually for 6 years with over 350 delegates with the patient voice at the heart of it. Through co-production it has been a major success by improving practice and changing the young adult experience of healthcare internationally for the better. Lessons learnt include health literacy, shared decision making and practical management of complex kidney diseases through the lens of young people – all of which are very much applicable from cradle to old age. We’d like to bring a flavour of this exciting meeting to UKKW where it will attract the whole of the mainstream MDT nationally and Internationally.

We plan to divide our 90 minutes into four or 5 session, each illustrated by patient voices, with contributions from both paediatric and adult MDT clinicians in each session.

**Additional comments**

Moving on Up Together Team, BAPN, Special Interest group in Transition, Young adult kidney Group, NKF, KCUK,

**Session proposers/organisers**

The Moving on Up Together Team: Professor Neil Turner, Dr Yincent Tse, Dr Arvind Nagra

Jan Dudley, President of the BAPN

**Submitted by**

arvind nagra

**Addressing Frailty in Chronic Kidney Disease**

**Theme:** ["Rehabilitation, exercise and lifestyle","Renal nutrition"]

**Session length:** 90 Minute Session

**Speakers proposed**

1. Dr Adnan Sharif

 Consultant Nephrologist

 University Hospitals Birmingham NHS Foundation Trust, UK

 Presentation: Should frailty assessment be incorporated into routine nephrology practice? (20 mins)

 2. Professor James Burton

 Professor of Renal Medicine

 University of Leicester, UK

 Presentation: Exercise interventions to reverse frailty in chronic kidney disease (20 mins)

 3. Professor Luv van Loon

 Professor of Exercise Physiology and Nutrition

 Maastricht University Medical Centre, The Netherlands

 Presentation: Does intradialytic protein ingestion combined with exercise training improve muscle mass and strength in haemodialysis patients? (20 mins)

**Rationale/Importance**

Frailty, defined as a state of increased vulnerability to physical stressors as a result of progressive and sustained degeneration in multiple physiological systems, is highly common among patients with chronic kidney disease (CKD). In fact, the prevalence of frailty has been reported to be up to 73% for non-dialysis-dependent CKD and haemodialysis populations. Frailty is independently linked with adverse clinical outcomes in all stages of CKD, and is associated with an increased risk of mortality and hospitalisation, and inferior quality of life. In recent years, various research groups have made efforts to create an operational definition of frailty, aiming to facilitate its diagnosis in addition to categorizing its severity. At present, the is no consensus on the best approach of frailty assessment in clinical practice. As such, priority has been placed on any efforts to identify frailty in CKD. Recognising frailty should prompt a holistic approach in patient assessment in order to address risk factors that may exacerbate its progression. It is important to ensure patients receive appropriate support to mitigate physical and mental burden caused by frailty. Individualised exercise programmes may be offered, and adequate nutritional intake is essential. A greater understanding of frailty assessment and various interventional strategies aiming to combat frailty is important for multi-professional team members who are involved in the care of these vulnerable patients.

The objectives of the session are:

1. To gain a greater understanding of different frailty assessment tools and their associations with clinical outcomes

2. To identify the most suitable frailty assessment tool in CKD

3. To explore different exercise interventions aiming to reverse frailty in CKD

4. To understand the importance of adequate nutrition and potential nutritional implementation strategies in alleviating frailty in CKD

This session will consist of 3x 20-minute invited presentations, followed by a 10-minute Q&A. It will also include 2x 10-minute relevant oral abstract presentations. Dr Adnan Sharif will provide a comparative discussion on different frailty assessment tools and their correlations with clinical outcomes. Professor James Burton will discuss the importance of aerobic and anaerobic exercise interventions in reversing frailty in CKD. Professor Luv van Loon will focus on alleviating frailty with exercise training combined with intradialytic protein ingestion.

At the end of the session, the audience would have gained the most up-to-date knowledge on frailty assessment, and recognised the importance of exercise and nutrition interventions in combating frailty in CKD. Successful implementation of the knowledge gained from this session will facilitate a patient-centred approach in the management of patients with CKD.

**Additional comments**

This session will be a potential co-badging session between Renal Rehabilitation Network and Renal Nutrition Group. This proposal has been approval by the Renal Nutrition Group.

**Session proposers/organisers**

Dr Richard Borrows, Consultant Nephrologist, University Hospitals Birmingham NHS Foundation Trust

Dr Winnie Chan, Postdoctoral Research Fellow & Renal Dietitian, University of Birmingham

Both Dr Borrows and Dr Chan have approved this application.

**Submitted by**

Winnie Chan

**Physical activity, rehabilitation, and exercise in kidney disease: 5 years later, where are we now?**

**Theme:** ["Rehabilitation, exercise and lifestyle"]

**Session length:** 60 Minute Session

**Speakers proposed**

Potential talk titles and speakers:

Choice from authors involved in guidelines – Latest advances in the field of physical activity, rehabilitation, and exercise in kidney disease

Nephrologist (e.g., Prof James Burton) – What do I say to someone asking “I want to increase my physical activity levels”? Practical advice for healthcare professionals.

Dr Matthew Graham-Brown / Dr Heather MacKinnon / Dr Adnan Sharif / Dr Matthew Armstrong / Dr Ellen Castle / etc. – Prehabilitation for kidney transplant candidates: Is it time?

A choice of speakers could talk to this (e.g., Maddy Warren, Stuart Smith) – Physical activity and kidney disease: Perspectives from a person living with kidney disease

**Rationale/Importance**

Rehabilitation, including exercise and physical activity is crucial for maintaining or recovering both physical function and quality of life, and for supporting those whose health is deteriorating. It well known that reducing sedentary behaviour, increasing physical activity and initiating rehabilitation programs counteract cardiovascular risk and frailty, limit deconditioning and sarcopenia, and improve mobility, without side-effects. Yet, physical activity and rehabilitation-based interventions often requested by CKD patients themselves, are scarcely available. A modern renal workforce needs to be well informed of the benefits of multi-disciplinary rehabilitation and equip to initiate conversations that can encourage and support their patients to be more physically active and include professions with specialisms in rehabilitation and physical activity prescription. These skills will also support the anticipated Renal Services Transformation programme, which aims to improve care and to support people to live well with kidney disease.

It has been 5 years, since Harrogate 2018, when UK Kidney Week had a designated session highlighting the latest advances in the field of rehabilitation, physical activity, and exercise in kidney diseases. During these 5 years, there has been significant advances in our understanding of physical activity, rehabilitation, and exercise interventions for people living with kidney disease, and the results of several significant projects and initiatives from the UK have been reported. These include randomised control trials of intradialytic exercise (PEDAL and CYCLE-HD), the publication of the first ever exercise and lifestyle clinical practice guidelines, the development of novel digital health interventions (e.g., KIDNEY BEAM, My Kidneys and Me, ExeRTiOn), and the development of the Global Renal Exercise Network.

This session will review the latest advances in the field and provide the audience with up-to-date how-to knowledge of the importance of physical activity, rehabilitation, and exercise in CKD.

**Additional comments**

Affiliated with UKKA Rehabilitation Network and Global Renal Exercise Network (GREX)

**Session proposers/organisers**

Dr Thomas Wilkinson, Research Fellow, University of Leicester, tjw26@le.ac.uk

Dr Sharlene Greenwood, Consultant Physiotherapist, King's College Hospital NHS Trust; Honorary Senior Lecturer, King's College London, Sharlene.greenwood@nhs.net

Dr Hannah You

**Submitted by**

Thomas Wilkinson

**The impact of food processing and diet quality on nutrition therapy for adults living with kidney disease**

**Theme:** ["Renal nutrition"]

**Session length:** 60 Minute Session

**Speakers proposed**

Kelly Picard

**Rationale/Importance**

Food processing significantly impacts the mineral content of foods, in particular impacting potassium, sodium and phosphorus content. Processed foods are also associated with worse diet quality. Currently nutrition recommendations in renal nutrition tend to focus on restriction of minimally processed healthy foods to help lower potassium and phosphorus intake, however this practice is increasingly being called into question. This session will provide important updates on the impact of food processing on mineral content in foods and propose ways to consider food processing more fully in nutrition care for patients.

**Additional comments**

**Session proposers/organisers**

I received an email from Angeline Taylor a dietitian who works with NHS requesting that I submit this proposal to participate in UK Kidney Week. I am submitting this proposal on behalf of myself at Angeline's request. Angeline and I have no previous relat

**Submitted by**

Kelly Picard

**A Multicultural Diet Dietitian's Handbook to support culturally appropriate dietary advice for patients from ethnic minority background.**

**Theme:** ["Renal nutrition"]

**Session length:** 90 Minute CPD/CME Session

**Speakers proposed**

Gabby Ramlan, Clinical Lead Dietitian

Deepa Kariyawasam, Advanced Renal Specialist Dietitian

**Rationale/Importance**

As renal dietitians, we identified the type of food preferred by patients from diverse ethnicity background can be varied between ethnic groups. We recognised there are limited resources available for our patients but most importantly we identified the need to support dietitians in providing culturally appropriate dietary advice to patients from ethnic minority background. Therefore the advice given by a dietitian should reflect the cuisines consumed by individuals with CKD. This is to address inequality in providing culturally appropriate dietary advice received by patients and lack of inclusivity.

A previous audit of patients from London dialysis units showed that 74% of men and 96% of women from Black, Asian and minority ethnic (BAME) groups would like ethnic specific dietary information. A series of BAME low potassium diet sheets for patients to encompass South Asian, Chinese and Far Eastern, African-Caribbean and Eastern European was developed in 2018 by seven experienced renal dietitians and was officially published in October 2019. During the pilot of our BAME low potassium diet sheets, dietitians in the UK supported the idea of a handbook specific to culturally appropriate dietary advice, especially in managing hyperkalaemia. This was also confirmed at the UK Kidney Week (UKKW) BAME low potassium diet workshop in 2019 attended by mainly health professionals working with individuals with renal disease. They believe that this could guide their clinical dietary decision-making.

With the support from British Dietetics Association (BDA - Renal Nutrition Group), we developed evidence based multicultural diet handbook for dietitians focusing on African-Carribean, Eastern European, Chinese and Far Eastern as well as South Asian diet as our first initiative to reduce the gap in knowledge. We are planning to expand the dietitians handbook in the future.

**Additional comments**

**Session proposers/organisers**

British Dietetics Association, Renal Nutrition Group:

Multicultural Diet Working Group

Gabby Ramlan, Newham University Hospital Barts Health NHS Trust

Deepa Kariyawasam, King's College University Hospital NHS Trust

Ruple Patel, Epsom and St Helier Uni

**Submitted by**

Gabby Ramlan