**UKKW programme committee workstream 1**

**30/11/22**

**Attendees:** Tim Bowen, John Sayer, Kieran McCafferty, Caesar Chakraborty, Soma Meran, Sarah Crimp

**Sessions**

**Journal Club Gold 2023**

Yes

**Wales Kidney Research Unit - connecting early career researchers, patients and the public**

Yes – to be part of the local stream

**PTLD and EBV positive: The good, the bad and the devastating**

Very niche and only comprised of one case study. Could be considered for merging with a transplant session or with the proposal on intra-renal high-grade B cell lymphoma

**Joint Renal Health Data Network/ UK Renal Registry Session**

Yes. Could be merged with main UKRR session

**UK Renal Registry**

Yes, could be merged with Renal Health Data Network session

**UK Renal Trials Network Session - Getting deep into the nitty gritty of trials in nephrology**

Yes

**Intra-renal high-grade B cell lymphoma in a lady on long-term immunosuppression for ANCA vasculitis**

Only one case study. Could be considered for merging with PLTD proposal.

**Scientific advances in understanding glomerulonephritis**

Yes

**Treatment updates in Glomerulonephritis**

Yes

**Treatments in ANCA-associated vasculitis and infection prevention**

Yes

The above three proposals could form a GN track.

**A quick trip down the tubule - learning from the physiology of the renal tubule**

Yes

**Rare renal disease research - a new era**

Yes

**Autosomal Dominant Polycystic Kidney Disease: Genetics to Therapeutics in 2023**

Yes. More info needed on proposed speakers

**Therapeutic Plasma Exchange (PEx, Plasmapheresis)-Renal and non-renal indications, rationale and delivery**

Better as a mini symposium

**Care of sick renal patient: Development of a level 1.5 Renal Acute Care Unit (RACU) to provide respiratory support and SLED/SLED-F (PIHD)**

Fits in with the plasma exchange proposal. Could be a mini symposium. Fits better in workstream 4

**Co-designing interventions and research trials with patient and public involvement**

To be moved to workstream 2

**Inclusive Research - Underserved groups in Renal**

To be moved to workstream 2

**Gaps in the programme**

Basic science – Tim to lead on developing sessions.

**Journal Club Gold 2023**

**Theme:** ["Basic science","General nephrology including GN","Cardiovascular disease and diabetes","CKD","Transplantation Research","Haemodialysis Research","Paediatrics"]

**Session length:** 90 Minute Session

**Speakers proposed**

TBC: Will choose speakers from the following areas: GN, PD, HD, CKD, Tx, Paeds.

**Rationale/Importance**

I think last years session went well and the feedback was good (From memory), so looking to run the same session with updated trials.

Each speaker gets 15 mins for a journal that they think has made the biggest difference to their patients over the last year and it can't be their research. voting at the end. Not too serious...mild trash talk of others subspecialty is tolerated even encouraged...

**Additional comments**

**Session proposers/organisers**

Me

**Submitted by**

Kieran McCafferty

**Wales Kidney Research Unit -connecting early career researchers, patients and the public**

**Theme:** ["Basic science","General nephrology including GN","CKD","Behavioural, psychological and quality of life","Patient outcome and experience","Patient and public involvement"]

**Session length:** 90 Minute Session

**Speakers proposed**

Leah McLoughlin, Bangor University (health services research and qualitative research on renal replacement therapy planning, including in those fit for but declining listing for transplantation).

Luke Davies, Swansea University (Metabolic control of macrophage phenotype, including work conducted while a fellow at NIH, USA and now in collaboration with an academic team in Vienna developing novel Peritoneal Dialysis Fluid additives)

Bnar Talabani, Cardiff University (Wellcome Training Fellow: Characterising Macrophages in kidney disease by single cell sequencing). (Alternatives: Farah Latif, KRUK Fellow, CMV immune responses in transplant recipients. Or Tanya Smith, WCAT Fellow, understanding the differences between male and female kidneys at single cell level)

Potential to replace abstracts with patient/carer presentations on experience of connecting to and shaping research activity (from the WKRU engagement programme) and/or a short presentation from Health and Care Research Wales (Director Kieron Walshe or Head of Programmes Michael Bowdery)

**Rationale/Importance**

Wales Kidney Research Unit is a Biomedical Research Unit Funded by Welsh Government via Health and Care Research Wales. It has an all-Wales remit and connects stakeholders including patients, families and carers, researchers, clinicians and commissioners across Wales. The benefits of the proposed session are:

1. A platform for early career researchers to communicate the research that they lead, with work covering the geographical and translational spectrum of work led from Wales

2. Illustration of the different funding model (good and bad) and route to participation in research in Wales -potentially very important for Welsh delegates in the year that the meeting is coming to Wales, potentially also of interest to non-Welsh delegates who are interested in partnering with or including Welsh teams

**Additional comments**

Potential for co-badging of session with Wales Kidney Research Unit and/or with Health and Care Research Wales (who are functionally equivalent to NIHR in England for many actions in Wales, and who have entered a partnership with KRUK for WKRU support and for fellowships awarded in Wales)

**Session proposers/organisers**

Donald Fraser, WKRU lead

I have discussed informally with colleagues in developing this idea. I have not approached potential speakers or funder representatives in advance of consideration of the idea by the UKKW committee

**Submitted by**

Donald Fraser

**PTLD and EBV positive: The good, the bad and the devastating**

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

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

**Speakers proposed**

Dr Timothy Lewis-Morris, Consultant Nephrologist Brighton and Sussex Hospitals

Dr Antonia Cronin, Consultant Nephrologist at Guy's and St Thomas;

Dr Rachel Hilton Constultant Nephrologist Guy's and St Thomas'

Dr Chris Farmer, Consultant Nephrologist East Kent Hospitals Trust

Paul Fields, Consultant Haematologist Guys and St Thomas

Dr Daniele Avenoso Consultant Haematologist Kings College Hospitals

Dr Satyen Gohil Consultant Haematologist University College London Hospitals

**Rationale/Importance**

1. A devastating case of primary EBV positive PTLD resistant to all treatments months after a transplant.

2. To remind us the risks associated with transplantation.

3. Update on the latest treatment of PTLD from the specialists running the trials

**Additional comments**

1. Could Co-badge this session with the British Transplantation Society (BTS)

2. Could co-badge with the British Society of Haematology

**Session proposers/organisers**

Dr Timothy Lewis-Morris, Consultant Nephrologist Brighton and Sussex Hospitals

Dr Antonia Cronin, Consultant Nephrologist at Guy's and St Thomas'

We can confirm we have approved this application.

**Submitted by**

Timothy Lewis-Morris

**Joint Renal Health Data Network/ UK Renal Registry Session**

**Theme:** ["Epidemiology, public health and prevention including Renal Registry"]

**Session length:** 60 Minute Session

**Speakers proposed**

\* Getting the question right-ProfNigel Brunskill and Miranda Scanlon- 20mins

\* Will cover importance of getting the question right and how to embed patient involvement throughout the process.

\* Finding the data- Dr Samira Bell 10- 15 mins

\* Will cover available data sources for research into the areas of covid, pharmacoepidemiology and healthcare pathways

\* Doing the right analysis- Prof Dorothea Nitsch 10-15 mins

\* Will discuss epidemiological design including novel techniques to assess causality and AI.

**Rationale/Importance**

The UK Renal Health Data Research Network (UKRHDRN) has been established to enable better use of renal health datasets, to improve renal care and enable future research discoveries. The network aims to be a source of expertise and experience in health data research and strives to develop collaboration between groups and individuals doing research on kidney diseases using large datasets. Its ultimate aim is to reduce the burden of kidney of disease and reduce inequalities in kidney disease and its treatment.

This session will help promote this work and hopefully encourage people into renal heath data research as well as providing guidance on how to navigate this,

**Additional comments**

Joint UKRR/ Renal Health Data Network/ KRUK

**Session proposers/organisers**

Prof Dorothea Nitsch- UKRR

Miranda Scanlon- Renal Health Data Network/ KRUK

Prof Nigel Brunskill- Renal Health Data Network

Dr Aisling McMahon- KRUK

**Submitted by**

Samira Bell

**UK Renal Registry**

**Theme:** ["Epidemiology, public health and prevention including Renal Registry"]

**Session length:** 90 Minute Session

**Speakers proposed**

15 min talk of Kitty Jager “How do international registry comparisons move the renal community forward?” (5min Q&A)

15 min talk of BAPN “ Congenital disease in the UKRR” (5min Q&A)

15 min talk by Smeeta Sinha “What comes after the RSTP – new strategic developments ” (5min Q&A)

**Rationale/Importance**

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**Additional comments**

3 talks and 3 abstracts please

**Session proposers/organisers**

Dorothea Nitsch, Retha Steenkamp, Ron Cullen, James Medcalf - All on behalf of the UKKA/UKRR

**Submitted by**

Zoe Plummer

**UK Renal Trials Network Session - Getting deep into the nitty gritty of trials in nephrology**

**Theme:** ["General nephrology including GN","Cardiovascular disease and diabetes","Transplantation Research","Haemodialysis Research"]

**Session length:** 90 Minute Session

**Speakers proposed**

EMPA-Kidney - main and secondary end points focussing on headline results and whether eGFR slopes could be a relevant important way of looking at renal trials - Will Herrington/Richard Haynes (Oxford)

Use and abuse of slopes in eGFR as the latest way to assess efficacy of interventions in CKD trials- Brendon Neuen (Sydney- but has agreed to be in UK around time of congress)

STOP-ACEi from inception to results - the story of how a UK team answered one of the most important issues in low clearance clinics - Sunil Bhandari

**Rationale/Importance**

It is an exciting time to be involved in clinical renal research with new data finally arriving which should be rapidly translated to the clinics. But what does it all mean and how did that research happen? We propose a session based around the most important clinical trials of this year in renal medicine but in addition to presenting headline results, we want to go 'under the hood'. How did the investigators initiate these trials? What are the takeaways that you might miss by just reading the abstract?

The issue of eGFR slopes seems to be a big talking point in publications of CKD trials. But does improved eGFR slope translate to clinical benefit? How does one assess 'acute', 'chronic' and 'total' slope? Does it matter? What about dips in eGFR with ACE and SGLT2 inhibitors? What does the practising nephrologist need to know and how do we communicate eGFR slopes with patients? The leading eGFR slope researcher Brendon Neuen is a master of demystifying this and has agreed in principle to speak on this. For family reasons he can be in UK during UKKW.

Hopefully the proposed session continues the theme of rigorous educational sessions proposed by UK Renal Trials Network, with lots of education for nephrologists and the team at all stages of career.

**Additional comments**

UK Renal Trials Network sessions

**Session proposers/organisers**

Patrick Mark (UKRTN, Univ of Glasgow), Kaitlyn Mayne (trainee, University of Oxford), Will Herrington (UKRTN, Univ of Oxford)

**Submitted by**

Patrick Mark

**Intra-renal high-grade B cell lymphoma in a lady on long-term immunosuppression for ANCA vasculitis**

**Theme:** ["General nephrology including GN","Case reports"]

**Session length:** 60 Minute Session

**Speakers proposed**

Maria Angela Gauci

**Rationale/Importance**

ANCA vasculitis is a disease which is associated with considerable morbidity and mortality. Not only does the disease itself result in significant cardiovascular disease and risk of ESKD, but it also leads to severe complications secondary to the immunosuppression that comes along with it. Data on duration of immunosuppressive therapy is still to be determined.

The authors depict a case of a 72 year-old lady with a history of ANCA vasculitis on maintenance azathioprine for 5 years who was diagnosed with AKI secondary to intra-renal high grade B cell lymphoma. The first differential diagnosis was that of rapidly progressive GN secondary to relapsed vasculitis. However, the renal biopsy revealed CD45 and CD20 positive lymphocytic infiltration with almost 100% Ki67 uptake. Her EBV viral load was negative. She was immediately started on R-CHOP and this led to significant improvement in her renal function.

**Additional comments**

This case highlights highlights interesting factors

1. Intra-renal lymphoma with absence of lymphadenopathy is extremely rare

2. She was EBV negative - could this be why it did not present so typically?

3. How long should we keep patients on maintenance immunosuppression? This lady was on maintenance Azathioprine for >5 years in view of persistently raised titers and general systemic symptoms. Longterm analyses are required to determine duration of IS in this subgroup of patients.

**Session proposers/organisers**

1. Dr Maria Angela Gauci

Renal registrar

Leeds teaching hospitals NHS trust

2. Dr Elizabeth Garthwaite

Consultant nephrologist

Leeds teaching hospitals NHS trust

**Submitted by**

Maria Angela Gauci

**Scientific advances in understanding glomerulonephritis**

**Theme:** ["General nephrology including GN"]

**Session length:** 60 Minute Session

**Speakers proposed**

Understanding the Kidney in ANCA-associated vasculitis -Professor Mark Little

From bench to bedside in anti-GBM disease- Dr Steve McAdoo

**Rationale/Importance**

Significant progress in our understanding of pathogenic mechanisms in glomerular diseases has not only allowed greater scientific insight but has also led to the identification of novel therapeutic targets.

**Additional comments**

Linked to the Glomerulonephritis Clinical Studies Group (GN CSG)

**Session proposers/organisers**

Session proposed and approved by Dr Rachel Jones (Cambridge) and Jon Barratt (Leicester) (UKKRC Glomerulonephritis Clinical Study Group co-chairs)

Suggested session chairs- Silke Brix (Manchester) and Andreas Kronbichler (Cambridge)

**Submitted by**

rachel jones

**Treatment updates in Glomerulonephritis**

**Theme:** ["General nephrology including GN"]

**Session length:** 90 Minute Session

**Speakers proposed**

Therapeutic approach to lupus nephritis in 2023. Professor Liz Lightstone

Emerging evidence for novel therapeutics in IgA nephropathy. Professor Jon Barratt

Rituximab for membranous nephropathy. Dr Arif Khwaja

**Rationale/Importance**

The treatment landscape is changing in glomerular diseases. This goal of this session is to update clinicians on data supporting newer treatments in Lupus Nephritis, IgA nephropathy and Membranous Nephropathy.

**Additional comments**

Linked to the Glomerulonephritis Clinical Study Group

**Session proposers/organisers**

Session proposed by Dr Rachel Jones (Cambridge) and Professor Jon Barratt (Leicester) on behalf of the Glomerulonephritis Clinical Study Group (GN CSG)

Suggested session chairs- Dr Lisa Willcocks (Cambridge), Dr Chee Kay Cheung (Leicester)

**Submitted by**

rachel jones

**Treatments in ANCA-associated vasculitis and infection prevention**

**Theme:** ["General nephrology including GN"]

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

**Speakers proposed**

Newer therapeutic approaches in ANCA-associated vasculitis - Professor David Jayne

Understanding COVID immunity in the immunosuppressed patient in 2023 -Dr Edward Carr

Preventing infection in autoimmune renal diseases- Dr Rona Smith

**Rationale/Importance**

The use of immunosuppression for ANCA-associated vasculitis and other immune mediated renal diseases requires a clear understanding of infection risk. This session will provide an update on newer treatment approaches for ANCA-associated vasculitis as well as current information on infection prevention for patients with vasculitis and other immune medicated renal diseases.

**Additional comments**

Linked to the Glomerulonephritis Clinical Study Group (GN CSG)

**Session proposers/organisers**

Session proposed by Dr Rachel Jones and Professor Jon Barratt on behalf of the Glomerulonephritis Clinical Study Group (GN CSG)

Suggested session chairs are Michelle Willicombe (Imperial), Rachel Jones (Cambridge)

**Submitted by**

rachel jones

**A quick trip down the tubule - learning from the physiology of the renal tubule**

**Theme:** ["Genetic and rare diseases"]

**Session length:** 90 Minute Session

**Speakers proposed**

1. Detlef Bochenhauer (Male)

2. Nilufar Mohebbhi (Female)

3. Fiona Karet (Female)

4. oral abstarcts or round table discussion / case based discussions

**Rationale/Importance**

The kidney tubules provide homeostasis by maintaining the external milieu that is critical for proper cellular function. This task is achieved by an orchestra of proteins, directly or indirectly involved in the tubular transport of water and solutes. Inherited tubulopathies are characterized by impaired function of one or more of these specific transport molecules. The clinical consequences can range from isolated alterations in the concentration of specific solutes in blood or urine to serious and life-threatening disorders of homeostasis.

**Additional comments**

Co-badge with rare disease,

Pharma may sponsor eg SIBNAYAL by Advicenne

**Session proposers/organisers**

John Sayer, Newcastle University

Stephen (Ben) Walsh (UCL)

**Submitted by**

John Sayer

**Rare renal disease research - a new era**

**Theme:** ["Genetic and rare diseases"]

**Session length:** 90 Minute Session

**Speakers proposed**

Rachel Lennon - The Alport Research Hub

Jonathan Barratt - Treatment on the RaDaR: what are the targets in IgA nephropathy?

Danny Gale - Advances in renal genomics

**Rationale/Importance**

The UK is one of the best places in the world for research into rare diseases, largely because of the NHS and embedded nationwide research initiatives such as the 100,000 Genomes Project, NHS Genomic Medicine Service and Rare Renal Disease (RaDaR) registry. Together, these initiatives are teaching us more and more about the biology underlying individually rare kidney diseases, with the combination of large-scale genomics and prospective clinical data collection being particularly powerful ways to advance clinical care. In turn, this knowledge provides a perfect substrate for laboratory and translational research that is exemplified by the Alport Research Hub, which this session will showcase.

**Additional comments**

Rare disease research in the UK is going through a renaissance with increasing involvement of the NHS, University researchers and Commercial partnerships, exemplified by exciting recent developments with both RaDaR and the Alport Research Hub. It is anticipated that this session will be of interest to many stakeholders in rare kidney disease research, especially commercial partners interested in developing or testing new therapies for rare kidney diseases. This session will also provide the opportunity for latest scientific advances in this area to be presented as oral abstracts.

**Session proposers/organisers**

Danny Gale

Rachel Lennon

Neil Turner

Elaine Davies

**Submitted by**

Daniel Gale

**Autosomal Dominant Polycystic Kidney Disease: Genetics to Therapeutics in 2023**

**Theme:** ["Genetic and rare diseases"]

**Session length:** 90 Minute Session

**Speakers proposed**

Suggest 3 x 20min talks with 2 allocated abstracts

Various ADPKD CSG members interested in speaking

Genetics - information about changes to genetic testing/increased access

Basic/lab science update or Clinical management/treatment update

Trials/Research in relation to James Lind Alliance & PKD Charity Top 10 ADPKD Research Priorities (published in BMJ 2022)

**Rationale/Importance**

ADPKD is the commonest inherited kidney condition and is the cause of kidney failure in 10% of our renal replacement therapy patients. All nephrologists and other members of the renal MDT therefore benefit from up to date knowledge and understanding about ADPKD. In the last few years there have been changes to the practice of genetic testing in ADPKD and a consensus of research priorities have been published.

No dedicated ADPKD session for a few years.

**Additional comments**

PKD charity (patient led)

**Session proposers/organisers**

Roslyn Simms (ADPKD CSG Chair) - on behalf of CSG & members

**Submitted by**

Roslyn Simms

**Therapeutic Plasma Exchange (PEx, Plasmapheresis)-Renal and non-renal indications, rationale and delivery**

**Theme:** ["Haemodialysis Service delivery"]

**Session length:** 60 Minute Session

**Speakers proposed**

Dr David Makanjuola, Dr Mysore Phanish, Dr Bhrigu Sood, acute dialysis nursing staff, haematology/neurology colleagues

**Rationale/Importance**

Plasma exchange is used as a treatment option for management of Anti-GBM disease, ANCA vasculitis, acute antibody mediated renal transplant rejection and other haematological/neurological indications. This session will discuss the procedure, technique, indications and complications

**Additional comments**

This session will involve dialysis nursing staff who deliver Plasmapheresis, can involve haematology and neurology colleagues to discuss non-renal indications for PEx.

**Session proposers/organisers**

Dr.Mysore K Phanish

Dr. David Makanjuola

Dr. Bhrigu Sood

Dr. Fiona Harris

All are from Renal unit, St Helier Hospital, Epsom and St Helier University Hospitals NHS trust, Carshalton, London

**Submitted by**

Mysore Phanish

**Care of sick renal patient: Development of a level 1.5 Renal Acute Care Unit (RACU) to provide respiratory support and SLED/SLED-F (PIHD)**

**Theme:** ["AKI","Haemodialysis Service delivery","Haemodialysis Quality improvement"]

**Session length:** 90 Minute Session

**Speakers proposed**

Dr. Mysore K Phanish , Dr Giada Azzopardi, Dr Marlies Ostermann, Acute dialysis nursing staff, Critical care staff

**Rationale/Importance**

Outside of critical care, there are challenges in providing renal and respiratory support for patients with AKI, significant electrolyte abnormalities, dialysis patients with intercurrent illnesses such as pneumonia, MI and pulmonary edema. Some of these patients are deemed unsuitable for ICU, will need optimisation pre-ICU admission or need a level 1.5 care that cannot be delivered on a standard renal ward. We developed a 4-bedded unit within our renal ward to provide CPAP/NIV, HFNC (Optiflow) during Covid-19 pandemic along with dialysis therapy which subsequently evolved to provide hybrid RRT (Slow Low Efficiency Dialysis/Diafiltration (SLED/SLED-F) also known as prolonged intermittent haemodialysis/diafiltration) for patients with sepsis, myocardial ischaemia and borderline haemodynamic stability. In this session we describe the service development model, training, explain the protocols, barriers and discuss lessons learnt.

**Additional comments**

A level 1.5 care provision within a renal ward allows prompt shifting of sick renal patients from ED and timely ICU step-downs, facilitates transfer from referring hospitals. SLED/SLED-F provide a viable alternative to CVVH/CVVDF for patients susceptible to hypotension on standard dialysis preventing clinical deterioration. This session can be done in collaboration with critical care outreach/critical care society.

**Session proposers/organisers**

Dr. Mysore K Phanish, consultant nephrologist, Renal unit, St Helier Hospital, Epsom and St Helier University Hospitals NHS trust (ESTH), Carshalton, London

Dr. Giada Azzopardi, ST4 Renal -Critical Care Specialist registrar Trainee (London)

Dr. Rebecca

**Submitted by**

Mysore Phanish

**Co-designing interventions and research trials with patient and public involvement**

**Theme:** ["Patient and public involvement"]

**Session length:** 60 Minute Session

**Speakers proposed**

Co-designing Kidney Beam – Ellen Castle/ Hannah Young/ Jules Mayes

Co-designing My Kidneys & Me ((MK&M) online self-management program) and SMILE (RCT evaluating MK&M) – Courtney Lightfoot

**Rationale/Importance**

The engagement of stakeholders in the development of interventions is a core element of the Medical Research Council’s (MRC) framework for developing and evaluating complex health interventions (Skivington et al., 2021). The MRC’s framework proposes that “meaningful engagement with appropriate stakeholders at each phase of the research is needed to maximise the potential of developing or identifying an intervention that is likely to have positive impacts on health and to enhance prospects of achieving changes in policy or practice” (Skivington et al., 2021). One method to meaningful engage stakeholders is co-design, which is increasingly being recognised by the NIHR.

Co-design is a participatory approach to the development of interventions and research trials that collectively brings together researcher, healthcare professional and patient experience to design potential interventions to address existing problems (Dawda, 2017). This approach ensures that potential interventions are produced with the understanding of the setting and context in order for the end result to meet the stakeholder needs. Designing interventions in this way means that they are more likely to be accepted by both providers and end users, and thus adopted and sustained (Sanders and Stappers, 2008).

This session aims to provide an understanding of the importance of active collaboration and involvement with patients to ensure interventions and research trials and meaningful and how to use a co-design approach to developing and evaluating interventions for people with kidney disease.

**Additional comments**

**Session proposers/organisers**

Courtney Lightfoot, University of Leicester, courtney.lightfoot@leicester.ac.uk

Ellen Castle, Brunel University, Ellen.Castle@brunel.ac.uk

**Submitted by**

Courtney Lightfoot

**Inclusive Research - Underserved groups in Renal**

**Theme:** ["Patient and public involvement"]

**Session length:** 90 Minute Session

**Speakers proposed**

Shivani Sharma

Neerja Jain

Smita Sinha

Sunil Daga

**Rationale/Importance**

Inequalities in outcome of kidney disease stems from very early stages of patient journey with renal services - beginning with research where a number time either underserved groups are excluded (non-English speaking) or not engaged /seven (ethnic minorities, lower socioeconomic backgrounds, elderly and female). number of efforts are going on nationally and would be important to share the experiences and use the conference as catalyst for change.

**Additional comments**

As above

**Session proposers/organisers**

Not discussed

**Submitted by**

Sunil Daga