The UK Renal Registry Patient Council

Ron Cullen

Chief Executive, UK Renal Registry

Ron has over 30 years of experience in the NHS. Starting his professional career as a biomedical scientist he went on to spend a great deal of his time working on the areas of governance and quality improvement. He has had several important roles in these areas including Director of the National Clinical Governance Support Team as well as Head of Healthcare Quality and Standards within the Department of Health. Ron has lectured and presented on quality improvement nationally and worldwide. When not working, Ron likes to spend time with his family and coaches an under thirteen Rugby Team.

Dr Fergus Caskey

Medical Director, UK Renal Registry

Having graduated from the University of Glasgow in 1993, Fergus went on to obtain a Masters in Public Health and Health Services Research and then a MD degree in the Cost-effectiveness of Dialysis in Europe from the University of Aberdeen. He became a Consultant Nephrologist in Bristol in 2005 and was appointed Medical Director of the UK Renal Registry in 2013. His research interests include the epidemiology of chronic kidney disease and end stage kidney disease, particularly around equity, the application of mixed methods research to understand the reasons behind observed differences and the measurement of patient reported outcomes.

Retha Steenkamp

Head of Operations

Retha started work at the UK Renal Registry as biostatistician in 2004 after a career in econometrics and financial modelling in the private sector. During her time at the UK Renal Registry as senior biostatistician, her focus was on study design, statistical methods and audit of the Renal Association (RA) guidelines. She has a special interest in survival analysis and adjusting for case-mix to enable a fairer comparison of patient outcomes between renal units, and to this end obtained a PhD in medical statistics in 2015 focussing on prognostic modelling in dialysis patients. She was appointed as Head of Operations at the UK Renal Registry in 2016 with responsibility for statistical analysis, audit of the RA guidelines, systems development, informatics and data processing.
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Fiona Loud
Chairperson

Fiona’s roles at present are Policy Director for Kidney Care UK, and co-chair for the Risk work stream for the Acute Kidney Injury National Programme. Fiona is Chair of the UK Renal Registry Patient Council, the West Herts Hospital Organ Donation committee and is vice chair at The Local Kidney Patients Association at Lister Hospital. In her spare time (though we find it hard to believe she has any!) Fiona takes things at a more relaxed pace and enjoys activities such as sleeping, reading and going for long walks with the family dog, Ollie.

Tracey Rose

Tracey first became involved with the UK renal community in 1995 when her eldest daughter was taken ill. Since, then both her daughters have had 3 kidney transplants between them; the cause remains unknown. During this 20+ year span, she has developed a personal insight into most aspects of kidney failure from diagnosis, to dialysis and other treatments. As a living donor herself, together with her family experience, she has developed a wide breadth of knowledge and understanding of the rigours of living with this chronic condition. She is now actively involved within the community, both raising awareness of the disease and working on several projects that aim to improve patient experience and support. Additionally she is a Patient and Public Voice member of the NHS Clinical Reference Group for Renal Services.

Sue Lyon

Sue was diagnosed with renal failure in 1977 at the age of 25, subsequently spending nine years on home haemodialysis until she received a deceased-donor kidney transplant in March 1986. After beginning her career in general publishing, Sue joined the staff of a medical journal and since 2000 she has been a freelance medical journalist, writer and editor. Sue is Vice-Chair of her hospital kidney patients’ association, Deputy Editor of the National Kidney Federation’s Kidney Life magazine, and a member of Kidney Care UK’s Patient Advisory Group and of ESPRIT, a multidisciplinary group supporting safe prescribing in transplantation. As a member of the UK Renal Registry Patient Council, Sue’s aim is to support the Registry’s essential role in providing the data needed to guide the research and evidence-based kidney care that will help to optimise shared decision-making and outcomes for her fellow kidney patients.
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Shahid Muhammad

Shahid is a Specialist Biomedical Scientist and member of the Healthcare Professions Council (HCPC), the Institute of Biomedical Sciences (MIBMS) and a Registered Scientist with the Science Council (RSci). Shahid is also a member for the British Blood Transfusion Society (BBTS). Shahid has built experience in laboratory and health research practices and his understanding surrounds the biomedical/clinical and social sciences. Shahid has provided multidisciplinary team working perspectives from laboratory to community and wider through over 80 publications. Shahid co-founded the Renal Patient Support Group (RPSG) in 2009 which is an evidence-based support group for patients and carers in chronic kidney disease; the group now has over 7000 members. As a Specialist Scientist, Shahid has been involved in the development of key practices through a number of working groups/panels. He was a member for the NHSBT Paediatric Kidney Advisory Group (PKAG-sub-committee 2009-2011) and the British Association for Paediatric Nephrology (BAPN 2011-2014). Shahid was involved in the development of the BAPN and the Nephrology Networks Guide (2012), and a member of the Kidney Research Education Initiative (KREI) (2010-2013). He has presented work locally, regionally, in various European countries and internationally and is also a regular contributor to The Biomedical Scientist.

Shahid has made encouraging contributions to inform renal and education initiatives/guidelines and is now a member of the UK Renal Registry patient council, a member for the Renal Clinical Trials Network (RCTRN) and the British Islamic Medical Association (BIMA). Shahid completed his IBMS Diploma in Specialist Practice by Thesis titled: Comparing Renal Biomarkers and their Utility to Monitor the Mainstay of Immunosuppression Therapy (2013). Shahid has worked at the Royal United Hospital (RUH) - Bath, NHS Blood and Transplant, Bristol/ Manchester, Microbiology/ Bacteriology with Public Health England (PHE) - South West Laboratory, Department of Haematology and Transfusion, The Royal Devon and Exeter (RD&E) NHS Foundation Trust and The Department of Haematology and Transfusion, Weston Area Healthcare NHS Trust.

Shahid highlights renal health of all patients needs to be considered and healthcare professionals should also be encouraged to build their practice generally in this regard owing to chronic kidney disease steadily increasing in the general population. Shahid has recently submitted his IBMS Fellowship thesis titled: Leadership and Management - The Need to Consider Renal Health in Transfusion Care and Research to Inform Best Practice (2016) and this work will form his prospective Chartered Scientist (CSI) candidacy under the science council.
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Mal Chestney

Up until 4 years ago Mal ran his own business and led a healthy and active life. Then, out of the blue, Mal was diagnosed with renal failure (stage 5) and was placed on dialysis, transplantation not being an option for him to consider. Since being diagnosed and unable to gain fruitful work, he felt that voluntary work was something to look into. Mal’s renal consultant suggested joining the committee of the local kidney patient advisory (KPA) group, which he did a year ago as the HDU patient rep. Since then Mal has been involved in, and taken responsibility for, quite a number of activities on behalf of the KPA, which have been fulfilling in many ways and for which he is grateful. Now Mal is looking forward to a similar role with the UK Renal Registry patient council, which to date has provided him with anticipation for the future.

Michael Abbott

Michael, known to us all as Bud, is Treasurer of the National Kidney Federation and Chairman of Gloucestershire Kidney Patients’ Association. He is on the board of the Transforming Participation in chronic kidney disease programme, the Measurement Workstream and the Communications Sub Group.

Michael served in the RAF for almost 30 years and then joined the Gloucestershire Constabulary managing the force radio workshops for a further 22 years. His passion is fair access to treatment for patients throughout the UK – as well as sport which includes rugby and sailing.

Despite Bud’s commitment to kidney charities he tells us the things he likes to do in his spare time are fine dining and sailing. If he could take anyone to dinner it would be Winston Churchill because he would like to hear more of his wicked sense of humour.

Peter Naish

Peter worked in housing associations for many years and chaired the National Federation of Housing Associations for three years, negotiating with government over funding. He moved to medical research (mental health) and then to set up a charity to receive 39 residential care homes from a local authority.

He ran the Equal Opportunities Commission for three years and then, seeking a change, an animal shelter. Other work included being a Special Trustee of Great Ormond Street, member of the Government’s Social Security Advisory Committee, chair of local family centres, home start etc.

At 56 Peter and his wife were on the point of adoption when what was thought to be flu turned out to be AKI and life changed. Peter went onto CAPD and had a transplant seven years ago.
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Peter lives with his wife and bearded collie just outside the Peak District. His main interests are music and philosophy/theology.

Claire Corps

Claire is a Doctor of Research Scientist working in the NHS. Claire's education includes her PhD in Energy Kinetics in Preserved Livers which she studied for in Leeds and an MSc in Immunology and Immunogenetics at the University of Manchester, preceded by her BSc (Hons) in Microbiology in Leeds.

Claire’s interest and knowledge in the programme is driven by her unique perspective on kidney disease, having had renal failure since childhood and following haemodialysis has been the recipient of both kidney and liver transplants. She is an active Committee Member of West Riding Kidney Patients Association and the Transforming Participation in chronic kidney disease programme.

Amateur dramatics are also on Claire’s lists of interests as well as the British Transplant Games and the Transplant Choir. While she describes her guilty pleasures as enjoying listening to Wham! and Abba, she’s also a member of MENSA – so probably best not to question her further about this!

Hakeem Adedoja

Having graduated with a degree in Accountancy in Nigeria in 1999 and in 2007 during his Master’s degree in the UK Hakeem was diagnosed with kidney disease and in 2011 went on dialysis; he was fortunate to receive a transplant in 2016. Hakeem received excellent treatment from the NHS and joining the UK Renal Registry patient council was his way of giving back to the community. Hakeem also runs a charity called the Hadiza foundation, which provides Education and Information about kidney disease, its causes, prevention and management within people of African and Caribbean origin in the UK.

Outside renal, Hakeem’s interests include playing basketball and military history.

Jonathan Bowman

Jonathan received a kidney transplant from his mum at the age of 15 back in August 2001. Jonathan is a fully qualified accountant and has made the most of his transplant by travelling round Australia.
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Guy Richards

Guy Richards is a patient at the Royal Devon Exeter Hospital Exeter and a trustee on their local kidney patient association. Guy is also a Director on the executive of the National Kidney Federation and a Director of Exeter Homes trust. Guy has been a kidney patient for 38 years and has received two transplants, with the first transplant lasting three years and the second transplant lasting nineteen years. Guy has now served on the UK Renal Registry patient council for two years.

Ewen MacLean

Ewen is a 63 year old grandfather of four, who has been a renal patient since 1987 and has tried and tested every modality of renal replacement therapy that exists to date. Transplanted in June 2016, Ewen works as an Advocacy Officer for Kidney Care UK covering Scotland.

Currently, Ewen serves on many renal groups with the hope to improve the lives of chronic kidney disease sufferers everywhere.

Keith Bucknall

Keith Bucknall was diagnosed with nephritis over 20 years ago. His kidney function finally reached the point where dialysis was needed on 27 December 2016. Spending three sessions a week tethered to a machine, being involved in the UK Renal Registry patient council helps pass time and gives him a purpose to support others by sharing his experience. He achieved an MSc in Social Research and hopes this will add value to his attendance at the meetings.

Keith cared for his mum who lived with dementia and belongs to a Service User and Carer group at a University supporting Social Work students. He continues to research dementia and its impact on the person and their families including the additional challenges if kidney failure is also present.

Get involved

We are always enthusiastic to hear from patients. Are you interested in finding out more about the UK Renal Registry, what the Patient Council does and how to get involved?

For further information regarding membership of this study group please email Jennifer.Barwell@renalregistry.nhs.uk

Members will meet quarterly, physically or virtually with ad hoc tasks and groups between meetings to enable work to be completed. Expenses will be covered by the UK Renal Registry.