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On Monday 16th April 2018, a Renal Workshop was held at Belfast City Hospital. The workshop was aimed at bringing together those with who are affected by, or have experience of end-stage kidney disease. It was held to help staff developing projects and research related to kidney disease to understand the context for future work, gather views of participants and receive support from those who understand the renal condition best. The event was organised by Dr Helen Noble, Dr Peter O'Halloran and Professor Joanne Reid from the School of Nursing and Midwifery at Queen's University Belfast (QUB) and Professor Peter Maxwell, from the School of Medicine, Dentistry and Biomedical Sciences. They were ably supported by Ciara Murphy from the Education Support Office at QUB.

The title of the event was: *Supportive Care For and With Kidney Patients, Families, and Healthcare Professionals*. We were joined by 60 healthcare staff, patients and carers including Professor Donal O'Donoghue, President of the UK Renal Association and Trustee of Kidney Care UK, and former MLA Joanne Dobson who had recently donated her kidney to her son Mark. In addition a number of prominent specialists from across the world were invited to share their knowledge and expertise. Following opening addresses from Professor Donna Fitzsimons, Head of School of Nursing and Midwifery, QUB, and Professor Peter Maxwell, consultant nephrologist, Belfast City Hospital, Professor Sara Davison, an expert international kidney doctor who travelled from the University of Alberta, gave the opening lecture. This addressed the role patients and carers play in helping develop services that are patient centred and meet their needs. She was followed by Policy Director and patient, Fiona Loud from Kidney care UK, who shared examples of patients and carers joining educational and research studies and helping to shape the development of best patient-centred renal practice.

In the afternoon we broke into 3 groups to discuss i) Decision making, ii) Advance care planning and iii) Cachexia (loss of weight, fatigue and weakness). In the decision making group, Professor Paul Roderick, consultant public health academic at the University of Southampton, spoke about the changing profile of patients being accepted onto kidney programmes including older patients who have to make difficult decision between dialysis and conservative management. William Johnston, a patient and Advocacy Officer for Northern Ireland, at Kidney Care UK, gave a moving

account of his life with kidney disease and included examples of treatment decisions he has made during his journey.

The advance care planning group heard from Dr Peter O'Halloran about the experiences of patients and their relatives who have been making Advance Care Plans in the renal units in the Belfast and Northern Trusts. Shashi Patel, a patient representative with Kidney Care UK described the challenges she has faced through many years of dialysis and the difficult decisions she has to make in relation to her health. Finally Professor Sara Davison discussed the research about what is important for patients and their relatives when it comes to advance care planning.

In the cachexia group an overview was given of the renal cachexia work to date and the acceptability and practicalities of potential interventions for the management of cachexia were discussed. Additionally the potential impact that cachexia could have not only on patients but also on carers, and the need for research to explore this in full was discussed with patients, carers and healthcare staff.

The event has been very well evaluated and together we have prioritized areas of renal healthcare on which to focus our work. The Northern Ireland Kidney Patient Association was well represented and a stand with information set up in the foyer. We would like to thank the Northern Ireland Kidney Research Fund for their valuable financial contribution which helped to fund this event. We were able to offer a very nice lunch and refreshments throughout the day and much chat occurred over break times. We hope to repeat the event in 2019.



From left: Joanne Dobson, Professor Peter Maxwell, Mark Dobson, Professor Donal O' Donoghue, Fiona Loud.



Members of the Northern Ireland Kidney Patient Association



Priorities for kidney patients in Canada presented by Professor Sara Davison



Professor Peter Maxwell giving an overview of the day chaired by Dr Helen Noble