

# Report from the Dialysis—getting the right balance conference

In this short conference report, the authors outline an exploration among stakeholders of the possible over- and underprovision of dialysis in the NHS. The British Renal Society was one of the collaborating organisations involved in this event.

■ dialysis ■ overtreatment ■ comprehensive conservative care ■ undertreatment

On 27 November 2019, 58 diverse stakeholders met in Bristol, UK, for a 1-day conference, ‘Dialysis – getting the right balance’. The organisers, Barny Hole, Lucy Selman and Anna Winterbottom, share an interest in understanding and improving the experiences of people who are deciding which treatment to have for advanced kidney disease (Hole, 2017; Winterbottom et al, 2018; Selman, 2019). The conference was designed to identify the organisational changes, research and resources needed to address possible over- and underprovision of dialysis in the NHS.

## What is already known?

Dialysis became available in the 1950s. Initially used in reversible kidney failure, it has been progressively provided to those not expected to recover kidney function (Cameron, 2002). Underprovision and rationing remained widespread for many years with most comorbid and older people

with end-stage kidney disease (ESKD) dying without dialysis. Following prioritisation of renal services during the late 20th century, dialysis provision was expanded (Department of Health and Social Care, 2004). Since the 1980s there has been a persistent and sizeable rise in the number of older and comorbid people commencing treatment (Hole et al, 2018).

While the abolition of unmet need is to be celebrated, concerns have arisen that some individuals may now be at risk of overtreatment (Grady, 2010; Moynahin, 2013; Born and Levinson, 2019). Dialysis carries considerable burdens in terms of time commitment, travel and disruption to everyday activities (Verberne et al, 2018). The survival benefit associated with dialysis depreciates with age and comorbidity (Hussain et al, 2013). The oldest and most unwell may not live longer on dialysis compared to those who choose to manage their symptoms with ‘comprehensive conservative care’ (CCC), which comprises all aspects of kidney management without dialysis (Murtagh et al, 2016). There is evidence that individuals accept shorter lives to avoid the burdens of dialysis, and that this underlies decisions to opt for CCC (Morton et al, 2010; Hole et al, 2016). Meanwhile, people approaching kidney failure report their preferences being overridden by family and clinicians and dialysis being prioritised over other options (Tonkin-Crine et al, 2015; Ladin et al, 2016; Selman et al, 2019). Wide variation in the kidney services available to this patient group reflect a lack of consensus and evidence regarding ‘best practice’ (Roderick et al, 2015).

It was from these parallel concerns relating to over- and undertreatment that the conference ‘Dialysis—getting the right balance’ was born. The aim was to foster a collaborative network to engage in controversial discussion and begin to redress potential imbalances in NHS kidney care. The objectives were to:

- Ascertain potential drivers of under- and overtreatment with dialysis
- Consider approaches to mitigate against these drivers
- Identify the resources and evidence needed to inform improvement.

## Pre-conference consultation

Prior to the conference, and to inform its content, the organisers consulted with members of the public, clinicians and other stakeholders. First, two patient and public involvement (PPI) events were run to develop conference content. Participants came from a wide range of backgrounds and ages, and included people with kidney disease, and those close to them. Areas of discussion included palliative and life-prolonging treatments and individuals’ preferences for each, and the idea of over- and undertreatment. Participants were disinclined to perceive ‘life-saving’ treatments as potentially overprovided. Nevertheless, they discussed their own preferences for rehabilitative and palliative care, and recounted stories of what, in retrospect, they saw as futile and burdensome treatment of their deceased loved ones.

This pre-conference work highlighted that, although overtreatment is a vogue topic in the academic medical literature, undertreatment was a greater concern

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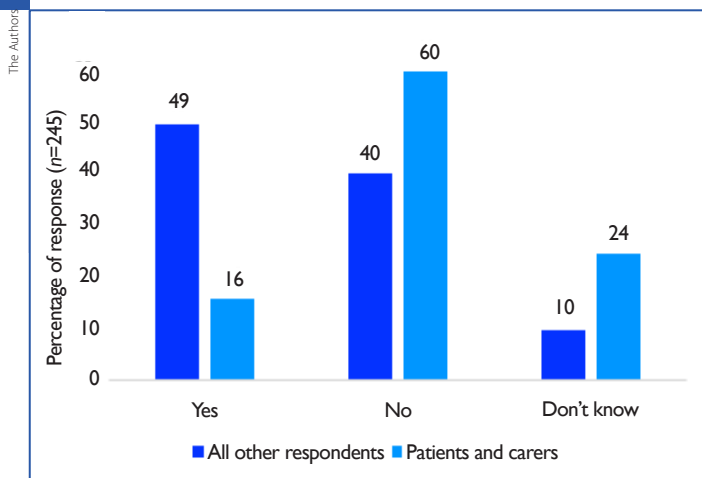
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**Figure 1.** Do you believe that dialysis is overprovided to any individual or group in the NHS? Bar chart showing 245 responses by respondent group: patients and carers

among a non-professional audience. To further explore these opinions and identify topics for debate during the conference, a survey was distributed via the collaborating organisations (see Acknowledgements) using social media and email. Participants were asked to consider whether dialysis is over- and underprovided and, if so, to identify what could be done to mitigate against this.

The 251 respondents included 87 people living with kidney disease and seven carers, 133 health professionals (comprising 102 kidney and 16 non-kidney clinicians, and 15 others involved in healthcare delivery and research), and 24 'other' interested parties. Overall, 34% felt dialysis was underprovided, 41% did not and 24% were unsure. For overprovision, these were, respectively, 36%, 48% and 16%. Responses from people living with kidney disease (patients and carers) and the other groups were largely similar with respect to underprovision. However, there was a marked disparity with respect to overprovision, with just 16% of patients and carers answering that dialysis is overprovided, compared with 49% of the remaining respondents (Figure 1).

Survey respondents were also asked the free-text question 'What do you consider to be the greatest threats to balanced dialysis provision?' The qualitative responses were coded thematically to create an analytical framework of themes and subthemes (Figure 2).

## The conference

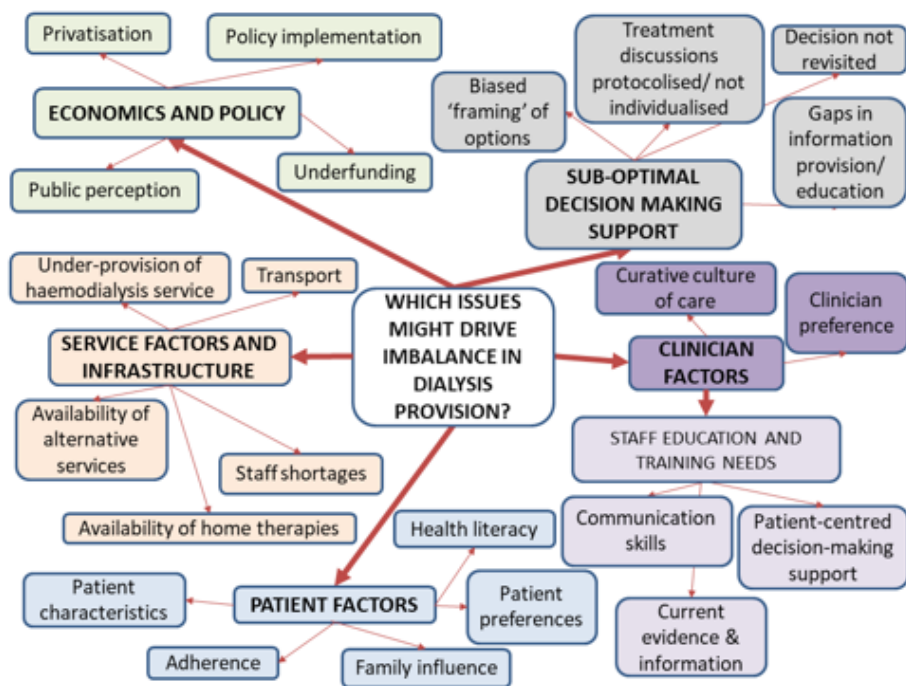
The day opened with introductions and a summary of the survey findings. Subsequent conference activities were guided by the qualitative survey data. Delegates were given copies of a sample of the free-text responses and worked alone, then collaboratively, to classify these within the framework provided (Figure 2) and consider whether the

response related to a driver of under- or overtreatment, or both. By the end of the exercise, delegates had coded and interpreted all 251 survey responses.

The morning session also included a presentation from a PPI member on the pre-conference meetings, and a 10-minute

play developed from interview transcripts with older people facing the possibility of kidney failure. This piece was designed to highlight the complexities of over- and undertreatment with 'life-saving' treatment from the patient perspective.

Following the morning's activities, delegates were allocated to five tables of mixed expertise. Each table was allocated one of the main themes from the coding of the survey responses (Figure 2) along with the response cards categorised under that theme. Each theme was discussed in detail, to identify drivers of over- and undertreatment and consider the approaches needed to mitigate against them. The whole group then developed recommendations in a facilitated discussion. The process and results will be published separately; however, preliminary recommendations included alignment of funding approaches for dialysis and CCC treatment, a need to recognise practice biases and reframe clinical decision-making around what is important to patients, and a requirement for higher-quality evidence to inform clinical practice.



**Figure 2.** Coding framework developed from free-text responses to the pre-conference survey question: 'What do you consider to be the greatest threats to balanced dialysis provision?' Main themes: economics and policy; suboptimal decision-making support; clinician factors; patient factors; service factors and infrastructure

The conference closed with evening lectures. The organisers co-presented findings from qualitative studies of ESKD decision-making from patient and health professional perspectives. Hilary Bekker, Professor of Medical Decision Making at the University of Leeds, concluded with a keynote lecture entitled 'Helping people make balanced dialysis decisions'. Professor Bekker's talk included examples of how information can be presented in ways known to boost people's ability to make informed, shared decisions about their kidney treatment.

## Conclusion and next steps

The conference and associated activities were successful in their aims. A collaborative, multidisciplinary stakeholder group was formed, and novel ideas relating to improving NHS kidney care were developed. Nevertheless, the challenges that lie ahead are substantial, and the conference raised more questions than answers. How can we judge whether the right amount of dialysis is available to those who want and need it? Why do so many clinicians have concerns that we overprovide dialysis? Do the concerns from the patient and professional groups reflect important undertreatment?

A full report detailing the pre-conference questionnaire findings and recommendations will be published in due course.

## Acknowledgements

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We express our gratitude to all those who completed the pre-conference survey and/or attended the conference. We also wish to acknowledge the work undertaken by Elspeth Penny from 2BU-Productions who developed the short play 'Out like Fudge' that featured at the patient and public event and the conference itself. If you would like more information about the event or the upcoming report, please contact: barnaby.hole@bristol.ac.uk or anna@winterbottom.co.uk. Twitter: @BarnyHole, @Lucy\_Selman, @OSCAR\_study, @DrAWinterbottom. **JKC**

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