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Making research outputs accessible to people with kidney disease: Implementing the Dialysis Decision Aid Booklet

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Background

Clinical guidance requires patients to be supported in making decisions between dialysis options.ⁱ

Delivery of pre-dialysis education and quality of patient information varies across services.ⁱⁱ

Patients are satisfied with their care, but want more support in making dialysis decisions.ⁱⁱⁱ

Our research group developed the Yorkshire Dialysis Decision Aid (YoDDA) booklet.

We assessed YoDDA's acceptability with patients making dialysis decisions across six UK centres: usual care, n=105; usual care +YoDDA, n=84.^{iv}

- Patients valued receiving YoDDA: it complemented their pre-dialysis care, helped them think about dialysis in the context of their lifestyle, and share decision making with their family
- Staff disseminated YoDDA in different ways to suit their pre-dialysis programmes

Aim of Poster

To describe the activities undertaken to get the research outputs from YoDDA into pre-dialysis practice.

Methods

The following quality assurance, knowledge transfer, professional training, resource adaptation, stakeholder collaboration and media activities have been undertaken:

- Disseminate YoDDA research via scientific publications and presentations.
- Raise awareness of YoDDA's utility to meet clinical guidelines to support patients' dialysis decision making via kidney professional career development workshops.
- Continue partnership with Kidney Research UK to:
 - Turn a research output (YoDDA) into an open-access patient resource (*Dialysis: Making the right choices for you: The Dialysis Decision Aid Booklet (2015)*^v www.kidneyresearchuk.org/DialysisDecisionAid).
 - Disseminate and monitor use of *The Dialysis Decision Aid* booklet by patients, carers, professionals, and others.
 - Profile the booklet appropriately through 'trade' publications, collaborative media releases and stakeholder membership channels.
 - Assimilate feedback and update in accordance with clinical guidance.
- Seek endorsement of *The Dialysis Decision Aid* booklet by quality assurance organisations.



Dr. Hilary Bekker and Dr. Andrew Mooney

"The Dialysis Decision Aid booklet is a great example of a robust, valuable resource which has been researched, developed and thoroughly evaluated to provide very real and immediate patient benefit. We very much hope it becomes a well-used tool for renal professionals and patients."

Elaine Davies, Director of Research Operations at Kidney Research UK

Findings – September 2014 to May 2016

- 90 booklets sent to all renal unit Clinical Directors (UK); 500 disseminated at conferences
- 400 booklets sent on request to patients, carers and staff
- 17 UK renal units ordered bulk copies (total 1300) for use in their pre-dialysis programmes
- 374 copies downloaded by patients, carers and staff; 600 page views via patient.co.uk
- 2 international organisations (Italy and Spain) have translated it for use in their countries
- The ACE Peer Educator pilot project in Birmingham (Kidney Research UK) uses the Dialysis Decision Aid booklet to engage patients, particularly from Black, Asian and Minority Ethnic (BAME) communities, in their treatment decisions and care.

The Dialysis Decision Aid booklet was developed through a Kidney Research UK-supported study, run in collaboration with Baxter Healthcare Ltd, the British Renal Society and Renal Association.

Baxter



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www.kidneyresearchuk.org

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Patient comments

"A wonderful booklet that details the options available. I have seen nothing else like it available and I am pleased to see something written so well and accurately that is particularly patient friendly."

(Carer)

"I wish I could have had access to the sort of information that this booklet offers in terms of making all the choices available for people to read. I believe it will help a lot of new patients and their families make informed choices on the treatment right for them."

(Patient on home haemodialysis for 21 years)

"This booklet gives so many answers about dialysis which I didn't have when I was first on it. It talks you through all the different options in clear language and, while it can't give you everything, it gives you a really good basic understanding of how dialysis works."

(Patient with kidney disease)

Endorsements

- **For use in pre-dialysis programmes:**
The European Renal Best Practice committee; The International Society of Peritoneal Dialysis
- **Meeting patient decision aid quality criteria:**
The International Patient Decision Aid Standards
- **Highly commended patient resource:**
The British Medical Association Patient Information Awards
- Supports the recommendations on information and education in the NICE guidelines on chronic kidney disease, acute kidney injury and peritoneal dialysis.



"This is a great resource and meets the needs of the audience for the purpose very well. It's a great decision aid as it covers the choices very comprehensively and helps the reader make judgements based on their lifestyle and needs... it's excellent and has clearly been thoughtfully and robustly developed."

BMA PIA 2014

Summary

Implementing research within practice is an active, dynamic and collaborative process. We found *The Dialysis Decision Aid* booklet is accessed independently by patients and/or via renal professionals using Kidney Research UK's website. Feedback indicates it is a valued resource, and enables patients to think differently about dialysis treatment decisions in the context of their life and illness management.

It meets clinical guidelines enabling staff to support patients making informed decisions between dialysis options. However, there is practice variation in its adoption across services in the UK. Longer-term follow-up will help identify how to support services' integration of this evidence-based resource into practice and its impact on care.

References

- i. National Clinical Guideline Centre – CG182. Chronic kidney disease: early identification and management for adults in primary and secondary care (2014) National Institute for Health and Clinical Excellence, UK.
- ii. Prieto-Velasco M, Bagnis CI, Dean J, Goovaerts A, Melander S, Mooney A et al. Pre-dialysis education in practice: a questionnaire survey of centres with established programmes. *BMC Research Notes* 2014, 7:730
- iii. Van Biesen W, van der Veer SN, Murphy M, Loblova O, Davies S. Patients' perceptions of information and education for renal replacement therapy: an independent survey by the European Kidney Patients' Federation on information and support on renal replacement therapy. *PLOS ONE* 2014; 9: e103914.
- iv. Winterbottom AE, Gavaruzzi T, Mooney A, Wilkie M, Davies SJ, Crane D... Bekker HL. Patient acceptability of the Yorkshire Dialysis Decision Aid (YoDDA) Booklet: a non-randomised comparison study (Peritoneal Dialysis International. 2015)
- v. Bekker HL, Winterbottom A, Gavaruzzi T, Mooney A, Wilkie M, Davies S, et al of the Yorkshire Dialysis Decision Aid (YoDDA) Research Projects. *Dialysis: making the right choices for you. The Dialysis Decision Aid Booklet*. Kidney Research UK: Peterborough, UK (2014) <https://www.kidneyresearchuk.org/DialysisDecisionAid>

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