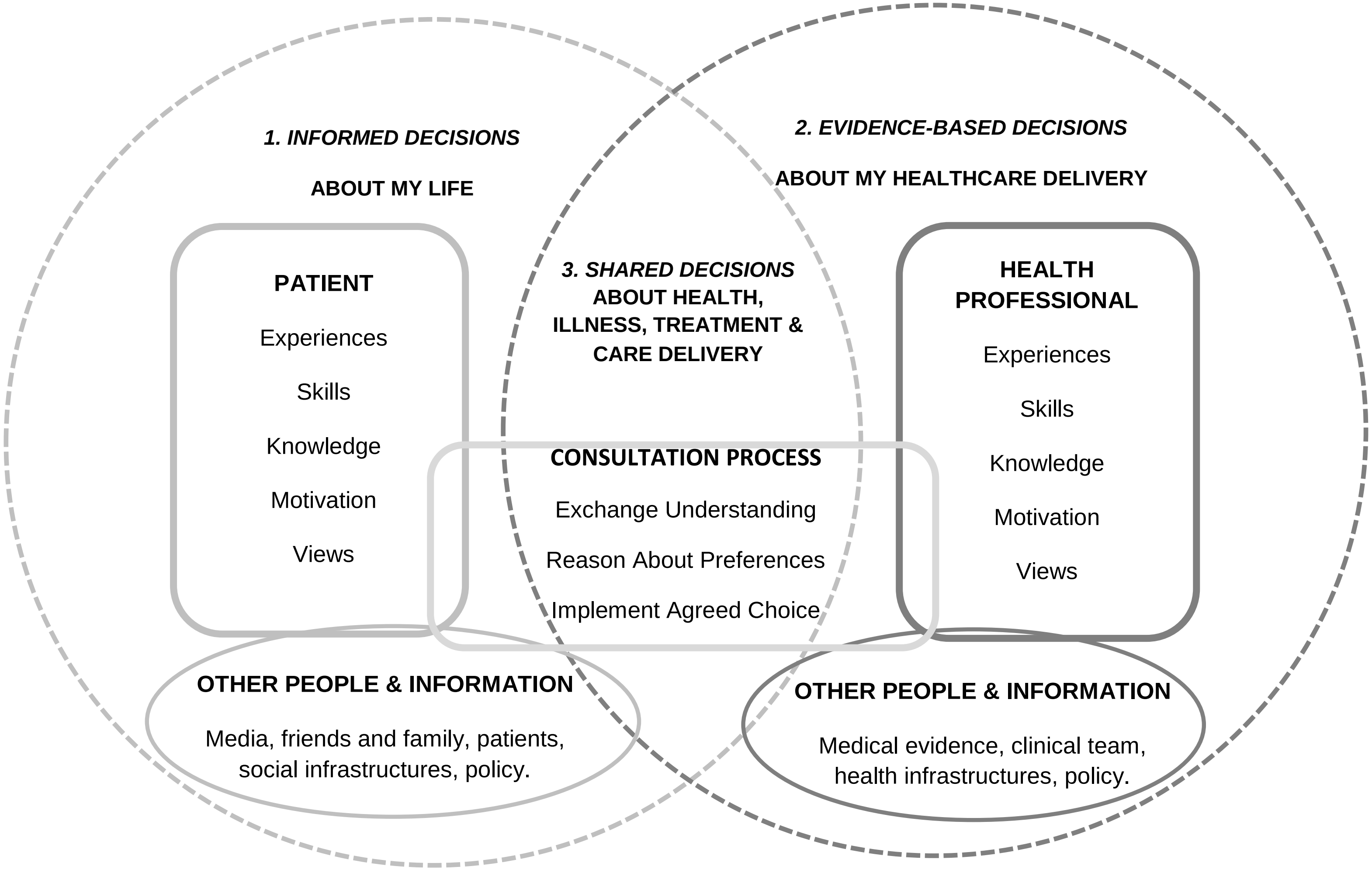
SUPPLEMENTARY MATERIALS.

Figure S1: Function decision aid for patient (1), professional (2) and patient-professional (3) to think differently about healthcare.

The YoDDA Booklet is a patient decision aid (1) to help people make informed dialysis decisions between options, in collaboration with staff delivering predialysis care and family members (earlier version of diagram appears in Breckenridge K, Bekker HL, van der Veer SN, Gibbons E, , Abbott D, … Caskey FJ. NDT Perspectives - How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. Nephrol Dial Transplant. 2015. doi: 10.1093/ndt/gfv209).



Box S2: Website information reviewed and experts reviewing YoDDA during its development (2010-2014).

Renal Website Information – national and international

American Association of Kidney Patients www.aakp.org
Baxter Renal Information Site www.renalinfo.com
British Kidney Patients association www.britishkidney-pa.co.uk
Edinburgh Renal Unit www.edren.org
European Renal Best Practice Advisory Group http://www.european-renal-best-practice.org/
Kidney Dialysis Information Centre www.kidneydialysis.org.uk
Kidney Foundation Canada www.kidney.ca/
Kidney Health Australia www.kidney.org.au/
Kidney Patient Guide www.kidneypatientguide.org.uk
Kidney Research UK www.kidneyresearchuk.org
Kidney School (US) www.kidneyschool.org/
Kidney Wise **(US)** www.kidneywise.org
National Kidney and Urologic Diseases Information Clearing House (US) http://kidney.niddk.nih.gov/kudiseases/pubs/kidneyfailure/index.htm
National Kidney Disease Education Program (US) http://nkdep.nih.gov/
National Kidney Foundation (US) www.kidney.org *and* UK National Kidney Federation www.kidney.org.uk
NHS **Choices -** Chronic Kidney Disease www.nhs.uk/conditions/Kidney-disease-chronic/
NHS **Choices -** Dialysis www.nhs.uk/conditions/dialysis/
NHS Chronic Kidney Disease www.nhs.uk/conditions/Kidney-disease-chronic/
NHS Dialysis www.nhs.uk/conditions/dialysis/
NHS Kidney Care www.kidneycare.nhs.uk (archived since 2014)
NIDDK (NIH, US) American Kidney http://kidney.niddk.nih.gov/kudiseases/pubs/kidneyfailure/index.htm
Renal Patients Association www.patients-association.com
The Renal Association www.renal.org

Expert Feedback for YoDDA by people from national and international organisations

Chair UK Renal Association and NHS Renal Tzar;
National Kidney Federation UK
Kidney Research UK (KRUK) – patient forum
International patient decision aids standards (IPDAS) http://decisionaid.ohri.ca/AZinvent.php
Executive Director. Medical Education Institute, Inc. www.meiresearch.org

Table S3: Steps and stages of YoDDA development and evaluation.

Step	**Actions**	**Framework/ Guidance Used**
1. Steering Group	*Regular feedback on every step of decision aid development, evaluation and implementation; Jan 2010 - Aug 2014*	
Participants	Decision scientists, clinical psychologist, nephrologists, renal nurse, general practitioner, health service researchers, eHealth scientist, health service research officer, national and regional patient reps.	Developing complex interventions, health services research methods, clinical guidelines, patient decision aid standards
2. Scope Problem	*Critical analysis health and decision context; Jun 2010 – Feb 2011*	
Health Context	Change in chronic disease management regimen from Chronic to Established Kidney Disease; shared decision making between patient and kidney health professionals.	Illness Representation Theory; Behaviour change and illness management; professional-patient communication.
Service Pathway	Predialysis programme alongside kidney disease management services offering centre or home, assisted and non-assisted renal replacement and conservative care pathways.	Kidney Service Framework; UK Renal Registry; Shared Decision Making.
Decision Makers	People diagnosed with sustained deterioration of kidney function, and carers; kidney health professionals.	Clinical Guidelines; Theories of effective decision making and communication.
Decision Points	Decision between haemodialysis (HD) and peritoneal dialysis (PD) options, nested under the kidney replacement options (dialysis; transplant) of the decision between conservative care (CC) and kidney replacement therapy (KRT) options.	Prescriptive decision making: making explicit, and representing, all options and their consequences, person's values and risk perceptions, and guidance to support trade-offs and active decision making.
3. Research Activity	*Submission protocols and materials for approval by ethics committee – from Jun 2010 – Jan 2013*	
Phase 1 studies (Alpha test – I)	Experimental studies with UK University staff and students presenting dialysis facts in different ways on people's choice: presentation by treatment modality, and in parallel, more balanced and less prone to bias than place of care and sequential presentation.	Ethics Committee, University of Leeds, UK
Phase 2 studies (Alpha test - II)	Study using qualitative methods with staff, patients and carers making decisions about dialysis and kidney disease management in Leeds and Sheffield, UK. Findings indicate leaflet should be useful to all people regardless of kidney disease and treatment experience.	Ethics committee, National Health Services Research Ethics Standards, UK.

Phase 3 study (Beta test – I)	Before and after intervention study using questionnaire methods with patients making dialysis decisions in Leeds, Sheffield, Bradford, Doncaster, York and Hull, UK. Findings in main text.	Ethics committee, National Health Services Research Ethics Standards, UK.
Phase 4 study (Beta test – II)	Randomised control trial delivered on-line for any patient, carer, health professional, and interested party assessing different versions of YoDDA, with and without patient experience of dialysis videos, across the UK. Findings consistent with phase 3 study findings.	Ethics committee, National Health Services Research Ethics Standards, UK.
Dissemination (2010+)	Presenting findings at kidney health professional, patient and decision science conferences and workshops, and kidney services.	Peer review conference committees.
4. Design	*Evidence Gathering and Synthesis between Sept 2010- Feb 2011*	
Patient need	Published studies of patients' dialysis decision making, health related quality of life, kidney disease management; analysis of leaflets and websites for patients with kidney disease (international).	Writing readable information for patients. Non-directive communication. IPDAS.
Professional need	Published studies of professionals' views towards dialysis modality and delivering predialysis care.	Clinical guidelines; policy, clinical champions in shared and informed decision making.
Service need	Observation and discussion with those using and providing predialysis services and education in the Yorkshire region.	IPDAS. Clinical guidelines.
5. Alpha Test II	*Pilot decision aid in appropriate contexts – Mar 2011- Jun 2011*	
Patient	Semi-structured interviews with 12 patients and 1 carer using internet and booklet version. Booklet version disseminated as part of predialysis education was favoured.	Relevance, accuracy and balance information; face-validity, utility and usability.
Professional	Semi-structured interviews with 8 kidney professionals. Booklet disseminated as part of predialysis education acceptable.	Relevance, accuracy and balance information; face-validity, utility and usability.
Assorted Stakeholder	At a regional meeting for kidney professionals, patients and carers asked to feedback, workshop convened for critical feedback.	Relevance, accuracy and balance information; face-validity, utility and usability.
External Critique	Patient representative UK / Australian kidney charity; Chair British Renal Association; NHS Renal Czar; IPDAS criteria process; Canadian Professor of Renal Nursing.	Relevance, accuracy and balance information; face-validity, utility and usability.
6. Revisions	*Finalising study materials and setting up feasibility study within six renal services in Yorkshire, UK Sep 2011 - Aug 2012.*	
Study Investigators & Steering Group	Revisions decision aid, ethics approval, local hospital research and development approval; meetings between study investigators, research nurses, and predialysis teams to implement study.	

7. Beta Test I	*A non-randomised comparison study within predialysis services; Feb 2012 - Mar 2013.*	
Study Investigators & Steering Group	All patients referred to all predialysis services in Yorkshire, UK invited to take part and questionnaire about experience of decision making; usual care (Feb-Aug); +YoDDA (Sept-Mar). See main text.	Acceptability and utility in supporting decisions about dialysis within the delivery of predialysis education.
8. Beta Test II	*A randomised controlled trial delivered on-line; Mar 2012- Feb 2013*	
	YoDDA research website advertised to all UK renal services, and members of National Kidney Federation. People who logged-on and consented to participate randomised to one of three versions YoDDA for review and to complete questionnaire.	Relevance, accuracy and balance information; face-validity, utility and usability.
9. Implementation	*Turning a decision aid for use in research project to one for public access (Apr 2013 – Feb 2014)*	
Study Investigators & Steering Group	Revisions to text from Beta testing findings, review of clinical evidence base, and explicit guidance on using the patient decision aid as part of a kidney care pathway rather than research project.	
Kidney Research UK	Re-branding and publication, marketing and implementation strategy, visibility and advertising via Charity documentation.	
External Endorsement	British Medical Association - Patient Information Awards (2014); European Renal Best Practice Guidelines and International Peritoneal Dialysis Society for services providing predialysis education (2014); IPDAS criteria (2014).	Patient and Professional kidney disease best practice criteria; International Patient Decision Aid Standards criteria.

Table S4: Function of techniques to support people's informed decision making about dialysis treatments.

Technique	Function on decision making process: de-bias information and/or encourage active thinking
1. *Accurate information about all options and their consequences.*	
Decision Map linking decision points and options with changes in kidney disease.	De-bias – all options represented simultaneously in one image Thinking – causal framework linking decisions, options and worsening health state
Evidence-based facts about chronic and established kidney disease, conservative care, renal replacement therapies from clinical guidelines.	De-bias – treatment options separated from service delivery options and care management pathways Thinking – seek information about treatments and service delivery
Evidence-based facts about professional and patient views and experiences of making decisions, quality of life and experience of illness and treatment, from surveys and patient educational leaflets.	De-bias – identify all consequences of treatment options and separate from management illness, and other people's opinions. Thinking – framework separating treatment decisions from adjustment to illness and longer-term care management.
2. *Structure to support understanding of established kidney disease, treatment decisions and long-term management.*	
Structure disease facts around theoretically informed themes: label and symptoms; cause; consequences; time-line; personal control, coping and/or cure. Structure treatment facts around theoretically informed themes: benefits; side-effects; iatrogenic effects; impact on life.	De-bias – include information relevant to patient making sense of illness and decision, and not service delivery. Thinking – enable causal links between kidneys, illness and treatment options to be made by patient.
Present similarities in preparing for having dialysis, maintaining a treatment regimen, reducing treatment-related side-effects, coping and adjusting to illness, range of health professional support and services, and engaging with care.	De-bias – separate adjusting and coping with a procedure and treatment regimen from making a decision between options. Thinking – preparation for procedures, management treatment options and engagement with kidney services.
Present differences in dialysis types by attributes in a parallel format (haemodialysis/ peritoneal dialysis description, method, regimen, etc)	De-bias –balance information provided about each option (equivalent length, content, etc) Thinking – chunking text and parallel presentation easier to process.
Present risk figures as percentages and frequencies with common denominator. Explanation why evidence for generic risk figures and/or life-expectancy statements is weak in this context.	De-bias – actual figure rather than another's judgment. Thinking – representation of likelihood in decisions.
Remove jargon and acronyms, list unusual terms in a glossary, avoid use of 'describing words' (e.g. adjectives, adverbs), use plain language to explain	De-bias – removes unnecessary information and other people's opinions. Thinking – helps people evaluate facts with their own judgements.

technical terms, and avoid complex or compound sentences.	
Use of third (people) rather than second (you) person, use of people rather than patient, and avoidance of modal verbs (e.g. should, would).	De-bias – all information presented as relevant, avoids other's opinion of an implied 'correct' action. Thinking – explicit evaluation of all information and with own values.
3. *Enable evaluation of facts with decision maker's values.*	
Use of explicit guidance statements on ways of thinking about the options and consequences, their impact on lifestyle and illness, talking with friends and family, and awareness of other's opinions.	De-bias – decision making seen as an activity; influence of other's choices made explicit Thinking – directs attention to consideration of all options, context of lifestyle, and other's opinions in decision making.
Use of self-completion questions about lifestyle, treatment options, treatment-lifestyle fit, and identification of preliminary preference.	De-bias – support evaluation all options rather than attributes. Thinking – helps evaluation of all options in context of lifestyle rather than delivery of healthcare.
An option-by-attribute table summarising options (CHD, HHD, CAPD, APD) and attributes (e.g. location, length and timing sessions). No prior categorisation as an advantage or disadvantage was used. In this context, an attribute of an option (e.g. travel to hospital) may be a pro by one person, and a con by another, i.e. value not evidence-based.	De-bias – attributes presented without another's opinion of whether it is an advantage or disadvantage. Thinking – summary table provides memory prompt to help comparison of chunked information across options for evaluation.
	Function on professional-patient communication in consultation
4. *Supporting shared decision making with predialysis team*	
Blank spaces and guidance to note reasoning and questions for discussion with health professionals.	Exchange reasoning about options. Clarify understanding and decision-specific information.
Guidance to ask for person-specific details related to their lifestyle, values and/or medical history that may impact on choice of treatment.	Provide values, illness experience, and lifestyle information. Ask for person-specific information relevant to decision.
Information on service providers' role in supporting self-managed and/or assisted care.	Discuss implementation of options.
Blank spaces for kidney service to add contact details and person-specific details of relevance to the decision.	Tailoring of information by service provider for inclusion in decision making and implementation choice.
List of other patient information and organisations to help manage, cope and adjust to kidney disease.	Peer support and disease management information.

Figure S5: Study Flow Diagram (2012-2013)