Shared Decision Making workshop

Dr Anna Winterbottom

Senior Health Services Researcher – Leeds Teaching Hospitals Trust

Visiting Associate Professor - University of Leeds

Dr Jyoti Baharani

Consultant renal physician – Heartlands Hospital, Birmingham

What is shared decision making?

“**Shared decision making (SDM) is an interactive process** in which patients and professionals collaborate to choose healthcare.”[4]

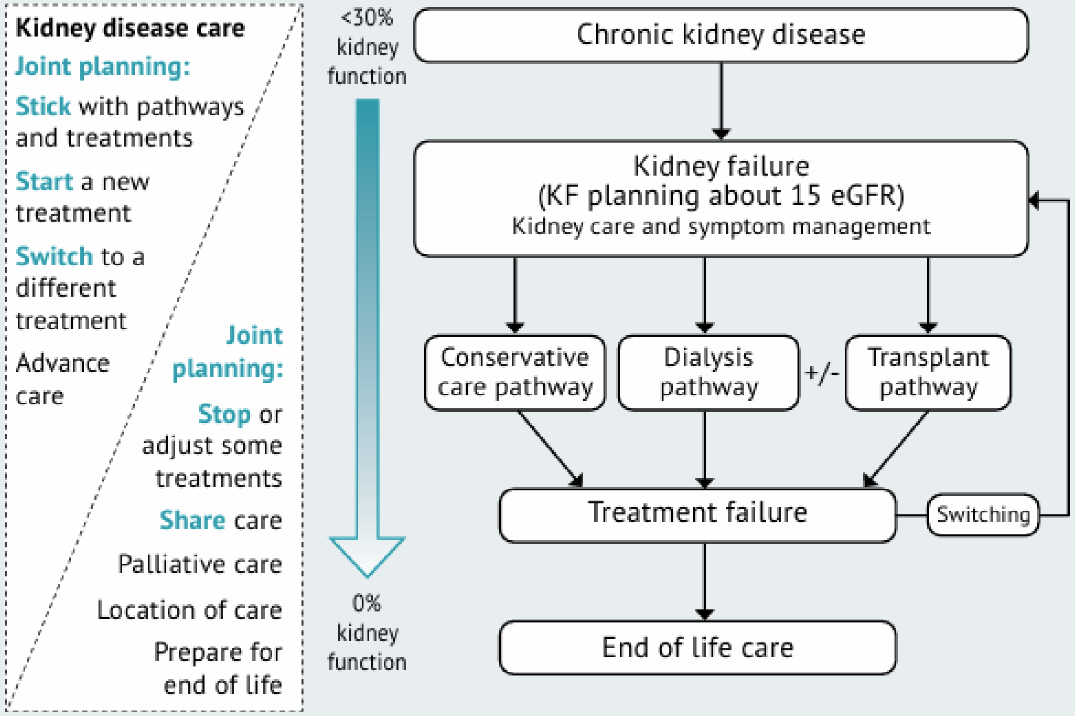
Both patient and professional[5]

- *Exchange Information* and knowledge about treatments
- *Express preference* and values about treatments
- Explicit reasoning about treatment choices
- Agree, and implement choice

4Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). Social Science Medicine, 44, 681-692.

5Légaré F, Ratté S, Stacey D, Kryworuchko J, Gravel K, Graham ID, Turcotte S. Interventions for improving the adoption of shared decision making by healthcare professionals. Cochrane Database Syst Rev. 2010 May 12;(5):CD006732.

Decisions, options, care pathways in kidney disease management



Kidney disease care

Joint planning:

Stick with pathways and treatments

Start a new treatment

Switch to a different treatment

Advance care

Joint planning:

Stop or adjust some treatments

Share care

Palliative care

Location of care

Prepare for end of life

<30% kidney function

0% kidney function

Chronic kidney disease

Kidney failure
(KF planning about 15 eGFR)
Kidney care and symptom management

Conservative care pathway

Dialysis pathway

+/-

Transplant pathway

Treatment failure

Switching

End of life care

Stick with the same treatment, i.e., maintain current regime, monitor disease progression and symptom management.

Start a new treatment – this may involve discussions around adding a new treatment, e.g., dialysis or medication.

Switch to a different treatment – this may involve discussions around changing dialysis modality or changing medication.

Stop some treatments and adjust – e.g., change dialysis and medication targets and sessions, stop some non-essential medications, relax dietary restrictions, or withdraw from dialysis.

Share care – accessing palliative, GP, and/or community-based care alongside current kidney care management.

People with kidney failure experience treatment decision making as problematic

- Report having no choice and that the options are ‘dialysis or death’[4-6]
- Place importance on maintaining quality of life/‘trade off’ longevity for time spent out of hospital[7]
- Report receiving no information/no other options other than the one they chose [8]
- Some regret starting dialysis; mis-match between expectations and reality[9]
- Feel that decisions are not shared with them[10]

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[4] Hole B, Rooshenas L, Morton R, Caskey F, Scanlon M, Coast J, Selman L. ‘It’s basically ‘have that or die’’: a qualitative study of older patients’ choices between dialysis and conservative kidney management. BMJ Open. 2025;15(3):e095185.

[5] Karlin J, Chesla CA, Grubbs V. Dialysis or Death: A Qualitative Study of Older Patients' and Their Families' Understanding of Kidney Failure Treatment Options in a US Public Hospital Setting. Kidney Med. 2019;1(3):124-30.

[6] Winterbottom A, Bekker HL, Conner M, Mooney A. Choosing dialysis modality: decision making in a chronic illness context. Health Expect. 2014;17(5):710-23.

[7] Morton RL, Snelling P, Webster AC, Rose J, Masterson R, Johnson DW, Howard K. Factors influencing patient choice of dialysis versus conservative care to treat end-stage kidney disease. CMAJ. 2012 Mar 20;184(5):E277-83.

[8] Van Biesen W, van der Veer SN, Murphey 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 Jul 31;9(7):e103914.

[9] Stringer S, Baharani J. Why did I start dialysis? A qualitative study on views and expectations from an elderly cohort of patients with end-stage renal failure starting haemodialysis in the United Kingdom. Int Urol Nephrol. 2012;44(1):295-300

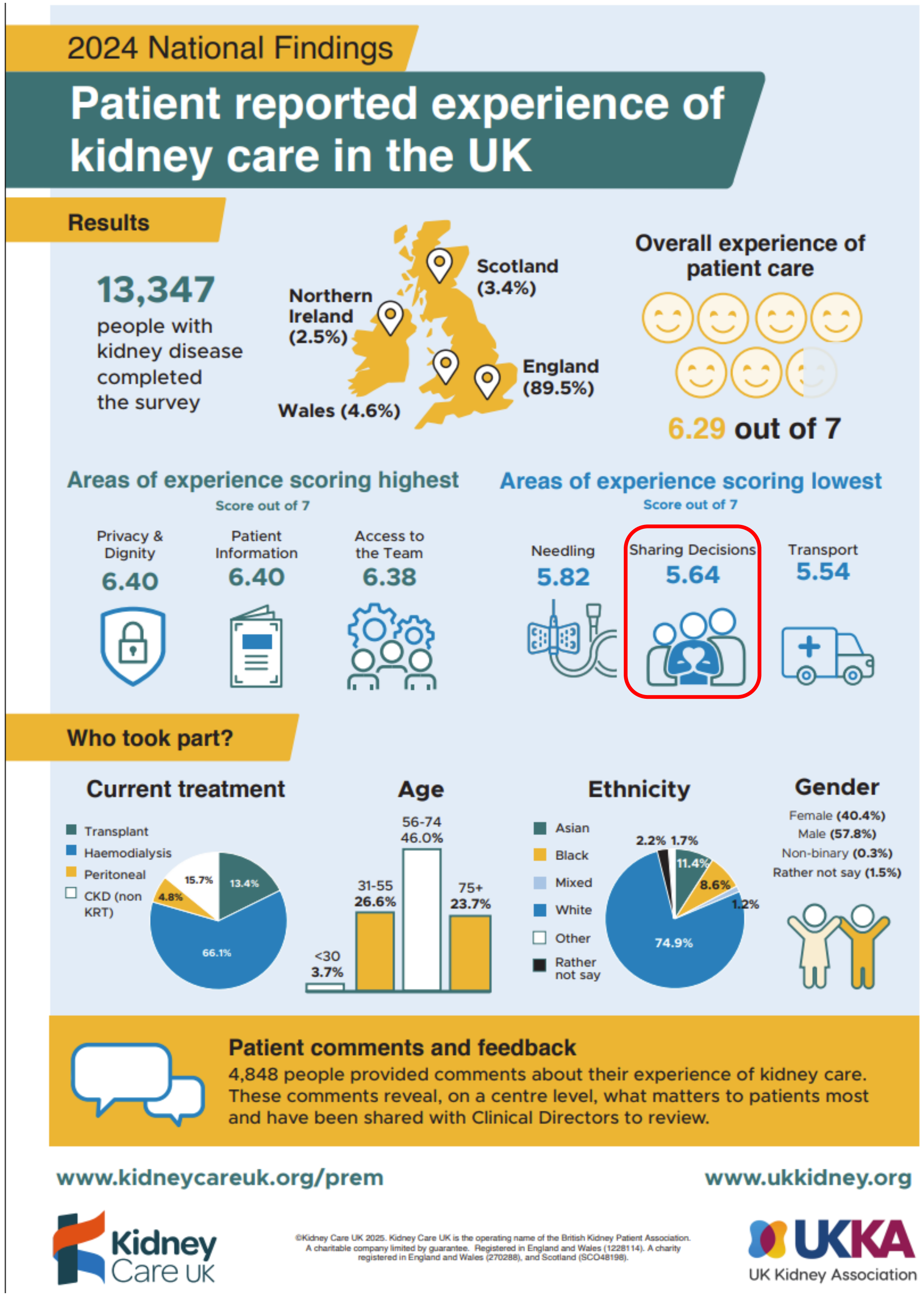
[10] Kidney Patient Reported Experience Measure, UK Kidney Association, 2025

So why is there a mis-match between policy and experience?

PATIENT-CENTRED CARE*	SHARED DECISION MAKING
Establish a rapport	Introduce roles
Agenda setting	Introduce choice in a balanced way
Gather information - questioning style (open/leading/closed)	Increase health literacy
Reflection	Talking about advantages and disadvantages
Active listening – responding to cues	Make explicit clinical reasoning
Silence	Support deliberation
Empathy	Elicit values and preferences
Provide information	Evaluate and agree upon decision(s)
Summarise	Use decision support resources
Teach back	
Implement decision	

*Inspired by Pawlikowska, T et al. Consultation models. In: Charlton R (ed.) Learning to consult. Oxford: Radcliffe Publishing Ltd., 2007, pp. 178215.

How do people with kidney failure experience SDM?



2024 National Findings

Patient reported experience of kidney care in the UK

Results

13,347
people with kidney disease completed the survey

Scotland (3.4%)
Northern Ireland (2.5%)
England (89.5%)
Wales (4.6%)

Overall experience of patient care

6.29 out of 7

Areas of experience scoring highest

Score out of 7

Privacy & Dignity	Patient Information	Access to the Team
6.40	6.40	6.38

Areas of experience scoring lowest

Score out of 7

Needling	Sharing Decisions	Transport
5.82	5.64	5.54

Who took part?

Current treatment

- Transplant 13.4%
- Haemodialysis 66.1%
- Peritoneal 4.8%
- CKD (non KRT) 15.7%

Age

- <30 3.7%
- 31-55 26.6%
- 56-74 46.0%
- 75+ 23.7%

Ethnicity

- Asian 11.4%
- Black 8.6%
- Mixed 1.2%
- White 74.9%
- Other 1.7%
- Rather not say 2.2%

Gender

Female **(40.4%)**
Male **(57.8%)**
Non-binary **(0.3%)**
Rather not say **(1.5%)**

Patient comments and feedback

4,848 people provided comments about their experience of kidney care. These comments reveal, on a centre level, what matters to patients most and have been shared with Clinical Directors to review.

www.kidneycareuk.org/prem

www.ukkidney.org

Kidney Care UK

UKKA
UK Kidney Association

Variation in AKCC practice

- symptom management
- education to make healthy lifestyle choices
- *treatment decision making*
- monitoring disease progression
- consideration of transplant suitability
- preparation for treatment, e.g., fistula creation
- family carer support
- anaemia management
- social care signposting[3]

[3] Ormandy, et al., On behalf of the ANN UK Advanced Kidney Care Community of Practice and supported by Kidney Care UK Nursing practice patterns in advanced kidney care. Journal of Kidney Care Volume 9, Number 1

Purpose of today’s SDM workshop

- Two role play scenarios
- List of key resources

Closing remarks

1. SDM is a distinct skill set
2. There is always a choice – even when it feels uncomfortable
3. Start with what matters most
4. Variation exists – consistency matters
5. If we don't measure it, we can't improve it
6. Language shapes decisions
7. It doesn't have to mean more time, it may require a shift in focus or restructure the conversation

One thing that I will do differently in my next AKC clinic.....

Future work in preparation

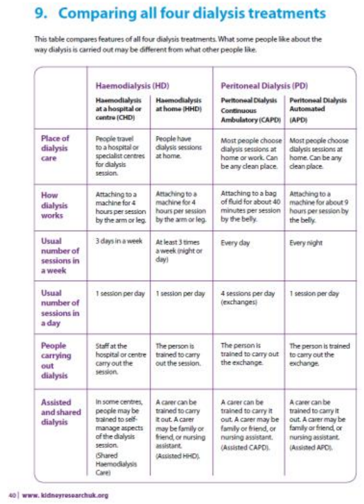
Mapping **KI**d**N**ey care pathways to support **D**ecision making for older people with kidney failure: **KIND** study

Programme Development Grant, May 2026.

Aim: to develop, evaluate and implement the KIND intervention to support older adults making decisions about dialysis and CKM.


Figure 2: Symptoms of kidney failure


Use these examples to tell us what is important in your life.


9. Comparing all four dialysis treatments

This table compares features of all four dialysis treatments. What some people like about the way dialysis is carried out may be different from what other people like.

	Haemodialysis (HD)		Peritoneal Dialysis (PD)	
	Haemodialysis at a hospital or centre (CHD)	**Haemodialysis at home (HHD)**	**Peritoneal Dialysis Continuous Ambulatory (CAPD)**	**Peritoneal Dialysis Automated (APD)**
Place of dialysis care	People travel to a hospital or specialist centres for dialysis session.	People have dialysis sessions at home.	Most people choose dialysis sessions at home or work. Can be any clean place.	Most people choose dialysis sessions at home. Can be any clean place.
How dialysis works	Attaching to a machine for 4 hours per session by the arm or leg.	Attaching to a machine for 4 hours per session by the arm or leg.	Attaching to a bag of fluid for about 40 minutes per session by the belly.	Attaching to a machine for about 9 hours per session by the belly.
Usual number of sessions in a week	3 days in a week	At least 3 times a week (night or day)	Every day	Every night
Usual number of sessions in a day	1 session per day	1 session per day	4 sessions per day (exchanges)	1 session per day
People carrying out dialysis	Staff at the hospital or centre carry out the session.	The person is trained to carry out the session.	The person is trained to carry out the exchange.	The person is trained to carry out the exchange.
Assisted and shared dialysis	In some centres, people may be trained to self-manage aspects of the dialysis session. (Shared Haemodialysis Care)	A carer can be trained to carry it out. A carer may be family or friend, or nursing assistant. (Assisted HHD).	A carer can be trained to carry it out. A carer may be family or friend, or nursing assistant. (Assisted CAPD).	A carer can be trained to carry it out. A carer may be family or friend, or nursing assistant. (Assisted APD).

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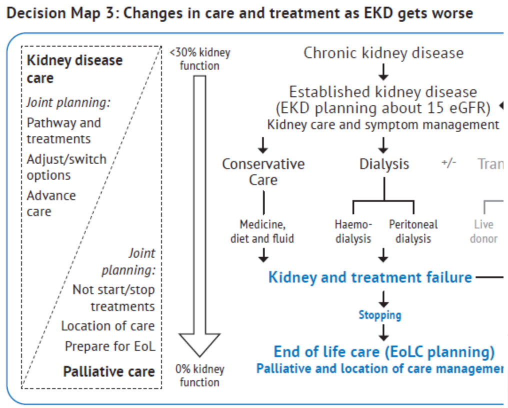
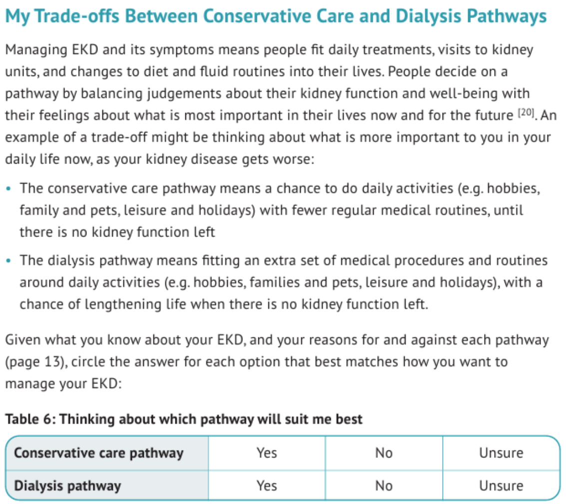

Decision Map 3: Changes in care and treatment as EKD gets worse


My Trade-offs Between Conservative Care and Dialysis Pathways

Managing EKD and its symptoms means people fit daily treatments, visits to kidney units, and changes to diet and fluid routines into their lives. People decide on a pathway by balancing judgements about their kidney function and well-being with their feelings about what is most important in their lives now and for the future [20]. An example of a trade-off might be thinking about what is more important to you in your daily life now, as your kidney disease gets worse:

- The conservative care pathway means a chance to do daily activities (e.g. hobbies, family and pets, leisure and holidays) with fewer regular medical routines, until there is no kidney function left
- The dialysis pathway means fitting an extra set of medical procedures and routines around daily activities (e.g. hobbies, families and pets, leisure and holidays), with a chance of lengthening life when there is no kidney function left.

Given what you know about your EKD, and your reasons for and against each pathway (page 13), circle the answer for each option that best matches how you want to manage your EKD:

Table 6: Thinking about which pathway will suit me best

Conservative care pathway	Yes	No	Unsure
Dialysis pathway	Yes	No	Unsure

Key messages

The way information is presented affects peoples’ decisions.

We can support peoples’ active thinking, improve clinicians’ skills and share reasoning.

Tea break

Second interactive workshop 14.45– 15.35

<table>
<tr>
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Room: Connect (floor 4)
Dr Anna Winterbottom
Dr Jyoti Baharani</td>
<td>Smooth transition onto home dialysis
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Dr Shivanand Chavan</td>
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Dr Janette Moran</td>
<td colspan="2">Improving quality of life with symptom management
Room: Room: Escape (floor 4)
Dr Kathrine Parker
Prof. Helen Hurst</td>
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Grab a coffee and check out the industry room – Room BOND 4th Floor

Third interactive workshop 15.35– 16.25

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