

Shared Decision-Making in Advanced Kidney Care

Dr Andrew Mooney
Consultant Renal Physician
Leeds

People who really know what they're talking about



- Dr Anna Winterbottom
- a.e.winterbottom@leeds.ac.uk



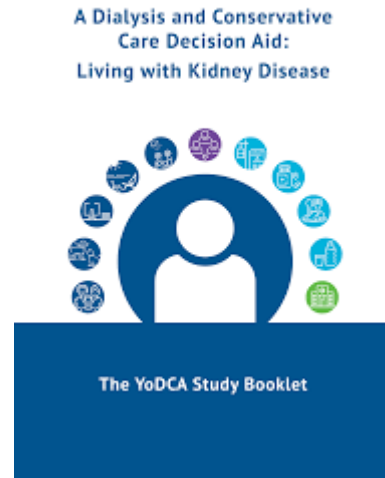
- Professor Hilary Bekker
- h.l.bekker@leeds.ac.uk

Decision Making in AKC

- The Dialysis Decision Aid Booklet
- Co-produced with Kidney Research UK
- Available through their website



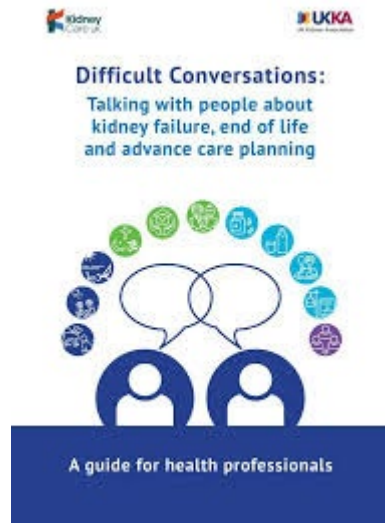
Decision Making in AKC



- The Yorkshire Dialysis and Conservative Care Decision Aid
- Co-produced with support from Kidney Research Yorkshire
- Search “YoDCA”

Decision Making in AKC

- The Difficult Conversations Booklet
- Produced with support from Kidney Care UK



Decision Making in AKC

- Why did we produce these resources?
- An introduction to decision making...

How we make decisions

How many ways are there of making a decision?

How we make decisions

■ There are only two ways!

- Heuristic - settling for an option that will do
- Systematic - learning the pros and cons of each option, weighing them up with our own beliefs, and choosing one

How we make decisions

■ Heuristic



■ Systematic



Patient Dialysis Decision Making

- When choosing a dialysis option, we want patients to make a ***SYSTEMATIC*** decision - this is associated with improved outcomes (improved compliance etc)
- All of us, all the time, want to shortcut this difficult process and make a ***HEURISTIC*** decision - and this includes dialysis patients

Patient Dialysis Decision Making

- The way we interact and give our patients information might actually cause them to more likely make a *heuristic* decision than a systematic one

Patient Dialysis Decision Making

- It is established that human beings (including patients) are more likely to make a *heuristic* decision if they are overloaded with information, and/or given information they don't properly understand

Patient Dialysis Decision Making

- About 20 years ago, we started studying how information was presented to patients
- This has continued, but to give a flavour, here are 3 examples
- Firstly, we contacted all the UK renal units to ask them for the information leaflets they gave to patients to support dialysis decisions; we also contacted the major renal charities

How good are (were) we at presenting dialysis information to patients?

- Variety of leaflets (31 in total across UK) – some PD, some HD, some both
- Readability
- Information included

How good are (were) we at presenting dialysis information to patients?

- Variety of leaflets (31 in total across UK) – some PD, some HD, some both
 - Patients read some and not others
- Readability
 - Patients unable to read owing to complexity
- Information included
 - Not designed to help choose between options

How good are (were) we at presenting dialysis information to patients?

- Put information side by side – classified as “option” (column) and “attribute” (row) – means people get same amount of info wherever they get to
- Aim for reading age 11 (tabloid newspapers achieve this)
- Information for choice is different from information for adherence, attendance, etc

	PD	HD
Place	Home	Home or Hospital
Frequency	Most days	3x/week
Access	Tube in belly	Needles in arm
Timing	Day or night	Usually day

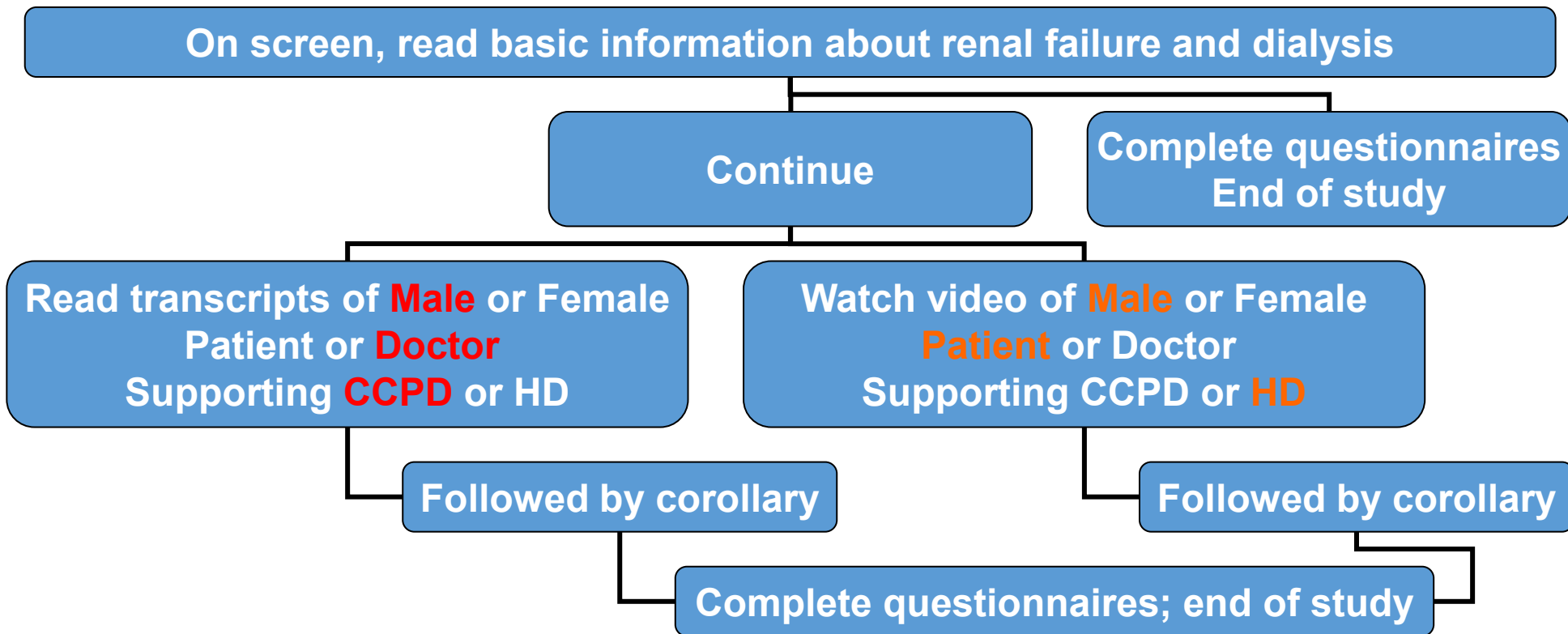
Study 2

- Assess the impact of patient and doctor narratives (ie case histories) in written and video format on decision making regarding choice of dialysis modality

Study Structure and Measurements Undertaken

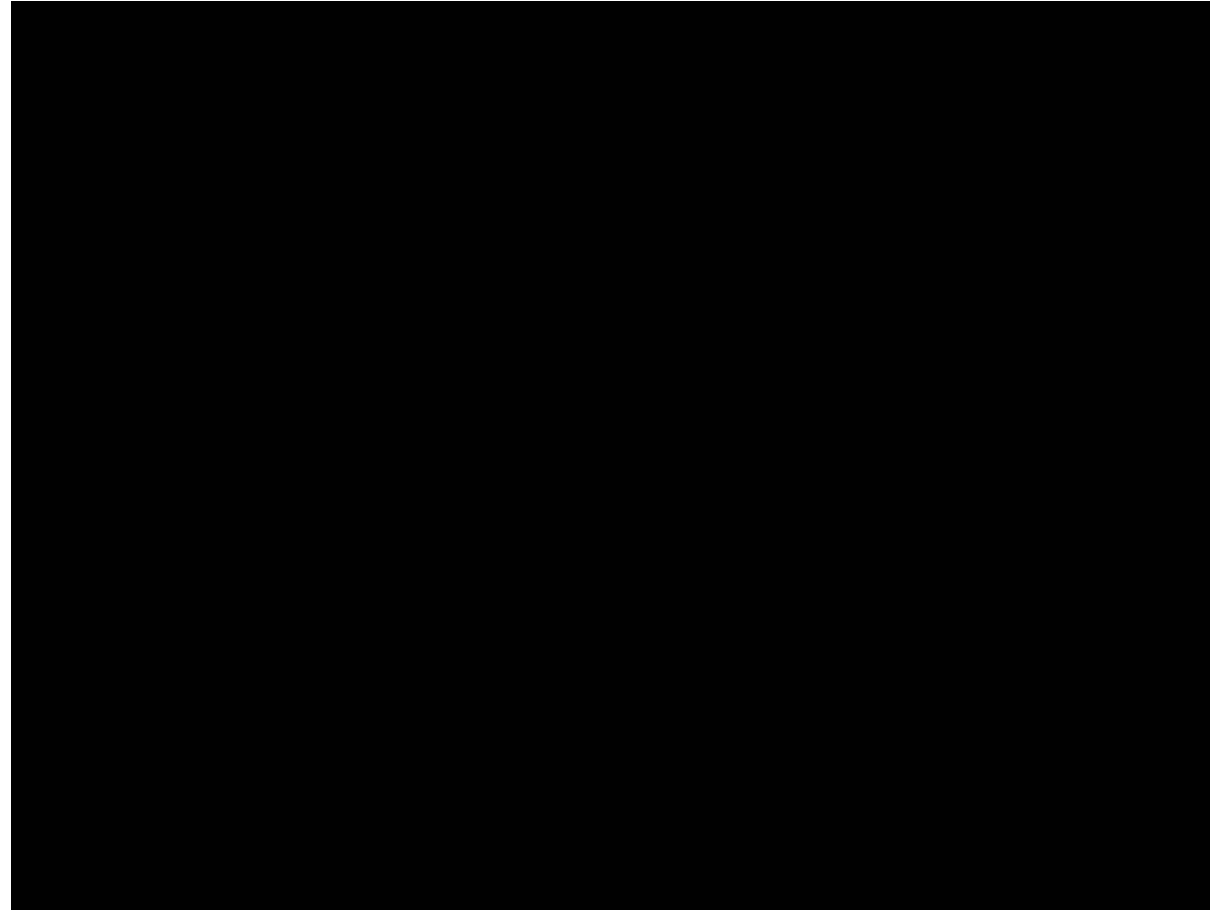
- On-line study
- Email sent to list of students 9 universities, inviting participation with an incentive of entering a draw for £150 prize
- Participants follow a link to a website and progress through screens to completion

Study Structure and Measurements undertaken

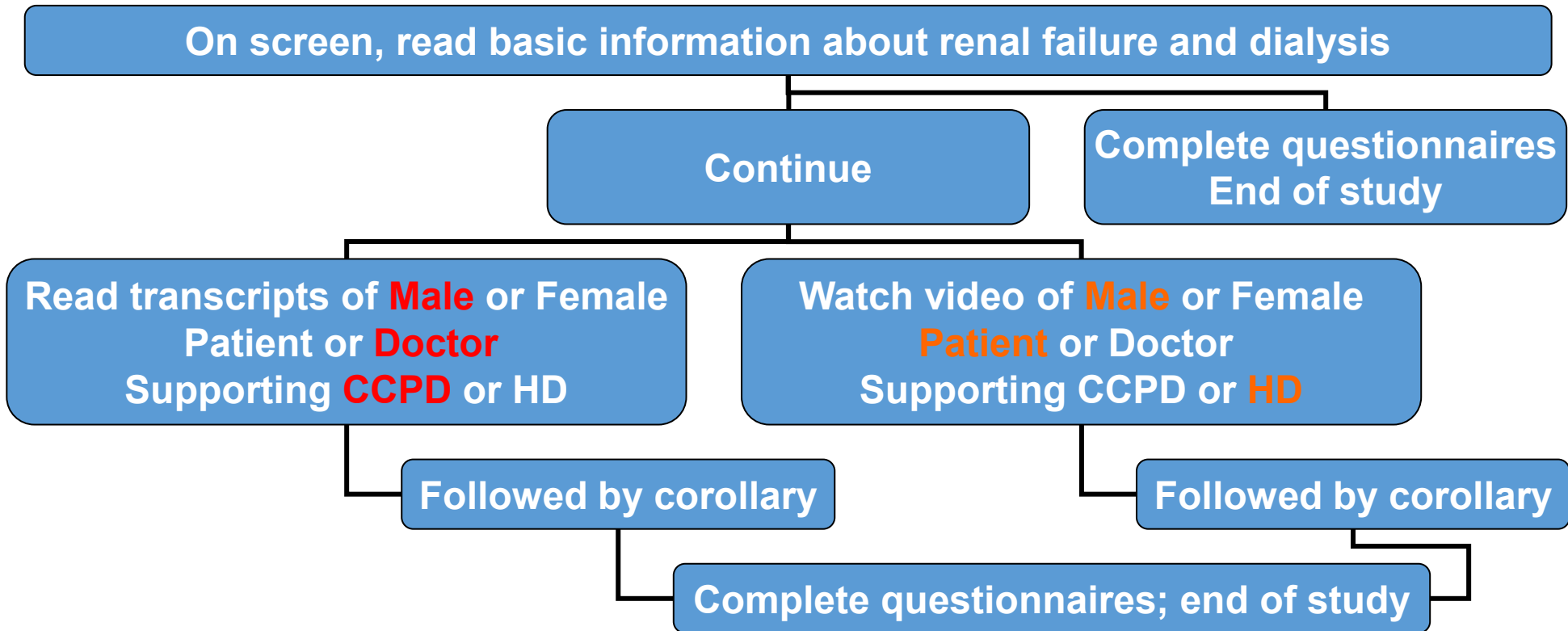


Study Structure and Measurements undertaken

■ Video clips



Study Structure and Measurements undertaken



Results

- The only significant variable influencing choice of dialysis modality was that participants tended to choose what the patient recommended...

What the heck...?

- How can we harness this for good?
- People can express either view if we put things a certain way

Having 2 points of view simultaneously...



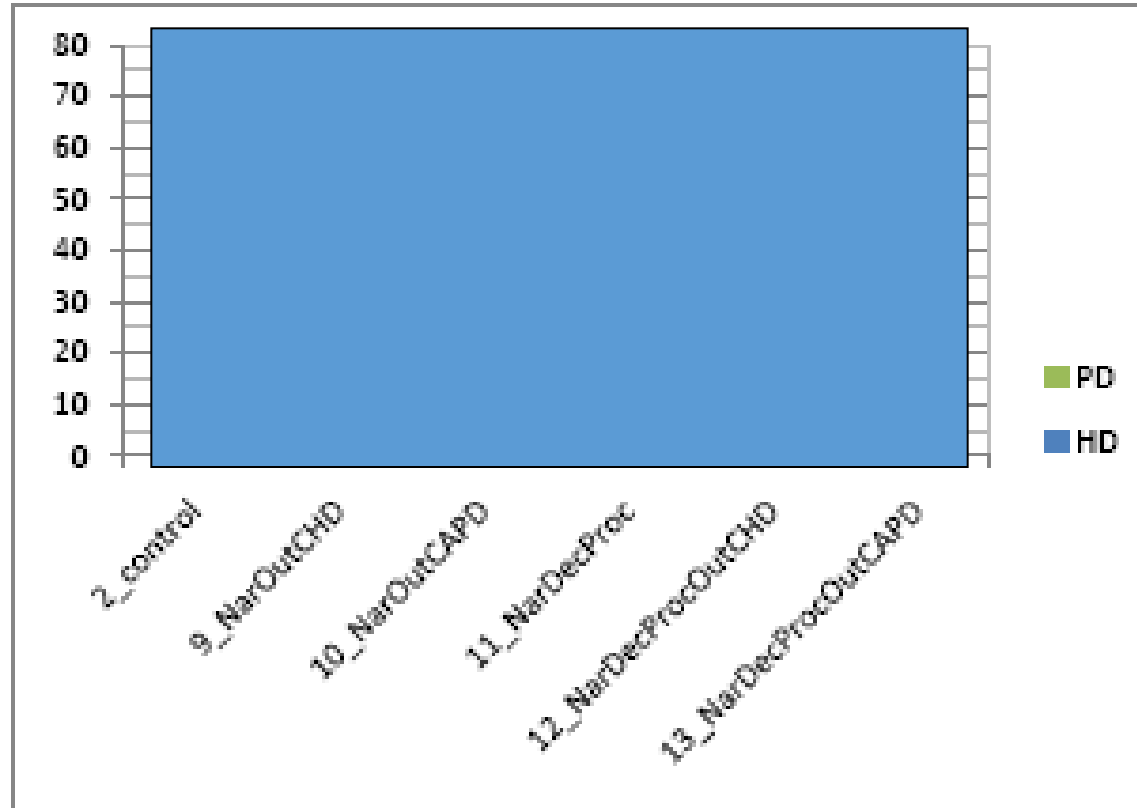
Having 2 points of view simultaneously...

- Can we do the same to renal patients???

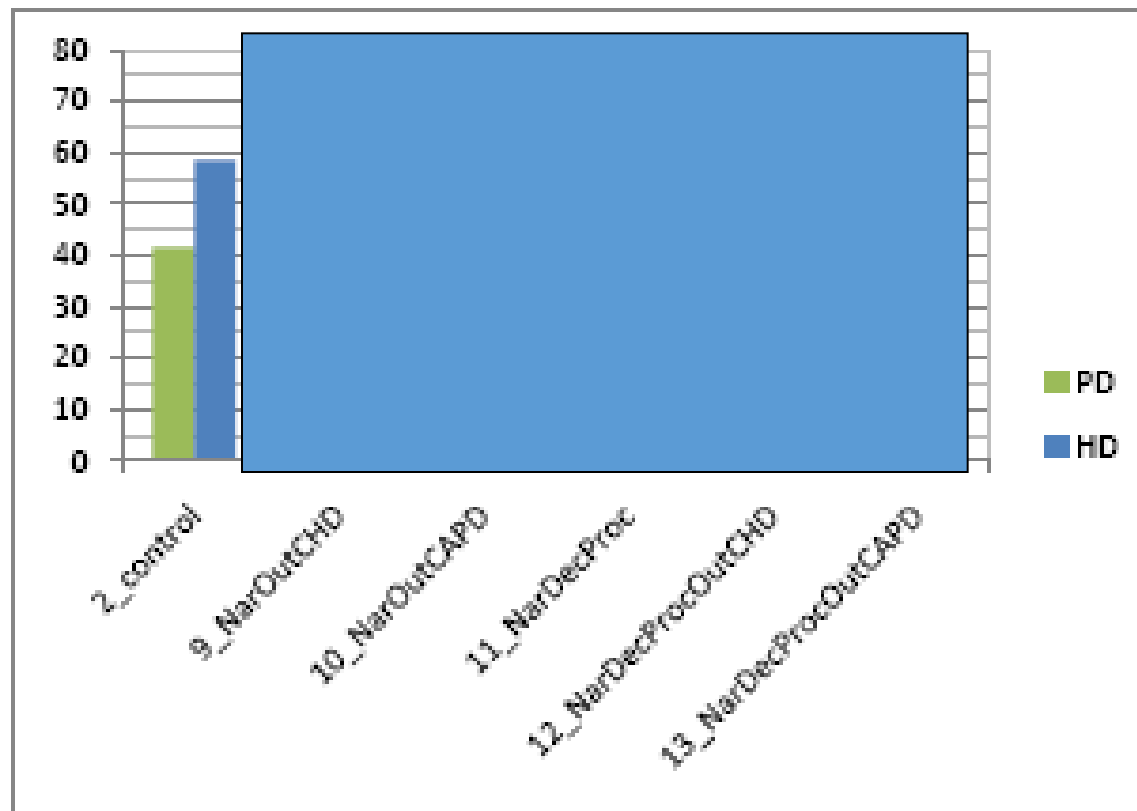
Study 3

- Participants recruited as per previous studies – 351 participants
- Given written narrative about patient considering dialysis
- Variables
 - Control – no information
 - Narrative explaining choice (I chose HD/PD because...)
 - Narrative explaining process (When deciding, I thought about...)
 - Narrative explaining process plus choice (When deciding, I thought about...then I chose HD/PD because...)

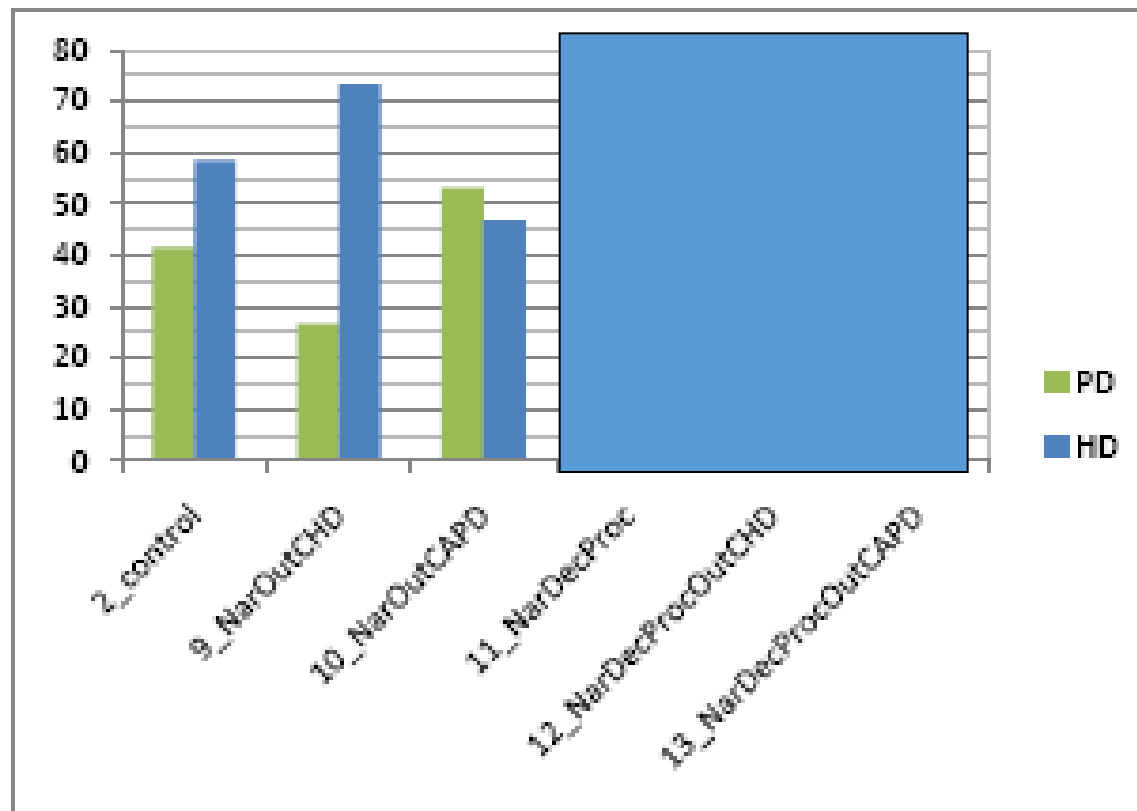
Study 3



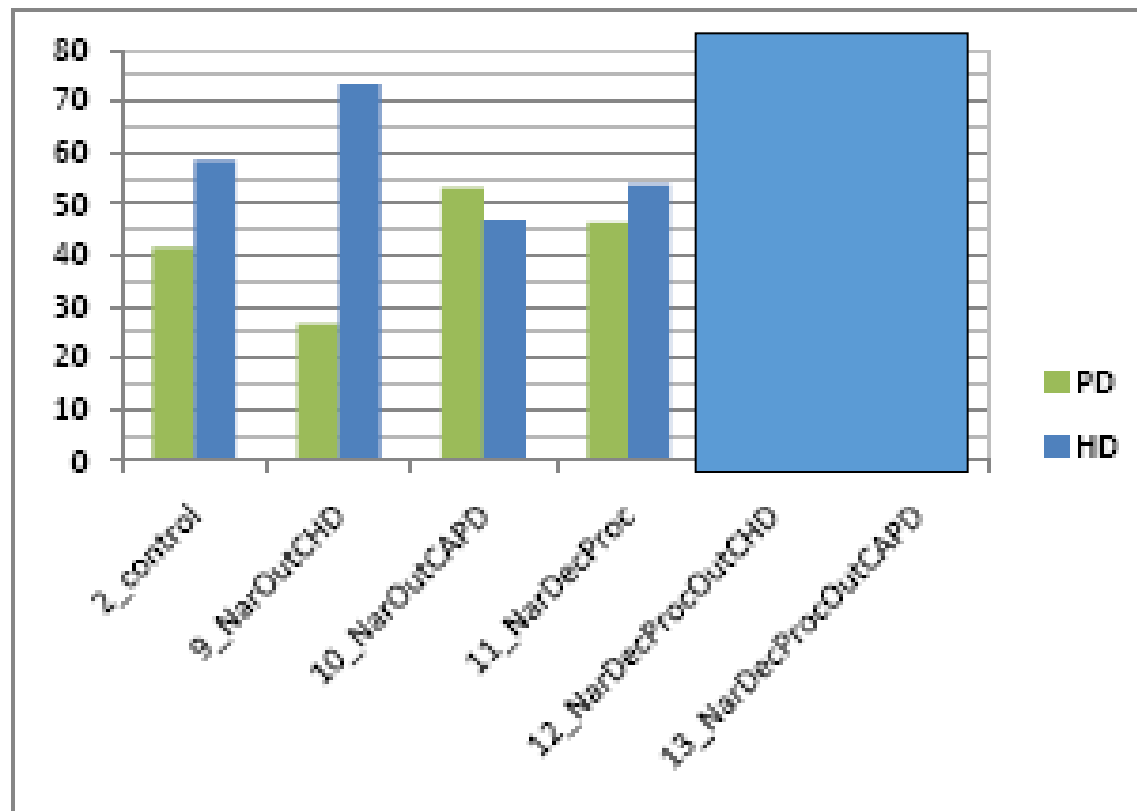
Study 3



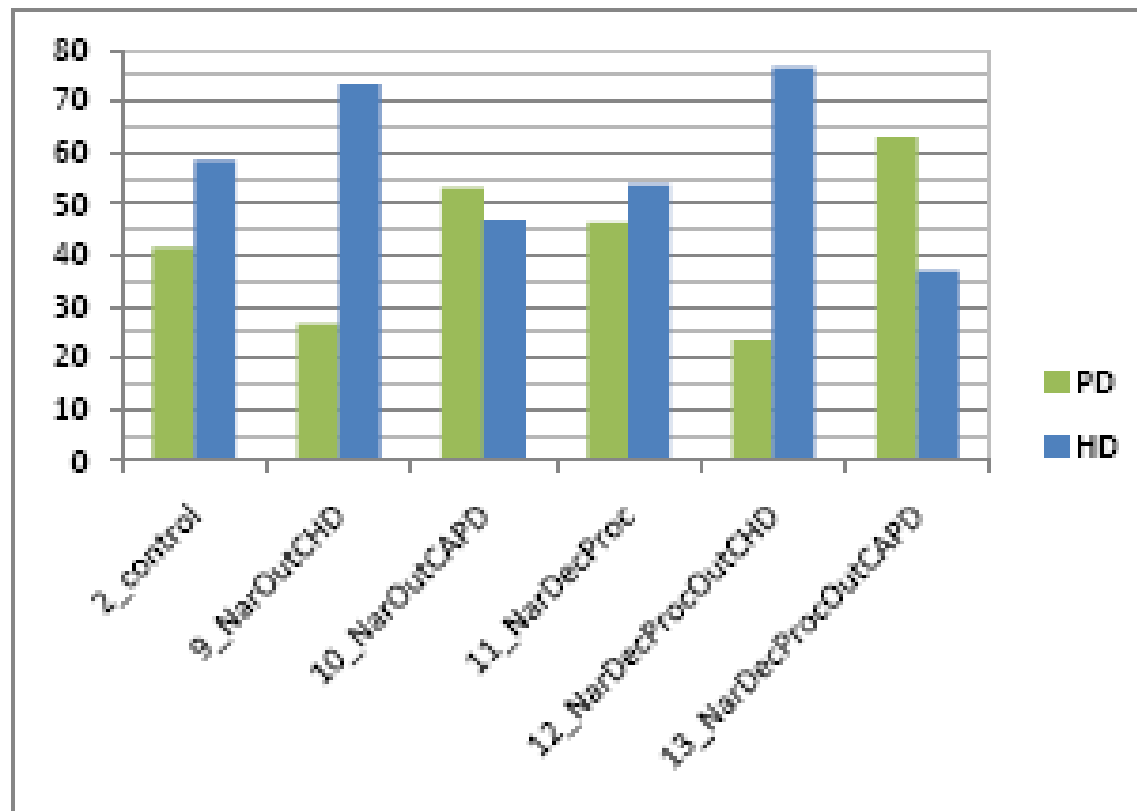
Study 3



Study 3



Study 3



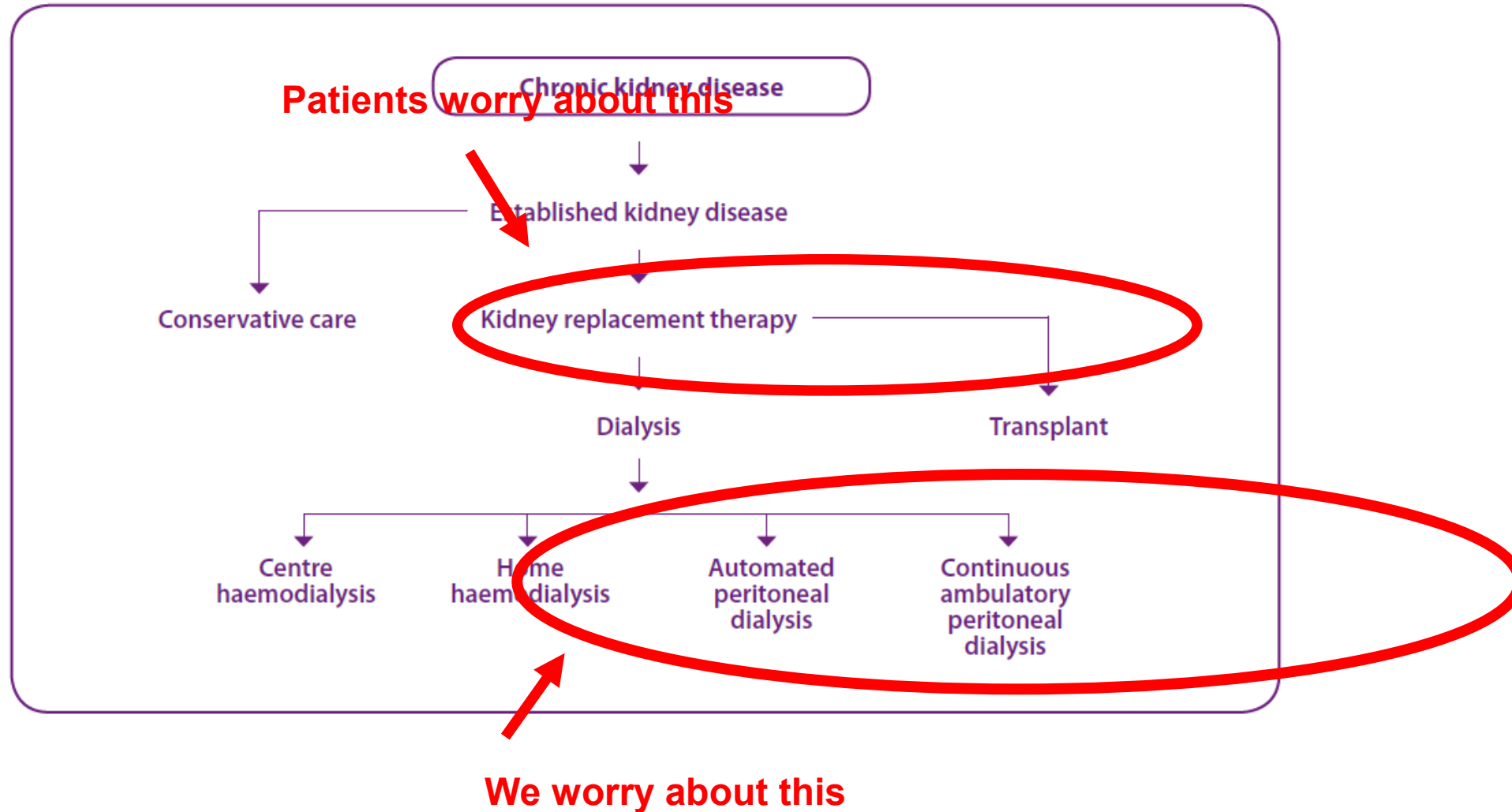
So, where does this get us?

- There are things we can do to make decision-making better
- Here are 5 top tips...

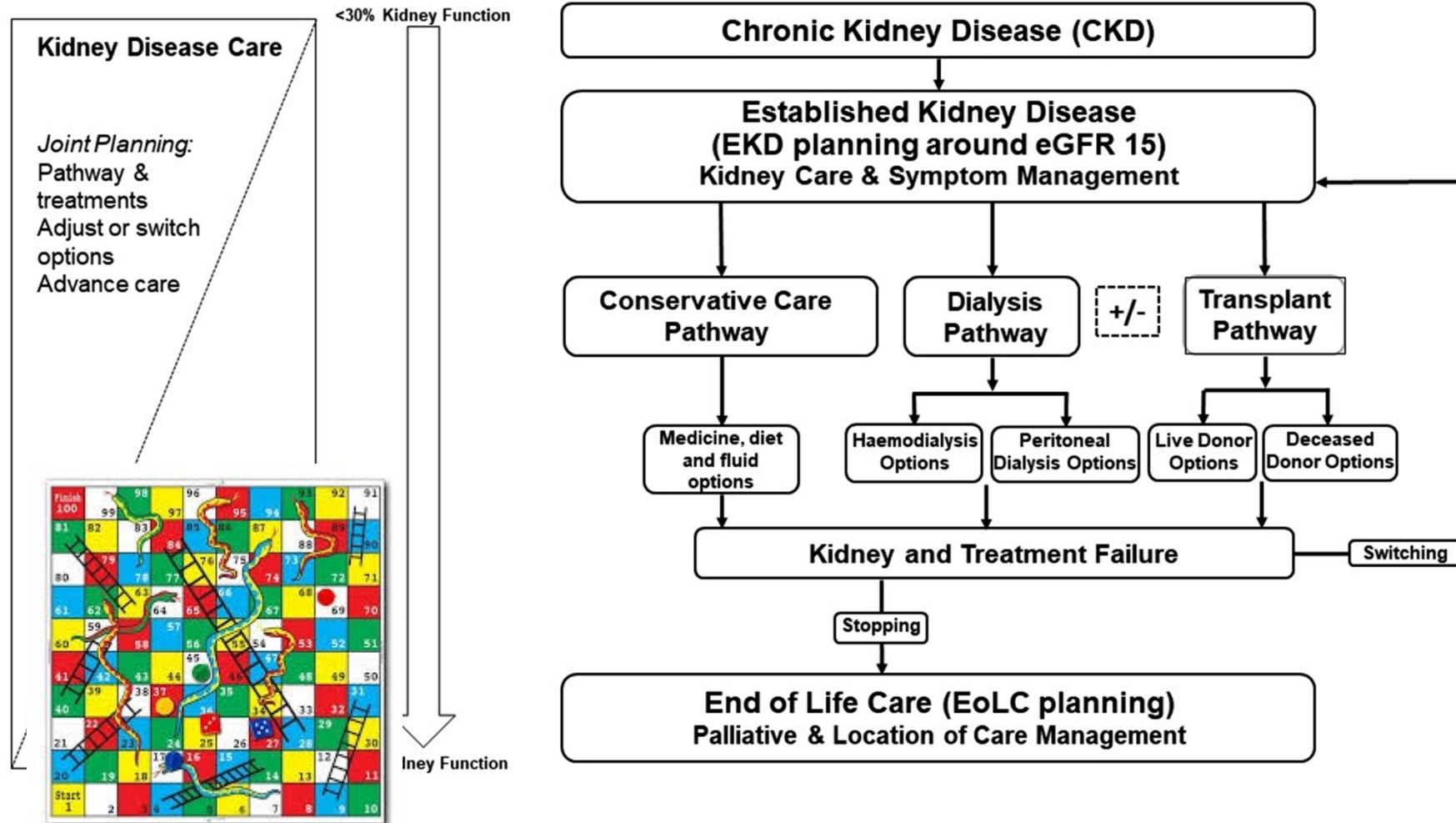
Top tips

- 1 – tell people when there is a decision to be made
- 2 – recognise that information to support decisions is different from information to increase knowledge, improve adherence, navigate treatment organisation, etc
- 3 – balance and structure the information – length, side by side, equalise pros and cons, etc
- 4 – simple written information or infographics work – more complex structures/videos can have unexpected effects
- 5 – trust it is worth you and the patient investing in – patients will tolerate difficulties and complications better

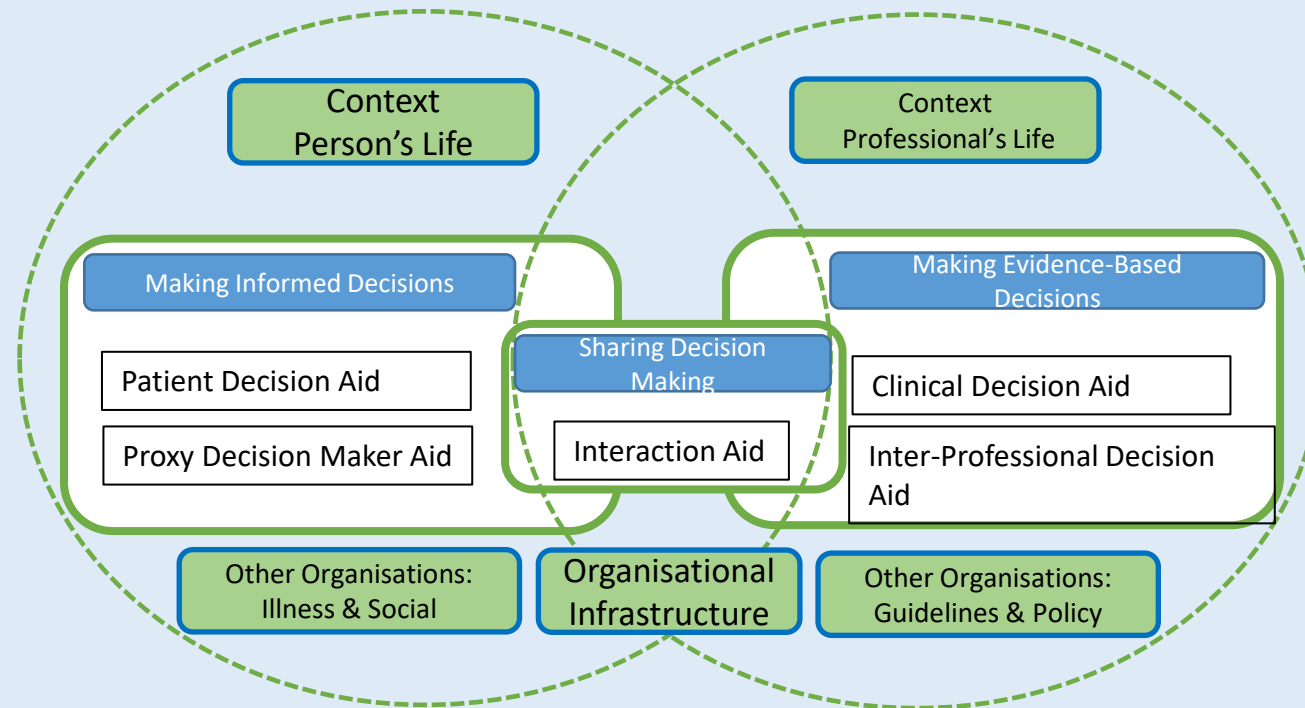
Decision Hierarchy



New schema

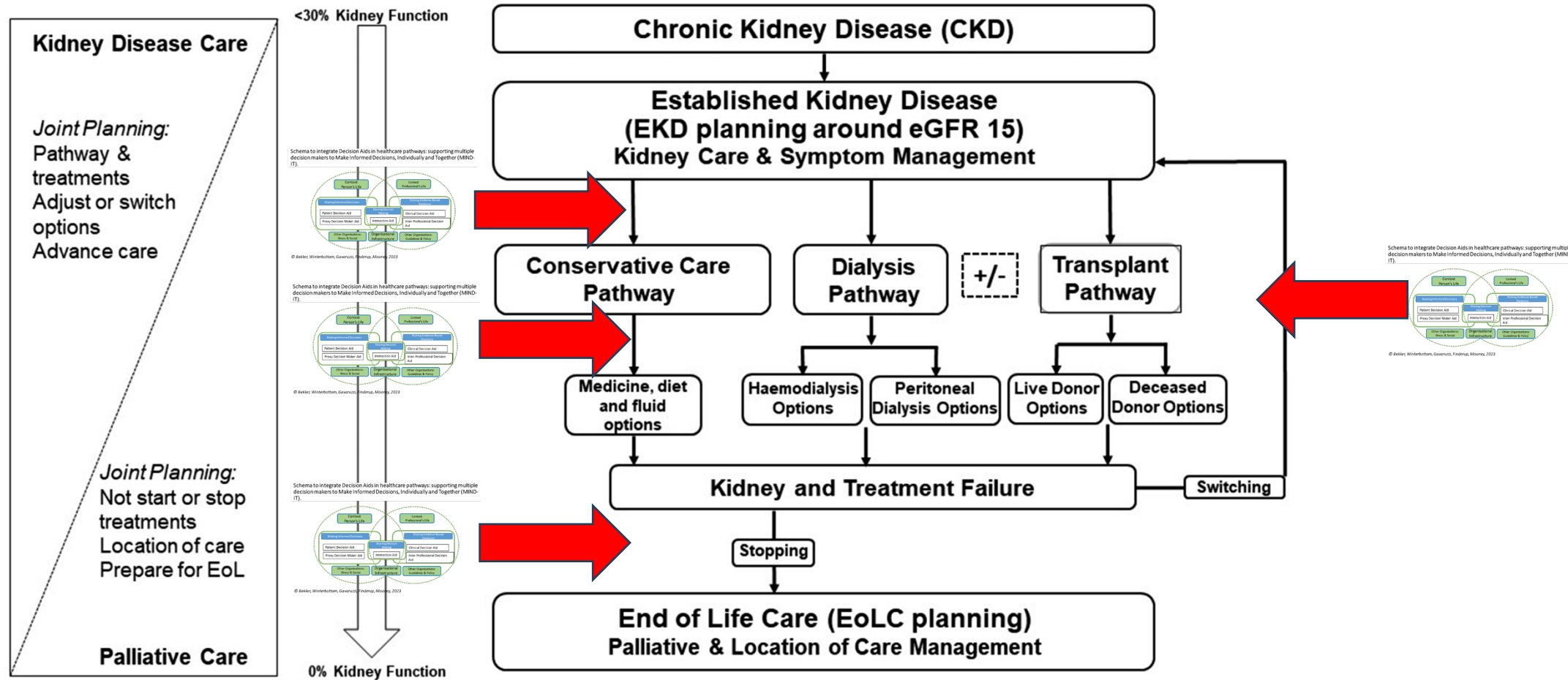


Schema to integrate Decision Aids in healthcare pathways: supporting multiple decision makers to Make Informed Decisions, Individually and Together (MIND-IT).

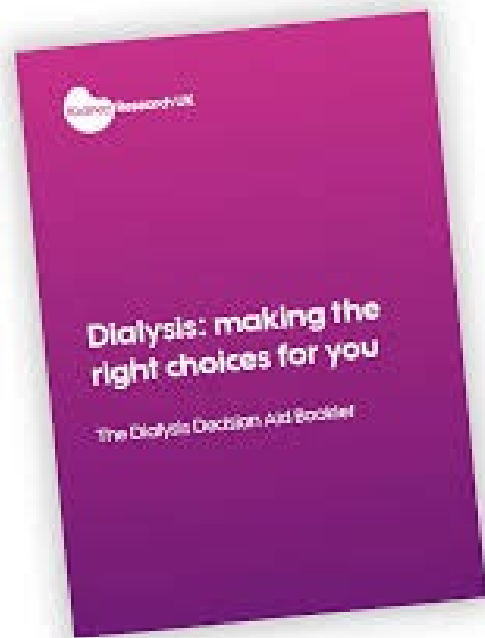


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New schema



How do you expect us to do that?



A Dialysis and Conservative
Care Decision Aid:
Living with Kidney Disease



The YoDCA Study Booklet



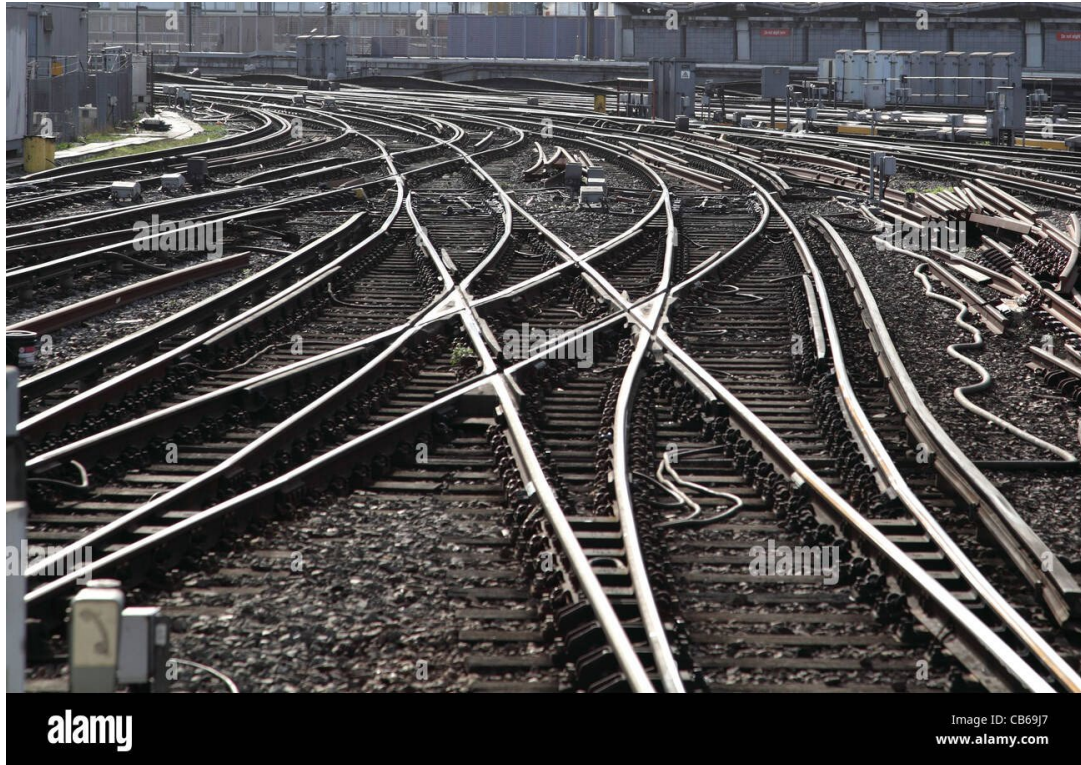
Difficult Conversations:
Talking with people about
kidney failure, end of life
and advance care planning



A guide for health professionals

Decision pathways

What I have shown you



What real life is like



Decision pathways

- The outcomes in advanced CKD are very poor
- Based on recent local audit, the commonest outcome in the commonest demographic is death prior to being on any pathway (Abstract submitted to UKKW 2026)

Summary

- Helping patients make decisions is associated with better outcomes
- There is a scientific basis for it
- We can all learn how to do it better

Acknowledgments



Acknowledgments

