




## CKJ REVIEW

# Shared decision making: a personal view from two kidney doctors and a patient

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## ABSTRACT

Shared decision making (SDM) combines the clinician's expertise in the treatment of disease with the patient's expertise in their lived experience and what is important to them. All decisions made in the care of patients with kidney disease can potentially be explored through SDM. Adoption of SDM in routine kidney care faces numerous institutional and practical barriers. Patients with chronic disease who have become accustomed to paternalistic care may need support to engage in SDM—even though most patients actively want more involvement in decisions about their care. Nephrologists often underestimate the risks and overestimate the benefits of investigations and treatments and often default to recommending burdensome treatments rather than discussing prognosis openly. Guideline bodies continue to issue recommendations written for healthcare professionals without providing patient decision aids. To mitigate health inequalities, care needs to be taken to provide SDM to all patients, not just the highly health-literate patients least likely to need additional support in decision making. Kidney doctors spend much of their time in the consulting room, and it is unjustifiable that so little attention is paid to the teaching, audit and maintenance of consultation skills. Writing letters to the patient to summarise the consultation rather than sending them a copy of a letter between health professionals sets the tone for a consultation in which the patient is an active partner. Adoption of SDM will require nephrologists to relinquish long-established paternalistic models of care and restructure care around the values and preferences of patients.

**Keywords:** decision-making, decision support techniques, health inequities, kidney diseases, patient-centred care, shared

## INTRODUCTION

The concept of shared decision making (SDM) was introduced to the UK National Health Service (NHS) in the 1990s [1, 2] alongside patient champions challenging the idea that 'doctor knows best' [2, 3]. Much has been written on the topic in the intervening years and we authors—a recently retired nephrologist (CT), one still in training (BH) and a kidney patient (MS)—became interested in SDM because it seemed so obviously the right

approach for people with kidney disease, many of whom face complex decisions about treatments where the burdens and benefits are finely balanced.

In this article we reflect on SDM in kidney medicine in 2023. We start by considering what SDM is and highlight the benefits to patients and clinicians. We describe challenges faced in the implementation of SDM and consider why it may be less widely practiced than it is promoted. We draw upon our experiences to

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suggest solutions that readers can use to make SDM work for them and their patients.

## WHAT IS SDM?

Although definitions of SDM may vary, there are some key components common to many SDM models such as describing treatment options, tailoring information, creating choice awareness, considering patient preferences and making of a decision [4]. This is reflected in the definition adopted by the National Institute for Health and Care Excellence (NICE), which aligns with our own practice:

Shared decision making is a joint process in which a healthcare professional works together with a person to reach a decision about care...choosing tests and treatments based both on evidence and on the person's individual preferences, beliefs and values. [5]

SDM has been described as the 'intersection of patient-centred communication skills and evidence based medicine' [6]. It recognises both the clinician's expertise in treatment of disease and, equally, the patient's autonomy and their expertise regarding what is important to them. The latter may have been gained as lived experience of their condition and treatments, as well as reflecting their own personal circumstances, preferences and needs. SDM is particularly suitable for 'preference-sensitive decisions'—those involving multiple 'clinically appropriate' options that provide only marginal benefit; where outcomes are unpredictable; or where the potential benefits and burdens differ markedly [7]. However, we believe that all decisions are suitable for SDM. Even when a clinician judges one option to be clearly better, the patient might take a different view: clinicians need to 'accept that the patient may have different views from healthcare professionals about the balance of risks, benefits and consequences of treatments' [8] and that patients have the absolute right to choose different options from those that the clinician recommends [9]—although the clinician does retain the responsibility of defining the clinically appropriate options.

Thus, well-implemented SDM becomes a systematic approach to care, applicable irrespective of whether a clinician might consider its application to a particular decision 'appropriate'. This applies even to treatments that may prolong life—such as dialysis—and to people who might be assumed to have particular values—like the young or very old. SDM does not preclude input from others. Indeed, SDM often involves consideration of the preferences of loved ones and the burdens placed upon them by therapy—these things are typically very important to patients. However, patients' autonomy should be primary and they should be supported to choose who influences decisions about their care.

Patient decision aids, where available, can form a part of SDM by summarising the available evidence relevant to a decision in an unbiased way. However, high-quality SDM can be achieved without decision aids, and overreliance on them risks disadvantaging those with limited literacy, those experiencing language barriers and those with cognitive impairment.

## THE BENEFITS OF SDM

Improved communication between the patient and clinician can build trust and should result in treatment plans that reflect more closely the patient's preferences and needs. SDM may well result in better adherence to treatments chosen after an active

decision rather than a treatment imposed by a doctor, although evidence to support this view is varied [10–12]. SDM can result in increased patient satisfaction, with less anxiety, more confidence in the decision made and better quality of life [13]. SDM interventions may even be more beneficial for disadvantaged groups than for those with higher literacy or socio-economic status [14].

A number of randomised studies have shown that the use of decision aids led to fewer patients opting for the more expensive option—elective surgery in most of these studies—than 'practice as usual' [15]. Although it remains uncertain that widespread adoption of SDM will generate healthcare savings [16], this remains one of the reasons why policymakers are so keen on SDM.

## WHERE ARE WE NOW?

Evidence from many settings suggests SDM is less available and of lower quality than we might hope [17]. Patients often want to know more than their clinicians think they do, while elicitation of their preferences appears uncommon [18]. Only 60% of adult inpatients in the NHS in 2015 were as involved in decision making as they wanted to be [19] and marked variation in SDM delivery is reported in UK kidney units [20]. In 2021, patient experience scores for SDM were lowest among those with CKD and who attend centre or satellite haemodialysis, higher for transplant and peritoneal dialysis and highest for those who have haemodialysis at home.

As the population has aged, comorbidity has become highly prevalent among patients with kidney disease: in a recent Scottish sample, only 2% of patients with CKD had no other conditions and 70% had at least three other conditions [21]. Therefore, most kidney specialists spend much of their time caring for older people with complex comorbidities. These people are often attending other specialist clinics and are usually prescribed multiple medications and interventions based on guidelines derived from trials that largely recruited younger people with single-organ disease. For them, SDM is at the heart of person-centred care and is an essential component of making sure that they are treated as an individual rather than a collection of conditions.

Meanwhile, the evidence suggests that those who allow their clinician to take the lead may be at risk of overtreatment. Nephrologists frequently censor or modify prognostic information in ways that may lead to misguided expectations of cure and transplantation [22, 23]. Overestimation of the value that patients place on prolonging survival [24, 25] may lead to prioritisation of life-prolonging interventions, with focus on the benefits and minimisation of the risks of treatments—a phenomenon also described in cancer medicine [26, 27]. For instance, Ramer *et al.* [25] showed that 49% of older adults with advanced CKD rated maintenance of independence as their top priority, with almost as many ranking staying alive as their last or second-last priority. The result may be that doctors recommend more interventional treatments for their patients than they would accept themselves [28].

## Decisions between treatments for kidney failure

The decisions that face patients approaching end-stage kidney disease—between dialysis, conservative kidney management and pre-emptive transplantation—are highly preference sensitive. Clinicians should be sharing what is known about how effective kidney failure treatments are at prolonging life and maintaining independence, along with the burdens, including frequency and location of care. But clinical practice is not

uniform. For instance, variation in rates of dialysis withdrawal are better explained by the attributes of units and physicians than by case mix: rates are highest in units where conservative kidney management is routinely discussed and lowest where dialysis is seldom recommended to those >80 years of age [29].

There is little high-quality evidence informing decisions between dialysis and conservative kidney management. Without it, and in the absence of SDM, it is easy to imagine how dialysis might remain the 'default' option. Patients may not even recognise that the decision to prepare for or initiate dialysis is theirs to make and may defer to their family or clinical team [30]. Failure to establish patients' preferences in this setting may put them at high risk of overtreatment, not providing sufficient quality of life or survival benefit to offset the treatment burdens [31]. Decisions about treatment for kidney failure are often formed over years. Patients may delay dialysis initiation as an act of self-efficacy [32], 'decide not to decide' [33] or postpone the decision [34]—living life day by day. This makes it difficult to choose a time point at which to audit SDM in this context [18]. Without good lines of communication, clinicians can be frustrated by such behaviours, interpreting them as indecision [27], and may be at risk of assigning patients to treatment 'pathways' that do not align with what those individuals have decided to do [35], contrary to the principles of SDM.

Audit-based performance management can also discourage SDM. For instance, while arteriovenous fistula formation is associated with better medical outcomes, it carries risks and burdens that some people may believe outweigh the benefits. Furthermore, the process of establishing access in the absence of SDM about a preferred type of dialysis presupposes that the patient will choose haemodialysis [36]. Clear conflict between 'best practice' and preference-sensitive care is evident.

## CHALLENGES WITH SDM FOR CLINICIANS

Even for those who champion its values, SDM can feel difficult. Attempting to implement SDM in routine kidney care requires new ways of consulting, more artful than the time-honoured approach of telling patients what they should do. C.T. first actively implemented SDM in 2004 when nephrology, a specialty shaped by treatments developed to prolong life, seemed unprepared for including patients as partners in their own care. Senior colleagues had been trained in an era where paternalism was the norm. Junior staff were focused on learning skills required for passing specialty exams—which did not include consultation skills. The usual barriers were mooted: decisions to which SDM doesn't apply, insufficient time and the lack of appetite and ability of patients to take part [37]. Based on evidence and our own experience, we describe some of the challenges those wishing to implement or extend SDM may face—within themselves, with patients or within the environment in which they work.

### Personal challenges

As C.T. discovered, moving towards SDM requires deliberate adjustment of long-established patterns. Honesty about a life with kidney disease involves discussing painful truths and preparing for a future that 'nobody wants to talk about'. These adjustments deconstruct the charade that doctors know what is best and what the future holds—and can feel exposing. Recognising the lack of evidence to inform choices means those providing SDM find themselves saying 'I don't know' more often. Acknowledging life's uncertainties means 'we cannot know' is frequent too.

### Variable health literacy and patient activation

Simply giving patients the information necessary to make a balanced decision between two treatment options is not enough: the information must be tailored to the individual patient's experience, values and preferences and to their health literacy and activation status. Without this conscious approach to SDM, clinicians may find themselves leading the patient, creating unintentional bias by the way options and information are presented (such as 'here are the treatment options; I think you will see that A is the best one for you') or may transfer all of the decisional responsibility onto the patient without negotiation (e.g. 'here are the treatment options, which do you want?'). They may differ in their approach depending on the perceived health literacy of the patient or due to assumptions about the needs of an individual based on their socio-economic, ethnic or cultural background [38]. Patients with high levels of health literacy may have already been making sure they were involved in decisions about their care. The challenge in creating equity of access means not only offering it as an individual-level intervention to those who demand it or with whom it feels easy, but to implement SDM where it is most needed [14].

### Patient attitudes

Some patients will be accustomed to 'old-fashioned' paternalistic decision making, and this long-established power imbalance can be difficult to tackle [13, 39]. Patients who have already been assigned to treatment pathways, e.g. an older, frailer person with a long-established plan for dialysis, may be less amenable to the introduction of SDM than they would have been had decision making been practiced as a continuous process [35].

There is extensive literature on the importance of patients' trust in doctors. But blind trust favours paternalism. It is equally important that doctors trust patients and accept scepticism and challenge [40]. Sometimes patients' scepticism about SDM will manifest as suspicion, perhaps deriving from the notion that SDM represents a form of resource rationing. However, where SDM is done well, with all options being presented and the patient having a role in the choice, it is less likely to be seen as rationing.

In some cultures, relatives of patients and faith leaders may have considerable influence and input into decisions and patients may be less receptive to making shared decisions with their clinicians. Developing culturally competent supportive communication styles may encourage engagement [41].

### Provider issues

Several aspects of the organisation of care of long-term kidney patients can impede the adoption of SDM. This includes the division of responsibility for ongoing care between multiple providers with different levels of commitment to SDM. SDM can suffer due to the lack of private space in dialysis units and, in all settings, from time pressures. As discussed above, clinical performance targets can also discourage adoption of SDM.

### Decision aids

Patient decision aids (PDAs) have been shown across a wide variety of contexts to help patients feel more knowledgeable, better informed and clearer about their values and to be more active in decisions about their care [42]. Although high-quality SDM can be achieved without PDAs, no practitioner can

possibly assimilate the evidence—or lack of it—relevant to all decisions faced by kidney patients. While guidelines are rigorously developed and generally endorse SDM, they typically provide no means to facilitate it. In the UK, NICE has endorsed SDM, but to date has only produced 25 PDAs, in contrast with the thousands of recommendations included in 1654 currently available statements [43]. Internationally, Kidney Disease: Improving Global Outcomes (KDIGO) suggests that ‘Each patient needs help to arrive at a management decision that is consistent with his or her values and preferences’ [44] for their GRADE Level 2 guidelines. The KDIGO guidelines on blood pressure in CKD [45] and glomerular diseases [46] each contain a commitment in the Foreword to ‘generation of patient decision aids direct from the evidence syntheses used to support the guideline’, but unfortunately this commitment has been abandoned (KDIGO, personal communication to C.T.), allowing the impression that the organisation has reverted to a paternalistic position in which guidelines tell doctors what to do to their patients, leaving the patient as a passive recipient of care rather than an active partner in life-changing decisions.

Available materials to support decisions between kidney failure treatments have been of mixed quality and content and are not widely used or always positively received [27, 47]. For many ‘routine’ decisions in nephrology, adequate evidence is simply unavailable; e.g. when to initiate or increase phosphate binder therapy, how to treat pruritus, how to treat leg cramps or how to set a target weight on dialysis. This lack of evidence does not preclude SDM, but it does make it difficult for clinicians to help individuals to understand and weigh the pros and cons of available treatments. The evidence is particularly lacking regarding how patients with kidney disease weigh treatment options available to them. The SONG initiative [48] has gone some way towards addressing this gap, but there is much more to do. The ICHOM initiative [49] also provides valuable measurement instruments on patient-reported outcomes but does not, by itself, provide the tools to improve these outcomes.

Although PDAs can help in presenting unbiased information, this is dependent on which decisions and outcomes are included. This requires both medical perspectives (including the medical diagnoses and the biomedical outcomes associated with various options) and patient perspectives (including, for instance, the perceived ‘burden’ and side effects of different treatment options).

## THE WAY FORWARD—BEST PRACTICE

### At a provider level

#### Address the need for change

A shift is needed from a focus on purely biological outcomes (for instance, biochemistry, hospitalisations and survival) to a care model in which more importance is attached to patient-centred outcomes, particularly in the care of patients with chronic disease. SDM explicitly requires patients’ values and preferences to be considered during decision making and will therefore facilitate this shift in how decisions are made and presented as part of truly person-centred care. This has been discussed in detail by Verberne *et al.* [50].

#### Embed SDM at an organisational level

SDM is the responsibility of service providers as well as individual clinicians. Services must ensure that time, space and treatment flexibility permit individuals’ preferences to guide

their care. Including high-level leadership, working with a patient leader and making connections through kidney networks and quality improvement initiatives can embed SDM within a structure that supports its use.

### At an individual level

#### See the person in front of you

We all should be aware that we are occasional visitors in our patients’ lives: a person with kidney failure may have a consultation with a kidney specialist for perhaps 15 minutes every 3 months—0.01% of the time they spend living with the condition. People are experts in what matters to them and should be routinely and carefully asked about their values and preferences before any treatment decisions are made: unquestioning ‘cookbook medicine’ implementation of guidelines, however strong the evidence base, debases medical practice. Don’t let a focus on process and outcomes override obligations to the individual in front of you.

#### Don’t lead patients to do what you want

There is a moral obligation on doctors not to abuse the trust patients have in them by coercing them into taking courses of action that they might not freely take if their values and preferences were fully accounted for. Help people to weigh the long-term risks against burdens of treatment based on their own needs, wishes, hopes and fears.

#### Write to your patient

The majority of secondary care clinicians in the UK currently summarise consultations with a ‘clinic letter’ sent to the patient’s primary care physician. This format treats the patient as an observer of decisions about their care rather than as a partner and perpetuates the ‘paternalistic’ nature of healthcare. We found that changing the format of clinic letters followed naturally from a SDM approach. Clinic letters are addressed to the patient, summarising what was discussed and agreed upon, but include a section directed to the primary care physician, and specifying precisely which actions are required from both. The UK Academy of Medical Royal Colleges has issued guidance endorsing this approach [51].

#### Learn the skills

Clinicians must learn and prioritise the skills needed to guide patients to make decisions in a way that is often novel to both parties. Change the way you communicate with patients: be ready for patients to ask ‘What do you recommend, doctor?’, but coach yourself to respond, ‘I can’t recommend a particular treatment without knowing more about what is important to you’. Do not underestimate patients’ capacity to take part in decision making. Helping patients to break free from deferential models of decision making can be particularly challenging, but it is key to realising the benefits of SDM. Get comfortable with asking people about what is important to them—and listening to their reply—and be prepared to question your own dogma about what treatments are ‘best’.

There is a strong case for providing communication training to kidney doctors, like that given to primary care doctors. In the absence of formal training, it is still possible to work on improving communication skills. NICE provides a resource suitable for all healthcare professionals that aims to equip people with the skills and knowledge they need to have good-quality shared

decision-making conversations with the people they are caring for [5].

#### Create the environment

While the ward, clinic and dialysis unit are suboptimal places for SDM, they are where it must take place. Practical solutions are available to improve patients' opportunity to take part in decisions about their care. Invite them to bring loved ones or caregivers to the clinic and onto the ward. Provide them with records of consultations that allow them to reflect, take the decision home and discuss it with others. Consider inviting patients to record consultations on their phone—they may be doing so without your knowledge anyway, but knowing this might mean you do an even better job. Take extra time to consult well—our experience is that this is a classic opportunity for 'slow medicine' [52]. In an era where continuity of care has often been lost, patients' values may not have been shared before, and extra time is needed to explore these and to decide what decisions are needed and how these might be made. Actively resisting the pressure for a quick decision pays back in the longer term, through a better clinician–patient relationship and a smoother future clinical course.

#### Use patient decision aids where available and appropriate

PDAs have been developed to support decisions between dialysis modalities and conservative kidney management [53, 54]. Using these will help to ensure that all treatment options are presented and the relative benefits and burdens of each are discussed.

#### Develop decision aids

Learning how to use existing evidence to develop PDAs would arguably be a better way to augment clinical training than many research or audit projects.

#### Help make research more relevant

SDM may include offering the opportunity to participate in trials to people you have reservations about. Barriers to trial recruitment of older people and those with multiple health problems are well established, and include clinician attitudes: being a gatekeeper is a paternalistic trait [55]. The communication skills learned from recruitment and SDM may cross-pollinate, while illuminating the uncertainties of so much that we do. The use of SDM in nephrology deserves a stronger evidence base itself—and developing this is another role for practicing specialists.

#### Be a role model

Implementing SDM in your own practice and making it visible is one way to persuade colleagues and change provider culture.

#### Just do it anyway

Persevere! All new things feel difficult: SDM is worth doing because it is morally right [56]. Do not pretend to yourself that the decisions in nephrology are not amenable. Even where you have only one intervention to offer, there is always the option of declining it. When two or more options are available, which is best, whether a benefit is marginal and what level of certainty, benefit or burden is acceptable must be evaluated through the lens of the patient's preferences. Do not 'allow perfection to be the enemy of the good'. Even the provision of balanced

information about options and asking about what matters to patients is a step on the way.

As M.S. wrote 10 years ago: 'SDM requires the capacity to consider that you might be mistaken, as you research, discuss, listen, negotiate and divine your way to an answer that may or may not be the right one. SDM is easier, however, when there is a relationship of trust between the healthcare professional and the patient—a continuity of care that allows the patient to be seen as a person in their own right, with a life lived beyond the consulting room, where they manage their condition daily and are hopefully supported by friends, family or faith' [57].

## CONCLUSION

Adoption of SDM into the routine care of patients with kidney disease is overdue. Twenty years from now, it is inconceivable that patients across the world will accept medical paternalism: the information revolution will transform medical practice. Our specialty has a choice. We can continue to drag our feet, to issue guidelines without accompanying decision aids and to ignore patients' demands for greater participation in decision making or we can, as we have before, set the example for other specialties to follow.

## OUR MOTIVATIONS TO ENDORSE SDM

C.T.'s interest in SDM developed during a Health Foundation Quality Improvement Fellowship at the Institute for Healthcare Improvement (IHI) in 2003–2004. The IHI had adopted the mantra 'no decision about me without me' and were promoting shared decision making in their programs. While at the IHI, C.T. met Michael Barry [58] to discuss clinical practice guidelines and began to understand some of the limitations of the model of clinical practice in which guidelines were directed at clinicians, with the implicit assumption that patients would do what their clinician advised. On returning to the UK he started to incorporate SDM into routine clinical practice as a general nephrologist, and also, as Chair of the UK Renal Registry, developed a national survey of the quality of decisions made by patients receiving care for advanced CKD in UK kidney units [59]. This work was funded by NHS Kidney Care thanks to the late Donal O'Donoghue [60], who realised, before many others, the importance of patient involvement in kidney care. C.T. also gave advice on the content of web-based decision aids that were developed for use in the 'Right Care' program of the English NHS (no longer available) and has recorded video clips illustrating consultations with and without SDM [61].

B.H. became interested in SDM as a trainee before his first experience with kidney medicine. He had become concerned that he was seeing treatments started that carried burdens that had not been truly negotiated with recipients. Sitting in on outpatient clinics and observing what usually goes on behind closed doors, he was able to learn from a minority of clinicians, including C.T., who were able to genuinely involve patients and their families in their care, and many others who struggled, or declined, to do so. He developed a particular interest in how people make decisions between treatments for kidney failure, which became the subject of his PhD [62].

M.S. has been a kidney patient with polycystic kidney disease for 40 years, having had a live donor kidney transplant in 2006 and a bilateral nephrectomy the following year. She has been a health service user representative in both the fields of maternity and kidney care, advocating for patient choice and working

for the improvement of the patient care experience. She is currently the lay advisory group lead at Kidney Research UK.

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## AUTHORS' CONTRIBUTIONS

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## CONFLICT OF INTEREST STATEMENT

The results presented in this article have not been published previously in whole or in part, other than in abstract format.

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