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## RESEARCH ARTICLE

# Managing uncertainty in multidisciplinary renal team meetings: decision-making processes and complex challenges in kidney transplant listing

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Multidisciplinary team (MDT) meetings are common to many fields of medicine and widely established internationally. They are intended to ensure higher-quality decision-making and improved patient outcomes. For patients with end-stage kidney disease (ESKD), decisions on whether to place marginally suitable candidates on the kidney transplantation waiting list can be challenging and as such they are supported by MDT meetings. Uncertainty in terms of the best course of action can be linked with a dearth of knowledge or evidence on specific medical conditions and likely implications for successful transplantation, but also on unforeseen outcomes influenced by patient behaviours. In this project, we observed how MDT meetings work in practice in kidney transplant listing, unpacking issues of risk and uncertainty in transplant decision-making processes. Our findings indicate that a central value of MDT meetings is managing medical uncertainty and psychosocial risks, and distributing responsibility for complex transplant listing decisions to ensure equity of access to transplantation as well as an efficient use of scarce kidneys. This sheds light on strategies enacted to mitigate these risks and uncertainties, and the role played by different types of knowledge (experiential versus scientifically evidence-based) in the overall decision-making process.

**Keywords:** multidisciplinary team meetings; decision-making; medical uncertainty; complex cases; transplantation; transplant listing decisions

## Introduction

Multidisciplinary team (MDT) meetings are common to many fields of medicine and widely established within the UK National Health Service, albeit with variation in structure and function (Taylor et al., 2012). They are intended to ensure higher-

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quality decision-making and improved patient outcomes (Blazeby et al., 2006; Mickan, 2005; Wagner, 2004). Research in the field shows that decisions made by an MDT are more likely to be in accord with national guidelines than those made by individual clinicians alone (Chang et al., 2001; Wilcoxon et al., 2011).

Most of the literature on MDTs deals with clinical decision-making, especially in cancer care. It looks at their effectiveness in the decision-making process (Fleissig et al., 2006), whether MDTs are cost-effective (Ke et al., 2013) and which factors influence the implementation of MDT treatment plans (Raine et al., 2014). Views on their effectiveness are mixed (Bosch et al., 2009; Lamb et al., 2012) and the degree to which MDT meetings have been incorporated into clinical specialities varies widely (Raine et al., 2014).

Despite the potential centrality of MDT meetings in the delivery of care to patients with cancer and other chronic diseases, and the Department of Health policy support for MDT meetings (Department of Health, 2007a; 2007b), very little is known about how these meetings work in practice. What is known suggests wide divergence; these teams vary considerably with respect to their context (e.g., the influence of national directives), features (e.g., group processes and size composition) and the extent to which there is meaningful patient involvement (Raine et al., 2014). In this study our main aim was to observe how MDT meetings work in practice in kidney transplant listing, to provide insight into the practical work and processes of transplant decision-making and conceptions of risk and uncertainty.

## **Context**

There are two transplant options for those with end-stage kidney disease (ESKD): they can have a kidney from either a deceased or a live donor. Irrespective of the source of the kidney, all patients are assessed to see whether they are suitable for transplantation or not. For those with a compatible live donor (such as a family member or a friend), the process of waiting becomes shorter. For those without a compatible live donor, activation on the waiting list or listing may be taken into consideration. However, to be 'listed' (put on the transplant list) a patient needs to meet certain health criteria. For patients with ESKD, decisions on whether to place marginally suitable candidates on the transplantation waiting list (including elderly patients with multiple interacting co-morbidities) can be challenging and involve multiple uncertainties.

Managing individual and collective uncertainty takes a central focus of interactional work in medicine (Rapley & May, 2009). Uncertainty may be linked with different factors, such as the impossibility of grasping all aspects of medical knowledge, skills, and technology. However, there may also be a lack of evidence surrounding specific conditions because research on the issues at stake has not been undertaken or because varying and contradictory results do not lead to a clear consensus. Moreira and colleagues describe this process as, 'a general feature of biomedicine's epistemic and technological dynamics, in that the production and temporary stabilisation of biomedicine's knowledge and entities requires continuous "uncertainty work" in the clinic' (2009:685).

Patient-centred factors, such as patient choice, behaviour (such as 'non-adherence' with immunosuppressant drugs) and co-morbidity, can also be a source of individual and collective uncertainty, which can have an important influence on the decision-making process (Kidger et al., 2009; Lanceley et al., 2008). Despite the move to adherence and shift away from compliance (Porter

et al., 1999), in this paper we use the term compliance, rather than adherence, because this was the term used by our participants -so it is used as an emic or 'members' term'. 'Patient compliance to medication is defined as the extent to which a person's medication-taking behaviour conforms to medical or healthcare professionals' advice' (Nichol et al., 1999, p. 531). Patient compliance with medical instructions has provided a focus for a large amount of research work in medicine and social science (Donovan & Blake, 1992), whereby non-compliant patients have been variously represented, sometimes characterised by 'deviant behaviour' and therefore blame-worthy (ibid, 1992).

When faced with the substantial unpredictability as to the kidney transplant outcome and a time pressure to select an appropriate treatment decision, patients with psychological and social contraindications to transplantation (e.g., non-compliance to medications, drug use, ambivalence) can present an ethical challenge for transplant practitioners (Gordon, 2000). In kidney transplant listing, uncertainty can arise from the competing imperatives of ensuring equity of access to transplantation on the one hand, and an efficient and effective use of scarce kidneys on the other hand (Gordon, 2000). These findings were identified by the only study we found in the literature investigating multidisciplinary team (MDT) meetings in the renal transplantation care setting. This was carried out by a medical anthropologist in the USA.

Clinical intuition and doubt are inescapable features of clinical decision-making and although uncertainty can at best be reduced or at least be managed, it can never be eliminated from medical decision-making (Hall, 2002; West & West, 2002). However robust the evidence, clinicians face the dilemma of applying it to individual patients (Fox, 2002; Griffiths et al., 2005). This dilemma is extensively discussed within related disciplines, such as medical philosophy, ethics, and health policy (Beresford, 1991; Gorovitz & MacIntyre, 1976; Tanenbaum, 1993; 1999).

Our study contributes to these discussions by illuminating the 'myth of certainty' (West & West, 2002, p. 319) through an empirical examination of real-time interactions in kidney MDT settings. In line with previous research on unpredictability and risk, we reflect upon the process of managing and negotiating unpreventable uncertainties (Zinn, 2006) in the renal transplantation care setting in the UK. Specifically, Zinn's (2016) discussion of the relevance of in-between strategies in decision-based processes based on trust, intuition and emotion provides a useful lens for viewing the work done in the kidney transplant MDT. He examines the impact of tacit or experiential knowledge to deal with risk and uncertainty rather than expert knowledge or scientific expertise, thus contributing to debates surrounding ways of knowing in healthcare and what evidence-based practice means in practice.

## Methods

The surgical implantation of transplant kidneys only takes place in a limited number of centres in the UK: there are 23 kidney transplant centres across the country serving 71 renal units. The non-transplanting centres typically care for the patient before and after the transplant operation (timing of repatriation after transplantation from the transplant centre varies depending on the centres).

The ATTOM (Access to Transplantation and Transplant Outcome Measures) study's national survey (Pruthi et al., 2018) about the structure and organisation of all the 71 UK renal units identified that the use of MDT meetings in decisions to list patients for

transplantation was common in 95 per cent of transplant units (22/23) and 67 per cent of non-transplanting units (32/48). The frequency of the MDT meetings was on average every 4.2 weeks (range: 1–16; median 4; IQR 1–4). Regarding the types of patients discussed in meetings, 36 per cent of transplant units and 28 per cent of non-transplant units reported that they discussed all patients in MDTs. The remaining units (64 per cent and 72 per cent, respectively) reserved MDTs for the discussion of ‘complex’ patients within their MDT meetings. Patients and family members do not typically participate in these meetings.

Information collected during the ATTOM national survey (Pruthi et al., 2018) helped the team to purposively sample a range of 11 renal units according to the geographical location, team composition, presence of a unit protocol for transplantation, frequency of MDT meetings and whether they discussed ‘complex’ patients – that is those patients with multiple co-morbidities, high risk for poor outcomes, and high cost (Rudin et al., 2017). Our study objective was to understand how MDT meetings work in practice in kidney transplant listing, and to explore and unpack the discussion of issues of risk and uncertainty in transplant decision-making processes.

As part of the NIHR-funded ATTOM project, we observed 11 MDT meetings in purposively sampled UK renal units to understand how MDT meetings work and how decisions are constructed and negotiated in real time, focusing in particular on decisions about listing patients for kidney transplantation and on possible live donors. We aimed to explore how clinicians discussed individual patients in MDT meetings and identify specific factors that practitioners invoked as important when discussing their decisions to list patients for transplantation.

Meetings in 10 transplant units and in 1 non-transplant unit (775 minutes of observation in total) were observed between December 2014 and August 2015. We aimed to observe one meeting in each of the selected units. Information was sought prior to the meetings on the role of MDT members, agenda items and room layout. Meetings were audio-recorded when the chair and the team consented. This study and method of consent received ethical approval (REC reference 11/EE/0120). Audio-recordings were transcribed verbatim and anonymised to assure confidentiality and anonymity of the patients and places discussed in the meetings and of the participating staff. Patients were not informed about this study. Consent to participate and audio-record the meetings came from staff members only. We were unable to audio-record two of the MDT meetings we observed due to participants’ worries surrounding patients’ confidentiality. Where possible, two researchers attended each meeting so that detailed field notes could be made (first author’s initial with either last author’s initials or third author’s initials).

This was a qualitative study, involving non-participant observation to capture conversations surrounding the decision-making process. We used a semi-structured approach to non-participant observation to record an in-depth understanding of how patients were constituted during case presentations and how risk and uncertainty are invoked through discussion during these meetings. Researchers sat at the back of the meeting rooms to focus on taking notes about the group interactions. Researchers were not clinically trained, and all three had a background in social sciences (Anthropology, Sociology and Psychology).

Observation forms (please see Form A1 in the [Appendix](#)) were used to log the main content of the meetings. The forms included field notes about information sharing and communication, leadership style, cohesion, factors influencing decision-making and the

final outcome of meetings, including whether specific risks and/or uncertainties were discussed. Informal conversations took place with some of the MDT participants before or after the observation of the meeting. No additional interviews took place with research participants because our main aim was to capture the discussions and decision-making processes within meetings.

Regarding the frequency of MDT meetings in the units visited, five units had meetings every week, one unit every two weeks, four every month and one unit every 8 weeks. Six of the meetings that were observed discussed complex patients only (5 transplant units and 1 non-transplant), whereas others discussed all patients being considered for transplant listing. There were differences in the number of staff attending the MDT meetings observed, with a minimum of five to a maximum of 25 staff members per meeting; median of 11 participants (IQR = 5). Whilst the composition of MDTs varied, all MDT meetings included nephrologists, surgeons and co-ordinators (with varying job titles including transplant recipient co-ordinator, live donor co-ordinator, nurse co-ordinator). Only one MDT meeting had no surgeons in attendance. Other healthcare professionals attending variously included pharmacists, anaesthetists, clinical scientists, pathologists, secretaries and dieticians. One unit had a 'complex clinic' attended only by a nephrologist and a transplant surgeon to discuss more complex cases, with others joining later to discuss the listing of all other chronic kidney disease (CKD) patients.

Observed meetings lasted from 26 to 110 min, with a median of 49 min. Most of the discussions dealt with recipients (174) rather than live donors (39). It is important to clarify that some discussions in the MDT meetings we observed were about donor patients (live donors) under the team's care rather than the decision to list only. Between 2 and 91 patients were discussed in meetings with a median of 8 per meeting.

Anonymised transcripts of MDT meetings and accompanying field notes were analysed using thematic analysis (Braun & Clarke, 2006) assisted by QSR NVivo V.10 software. Although this was mainly an inductive process, we did draw on concepts and ideas found in the literature to help identify, characterise, and explain the data. Following principles of constant comparison, we thematically analysed data in an iterative manner. This involved moving back and forth between transcripts, audio-recordings and field notes (Quinn Patton, 2005; Silverman, 2006). Familiarisation with the data and the content and process within each MDT aided the production of summaries of each observation (Barbour & Barbour, 2003). After repeated readings (while listening to recordings) MC and GML developed an early coding framework based on five MDT meetings. 'Crude counts' of observations and themes provided an indication of their frequency (Silverman, 2006). In a sample of five transcribed MDT meetings, other team members independently checked the validity of the early codes and the accuracy and consistency of their application to the data. The consistency of coding and interpretation was also checked during analysis by revisiting annotated transcripts at different time periods. Codes were iteratively developed by all investigators and eventually all data organised and codes merged to generate themes that captured the key features of MDTs with special reference to factors which appeared important in terms of influencing participants' decisions to list. Theme descriptions (in the findings section) were obtained through an integration between observation fieldnotes and transcripts of the group conversation.

## **Findings**

### ***Formats of MDT meetings***

In meetings where a large number of patients were presented, patients were quickly introduced; often a decision had already been taken outside the meeting by individual consultants and the team members were approving that decision as a group. The participation of those present and the consequent nature of the decision-making process varied across the 11 units visited. In some MDTs all members appeared to be free and able to participate equally in the overall discussion and final decision, whereas in others the seniority of some staff members appeared to shape the degree of participation (for example, senior surgeons and nephrologists displayed a more authoritative stance and appeared to have a bigger role in directing the final decision). In some cases, decisions had clearly been made outside of the meetings, and were, it seemed, taken to the MDTs to enable formal ratification of those decisions. Meetings in two units were structured quite differently: in the first case, there was a ‘general’ CKD meeting attended by several different healthcare professionals and another meeting only attended by a leading nephrologist and surgeon to discuss complex cases (defined as a ‘complex clinic’). In the second case, a leading nephrologist with recipient and live donor coordinators attended the meeting to discuss all the patients. In three units, there were specific unit protocols in place based on a traffic light system (e.g. green, amber, or red whereby red was assigned to high-risk patients) and teams used scores to guide assessment of the level of complexity of individual cases.

### ***Thematic analysis***

We focussed our analysis on understanding first how patients were presented and second how management options were discussed and decisions implemented or deferred following the patient presentations. Hence, thematic analysis identified findings on patient case presentation (when discussing complex cases) and decision-making. Exemplary quotations are used throughout to evidence our key findings.

### ***Constituting the patient during case presentation***

As might be expected, patients were constituted through their clinical characteristics and particular risk factors (Silverman, 1981), but this work also involved recounting individual patient behaviours. These were presented as particularly relevant when they represented a threat to patient compliance and ultimately the success of transplantation.

In the section below, we show examples of how patients were constituted through their clinical risk factors and their level of compliance. The latter was discussed in terms of psychosocial factors and individual behaviours. Disability and capacity to consent were also invoked as relevant to the discussions and decision-making process. Finally, we look at how medical uncertainty was, perhaps unsurprisingly, an omnirelevant feature of the MDT meetings observed (whether implicit or explicit).

### ***Constituting the patient: The case of clinical risk factors***

The MDT teams discussed different clinical risk factors when engaging in discussions about patient suitability for transplantation. [Table B1](#) in the [Appendix](#) lists the range of clinical risk factors discussed at the MDTs. In [Extract 1](#) below, we provide an example of

the way in which patients are constituted -this is a verbatim transcription of the MDT conversation:

Extract 1

(Transplant surgeon 1): Yes, he's a xx-year-old gentleman, end stage renal disease, secondary to diabetes. He also has hypertension and cerebral infarct on CT, but no dysfunction and also a history of DVT [deep vein thrombosis] in the right lower limb, he was on warfarin [an anticoagulant used in the treatment of thrombosis] but stopped in 20×x. Also, he has an amputation of forefoot, right forefoot due to diabetic ulcer in 20×x. His BMI [body mass index] is 23 and his cardiac work up, recent cardiac work up, echo showed ejection fraction of 50 to 55. MPI [Myocardial Perfusion Imaging, a test done to see if the heart is at risk of ischaemia at stress] show no ischaemic changes. He has duplex [ultrasound test that shows how well blood is flowing through the carotid arteries] in his femoral vessel which showed good flow in the iliac vessel, there's no evidence of thrombosis in the veins and this was in 20×x, I think, the duplex, so this needs to be repeated. CT showed extensive calcification in the pelvis, we're going to see this now, and his thrombophilia screen was negative. From the last meeting to transfer the CT images, there was an issue about his history of heart failure, he was followed up in heart failure clinic, so he needed a referral to cardiology.

In Extract 1 a comprehensive list of factors is presented including patient co-morbidities, such as, for instance, malignancies, vascular disease, diabetes and hypertension. Body Mass Index (BMI) was also discussed when deemed to be too high, as well as a summary of relevant test results and transplant work up. This Extract also hints at the routine and rapid-fire presentation of the list of risks, which is easier to appreciate when listening to the recording of course, as well as the use of technology and tests to support the list of relevant features (for example, through CT – CT scan or computed tomography to reveal anatomic details of internal organs).

During the discussion of these complex case presentations, questions followed during the MDT meeting and MDT members shared further relevant information and clarifications. These presentations often represented the starting point for discussion. In some cases, the information shared might have been a reminder of previous conversations if a complex patient was repeatedly brought to the attention of the team in previous meetings, or if the group needed to wait for test results before proceeding with a decision.

***'Compliance'***

Patients were constituted through a variety of characteristics, such as disability, capacity to consent and individual behaviours (such as smoking, drinking alcohol and whether they did not attend a clinic-DNA), all of which were discussed as potentially affecting patient compliance. Patient compliance was constructed as a key concern for the health care team as were psycho-social factors that could affect possible compliance. Below in Extract 2 a nephrologist 1 in the following extract, a verbatim transcription of a patient presentation during a MDT meeting:

Extract 2

(Nephrologist 1): He's in a wheelchair, he's a very compliant patient, presented quite late, he went on to dialysis after a week period in low clearance.

Similarly, transplant surgeon 2 describes another patient, discussing compliance as an important factor:



Extract 3

(Transplant surgeon 2): So [name] saw her in January, [name] two previous transplants; first on the left side in xx, functioned till xx, failed. There were some questions about compliance.

In Extract 3 transplant surgeon 2's reporting conveyed some distance from the patient, implying that he/she might not know the patient very well. This was also strengthened using the impersonal ('There were some questions about compliance'). Those questions were not made explicit during the case presentation. This example is reminiscent of Goffman's work on footing work (1981); he suggests that a speaker is not a unitary entity. The speaker, in this specific case, is an animator rather than an author, which means that he/she physically produces the words rather than selecting them. In contrast, in the extract below transplant surgeon 3 and MDT chair discussions suggest they know the patient ('Over the four months that I've seen him'), taking on the role of author:

Extract 4

(Transplant Surgeon 3 and MDT chair): He has obsessional thoughts about having a girlfriend, admitted that his life is completely meaningless without one to the point that he remains uncertain about whether he would want a kidney transplant without a girlfriend. Over the 4 months that I've seen him, there has only been moderate improvement in his thinking, which appears not to have been sustained.

(Nephrologist 2): I suppose the question there is to what extent that will impact on his compliance with treatment?

Disability and patient capacity to consent were also taken into consideration when discussing the transplant outcome and issues related with compliance. In the extract below, healthcare professionals talked about a patient's social environment, and capacity to communicate and consent:

Extract 5

(Transplant surgeon 4): Can she understand you?

(Transplant co-ordinator 1): I wouldn't say, they say that she can be involved in what she wants to eat or you know, if they show her things she says kind of yes or no. And in her own way – she doesn't say words, she doesn't have a comprehension of language as such but there's another girl in the home who has similar syndrome and ability to her, and the staff feel that they communicate with each other, they laugh with each other. Her family, and her carers fully believe that they can communicate with her. I couldn't ask her a question and she give me any kind of answer, it's not like that. She can't say words to me.

In the end, following discussion with the MDT participants after the case presentation, the final decision was made when the team agreed that the transplant would improve the patient's quality of life despite her disability.

Smoking and drinking alcohol were also discussed as individual behaviours that could jeopardise the prospects of a positive transplant outcome. When it came to smoking, nephrologist 2 and 3 agreed with a transplant co-ordinator that the patient needed a stress test before he could be admitted on the waiting list as the conversation below shows:

Extract 6

(Nephrologist 2): And he's kept smoking, he's got poor exercise tolerability ... he ought to have a stress test, I think.

(Nephrologist 3): Yes, so before we accept him onto our list ...

(Transplant co-ordinator 2): Yes.

However, the negative impact of drinking was left implicit during the MDT discussions we observed. There was a taken-for-granted shared knowledge of this behaviour and the potential for a deleterious impact on transplant outcomes. The conversation between transplant co-ordinator 3 and nephrologist 4 in Extract 7 illustrates this:

Extract 7

(Transplant co-ordinator 3): The patient drinks 10 cans a day, 70 units a week.

(Nephrologist 4): Yes. The only issue is drinking.

Whether patients had a history of attending their medical appointments or not was also constituted as a risk to successful transplantation and thereby a patient behaviour or characteristic worthy of consideration. When talking in the meetings healthcare professionals typically classified those patients that did not attend as 'DNA'. DNA behaviour was discussed as a potential indicator of or 'category-bound' (Sacks & Jefferson, 1995) with non-compliance behaviours post-transplant:

Extract 8

(Nephrologist 5): Ok. I think my first one here is [name], who ... a young lady with bad FSGS [Focal Segmental Glomerulosclerosis, which refers to scar tissue that forms in parts of the kidney called glomeruli] who lost her first kidney quite early on, and I think she's reluctant and also, we're slightly reluctant at present, but that hasn't really changed. So, [name] has, I think, DNA'd twice my offer to meet her in clinic to discuss her non-compliance, which probably suggests that it is a bit of an issue ... at least with that we know that the health care assistant has directly spoken to her.

In this section, the MDT data have allowed insight into the way in which patient cases were constructed in meetings, the issues at stake and factors that might militate against or optimise the chances of a successful transplant outcome in renal MDT meetings. Analysis illustrated a careful articulation of and then weighing of evidence. In so doing, the elusive nature of the 'perfect' candidate for transplantation in these complex case discussions was invoked. During patient case presentations in MDT meetings, complex patients might be constructed and viewed through a diverse lens linked with the risk of non-compliance. Referrals to other medical specialities were used as ways to facilitate the ruling out of the risks raised to enable a final decision about whether to list for transplantation. Medical abbreviations were widely used and accepted, and team discussions were sometimes based on tacit knowledge as well as on (un)written procedures. Sometimes the reasoning and consequences of topics discussed were implicit, assuming participants' shared and mutual understanding of the relevance of material included in presentations for team consideration.

Healthcare professionals talked about the importance of meeting the patient face-to-face to overcome doubts and to shed light on the reasons behind their behaviours. Healthcare professionals discussed how to assess the relevance of different types of

uncertainty. For example, they discussed uncertainty about patients' behaviours in terms of compliance, but also medical uncertainty borne from limited evidence on a specific medical condition. In the next section, we focus on discussions of medical uncertainty and decisions to list for transplantation. This section and the following one explicitly describe how 'uncertainty work' (Moreira et al., 2009, p. 685) was continuously enacted in MDT meetings due to patients' behaviours (psychosocial factors) or medical uncertainty. In the next section, we focus on medical uncertainty through examples of complex patient cases in transplant decision-making processes.

### ***Medical uncertainty***

Medical uncertainty was, unsurprisingly, a visible feature of the MDT meetings that were organised to focus on their complex patient cases. This uncertainty was variously linked with patients with rare conditions which were likely to, or at least had the potential to, complicate transplantation. Equally, a deficit of information or credible evidence on specific conditions and how these may affect transplant outcomes were also topicalised during discussions.

Not all discussions were about listing only but included potential live donor patients too. For instance, in the extract below, MDT members discussed how a donor-developed chronic pain after donation and how none of the consultants were able to explain it. Therefore, MDT members discussed whether it would be helpful to refer the patient to a different speciality. Transplant surgeon 5 explained:

Extract 9

(Transplant surgeon 5): Yeah. So, the last one is a chap that [name of consultant] mentioned briefly, [name of patient], who was a donor to his friend just over a year ago, and had severe pain right from the word go, about approximately day two, which was entirely normal, went home after about ten days. I think he has had some issues at the time. Since then his, I suppose, failure to thrive, to better describe it. He has had chronic pain. He feels his life has been devastated by this. He looks like an invalid when he comes in. You saw him at six months I think, [name of consultant]. He came back to see [name of consultant] a month or so ago because he really wasn't getting anywhere. He's been through the pain clinic in [name of the place]. [Name of consultant] saw him, didn't really have any ideas, we did a CT which was completely normal. So, [name of consultant], basically says his own thought is, is there any other speciality, such as gastro? Basically, saying does anyone else have any ideas because he doesn't.

On the other hand, the following extract shows how difficult it was to assess the situation when dealing with rare cases and a dearth of information/evidence on a particular condition. In Extract 10, consultants utilised the Internet to find the only published article to discuss the rare condition -verbatim extract of the discussion:

Extract 10

(Nephrologist 6): Hyper protein is thought to be his systemic and can occur . . .

(Nephrologist 7): Three cases in the literature (laughs).

(Transplant Surgeon 6): Ok.

(Nephrologist 6): So, it's very rare.

[Participants talking over one another]

(Nephrologist 8): Dr. Google says [laughs]. Nephrologists googling ...

(Nephrologist 6): There's an article from 1997 in NDT [Nephrology Dialysis Transplantation – journal], that's the only one I could find.

(Nephrologist 7): That's the one.

(Nephrologist 6): Is that the one you were looking at?

(Nephrologist 7): Yeah. As [name] says, p-google, Physician Google.

During our observations this was the only time consultants used the Internet/Google during the MDT meeting.

A traffic light system was also applied in some units to indicate which patients needed to be reviewed and was an indication of how much medical uncertainty there may be around these individual cases – especially when amber was the final result. In one unit this was used to pre-emptively select high risk patients for the group MDT discussion. In other units, other scores, such as the Newcastle Score, informed their guidelines on the listing of 'complex' patients. The Newcastle Score identified the risk of mortality for patients at 2 years post transplantation. These classification systems represented strategies to deal with uncertainty work in the clinic (Moreira et al., 2009) to achieve a final outcome for very complex patients. They represented collective 'classifications of risk and uncertainty' (Riesch, 2013, p. 29).

### ***Theme 2. Decision-making processes in the MDT meetings***

MDT narratives included decisions to list or not list, and whether to accept live donors or not. These included either a group decision or an individual in a specific role (for example a transplant coordinator, or a MDT chair) taking a lead in articulating the preferred decision and inviting agreement, based on the unit protocol. The discussions were aimed at clarifying any sources of doubt to enable a final consensus to be reached. These were identified as strategies to mitigate medical uncertainty. In the section below, we analyse how a decision was enabled through team support and how group consensus was legitimated through a final check.

#### ***Enabling a decision through team support***

Extract 11 provides a verbatim transcription of the MDT conversation, to illustrate how a team mobilised knowledge of a patient's clinical risk factors to enable decisions to be made in the MDT space:

Extract 11

(Nephrologist 9 and MDT chair): If you take everything else out, is the GAVE [Gastric antral vascular ectasia] insurmountable?

(Nephrologist 10): Yes.

(Nephrologist 9 and MDT chair): No, no, I mean before transplantation. I know that ...

[Nephrologists, surgeon, and lead anaesthetist discuss issues around the patient's blood pressure and aortic stenosis]

(Nephrologist 11): I mean I think our experience of transplanting people with very low blood pressure is not encouraging. Even that in isolation we've had terrible experiences in people who are very hypotensive. They don't perfuse the kidney, they go prolonged ATN [acute tubular necrosis], the grafts don't seem to last very long and then you add on the top of that the GAVE, 25 years of diabetes with BMI average must be over 35.

(Nephrologist 9 and MDT chair): Yes.

(Nephrologist 10): Her poor functional status, her Aortic Stenosis, her anaesthetic risk, I think for me it's a non-starter unfortunately. It's better. . .

(Nephrologist 11): Yes, I can't see it happening.

(Transplant Surgeon 7): Anyone disagree with that?

(Transplant Surgeon 8): No.

(Transplant Surgeon 9): No.

(Transplant Surgeon 7): Okay, so permanently unfit.

(Nephrologist 10): She'll be very disappointed, but I think she's gone beyond that.

(Nephrologist 11): I think she will withdraw.

(Nephrologist 10): Withdraw from dialysis. Yes, she may well.

(Lead Anaesthetist 1): It's very sad, but yes.

(Nephrologist 9 and MDT chair): Yes, we can't change our decisions.

In the extract above, the team defined the patient as permanently unfit for transplant listing and healthcare professionals discussed whether, consequently, she would withdraw from dialysis. This was not an easy decision to take (the lead anaesthetist 1 reported that it was *'very sad'*): this was also evidenced by the sober tone of voices described in our fieldnotes. The team helped individual consultants to support each other through the sharing of views and the discussion of different factors. Discussion led to team consensus on the most appropriate outcome, following a series of strategic questions, and in turn had the effect of publicly transferring the responsibility from an individual to a 'team'. It is worth noting the central role played by nephrologists in this specific case and how decisions are informed by past experiences and knowledge gleaned therein to help build evidence for a non-transplantation outcome. The extract ends with 'we' and 'our', a language that signals a joint decision, calling forth the collective 'voice' of medicine (Mishler, 1984).

### ***Group consensus and check***

When comparing how group checks for decisions were managed it was notable that there were several approaches. Group hierarchy played an important factor in some meetings, with MDT chairs playing a key role in facilitating group consensus (Brown et al., 2016). Observations also captured senior surgeons play an important role in some MDT interactions, facilitating the decision-making process. This is in line with previous literature on the construction of surgeons in medicine, a profession that has usually attracted individuals that are perceived by other healthcare professionals as having strong personalities, courage, and comparatively high levels of expertise (Green et al., 2017). Similarly, senior nephrologists were also taken into more consideration when it came to challenging decisions in MDT meetings.

The decision described in the previous section was checked by transplant surgeon 7, by explicitly inviting members to be forthcoming should they disagree the decision being formed. Interactional research has shown that social actors avoid dis-preference (Buttny, 1993) and have a tendency towards affiliative moves such as agreeing versus disagreeing so for members to disagree in the case above would have taken a certain amount of interactional work. By contrast, in the next extract, transplant surgeon 10 asked the other team members ‘*so let’s just go around the room?*’ to invite different views and perspectives before the final decision was made. Group consensus was achieved:

Extract 12

(Transplant Surgeon 10): [psychologist]’s passed her now, we are printing the letter. [lead anaesthetist 2], what do you think from your point of view, let’s just go around the room?

(Nephrologist 12): So, I think she’s going to be difficult. I mean I think she’ll be at risk of rejection, and I think her [blood] pressure will be tricky, but I think she will turn up and I think she will probably take her tablets, and I think on that basis she should probably have a better chance. Medically, I think she is alright. In terms of fitness for surgery, anaesthesia ...

In another meeting, agreement was sought before moving to the next stage:

Extract 13

(Transplant surgeon 11 and MDT chair): So, if everybody’s happy and has nothing better to add about [name], we’re just going to hear about the donor and the kidney that she’s going to be receiving.

Meetings were also described by some MDT team members as a ‘*final check*’ to make sure all recipients were being ‘worked up’ for transplantation and there was no delay:

Extract 14

(Nephrologist 12): So essentially these two are live donor coordinators as they’ve just said. We have recipient coordinators. They’re stuck with a patient and hopefully they come right now. We read work up and is there a delay? If so, why is there a delay? What is happening and what have they got medical assessments, pretty much to go through the work up and also live donor patients who already have the donor being worked up they will tell us about the stage of the donor work up, are there any issues there? Then we do a final checklist for the recipient. We would do a final checklist before they are listed, whether they go on a list or are listed to be suspended for a live donor. The process is the same. So, all that will be done and on the final check then they’ll be listed and if they have a live donor who is already worked up and everything is ready we will also plan dates. So, the whole process takes place in this meeting.

In and through their talk the interactants constructed a system of group consensus and final checks to enable individual consultants to discuss sources of doubt and to agree on a course of action most likely to result in the best outcome for each individual patient. Regardless of the amount of information sifted, presented, and discussed, uncertainty seemed to be an omnirelevant feature at the point of making (or beginning to make) clinical decisions for individual patients (West & West, 2002). Some MDT team members mentioned to us that the MDT meeting helped them to take decisions ‘*in an evidence based and objective fashion*’. In the meetings, clinician discourse invoked the role of clinical intuition and experience as evidenced in informal/idiomatic expressions such as ‘*my gut feeling*’. The challenging nature of medical practice has been described

as based on the tension or co-existence between professional expertise and intuitive judgement (May et al., 2006; Woolley & Kostopoulou, 2013). Some MDT team members also told us that decisions were often or sometimes (depending on the units) taken outside the meetings and then officially ratified when staff members come together in MDT meetings, reflecting the reality of the distributed nature of decision-making (Rapley & May, 2009).

In the extract below taken from our fieldnotes, the distributed nature of decision-making is made explicit. Moreover, the role of healthcare professionals in presenting their patients is seen as fundamental in moving the listing decision-making process forward. Healthcare professionals may act as patients' advocates, clarifying reasons for decisions, or as information finders through questioning in search for clarification surrounding risks and uncertainties.

*Fieldnotes: Nephrologist 1 (N1) presents case as she is the person who added patient to the agenda. N1 gives details about patients to the group and describes history. N1 clarifies reasons why she wants to add patient to the tx waiting list. N1 states there is confusion about a note on the patient's file which highlights risk of bleeding and queries whether patient needs to talk with transplant surgeons again. Chair raises query. Surgeon 1 (S1) clarifies that they have a protocol in place for managing coagulation. Nephrologist 2 (N2) makes comment. N1 clarifies that patient has normal ECHO and exercise test. Summarises previous correspondence. N1 looks at both surgeons whilst discussing for clarification and approval. N1 presents comments from another surgeon who is not in meeting, looks at surgeons present who both nod in agreement to clarify that what N1 has been told is correct. Chair also checks with both S1 and S2 that they are happy. S2 comments on the patient's situation. S1 and S2 have own conversation between themselves whilst N1 keeps talking. Chair clarifies details. Group have discussion about allergy status of patient. They confirm that allergy will be added to computer database. N2 queries a point. S2 queries a point. Chair and N2 comment. Chair summarises and confirms everyone is happy to add patient to list.*

The fieldnote above highlights how nephrologist 1 has 'added a patient to the agenda' and later 'clarifies reasons why she wants to add the patient to the tx [transplant] waiting list'. As in the previous section about constituting patients, we observed the importance for healthcare professionals of meeting the patient face-to-face and establishing a relationship with them. When the healthcare professionals manage to establish trust relationships with patients, the patient outcomes generally improve (Dibben & Lean, 2003). Moreover, previous research in transplant decision-making has also shown that physicians reported 'a tendency to argue more strongly for patients with whom they had a long-standing relationship' (Volk et al., 2011, p. 6), becoming important patient advocates and representing them more prominently in MDT meetings. This may be possibly through processes whereby knowing patients better, healthcare professionals were able to overcome some of the uncertainty that came with patients' psychosocial complexities. In line with previous literature (Doyle et al., 2014), some MDT teams relied on psychologists to evaluate patients' psychosocial issues.

## Discussion

In the MDT meetings we observed, patients and family members were not present. Rather, healthcare professionals presented patients and their family/social context, carefully sifting information and trying to ensure fairness when characterising the

patients fit for transplantation. The MDT decisions we observed considered clinical risks as well as issues related to patient compliance and the uncertainty of the transplant outcome. Compliance and non-attendance (DNA) of medical appointments were constructed as risks and as ways to constitute patients (Silverman, 1981). In the meetings we attended, team conversations surrounding the risk of non-compliance and MDT members' perception of risk associated with adverse transplant outcomes clearly shaped the decision-making process, which was characterised by strategic question and answer exchanges between the diverse team members. Previous research has explored how strategic questions may be used to communicate team and professional identity, and collegial decisions (Arber, 2008). Additional studies have focused on how a patient's psychological and social information is addressed in interdisciplinary team meetings (Arber, 2007; Wittenberg-Lyles, 2005) and how sharing psychological and social stories helped build a positive relationship among team members (Arber, 2007; Li, 2004; 2005). This was also the case in our study, where team conversations were constructed around uncertainty surrounding patient behaviours. Through MDT group discussions, responsibility to grapple with and understand uncertainty appears to be 'distributed' amongst a group of healthcare professionals (Rapley & May, 2009), which has the potential to unburden individual consultants; this appears to 'share' the eventual decision and to accept it, even when it is very '*sad*' or when the final outcome is perceived as unsure. The case about a patient assessed as permanently unfit for listing was particularly evocative of the emotional challenges staff members may have to manage. Establishing long-term relationships with patients based on trust may mean healthcare professionals represent missing patients in meetings, becoming their advocates. However, even after advocating for them, the group could decide not to add them to the waiting list because of the high level of medical or psychosocial uncertainty.

Decisions about kidney transplant listing entailed a complex process, happening over time and often across different locations – with referrals to other medical specialities if necessary to manage and where possible to mitigate specific risks. The sharing of responsibility was a central feature to manage uncertainty and to negotiate the achievement of a final team ratified decision, constructed to be in the patients' best interests. The participation of those present and the consequent nature of the decision-making process varied across the 11 units visited. Indeed, in part, the team meeting environment appeared to shape the decision-making process (Wittenberg-Lyles & Parker Oliver, 2007). In some MDTs seniority, group hierarchy and staff members' roles appeared to have an impact on the degree of participation (e.g., senior surgeons and nephrologists displayed a more authoritative stance and seemed to have a bigger role in presiding over the final decision). In some cases, decisions had evidently been made outside of the meetings and were formally ratified in the meetings. There were no cases in our study where consensus was not reached. The closest to this was an agreement among MDT members to defer until further information could be gathered to support a decision later.

Clinicians' discourses, characterised by a wide variety of medical abbreviations and tacit knowledge, conveyed a strong sense of concern about the potential for a transplant to fail with the corollary of this being a lost kidney, thus implying important ethical challenges around equity on one hand and scarcity of organs on the other hand (Gordon, 2000). Fairness and equity of access to transplantation are issues that have widely permeated transplant medicine throughout its history (Kaufman, 2013; Swazey, 2017 [2002]). The high demand for transplant organs has framed the discourse around their



scarcity and intense organ shortages increase the gap between supply and demand each year (Sharp, 2013) and affect the decision-making process surrounding activation of patients on the waiting list. There was a sense in the discussions that it was not only about the equity of access, but also about the efficient use of limited organs. This discourse around efficiency was framed by the multiple clinical and psychosocial risks and uncertainties the multidisciplinary group had to consider carefully before making a decision to be presented to the patients.

Some patients were very difficult to assess because of these clinical and psychosocial risks and uncertainties. These involved patients that were difficult to think about because they presented a higher level of uncertainty in clinical terms (medical uncertainty) but also in terms of their behaviour or their capacity to consent (psychosocial uncertainty). These included individuals that were not really convinced about transplantation and therefore did not attend clinical assessments, vulnerable adults affected by disability or patients that were constituted as high risk because of specific health behaviours and or through their actual or anticipated non-compliance. These patients were not easy to classify and categorise; they acquired a liminal state, as conceptualised by Little et al. (1998), and provided an insight into symbolic boundary-maintenance (Douglas, 2002). This symbolic boundary maintenance between different risks and uncertainties was enacted through group classification systems (traffic light system and Newcastle Score), which categorised patients through their specific medical and psychosocial characteristics. The discussion of patients' clinical factors and individual behaviours also provided an example of how healthcare professionals engaged in boundary work between themselves in order to differentiate and position the authority of their medical or surgical subspecialties (Burri, 2008; Conn et al., 2016).

## Conclusions

In this study we have suggested variation across MDT meetings when it comes to frequency and duration of meetings, number of staff members attending, staff members' roles, type and number of patients discussed (whether complex or CKD patients) and discussion topics (whether listing decision or acceptable live donor). Beyond these descriptive parameters, our study provides insight into the complex issues that multidisciplinary teams routinely present and address when assessing patients for transplant listing and living donation.

Our research also provides for an empirical insight into the presence of uncertainty and the construction of clinical and psychosocial risks and uncertainties when considering patients for kidney transplantation. For instance, compliance and non-attendance or the risk of repeat 'did not attend' (DNA) appointments were discussed and managed to enhance the chance of an effective use of scarce kidneys. Managing these uncertainties is in large part accomplished through interactional work (Rapley & May, 2009) and the creation of in-between strategies based on what some have called 'tacit knowledge' (Zinn, 2016). Weighing of differing kinds of evidence and different ways of knowing in healthcare (experiential and evidence-based knowledges) enable collective decisions through continuous 'uncertainty work' in healthcare settings (Moreira et al., 2009).

In the MDT meetings we observed, patients and family members were not present. Rather, healthcare professionals present patients and their family/social context, sometimes through impersonal 'footing work' (Goffman, 1981) when they have not met the patients, and sometimes as 'advocates' when they know them well. This has implications

for patients' representation and constitution in meetings, and potentially equity of access to the waiting list.

Zinn discusses how managing risks and uncertainties happens through rational and in-between strategies (2016): the former is based on the calculation of pros and cons (in our study these were clinical factors and classifications systems, such as the traffic light system and the Newcastle Score), while the latter are based on trust, intuition and emotion. These in-between strategies are built through trustworthy social relationships – whether these are constructed with patients or with other professionals. Experiential evidence in these decision-making processes enhances the likelihood of a robust collective decision to optimise the efficient use of scarce organs and to overcome psychosocial uncertainties that emerge through patients' behaviours. This practical uncertainty work, others have argued, performs an essential role in the continuation of scientific knowledge production, the legitimation of professional orientations, and the validation of decision-making processes (Pickersgill, 2011).

However robust the evidence may seem to be, clinicians face the dilemma of interpreting and applying this evidence to individual patients. Therefore, there is a return to the role of the scientific evidence base vs or complemented by experiential knowledge often formed through relationships with and/or knowledge of the patient, as Griffiths et al. (2005) have discussed in their work. Decisions are often taken in dynamic and changing environments based on incomplete information and in contexts in which risk is considered and minimised. However, based on our observations, uncertainty was lived with and contained through team checks and counterchecks, thereby reducing the weight of individual responsibility in decision making. Indeed, MDT meetings when inspected empirically appear to provide a clear vehicle for healthcare professionals to share, process and manage the complexity and the uncertainty surrounding transplant listing decisions.

Our study also helps to build an empirically founded evidence base of just how complex these decisions can be and how vigilant MDT members are in the sifting of this complex biographical, experiential, and medical data to navigate towards a consensus agreement and final decision about what to do next. However, further research is warranted to understand whether greater multi-disciplinarity in MDT meetings is associated with more effective decision-making for transplant listing and indeed what features are likely to optimise the decision-making process. Future work could also examine the association between MDT decision implementation and improvements in patient outcomes, and implications for further interdisciplinary collaboration.

Finally, our thematic analysis has highlighted some areas for future, more detailed analyses including how the meetings work sequentially, how different participants seize or keep the interactional floor, take turns more generally, work to persuade for or against a particular course of action, sources of trouble, resistance or miscommunication and how, specifically, decisions are eventually accomplished. This more detailed work could result in recommendations to help train participating members in how best to understand, organise and participate in the crucial process of an MDT.

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**Appendix**

Form A1

**FORM ONE: Context/Meeting attendance/Main Content**

***INFORMATION TO BE COMPLETED PRIOR OR AT THE BEGINNING OF THE MEETING***

MDT meeting location:                      Date:                      Start/End Time:  
 Observer (initials):  
 No. of team members present:  
 Was a copy of the agenda provided?                      Yes/No  
 Clear structure:                      Yes/No  
 Room Layout/Seating Plan:                      (plan – please attach with participants’ initials):  
 Resources used:  
 Last time Minutes                      Yes/No (copy attached if provided)  
 Action Plan Feedback                      Yes/No (copy attached if provided)

LOG/MAIN CONTENT

<b>Main content of the discussion</b>	<b>Timing</b>	<b>Initials for transcripts</b>	<b>Role, Grade</b>	<b>Observation Notes (Keep in mind: -Information sharing and communication; - Leadership style; - Cohesion; -factors influencing decision-making; -final outcome)</b>
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Table B1. Clinical risk factors discussed at the MDTs we observed.

Clinical Risk factors discussed at MDTs
-Age
-BMI
-Compatibility with donor
-Living donor/pre-emptive transplantation
-Medical history and co-morbidities (e.g. diabetes and hypertension).
-Pre-Dialysis or on Dialysis
-Mental health
-Relisted patient
-Renal function/GFR/end stage renal disease
-Antibodies
-Blood Type
-DSA or crossmatch (determination of the presence or absence of donor HLA specific antibodies - DSA- in a patient by comparing the patient’s HLA antibody specificity profile to the HLA type of the proposed donor)
-Risk of bleeding
-Risk of immune suppression
-Test results (transplant work-up)
-Mobility
-Life expectancy
-Malignancies
-Family medical history