

## Original Article

# Navigating choices: understanding the decision-making journey of patients with localised kidney cancer

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## Objective

To explore patients' experience of decision making regarding treatment of localised kidney cancer.

## Methods

A total of 21 patients with localised kidney cancer, across three countries, participated in either four focus groups or seven semi-structured interviews that lasted on average 2 h. Focus groups and interviews were all conducted in the participants' native language, recorded, transcribed and (if applicable) translated into English. Thematic analysis was used to develop a codebook and identify themes.

## Results

All participants expressed a desire to be actively involved in the treatment decision-making process. However, due to the emotional toll of the cancer journey, which often necessitates quick decisions, actively engaging in the decision-making process was described as challenging. The study revealed 12 key themes. These themes included the impact of diagnostic paths, patient characteristics, patient empowerment, health literacy, source of support, fear of recurrence, trust in treatment and healthcare providers, shared decision making (SDM), professional interaction, personal belief system, and organisational and administrative issues.

## Conclusions

The findings highlight the complexity of decision making, underscoring the desire for patient involvement, SDM, and clear communication. We reveal a significant gap between research recommendations and clinical practice, emphasising the need to translate research findings to clinical application to enhance patient-centred care.

## Keywords

kidney cancer, treatment decision making, shared decision making, active surveillance, nephrectomy, ablation

## Introduction

In the last two decades, the number of patients diagnosed with small kidney masses has more than doubled, with most of the tumours smaller than 4 cm in size. Despite the small size, 80% of these kidney tumours are malignant [1,2].

Evidence has established that, even if cancerous, these small tumours might not spread or grow, meaning patients may never need invasive treatments [3]. In clinically fit patients, nephron-sparing surgery is the standard treatment for small kidney cancers. However, less invasive treatments such as

ablation (i.e., radiofrequency ablation and cryoablation) or active surveillance (i.e., closely monitoring for evidence of progression) are now available as well [4,5]. These treatment alternatives are associated with different risks and side effects. Surgery is effective but with risk of complications (e.g., bleeding) and treatment-related long-term side effects, such as reduced kidney function (e.g., chronic kidney disease). Ablative techniques may result in residual tumour requiring salvage treatment and may produce side effects, such as injury to normal kidney [6–8]. Active surveillance is a safe option for carefully selected patients with slow growth rates

(active surveillance studies report tumour growth rates ranging from 0.09 cm per year to 0.86 cm per year) [6,9]. The current guidelines do not highlight one of these three treatments as the preferred option and, to date, the only randomised controlled trial comparing treatment options for low-stage kidney cancer (radical vs partial nephrectomy) was underpowered [10]. The availability of these competing alternative treatments emphasises the need for shared decision making (SDM) by the patient and clinician. This study was designed to better understand how patients experience decision making, using a series of focus groups and interviews.

## Methods

### Design and Ethical Approval

A semi-structured interview guide was developed using the treatment decision-making framework described by Glazer *et al.* [11,12] (Tables S1 and S2). The discussion guide helped to structure the focus groups and interviews, i.e., participants were informed about the research and ethical components, and any remaining questions were resolved before the participants were introduced to the questions. The framework was developed particularly for oncology patients. It is centred around the following three 'domains of influence': (1) kidney cancer-specific characteristics; (2) decision maker-related factors; and (3) contextual factors [11].

The intent was primarily to perform focus group, however, participants who were not able to attend the focus groups or who preferred a one-to-one conversation were given the option of an interview. The COREQ (COnsolidated criteria for REporting Qualitative research) checklist was used as a framework for good conduct for the study (Tables S1 and S2).

King's College London (KCL; LRS/DS-20/21-22307) sought and granted ethics approval to recruit patients through the International Kidney Cancer Coalition (IKCC)-affiliated national patient associations: Kidney Cancer UK and *Das Lebenshaus* in Germany. The IKCC supported the recruitment in the Netherlands of the von Hippel–Lindau syndrome (VHL) patients. The Erasmus University Medical Centre (MC; MEC-2022-0442) approved the ethics application to recruit via the Erasmus University Medical Centre. All participants signed a General Data Protection Regulation-approved informed consent form.

The research was conducted by two experienced post-doctoral qualitative researchers, K.B. and L.V. (both female), allowing interviews to be held in the participants' native languages (German, Dutch and English). Following the first focus group session, the transcripts were shared with N.K. for additional clinical feedback. The research team did not have any prior relationship with the participants.

### Participants

Using a selective sampling method, participants (adults aged >18 years) were invited based on their initial kidney cancer diagnosis via e-mail. This was a multicentre study, conducted across three countries: Germany, the Netherlands and the United Kingdom.

One of the focus groups (four participants) consisted of individuals with the kidney cancer predisposition VHL, who had been undergoing different types of treatment over the years and who had been part of the IKCC. This group is particularly interesting because their experiences differ, potentially impacting their treatment decision-making experience. We therefore clearly highlight here the responses obtained from the VHL focus group.

### Data Collection and Analysis

Patients were recruited with the support of the IKCC and Erasmus University Medical Centre. Microsoft Teams was used to conduct and record the online focus groups and one-on-one interviews. The Microsoft Teams application was used to transcribe the English and German focus groups and interviews. The Dutch focus groups and interviews were transcribed by the researcher (L.V.) or a professional transcription service. The German and Dutch interviews were translated into English by native speakers (K.B., L.V.) to include those interviews in the analysis.

To develop a rigorous and replicable analysis, a codebook was developed using the framework proposed by Glatzer *et al.* as the underlying structure [13,14]. To analyse the data, thematic analysis was used, the coding was conducted by K.B. using NVIVO, and the codes were reviewed for accuracy by L.V. and N.K. [13,14].

## Results

A total of 21 individuals from the Netherlands ( $n = 11$ ), Germany ( $n = 4$ ) and the United Kingdom ( $n = 6$ ) participated in either four online focus groups or seven online semi-structured interviews that lasted on average 2 h (nobody dropped out). The analysis revealed 12 themes across the Glatzer *et al.* framework [11] (Figure 1, Table S1), which are discussed below. The most discussed themes were: SDM and source of support, followed by patient empowerment.

### Kidney Cancer-Specific Factors

#### Impact of the Diagnostic Path on Treatment Decision Making

Being diagnosed with kidney cancer as a result of other investigations, i.e., incidental findings, negatively impacted the

treatment decision-making process. Both the UK and German group participants discussed feeling overwhelmed by their diagnosis and being rushed to make a treatment decision, indicating that additional time would have supported them in their decision-making process.

### Specific Sociodemographic and Clinical Characteristics Influencing Treatment Decision Making

Participants felt that specific patient characteristics can influence treatment decision making, such as the demographic factors 'age' and 'comorbidities'. For example, older patients with existing health conditions may feel more inclined to choose less invasive treatment options, reflecting their concerns about longevity and overall health status.

#### Decision Maker-Related Factors

##### Patient-Specific Factors

*Patient Empowerment* To take an active role in their healthcare, seeking clear communication and information from their clinicians was expressed by participants as a way to feel empowered. Participants stressed that being informed about their treatment plans was essential for their confidence and engagement, enabling them to voice their thoughts and concerns without feeling like a nuisance.

*Health Literacy and Information Needs* The influence of personal experience and medical knowledge on treatment decisions was another source of discussion. Higher health literacy seems to help patients better understand their disease, their treatment options, and what to expect. Moreover, participants discussed their comprehension of information during the process of diagnosis and its impact on treatment decisions. Participants expressed their confusion surrounding medical jargon, leading some to seek clarification through online searches.

*Source of Support* Participants highlighted the importance of psychological/emotional support in decision making (Table S2). They mostly felt supported by healthcare providers in their physical recovery but felt they were left alone to deal with their mental health. Moreover, involving family in the decision-making process was expressed to be difficult or helpful; depending on the situation, this could help with the comprehension of the information but could also lead to additional emotional stress.

*Fear of Recurrence* Participants also reported that fear of recurrence had a significant impact on their treatment decisions. Concerns were expressed about the possibility of the cancer returning, which influenced the thoughts and

actions of the participants. This anxiety often led individuals to contemplate what management would look like in the future and what signs they should monitor for, underscoring the psychological weight that such fears can have on their overall treatment choices.

*Trust in the Treatment Option and Treating Healthcare Provider* Trust in the treatment option (or lack thereof) was highlighted in the German and UK focus groups and interviews, as well as trust in the treating clinician. Participants highlighted their concerns when they were faced with differing recommendations from various healthcare professionals, which undermined their confidence in the treatment process. The lack of a clear consensus among consultants could lead to feelings of overwhelm and confusion, making it difficult for participants to process their options effectively. In Germany, the focus group agreed that a second opinion was very helpful and increased their feeling of security in whether they were making the right decision or not. In the United Kingdom and the Netherlands, participants expressed how multi-disciplinary team discussions increased their confidence in the treatment options presented.

*Patient–Physician Interaction: Importance and Aspects of SDM* The importance of SDM in kidney cancer treatment was extensively discussed across the three countries. Active involvement in the treatment decision-making process helped to better understand the side effects and overall treatment journey, allowing the participants to feel more informed about their choices. They noted it helped when healthcare professionals provided a realistic picture of the long-term risks associated with different treatment options, highlighting the trade-offs involved. Clear communication about the consequences of decisions was crucial in empowering patients to make choices aligned with their values and preferences.

##### Physician-specific Factors

*Professional Interaction* The professional interaction with the clinician played an important role for the participants in physician decision making. An empathetic doctor significantly impacted their experience. They valued not only the clinician's competence but also the clinician's ability to connect on a personal level, emphasising the importance of eye contact and a compassionate approach.

*Personal Biases and Motivations in Treatment Recommendations* The impact of personal biases and motivations on treatment recommendations for kidney cancer was expressed by participants. For instance, one participant compared the situation to seeking advice about a car: a salesman might suggest replacing it instead of repairing it, while a mechanic would likely advocate for a repair. This

analogy highlighted the potential for healthcare professionals' personal preferences and specialisations to influence their treatment recommendations, raising questions about the objectivity of their advice.

## Contextual Factors

### Organisational Issues

The availability and accessibility of diagnostic and treatment options for kidney cancer influenced the treatment decision making of the focus group participants. Participants expressed concerns that doctors often focused on what they could offer within their own hospitals, suggesting that financial considerations might impact the recommendations given.

Some participants expressed a clear preference for online/telephone consultations, whereas other participants highlighted that the method of consultation should be dependent on the information that is being communicated. For instance, participants felt that an initial consultation should be face-to-face, as this helps establish a relationship with the doctor. However, once patients have become familiar with their healthcare providers, the participants believed that follow-up communications, such as laboratory results, could be appropriately handled via telephone.

### Administrative Issues

Participants' experience of their healthcare system had a direct impact on their level of trust, especially episodes of miscommunication between hospitals and/or departments. Instances of such miscommunication contributed to feelings of frustration and confusion. Participants discussed the importance of effectively navigating the healthcare system, noting that their ability to do so significantly affected their mental health and overall trust in the system.

How best to navigate the healthcare system was picked up by the participants as a factor that impacted their mental health and trust in the system and choosing the 'right' hospital for kidney cancer treatment played a particular role in the experience of participants. For instance, one participant expressed that being treated in a smaller, more accessible hospital was beneficial because it allowed family members to visit daily, which provided emotional support. In contrast, the larger university hospitals, while potentially offering more advanced treatments, posed challenges related to distance and accessibility for their loved ones.

## Discussion

This study explored factors that affect patients' decision making by recording the perspectives of the treatment decision-making process of patients across the United

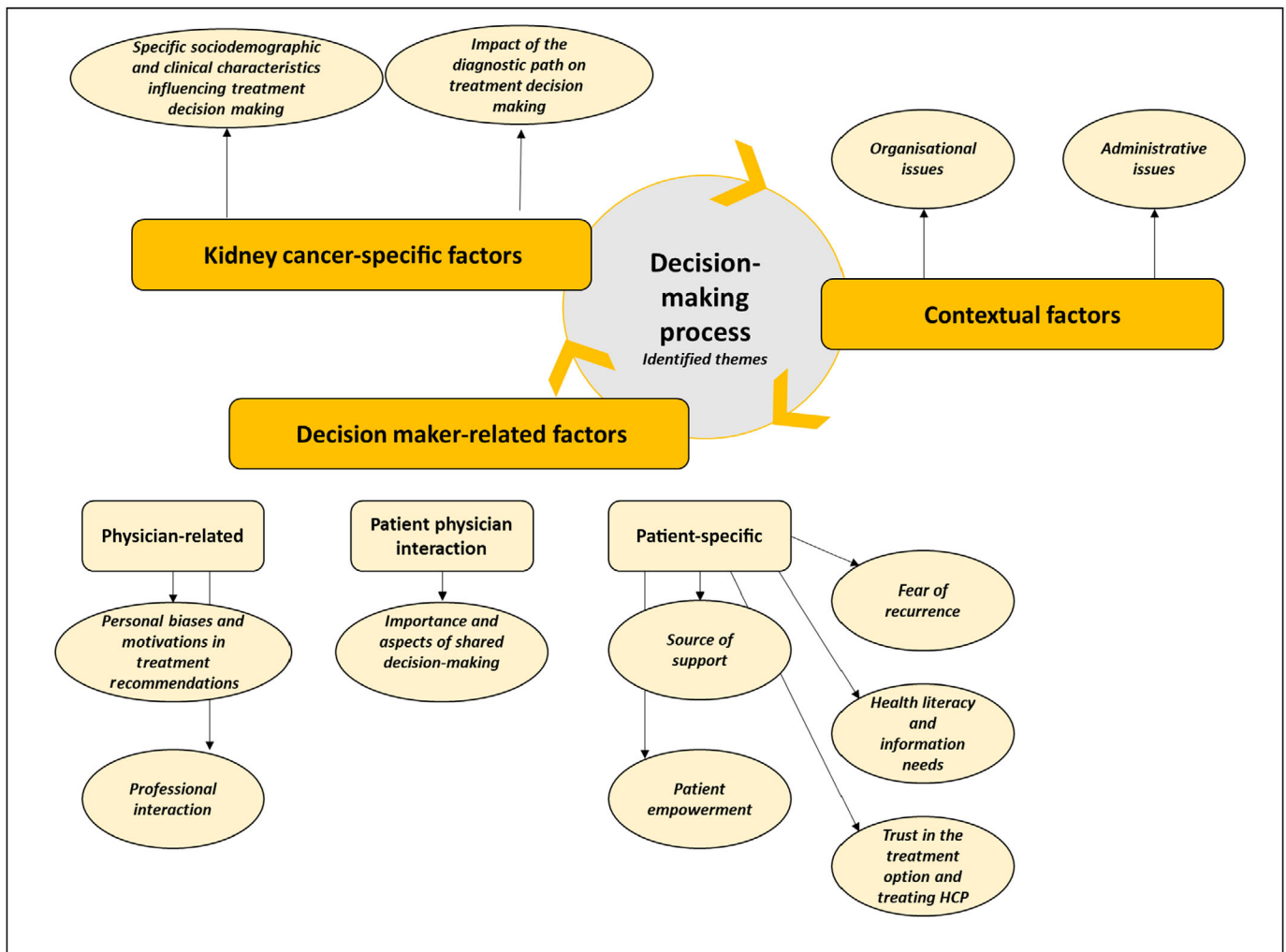
Kingdom, the Netherlands and Germany. The study improved our understanding of the factors that influence treatment decision making for patients across three countries (Fig. 1).

The impact of incidental findings, included in 'kidney cancer-specific decision maker-related factors', on decision making was significant for the participants, who were overwhelmed by an unexpected kidney cancer diagnosis, and who struggled to comprehend the given diagnosis. Making decisions related to cancer often involves predicting how different courses of action will make one feel, which can be challenging when faced with a sudden diagnosis and unfamiliar treatment options [15]. This emphasises the need for improved communication and support during the diagnostic process to better prepare patients to cope with potential incidental findings and help them select a treatment.

Across cancer care and in our study, included in the 'decision maker-related factors', patient empowerment has been shown to positively impact patient satisfaction with care, increase adherence to treatment self-management, and result in better clinical outcomes [16,17]. Patient empowerment was also linked to 'health literacy and information needs'. Across all countries, participants agreed that, to enable them to make an informed treatment decision, it was crucial for them to understand the diagnosis, all treatment options, and the consequences of each choice. According to Edwards *et al.* [18], by fostering a collaborative relationship between healthcare professionals and patients, it is possible to overcome the barriers to health literacy and facilitate better health outcomes.

The most prominent theme among participants was related to the 'source of support'. The importance of receiving psychological support was stressed, as participants often felt isolated, had difficulty communicating their diagnosis to their friends and families, and/or felt pressured to make a quick treatment decision without the appropriate support. A recent study in the field of prostate cancer revealed that time pressure shortly after diagnosis predicted long-term decisional regret in their research participants [19]. Therefore, for patients to be able to better cope with a kidney cancer diagnosis, research suggests the provision of additional psychological support is necessary as it conveys a feeling of control [20–22].

Addressing 'fear of recurrence' was identified as a prevalent unmet need among cancer patients in our study. The scientific literature highlights that fear of recurrence may result in emotional and physical distress and reduced quality of life, and stresses the importance of early recognition and support (e.g., a psychologist supporting the patient to make informed treatment decisions that are not solely motivated by fear) [23].

**Fig. 1** Identified themes. HCP, healthcare provider.

Closely linked to this, the theme of ‘shared decision making’ was considered a significant topic among the participants and has been accepted across cancer care as having a positive impact on patient satisfaction and clinical outcomes. The American Society of Clinical Oncology recommends that clinicians communicate effectively, including through the use of medical interpreters and plain language for patients with low health literacy. Visual aids should also be used to help patients to understand their diagnosis and treatment options. In addition, family involvement in discussions should be encouraged, especially during crucial points in care [24]. Furthermore, the literature indicates that decision aids across cancer care are valuable and enhance SDM [25,26]; however, participants in the focus groups had not yet experienced their use.

Approximately one third of our participants reported a lack of support along their journey, primarily due to

‘administrative issues (contextual factors)’, such as poor communication between healthcare organisations, leading to delays in follow-up care. Similar reports already exist in the literature, where it is also pointed out that such administrative issues significantly impact the mental well-being of patients who feel they are losing control of their healthcare [27].

The main limitation of the focus groups/interviews was the partial self-selection of participants. Thirteen patients, who were in contact with their patient associations, were recruited. This might have influenced the health literacy of participants, suggesting they might be better informed than the ‘average’ patient and therefore might undermine the representability of the sample; hence, we adapted our recruitment process to invite patients via the Erasmus University Medical Centre.

In conclusion, the experiences shared by participants in the focus groups and interviews offer further insights into the complex components of decision making faced by patients with localised kidney cancer. All participants expressed a desire to be involved in the decision-making process. However, due to the emotional toll of the cancer journey, which often requires quick decisions, actively engaging in the decision-making process was described as challenging.

The study highlights the need for healthcare providers to improve communication and support during diagnosis, as patients often feel overwhelmed by unexpected news. Clear, compassionate guidance enables patients to understand and consider their treatment options with confidence. A key theme identified with regard to improving decision making was SDM. Clinicians should actively involve patients in discussions about their care, explore greater use of decision aids, and support patient understanding throughout the process.

Research in cancer care stresses the importance of SDM and clear communication as key elements, however, our study shows that current guidance seems not to facilitate SDM as it does not take the multifactorial process of decision making into consideration as well as the challenges faced by patients in engaging in SDM during this period of diagnosis.

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## Disclosure of Interests

None declared.

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Abbreviations: IKCC, International Kidney Cancer Coalition; SDM, shared decision making; VHL, von Hippel–Lindau syndrome.

## Supporting Information

Additional Supporting Information may be found in the online version of this article:

**Table S1.** Semi-structured topic guide.

**Table S2.** Domain, subdomain, themes, codes and illustrative quotes on treatment decision making.