



We need to listen

World Kidney Cancer Day | 20 June 2024



Being listened to

Decision making should be a collaborative process between patients and healthcare professionals (HCPs)

As a patient, you should receive enough information to have open discussions with your healthcare professional (HCP). Patient organisations are a great resource of information about different options and possibilities your local health systems offers, but asking questions and having open conversations can help ensure care is tailored to you.

You play a crucial role in your healthcare decisions. Being equipped with knowledge about kidney cancer and treatment options allows you to advocate for your own care. Here are some resources to assist you:

Decision Aid Booklets

The International Kidney Cancer Coalition (IKCC) and Action Kidney Cancer have developed shared decision aids for kidney cancer patients, caregivers and families.

These booklets provide valuable information to help you navigate the decisions ahead. You can download or print them from the IKCC website.¹

Open Communication

Shared decision-making involves open communication with your healthcare provider. Even if there's only one treatment option available, understanding what's happening to your body empowers you with knowledge and helps you feel more in control.²

What is Shared Decision Making (SDM)?

SDM is a process, which ensures patients are supported to make decisions about their care and treatment which are right for them. It is a collaborative process and it starts with a conversation between the patient, who is receiving care, and the healthcare professional, delivering the care.

SDM supports individuals to make decisions that are right for them, based on the clinician's expertise and the patient's preferences.³

The conversation brings together:

- The clinician's expertise, such as treatment options, evidence, risks and benefits.
- What the patient knows best: their preferences, personal circumstances, goals, values and beliefs.



What is its purpose?

SDM is a core component of person-centred care, with patients actively being involved in decisions about their own care and treatment.

Working with your HCP can ensure your beliefs and needs are listened to, whilst understanding the risks and benefits of available care options.^{4 5}

How involved do I have to be?

It is an individual choice of how involved in your care you want to be. Working alongside your HCP and having open conversations can help to tailor care to your needs. Many HCPs recognise SDM as a continuing process, understanding that choices made are reversible if you change your mind.⁶

SDM gives you the opportunity to choose to what degree you want to engage in decision making. Some people prefer not to take an active role in making decisions with their healthcare professionals.⁷

How can this help me?

Research studies have consistently shown⁸ that when people are more involved in decisions, they:

- Have fewer regrets about decisions to do with their health and care
- Report better relationships with clinicians
- Adhere better to treatment
- Report a better experience including more satisfaction with the outcome.

For further information, below are some useful resources:

- International Kidney Cancer Coalition – **Decision aid resources**
- Action Kidney Cancer – **Shared decision making**
- National voices – **Supporting shared decision making**

Please contact your IKCC affiliate member for country specific advice.

- 1 Action Kidney Cancer. Shared decision making. Available at: <https://actionkidneycancer.org/help-support/shared-decision-making/>
- 2 News Medical Life Sciences. Two Cents' Worth: Shared decision making in renal cell carcinoma (RCC). Available at: <https://www.news-medical.net/news/20221215/Two-Cents-Worth-Shared-decision-making-in-renal-cell-carcinoma-%28RCC%29.aspx>
- 3 NHS. Shared decision making. Available at: <https://www.england.nhs.uk/personalisedcare/shared-decision-making/>
- 4 National Voices. Supporting Shared decision making. Available at: <https://www.nationalvoices.org.uk/publication/supporting-shared-decision-making/>
- 5 Healthwatch Cambridgeshire. Empowering patients to share decision making on treatment and care. Available at: <https://www.healthwatchcambridgeshire.co.uk/news/2021-06-21/empowering-patients-share-decision-making-treatment-and-care#:~:text=The%20new%20guideline%2C%20from%20the%20National%20Institute%20for,to%20and%20that%20their%20needs%20are%20put%20first.>
- 6 BMC. 2022. Practices and perspectives of patients and healthcare professionals on shared decision-making in nephrology. Available at: <https://bmcnephrol.biomedcentral.com/articles/10.1186/s12882-022-02887-4>
- 7 <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making>
- 8 NHS. 2019. Shared decision making guide. Available at: <https://www.england.nhs.uk/wp-content/uploads/2019/01/shared-decision-making-summary-guide-v1.pdf>