



in collaboration with



Together for Kidney Cancer

Driving shared decision making in
kidney cancer care: an action plan

BY THE KIDNEY CANCER COMMUNITY, FOR THE COMMUNITY

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Introduction by Dr Michael Jewett

Welcome to the first shared decision making action plan for kidney cancer. I'm grateful to Ipsen for their support and leadership to drive the process to develop this unique and innovative plan. Making the right decisions is critical to optimize all outcomes that are important to patients, those touched by the diagnosis as well as the clinical teams and the entire health care system including the payors, public, and private.

Every person living with kidney cancer has different preferences and priorities when it comes to making decisions about their care. While preferences vary, the IKCC's Global Patient Survey found that over half of people living with kidney cancer said that they weren't as involved as they wanted to be in decisions about their care.¹ This statistic has not changed in the six years the survey has been conducted. We can do better.

Shared decision making is defined as an approach where healthcare professionals provide the best possible information to people living with kidney cancer, who then choose the right approach for themselves after considering their own values and preferences. It involves actively discussing care decisions and jointly considering all options. It relies on healthcare professionals as experts to inform and educate, ensure that patients and those affected by the diagnosis feel included and recognized as experts on their own bodies and disease experience. Finally, it is critical that clinicians recognize that the final choice is made by the patient and that choice should be respected, even if it might include a decision not to undergo potentially curative treatment.

The adoption of a shared decision making approach can have a positive impact on well-recognized treatment outcomes, including overall survival, quality of life, and treatment adherence. Shared decision making is clearly critical to quality healthcare, which is why it is important for the practice to become more widespread.^{2,3}

To bring about this needed change, we gathered healthcare professionals, patient advocates, patients, and carers from the kidney cancer community to help solve a complex challenge that can impact care received by people living with kidney cancer. This resulting action plan emphasizes the need for immediate action to drive awareness of shared decision making, build confidence in patients, empower people through education, better equip healthcare professionals, encourage the use of decision aids, and champion initiatives that can transform healthcare infrastructure.

We're asking all people within the kidney cancer community, the healthcare industry, government, and regulatory bodies to help drive and support the actions included within these pages. Together, we can improve the lives of people living with kidney cancer.

Thank you.

Dr Michael Jewett

Board Chair, International Kidney Cancer Coalition (IKCC)
Advocate and Professor of Surgery (Urology), Princess Margaret Cancer Centre and the University of Toronto, Canada.

1. International Kidney Cancer Coalition. Aug 2023. Global Survey 2022, Global Report; 2. European Cancer Organisation. Mar 2024. Shared Decision Making; 3. Fiorillo A, et al. Ann Gen Psychiatry. 2020;19:43.

Created by the kidney cancer community, for the community

This **action plan** has been co-created with a select group of healthcare professionals, patient advocates, patients, and carers within the kidney cancer community via a roundtable and one-to-one conversations. The goal of the discussions was to understand the current attitudes, behaviors, barriers, and enablers to shared decision making. These insights were used to generate tangible actions that can be taken forward by members of the community, to support widespread adoption of shared decision making for the benefit of patients and healthcare systems.

The proposed actions have been informed by global market research and the roundtable discussions, reflecting the experts' own views and perspectives, based on their first-hand experiences.

The intention of this document is to provide the kidney cancer community with support in advocating for relevant and pragmatic actions that can drive positive change, helping to pave the way for shared decision making for all those who want it.

Thank you to the co-creators of this action plan:

- **Claudia Ungarelli**, Caregiver; volunteer and advocate, Italian Kidney Cancer Association (ANTURE)
- **Daniel Tigges**, Patient and advocate
- **Dr Harm van Melick**, Urologist, St. Antonius Hospital Nieuwegein-Utrecht, The Netherlands
- **Karin Kastrati**, Manager, Nierenkrebs-Netzwerk Deutschland, Germany
- **Dr Maria José Juan Fita**, Medical Oncologist, Hospital Instituto Valenciano de Oncologia
- **Dr Martin Bögemann**, Professor of Uro-oncology, Münster University Medical Center, Germany
- **Dr Michael Jewett**, Board Chair of IKCC; advocate and Professor of Surgery (Urology), Princess Margaret Cancer Centre and the University of Toronto, Canada
- **Dr Rachel Giles**, Advocate
- **Rose Woodward**, Patient and Co-Founder of Action Kidney Cancer
- **Prof. Stênio de Cássio Zequi**, Chairman, Urology Department, AC Camargo Cancer Center, Brazil
- **Steve Pointon**, Patient advocate, Action Kidney Cancer

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1 Drive awareness of the benefits of shared decision making and the unmet need the approach can address

When it comes to shared decision making and especially the lack of awareness, appreciation is very important. People don't know how important shared decision making is, especially patients.

The concept of shared decision making has been present in healthcare for over 20 years, yet there is limited knowledge and advocacy for the benefits of it, both for people living with kidney cancer and healthcare professionals who care for them. Stronger belief in how shared decision making can transform people's experience is needed.

DEVELOP A COHESIVE NARRATIVE

Shared decision making is often explained differently across the globe, which can impact the perception of the practice by healthcare professionals and make the process seem convoluted to people living with kidney cancer. A clear and universal narrative with explanations, evidence, economic rationale, and expectations of shared decision making is vital to ensure that people receive consistent information on the approach, that they understand the benefits, and have confidence in the concept.

GENERATE TRACTION VIA HIGH-PROFILE PLATFORMS

Events, congresses, and campaigns offer focused opportunities to reach many more members of the kidney cancer community. The priority should be ensuring that patient engagement and shared decision making is a prominent part of the agenda, which could be achieved by:

- Placing the patient track or stream on center stage around premium time slots at congresses.
- Offering virtual attendance and discussion to make it accessible for those unable to attend in-person.
- Sponsorship of patient-focused seminars at clinical congresses in the plenary.
- Aligning a patient engagement and shared decision making keynote with the latest advances in disease management.
- Integrating the voices of people living with kidney cancer in discussions at key medical meetings.
- Lobbying for shared decision making to be the core theme at key congresses.

TAP INTO GLOBAL PATIENT ADVOCACY NETWORKS

The practice of shared decision making can vary based on country cultures and attitudes from both the healthcare professionals and people living with kidney cancer. For the approach to resonate with the kidney cancer community around the world, national patient advocacy groups will play an important role in widely sharing the benefits of shared decision making. By tapping into the networks of global patient advocacy groups, such as the International Kidney Cancer Coalition (IKCC), more people can be made aware of shared decision making, for example, through the dissemination of localized national awareness campaigns.

PURSUE PARTNERSHIPS TO EXPAND AWARENESS

Greater awareness of shared decision making as a practice and the benefits of the approach are layered parts of the same challenge. There are people who will not be aware of shared decision making and may want to participate with their healthcare professional. Opportunities to expand awareness could include:

- Engaging with hospitals – digital screens could be utilized to inform people about shared decision making featuring a QR code to learn more.
- Partnering with media platforms – podcasts by both healthcare professionals and people living with kidney cancer who are advocates of shared decision making can provide more information.
- Partnering with social scientists – to better understand the behavior shift needed to more widely implement shared decision making.



2 Build confidence in people living with kidney cancer to feel equipped to participate in shared decision making

People living with kidney cancer are best able to participate in decisions about their treatment when they have the appropriate support, guidance, and information. Taking steps to build confidence in people will enable them to be a part of the decision making process.

HELP PEOPLE TO FEEL “IN CONTROL”

A kidney cancer diagnosis can make some people feel as though they have lost control over their body and life. It is critical that people get the support and guidance they need to help manage these changes at different points in their care. This can extend to:

- **Reducing time pressure on decision making** – people may need more time to digest and understand information provided by their healthcare professional, before asking questions or making decisions about their treatment.
- **Encouraging people living with kidney cancer to ask for a second opinion** – as this could form part of the person’s own research process and understanding of the treatment pathway that is best for them.
- **Suggesting that people living with kidney cancer bring a loved one to healthcare appointments** – helpful for additional support, listening, and note-taking during a challenging time that can feel stressful when the person is alone.

SIGNPOST TO SUPPORT

The most vulnerable time for people is often between diagnosis and treatment, where people are rapidly learning about the disease and the options available to them. Knowing where to go and who to turn to can feel overwhelming, whilst searching for information online can lead to incorrect or outdated information that can worsen the worry. Clear signposting to charities, counselors, and patient support groups by healthcare professionals upon diagnosis can help people living with kidney cancer to leave their appointment feeling equipped with the right contacts for additional support, information, and details about shared decision making.

PROVIDE ACCESS TO A FULL MULTIDISCIPLINARY TEAM WHERE POSSIBLE

Multidisciplinary teams can play an important role in holistically supporting people living with kidney cancer. Specialists within the team can extend beyond physicians and nurses to psychologists and nutritionists who can provide care across all areas of managing the disease. The role of a team can also include sharing information about the disease, discussing treatment options, and answering questions. Frequent and well-structured communication between the multidisciplinary team is vital to support both the team providing care and the people living with kidney cancer.

CONSIDER DEMOGRAPHIC DIFFERENCES

Patient preferences for receiving information can vary based on certain demographics, such as age, education level, and location; so, considerations must be made for how best to reach different types of people to ensure that they feel included. For example, age can influence the channels that people prefer to use, with some preferring digital access and others preferring printed resources for items, such as information posters and decision aids.

“Patients are often under time pressure during discussions with the doctors or with the healthcare professionals. Nobody should make a decision under pressure, and nobody should make a decision at that time.”

3 Empower people to unlock the full potential of shared decision making through education and training

80% of diagnoses that you do in real life as a doctor are done by talking.

Healthcare moves at a rapid pace, whether it is treatment innovation, new medical techniques, or care practices that are consistently improving. It can be a complex space to navigate for both healthcare professionals and people living with kidney cancer. Education is critical to embed a shared decision making approach into clinical practice.

GUIDE PEOPLE TOWARDS HEALTH LITERACY

Access to balanced and accurate information about kidney cancer and the treatment options available to people is essential. Housing this information in a central place, such as through patient advocacy groups or in hospitals, will help people feel confident that what they are reading is correct and up-to-date. Many patient advocacy groups offer a range of materials and guidance that can help people feel armed with enhanced knowledge, understanding, and awareness of the discussions and what questions to ask.

With more people having access to their patient dossiers and test results, further education on medical terminology and learning how to read pathology reports, for example, may help people who want more clarity on the disease. Collaboration and partnership of pharmaceutical companies, healthcare professionals, and patient advocacy groups would increase the breadth of resources, such as lay summaries of clinical trials, educational tools, and support that patients can receive during their care.

SHARE FIRST-HAND EXPERIENCES WITH OTHER PEOPLE LIVING WITH KIDNEY CANCER

Online forums, peer support groups, and buddy programs can provide a platform for people to openly discuss experiences with treatment and care. This exchange can provide much-needed solidarity that some people living with kidney cancer need, as well as an understanding of how other people may have navigated a shared decision making approach with their healthcare professional. However, these platforms must be carefully monitored to ensure any misinformation is handled.

SHARE FIRST-HAND EXPERIENCES WITH OTHER HEALTHCARE PROFESSIONALS

Advocates of shared decision making can be impactful ambassadors for the benefits of the approach in clinical practice. Presence at key congresses and medical meetings could support ambassadors in engaging with peers and sharing their real-world experiences with shared decision making and the positive impact it can have for them and people living with kidney cancer. This could be coupled with:

- Regular networking touch-points to share learnings.
- Offers of support using tools via mentoring.
- Alerting others to information that needs updating.
- Connecting with other healthcare professionals globally via closed online forums and social media channels.

INSTILL SHARED DECISION MAKING IN TRAINING FOR HEALTHCARE PROFESSIONALS

For shared decision making to be a success, healthcare professionals must feel equipped with the essential skills to put shared decision making into practice. Programs that capture all healthcare professionals early in their careers or medical training, with a focus on patient engagement as a core module in the curricula, could instill the importance of patient-centered care and contribute to positive outcomes throughout their careers. For all healthcare professionals, further support could be provided through:

- Academic sponsorship for new training and academic research into innovative shared decision making solutions.
- Training conducted by ambassadors of shared decision making on how to implement the approach in clinical practice, supported by a CME accreditation.
- Sharing patient stories via videos and case studies as a useful tool to understand perspectives, and plain-language communication, supported by role-play training of the patient experience.



4 Encourage use of tailored decision aids and tools as devices to support shared decision making

Shared decision making tools are developed for patients, but as healthcare professionals, we can see advantages in our own practice and improvements for all parties involved.

Healthcare professionals and people living with kidney cancer are more likely to adopt a shared decision making approach if they have access to the right, localized shared decision making aids and tools. We must amplify currently available tools and support the development of alternative aids that resonate with people around the world.

DRIVE CROSS-COMMUNITY COLLABORATION

For decision aids and tools to be useful for the kidney cancer community, healthcare professionals and people living with kidney cancer must have input. As a first step, an exercise to identify existing aids and tools, adapting them for unique country needs and sharing them widely is needed. Healthcare professionals can also guide on the right information and questions to ask during time-limited appointments. People living with kidney cancer can ensure the information included is both needed and wanted in a decision aid, and that medical complexities are digestible for all people with varying levels of disease knowledge and educational backgrounds.

DEVELOP DIFFERENT FORMATS FOR DIFFERENT NEEDS

Not every person living with kidney cancer wants the same level of information, which is why tailored aids and tools are important. Beyond adaptation to suit differing languages, cultures, and national healthcare systems' processes, tools should offer baseline information that is concise and avoids overwhelming the reader. More information should also be available as needed should the person want to learn more, which can vary based on factors such as individual preference or how advanced the cancer is. Digital formats, such as engaging and informative videos and images to illustrate treatment pathways and options, can lend themselves well to this. To accommodate people's needs and preferences, these aids and tools should also be made available in print and include checklists and infographics for support pre-, during, and post-appointment.

PERSONALIZE INFORMATION AND SUPPORT

Tailoring for individual people can be transformative. Current information can sometimes feel too generalized, so the introduction of customized aids and tools could greatly support the decision making process. Utilization of current questionnaires for people to share information on themselves and their priorities, such as lifestyle and relationships, coupled with their own specific health situation, could create personalized reports to better equip conversations about personalizing care. This could extend to "information prescriptions", which can be produced by healthcare professionals based on the person's individual combination of disease and care, resulting in information and signposting to resources specific to that situation.

STANDARDIZE GUIDANCE

To better support healthcare professionals and people living with kidney cancer in using decision aids effectively, standardized guidance and a structure on how to implement the tools would be effective. An understanding of who is responsible, and when and how to utilize different types of tools can make the shared decision making process easier to implement. Introducing new tools can be met with uncertainty, especially with regard to the time needed to learn how to use them. However, confident use of decision aids and tools can save time in the long-term as efficiency and quality of conversations improve. To support learning how to use tools, congresses and medical meetings could provide a platform for ambassadors, patient advocacy groups, and medical societies to disseminate aids and teach best practice on use.



5 Champion initiatives that can transform healthcare infrastructure now and in the future

“If we don't put a value on communication, information and shared decision making, medical professionals and policymakers cannot know how valuable it is in terms of decreased costs and improved quality.”

Small changes in healthcare infrastructure and systems can have a significant impact on the way people living with cancer receive care. We must continue to drive the incremental changes needed across healthcare systems around the world so all people living with kidney cancer receive the treatment that is right for them.

LOBBY FOR GOVERNMENT SUPPORT

The benefits of shared decision making are clear and evidence-based, and widespread adoption could be expedited through support from policymakers. Building a comprehensive **economic rationale***, grounded in hard data and statistics, coupled with stories from people living with kidney cancer, could create the leverage needed to instigate change. By demonstrating the benefits of and rationale for the adoption and utilization of shared decision making to healthcare systems, resulting resources, infrastructure adjustments, and support could transform care. An example of successful government buy-in and advanced support is the Netherlands, where shared decision making ambassadors have worked with the Government to co-establish a subscription service of shared decision making aids and tools across oncology. This has helped to get the right tools to the right people at the right time.

SHIFT DECISION MAKING DYNAMICS

In some countries, cultural variations can mean shared decision making is difficult to achieve because healthcare professionals, as medical experts, handle all treatment decisions. It can be difficult for people living with kidney cancer to feel able to ask questions and share their preferences. Illustrating the practical benefits, positive outcomes, and clinical evidence as a result of shared decision making, could help healthcare professionals feel comfortable in the knowledge that a person is not questioning their judgment or expertise, but rather offering a perspective on their lifestyle and values to be considered as part of the treatment plan. Local patient advocacy groups can play an important role here to support with specialized activities at a national level and even encourage healthcare professionals to be a part of the patient advocacy group.

LEVERAGE ADVANCING TECHNOLOGIES

Technologies such as artificial intelligence have progressed exponentially over the past few years and can offer a solution to one of the most pressing challenges faced by healthcare systems: time. Healthcare professionals are time-poor, yet people living with kidney cancer need as much time as possible to ask questions and discuss treatment options. Utilizing programs, such as gamification apps and chatbots, could create a triage space. People can ask questions and request more information that could either be provided from a cloud-based system or signposted, helping to inform, educate, and prepare people for future appointments with their healthcare professional. Research has also shown that people are more likely to share important information via a chatbot than with a human, for fear of judgment.⁴ Artificial intelligence could also be used to generate personalized decision aid tools and questions to ask that are tailored to individuals.

ADVOCATE FOR UNIVERSAL SHARED DECISION MAKING INCLUSION IN GUIDELINES

Currently, only one set of medical guidelines for kidney cancer includes shared decision making.⁵ Championing universal inclusion of shared decision making within all international, country, and regional care guidelines, reflecting clear expectations, robust data, recommendations, and the patient perspective, could strongly encourage more widespread adoption of shared decision making across the globe.

*The economic impact of the adoption of shared decision making can be represented as:
value-based healthcare = quality + cost effectiveness



4. Lucas GM, et al. Comput Hum Behav. 2014;37:94–100; 5. European Association of Urology. Mar 2024. Guidelines, Renal Cell Carcinoma.

Together for Kidney Cancer is a global disease-awareness initiative created by Ipsen, in partnership with the IKCC, for healthcare professionals and people living with kidney cancer. The aim is to raise awareness of the importance of empowering and equipping the kidney cancer community to take more active roles in shared decision making when it comes to treatment and care decisions. The illustrations used throughout this action plan reflect real patient stories, visualizing people's unique experiences living with kidney cancer.

Together, we can improve the lives of people living with kidney cancer.

