Understanding the needs of kidney cancer patients, globally

Developing a survey to provide actionable insights
across different countries

Introduction

The International Kidney Cancer Coalition (IKCC) is an independent international network of patient organisations that focus on kidney cancer. Its mission is to empower and represent the kidney cancer community through advocacy, awareness, information, and research with a vision to reduce the global burden of kidney cancer.

The organisation was created from a strong desire among national kidney cancer patient groups to network, cooperate and share materials, knowledge and experiences from around the world.

Every year, an estimated 431,000 people worldwide are diagnosed with kidney cancer, and this number is on the rise globally. Therapies have improved, but little is known about the variances in patient experience from country to country, including unmet needs and best practices in patient education, quality of life and involvement in clinical trials and registries.

IKCC launched a successful survey of their members in 2018, with the intention to run it every two years. This survey cycle allows them to identify best practices whilst monitoring trends and exploring topics of particular interest to affiliate organisations.

Picker was appointed in 2020 to administer the program, including updating the patient questionnaire, to further explore and benchmark worldwide patient experience.

Challenges

IKCC represents smaller organisations spread across the world, which specialise in different types of cancers and where treatment protocols differ between countries. Working with a diverse community created several challenges, the survey needed to:

- balance the needs of multiple stakeholders, each with different aims that could conflict;
- be accessible in 13 languages;
- provide actionable insights, enabling local organisations to improve patients' lives; and
- the question wording needed to work globally, whilst being relevant and understandable in each country.

IKCC also wanted to collect global data to improve collective understanding of patient experiences worldwide and look for best practices to share.

Actions

Before launch, the readability and serviceability of the questionnaire were tested by IKCC local affiliates in each country. This involved testing the questions with the patient population to check that language and queries were recognisable and relevant.

We updated the patient questionnaire to further explore patient experience, this included understanding:

- Patient knowledge - expectations of treatment and shared decision making.
- Clinical trials - research awareness and sources of information.
- Quality of life and overall health status of respondents.

The 2020 survey also included special areas of inquiry such as:

- Biopsy practice - experience and willingness to repeat in the future.
- Physical activity - to what extent do patients undertake physical activity as part of their overall survivorship.
- Patient Health Engagement Scale - to what extent do patients make sense of their health status and their perceived role in the healthcare journey?

The 2020 IKCC global patient survey explored experience at three key touchpoints: diagnosis, treatment planning; and overall care and treatment. It was published in 13 languages and promoted through IKCC affiliates and partners, as well as via IKCC social media and web pages. To improve accessibility, paper versions of the survey were also distributed by local affiliates.

Impact

This fresh and comprehensive collection of data means that more can finally be understood about kidney cancer experiences internationally – meeting needs and providing insight that was previously lacking. The breadth of the data collection – across 40 countries – offers a reliable, applicable model that can be used in evidence-gathering.

Kidney cancer patient organisations and medical professionals will be able to use the results and insights as a conversation point between communities, and for the planning and sharing of best practice. At a local level, individual countries can use their reports to drive improvements in care provision and access more detailed analysis.

Going Forward

The results of this survey will continue to inform global and national work in a variety of ways, including identifying trends, measuring progress, and identifies priorities for the IKCC. This rigorous, evidence-based model is also applicable to other partner organisations looking at the management of other conditions, which would further increase its relevance and scope.

Testimonial

"Picker showed us the importance of getting the questions right initially, to be able to generate the data needed for analysis."

Julia Black, Operations Manager, International Kidney Cancer Coalition

About Picker

We are a leading international health and social care charity. We carry out research to understand individuals' needs and their experiences of care.

We work with NHS trusts, government bodies, charities, academic institutions, and commercial organisations, and are an approved contractor for the CQC.

Our eight Principles of Person Centred Care provide an internationally renowned quality improvement framework.

The Picker Principles

Fast access to reliable health advice

Effective treatment delivered by trusted professionals

Continuity of care and smooth transitions

Involvement and support for family and carers

Clear information, communication and support for self-care

Involvement in decisions and respect for preferences

Emotional support, empathy and respect

Attention to physical and environmental needs

About IKCC

The International Kidney Cancer Coalition (IKCC) is an independent international network of patient organisations that focus exclusively, or include a specific focus, on kidney cancer.

The organisation was born from a very strong desire among national kidney cancer patient groups to network, cooperate and share materials, knowledge, and experiences from around the world.

Picker Institute Europe
Suite 6, Fountain House
1200 Parkway Court
John Smith Drive
Oxford OX4 2JY

+44 (0)1865 208100
picker.org

Registered Charity in England and Wales: 1081688
Registered Charity in Scotland: SC045048
Registered Company Limited by Guarantee: 03908160