Appendix 3: Methodology

Background

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.

The IKCC 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.

Picker was commissioned by the IKCC to run their 2020 biennial Global Patient Survey targeted at patients with kidney cancer or a kidney growth, their carers or caregivers.

Picker is an international charity dedicated to ensuring the highest quality health and social care for all, always. We conduct research to understand patient care needs and experiences, and are here to:

○ Influence policy and practice so that health and social care systems are always centred around people's needs and preferences.

○ Inspire the delivery of the highest quality care, developing tools and services which enable all experiences to be better understood.

○ Empower those working in health and social care to improve experiences by effectively measuring, and acting upon, people's feedback.

Picker's expertise covers all stages of research from design, sampling and questionnaire development to execution, analysis, and reporting. Our Principles of Person Centred Care are an internationally recognised quality improvement framework that we use to produce actionable, insightful results. We empower our partners to act upon their results to deliver the highest quality person centred care for all, always.

Purpose of the Global Patient Survey

The IKCC launched its first Global Patient Survey in 2018. This was the first-ever international survey of kidney cancer patient and carer experiences. This survey sought to improve collective understanding of patient experiences worldwide, look for best practices, and to empower patient organisations with information that they could act upon. In 2018, 1,983 patients and carers from 43 countries shared their views and experiences.

Following this successful launch, the IKCC intend to run the Global Survey every two years, continuing to identify best practices whilst monitoring trends and exploring topics of special interest to Affiliate Organisations.

2020 Questionnaire development

Following a review of the 2018 survey findings and consultation with IKCC Affiliate Organisations and the IKCC Medical Advisory Board, the survey instrument was updated to include specific topics that would potentially be actionable to improve patient care. Specific topics added included:

- Biopsy

- Physical activity

- Patient activation

In total, the survey covered the following core areas:

- **Patient knowledge, expectations of treatment and shared decision making**

  To what degree have patients been made aware of and have an understanding of their diagnosis, including stage, subtype, treatment options, and expected side effects?

  - Of those who did not understand their disease, who are they and how can they be reached?

  - What are patient's primary sources of information? What is missing?

  - What are patient's expectations for treatment? For side effects?

  - To what degree are patients involved in making treatment decisions (Shared Decision Making)? Who else is involved and to what degree?

  - Are patients receiving biopsies and to what extent would they be willing to receive one in the future?

- **Clinical trials, research awareness and sources of information**

  To what extent are patients made aware of potential advancements in care (including surgical advances, immunotherapy, targeted treatments, radiation therapy, and palliative care, and what are their expectations?

  - Have any healthcare professionals discussed clinical trials with patients?

  - Have patients enrolled (if No, what were the reasons/barriers; if Yes, what were the reasons)

  - What are patient's sources of information for clinical trials?

  - What are patient's expectations for clinical trials?

- **Quality of life and overall health status of respondents**

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What are respondents' current levels of physical activity and what psychosocial burdens are patients living with, and how do these issues affect their day to day lives?

- To what extent do patients undertake physical activity as part of their overall survivorship?

- What are patient psychosocial and emotional wellbeing needs?

- What are the unmet needs to support patient's goals for Quality of Life (QoL)?

- Which patients are not seeking help/support? Why?

- To what extent have patients made sense of their health status and their perceived role in the healthcare journey?

The survey also included demographic questions, including country of residence, age, gender, kidney cancer subtype, cancer stage at diagnosis, time since diagnosis and current cancer stage.

Before starting the survey, respondents were informed of the purpose of the programme; that completing the survey was voluntary and any feedback will be kept confidential; and how the results will be used.

The English (UK) questions were translated into 12 languages, by an approved language translation service using native speakers to translate and proofread. The final translations were also reviewed by fluent IKCC members. The survey was published in the following languages:

- Brazilian Portuguese
- Dutch
- English (UK)
- English (US)
- French
- French (Canadian)
- German
- Hindi
- Japanese
- Korean
- Polish
- Portuguese
- Spanish

Before launch, the complete survey was tested for readability and useability by the IKCC via their global affiliates.

Survey fieldwork

The survey was hosted on the third-party online survey portal Qualtrics. It was administered through an open link, distributed by IKCC global affiliates to patients with kidney cancer or a kidney growth and their caregivers.

The survey was available online between 29 October 2020 and 5 January 2021. It was promoted at regular intervals by the IKCC global affiliates and partners, as well as advertised via the IKCC and partner organisation social media and webpage.

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During the fieldwork period there was the worldwide global pandemic, COVID-19. important to note, this may have affected response rates, and might have influenced how people responded to the survey questions.

Analysis and reporting

Standard validation practices have been used in the survey tool and on the data collected, in this and associated reports to improve representativeness. Practices are outlined below:

Questionnaire routing

To improve respondent experience, routed questions were used in the survey tool. This ensured that respondents were only shown questions that were relevant to them. For example: Q27: "Have you ever been invited to participate in a cancer clinical trial?". Only respondents that answered "Yes" to this question, were directed to Q28: "Did you agree to participate in the cancer clinical trial?".

Consequently, some questions were only asked of a subset of respondents. Furthermore, respondents had the ability to leave questions blank. This means that the total number of respondents may fluctuate between questions. Where applicable the total number of respondents, or base size, is indicated with the abbreviation n.

Data cleaning and validation

When the survey closed, the raw data were analysed and feedback that did not meet the inclusion criteria was removed. Criteria for inclusion involved 6 or more completed questions of which a minimum of three needed to be consecutive.

Data were also analysed for repeated entries through the open link and Bot Detection. This involved assessment of metadata including location data and Q_RecaptureScore[1]. Any suspect data were analysed for potential ballot box stuffing through repeated entry. 325 responses were deleted as they did not meet the inclusion criteria.

Derived questions

In the interest of accuracy and ensuring that the results are representative, derived questions have been used when reporting feedback, where necessary.

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[1] Q_RecaptchaScore is an automated feature for Bot Detection in the online survey platform Qualtrics, which was used for this programme. Source Technology is from Google's invisible reCaptcha. A score of greater than or equal to 0.5 indicates that the respondent is likely a human as opposed to an automated bot.

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Some questions were not applicable to all respondents but were not proceeded by a filter/routing question. These questions have response options such as "I did not need" or "Don't know / Can't remember". Overall percentages were calculated removing these respondents – see example below. This ensures that the reported data remains focussed on those respondents to whom the question applied or who could recall the details. These questions are indicated using a plus (+) symbol, e.g., Q8 becomes Q8+.

Example: Derived questions

Q8 - WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what subtype of kidney cancer or kidney growth you had?				**Q8+ - WHEN YOU WERE FIRST CORRECTLY DIAGNOSED, were you told what subtype of kidney cancer or kidney growth you had?**		
Yes…	852	42%		Yes…	852	48%
No…	909	46%		No…	909	52%
Not sure…	243	12%				
Total…	*1,994*	*100%*		*Total…*	*1,751*	*100%*

Full frequency tables can be found in Appendix 2.

Data presentation

Throughout this report, percentages have been rounded to 0 decimal places. This means that sometimes the total for a single-response question can be just below or above 100%.