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Platinum Opinion

Setting Research Priorities in Partnership with Patients to Provide Patient-centred Urological Cancer Care

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There is a growing body of work advocating that research funding should be matched to the societal burden of a disease, which goes beyond simple mortality measures. Renal cell carcinoma (RCC) is a good example of this problem. RCC contributes to a greater average number of years of life lost (a measure of cancer burden that depends on patient age at death and the number of deaths at each age) than other urological, colorectal, and haematological cancers [1]. Despite its increasing prevalence, RCC receives a disproportionately small fraction of the cancer research budget across the UK, USA, and Australia [1,2]. It follows that research priorities should be identified using transparent and rigorous methodology to maximise output, avoid research waste, and facilitate international collaboration [3]. Furthermore, there is a well-documented discrepancy in prioritisation of the research agenda between patients and researchers [4]. Therefore, patient and carer participation in priority-setting is crucial. The James Lind Alliance (JLA) was developed to facilitate researcher, carer, and patient collaboration within priority setting partnerships using standardised methods [5]. A number of national and international organisations, including the UK National Cancer Research Institute (NCRI) and the National Institute for Health Research (NIHR), have emphasised consumer participation in priority-setting as a key goal in their strategic agenda, and they collaborate with the JLA to achieve this [6,7]. This has sparked international efforts to establish robust research priorities for a number of cancer types. A highly successful initiative identified research gaps in breast cancer in 2008 and was updated in 2013 [8]. This work has led to tangible research advances, and the source manuscript has been cited nearly 150 times [8]. This was followed by research gap analyses in other disease areas, including colorectal cancer.

We established the Renal Cancer Gap Analysis Collaborative with the aim of developing a consensus statement regarding research priorities in RCC. The collaborative was composed of clinicians, researchers, patients, and carers, the results are published in European Urology Focus [9]. We included the full spectrum of RCC from curative to metastatic disease. The project consisted of two phases: research gaps (RGs) were identified in phase I and the RGs were scored in phase II using a multistep Delphi process to achieve consensus regarding the most critical. In phase I, 44 key opinion leaders from five different European countries (UK, Portugal, France, Sweden, and the Netherlands) submitted literature reviews on 24 key themes across the RCC disease spectrum. The reviews were summarised in plain English and distributed among RCC patients and carers via the charity Kidney Cancer UK. Group discussions involving disease experts and patients, as well as detailed one-to-one interviews with patients, were undertaken. Following three consensus meetings among clinicians and patients, 39 RGs were identified for inclusion in phase II. Subsequently, 82 experts scored these gaps on a 9-point scale (1–3 = not important; 4–6 = important; 7–9 = critical) during three online Delphi surveys. The aim of the surveys was to reach a consensus, defined as ≥70%

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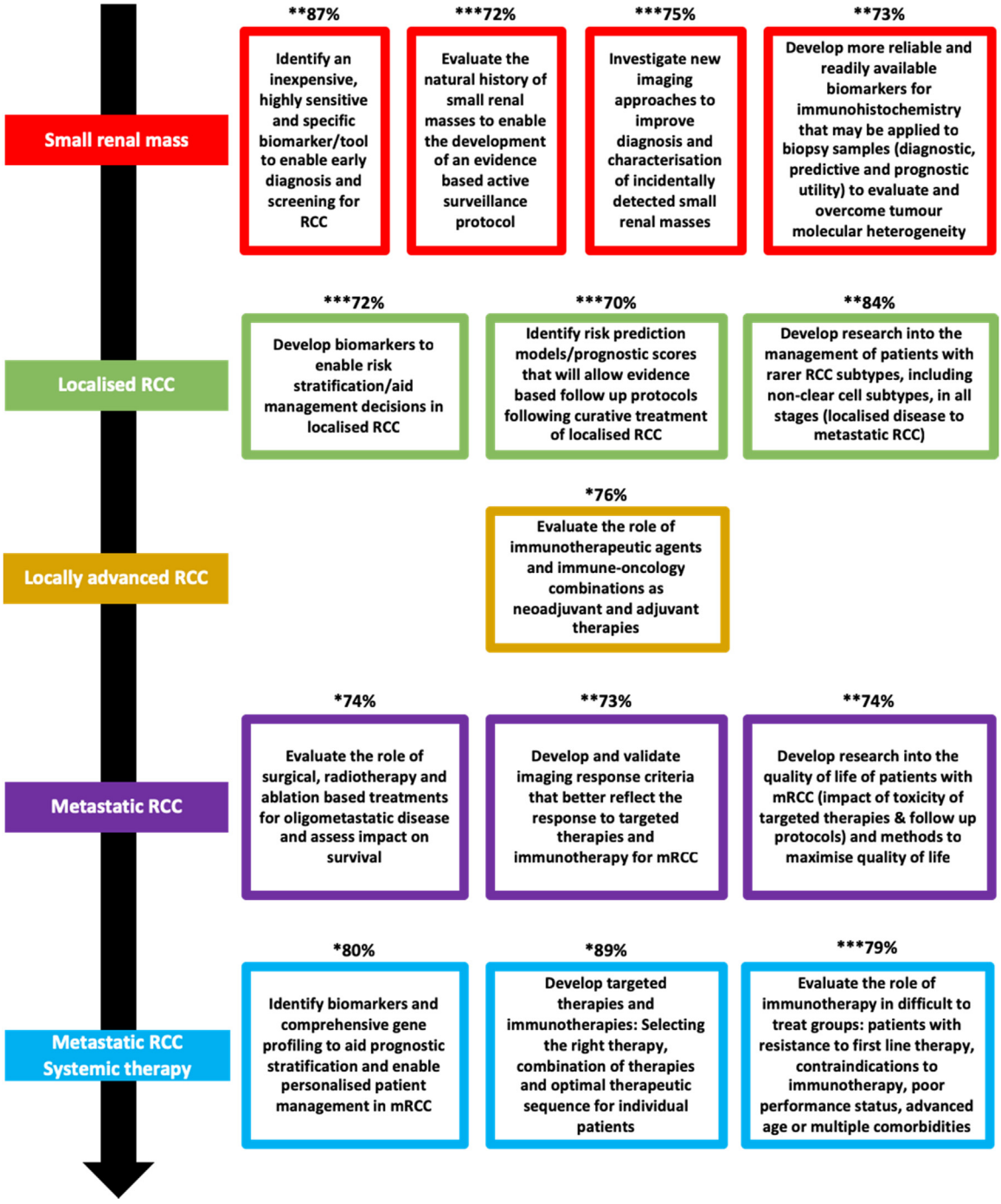

Fig. 1 – The 14 critical research gaps identified and their alignment to the main themes/stages along the journey for a patient with renal cell carcinoma (RCC), from small renal masses to metastatic disease. Data denote the percentage of participants who scored the research gap as "Critical" in the Delphi survey. Asterisks indicate during which iteration consensus was reached: * = first survey, ** = second survey, and * = third survey.**

agreement by experts. Patients reviewed the results of the Delphi surveys and provided feedback. This work resulted in the identification of 14 crucial RGs across a broad range of RCC themes (Fig. 1).

Patient and carer involvement throughout this work was critical. Our work identified different RGs to a previous RCC initiative not directly involving patients, which placed greater emphasis on understanding tumour biology, genomic and epigenetic factors, and epidemiology [10]. Conversely, initiatives in which patient participation was central uncovered RGs across similar overarching themes highlighted by our work, including early detection, and personalised patient management and follow up [11]. RGs deemed crucial in our work focus on maximising quality of life and managing often overlooked groups, such as individuals with low performance status and rarer RCC

subtypes. Furthermore, the inclusion of qualitative data obtained via patient interviews was crucial in highlighting important RGs pertinent to topics that are often overlooked by researchers; such as patient education, improved patient–doctor communication, mental health, the influence of social media, and support groups. Independent patient surveys have highlighted the significance of these issues for RCC patients and carers [12].

Effective patient/carer input requires investment from both clinicians and consumers. With appropriate training and support, expert patients can develop a deep understanding of the research process while retaining a connection to the realities of patients' concerns. It remains important to have wider consultations reaching a cross-section of the patient community. For this, patients need plain-language summaries and facilitators able to guide deeper discussions. Patient groups and charities are a useful means to achieve this input. Technology brings opportunities for involving patients much more easily. Established online patient networks can offer rapid access to patients willing to undertake surveys and review content, and a conduit to communicate about research design, delivery, and dissemination. Engagement with patient advocates with good links to these networks provides an ongoing real-time insight into emerging issues impacting research needs. Smartphone technology facilitates easier collection of patient-reported outcome measures and quality-of-life data. Consultation with a broader selection of patients who might not have access to the Internet is important and can be facilitated by both clinicians and patient networks.

The work described in *European Urology Focus* represents the most contemporary and systematic priority-setting initiative in RCC to date, focusing on a European setting [9–11]. Although the majority of participants represent a UK and European setting, a Canadian project published in *European Urology* identified overlapping research priorities, which suggests that these might be common to all Western settings [11]. Further research should focus on fostering international collaborations to bridge the RGs identified and on evaluating geographic variations in international research needs. The process of priority-setting should be continuous, as research advances in one domain may shift the future balance of relative importance for patients and researchers. Identification of research priorities with the involvement of consumer representatives and using standardised methods should be a key goal for all cancer types.

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