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 dependent 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 enable international collaboration (3). Furthermore, there is a well-documented discrepancy between the prioritisation of the research agenda by patients and researchers (4). As such, 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 key goals within their strategic agenda and they collaborate with the JLA to achieve this (6,7). This has sparked international efforts to establish robust research priorities in 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 has been followed by research gap analyses in other disease areas. including colorectal cancer.

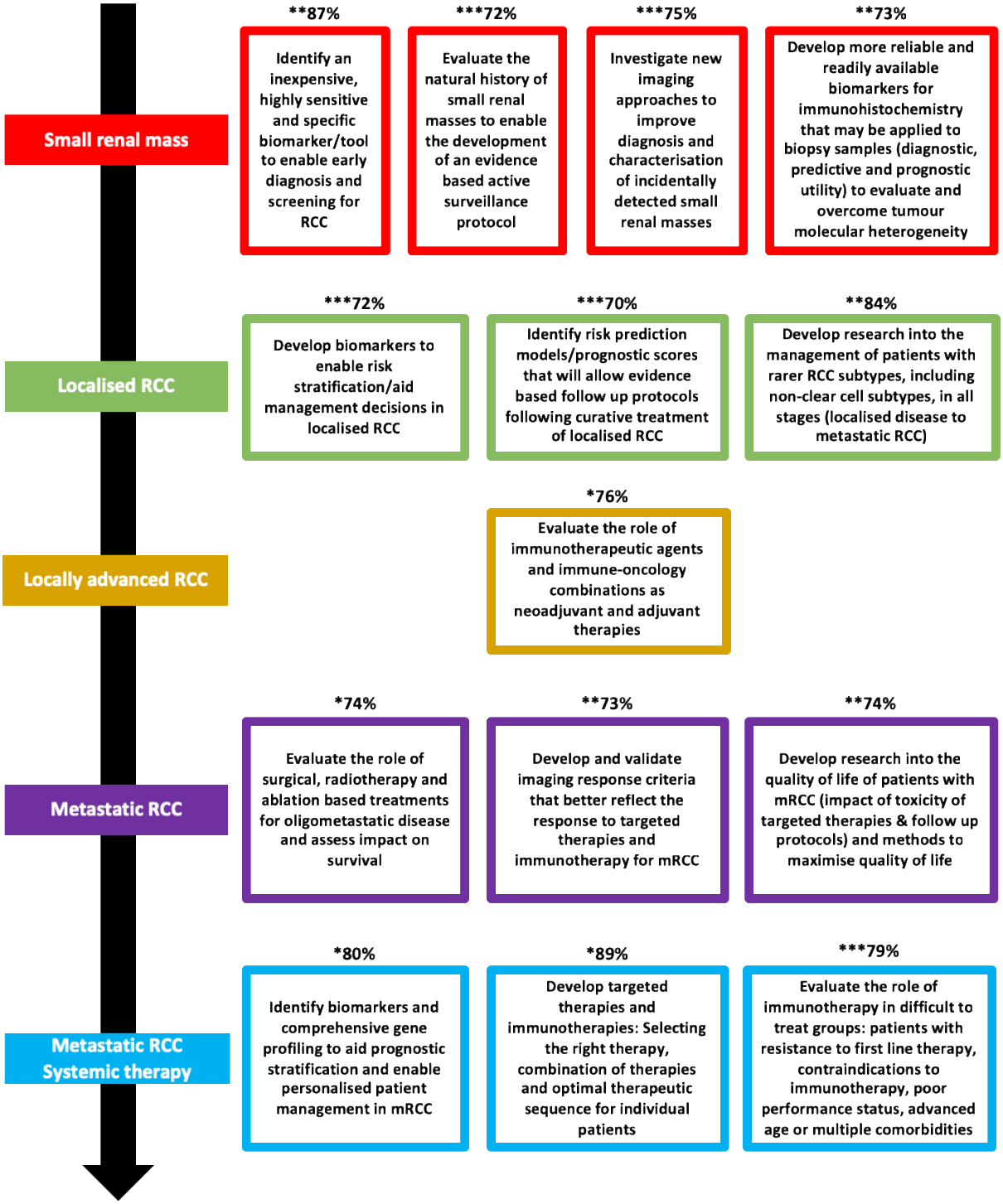
We established the Renal Cancer Gap Analysis Collaborative with the aim of developing a consensus statement regarding research priorities in RCC. The collaborative was composed of clinicians, researchers, patients and carers and the results have been published in a recent issue of *European Urology Focus* (9). We included the full spectrum of RCC from curative to metastatic disease. The project consisted of two phases: in phase I, research gaps (RGs) were identified and in phase II, RGs were scored through 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 amongst patients with RCC 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 amongst clinicians and patients, 39 RGs were identified for inclusion in phase II. Subsequently, experts (N=82) scored these gaps on a 9-point scale (1-3: Not important; 4-6: Important; 7-9: Critical) during three online Delphi surveys. The surveys aimed to reach a consensus, defined as ≥ 70% agreement by experts. Patients reviewed the results of the Delphi surveys and provided feedback. This work has resulted in the identification of fourteen crucial RGs, across a broad range of RCC themes (Figure 1).

Patient and carer involvement throughout this work was critical. Indeed, 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, personalised patient management and follow up (11). Research gaps deemed crucial in our work focus on maximising quality of life and managing often overlooked groups, such as individuals with reduced performance status and rarer RCC subtypes. Furthermore, the inclusion of qualitative data obtained through patient interviews was crucial in highlighting important RGs pertinent to topics which 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 patients with RCC and carers (12).

Enabling 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 whilst 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 patient online 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 enables PROMS and quality of life data to be easier to collect. Consultation with a broader selection of patients who may not be internet enabled is important and can be facilitated by both clinicians and patient networks.

The work described in this month's issue of *EU 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 suggesting these may be common to all Western settings (11). Further research should focus on fostering international collaborations to bridge the research gaps identified; as well as evaluating geographical variation between 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. The identification of research priorities, involving consumer representatives and using standardised methods, should be a key goal for all cancer types.

Figure 1: The fourteen critical research gaps identified, and how these are aligned to the main themes/stages along the RCC patient journey, from small renal masses to metastatic disease. The figure demonstrates the percentage of participants that scored the research gap as "Critical" in the Delphi survey. The asterisks indicate during which iteration consensus was achieved (i.e. *= consensus achieved in the first survey; **= second survey; ***=third survey).



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