

The Top 10 Retinoblastoma Research Priorities in Canada as Determined by Patients, Clinicians and Researchers: A Patient-Oriented Priority-Setting Partnership

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For which topic were research priorities identified?

retinoblastoma

In which location was the research priority setting conducted?

North America - Canada

Why was it conducted at all?

Research priority setting identifies the research most relevant to and valued by stakeholders. This is necessary given that most funded research does not reflect the priorities of patients and clinicians, potentially reducing its impact. The retinoblastoma research community in Canada practices patient engagement; however, a formal process to ensure equitable, diverse and sustainable inclusion was established only recently. The National Retinoblastoma Patient Engagement Strategy was formed in Canada in 2016. The Canadian Retinoblastoma Research Advisory Board (CRRAB), a national multidisciplinary group composed of patients, caregivers, clinicians, researchers and other stakeholders, leads the strategy.

What was the objective?

to jointly determine the top 10 retinoblastoma research priorities in Canada for people affected by retinoblastoma, clinicians and researchers

What was the outcome?

a ranking list of 10 research questions

How long did the research prioritization take?

October 2017 - December 2017

Which methods were used to identify research priorities?

JLA method

How were the priorities for research identified exactly?

Step 1: collecting questions: via survey, participants were asked: "What questions about retinoblastoma would you like to see answered by research?", 175 questions submitted. Step 2: data processing: duplicates removed, categorized, 46 questions removed, resulting in 129 questions across 12 categories. Step 3: interim ranking: steering group reviewed questions, produced refined list of 96 questions, check against evidence, steering group ranked questions, to ensure fair weighting a steering committee patient rank and a steering committee non-patient rank were calculated individually and then combined to produce an adjusted steering committee interim ranking, by consensus steering committee decided on a list of 30 questions to be ranked at the priority-setting workshop. Step 4: workshop: with nominal group technique, small groups ranked 30 questions, aggregate ranking computed, 3 new small groups formed and ranking again, again aggregate ranking computed, consensus on top 10

Which stakeholders took part?

People affected by retinoblastoma, family/friends/carers, clinicians (ophthalmologists, oncologist, genetic counsellors, child life specialists, molecular geneticist, social workers), researchers. Survey: 59 participants: 38 patients (64%) and 21 non-patients (36%). Workshop: 20 participants: 10 patients and 10 non-patients.

How were stakeholders recruited?

People were invited to participate in any stage of the priority setting process if they were a resident of Canada, and were a patient with retinoblastoma (i.e., diagnosed with retinoblastoma or a family member or friend of someone diagnosed with retinoblastoma) or a clinician or researcher interested in retinoblastoma. A convenience sample was recruited. Members of the CRRAB shared recruitment materials in their eye clinics and on social media, and existing networks such as the Canadian Retinoblastoma Research Registry, the Canadian National Retinoblastoma Tumor Board and the Canadian Association of Genetic Counsellors shared the materials widely. Snowball sampling was encouraged among the CRRAB community.

Which stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process. They were part of a steering group. The steering group consisted of 15 members: 4 patients and 11 non-patients. The members were involved in data processing and interim ranking.

