



Setting the agenda on health

Health and biomedical research agendas are often determined without the input of patients or care givers, which begs the question of whether medical investment is really focused on the most critical areas. To address this, the King Baudouin Foundation recently launched three priority setting pilot projects to assess whether researchers and other stakeholders can arrive at a consensus on the best way forward.

Researchers and academics, patients and care givers were brought together in an inclusive consultative process designed to achieve consensus on critical research priorities. The pilots, supported by the KBF Mind the Gap! project, addressed three topics: going back to work after a period of incapacity; the use of biobanks for research on non-alcoholic liver diseases; and Tuberous Sclerosis Complex (TSC), a rare genetic disease that causes benign tumors

to grow in certain organs. In each case, these multi-stakeholder exercises demonstrated how high-priority research questions that require action can be effectively discussed and identified.

Tuberous sclerosis complex

Professor Anna Jansen from University Hospital Brussels, who was involved in the TSC pilot, says that a key advantage of multi-stakeholder dialogues is that they not only enable patients and professionals

to identify priorities; they also provide an opportunity for each side to explain exactly why a certain issue is important to them.

"I attended a KBF-organized workshop in 2015 on evaluating multi-stakeholder priority setting and this was an eye-opening experience for me," she says. "I recognized that this methodology, which has not been applied to TSC before, could really benefit patients and medical professionals."

"We felt that there were a number of aspects related to quality of life issues that have perhaps not been as well researched as medical issues," she says. "There was an imbalance between what is important for patients and what is important for researchers. This initiative was an opportunity for each side to explain where they were coming from."

Recognizing priorities

Medical professionals and patients came up with a lot of research questions – Jansen estimates around 30 to 40 from each side – in preparation for the final consensus meeting. These questions were then prioritized and a final list of 15 TSC research priorities identified.

"Being heard in this way and having an impact on a possible research agenda has helped to counter the feeling of powerlessness that people

often experience in relation to this disease," explains Eva Schoeters, President of be-TSC and the face of this patient organization for this pilot project.

"Our hope is that the outcome of this exercise in priority setting will have a real impact on decisions made by researchers. If everything goes well, the real work is now only just beginning, based on this excellent guideline: research should be able to answer the questions that are a priority for every person who is affected by TSC, whether personally or professionally."

Anna Jansen notes that from the final list of 15 priorities, there are many that researchers would instantly recognize, such as preventing the disease and finding better pathways to treatment, but also a lot of questions that zoom into the organization of care and how

society deals with the disease. "These priorities were more prominent than might have been anticipated at the start of this exercise," she says.

Next steps

A KBF report is being produced on the methodology for priority setting by multi-stakeholder dialogue and the lessons learned. This can serve as a source of inspiration for people wishing to carry out similar exercises in any area of health research.

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ANNA JANSEN,
Professor from University
Hospital Brussels



PRIORITY SETTING

Multi-stakeholder dialogue for priority setting in health research is an inclusive, participatory, multi-actor process in which researchers, patients, members of the public, but also caregivers (informal and formal), governmental representatives, and funders, work together to prioritize, plan, conduct and disseminate research. Effective and targeted health research means making good use of finite resources while delivering solutions to those in need.

MORE INFO?

Reports from the KBF Mind the gap! projects are now available, as is an overarching methodological report: NASH and Biobanks, Work incapacity, TSC, Methodological report. You can read or download them for free on www.kbs-frb.be