

Three Parties, One Direction: Research Priorities in Adults with Congenital Heart Disease. What Do Professionals, Patients and Relatives Want to Know?

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For which topic were research priorities identified?

congenital heart disease

In which location was the research priority setting conducted?

Europe - Germany

Why was it conducted at all?

So far, investigations to identify future research topics in the field of congenital heart disease (CHD) were carried out by means of surveys either among professionals or patients. While most surveys among professionals concentrated exclusively on medical topics, the focus of patient surveys was placed on patients' general desires, worries and needs regarding medical, psychosocial or lifestyle issues. The present investigation by means of an online survey aimed at covering both physicians' assessment of the need for future research, as well as capturing the perspective of those affected.

What was the objective?

to assess both physicians' assessment of the need for future research, as well as to capture the perspective of those affected

What was the outcome?

a ranking list of 4 research topics

How long did the research prioritization take?

No information provided.

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: survey: list of 12 research topics/problem areas, participants were asked to rate need for research for each topic

Which stakeholders took part?

Four groups of patients with CHD (Fontan circulation, transposition of the great arteries after atrial switch AS and after arterial switch operation ASO, tetralogy of Fallot TOF), their relatives, as well as medical experts from the field of chd (paediatric cardiology, cardiology and cardiac surgery). 671 participants: 596 patients/ relatives and 75 physicians (57.3% paediatric cardiologists, 28% cardiologists, 10.7% cardiac surgeons, 4% other).

How were stakeholders recruited?

Four groups of CHD patients that represent a chronically ill population were chosen from the patient collective of the NRCHD (Fontan circulation, transposition of the great arteries [TGA] after atrial switch [AS], TGA after arterial switch operation [ASO], tetralogy of Fallot [TOF]). Therefore, the criteria for inclusion were the presence of a cardiac main diagnosis/cardiac condition qualifying for one of the four CDH groups, the availability of a current e-mail address (of adult individuals) and the absence of chromosomal abnormalities that limit cognitive capacity. Experts in the field of CHD compiled research topics of potentially high clinical significance. On this basis, a list consisting of twelve groups of topics each was compiled for each of the four CHD groups; the compiled sets of questions were divided into two categories (primarily psychosocial" and primarily medical") and reviewed by an expert panel. The expert panel comprised of (paediatric) cardiologists or congenital cardiac surgeons with long-standing experience in the field of CHD. In addition to representatives of German heart centres, recognized academics in the field of CHD and the members of the Management Boards of the German Competence Network for Congenital Heart Defects (CNCHD) and the NRCHD were included in the expert panel.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.