

# Research Priorities in Single-Ventricle Heart Conditions: A United Kingdom National Study

Drury et al. (2019)

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## For which topic were research priorities identified?

single-ventricle heart conditions

## In which location was the research priority setting conducted?

Europe - United Kingdom

## Why was it conducted at all?

Patients with single-ventricle heart conditions have complex healthcare needs. Although there are expectations of improving outcomes, the Fontan circulation remains a life-limiting condition with limited treatment options. Consequently, there is a demand for research to understand the impact of living with this condition and improve outcomes for patients and families throughout their journey. The International Fontan Interest Group has been established as a collaborative initiative to improve outcomes and has called for engagement of stakeholders to direct research priorities.

## What was the objective?

to bring together stakeholders in the United Kingdom to establish national priorities for research in single-ventricle heart conditions

## What was the outcome?

a list of 30 research questions

## How long did the research prioritization take?

Survey: October 2017 - December 2017. Interim ranking: February 2018. Workshop: April 2018.

## Which methods were used to identify research priorities?

JLA method

## How were the priorities for research identified exactly?

Step 1: identifying gaps in knowledge: via survey, participants were asked: What questions would you like to see answered by future research for patients who have a single-ventricle heart condition?, participants invited to pose up to three questions, 340 research questions submitted. Step 2: data processing. responses collated, reviewed, duplicates removed, out-of-scope removed, remaining questions rephrased for clarity and consistency of terminology and classified according to the current literature as unanswered by current research, already answered by published research or unable to be answered by scientific research, 204 unanswered questions remained which were divided into 20 categories. Step 3: interim ranking: via survey, participants were asked to rank the 20 categories in order of priority, for the top 3 categories participants were asked to rank each question within category, highest-ranking categories were taken forward along with the 5-7 highest ranking questions in each category. Step 4: final prioritization: workshop: before workshop participants provided with list of categories and questions, during workshop: small and large group discussions and rankings with nominal group technique

## Which stakeholders took part?

Patients, parents, healthcare professionals, researchers, and charities. Survey: 128 participants. Interim ranking: 65 participants. Workshop: 39 participants.

## How were stakeholders recruited?

Survey 1: An electronic link was disseminated by two national patient charities, Little Hearts Matter and The Somerville Foundation, via e-mail, newsletters, and social media such as Facebook and Twitter. Professional groups were contacted via the organizational mailing lists of the British Congenital Cardiac Association (BCCA), Society for Cardiothoracic Surgery (SCTS) and Paediatric Intensive Care Society Study Group (PICS-SG), and publicised at national meetings. United Kingdom-based researchers, heart charities, research funders, and National Health Service commissioners of congenital heart services were contacted directly via e-mail. Survey 2: An iterative process of invitation was used to ensure an adequate balance by role, age/experience, gender, and location, with the first invitations sent out 8 weeks in advance.

## 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.