

Congenital Heart Disease Priority Setting Partnership Communication Plan for the initial survey, June-September 2021

CHD PSP website: www.birmingham.ac.uk/congenital-psp

Email: congenitalPSP@contacts.bham.ac.uk

Partner Organisations

Children’s Heart Federation

Somerville Foundation

British Congenital Cardiac Association (BCCA)

Society for Cardiothoracic Surgery in Great Britain and Ireland (SCTS)

Little Hearts Matter

Tiny Tickers

Max Appeal

Birmingham Children’s Hospital Charity

Young at Heart

Paediatric Critical Care Society (PCCS)

Congenital Cardiac Anaesthesia Network (CCAN)

Paediatricians with Expertise in Cardiology Specialist Interest Group (PECSIG)

Society of Clinical Perfusion Scientists (SCPS)

Congenital Cardiac Nurses Association (CCNA)

British Adult Congenital Cardiac Nurse Association (BACCNA)

Centre for BME Health, Leicester

Social media

twitter: @congenitalPSP <https://twitter.com/CongenitalPSP>

Facebook: <https://www.facebook.com/congenitalpsp/>

Instagram and TikTok: to be promoted via partners social media accounts

Social media guidance

- Include the link to the survey: <https://redcap.link/congenitalPSP>
- Include the hashtag #CHDpriorities where possible
- Encourage followers to share with 'please RT'
- Tag key partner organisations as well as your own for credibility, such as @CHFEd @_theSF @bccu_uk @SCTSUK @LindAlliance

Suggested tweets

Have YOUR say on the future of Congenital Heart Disease research! Tell us the questions you want answered by research in the #CHDpriorities UK national survey in partnership with @CHFEd @_theSF @LindAlliance <https://redcap.link/congenitalPSP>

What questions do you have about Congenital Heart Disease? Have YOUR say in the #CHDpriorities UK national survey in partnership with @CHFEd @_theSF @bccu_uk @SCTSUK @LindAlliance Take part at <https://redcap.link/congenitalPSP>

Help Congenital Heart Disease research focus on what matters to you as a healthcare professional. Complete the #CHDpriorities UK national survey in partnership with @bccu_uk @SCTSUK @LindAlliance <https://redcap.link/congenitalPSP>

Share #CHDpriorities UK survey with your colleagues, patients, and their parents so their questions about Congenital Heart Disease are heard and represented in future research @bccu_uk @SCTSUK @LindAlliance <https://redcap.link/congenitalPSP>

What questions do you want answered by Congenital Heart Disease research? Complete the #CHDpriorities UK survey online <https://redcap.link/congenitalPSP> or download in English, Welsh, Polish, Bengali, Urdu, Gujarati, or Hindi from www.birmingham.ac.uk/congenital-psp @LindAlliance

Suggested Facebook posts

Initial post

Have YOUR say on the future of Congenital Heart Disease research!

A national study has been launched to identify and prioritise the areas of future research in congenital heart disease that are most important to patients, their families, and healthcare professionals in the UK. <Partner organisation name> are supporting this project to help ensure that *[either patients' or parents' and families']* voices are heard. This is your chance to have your say – **so we want to hear from you!**

The survey is now open and can be completed online at: <https://redcap.link/congenitalPSP> or is available to download as a PDF in English, Welsh, Polish, Bengali, Urdu, Gujarati, and Hindi.

Follow-up posts

Have YOUR say on the future of Congenital Heart Disease research! Tell us the questions you want answered by research in the UK national survey in partnership with @CHFEd @thesomervillefoundation <https://redcap.link/congenitalPSP>

What questions do you have about Congenital Heart Disease? Have YOUR say in the UK national survey in partnership with @CHFEd @thesomervillefoundation @SCTSGBI BCCA and James Lind Alliance. Take part at <https://redcap.link/congenitalPSP>

What questions do you want answered by Congenital Heart Disease research? Complete the UK national survey online <https://redcap.link/congenitalPSP> or download in English, Welsh, Polish, Bengali, Urdu, Gujarati, or Hindi from www.birmingham.ac.uk/congenital-ppsp thanks to @EastMidlandsBMCCentre

Clinic and other in person contact

Poster available to display in clinic or other public areas, including QR code for direct access to the online survey.

Survey PDFs available to download from www.birmingham.ac.uk/congenital-ppsp in English, Welsh, Polish, Bengali, Urdu, Gujarati, and Hindi.

Collected responses can be scan/photographed and emailed to: congenitalPSP@contacts.bham.ac.uk, or posted in an envelope to: **Freepost CONGENITAL PSP** (no stamp required).

Text for charity partner – email, newsletter, and websiteBritish Congenital
Cardiac AssociationSCTS
Society for Cardiothoracic Surgery
in Great Britain and Ireland**Have YOUR say on the future of Congenital Heart Disease research!**

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What questions would you like to see answered by research, relating to the diagnosis, treatment, or outcomes of congenital heart disease?

The survey is now open and can be completed online at: <https://redcap.link/congenitalPSP> or is available to download as a PDF in English, Welsh, Polish, Bengali, Urdu, Gujarati, or Hindi.

It should take no more than 10 minutes to complete and with your help, the findings will be used to:

- Develop a national strategy, to address the issues that matter most
- Guide the design of future studies, aimed at improving the clinical care and day-to-day lives of children and adults born with congenital heart disease

and so will have a major impact on the direction of congenital heart disease research in the UK!

This study is funded by George Davies, the high street fashion entrepreneur behind brands such as Next, Per Una, and George at Asda, through a generous donation to the Birmingham Children's Hospital Charity, as his granddaughter has previously undergone complex cardiac surgery.

For more information about the Congenital Heart Disease Priority Setting Partnership, please visit:

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twitter: @congenitalPSP

Facebook: congenitalPSP

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