

Where do we go from here?

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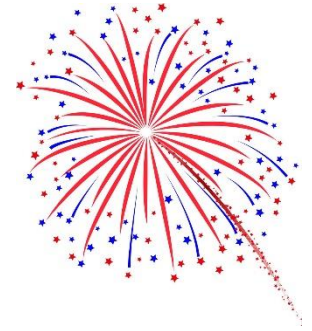
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Thursday 23rd & Friday 24th June 2022

Thank you!

Congenital Heart Disease PSP: timeline



16th March 2021

Initial steering committee meeting

October 2021-March 2022

Filter questions, generate summary questions, check against evidence

May-June 2022

Identify top priorities
approx. 25 questions in each track

July-November 2022

Develop national plan to address priorities
Launch priorities and plan at BCCA national meeting



June-October 2021

Initial survey open, online/paper formats, promote via social media, target seldom heard groups

March-May 2022

Second survey open, split into child/antenatal and adult tracks, wide distribution, vote to prioritise topics

June 2022

Two final workshops, in person events in Birmingham, to generate child/antenatal and adult Top 10 lists

Dissemination

- Launch priorities at BCCA annual conference in Birmingham, 7-8th November 2022
- Publish in peer-reviewed journal
 - Submit to the journal *Heart*, aim for synchronous publication with launch
 - Acknowledge workshop participants: **please sign** to include name, role +/- centre
 - Secondary papers on out-of-scope questions and ethnic engagement
- Promote to CHD community
 - Publicise Top 10 lists via partner organisations and media
 - Produce two booklets:
 - 1) priorities
 - 2) national strategy on how to address them

Next steps

- PSP will be the catalyst for a sea change in CHD research in the UK
- Develop and consult on national strategy to address the 20 priorities identified
 - Seek endorsement from BCCA, SCTS and national charity partners
- 1. Set-up **network** for conducting multi-centre CHD research and trials
 - Similar to the US Paediatric Heart Network
- 2. Set-up national CHD **patient & public involvement** (PPI) groups
- 3. Establish **working groups** to focus on one or more priorities
 - Define research questions, develop proposals, apply for funding

Network

- UK & Ireland network for conducting multi-centre CHD research and trials
- Adapt model of the Pediatric Heart Network in the US
 - Set-up in 2001, conducted 23 studies including 12 clinical trials
 - Studies ranging from 20 to 1,250 patients
 - >150 peer-reviewed publications, >75 abstract presentations
 - Transformed landscape of paediatric and ACHD clinical research in North America
- Visited PHN at NIH in Bethesda, MD, funded by BHF
 - Insight into set-up & running network, conducting trials
 - Shared key documents incl. manual of operations
 - Attended biannual PHN steering committee meeting



Network

- Develop a similar network model, affiliated to BCCA and SCTS
- Utilise existing infrastructure: BHF-CRC, NIHR CRN and RDS, experienced CTUs
- Investigator-initiated and led
 - Clinical trials and important observational studies, with training and support
- Collaborative
 - Studies open to all centres, without obligation, develop experience over time
 - Clear and agreed terms of reference, PI at each centre
 - Involve patients & their families in all aspects
 - Once network established, biannual investigator meeting to discuss, plan & learn
- Answer the most important questions → change clinical practice

PPI groups

- National CHD patient & public involvement (PPI) groups
 - Child/antenatal CHD group
 - Adult CHD group
- Role of PPI groups
 - Actively contribute to development, conduct and reporting of research
 - Participate in network and working groups
 - Training on involvement in research
 - Potential for co-production i.e. clinician/patient-led research
- Establish links with NIHR Centre for Engagement and Dissemination

Working groups

- Establish working groups to focus on one or more of the 20 priorities
 - Each comprised of HCP and PPI members → link with PPI group
 - Overseen and supported by network and BHF-CRC
- Role of working groups
 - Translate priorities into research question(s)
 - Coordinate project development and funding applications
- Apply for funding
 - NIHR rolling call *specific* for JLA PSP-identified priorities: HTA, EME, HSDR, PHR
 - BHF strategy identifies CHD research as ‘urgent’ priority ¹

¹ British Heart Foundation. *Our strategy to 2030*.



NIHR James Lind Alliance Priority Setting Partnerships rolling call



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31 August 2021

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1.2 - December 2021

Contents

1. [How to apply and supporting information](#)
2. [Deadline for proposals](#)
3. [Contact information](#)

Call for the research studies addressing James Lind Alliance (JLA) Priority Setting Partnerships' (PSPs) research priorities

The [JLA Priority Setting Partnerships](#) facilitate patients, carers and clinicians to work collaboratively to identify research priorities in particular areas of health and care. Their aim is to ensure that health research funders are aware of the issues that are important to the people who need to use the research in their daily lives.

The NIHR research programmes (Efficacy and Mechanism Evaluation (EME), Health and Social Care Delivery Research (HSDR), Health Technology Assessment (HTA) and Public Health Research (PHR), fund research across the National Health Service (NHS), public health and social care to meet the needs of those who plan, provide and receive care and services. The programmes recognise the importance of the research priorities identified by

Legacy

How should we determine the success of the PSP?

- PPI: Establish national CHD PPI groups, within 1 year
- Collaboration: network as platform for multi-centre trials
 - Number of funded trials, centres involved, patients recruited, at 5 and 10 years
- Workforce: expand UK CHD research activity, develop next generation
 - Number of NIHR academic trainees/Chairs in CHD, at 10 years
- Impact of research → change clinical practice
 - Number of high-impact publications
 - Incorporation into national & international CHD guidelines, at 10 years

Summary

- The PSP workshops are just the end of the beginning!
- 2 x Top 10 lists of priorities for research
 - Launch at BCCA annual conference in November
- National strategy on how to address them
 - UK & Ireland network, similar to PHN
 - National PPI groups
 - Working groups to address priorities
- Ultimate legacy of PSP will be how it leads to changes in clinical practice and outcomes

Thank you

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