



Thames Valley and Wessex  
**Congenital Heart  
Disease Network**

Children's and adult services

**Research Strategy  
2021 - 2025**

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<p><b>Summary:</b></p> <p>This document outlines the Thames Valley and Wessex Congenital Heart Disease Network: Children's and Adult Services Research Strategy aligned to the NHS Paediatric Congenital Heart Disease Standards (2015), Health Education England Innovation and Research Strategy (2015) and the NIHR Biomedical Research Units at University Hospital Southampton NHS Foundation Trust (UHS) and Oxford University Hospital NHS Foundation Trust.</p> <p>This strategy is accompanied by a separate, flexible operational plan, which will be regularly updated throughout its life span, reflecting changes including the impact of COVID-19 and policy changes. The plan will be monitored by the Thames Valley and Wessex Congenital Heart Disease Network Board.</p>	

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## 1. OVERVIEW

Patient care is significantly improved through research, innovation and quality improvement with better outcomes and improved treatment pathways. Research in addition provides opportunities and job satisfaction for staff. Hospitals and operational networks which are 'research active' have lower mortality rates, including even those who have not participated in research.

Participation in research has been identified as a priority within the NHS England CHD Service Specification and Standards 2016, which state that Congenital Heart Disease Networks should have:

1. A research and operational strategy, with an adequately resourced project pipeline
2. Stakeholder engagement from within the CHD network addressing key priorities to benefit patient care
3. Close links with a range of academic departments in Higher Education Institutions from within the operational network

### 1.1 Purpose

The purpose of this strategy is to document existing key research areas amongst regional organisations, as well as identifying a pipeline of future research activity within the network. Research activity will be reported annually and presented to the Clinical Governance Group, which has designated responsibility for research by the CHD Operational Network Board. Further dissemination of the research strategy will occur via the TVW CHD Operational Network website.

This strategy is accompanied by a separate, flexible operational plan, which will be regularly updated and reflects changes including the impact of COVID-19 and any policy changes. The plan will be monitored by the Thames Valley and Wessex Congenital Heart Disease Network Board.

### 1.2 Aim

The ambition of the TVW CHD ODN is to improve outcomes for patients with CHD. There is a need to consider a life course approach through the development of inception cohorts and nested cohort studies.

Overarching quality improvement and research themes will include nutrition, well-being, exercise and patient experience in order to develop individualized treatment, which is inclusive of the voice of patients and their families.

## **2. Introduction**

The Thames Valley and Wessex (TV&W) congenital heart disease (CHD) service is committed to, improving healthcare outcomes for patients with CHD and their families. This is achieved through a program of quality improvement, continuous professional development, education and research. Patient care is significantly improved through research, innovation and quality improvement leading to better treatment pathways and outcomes.

### **2.1 Quality improvement and education**

The congenital heart disease teams engage in a range of teaching and training activities aimed at developing, maintaining and overseeing the development of network staff. Activities are run in a collaborative manner at specialist centres in Southampton and Oxford with the support of other clinicians, paediatricians with specialist interest in cardiology (PECS), cardiac nurses and allied health professionals (AHP) in network hospitals.

### **2.2 Patient and Public Involvement (PPI)**

Adults and children with CHD are at the centre of everything the TV&W CHD network does. Adult, children and family PPI representatives are regularly consulted to ensure quality improvement and research activities are relevant, acceptable and feasible for patients to be involved in.

### **2.3 Research**

Research is an integral part of the service's mission to constantly improve care and outcomes for adults and children with CHD. The TVW Regional Network research partners include leading national organisations of University Southampton NHS Foundation Trust and Oxford University Hospital Foundation Trust along with their university partners University of Southampton and Oxford University. Clinical studies are carried out at the National Institute Health Research (NIHR) Clinical Research Facilities supported by dedicated research staff.

### 3. Development of research strategy priorities and principles

The Thames Valley and Wessex CHD network builds on the heritage of the Higher Education Institutes within the network, with a considered focus on nutritional and physiological health to improve outcomes and reduce disease burden.

An online survey was undertaken in order to understand key research interests of stakeholders. Twenty-seven health care professionals and patients participants completed the survey, of which 70% were clinicians, with the remainder split between Nursing, Allied Health Professionals and patients. Responses indicate individuals were; interested in research 44% (n=12), could see the value of research 89% (n=24), although the majority of individuals did not have sufficient capacity to complete research 40% (n=11), with no prospective cover 55% (n=15). Key themes arising from the open comments related to; funding, research training, including grant writing, statistics and support and time available to complete research.

Four themes were identified from the stakeholder engagement **NEW-R**, which fit in with the National Institute Health Research Biomedical Research Centres (NIHR-BRC) of UHS /OUH.

1. **Nutrition (N)**; pre-habilitation, perioperative, rehabilitation
2. **Exercise (E)**: physical activity, conditioning
3. **Wellbeing (W)**; decision making, patient and staff mental health and well-being
4. **Resilience (R)**; peri-operative stressors, bench to bedside

# TVW Research Principles

## TVW Research Strategy Principle 1: Nutrition (N)

**To improve growth and outcomes of children with CHD through the life course with particular reference to periods of nutrition pre-habilitation, perioperative nutrition support and post-operative nutrition rehabilitation**

**Our overall research aim is to**

1. To improve short and longer term growth and outcome of children with CHD through the life course through the characterisation of metabolic maturation, ensuring they are able to achieve their full potential through the provision of personalised nutrition care.

**In the TVW CHD network we will:**

### **AIM**

- 1. Develop collaborations with researchers to deliver high quality research in children with CHD using a life course approach; with particular reference to periods of nutrition prehabilitation, peri-operative nutrition support and post-operative nutrition rehabilitation**

### **OBJECTIVES**

- A. To undertake strategic planning to develop a four year strategy and yearly operational plan towards an enabling research culture within the TWV ODN with respect to Nutrition.
- B. To develop 6 – 12 month TWV CHD research internships (one per principle) to support early career researchers applying for grant or fellowship awards, as well as those interested in developing research skills (bench to bedside) with particular reference to nutrition prehabilitation, peri-operative support and post-operative rehabilitation.
- C. To complete patient and public involvement in the next 12 months to develop research ideas within the Nutrition theme including; prehabilitation, peri-operative support and post-operative rehabilitation.
- D. Within the next 12 months identify researchers interested in developing researchable questions relating to Nutrition in relation to nutrition prehabilitation, peri-operative nutrition support and post-operative nutrition rehabilitation.
- E. Within the next 12 months identify existing research leaders and mentors to support those new to research or early career researchers within the field of Nutrition.
- F. To support successful grant applications within Nutrition and the sub-themes of nutrition prehabilitation, peri-operative support and post-operative rehabilitation.
- G. Within the next four years high quality research related to periods of prehabilitation, peri-operative support and post-operative rehabilitation.

## TVW Research Strategy Principle 2: Exercise (E)

To improve health outcomes across the life course using multi-modal strategies including: nutrition, exercise and psychological wellbeing (NEW).

**Our overall research aim is to**

1. To use a life course approach to reduce the prevalence of abnormal body composition and obesity in children and adults with CHD through the design of engaging multi-modal physical activity, nutrition and psychological well-being programmes.

**In the TVW CHD network we will:**

### **AIM**

**Develop an enabling research culture within the TWV CHD ODN which facilitates the delivery of high quality research related to multi-modal rehabilitation research.**

### **OBJECTIVES**

- A. To undertake strategic planning to develop a four year strategy and yearly operational plan towards an enabling research culture within the TWV ODN with regards Physical activity.
- B. To develop 6 – 12 month TWV CHD research internships (one per principle) to support early career researchers applying for grant or fellowship awards, as well as those interested in developing research skills relating to physical health including physical activity and multi-modal rehabilitation research.
- C. To complete patient and public involvement in the next 12 months to develop research ideas within the two sub-themes of resilience including physical health including physical activity and multi-modal rehabilitation research.
- D. Within the next 12 months identify researchers interested in developing researchable questions relating to physical health including physical activity and multi-modal rehabilitation research.
- E. Within the next 12 months identify existing research leaders and mentors to support those new to research or early career researchers in the field of Physical Activity.
- F. To support successful grant applications within health and sub-themes of with regards to physical health including physical activity and multi-modal rehabilitation research.

## TVW Research Strategy Principle 3: Well-being (W)

To improve the experience of patients with CHD and their families by improving their quality of life

**Our overall research aim is to**

1. Increase the amount and quality of research relevant to improving Well Being amongst children and adults with CHD, and individuals caring for them including health care professionals.

**In the TVW CHD network we will:**

### **AIM**

1. **Develop an enabling research culture within the TWV CHD ODN which facilitates the delivery of high quality research related to Mental Health and Wellbeing (staff and patients), patient experience, physical health, transition to adult services and decision making.**

### **OBJECTIVES**

- A. To undertake strategic planning to develop a four year strategy and yearly operational plan towards an enabling research culture within the TWV ODN with respect to Wellbeing.
- B. To develop 6 – 12 month TWV CHD research internships (one per principle) to support early career researchers applying for grant or fellowship awards, as well as those interested in developing research skills
- C. To complete patient and public involvement in the next 12 months to develop research ideas within Well-being with sub-themes of; patient experience, transition and decision making.
- D. Within the next 12 months identify researchers interested in developing researchable questions relating to Well-being; patient experience, transition and decision making.
- E. Within the next 12 months identify existing research leaders and mentors to support those new to research or early career researchers with the field of Well-being.
- F. To support successful grant applications within Well-being with sub-themes; patient experience, transition and decision making.
- G. Within the next four years high quality research related to Well-being.
- H. To develop research considering parent, child, adult and staff well-being strategies identifying aspects which are unique to each group.

## TVW Research Strategy Principle 4: Resilience (R)

To use health data science to better understand resilience with a view to improving short and longer term health outcomes.

**Our overall research aim is to**

1. Using health data science and basic science techniques to improve our understanding of peri-operative stressors and the development of resilience.

**In the TVW CHD network we will:**

### **AIM**

**To develop an enabling research culture within the TWV CHD ODN which facilitates the delivery of high quality research using health data science and basic science techniques to improve short and longer term outcomes.**

### **OBJECTIVES**

- A. To undertake strategic planning to develop a four year strategy and yearly operational plan towards an enabling research culture within the TWV ODN with respect to Resilience.
- B. To develop 6 – 12 month TWV CHD research internships (one per principle) to support early career researchers applying for grant or fellowship awards, as well as those interested in developing research skills relating to resilience and post-operative stressors.
- C. To complete patient and public involvement in the next 12 months to develop research ideas within the two sub-themes of resilience including; relating to resilience and post-operative stressors.
- D. Within the next 12 months identify researchers interested in developing researchable questions relating to resilience and post-operative stressors.
- E. Within the next 12 months identify existing research leaders and mentors to support those new to research or early career researchers within the theme of Resilience.
- F. To support successful grant applications within the sub-themes of resilience and post-operative stressors.