

# Headlines Craniofacial Support

## 5-Year Research Strategy

### 2022-2027

Research is one of the three charitable purposes in the constitution of Headlines Craniofacial Support, which is registered with the Charity Commission of England and Wales and the Office of the Scottish Charity Regulator. The charity has an obligation to its members and its wider community to facilitate research that supports the charity's objectives.

#### Charitable Purposes:

*“To preserve and protect the health and promote the welfare of people with craniosynostosis and rare craniofacial conditions by:*

- 1) Providing support throughout their life to overcome the physical, psychological and social impacts of living with these conditions;*
- 2) Facilitating research that seeks to advance understanding, ensures the provision of quality care, and identifies the best treatments;*
- 3) Raising awareness and educating people to improve public understanding of craniosynostosis and rare craniofacial conditions.”*

In March 2021, the Trustees of Headlines Craniofacial Support designated funding to set up the first Headlines Research Fund.

In May 2021, a Research Committee was convened for the first time in the charity's history comprising of 7 members, including an adult lay member.

In September 2021, the Research Committee began the process of developing the charity's evidence-based Research Strategy to be formally launched to the public in Spring 2022.

The 5-year Research Strategy and the evidence for its development in the form of the “Research Strategy Framework” are below.

# Research Strategy

## 1. FACILITATE ACADEMIC AND CLINICAL RESEARCH

This strategic element aims to:

- **Fund research in five specific research Themes that have been identified through a stakeholder consultation, encompassing the Top 10 Research Priority Questions in Craniosynostosis:**
  - **Cause**
  - **Diagnosis**
  - **Treatment**
  - **Physical and mental development**
  - **Awareness**
- **Short term objectives:**
  - **Support the funding of project grants that address the identified Themes**
- **Long term objectives:**
  - **Encourage early career researchers with a platform for career development in the field of craniosynostosis and rare craniofacial conditions (by funding PhD students and Clinical Research Fellowships)**

## 2. SUPPORT SOCIAL CARE AND POLICY RESEARCH

This strategic element aims to:

- **Facilitate social care research and educational support to improve quality of life and enhance independence**
- **Inform policy making in health, social care and education**

### **3. ENGAGE PATIENTS, CARERS AND FAMILIES IN RESEARCH – Patient and Public Involvement/Engagement (PPI/E)**

**This strategic element aims to:**

- **Support research that reflects patient views and priorities through the development of a Patient, Carer and Family Voices in Research Network**
- **Act as a conduit for bringing the Headlines Community and researchers together**
- **Work with researchers to educate the Headlines Community about research**

### **4. ENHANCE COMMUNICATION AND COLLABORATION**

**This strategic element aims to:**

- **Communicate research findings to the Headlines Community, our supporters and funding partners**
- **Co-fund research through partnerships and collaborations with other funders, corporate partners, foundations and trusts**
- **Work with research institutions and other appearance health related charities to improve care**
- **Engage with all health professionals, NHS commissioners and policy makers to improve clinical provision and enhance pathways of care**

**Finally, the strategy enables Headlines Craniofacial Support to embrace its vision “for a world where the physical, psychological and social impacts of craniosynostosis and rare craniofacial conditions are no more.”**

# The Research Strategy Framework

This Framework was developed and approved by the Headlines Craniofacial Support Research Committee as the basis for the new research strategy for the charity. The objective was to gather all the evidence obtained through consultation with clinicians, researchers, patients and carers and feed that information into the new strategy.

## Stakeholder engagement

Between 2016 and 2017 a range of stakeholders including patients, carers and health professionals were engaged in an activity that led to the definition of the “*Top Ten priority research questions for craniosynostosis*”. This list was compiled following a similar but simplified process to that used in the James Lind Alliance Priority Setting Partnerships ([www.jla.nihr.ac.uk](http://www.jla.nihr.ac.uk)). A list of over 30 questions was gathered through a community-wide consultation exercise. These were then reduced to 17 questions, which were discussed at the Headlines Research Conference in February 2017. The 17 questions were then circulated to the membership via email for further ranking. Members who participated were asked to rank each question using an online survey monkey questionnaire. The resultant ranked list provided the Top Ten Priority Research Questions (Appendix 1).

Between 2017 and 2018, Headlines Craniofacial Support developed and implemented a new Charity Strategy following consultation with members and trustees. The Strategy was formulated and launched in February 2018. The 5-year strategy identified three key areas, which were then integrated into the updated charitable purposes and constitution as noted above (Appendix 2).

In February 2021, The Journal of Craniofacial Surgery published an “*Updated Guideline on Treatment and Management of Craniosynostosis*” by Irene M.J. Mathijssen, MD, PhD, Chair of the Working Group Guideline for Craniosynostosis, who is based at Department Plastic and Reconstructive Surgery and Hand Surgery, Erasmus Medical Center, Rotterdam, The Netherlands (vol **32**, pages 371-450).

The Guideline was the output from the Working Group for Craniosynostosis. The content of this Guideline is based on evidence from published scientific research. Relevant articles were identified using systematic searches in Medline, Embase, and the Cochrane Library. In the preparatory phase the patient perspective was taken into account by engaging with the Patient Federation Netherlands for written input on bottlenecks in care i.e. any issues that parents or patients encounter during their care. The Working Group also forwarded the request for the submission of

bottlenecks to LAPOSA which is the charitable Patient Support Group for patients with craniofacial anomaly in the Netherlands, and Stichting Kind en Ziekenhuis (The Child and Hospital Foundation). However, no bottlenecks were submitted. Patient input was also received from the Chair of LAPOSA who had a seat on the Working Group. Once the Guideline had been drafted it was circulated to these organisations again for review before publication. The content of this Guideline can be found in Appendix 3.

More recently, on 22<sup>nd</sup> March 2021, the Trustees of Headlines Craniofacial Support designated £20,000 to a new research fund, which was launched in May 2021. At the same time a Research Committee was established to support the awarding of research grants and the development of the charity's first Research Strategy.

## **Research Strategy Content Development**

In November 2021, the Research Committee was convened to discuss the development of the new Research Strategy. It was agreed that research funding should aim to address the needs of members and wider community.

The Committee reviewed the documents highlighted above and concluded that the best way to integrate the findings into a strategy was by identifying common themes.

Following analysis of the two documents listed above, five Themes have been identified. The full analysis can be found in Appendix 4.

The Research Committee reviewed these Themes to ensure each question raised by the various consultations with stakeholders could be assigned to a particular category within these themes. The five Themes were agreed by all committee members in December 2021.

### ***Cause***

Q4 - What are the causes of single suture and non-syndromic synostosis?

Q8 - Are there links between Craniosynostosis and other medical conditions (autism/dyslexia/gynaecological/gastro/endocrine/bones)?

### ***Diagnosis***

Q5 - Can better scans/monitoring help identify Craniosynostosis during pregnancy?

## **Treatment**

Q2 - What is the most reliable way to determine whether a child has a level of intracranial pressure that could cause impaired brain function?

Q3 - Which types of craniofacial surgery work best, and what is the optimum age to perform them?

Q9 - What is the risk of further surgery for each of the craniofacial conditions?

## **Physical and mental development**

Q1 -What are the long-term effects on development for a) syndromic and b) non-syndromic craniofacial patients – physical and psychological?

Q7 - How is an adult patient affected physiologically by their craniofacial condition – intracranial pressure/risk of stroke/other issues – and how are they monitored?

Q10 - Are adult craniofacial patients likely to suffer from mental health difficulties, or are they more resilient, due to their upbringing with the condition?

## **Awareness**

Q6 - What do paediatricians, GPs and health visitors know about this craniofacial conditions, and what is the most effective way to improve their knowledge?

The Research Committee also agreed that the research strategy should identify short and long-term objectives. It should be noted that the ability to meet these objectives is very much dependent on the potential growth of the charity both in terms of income and staff resources over the next 5 years.

1. Short term objectives
  - a. Support the funding of small project grants that address the identified Themes
  - b. Support PPI/E in research
  - c. Support social care, policy change and public interest
  - d. Support communication and dissemination of research findings to our community
2. Long term objectives
  - a. Encourage early career researchers by developing a platform for career development in the field of craniosynostosis and rare craniofacial conditions (by funding PhD students and Clinical Fellowships).

- b. Support collaborations and partnerships with other funders, corporate partners, foundations and trusts.

Funding models to be considered for the implementation of short- and long-term objectives are listed in Appendix 5.

# Appendix 1

## Top Ten Priority Research Questions

1. What are the long-term effects on development for a) syndromic and b) non-syndromic craniofacial patients – physical and psychological?
2. What is the most reliable way to determine whether a child has a level of ICP that could cause impaired brain function?
3. Which types of craniofacial surgery work best, and what is the optimum age to perform them?
4. What are the causes of single suture and non-syndromic synostosis?
5. Can better scans/monitoring help identify Craniosynostosis during pregnancy?
6. What do paediatricians, GPs and health visitors know about craniofacial conditions, and what is the most effective way to improve their knowledge?
7. How is an adult patient affected physiologically by their craniofacial condition – intracranial pressure/risk of stroke/other issues – and how are they monitored?
8. Are there links between Craniosynostosis and other medical conditions (autism/dyslexia/gynaecological/gastro/endocrine/bones)?
9. What is the risk of further surgery for each of the craniofacial conditions?
10. Are adult craniofacial patients likely to suffer from mental health difficulties, or are they more resilient, due to their upbringing with the condition?

## Appendix 2

### 5 Year Charity Strategy

<b>Awareness &amp; Education</b>  <i>Raise awareness and educate people to improve public understanding of craniosynostosis and rare craniofacial conditions</i>	<b>Support &amp; Living with the Condition</b>  <i>Support people with craniosynostosis and rare craniofacial conditions throughout their life to overcome the physical, psychological and social impacts of living with these conditions</i>	<b>Research &amp; Provision of Care</b>  <i>Support research that seeks to advance understanding, ensures the provision of quality care, and identifies the best treatments for craniosynostosis and rare craniofacial conditions</i>
<p><b><i>Provide information on the condition</i></b></p> <ul style="list-style-type: none"> <li>• Making sure people understand their condition and have the information available to them when they need it</li> <li>• Working with experts in the conditions to keep the patient information up to date</li> </ul>	<p><b><i>Support</i></b></p> <ul style="list-style-type: none"> <li>• Bringing members and families together at regular and annual events to share experiences</li> <li>• Supporting people on the helpline and through social media groups</li> <li>• Developing a teen and young adults programme</li> <li>• Supporting all members throughout their life</li> </ul>	<p><b><i>Advance understanding, improve diagnosis and improve treatments</i></b></p> <ul style="list-style-type: none"> <li>• Identifying research priorities</li> <li>• Supporting health professionals and researchers to undertake research and enhance knowledge</li> <li>• Involving patients in research</li> </ul>

<p><b><i>Raise awareness of the condition and increase the public profile</i></b></p> <ul style="list-style-type: none"> <li>• Making the public aware of the conditions and the charity through events, website, newsletters and social media</li> <li>• Running campaigns to highlight the condition such as Craniofacial Awareness Week</li> <li>• Attendance and presenting at relevant meetings and conferences</li> <li>• Partnering and collaborating with other relevant organisations to increase profile of our work</li> </ul>	<p><b><i>Living with the condition</i></b></p> <ul style="list-style-type: none"> <li>• Helping people gain access to psychological and social support</li> <li>• Connecting people with experts in the community</li> <li>• Linking up with national and local initiatives on improving daily life of people with differences</li> <li>• Providing welfare grants</li> </ul>	<p><b><i>Enhance care, improve standards and quality of life for people with the condition</i></b></p> <ul style="list-style-type: none"> <li>• Bringing health professionals and patients together to discuss needs</li> <li>• Working with health commissioners and governing bodies to improve care</li> </ul>
<p><b>BY WHEN: 2023</b></p>	<p><b>BY WHEN: 2023</b></p>	<p><b>BY WHEN: 2023</b></p>

## **Appendix 3**

### **Updated Guideline on Treatment and Management of Craniosynostosis**

Chapter 1. Introduction

Chapter 2. Methodology for guideline development

Chapter 3. Referral and diagnostics

Chapter 4. Perioperative care

Chapter 5. Surgical treatment of isolated, non-syndromic craniosynostosis

Chapter 6. Surgical treatment of multi-suture and syndromic craniosynostosis – the cranial vault

Chapter 7. Surgical treatment of syndromic craniosynostosis – FACE

Chapter 8. Increased intracranial pressure

Chapter 9. Hydrocephalus

Chapter 10. Chiari

Chapter 11. Visual, refractive and motility impairments

Chapter 12. Respiratory disorders

Chapter 13. Hearing impairments and speech/language development

Chapter 14. Dentofacial abnormalities

Chapter 15. (Neuro)cognitive, socio-emotional and behavioural functioning

Chapter 16. Psychosocial functioning

Chapter 17. Criteria for craniosynostosis expertise center and team members

## Appendix 4

### Categorisation of priority questions and key areas identified in the Guideline under the research themes

#### ▪ Cause

- Q4 - What are the causes of single suture and non-syndromic synostosis?
- Q8 - Are there links between Craniosynostosis and other medical conditions (autism/dyslexia/gynaecological/gastro/endocrine/bones)?

#### ▪ Diagnosis

- Q5 - Can better scans/monitoring help identify Craniosynostosis during pregnancy?

Chapter 3. Referral and diagnostics

#### ▪ Treatment

- Q2 - What is the most reliable way to determine whether a child has a level of ICP that could cause impaired brain function?
- Q3 - Which types of craniofacial surgery work best, and what is the optimum age to perform them?
- Q9 - What is the risk of further surgery for each of the craniofacial conditions?

Chapter 5. Surgical treatment of isolated, non-syndromic craniosynostosis

Chapter 6. Surgical treatment of multisuture and syndromic craniosynostosis – the cranial vault

Chapter 7. Surgical treatment of syndromic craniosynostosis – FACE

Chapter 8. Increased intracranial pressure

Chapter 9. Hydrocephalus

Chapter 10. Chiari

Chapter 11. Visual, refractive and motility impairments

Chapter 12. Respiratory disorders

Chapter 13. Hearing impairments and speech/language development

Chapter 14. Dentofacial abnormalities

▪ **Physical and mental development**

- Q1 -What are the long-term effects on development for a) syndromic and b) non-syndromic craniofacial patients – physical and psychological?
- Q7 - How is an adult patient affected physiologically by their craniofacial condition – intracranial pressure/risk of stroke/other issues – and how are they monitored?
- Q10 - Are adult craniofacial patients likely to suffer from mental health difficulties, or are they more resilient, due to their upbringing with the condition?

Chapter 15. (Neuro)cognitive, socio-emotional and behavioural functioning

Chapter 16. Psychosocial functioning

▪ **Awareness**

- Q6 - What do paediatricians, GPs and health visitors know about craniofacial conditions, and what is the most effective way to improve their knowledge?

## **Appendix 5**

### **Funding Models for Research Grants**

**The following types of grants are typically awarded by medical and health research charities.**

#### ***Annual Project Grants***

A Project Grant is an award given to fund a specific piece of research at a university, hospital or research institution. The Principal Investigator will be based at a UK institution and may collaborate with other experts in their field, but collaboration is not essential for these grants.

Project Grants are generally advertised by charities for a period of research to be undertaken for up to 3 years with a budget of up to £180,000 per award.

Small Project Grants are generally advertised by charities for a period of research to be undertaken for up to 2 years with a budget of between £10,000 to £25,000 per award.

#### ***Programme Grants***

Research funded through a Programme Grant typically consists of an interrelated group of high-quality projects focused on a coherent theme. The grant is awarded for a minimum of three years and will include a Lead Investigator and a number of collaborations with other researchers in order to achieve its goal.

Programme Grants are generally advertised by charities for a period of research to be undertaken for up to 5 years with a budget of £800,000 or more per award.

#### ***Researchers Career Development Grants – Fellowships and PhD Studentships***

These types of grants are designed to fund individual salaries and research support costs. They encourage people to specialise and develop a career in a specific field and support the development of future specialist experts in those fields.

Approximately 60% of AMRC member organisations fund Fellowships and postgraduate PhD Studentships, hence such a programme of research could also

allow the charity to form funding partnerships with a number of other organisations, trusts and foundations.

Estimated annual costs attributable to this programme are included for illustrative purposes only, and can be scaled up or down depending on available resources for research in any given year, or the quality of applications received.

To achieve this programme:

i) Clinical Research Fellowships

These aim to encourage junior medics with a basic clinical qualification ( $\pm$  a Batchelor's degree) to develop into outstanding academic clinicians and future scientific leaders in this field. End goal – MPhil, MD or PhD, roughly equating with 1, 2 or 3 years of study, respectively.

Fellowships range from £50,000 to £70,000 per year. Total cost of up to £210,000 over three years (depending on location) plus up to £15,000 per annum consumables budget.

ii) Postgraduate PhD Studentships

These enable junior researchers with BSc or equivalent degrees to undertake medical or scientific research.

A 3-year Studentship award: stipend of £18,000-£22,000 and research costs of up to £15,000 per year. Total cost of studentship of up to £90,000 over three years (depending on location).