




# BMJ Open UK Chiari 1 Study: protocol for a prospective, observational, multicentre study

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## ABSTRACT

**Introduction** Chiari 1 malformation (CM1) is a structural abnormality of the hindbrain characterised by the descent of the cerebellar tonsils through the foramen magnum. The management of patients with CM1 remains contentious since there are currently no UK or international guidelines for clinicians. We therefore propose a collaborative, prospective, multicentre study on the investigation, management and outcome of CM1 in the UK: the *UK Chiari 1 Study* (UKC1S). Our primary objective is to determine the health-related quality of life (HRQoL) in patients with a new diagnosis of CM1 managed either conservatively or surgically at 12 months of follow-up. We also aim to: (A) determine HRQoL 12 months following surgery; (B) measure complications 12 months following surgery; (C) determine the natural history of patients with CM1 treated conservatively without surgery; (D) determine the radiological correlates of presenting symptoms, signs and outcomes; and (E) determine the scope and variation within UK practice in referral patterns, patient pathways, investigations and surgical decisions.

**Methods and analysis** The UKC1S will be a prospective, multicentre and observational study that will follow the British Neurosurgical Trainee Research Collaborative model of collaborative research. Patients will be recruited after attending their first neurosurgical outpatient clinic appointment. Follow-up data will be collected from all patients at 12 months from baseline regardless of whether they are treated surgically or not. A further 12-month postoperative follow-up timepoint will be added for patients treated with decompressive surgery. The study is expected to last three years.

**Ethics and dissemination** The UKC1S received a favourable ethical opinion from the East Midlands Leicester South Research Ethics Committee (REC reference: 20/EM/0053; IRAS 269739) and the Health Research Authority. The results of the study will be published in peer-reviewed medical journals, presented at scientific conferences, shared with collaborating sites and shared with participant patients if they so wish.

## BACKGROUND

Chiari 1 malformation (CM1) is a structural abnormality of the hindbrain characterised by the descent of the cerebellar tonsils

## Strengths and limitations of this study

- The UK Chiari 1 Study (UKC1S) will be a prospective multicentre study of the management of patients with Chiari 1 malformation.
- Contrary to other studies which focus on surgical management only, the UKC1S will study patients who have been managed with and without surgery.
- The UKC1S is adopting a trainee-led study process that has been shown to be deliverable and effective.
- This study will offer an insight into the contemporary trends in the neurosurgical management of Chiari 1 malformation in the UK.
- The study uses different quality of life measures for adults and children, so no direct comparison between these groups will be possible.

through the foramen magnum. It is one of six Chiari malformations described,<sup>1</sup> but is the most common of these and has an estimated prevalence of approximately 8 in 1000 people.<sup>2</sup> CM1 affects patients of all ages, but more commonly presents in late childhood or early adulthood.

CM1 is a heterogeneous condition. The natural history of CM1 in some patients is relatively benign and some patients remain asymptomatic.<sup>3</sup> Other patients with CM1 may have significant symptoms, neurological deficits and complications.<sup>4</sup> Crowding of the neural structures in the foramen magnum can present with brainstem, cerebellar and spinal cord symptoms. There may be disruption to the normal flow of cerebrospinal fluid (CSF) through the foramen magnum and 50% of imaged patients have an associated spinal cord syrinx, and a small number of patients develop hydrocephalus.<sup>5</sup>

Despite the Chiari malformations being classified in 1891,<sup>6</sup> the aetiology, classification, diagnosis, natural history, investigation and management of CM1 remain as highly



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contentious subjects. There are currently no UK or international guidelines for the investigation or management of CMI.<sup>7</sup>

Surgery to decompress the craniocervical junction (often termed foramen magnum decompression (FMD)) remains the mainstay of surgical management. The surgical technique for decompressive surgery varies widely between centres and surgeons.<sup>8,9</sup> FMD can comprise 'bone-only decompression', but can also include dural opening, arachnoid opening, duraplasty and tonsillar resection. Recent evidence suggests that there may be differences in efficacy and outcomes between these techniques,<sup>10,11</sup> but further evidence is required. The use of intraoperative technologies, such as ultrasonography, to inform surgical decisions also requires further evidence of efficacy.<sup>12</sup> CSF diversion has also been advocated as a possible primary strategy for the management of symptomatic CMI with evidence of abnormal intracranial pulsatility.<sup>13</sup>

Current evidence in CMI consists mostly of relatively small, single-centre and/or retrospective studies. While evidence in CMI is available on a national scale in other countries,<sup>14</sup> there are no UK-wide studies that have reported or compared the scope or variation in contemporary neurosurgical workload, practice and outcomes. Multicentre US databases have offered larger scale analyses of surgical outcomes, but these are retrospective and only focus on surgically managed patients.<sup>9,15</sup> While there are some retrospective studies,<sup>3,16</sup> there is a distinct lack of prospective studies investigating outcomes in conservatively managed patients. The lack of evidence in this field makes it difficult for surgeons to decide which patients surgery should be offered and which patients can be managed without surgery. There is a clear need for large-scale and non-biased data and we therefore propose a collaborative, multicentre and prospective study of the investigation and management of CMI in the UK.

## METHODS

### Objectives

The primary objective of the study is to determine the change in health-related quality of life (HRQoL) between the first neurosurgical clinic appointment and at 12 months of follow-up of patients with CMI. Our secondary objectives are to: (A) determine HRQoL at 12 months following surgery; (B) measure complications and need for reoperation within 12 months of surgery; (C) determine the natural history of patients with CMI treated conservatively without surgery; (D) determine the radiological correlates of presenting symptoms, signs and outcomes; and (E) determine the scope and variation within UK practice in referral patterns, patient pathways, investigations and surgical decisions.

### Design

The *UK Chiari 1 Study* (UKC1S) will be a prospective, multicentre, observational study. The study is purely observational and will not alter patient care in any way.

The study will follow the British Neurosurgical Trainee Research Collaborative (BNTRC) model for multicentre and trainee-led collaboration.<sup>17</sup> Each participating UK neurosurgical unit (NSU) will be required to commit both a consultant principal investigator (PI) and a trainee co-PI. As many interested consultants as possible are welcome to participate as collaborators. We are particularly interested in the collaboration of consultant neurosurgeons who have an interest in CMI and who see substantial numbers of patients with CMI. Considering the length of the study, trainee investigators may be required to hand over the trainee co-PI role to another trainee during the study course, but this will not interfere with the study design. All UK NSUs will be invited to participate.

Each participating NSU is permitted to begin a 12-month recruitment period between 8 October 2020 and 7 April 2021. The overall study, therefore, will be completed on 6 April 2024.

### Inclusion criteria

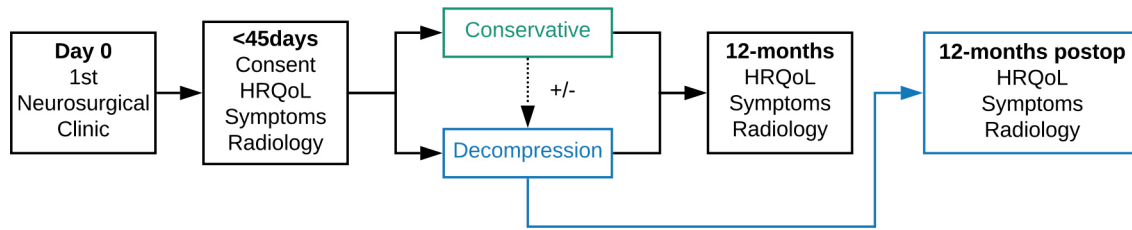
Participants will be patients with a new diagnosis of CMI presenting to neurosurgical clinic for the first time within the one year recruitment stage of the study. We will recruit both adults and children of any age to the study. While at least 5 mm of herniation below the foramen magnum is often used to decide the diagnosis of CMI, such an arbitrary threshold is not specified in this study. Since this is a pragmatic study, we instead choose to include all patients who have been diagnosed with CMI by their consulting neurosurgeon.

### Exclusion criteria

Patients may not enter the study if they are considered to have an alternative Chiari malformation, history of spinal dysraphism or if they have already undergone neurosurgical intervention (excluding lumbar puncture) for CMI or an alternate neurological diagnosis.

### Outcome measures

The study will collect both patient-reported or parent-reported (hereafter referred to simply as patient-reported) and surgeon-reported data. The study design allows for remote, online data collection and therefore does not require patients to make further physical visits to the hospital or any other facility. Participants will be required to provide patient-reported data at baseline and 12 months following baseline (figure 1 and table 1). Additionally, if the patient undergoes decompressive surgery, then they will be asked to provide patient-reported data 12 months after their surgery. This patient-reported model of data collection has been piloted and shown to be feasible by the Understanding Cauda Equina Study.<sup>18</sup> Surgeon-reported data will require observational data collection from patient notes, imaging and surgical logs.



**Figure 1** Study process. HRQoL, health-related quality of life.

The data fields for collection are available as online supplemental material.

Patient-reported data at baseline, 12 months and, if applicable, 12 months following surgery will consist of an online questionnaire regarding symptoms and HRQoL. HRQoL will be measured in adults (16 years and above) using the 36-Item Short Form Health Survey (UK version). HRQoL will be measured in children (2–15 years) using the age-appropriate parent-reported Pediatric Quality of Life Inventory (PedsQL; UK version). Written permission was given by the Mapi Research Trust ([www.mapi-trust.org](http://www.mapi-trust.org)) to use the PedsQL questionnaires free of charge. Children less than two years of age will be recruited into the study, but not included in the HRQoL analyses.

### Screening and consent

Patients who satisfy all of the inclusion and exclusion criteria will be identified by participating neurosurgical consultants and trainees. The neurosurgical team will ask permission for the patient to be contacted by the study team (ie, the researchers working on the study at that particular hospital/NSU) via telephone and this will be documented in the patient’s notes.

After identification, patients will be contacted via telephone by a member of the study team who will explain the details of the study, its aims and what it involves for the participant. The person who obtained the consent must be suitably qualified and experienced and has been authorised to do so by the principal investigator. The study will be explained and if the patient agrees then the patient will be sent an email that contains a PDF version of the participant information sheet and a hyperlink to

the digital consent form. The digital consent form will be a submission form linked to our Research Electronic Data Capture (REDCap) study database. Patients will explicitly be consented for their name, email address and phone number to be stored on the database. Patients will draw an electronic signature, type their name and type the date on the electronic consent form.

The parents or legal guardians will consent for children (<16 years) approached for the study and the parents’ contact details will be used. If a child turns 16 years of age during the study period, then the patient will be re-consented to remain in the study using the same procedures as described for adults. Those who are unable to consent to the study themselves may be enrolled by their next of kin.

At the time of consent, an additional option will be for patients to consent to being contacted for future studies. We acknowledge that a one-year follow-up is too short in order to determine the outcomes and reveal the management decisions in this long-term condition, but the study timeline is pragmatically built on the collaborative BNTRC model. We plan, however, for a future study to collect outcome data at five and/or 10 years, but these are considered separate and are not within the current study protocol.

During the course of the study a participant may choose to withdraw early from the study at any time.

### Statistical analysis plan

The study outcomes will be measured using quantitative data. There is no qualitative component to the study.

For the primary outcome, the baseline and 12-month HRQoL assessments will be used for analysis. For all patients, comparison will be made between baseline and 12 months, but both will also be compared against the UK normative data sets. For the secondary outcome in the subgroup undergoing decompressive surgery, HRQoL data will be similarly compared with baseline and to UK normative data sets. Adult and paediatric HRQoL will be analysed separately since the measurement tools are different. For each follow-up timepoint, patient-reported data (digital questionnaires) must be completed within 45 days from the target date to be included in the analysis.

Further comparisons of outcome data will be made between specific surgical techniques used, baseline symptoms and radiological findings. Descriptive statistics will be used to report the data from the exploratory objectives, regarding referral pathways, investigations and

**Table 1** Study timeline and assessments

Procedures	Day 0	12 months	12 months postoperative*
First neurosurgical clinic	✓		
Patient identified	✓		
Patient approached	✓		
Patient consented	✓		
Patient-reported data	✓	✓	✓
Surgeon-reported data	✓	✓	✓

\*Only for patients undergoing decompressive surgery.



management strategies for CMI in UK neurosurgical practice.

Statistical significance will be set at  $p < 0.05$ .

A pilot retrospective data review from two NSUs (Birmingham and Oxford) showed that, in one month, one unit found 11 patients and the other found four patients who met the inclusion criteria aforementioned. Based on these limited data, if 18 participating units saw this average of seven patients per month, over the 12-month recruitment periods there would be around 1500 eligible patients. Considering that not all patients will agree to take part and that some patients may be missed, we realistically aim for a recruitment target of at least 500 patients.

### Patient and public involvement

The study design has been presented to and has received feedback from the Ann Conroy Trust, a charity and support group for patients with Chiari malformations and syringomyelia. Patients will be given the additional option on the consent form to be contacted following the completion of the study for the synopsis of the overall study results to be emailed to the email address they provided.

## ETHICS AND DISSEMINATION

### Approvals

Oxford University Hospitals NHS Foundation Trust will act as the study sponsor. Approval has been granted by the East Midlands Leicester South Research Ethics Committee (REC reference: 20/EM/0053; IRAS 269739) and the Health Research Authority. Each NSU will require written approval from their local Research and Development department.

The UKCIS was selected for support by the BNTRC following an open national call for projects in 2018. It has been reviewed by the BNTRC Committee, the Society of British Neurological Surgeons Academic Committee and the British Syringomyelia Chiari Group.

Quality assurance procedures will be conducted by the sponsor site. The study may be monitored, or audited in accordance with the current approved protocol, Good Clinical Practice, relevant regulations and standard operating procedures.

The investigators will ensure that this study is conducted in accordance with the principles of the Declaration of Helsinki. The investigators will ensure that this study is conducted in accordance with relevant regulations and with Good Clinical Practice. While it is not an absolute requirement, we would encourage all collaborators to complete their Good Clinical Practice training prior to the start of their involvement in the study.

### Data management

Data will be entered onto a secure online database platform called REDCap (<https://projectredcap.org/>).<sup>19</sup> REDCap has been used extensively in clinical studies

by the National Health Service (NHS) and UK universities, including recent studies by the STARSurg collaborative.<sup>20</sup> Online data capture has been used successfully by previous BNTRC studies, such as the Understanding Cauda Equina Study.<sup>18</sup>

All information will be kept strictly confidential and the study will comply with the Data Protection Act 1998 and the European Union General Data Protection Regulation (GDPR).

Every member of the local study teams will be given personal log-in details in order to input data into the database. Local study team members will have full access to their local data, but not the data of other participating NSUs. The sponsor site will have full access to all of the data (from every NSU) to allow multicentre data analysis, ensure ongoing validity of the study or to follow-up with patients. The REDCap system also allows the sponsor site full visibility of the electronic audit trail that tracks all user activity on the database, allowing full accountability of its usage and to ensure standard operating procedures are maintained.

Once a patient electronically signs the consent form, the REDCap system will automatically assign the patient a unique UKCIS ID number. Each NSU will keep a log of the corresponding local ID number or NHS number on their local secure NHS system. With their consent, each patient's name, email address and phone number will be securely stored on the database and are hidden behind access controls so that only the local site and sponsor site can see them. Other than on the consent form, the name and any other identifying detail will not be included in any study data electronic file.

Following completion of the study, all data recorded on the database will be downloaded by the sponsor site and retained within the secure electronic NHS system for a maximum of 10 years following completion of the study. Paper documentation will be retained in appropriately secure NHS storage and electronic data will be stored on the sponsor NHS server. Data, including the separately stored consent forms, will be retained further if patients have been consented to being contacted for future studies.

### Data confidentiality

The study will comply with the GDPR and Data Protection Act 2018, which require data to be deidentified as soon as it is practical to do so. The processing of the personal data of participants will be minimised by making use of a unique participant study number only on all study documents and any electronic database(s), with the exception of the consent form where the patients must type their name and sign the form. All documents will be stored securely and only accessible by study staff and authorised personnel. The study staff will safeguard the privacy of participants' personal data.

### Funding

This study is kindly supported by the Ann Conroy Trust, primarily a support group for those affected by Chiari

malformations, syringomyelia and associated conditions ([www.annconroytrust.org](http://www.annconroytrust.org)).

### Dissemination plan

We intend to publish and present our study outcomes in peer-reviewed medical journals and conferences, respectively. In publications including national data, as per the BNTRC<sup>17</sup> and Association of Surgeons in Training (ASiT)<sup>21</sup> models, all participating researchers will be named as PubMed-citable collaborators. The REDCap database allows visibility of data input and will ensure that named collaborators have contributed towards the study. Authorship will be decided in accordance with the *International Committee of Medical Journal Editors*. As per the BNTRC constitution, the senior author will be the BNTRC (<https://www.bntrc.org.uk/about-us>). The steering committee and BNTRC will retain ownership of the entire national data set and the right to publish the data. Local data, however, will be available to the local investigators to facilitate local audit. Local outputs must acknowledge the UKCIS. This study is intended as a research study in order to inform further research and perhaps future clinical practice. Variance in practice or the outcomes of individual NSU or neurosurgeon will be available for each NSU to review, but NSU or individual neurosurgeon identifying data will not be exposed publicly or to any other NSU.

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