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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.

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.

BACKGROUND

Chiari 1 malformation (CM1) is a structural abnormality of the hindbrain characterised by the descent of the cerebellar tonsils through the foramen magnum. It is one of six Chiari malformations described,[1] but is the most common of these and has an estimated prevalence of approximately 8 in 1000 people.[2] 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.[3] Other patients with CM1 may have significant symptoms, neurological deficits and complications.[4] 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.[5]

Despite the Chiari malformations being classified in 1891,[6] 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 CM1.[7]

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.[8 9] 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,[10 11] but further evidence is required. The use of intraoperative technologies, such as ultrasonography, to inform surgical decisions also requires further evidence of efficacy.[12] CSF diversion has also been advocated as a possible primary strategy for the management of symptomatic CM1 with evidence of abnormal intracranial pulsatility.[13]

Current evidence in CM1 consists mostly of relatively small, single-centre and/or retrospective studies. While evidence in CM1 is available on a national scale in other countries,[14] 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.[9 15] While there are some retrospective studies,[3 16] 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 CM1 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 CM1. 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 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.

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.[17] 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 CM1 and who see substantial numbers of patients with CM1. 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 CM1 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 CM1, 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 CM1 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 CM1 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.[18] Surgeon-reported data will require observational data collection from patient notes, imaging and surgical logs.

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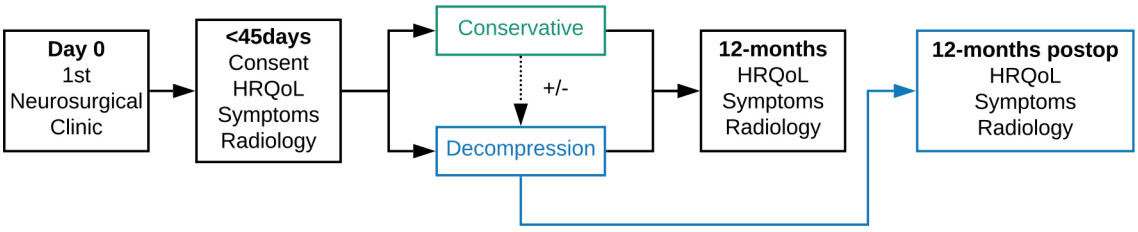

Figure 1 Study process. HRQoL, health-related quality of life.

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) 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 reconsented 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.

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.

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

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management strategies for CM1 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 UKC1S 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/).[19] REDCap has been used extensively in clinical studies by the National Health Service (NHS) and UK universities, including recent studies by the STARSurg collaborative.[20] Online data capture has been used successfully by previous BNTRC studies, such as the Understanding Cauda Equina Study.[18]

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 UKC1S 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.

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malformations, syringomyelia and associated conditions (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[17] and Association of Surgeons in Training (ASiT)[21] 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 UKC1S. 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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Contributors RJP: study conception, study design, writing of the manuscript and editing of the manuscript. FTA, WCS, AGK, RL, WBL, JJ: study conception, study design and editing of the manuscript. EWD, LW: study design and editing of the manuscript.

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Confidential

Welcome to the UK Chiari 1 Study

1) Continue to consent form? ◯ Yes

Confidential

Consent form: adults

Please read the 'Patient Information Sheet' prior to completing the consent form.

The researcher who contacted you will have been through the details of the study with you, but if you have any further questions or any concerns then please contact them again to discuss these.

When you are ready, please complete the consent form. It requires your name, signature, email address and phone number.

2)	I confirm that I have read the information sheet dated 17/3/20 (Version 1.1) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	◯ Yes ◯ No
3)	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	◯ Yes ◯ No
4)	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the Sponsor, from regulatory authorities and from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	◯ Yes ◯ No
5)	I understand that my name, email address and phone number will be stored on a secure, password-protected online database (REDCAP) for the duration of the study. I understand that my name, email address and phone number will remain on the Sponsor's secure, NHS computer system for up to 10-years following completion of the study.	◯ Yes ◯ No
6)	I agree to take part in this study.	◯ Yes ◯ No
7)	OPTIONAL I agree to be contacted about ethically approved research studies for which I may be suitable. I understand that agreeing to be contacted does not oblige me to participate in any further studies.	◯ Yes ◯ No
8)	OPTIONAL: I would like to be emailed a synopsis of the overall study results following completion of the study	◯ Yes ◯ No
9)	Patient first name	_____
10)	Patient second name	_____

Confidential

11) Patient email address

_____

12) Patient phone number

_____

13) Patient signature

_____

14) Date of Consent:

_____

Confidential

Consent (parents)

Please read the 'Patient Information Sheet' prior to completing the consent form.

The researcher who contacted you will have been through the details of the study with you, but if you have any further questions or any concerns then please contact them again to discuss these.

When you are ready, please complete the consent form. It requires your name, signature, email address and phone number.

15)	I confirm that I have read the information sheet dated 16/06/20 (Version 1.3) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	◯ Yes ◯ No
16)	I understand that my child's participation is voluntary and that I am free to withdraw my child's participation at any time without giving any reason, without my child's medical care or legal rights being affected.	◯ Yes ◯ No
17)	I understand that relevant sections of my child's medical notes and data collected during the study may be looked at by individuals from the Sponsor, from regulatory authorities and from the NHS Trust, where it is relevant to my child's taking part in this research. I give permission for these individuals to have access to my child's records.	◯ Yes ◯ No
18)	I understand that my child's name will be stored on a secure, password-protected online database (REDCAP) for the duration of the study. I understand that my child's data will remain on the Sponsor's secure, NHS computer system for up to 10-years following completion of the study.	◯ Yes ◯ No
19)	I understand that my name, email address and phone number will be stored on a secure, password-protected online database (REDCAP) for the duration of the study. I understand that my name, email address and phone number will remain on the Sponsor's secure, password-protected, NHS computer system for up to 10-years following completion of the study.	◯ Yes ◯ No
20)	I agree for my child to take part in this study.	◯ Yes ◯ No
21)	OPTIONAL: I agree to be contacted about ethically approved research studies for which my child may be suitable. I understand that agreeing to be contacted does not oblige my child to participate in any further studies.	◯ Yes ◯ No

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22) OPTIONAL:

I would like to be emailed a synopsis of the overall study results following completion of the study

◯ Yes
◯ No

23) First name of your child

_____

24) Second name of your child

_____

25) Name of consenting parent / responsible adult to the patient

_____

26) Relationship of consenting parent / responsible adult to the patient

_____

27) Parent / responsible adult email address

_____

28) Parent / responsible adult phone number

_____

29) Parent / responsible adult signature

_____

30) Date of Consent:

_____

Confidential

Age

This section is to determine whether or not your child needs to complete an assent form about the study.

31) Please select the age range for your child.

◯ Less than 6-years-old
◯ 6 - 9 years old
◯ 10 - 15 years old

Confidential

Assent (children)

This assent form asks the child to make their own decision on whether or not they want to be enrolled in this study.

If your child is aged 6-years or older, they are required to complete this form. If this is the case, parents and guardians, please complete this assent form together with your child.

If you child is younger than 6-years of age, you are not required to complete this section. If this is the case, just click 'submit below.

My parent/guardian has explained the study to me, and I understand it.	◯ Yes ◯ No
I understand that being part of this study is my choice and that I don't have to do it if I don't want to.	◯ Yes ◯ No
I understand that my parent / guardian will be answering questions about me and sharing the answers with the study team.	◯ Yes ◯ No
I understand that I can quit this study at any time.	◯ Yes ◯ No
I am happy to take part in this study.	◯ Yes ◯ No

Write your name here: _____

Confidential

Baseline (surgeon-reported)

Has the patient signed the consent form?	◯ Yes ◯ No (If not, stop.)

Demographics

Date of birth	_____
Sex	◯ Male ◯ Female

Patient pathway

Date of first neurosurgery clinic	_____
Is the date of the imaging first confirming the CM1 known?	◯ Yes ◯ No
Date of imaging first confirming the CM1	_____
What was the imaging modality that first confirmed the diagnosis?	◯ CT head ◯ MRI head ◯ Other (specify) ◯ Unknown
If other, specify	_____
Was there radiological evidence of hydrocephalus on the first scan?	◯ Yes ◯ No ◯ Unknown
What type of clinician directly referred the patient to the neurosurgeon?	◯ GP ◯ Neurologist ◯ Paediatrician ◯ ED doctor ◯ Orthopaedic surgeon ◯ Other (specify)
Specify 'other' type of clinician	
Is the date of referral to neurosurgery known?	◯ Yes ◯ No (= the date the referral letter was sent)
Date of referral to neurosurgery from referring clinician	_____

Confidential

What was the reason for the referral?	◯ Incidental finding ◯ Symptomatic ◯ Scoliosis ◯ Unknown ◯ Other (specify)
Specify 'other' reason for referral	_____
Did the patient present with or was found to have scoliosis?	◯ Yes ◯ No
What was the neurosurgical management plan made at the first clinic?	☐ Conservative management ☐ Request for more investigations ☐ Refer to a different neurosurgeon at the same neurosurgical unit ☐ Refer to a different neurosurgeon at a different neurosurgical unit ☐ Refer to a different speciality ☐ List for foramen magnum decompression ☐ List for CSF diversion ☐ List for ICP monitoring ☐ Unknown ☐ Other (specify)
Which other speciality was the patient referred to?	_____
Specify 'other' management plan	_____
Is there a planned follow-up for the patient?	◯ Yes ◯ No ◯ Unknown

Past medical history

Does the patient have a past or current history of:	☐ Genetic syndrome ☐ Connective tissue disorder ☐ Craniosynostosis ☐ Other craniofacial condition ☐ Other congenital malformation ☐ Other past medical history ☐ None ☐ Unknown
Please specify further details of the diagnoses indicated in the prior question	_____

Confidential

Baseline (patient-reported; adults)

Please complete this survey.

This survey will ask you about your symptoms and about your quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

How long ago did your symptoms start?	_____ (Answer in terms of years and months. Or, type 'n/a' if there have been no symptoms.)
Do you suffer from headaches?	◯ Yes ◯ No
Where is your headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head (Select all options that apply)
Is your headache made worse by coughing and/or straining?	◯ Yes ◯ No
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you have any of the following symptoms in your arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) do you experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Do you have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Do you have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Do you have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Do you have any past or other current medical problems? If yes, please list these below.	_____
To the best of your knowledge, do any of your following family members have a diagnosis of a Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

	Quality of Life Questionnaire (SF-36)	
1	In general, would you say your health is:	◯ Excellent ◯ Very good ◯ Good ◯ Fair ◯ Poor
2	Compared to one year ago, how would you rate your health in general now?	◯ Much better now than one year ago ◯ Somewhat better now than one year ago ◯ About the same as one year ago ◯ Somewhat worse now than one year ago ◯ Much worse now than one year ago

Confidential

The following questions are about activities you might do during a typical day.

Does your health now limit you in these activities? If so, how much?

		Yes, limited a lot	Yes, limited a little	No, not limited at all
3a	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
3b	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
3c	Lifting or carrying groceries	○	○	○
3d	Climbing several flights of stairs	○	○	○
3e	Climbing one flight of stairs	○	○	○
3f	Bending, kneeling or stooping	○	○	○
3g	Walking more than a mile	○	○	○
3h	Walking half a mile	○	○	○
3i	Walking one hundred yards	○	○	○
3j	Bathing or dressing yourself	○	○	○

Confidential

	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	Yes	No
4a	Cut down on the amount of time you spent on work or other activities	○	○
4b	Accomplished less than you would like	○	○
4c	Were limited in the kind of work or other activities	○	○
4d	Had difficulty performing the work or other activities (for example, it took extra effort)	○	○

Confidential

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

		Yes	No
5a	Cut down on the amount of time you spent on work or other activities	◯	◯
5b	Accomplished less than you would like	◯	◯
5c	Don't do work or other activities as carefully as usual	◯	◯

6	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?	◯ Not at all ◯ Slightly ◯ Moderately ◯ Quite a bit ◯ Extremely
7	How much bodily pain have you had during the past 4 weeks?	◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe
8	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	◯ Not at all ◯ A little bit ◯ Moderately ◯ Quite a bit ◯ Extremely

Confidential

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest the way you have been feeling.

How much of the time during the past 4 weeks

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9a	did you feel full of life?	◯	◯	◯	◯	◯	◯
9b	have you been a very nervous person?	◯	◯	◯	◯	◯	◯
9c	have you felt so down in the dumps that nothing could cheer you up?	◯	◯	◯	◯	◯	◯
9d	have you felt calm and peaceful?	◯	◯	◯	◯	◯	◯
9e	did you have a lot of energy?	◯	◯	◯	◯	◯	◯
9f	have you felt downhearted and low?	◯	◯	◯	◯	◯	◯
9g	did you feel worn out?	◯	◯	◯	◯	◯	◯
9h	have you been a happy person?	◯	◯	◯	◯	◯	◯
9i	did you feel tired?	◯	◯	◯	◯	◯	◯

10 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

◯ All of the time
◯ Most of the time
◯ Some of the time
◯ A little of the time
◯ None of the time

Confidential

How true or false is each of the following statements for you?					
	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
11a I seem to get ill more easily than other people	○	○	○	○	○
11b I am as healthy as anybody I know	○	○	○	○	○
11c I expect my health to get worse	○	○	○	○	○
11d My health is excellent	○	○	○	○	○

Confidential

Baseline (parent-reported; children 13-15yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

How long ago did your child's symptoms start?	_____ (Answer in terms of years and months. Or, type 'n/a' if there have been no symptoms.)
Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)

Confidential

Does your child suffer from back pain?	◯ Yes ◯ No
On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Does your child have any past or other current medical problems? If yes, please list these below.	_____
To the best of your knowledge, do any of your child's following family members have a diagnosis of a Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your child's family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

In the past ONE month, how much of a problem has your teenager had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feedling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying what will happen to him or her	○	○	○	○	○
Getting on with other teenagers	○	○	○	○	○
Other teenagers not wanting to be his or her friend	○	○	○	○	○
Getting teased by other teenagers	○	○	○	○	○
Not being able to do things that other teenagers his or her age can do	○	○	○	○	○
Keeping up with other teenagers	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children 8-12yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

How long ago did your child's symptoms start?	_____ (Answer in terms of years and months. Or, type 'n/a' if there have been no symptoms.)
Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)

Confidential

Does your child suffer from back pain?	◯ Yes ◯ No
On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Does your child have any past or other current medical problems? If yes, please list these below.	_____
To the best of your knowledge, do any of your child's following family members have a diagnosis of a Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your child's family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children 5-7yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

How long ago did your child's symptoms start?	_____ (Answer in terms of years and months. Or, type 'n/a' if there have been no symptoms.)
Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)

Confidential

Does your child suffer from back pain?	◯ Yes ◯ No
On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Does your child have any past or other current medical problems? If yes, please list these below.	_____
To the best of your knowledge, do any of your child's following family members have a diagnosis of a Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your child's family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores, like picking up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with school activities	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children 2-4yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

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On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Does your child have any past or other current medical problems? If yes, please list these here.	_____
To the best of your knowledge, do any of your child's family members have a diagnosis of Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your child's family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

In the past month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking	○	○	○	○	○
Running	○	○	○	○	○
Participating in active play and exercise	○	○	○	○	○
Lifting heavy things	○	○	○	○	○
Bathing	○	○	○	○	○
Helping to pick up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Having trouble sleeping	○	○	○	○	○
Worrying	○	○	○	○	○
Playing with other children	○	○	○	○	○
Other children not wanting to play with him or her	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Doing the same nursery / day care activities as peers	○	○	○	○	○
Missing nursery / day care because of not feeling well	○	○	○	○	○
Missing nursery / day care to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children < 2yrs)

Please complete this survey.

This survey will ask you about your child's symptoms.

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

How long ago did your child's symptoms start?	_____ (Answer in terms of years and months. Or, type 'n/a' if there have been no symptoms.)
Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)

Confidential

Does your child suffer from back pain?	◯ Yes ◯ No
On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Does your child have any past or other current medical problems? If yes, please list these below.	_____
To the best of your knowledge, do any of your child's following family members have a diagnosis of a Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your child's family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

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12-month (surgeon-reported)

Has the patient, if eligible, completed their 12-month survey?	◯ Yes ◯ No

Multidisciplinary team

Was the patient's CM1 discussed in a neurosurgical multidisciplinary team?	◯ Yes ◯ No ◯ Unknown
Date of (first) multidisciplinary team discussion	_____

First MRI head

Did the patient have an MRI head?	◯ Yes ◯ No ◯ Unknown
Is the date of the first MRI head known?	◯ Yes ◯ No
What was the date of the first MRI head?	_____
Are you able to review the images from the MRI head?	◯ Yes ◯ No
Is there ventriculomegaly evident on the first MRI?	◯ Yes ◯ No
What was the maximum tonsil herniation measurable?	_____ (In mm below McRae's line. State the maximum. Can be either on the right or left.)
What is the anterior-posterior diameter of the foramen magnum?	_____ (In mm)
Was there evidence of syringobulbia on first MRI head?	◯ Yes ◯ No ◯ Unknown

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First MRI spine

Did the patient undergo spinal MRI?	◯ Yes ◯ No ◯ Unknown
Is the date of the spinal MRI known?	◯ Yes ◯ No
What was the date of the first spinal MRI?	_____
Are you able to review these images?	◯ Yes ◯ No
Did the first spinal MRI include the following spinal segments?	☐ Cervical ☐ Thoracic ☐ Lumbar ☐ Sacral ☐ Unknown
Was syringomyelia detected on the first MRI spine?	◯ Yes ◯ No
What was the level(s) of the syrinx?	_____ (e.g. C3 - T1)
What was the maximum anterior-posterior diameter of the syrinx?	_____ (In mm.)

Were any of the following other imaging modalities performed?

☐ MRI flow-studies
☐ Flexion / extension cervical spine x-rays
☐ CT venography
☐ MRI venography
☐ Other
☐ None
☐ Unknown

Specify 'other modality' _____

Foramen magnum decompression

Did the patient undergo a foramen magnum decompression (FMD) since baseline?	◯ Yes ◯ No
Date of FMD	_____

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Temporary CSF diversion	
Did the patient undergo temporary CSF diversion at any point?	◯ Yes ◯ No
Date of first temporary CSF diversion	_____
Form of first temporary CSF diversion	◯ Lumbar puncture ◯ Lumbar drain ◯ External ventricular drain ◯ Other
Specify 'other' method of CSF diversion	_____
What was the indication for the first temporary CSF diversion?	◯ Hydrocephalus ◯ Raised ICP confirmed on ICP monitoring ◯ Clinically suspected raised ICP not confirmed on ICP monitoring ◯ Other ◯ Unknown
Specify 'other' indication	_____

Permanent CSF diversion	
Did the patient require permanent CSF diversion at any point?	◯ Yes ◯ No
Date of first permanent CSF diversion procedure?	_____
Form of first permanent CSF diversion	◯ Shunt (specify) ◯ Endoscopic third ventriculostomy ◯ Other
Shunted from... (where is the proximal catheter?)	◯ ventricle ◯ other
Specify other location of proximal catheter.	_____
Shunted to....(where is the distal catheter going to?)	◯ peritoneum ◯ pleura ◯ heart ◯ subarachnoid space ◯ other (specify)
Specify other location of distal catheter.	_____
Specify 'other' method of CSF diversion	_____

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What was the indication for the first CSF diversion?	◯ Hydrocephalus ◯ Raised ICP confirmed on ICP monitoring ◯ Clinically suspected raised ICP not confirmed on ICP monitoring ◯ Other ◯ Unknown
Specify 'other' indication	_____

Intracranial pressure monitoring

Did the patient undergo (invasive) intracranial pressure (ICP) monitoring at any point?	◯ Yes ◯ No
Were the results interpreted to be in a normal or abnormal?	◯ Normal ◯ Abnormal ◯ Unknown
Mean ICP reading (if known)	_____ (In mmHg)
Mean pulse amplitude (if known)	_____
Did the most recent imaging prior to ICP monitoring show ventriculomegaly?	◯ Yes ◯ No ◯ Unknown

Follow up

Has the patient been seen again in the neurosurgical clinic?	◯ Yes ◯ No
Is the date of the follow-up clinic neurosurgical clinic known?	◯ Yes ◯ No
Date of follow up clinic	_____
If yes, what is the neurosurgical management plan?	◯ Conservative management ◯ Request for more investigations ◯ Refer to a different neurosurgeon at the same neurosurgical unit ◯ Refer to a different neurosurgeon at a different neurosurgical unit ◯ Refer to a different speciality ◯ Surgery ◯ List for foramen magnum decompression ◯ List for CSF diversion ◯ List for ICP monitoring ◯ Unknown ◯ Other (specify)

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Specify 'other' management plan	_____
Has the patient had a repeat MRI brain?	◯ Yes ◯ No ◯ Unknown
Is the date of the repeat MRI head known?	◯ Yes ◯ No
Date of repeat MRI brain	_____
Are you able to review the images from the MRI head?	◯ Yes ◯ No
Is there ventriculomegaly evident on the repeat MRI?	◯ Yes ◯ No
What is the maximum tonsil herniation measurable?	_____ (In mm below McRae's line. State the maximum. Can be either on the right or left.)
What is the anterior-posterior diameter of the foramen magnum?	_____ (In mm)
Was their evidence of syringobulbia on first MRI head?	◯ Yes ◯ No ◯ Unknown
Has the patient had a repeat MRI spine?	◯ Yes ◯ No ◯ Unknown
Is the date of the repeat MRI spine known?	◯ Yes ◯ No
Date of repeat MRI spine	_____
With regards to syringomyelia, which of the following is true for the patient?	◯ Still no syrinx ◯ Worsening syrinx ◯ No change in syrinx ◯ New syrinx
What was the level(s) of the syrinx?	_____ (e.g. C3 - T1)
What was the maximum anterior-posterior diameter of the syrinx?	_____ (In mm)

Confidential

Baseline (patient-reported; adults)

Please complete this survey.

This survey will ask you about your symptoms and about your quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Do you suffer from headaches?	◯ Yes ◯ No
Where is your headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head (Select all options that apply)
Is your headache made worse by coughing and/or straining?	◯ Yes ◯ No
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you have any of the following symptoms in your arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) do you experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Do you have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Do you have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Do you have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

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	Quality of Life Questionnaire (SF-36)	
1	In general, would you say your health is:	◯ Excellent ◯ Very good ◯ Good ◯ Fair ◯ Poor
2	Compared to one year ago, how would you rate your health in general now?	◯ Much better now than one year ago ◯ Somewhat better now than one year ago ◯ About the same as one year ago ◯ Somewhat worse now than one year ago ◯ Much worse now than one year ago

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The following questions are about activities you might do during a typical day.

Does your health now limit you in these activities? If so, how much?

		Yes, limited a lot	Yes, limited a little	No, not limited at all
3a	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
3b	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
3c	Lifting or carrying groceries	○	○	○
3d	Climbing several flights of stairs	○	○	○
3e	Climbing one flight of stairs	○	○	○
3f	Bending, kneeling or stooping	○	○	○
3g	Walking more than a mile	○	○	○
3h	Walking half a mile	○	○	○
3i	Walking one hundred yards	○	○	○
3j	Bathing or dressing yourself	○	○	○

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	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	Yes	No
4a	Cut down on the amount of time you spent on work or other activities	○	○
4b	Accomplished less than you would like	○	○
4c	Were limited in the kind of work or other activities	○	○
4d	Had difficulty performing the work or other activities (for example, it took extra effort)	○	○

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During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

		Yes	No
5a	Cut down on the amount of time you spent on work or other activities	◯	◯
5b	Accomplished less than you would like	◯	◯
5c	Don't do work or other activities as carefully as usual	◯	◯

6	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?	◯ Not at all ◯ Slightly ◯ Moderately ◯ Quite a bit ◯ Extremely
7	How much bodily pain have you had during the past 4 weeks?	◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe
8	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	◯ Not at all ◯ A little bit ◯ Moderately ◯ Quite a bit ◯ Extremely

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These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest the way you have been feeling.

How much of the time during the past 4 weeks

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9a	did you feel full of life?	◯	◯	◯	◯	◯	◯
9b	have you been a very nervous person?	◯	◯	◯	◯	◯	◯
9c	have you felt so down in the dumps that nothing could cheer you up?	◯	◯	◯	◯	◯	◯
9d	have you felt calm and peaceful?	◯	◯	◯	◯	◯	◯
9e	did you have a lot of energy?	◯	◯	◯	◯	◯	◯
9f	have you felt downhearted and low?	◯	◯	◯	◯	◯	◯
9g	did you feel worn out?	◯	◯	◯	◯	◯	◯
9h	have you been a happy person?	◯	◯	◯	◯	◯	◯
9i	did you feel tired?	◯	◯	◯	◯	◯	◯

10 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

◯ All of the time
◯ Most of the time
◯ Some of the time
◯ A little of the time
◯ None of the time

Confidential

How true or false is each of the following statements for you?					
	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
11a I seem to get ill more easily than other people	○	○	○	○	○
11b I am as healthy as anybody I know	○	○	○	○	○
11c I expect my health to get worse	○	○	○	○	○
11d My health is excellent	○	○	○	○	○

Confidential

12-month follow up (parent-reported; children 13-15yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your teenager had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feedling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying what will happen to him or her	○	○	○	○	○
Getting on with other teenagers	○	○	○	○	○
Other teenagers not wanting to be his or her friend	○	○	○	○	○
Getting teased by other teenagers	○	○	○	○	○
Not being able to do things that other teenagers his or her age can do	○	○	○	○	○
Keeping up with other teenagers	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month follow up (parent-reported; children 8-12yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children 5-7yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores, like picking up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with school activities	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month follow up (parent-reported; children 2-4yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking	○	○	○	○	○
Running	○	○	○	○	○
Participating in active play and exercise	○	○	○	○	○
Lifting heavy things	○	○	○	○	○
Bathing	○	○	○	○	○
Helping to pick up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Having trouble sleeping	○	○	○	○	○
Worrying	○	○	○	○	○
Playing with other children	○	○	○	○	○
Other children not wanting to play with him or her	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Doing the same nursery / day care activities as peers	○	○	○	○	○
Missing nursery / day care because of not feeling well	○	○	○	○	○
Missing nursery / day care to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month follow up (parent-reported; children < 2yrs)

Please complete this survey.

This survey will ask you about your child's symptoms.

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

12-month post-FMD (surgeon-reported)

Has the patient, if eligible, completed their 12-month post-FMD survey?	◯ Yes ◯ No

Foramen magnum decompression

Did the patient undergo FMD? (if not, then do not complete this section)	◯ Yes ◯ No
Is the date of the FMD known?	◯ Yes ◯ No
Date of FMD	_____
Grade of primary surgeon	◯ Consultant ◯ Senior fellow / registrar grade ◯ ST8 ◯ ST7 ◯ ST6 ◯ ST5 ◯ ST4 ◯ ST3 ◯ ST2 ◯ ST1 ◯ Other SHO grade ◯ Other ◯ Unknown
Specify 'other' grade	_____
Which of the following surgical techniques were used? (tick all that apply)	☐ Suboccipital craniectomy ☐ C1 removed ☐ C2 removed ☐ Durotomy ☐ Arachnoid opened ☐ Tonsils shrunk/cauterized
How was the dura managed at the end of the operation?	☐ Primary dural closure ☐ Duraplasty ☐ Dura laid open
Specify duraplasty material used	_____
Start time of operation (i.e. 'knife-to-skin')	_____
End time of operation (i.e. surgeon finished)	_____

Confidential

Intraoperative complications (tick all that apply)	☐ None ☐ Haemorrhage ☐ Anaesthetic complication ☐ Death ☐ Other
Define 'other' intraoperative complication(s)	_____
Date of discharge from hospital	_____
Did any of the following complications occur at any time during the postoperative phase (i.e. either as inpatient or outpatient)?	☐ None ☐ CSF leak ☐ Pseudomeningocele ☐ Neurological deterioration ☐ Infective meningitis ☐ Chemical meningitis ☐ Hydrocephalus ☐ Need for CSF diversion ☐ Subdural hygroma ☐ Delayed wound healing ☐ Wound infection ☐ Seizure(s) ☐ Hospital-acquired infection ☐ Deep vein thrombosis ☐ Pulmonary embolus ☐ Unplanned ITU admission ☐ Unplanned re-admission to hospital following discharge ☐ Death ☐ Other ((tick all that apply))
Specify 'other' postoperative complication	_____

Temporary CSF diversion

Did the patient undergo temporary CSF diversion since the last data collection (12-months post-baseline)?	◯ Yes ◯ No
Is the date of temporary CSF diversion known?	◯ Yes ◯ No
Date of temporary CSF diversion	_____
Form of temporary CSF diversion	◯ Lumbar puncture ◯ Lumbar drain ◯ External ventricular drain ◯ Other
Specify 'other' method of CSF diversion	_____

Confidential

What was the indication for the temporary CSF diversion?	◯ Hydrocephalus ◯ Raised ICP confirmed on ICP monitoring ◯ Clinically suspected raised ICP not confirmed on ICP monitoring ◯ Other ◯ Unknown
Specify 'other' indication	_____
If there were other events of temporary CSF diversion, please provide the same details above for each event.	_____

Permanent CSF diversion

Did the patient require permanent CSF diversion since the last data collection (12-months post-baseline)?	◯ Yes ◯ No
Is the date of permanent CSF diversion known?	◯ Yes ◯ No
Date of permanent CSF diversion procedure?	_____
Form of permanent CSF diversion	◯ Shunt (specify) ◯ Endoscopic third ventriculostomy ◯ Other
Where is the proximal catheter?	◯ ventricle ◯ other
Specify 'other' proximal catheter location	_____
Where is the distal catheter?	◯ peritoneum ◯ pleura ◯ heart ◯ subarachnoid space ◯ other
Specify 'other' distal catheter location	_____
Specify 'other' method of CSF diversion	_____
What was the indication for the permament CSF diversion?	◯ Hydrocephalus ◯ Raised ICP confirmed on ICP monitoring ◯ Clinically suspected raised ICP not confirmed on ICP monitoring ◯ Other ◯ Unknown
Specify 'other' indication	_____

Confidential

If there were any other events of permanent CSF diversion, then please list the same details as above for these additional events.	_____

Follow up

Has the patient been seen again in the neurosurgical clinic?	◯ Yes ◯ No
Is the date of the follow-up clinic neurosurgical clinic known?	◯ Yes ◯ No
Date of follow up clinic	_____
If yes, what is the neurosurgical management plan?	◯ Conservative management ◯ Request for more investigations ◯ Refer to a different neurosurgeon at the same neurosurgical unit ◯ Refer to a different neurosurgeon at a different neurosurgical unit ◯ Refer to a different speciality ◯ Surgery ◯ List for foramen magnum decompression ◯ List for CSF diversion ◯ List for ICP monitoring ◯ Unknown ◯ Other (specify)
Specify 'other' management plan	_____
Has the patient had a repeat MRI brain?	◯ Yes ◯ No ◯ Unknown
Is the date of the repeat MRI head known?	◯ Yes ◯ No
Date of repeat MRI brain	_____
Are you able to review the images from the MRI head?	◯ Yes ◯ No
Is there ventriculomegaly evident on the repeat MRI?	◯ Yes ◯ No
What is the maximum tonsil herniation measurable?	_____ (In mm below McRae's line. State the maximum. Can be either on the right or left.)
What is the anterior-posterior diameter of the foramen magnum?	_____ (In mm)

Confidential

Was there evidence of syringobulbia on first MRI head?	◯ Yes ◯ No ◯ Unknown
Has the patient had a repeat MRI spine?	◯ Yes ◯ No ◯ Unknown
Is the date of the repeat MRI spine known?	◯ Yes ◯ No
Date of repeat MRI spine	_____
With regards to syringomyelia, which of the following is true for the patient?	◯ Still no syrinx ◯ Worsening syrinx ◯ No change in syrinx ◯ New syrinx
At what level(s) is the syrinx seen?	_____ (e.g. C3 - T1)
What is the maximum anterior-posterior diameter of the syrinx?	_____ (In mm.)

Confidential

12-month questionnaire following surgery

Please complete this survey.

This survey will ask you about your symptoms and about your quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Do you suffer from headaches?	◯ Yes ◯ No
Where is your headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head (Select all options that apply)
Is your headache made worse by coughing and/or straining?	◯ Yes ◯ No
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you have any of the following symptoms in your arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) do you experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Do you have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Do you have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Do you have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

	Quality of Life Questionnaire (SF-36)	
1	In general, would you say your health is:	◯ Excellent ◯ Very good ◯ Good ◯ Fair ◯ Poor
2	Compared to one year ago, how would you rate your health in general now?	◯ Much better now than one year ago ◯ Somewhat better now than one year ago ◯ About the same as one year ago ◯ Somewhat worse now than one year ago ◯ Much worse now than one year ago

Confidential

The following questions are about activities you might do during a typical day.

Does your health now limit you in these activities? If so, how much?

		Yes, limited a lot	Yes, limited a little	No, not limited at all
3a	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
3b	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
3c	Lifting or carrying groceries	○	○	○
3d	Climbing several flights of stairs	○	○	○
3e	Climbing one flight of stairs	○	○	○
3f	Bending, kneeling or stooping	○	○	○
3g	Walking more than a mile	○	○	○
3h	Walking half a mile	○	○	○
3i	Walking one hundred yards	○	○	○
3j	Bathing or dressing yourself	○	○	○

Confidential

	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	Yes	No
4a	Cut down on the amount of time you spent on work or other activities	○	○
4b	Accomplished less than you would like	○	○
4c	Were limited in the kind of work or other activities	○	○
4d	Had difficulty performing the work or other activities (for example, it took extra effort)	○	○

Confidential

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

		Yes	No
5a	Cut down on the amount of time you spent on work or other activities	◯	◯
5b	Accomplished less than you would like	◯	◯
5c	Don't do work or other activities as carefully as usual	◯	◯

6	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?	◯ Not at all ◯ Slightly ◯ Moderately ◯ Quite a bit ◯ Extremely
7	How much bodily pain have you had during the past 4 weeks?	◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe
8	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	◯ Not at all ◯ A little bit ◯ Moderately ◯ Quite a bit ◯ Extremely

Confidential

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest the way you have been feeling.

How much of the time during the past 4 weeks

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9a	did you feel full of life?	◯	◯	◯	◯	◯	◯
9b	have you been a very nervous person?	◯	◯	◯	◯	◯	◯
9c	have you felt so down in the dumps that nothing could cheer you up?	◯	◯	◯	◯	◯	◯
9d	have you felt calm and peaceful?	◯	◯	◯	◯	◯	◯
9e	did you have a lot of energy?	◯	◯	◯	◯	◯	◯
9f	have you felt downhearted and low?	◯	◯	◯	◯	◯	◯
9g	did you feel worn out?	◯	◯	◯	◯	◯	◯
9h	have you been a happy person?	◯	◯	◯	◯	◯	◯
9i	did you feel tired?	◯	◯	◯	◯	◯	◯

10 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

◯ All of the time
◯ Most of the time
◯ Some of the time
◯ A little of the time
◯ None of the time

Confidential

How true or false is each of the following statements for you?					
	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
11a I seem to get ill more easily than other people	○	○	○	○	○
11b I am as healthy as anybody I know	○	○	○	○	○
11c I expect my health to get worse	○	○	○	○	○
11d My health is excellent	○	○	○	○	○

Confidential

12-month post-FMD (parent-reported; children 13-15yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feedling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying what will happen to him or her	○	○	○	○	○
Getting on with other teenagers	○	○	○	○	○
Other teenagers not wanting to be his or her friend	○	○	○	○	○
Getting teased by other teenagers	○	○	○	○	○
Not being able to do things that other teenagers his or her age can do	○	○	○	○	○
Keeping up with other teenagers	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month post-FMD (parent-reported; children 8-12yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children 5-7yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores, like picking up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with school activities	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month post-FMD (parent-reported; children 2-4yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking	○	○	○	○	○
Running	○	○	○	○	○
Participating in active play and exercise	○	○	○	○	○
Lifting heavy things	○	○	○	○	○
Bathing	○	○	○	○	○
Helping to pick up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Having trouble sleeping	○	○	○	○	○
Worrying	○	○	○	○	○
Playing with other children	○	○	○	○	○
Other children not wanting to play with him or her	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Doing the same nursery / day care activities as peers	○	○	○	○	○
Missing nursery / day care because of not feeling well	○	○	○	○	○
Missing nursery / day care to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month post-FMD (parent-reported; children < 2yrs)

Please complete this survey.

This survey will ask you about your child's symptoms.

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

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On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

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On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

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Welcome to the UK Chiari 1 Study

1) Continue to consent form? ◯ Yes

Confidential

Consent form: adults

Please read the 'Patient Information Sheet' prior to completing the consent form.

The researcher who contacted you will have been through the details of the study with you, but if you have any further questions or any concerns then please contact them again to discuss these.

When you are ready, please complete the consent form. It requires your name, signature, email address and phone number.

2)	I confirm that I have read the information sheet dated 17/3/20 (Version 1.1) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	◯ Yes ◯ No
3)	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	◯ Yes ◯ No
4)	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the Sponsor, from regulatory authorities and from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	◯ Yes ◯ No
5)	I understand that my name, email address and phone number will be stored on a secure, password-protected online database (REDCAP) for the duration of the study. I understand that my name, email address and phone number will remain on the Sponsor's secure, NHS computer system for up to 10-years following completion of the study.	◯ Yes ◯ No
6)	I agree to take part in this study.	◯ Yes ◯ No
7)	OPTIONAL I agree to be contacted about ethically approved research studies for which I may be suitable. I understand that agreeing to be contacted does not oblige me to participate in any further studies.	◯ Yes ◯ No
8)	OPTIONAL: I would like to be emailed a synopsis of the overall study results following completion of the study	◯ Yes ◯ No
9)	Patient first name	_____
10)	Patient second name	_____

Confidential

11) Patient email address

_____

12) Patient phone number

_____

13) Patient signature

_____

14) Date of Consent:

_____

Confidential

Consent (parents)

Please read the 'Patient Information Sheet' prior to completing the consent form.

The researcher who contacted you will have been through the details of the study with you, but if you have any further questions or any concerns then please contact them again to discuss these.

When you are ready, please complete the consent form. It requires your name, signature, email address and phone number.

15)	I confirm that I have read the information sheet dated 16/06/20 (Version 1.3) for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	◯ Yes ◯ No
16)	I understand that my child's participation is voluntary and that I am free to withdraw my child's participation at any time without giving any reason, without my child's medical care or legal rights being affected.	◯ Yes ◯ No
17)	I understand that relevant sections of my child's medical notes and data collected during the study may be looked at by individuals from the Sponsor, from regulatory authorities and from the NHS Trust, where it is relevant to my child's taking part in this research. I give permission for these individuals to have access to my child's records.	◯ Yes ◯ No
18)	I understand that my child's name will be stored on a secure, password-protected online database (REDCAP) for the duration of the study. I understand that my child's data will remain on the Sponsor's secure, NHS computer system for up to 10-years following completion of the study.	◯ Yes ◯ No
19)	I understand that my name, email address and phone number will be stored on a secure, password-protected online database (REDCAP) for the duration of the study. I understand that my name, email address and phone number will remain on the Sponsor's secure, password-protected, NHS computer system for up to 10-years following completion of the study.	◯ Yes ◯ No
20)	I agree for my child to take part in this study.	◯ Yes ◯ No
21)	OPTIONAL: I agree to be contacted about ethically approved research studies for which my child may be suitable. I understand that agreeing to be contacted does not oblige my child to participate in any further studies.	◯ Yes ◯ No

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22) OPTIONAL:

I would like to be emailed a synopsis of the overall study results following completion of the study

◯ Yes
◯ No

23) First name of your child

_____

24) Second name of your child

_____

25) Name of consenting parent / responsible adult to the patient

_____

26) Relationship of consenting parent / responsible adult to the patient

_____

27) Parent / responsible adult email address

_____

28) Parent / responsible adult phone number

_____

29) Parent / responsible adult signature

_____

30) Date of Consent:

_____

Confidential

Age

This section is to determine whether or not your child needs to complete an assent form about the study.

31) Please select the age range for your child.

◯ Less than 6-years-old
◯ 6 - 9 years old
◯ 10 - 15 years old

Confidential

Assent (children)

This assent form asks the child to make their own decision on whether or not they want to be enrolled in this study.

If your child is aged 6-years or older, they are required to complete this form. If this is the case, parents and guardians, please complete this assent form together with your child.

If you child is younger than 6-years of age, you are not required to complete this section. If this is the case, just click 'submit below.

My parent/guardian has explained the study to me, and I understand it.	◯ Yes ◯ No
I understand that being part of this study is my choice and that I don't have to do it if I don't want to.	◯ Yes ◯ No
I understand that my parent / guardian will be answering questions about me and sharing the answers with the study team.	◯ Yes ◯ No
I understand that I can quit this study at any time.	◯ Yes ◯ No
I am happy to take part in this study.	◯ Yes ◯ No

Write your name here: _____

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Baseline (surgeon-reported)

Has the patient signed the consent form?	◯ Yes ◯ No (If not, stop.)

Demographics

Date of birth	_____
Sex	◯ Male ◯ Female

Patient pathway

Date of first neurosurgery clinic	_____
Is the date of the imaging first confirming the CM1 known?	◯ Yes ◯ No
Date of imaging first confirming the CM1	_____
What was the imaging modality that first confirmed the diagnosis?	◯ CT head ◯ MRI head ◯ Other (specify) ◯ Unknown
If other, specify	_____
Was there radiological evidence of hydrocephalus on the first scan?	◯ Yes ◯ No ◯ Unknown
What type of clinician directly referred the patient to the neurosurgeon?	◯ GP ◯ Neurologist ◯ Paediatrician ◯ ED doctor ◯ Orthopaedic surgeon ◯ Other (specify)
Specify 'other' type of clinician	
Is the date of referral to neurosurgery known?	◯ Yes ◯ No (= the date the referral letter was sent)
Date of referral to neurosurgery from referring clinician	_____

Confidential

What was the reason for the referral?	◯ Incidental finding ◯ Symptomatic ◯ Scoliosis ◯ Unknown ◯ Other (specify)
Specify 'other' reason for referral	_____
Did the patient present with or was found to have scoliosis?	◯ Yes ◯ No
What was the neurosurgical management plan made at the first clinic?	☐ Conservative management ☐ Request for more investigations ☐ Refer to a different neurosurgeon at the same neurosurgical unit ☐ Refer to a different neurosurgeon at a different neurosurgical unit ☐ Refer to a different speciality ☐ List for foramen magnum decompression ☐ List for CSF diversion ☐ List for ICP monitoring ☐ Unknown ☐ Other (specify)
Which other speciality was the patient referred to?	_____
Specify 'other' management plan	_____
Is there a planned follow-up for the patient?	◯ Yes ◯ No ◯ Unknown

Past medical history

Does the patient have a past or current history of:	☐ Genetic syndrome ☐ Connective tissue disorder ☐ Craniosynostosis ☐ Other craniofacial condition ☐ Other congenital malformation ☐ Other past medical history ☐ None ☐ Unknown
Please specify further details of the diagnoses indicated in the prior question	_____

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Baseline (patient-reported; adults)

Please complete this survey.

This survey will ask you about your symptoms and about your quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

How long ago did your symptoms start?	_____ (Answer in terms of years and months. Or, type 'n/a' if there have been no symptoms.)
Do you suffer from headaches?	◯ Yes ◯ No
Where is your headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head (Select all options that apply)
Is your headache made worse by coughing and/or straining?	◯ Yes ◯ No
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you have any of the following symptoms in your arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) do you experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Do you have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Do you have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Do you have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Do you have any past or other current medical problems? If yes, please list these below.	_____
To the best of your knowledge, do any of your following family members have a diagnosis of a Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

	Quality of Life Questionnaire (SF-36)	
1	In general, would you say your health is:	◯ Excellent ◯ Very good ◯ Good ◯ Fair ◯ Poor
2	Compared to one year ago, how would you rate your health in general now?	◯ Much better now than one year ago ◯ Somewhat better now than one year ago ◯ About the same as one year ago ◯ Somewhat worse now than one year ago ◯ Much worse now than one year ago

Confidential

The following questions are about activities you might do during a typical day.

Does your health now limit you in these activities? If so, how much?

		Yes, limited a lot	Yes, limited a little	No, not limited at all
3a	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
3b	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
3c	Lifting or carrying groceries	○	○	○
3d	Climbing several flights of stairs	○	○	○
3e	Climbing one flight of stairs	○	○	○
3f	Bending, kneeling or stooping	○	○	○
3g	Walking more than a mile	○	○	○
3h	Walking half a mile	○	○	○
3i	Walking one hundred yards	○	○	○
3j	Bathing or dressing yourself	○	○	○

Confidential

	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	Yes	No
4a	Cut down on the amount of time you spent on work or other activities	○	○
4b	Accomplished less than you would like	○	○
4c	Were limited in the kind of work or other activities	○	○
4d	Had difficulty performing the work or other activities (for example, it took extra effort)	○	○

Confidential

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

		Yes	No
5a	Cut down on the amount of time you spent on work or other activities	◯	◯
5b	Accomplished less than you would like	◯	◯
5c	Don't do work or other activities as carefully as usual	◯	◯

6	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?	◯ Not at all ◯ Slightly ◯ Moderately ◯ Quite a bit ◯ Extremely
7	How much bodily pain have you had during the past 4 weeks?	◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe
8	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	◯ Not at all ◯ A little bit ◯ Moderately ◯ Quite a bit ◯ Extremely

Confidential

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest the way you have been feeling.

How much of the time during the past 4 weeks

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9a	did you feel full of life?	◯	◯	◯	◯	◯	◯
9b	have you been a very nervous person?	◯	◯	◯	◯	◯	◯
9c	have you felt so down in the dumps that nothing could cheer you up?	◯	◯	◯	◯	◯	◯
9d	have you felt calm and peaceful?	◯	◯	◯	◯	◯	◯
9e	did you have a lot of energy?	◯	◯	◯	◯	◯	◯
9f	have you felt downhearted and low?	◯	◯	◯	◯	◯	◯
9g	did you feel worn out?	◯	◯	◯	◯	◯	◯
9h	have you been a happy person?	◯	◯	◯	◯	◯	◯
9i	did you feel tired?	◯	◯	◯	◯	◯	◯

10 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

◯ All of the time
◯ Most of the time
◯ Some of the time
◯ A little of the time
◯ None of the time

Confidential

How true or false is each of the following statements for you?					
	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
11a I seem to get ill more easily than other people	○	○	○	○	○
11b I am as healthy as anybody I know	○	○	○	○	○
11c I expect my health to get worse	○	○	○	○	○
11d My health is excellent	○	○	○	○	○

Confidential

Baseline (parent-reported; children 13-15yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

How long ago did your child's symptoms start?	_____ (Answer in terms of years and months. Or, type 'n/a' if there have been no symptoms.)
Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)

Confidential

Does your child suffer from back pain?	◯ Yes ◯ No
On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Does your child have any past or other current medical problems? If yes, please list these below.	_____
To the best of your knowledge, do any of your child's following family members have a diagnosis of a Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your child's family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

In the past ONE month, how much of a problem has your teenager had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feedling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying what will happen to him or her	○	○	○	○	○
Getting on with other teenagers	○	○	○	○	○
Other teenagers not wanting to be his or her friend	○	○	○	○	○
Getting teased by other teenagers	○	○	○	○	○
Not being able to do things that other teenagers his or her age can do	○	○	○	○	○
Keeping up with other teenagers	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children 8-12yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

How long ago did your child's symptoms start?	_____ (Answer in terms of years and months. Or, type 'n/a' if there have been no symptoms.)
Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)

Confidential

Does your child suffer from back pain?	◯ Yes ◯ No
On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Does your child have any past or other current medical problems? If yes, please list these below.	_____
To the best of your knowledge, do any of your child's following family members have a diagnosis of a Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your child's family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children 5-7yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

How long ago did your child's symptoms start?	_____ (Answer in terms of years and months. Or, type 'n/a' if there have been no symptoms.)
Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)

Confidential

Does your child suffer from back pain?	◯ Yes ◯ No
On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Does your child have any past or other current medical problems? If yes, please list these below.	_____
To the best of your knowledge, do any of your child's following family members have a diagnosis of a Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your child's family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores, like picking up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with school activities	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children 2-4yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Does your child have any past or other current medical problems? If yes, please list these here.	_____
To the best of your knowledge, do any of your child's family members have a diagnosis of Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your child's family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

In the past month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking	○	○	○	○	○
Running	○	○	○	○	○
Participating in active play and exercise	○	○	○	○	○
Lifting heavy things	○	○	○	○	○
Bathing	○	○	○	○	○
Helping to pick up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Having trouble sleeping	○	○	○	○	○
Worrying	○	○	○	○	○
Playing with other children	○	○	○	○	○
Other children not wanting to play with him or her	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Doing the same nursery / day care activities as peers	○	○	○	○	○
Missing nursery / day care because of not feeling well	○	○	○	○	○
Missing nursery / day care to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children < 2yrs)

Please complete this survey.

This survey will ask you about your child's symptoms.

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

How long ago did your child's symptoms start?	_____ (Answer in terms of years and months. Or, type 'n/a' if there have been no symptoms.)
Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)

Confidential

Does your child suffer from back pain?	◯ Yes ◯ No
On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)	_____
Does your child have any past or other current medical problems? If yes, please list these below.	_____
To the best of your knowledge, do any of your child's following family members have a diagnosis of a Chiari 1 malformation?	◯ Yes ◯ No
Which member(s) of your child's family is known to have a Chiari 1 malformation?	☐ Mother ☐ Father ☐ Son ☐ Daughter ☐ Maternal grandfather ☐ Maternal grandmother ☐ Paternal grandfather ☐ Paternal grandmother ☐ Maternal aunt ☐ Maternal uncle ☐ Paternal aunt ☐ Paternal uncle ☐ Other
Specify 'other' relative	_____

Confidential

12-month (surgeon-reported)

Has the patient, if eligible, completed their 12-month survey?	◯ Yes ◯ No

Multidisciplinary team

Was the patient's CM1 discussed in a neurosurgical multidisciplinary team?	◯ Yes ◯ No ◯ Unknown
Date of (first) multidisciplinary team discussion	_____

First MRI head

Did the patient have an MRI head?	◯ Yes ◯ No ◯ Unknown
Is the date of the first MRI head known?	◯ Yes ◯ No
What was the date of the first MRI head?	_____
Are you able to review the images from the MRI head?	◯ Yes ◯ No
Is there ventriculomegaly evident on the first MRI?	◯ Yes ◯ No
What was the maximum tonsil herniation measurable?	_____ (In mm below McRae's line. State the maximum. Can be either on the right or left.)
What is the anterior-posterior diameter of the foramen magnum?	_____ (In mm)
Was there evidence of syringobulbia on first MRI head?	◯ Yes ◯ No ◯ Unknown

Confidential

First MRI spine

Did the patient undergo spinal MRI?	◯ Yes ◯ No ◯ Unknown
Is the date of the spinal MRI known?	◯ Yes ◯ No
What was the date of the first spinal MRI?	_____
Are you able to review these images?	◯ Yes ◯ No
Did the first spinal MRI include the following spinal segments?	☐ Cervical ☐ Thoracic ☐ Lumbar ☐ Sacral ☐ Unknown
Was syringomyelia detected on the first MRI spine?	◯ Yes ◯ No
What was the level(s) of the syrinx?	_____ (e.g. C3 - T1)
What was the maximum anterior-posterior diameter of the syrinx?	_____ (In mm.)

Were any of the following other imaging modalities performed?

☐ MRI flow-studies
☐ Flexion / extension cervical spine x-rays
☐ CT venography
☐ MRI venography
☐ Other
☐ None
☐ Unknown

Specify 'other modality' _____

Foramen magnum decompression

Did the patient undergo a foramen magnum decompression (FMD) since baseline?	◯ Yes ◯ No
Date of FMD	_____

Confidential

Temporary CSF diversion	
Did the patient undergo temporary CSF diversion at any point?	◯ Yes ◯ No
Date of first temporary CSF diversion	_____
Form of first temporary CSF diversion	◯ Lumbar puncture ◯ Lumbar drain ◯ External ventricular drain ◯ Other
Specify 'other' method of CSF diversion	_____
What was the indication for the first temporary CSF diversion?	◯ Hydrocephalus ◯ Raised ICP confirmed on ICP monitoring ◯ Clinically suspected raised ICP not confirmed on ICP monitoring ◯ Other ◯ Unknown
Specify 'other' indication	_____

Permanent CSF diversion	
Did the patient require permanent CSF diversion at any point?	◯ Yes ◯ No
Date of first permanent CSF diversion procedure?	_____
Form of first permanent CSF diversion	◯ Shunt (specify) ◯ Endoscopic third ventriculostomy ◯ Other
Shunted from... (where is the proximal catheter?)	◯ ventricle ◯ other
Specify other location of proximal catheter.	_____
Shunted to....(where is the distal catheter going to?)	◯ peritoneum ◯ pleura ◯ heart ◯ subarachnoid space ◯ other (specify)
Specify other location of distal catheter.	_____
Specify 'other' method of CSF diversion	_____

Confidential

What was the indication for the first CSF diversion?	◯ Hydrocephalus ◯ Raised ICP confirmed on ICP monitoring ◯ Clinically suspected raised ICP not confirmed on ICP monitoring ◯ Other ◯ Unknown
Specify 'other' indication	_____

Intracranial pressure monitoring

Did the patient undergo (invasive) intracranial pressure (ICP) monitoring at any point?	◯ Yes ◯ No
Were the results interpreted to be in a normal or abnormal?	◯ Normal ◯ Abnormal ◯ Unknown
Mean ICP reading (if known)	_____ (In mmHg)
Mean pulse amplitude (if known)	_____
Did the most recent imaging prior to ICP monitoring show ventriculomegaly?	◯ Yes ◯ No ◯ Unknown

Follow up

Has the patient been seen again in the neurosurgical clinic?	◯ Yes ◯ No
Is the date of the follow-up clinic neurosurgical clinic known?	◯ Yes ◯ No
Date of follow up clinic	_____
If yes, what is the neurosurgical management plan?	◯ Conservative management ◯ Request for more investigations ◯ Refer to a different neurosurgeon at the same neurosurgical unit ◯ Refer to a different neurosurgeon at a different neurosurgical unit ◯ Refer to a different speciality ◯ Surgery ◯ List for foramen magnum decompression ◯ List for CSF diversion ◯ List for ICP monitoring ◯ Unknown ◯ Other (specify)

Confidential

Specify 'other' management plan	_____
Has the patient had a repeat MRI brain?	◯ Yes ◯ No ◯ Unknown
Is the date of the repeat MRI head known?	◯ Yes ◯ No
Date of repeat MRI brain	_____
Are you able to review the images from the MRI head?	◯ Yes ◯ No
Is there ventriculomegaly evident on the repeat MRI?	◯ Yes ◯ No
What is the maximum tonsil herniation measurable?	_____ (In mm below McRae's line. State the maximum. Can be either on the right or left.)
What is the anterior-posterior diameter of the foramen magnum?	_____ (In mm)
Was their evidence of syringobulbia on first MRI head?	◯ Yes ◯ No ◯ Unknown
Has the patient had a repeat MRI spine?	◯ Yes ◯ No ◯ Unknown
Is the date of the repeat MRI spine known?	◯ Yes ◯ No
Date of repeat MRI spine	_____
With regards to syringomyelia, which of the following is true for the patient?	◯ Still no syrinx ◯ Worsening syrinx ◯ No change in syrinx ◯ New syrinx
What was the level(s) of the syrinx?	_____ (e.g. C3 - T1)
What was the maximum anterior-posterior diameter of the syrinx?	_____ (In mm)

Confidential

Baseline (patient-reported; adults)

Please complete this survey.

This survey will ask you about your symptoms and about your quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Do you suffer from headaches?	◯ Yes ◯ No
Where is your headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head (Select all options that apply)
Is your headache made worse by coughing and/or straining?	◯ Yes ◯ No
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you have any of the following symptoms in your arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) do you experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Do you have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Do you have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Do you have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

	Quality of Life Questionnaire (SF-36)	
1	In general, would you say your health is:	◯ Excellent ◯ Very good ◯ Good ◯ Fair ◯ Poor
2	Compared to one year ago, how would you rate your health in general now?	◯ Much better now than one year ago ◯ Somewhat better now than one year ago ◯ About the same as one year ago ◯ Somewhat worse now than one year ago ◯ Much worse now than one year ago

Confidential

The following questions are about activities you might do during a typical day.

Does your health now limit you in these activities? If so, how much?

		Yes, limited a lot	Yes, limited a little	No, not limited at all
3a	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
3b	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
3c	Lifting or carrying groceries	○	○	○
3d	Climbing several flights of stairs	○	○	○
3e	Climbing one flight of stairs	○	○	○
3f	Bending, kneeling or stooping	○	○	○
3g	Walking more than a mile	○	○	○
3h	Walking half a mile	○	○	○
3i	Walking one hundred yards	○	○	○
3j	Bathing or dressing yourself	○	○	○

Confidential

	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	Yes	No
4a	Cut down on the amount of time you spent on work or other activities	○	○
4b	Accomplished less than you would like	○	○
4c	Were limited in the kind of work or other activities	○	○
4d	Had difficulty performing the work or other activities (for example, it took extra effort)	○	○

Confidential

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

		Yes	No
5a	Cut down on the amount of time you spent on work or other activities	◯	◯
5b	Accomplished less than you would like	◯	◯
5c	Don't do work or other activities as carefully as usual	◯	◯

6	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?	◯ Not at all ◯ Slightly ◯ Moderately ◯ Quite a bit ◯ Extremely
7	How much bodily pain have you had during the past 4 weeks?	◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe
8	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	◯ Not at all ◯ A little bit ◯ Moderately ◯ Quite a bit ◯ Extremely

Confidential

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest the way you have been feeling.

How much of the time during the past 4 weeks

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9a	did you feel full of life?	◯	◯	◯	◯	◯	◯
9b	have you been a very nervous person?	◯	◯	◯	◯	◯	◯
9c	have you felt so down in the dumps that nothing could cheer you up?	◯	◯	◯	◯	◯	◯
9d	have you felt calm and peaceful?	◯	◯	◯	◯	◯	◯
9e	did you have a lot of energy?	◯	◯	◯	◯	◯	◯
9f	have you felt downhearted and low?	◯	◯	◯	◯	◯	◯
9g	did you feel worn out?	◯	◯	◯	◯	◯	◯
9h	have you been a happy person?	◯	◯	◯	◯	◯	◯
9i	did you feel tired?	◯	◯	◯	◯	◯	◯

10 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

◯ All of the time
◯ Most of the time
◯ Some of the time
◯ A little of the time
◯ None of the time

Confidential

How true or false is each of the following statements for you?					
	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
11a I seem to get ill more easily than other people	○	○	○	○	○
11b I am as healthy as anybody I know	○	○	○	○	○
11c I expect my health to get worse	○	○	○	○	○
11d My health is excellent	○	○	○	○	○

Confidential

12-month follow up (parent-reported; children 13-15yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your teenager had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feedling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying what will happen to him or her	○	○	○	○	○
Getting on with other teenagers	○	○	○	○	○
Other teenagers not wanting to be his or her friend	○	○	○	○	○
Getting teased by other teenagers	○	○	○	○	○
Not being able to do things that other teenagers his or her age can do	○	○	○	○	○
Keeping up with other teenagers	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month follow up (parent-reported; children 8-12yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children 5-7yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores, like picking up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with school activities	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month follow up (parent-reported; children 2-4yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

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On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

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On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking	○	○	○	○	○
Running	○	○	○	○	○
Participating in active play and exercise	○	○	○	○	○
Lifting heavy things	○	○	○	○	○
Bathing	○	○	○	○	○
Helping to pick up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Having trouble sleeping	○	○	○	○	○
Worrying	○	○	○	○	○
Playing with other children	○	○	○	○	○
Other children not wanting to play with him or her	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Doing the same nursery / day care activities as peers	○	○	○	○	○
Missing nursery / day care because of not feeling well	○	○	○	○	○
Missing nursery / day care to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month follow up (parent-reported; children < 2yrs)

Please complete this survey.

This survey will ask you about your child's symptoms.

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

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On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

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On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

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Please specify 'other' symptom(s)

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12-month post-FMD (surgeon-reported)

Has the patient, if eligible, completed their 12-month post-FMD survey?	◯ Yes ◯ No

Foramen magnum decompression

Did the patient undergo FMD? (if not, then do not complete this section)	◯ Yes ◯ No
Is the date of the FMD known?	◯ Yes ◯ No
Date of FMD	_____
Grade of primary surgeon	◯ Consultant ◯ Senior fellow / registrar grade ◯ ST8 ◯ ST7 ◯ ST6 ◯ ST5 ◯ ST4 ◯ ST3 ◯ ST2 ◯ ST1 ◯ Other SHO grade ◯ Other ◯ Unknown
Specify 'other' grade	_____
Which of the following surgical techniques were used? (tick all that apply)	☐ Suboccipital craniectomy ☐ C1 removed ☐ C2 removed ☐ Durotomy ☐ Arachnoid opened ☐ Tonsils shrunk/cauterized
How was the dura managed at the end of the operation?	☐ Primary dural closure ☐ Duraplasty ☐ Dura laid open
Specify duraplasty material used	_____
Start time of operation (i.e. 'knife-to-skin')	_____
End time of operation (i.e. surgeon finished)	_____

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Intraoperative complications (tick all that apply)	☐ None ☐ Haemorrhage ☐ Anaesthetic complication ☐ Death ☐ Other
Define 'other' intraoperative complication(s)	_____
Date of discharge from hospital	_____
Did any of the following complications occur at any time during the postoperative phase (i.e. either as inpatient or outpatient)?	☐ None ☐ CSF leak ☐ Pseudomeningocele ☐ Neurological deterioration ☐ Infective meningitis ☐ Chemical meningitis ☐ Hydrocephalus ☐ Need for CSF diversion ☐ Subdural hygroma ☐ Delayed wound healing ☐ Wound infection ☐ Seizure(s) ☐ Hospital-acquired infection ☐ Deep vein thrombosis ☐ Pulmonary embolus ☐ Unplanned ITU admission ☐ Unplanned re-admission to hospital following discharge ☐ Death ☐ Other ((tick all that apply))
Specify 'other' postoperative complication	_____

Temporary CSF diversion

Did the patient undergo temporary CSF diversion since the last data collection (12-months post-baseline)?	◯ Yes ◯ No
Is the date of temporary CSF diversion known?	◯ Yes ◯ No
Date of temporary CSF diversion	_____
Form of temporary CSF diversion	◯ Lumbar puncture ◯ Lumbar drain ◯ External ventricular drain ◯ Other
Specify 'other' method of CSF diversion	_____

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What was the indication for the temporary CSF diversion?	◯ Hydrocephalus ◯ Raised ICP confirmed on ICP monitoring ◯ Clinically suspected raised ICP not confirmed on ICP monitoring ◯ Other ◯ Unknown
Specify 'other' indication	_____
If there were other events of temporary CSF diversion, please provide the same details above for each event.	_____

Permanent CSF diversion

Did the patient require permanent CSF diversion since the last data collection (12-months post-baseline)?	◯ Yes ◯ No
Is the date of permanent CSF diversion known?	◯ Yes ◯ No
Date of permanent CSF diversion procedure?	_____
Form of permanent CSF diversion	◯ Shunt (specify) ◯ Endoscopic third ventriculostomy ◯ Other
Where is the proximal catheter?	◯ ventricle ◯ other
Specify 'other' proximal catheter location	_____
Where is the distal catheter?	◯ peritoneum ◯ pleura ◯ heart ◯ subarachnoid space ◯ other
Specify 'other' distal catheter location	_____
Specify 'other' method of CSF diversion	_____
What was the indication for the permament CSF diversion?	◯ Hydrocephalus ◯ Raised ICP confirmed on ICP monitoring ◯ Clinically suspected raised ICP not confirmed on ICP monitoring ◯ Other ◯ Unknown
Specify 'other' indication	_____

Confidential

If there were any other events of permanent CSF diversion, then please list the same details as above for these additional events.	_____

Follow up

Has the patient been seen again in the neurosurgical clinic?	◯ Yes ◯ No
Is the date of the follow-up clinic neurosurgical clinic known?	◯ Yes ◯ No
Date of follow up clinic	_____
If yes, what is the neurosurgical management plan?	◯ Conservative management ◯ Request for more investigations ◯ Refer to a different neurosurgeon at the same neurosurgical unit ◯ Refer to a different neurosurgeon at a different neurosurgical unit ◯ Refer to a different speciality ◯ Surgery ◯ List for foramen magnum decompression ◯ List for CSF diversion ◯ List for ICP monitoring ◯ Unknown ◯ Other (specify)
Specify 'other' management plan	_____
Has the patient had a repeat MRI brain?	◯ Yes ◯ No ◯ Unknown
Is the date of the repeat MRI head known?	◯ Yes ◯ No
Date of repeat MRI brain	_____
Are you able to review the images from the MRI head?	◯ Yes ◯ No
Is there ventriculomegaly evident on the repeat MRI?	◯ Yes ◯ No
What is the maximum tonsil herniation measurable?	_____ (In mm below McRae's line. State the maximum. Can be either on the right or left.)
What is the anterior-posterior diameter of the foramen magnum?	_____ (In mm)

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Was there evidence of syringobulbia on first MRI head?	◯ Yes ◯ No ◯ Unknown
Has the patient had a repeat MRI spine?	◯ Yes ◯ No ◯ Unknown
Is the date of the repeat MRI spine known?	◯ Yes ◯ No
Date of repeat MRI spine	_____
With regards to syringomyelia, which of the following is true for the patient?	◯ Still no syrinx ◯ Worsening syrinx ◯ No change in syrinx ◯ New syrinx
At what level(s) is the syrinx seen?	_____ (e.g. C3 - T1)
What is the maximum anterior-posterior diameter of the syrinx?	_____ (In mm.)

Confidential

12-month questionnaire following surgery

Please complete this survey.

This survey will ask you about your symptoms and about your quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Do you suffer from headaches?	◯ Yes ◯ No
Where is your headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head (Select all options that apply)
Is your headache made worse by coughing and/or straining?	◯ Yes ◯ No
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Do you have any of the following symptoms in your arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) do you experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) do you experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Do you have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Do you have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Do you have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

	Quality of Life Questionnaire (SF-36)	
1	In general, would you say your health is:	◯ Excellent ◯ Very good ◯ Good ◯ Fair ◯ Poor
2	Compared to one year ago, how would you rate your health in general now?	◯ Much better now than one year ago ◯ Somewhat better now than one year ago ◯ About the same as one year ago ◯ Somewhat worse now than one year ago ◯ Much worse now than one year ago

Confidential

The following questions are about activities you might do during a typical day.

Does your health now limit you in these activities? If so, how much?

		Yes, limited a lot	Yes, limited a little	No, not limited at all
3a	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	○	○	○
3b	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○	○	○
3c	Lifting or carrying groceries	○	○	○
3d	Climbing several flights of stairs	○	○	○
3e	Climbing one flight of stairs	○	○	○
3f	Bending, kneeling or stooping	○	○	○
3g	Walking more than a mile	○	○	○
3h	Walking half a mile	○	○	○
3i	Walking one hundred yards	○	○	○
3j	Bathing or dressing yourself	○	○	○

Confidential

	During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	Yes	No
4a	Cut down on the amount of time you spent on work or other activities	○	○
4b	Accomplished less than you would like	○	○
4c	Were limited in the kind of work or other activities	○	○
4d	Had difficulty performing the work or other activities (for example, it took extra effort)	○	○

Confidential

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

		Yes	No
5a	Cut down on the amount of time you spent on work or other activities	◯	◯
5b	Accomplished less than you would like	◯	◯
5c	Don't do work or other activities as carefully as usual	◯	◯

6	During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?	◯ Not at all ◯ Slightly ◯ Moderately ◯ Quite a bit ◯ Extremely
7	How much bodily pain have you had during the past 4 weeks?	◯ None ◯ Very mild ◯ Mild ◯ Moderate ◯ Severe ◯ Very severe
8	During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	◯ Not at all ◯ A little bit ◯ Moderately ◯ Quite a bit ◯ Extremely

Confidential

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest the way you have been feeling.

How much of the time during the past 4 weeks

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9a	did you feel full of life?	◯	◯	◯	◯	◯	◯
9b	have you been a very nervous person?	◯	◯	◯	◯	◯	◯
9c	have you felt so down in the dumps that nothing could cheer you up?	◯	◯	◯	◯	◯	◯
9d	have you felt calm and peaceful?	◯	◯	◯	◯	◯	◯
9e	did you have a lot of energy?	◯	◯	◯	◯	◯	◯
9f	have you felt downhearted and low?	◯	◯	◯	◯	◯	◯
9g	did you feel worn out?	◯	◯	◯	◯	◯	◯
9h	have you been a happy person?	◯	◯	◯	◯	◯	◯
9i	did you feel tired?	◯	◯	◯	◯	◯	◯

10 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

◯ All of the time
◯ Most of the time
◯ Some of the time
◯ A little of the time
◯ None of the time

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How true or false is each of the following statements for you?					
	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
11a I seem to get ill more easily than other people	○	○	○	○	○
11b I am as healthy as anybody I know	○	○	○	○	○
11c I expect my health to get worse	○	○	○	○	○
11d My health is excellent	○	○	○	○	○

Confidential

12-month post-FMD (parent-reported; children 13-15yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feedling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying what will happen to him or her	○	○	○	○	○
Getting on with other teenagers	○	○	○	○	○
Other teenagers not wanting to be his or her friend	○	○	○	○	○
Getting teased by other teenagers	○	○	○	○	○
Not being able to do things that other teenagers his or her age can do	○	○	○	○	○
Keeping up with other teenagers	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month post-FMD (parent-reported; children 8-12yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores around the house	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with schoolwork	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

Baseline (parent-reported; children 5-7yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past ONE month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking 100 metres	○	○	○	○	○
Running	○	○	○	○	○
Participating in sports activities or exercise	○	○	○	○	○
Lifting something heavy	○	○	○	○	○
Taking a bath or shower by him or herself	○	○	○	○	○
Doing chores, like picking up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Trouble sleeping	○	○	○	○	○
Worrying about what will happen to him or her	○	○	○	○	○
Getting on with other children	○	○	○	○	○
Other children not wanting to be his or her friend	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Paying attention in class	○	○	○	○	○
Forgetting things	○	○	○	○	○
Keeping up with school activities	○	○	○	○	○
Missing school because of not feeling well	○	○	○	○	○
Missing school to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month post-FMD (parent-reported; children 2-4yrs)

Please complete this survey.

This survey will ask you about your child's symptoms and about their quality of life

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)

Confidential

In the past month, how much of a problem has your child had with ...					
	Never	Almost never	Sometimes	Often	Almost always
Walking	○	○	○	○	○
Running	○	○	○	○	○
Participating in active play and exercise	○	○	○	○	○
Lifting heavy things	○	○	○	○	○
Bathing	○	○	○	○	○
Helping to pick up his or her toys	○	○	○	○	○
Having aches or pains	○	○	○	○	○
Feeling tired	○	○	○	○	○
Feeling afraid or scared	○	○	○	○	○
Feeling sad	○	○	○	○	○
Feeling angry	○	○	○	○	○
Having trouble sleeping	○	○	○	○	○
Worrying	○	○	○	○	○
Playing with other children	○	○	○	○	○
Other children not wanting to play with him or her	○	○	○	○	○
Getting teased by other children	○	○	○	○	○
Not being able to do things that other children his or her age can do	○	○	○	○	○
Keeping up when playing with other children	○	○	○	○	○
Doing the same nursery / day care activities as peers	○	○	○	○	○
Missing nursery / day care because of not feeling well	○	○	○	○	○
Missing nursery / day care to go to the doctor or hospital	○	○	○	○	○

Confidential

12-month post-FMD (parent-reported; children < 2yrs)

Please complete this survey.

This survey will ask you about your child's symptoms.

You should only do this once you have completed the consent form. If you have not yet completed the consent form, or if you are unsure, please contact your local study lead.

Does your child suffer from headaches?	◯ Yes ◯ No
Where is your child's headache located?	☐ Front of head ☐ Top of head ☐ Back of head ☐ Side of head ☐ Unknown (Select all options that apply)
Is your child's headache made worse by coughing and/or straining?	◯ Yes ◯ No ◯ Unknown
On average, at what level is the headache?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from neck pain?	◯ Yes ◯ No
On average, at what level is the neck pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child suffer from back pain?	◯ Yes ◯ No

Confidential

On average, at what level is the back pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Does your child have any of the following symptoms in their arms or legs?	☐ Weakness ☐ Abnormal or loss of sensation ☐ Muscle wasting ☐ Poor coordination ☐ Pain ☐ Other ☐ None (tick all that apply)
In which limb(s) does your child experience weakness?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience abnormal or loss of sensation?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience muscle wasting?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience poor coordination?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg (tick all that apply)
In which limb(s) does your child experience pain?	☐ Right arm ☐ Left arm ☐ Right leg ☐ Left leg

Confidential

On average, at what level is the limb pain?	◯ 0 (no pain) ◯ 1 ◯ 2 ◯ 3 ◯ 4 ◯ 5 ◯ 6 ◯ 7 ◯ 8 ◯ 9 ◯ 10 (worst pain possible)
Please specify 'other' symptom	_____
Does your child have any of the following visual symptoms?	☐ None ☐ Visual loss ☐ Blurred vision ☐ Double vision ☐ Intolerance to bright light ☐ Other (tick all that apply)
Specify 'other' visual symptom	_____
Does your child have any problems to do with hearing or balance?	☐ None ☐ Dizziness ☐ Poor balance ☐ Pressure feeling in ears ☐ Ringing in ears ☐ Reduced hearing ☐ A feeling that the room is spinning ☐ Poor coordination ☐ Other
Specify 'other' hearing or balance problem	_____
Does your child have any of the following problems?	☐ None ☐ Swallowing problems ☐ Speech problems ☐ Hoarseness ☐ Throat pain ☐ Facial pain ☐ Loss of sensation of the face ☐ Nausea ☐ Vomiting ☐ Loss of consciousness ☐ Shortness of breath ☐ Urinary incontinence ☐ Bowel incontinence ☐ Impotence (males) ☐ Other

Confidential

Please specify 'other' symptom(s)