



<b>CAVERNOMA ALLIANCE UK</b> <b>INFORMED CONSENT POLICY</b>
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**Created**

Date developed	By whom	Method of consultation and recommendations	Date agreed
14/04/2016	FilbyMoore		14/04/2016
<b>Schedule for revision</b>		This policy should be reviewed every three years or sooner if needed.	

**History of revisions**

Review date	By whom	Summary of changes made	Date implemented
27/06/2019	TB	Approved in same form	27/06/2019
05/05/2021	TB	Small revisions	05/05/2021

**Introduction**

1. Cavernoma Alliance UK (CAUK) supports children, young people<sup>1</sup>, vulnerable adults<sup>2</sup> and adults who are affected by cavernoma through promoting and protecting the physical and mental health of sufferers of cavernoma. This support is achieved through providing education, research and practical advice. CAUK also aims to advance the education of the general public in all areas relating to cavernoma.
2. CAUK is a membership organisation. As such, we welcome members who may have or be affected by cavernoma. It may be that individuals applying for membership of CAUK are

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<sup>1</sup> The Children Act 1989 defines a child as someone who has not yet reached their 18th birthday. The terms young person / young people are used as a courtesy.

<sup>2</sup> The Safeguarding Vulnerable Group Act 2006 defines a vulnerable adult as a person who is aged 18 years or older and:

- is living in residential accommodation, such as a care home or a residential special school;
- is living in sheltered housing;
- is receiving domiciliary care in his or her own home;
- is receiving any form of health care;
- is detained in a prison, remand centre, young offender institution, secure training centre or attendance centre or under the powers of the Immigration and Asylum Act 1999;
- is in contact with probation services;
- is receiving a welfare service of a description to be prescribed in regulations;
- is receiving a service or participating in an activity which is specifically targeted at people with age-related needs, disabilities or prescribed physical or mental health conditions or expectant or nursing mothers living in residential care (age-related needs includes needs associated with frailty, illness, disability or mental capacity);
- is receiving direct payments from a local authority/HSS body in lieu of social care services; or requires assistance in the conduct of his or her own affairs.

children or vulnerable adults. As part of our 'members forum' the stories of members are published online for other members to read.

3. As such, it is necessary to ensure that these individuals are fully aware of what it means to become a member of CAUK and what will happen with their stories. In other words, it may be necessary to ensure that these individuals give 'informed consent'.

### **What is informed consent?**

4. Before using a participant's (or other person's) story or image in any publicity (i.e. on the website) it is necessary to get their full consent and ensure they fully understand what giving their consent actually means.
5. In the case of children/vulnerable people, informed consent is: "given by a competent individual who has received the necessary information; who has adequately understood the information; and who, after considering the information, has arrived at a decision without having been subjected to coercion, undue influence or inducement, or intimidation" (Council for International Organizations of Medical Sciences).
6. Further, where children are concerned, CAUK should also get the consent of the parent/guardian, but there may be circumstances where this is not possible. We should do what we can beforehand to identify any such parent/guardian to be consulted.
7. Should the young or vulnerable person that you are contacting not have a parent/guardian that you can contact or not be in agreement with your contacting them, you must consider the Fraser guidelines and be satisfied that the individual is 'Gillick competent' in so far as this can be applied (further to the case of *Gillick v West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402). To be so satisfied, you must check the following:
  - a. that the individual (although under the age of 16 years of age) will understand his position and the information you are giving them;
  - b. that you cannot persuade them to inform their parent/guardian(s) or allow you to;
  - c. that the individual is likely to consent to the publication of their story with or without parental/guardian consent;
  - d. that the individual is not likely to suffer as a result of this use of their story,
  - e. that the publication of this person's details on the website or in other material is not contrary to their best interests with or without parental/guardian consent.
8. Thus three basic principles also apply. Consent needs to be:
  - a. Informed: given in possession and understanding of the principal, relevant information - providing accessible and non-technical information about the 'publication' to the individuals details which is relevant to their decisions about whether or not to participate;
  - b. Competent: given by somebody able, in virtue of their age, maturity and mental stability, of making a free, considered choice. Thereby arranging consent by proxy (e.g. from parents of small children) where subjects are not competent to agree;
  - c. Voluntary: given freely and not as a result of coercive pressure (real or perceived) (e.g. by requiring written consent).
9. The Data Protection Act requires that the person knows:
  - a. who you are
  - b. what their information or photo will be used for
  - c. who else it may be passed to

### **CAUKs process for gaining consent and publishing members details**

10. Gaining initial consent: explain to the young or vulnerable person the following:
  - a. what the publication is about; why it is being conducted; who it is being conducted for; what the purpose of it is and what will happen as a result; where it will appear and who is likely to have access to it; who owns the copyright to the information (CAUK);
  - b. what will be expected of them if they agree to participate and how long their participation will take;
  - c. what anonymity and confidentiality mean in practice and an understanding that the participant:
  - d. does not have to participate; and
  - e. having agreed to participate can withdraw any time without detriment (e.g. to their membership)
  - f. To what extent the publication will be anonymous/confidential (all identifying features e.g. name, address, will be removed)
11. Drafting the publication: once initial verbal consent has been gained, develop the first draft of the publication. This then needs to be approved by the young / vulnerable person and their full consent, for its use needs to be sought. Send a written copy to the young / vulnerable and encourage them to make any amendments they feel necessary
12. Final consent: Once the young / vulnerable person has made any amendments and agreed the final draft, ask them to sign and return noting their consent to the publication (emailed consent is permissible).
13. Review date: As necessary, if there is a change in membership or the young / vulnerable person discloses further information which affects their consent, review the publication of the material and obtain consent again for the continuous publication as necessary and appropriate.

### **Issues to consider when gaining consent and drafting case studies:**

14. We will consider, on a case by case basis, issues that may affect the way in which we seek and gain informed consent, to ensure we are meeting the needs of individual young people. This may include factors such as age, learning disability, communication impairments, language, mental health issues, amongst others. Our considerations, to support all young people to give their informed consent may need to include:
  - a. Ensuring all information is accessible (e.g. clear, simple language)
  - b. In addition to providing written information, staff will also talk through this information with the young person either face to face or over the phone. This will enable staff to check that a young / vulnerable person has fully understood the information and allow the young person to ask questions.
  - c. Where a young/vulnerable person uses limited English we may consider using an interpreter, to ensure the young person can fully access and understand the information provided, to support them making an informed choice.

### **Anonymity**

15. Be clear that the publication will be anonymous if requested. We will not use identifying features, such as their name, address, etc. Young / vulnerable people can, if they wish, choose an alternative name to be used in the case study.

**Storage, management and use of case studies**

16. All publications will be stored on the CAUK website server and will clearly include the date of the consent for use of the publication, and for what purposes if these are limited.
17. Use of case studies should be cleared by the webmaster, Paul Oldham, and Ian Stuart, coordinator. Paul Oldham is responsible for the management of the server.
18. Before publications are used, the consent should be checked to ensure this still valid (e.g. for the purpose required) and has not expired.
19. Publication should not be altered (unless this is done with the renewed consent of the young / vulnerable person).