



James
Lind
Alliance

Priority Setting Partnerships

CAVERNOMA SURVEY

This is a paper copy of the survey. Although we have sent you a page for each of the main questions, we are very happy for you to send your answers on a separate sheet or sheets, simply heading each group of answers to indicate which of the six question you are answering. Although we prefer a printed response from a word-processing package (or a typewriter), please give a handwritten answer if you wish. Please post your responses back to the address at the end of the survey.

Overview

A new Priority Setting Partnership (PSP) has been launched to give everyone affected by cavernoma the opportunity to influence future research into its causes, diagnosis, treatment, care and prognosis.

Cavernomas are clusters of abnormal, leaky blood vessels that are found in many places in the body. However, the Cavernoma PSP is concerned only with cavernomas found in the brain, also known as cerebral cavernous malformations (CCMs), and spinal cord (the central nervous system) and which may cause a range of neurological symptoms including stroke and epileptic seizure(s).

Your participation will identify unanswered questions about cavernoma. We believe it is important that future research priorities are set by people with personal or professional experience of cavernoma.

The survey will be available from mid-January 2015 until the end of February 2015, and is available to complete as an online survey [www.cavernoma.org.uk/psp/] or can be completed as a paper copy on the pages below.

Please contact the Cavernoma PSP Administrator, Francesca Howarth, for further information at *e-mail* psp@cavernoma.org.uk or you can *phone* the CAUK office at 01305 213 876 and ask whoever answers.

Futher details are to be found on the PSP web site at:

www.cavernoma.org.uk/psp/ .

This is your chance to make your views known. Please answer the questions from any perspective that you wish.

By participating in this survey you are agreeing to allow us to publish the questions you identify in the UK Database of Uncertainties about the Effects of Treatments (UK DUETs - www.library.nhs.uk/duets). Your name will not be published.

Questions you would like to see answered

Please write the questions about brain or spine cavernoma that you would like to see answered on the relevant pages below. You can submit as many or as few questions as you like in answer to each question. Please add more pages if you run out of room.

1. What questions do you have about the **causes** of brain or spine cavernoma?

Examples: How do cavernomas arise?

What triggers symptoms?

2. What questions do you have about **diagnosis** (i.e. the recognition or identification of cavernoma based on symptoms, signs or test results)?

Examples: What type of tests should be used to diagnose cavernoma, and when?

3. What questions do you have about **treatments** (i.e. preventive, therapeutic, rehabilitative or palliative)?

Examples: Should I have Gamma-knife radiosurgery to treat my cavernoma?

Should a neurosurgeon operate on my cavernoma?

Should I take aspirin or other blood-thinning drugs if I have cavernoma?

Further explanation of some of the words used in this question.

Treatments:

preventive: an action designed to prevent you getting an ailment. Giving a child polio vaccine would be an example of preventive treatment. If a drug were available to stop cavernoma bleeding, that would be given as a preventive treatment.

therapeutic: an action to heal an ailment. Removing a cavernoma by surgery is a therapeutic treatment.

rehabilitative: an action to return you to normal life, perhaps after therapeutic action. For example, if your cavernoma causes you to have problems with, say, walking, a physiotherapist might undertake rehabilitative treatment to help you walk more normally.

palliative treatment is that which relieves pain, symptoms and stress caused by serious or life-threatening illnesses, improving a patients' quality of life. This is often, but not necessarily, used for patients in hospices near the end of their life.

4. What questions do you have about **care and support**?

Example: What activities should my son/daughter avoid at school if s/he has a cavernoma?

5. What questions do you have about **prognosis** (the predicted progression and outcome of cavernoma in an individual)?

Example: Can pregnancy increase the risk of a bleed from a cavernoma?

6. Do you have **any other questions** you would like to see answered?

Example: If there is no history of cavernoma in my family, could mine be inherited by my children?

Some questions about you

It would be really helpful to know a little more about you, so we would be grateful if you could answer the questions in this section. If there are particular questions that you would prefer not to answer, then just leave them blank.

Which of these best describes you? (Please tick all that apply)

- I have been diagnosed with cavernoma
- I am a carer, relative, friend or colleague of a person with cavernoma
- I am a health or social care professional
- I am part of an organisation representing people with cavernoma, their carers and relatives
- Other (please specify)

QUESTIONS FOR NON-HEALTHCARE PROFESSIONALS

e.g. Patients, Carers, Relatives

Where is your cavernoma?

Brain	<input type="checkbox"/>
Spine	<input type="checkbox"/>

At what age was your cavernoma (or the cavernoma of the person you care for) first diagnosed?

Age	<input type="text"/>
-----	----------------------

If you are answering as a carer, relative, friend or colleague of a person with (or who may have) cavernoma, please tell us what your relationship is to that person:

- Parent
- Husband/wife/partner or other relative
- Child
- Sibling
- Friend
- Colleague
- Other (please explain)

QUESTIONS FOR HEALTHCARE PROFESSIONALS

You only need to answer this question if you are answering as a clinician or health / social care professional. (Please tick ONE box)

In which area do you primarily work?

- Primary care
- Secondary care

What is your profession?

- Neurosurgeon
- Neurologist
- Stroke physician
- Medical geneticist
- Genetic Counsellor
- Paediatrician
- Obstetrician / gynaecologist
- Physiotherapist
- General Practitioner
- Midwife
- Occupational Therapist
- Nurse
- Psychiatrist
- Social Worker
- Other- please describe [insert text box]

QUESTIONS FOR EVERYONE

Gender:

M

F

Prefer not to say

What is your ethnic group?

Asian/ Asian British

Black/ African/ Caribbean/ Black British

Mixed/ multiple ethnicity

White

Other ethnic group

Prefer not to say

Age

It would help us to know your age – please tell us the year you were born (e.g. 1961)

Age:

Next steps

Would you like to be invited to take part in the next stage of the project, which is to vote for the questions you think are most important of all those submitted? You will be able to vote even if you haven't submitted any questions or taken part in the survey.

Yes No

If you answered 'yes', please tell us your preferred method of contact and supply your relevant contact details.

Email

Post

Contact details

Your details will be kept on a confidential and secure database in connection with the conduct, analysis, and follow-up of this survey, but will be used for no other purpose. We will not pass your details on to any third parties.

Name _____

Address _____

Email address _____

These are our contact details if you wish to contact us:

PSP Lead

David White: e-mail: chair@cavernoma.org.uk or phone 07757 063 044

Cavernoma PSP Administrator

Francesca Howarth: e-mail: psp@cavernoma.org.uk

or ***phone*** the CAUK office at 01305 213 876 and speak to whoever answers.

Thank you for completing this survey.

Please return this form to Francesca Howarth at:

CAUK

Suite 4, Somerleigh Gate

Somerleigh Road

DORCHESTER, Dorset DT1 1TL