



Cleft Lip and Palate Priority Setting Partnership



BACKGROUND INFORMATION – please read before completing survey

Have you ever asked your doctor, nurse or indeed anyone a question about clefting only to have them say that they don't know the answer? Can you think of any questions about clefting you'd like answered? Is there anything about its cause, diagnosis, treatment or long term outcome that you are uncertain about? Do you think that answering that question through research will help to improve the lives of people with a cleft?

This is your chance to make your views known.

The Cleft Lip and Palate Priority Setting Partnership (PSP) aims to work with people with clefts of the lip and/or palate, their carers and clinicians to identify and decide the most important research questions associated with clefting today.

For further information see <http://www.lindalliance.org/CleftPSP.asp>

Why is this project important?

Over 1000 infants are born every year with a cleft of the lip and/or palate. Such infants often require several surgical operations and lots of other healthcare intervention including hearing tests, speech therapy, dental care, orthodontic treatment and psychological support. However there remain lots of unanswered questions about clefting. The aim of this project is to find out what are the questions about clefting that **patients, carers** and **clinicians** most want answered.

What are 'unanswered questions about clefting?'

They are questions that cannot be answered at the moment by the existing research.

What will happen to the questions?

The questions which are submitted will be checked to ensure that they have not already been answered by reliable research. They will then be combined with questions which have been already identified through a review of existing research. These will then be entered into the UK Database of Uncertainties of the Effects of Treatments (UK DUETs – www.library.nhs.uk/duets). They will then go through a process of prioritisation, in which you can also get involved, to identify the 10 priorities for research which are of the most importance to patients, carers and clinicians. This list will be published and provided to organisations that fund research. For an example from another group see <http://www.lindalliance.org/JLASchizophreniaPSP.asp>

Why patients, carers and clinicians?

Research in health often overlooks the shared interests of patients, carers and clinicians. The pharmaceutical and medical technology industries and academia play essential roles in developing new treatments, diagnostic tests and so on but their priorities are not necessarily the same as those of patients, carers and clinicians. This means areas of potentially valuable research may be neglected.

Who is involved?

The organisations involved in this project include the James Lind Alliance (JLA), the Cleft Lip and Palate Association (CLAPA), the Craniofacial Society of Great Britain and Ireland (CFSGB&I), the British Association of Plastic, Reconstructive and Aesthetic Surgeons (BAPRAS) and NHS Evidence.

How can I get involved?

You can participate by completing our survey. It will take you around 5-10 minutes. You can do this in a number of different ways:

- **online:** www.clapa.com/survey
- **email / post:** download the survey from www.clapa.com/survey and send to
 - info@clapa.com
 - Cleft Lip and Palate Association, FREEPOST NAT7066, LONDON, EC1V 1BR
- **telephone:** call us on 020 7833 4883 to respond over the phone

You will be asked to give details of all your unanswered questions about clefting which you wish to be entered into the prioritisation process. You can enter as many or as few as you like. The survey will also ask you some optional questions about you and, if applicable, your organisation.

The closing date for the survey is 31st November 2011

Confidentiality and consent

Your contact details will be kept confidential and securely, in accordance with the Data Protection Act. As part of the process, your questions may be published in UK DUETs, and by participating in the survey you are agreeing to allow us to publish your questions. Your name/organisation will NOT be published in association with the question. For further information, or to see an example of what this will look like, go to www.library.nhs.uk/duets or contact us via the details below.

Contacts

For further information or if you have any comments or complaints about the process, please contact Katherine Cowan at the James Lind Alliance:

Email: patkinson@lindalliance.org Phone: 01865 517635

Post: James Lind Initiative, Summertown Pavilion, Middle Way, Oxford OX2 7LG

Useful websites

James Lind Alliance – www.lindalliance.org

CLAPA – www.clapa.com

BAPRAS - www.bapras.org.uk

CFSGB&I - www.craniofacialsociety.org.uk

UK DUETs - www.library.nhs.uk/duets