

RESULT Study (Review of Epidemiology and Service Use in Rare Long Term Neurological Conditions)

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Researchers at the University of Birmingham are looking for people with ataxia to volunteer to take part in a research study which aims to improve healthcare services for people with rare neurological conditions. This study aims to evaluate the services provided for people with rare long-term neurological conditions, including ataxia. It is funded by the Department of Health. A few years ago the Department of Health published the National Service Framework for longterm neurological conditions and this highlighted the need for quality standards in providing care and access to services. However, there is little accurate and reliable information about the views of service users and carers on the services currently provided. Without this information it is difficult for the service providers to make improvements. Therefore, the aim of this study is to ask people with ataxia for their views and experiences of health and social care services, and identify good practice as well as any shortcomings or gaps in service provision. We will present this information to policy makers and service providers and feed back to service users and health professionals.

As part of the study we will be asking people with ataxia to complete a questionnaire about their experiences and views of health and social care. The questionnaire will be available from 16th July 2010 and should take approximately 30 minutes to complete. The questionnaire will be available by post, online (www.result-survey.bham.ac.uk), email or telephone, and is available in a number of languages. If you are interested in taking part in this study, or to find out more, please contact Ed Savill (Primary Care Clinical Sciences, School of Health and Population Sciences, University of Birmingham, Edgbaston B15 2TT Telephone: 0121 414 8544 Email: saville@bham.ac.uk).

If you would like some support to complete the questionnaire, a carer can help you with it, or you can contact Ed Savill who will be happy to assist. Alternatively, if you live within reasonable traveling distance of the University of Birmingham you can opt to have a one-to-one interview at a time and location that is convenient for you.

For more support or information please contact: Ataxia UK, Lincoln House, Kennington Park, 1 – 3 Brixton Road. London SW9 6DE

Website: www.ataxia.org.uk.

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