

## **Evaluation of service provision for people with ataxia in north-west England**

The National Institute for Health Research's Research for Patient Benefit scheme has agreed to fund a two year, £155,000 project that will evaluate the provision of services for people with ataxia in the north-west of England.

The team that will conduct the research comprises experts from a range of disciplines (see below) and is being led by Dr John Ealing, consultant neurologist at Hope Hospital in Salford.

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Dr Caroline Sanders	Research Fellow in Medical Sociology, University of Manchester
Dr Iain Buchan	Director and Senior Lecturer in Public Health Informatics, University of Manchester
Dr Helen Kingston	Consultant Geneticist, St Mary's Hospital
Mr Alastair Kent	Director, Genetic Interest Group
Dr Julie Greenfield	Research Projects Manager, Ataxia UK

### **Background:**

People with long-standing conditions that affect different parts of the body often require access to many healthcare services from specialist centres, local hospitals and general practitioners. 'Ataxia' can affect a person's balance and coordination, mobility, speech, swallowing and vision. It results in significant physical, social and psychological disability but also presents substantial economic burden. Ideally, the provision of healthcare services would be done in a timely manner, providing seamless care between the different services.

In the Greater Manchester area, there is a relatively coherent multidisciplinary service for people with other degenerative conditions, e.g. motor neurone disease. However, anecdotal evidence suggests that ataxia service provision is patchy, unstructured and un-coordinated, although this has not yet been shown in a research study. Guidelines<sup>1</sup> produced at a national level by clinical experts recommend that

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people with ataxia should be seen in a specialist centre and list service standards that aim to improve patients' quality of life. Implementing these recommendations for all people with ataxia may have a significant impact on healthcare resources.

This study will be based in Greater Manchester and use interviews with adult patients, their carers and healthcare professionals to explore their experiences and to describe what it is like living with ataxia and how services are currently provided. Crucially, patients' views on the benefits of specialist services will be explored. The study will also measure the cost of providing the current services compared to those recommended by the guidelines. A survey will see if there is any variation in the services available for people with ataxia across the UK. This study will suggest how services for people with ataxia can be improved.

### **Summary of proposed research:**

**Phase 1:** This phase will explore experiences and management of the ataxia from the perspectives of patients themselves and those involved in their care. Interviews and diary entries will be used to assess the experiences of people with ataxia and interviews with carers, family members and healthcare professionals will also be undertaken. This phase will additionally describe the health burden for people living with ataxia.

**Phase 2:** This phase aims to identify how resources are used and what the associated costs to the NHS are. The costs of current ataxia services in Greater Manchester will be established and compared with the likely cost if national guidelines were implemented.

**Phase 3:** The data collected during phases 1 and 2 will be combined and used to assess how care is provided for the patients in the study and if it meets the national recommendations.

**Phase 4:** This phase will assess the types of services available for ataxia patients in England, the current demand for these services and the number of patients using the services. This will be done by a national survey of healthcare professionals. The data will reveal the current demand for services and any variability in their provision throughout England; such information is important for planning future service provision.

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