



*Modern Illness or a Thing of the Past?
Surveillance study of Sydenham's chorea among children and young people in
the UK and the Republic of Ireland*

What is Sydenham's Chorea?

Chorea is the term for abnormal movements described as rapid, irregular, aimless and involuntary. The most common cause of childhood chorea is Sydenham's chorea (SC), which is often accompanied by psychiatric symptoms such as obsessions and compulsions.

The condition is associated with prior infection with the bacteria *streptococcus*. Symptoms can range from mild to severe, and may impact on the child's ability to carry out activities of daily living. Psychiatric disorders triggered by SC may be long-lasting and disabling. Whilst SC may resolve within six months, it can follow a relapsing course for up to two years or longer.

Little is known about how frequently SC now occurs in the UK and the Republic of Ireland (ROI) or how often it may relapse. Given the impact on the lives of patients and families, there is a clear need for a prospective study of new cases. We have been working with the family charity the Sydenham's Chorea Association (<http://www.sydenhamschorea.org.uk/>) to develop this research.

The Sydenham's Chorea Study

SC is a post-streptococcal autoimmune movement disorder defined as purposeless, involuntary, non-stereotypical movements of the trunk or extremities, often associated with muscle weakness and emotional lability. It is frequently a clinical diagnosis (absence of laboratory confirmation of streptococcal infection does not preclude clinical confirmation).

Cases may be either:

- Suspected: cases presenting with chorea but no diagnosis of SC has yet been made.
- Confirmed: cases where a diagnosis of SC has been made and alternative causes have been excluded.

Please report children and young people aged 0-16 years who have or have had a suspected or confirmed diagnosis of Sydenham's chorea (e.g., by a paediatrician) and present to you for the first time within the current episode of care (regardless of whether this is their first contact with CAMHS or not) with one or more psychiatric symptoms. Please report any case even if you believe the case may have been reported from elsewhere.

Aims of the study

This study will provide us with more information on how many children are affected by this condition. Data collected will improve our understanding of the current problems associated with Sydenham's chorea. It will help us to identify the condition earlier and plan better services.

The project aims to answer the following questions:

- How many children with SC do child psychiatrists in the UK and ROI see over a year?
- What are the most common symptoms?
- How is SC currently assessed and managed in psychiatric services?
- What are the outcomes of children with SC over a two-year period?
- What is the impact on children's education and functioning?

We are carrying out this study in parallel with surveillance through the British Paediatric Surveillance Unit (BPSU), as children may present to paediatricians and/or psychiatrists. Together, our findings will fill the gap in scientific knowledge about the current pattern of SC in the UK and Ireland. This will support service development and planning, contribute to improving recognition of the disorder and facilitate pathways to appropriate investigation and treatment.

How long will it go on for?

The study will collect information on cases of SC for 13 months with some information requested at one and two-year follow-up. Thus, the study will last 37 months in total.

Who should be contacted if I have any questions about this study?

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Ethical approval: This study has been approved by London Bloomsbury REC (REC reference: 18/LO/0760) and has been granted Section 251 HRA-CAG permission (CAG Reference: 18/CAG/0086). This study has been granted Public Benefit and Privacy Panel for Health and Social Care (PBPP) approval in Scotland (PBPP reference: 1819-0077).