

BRITISH PAEDIATRIC SURVEILLANCE UNIT

Royal College of Paediatrics and Child Health
5-11 Theobalds Road, London WC1X 8SH

Tel: 020 7092 6173 Fax: 020 7092 6196 Email: bpsu@rcpch.ac.uk Web: <http://bpsu.inopsu.com>

Surveillance Study of Childhood/Adolescent Gender Identity Disorder in the UK and ROI

Abstract

This UK and Republic of Ireland study aims to determine the incidence of Gender Identity Disorder (GID) among children and young people aged 4-15.9 years. GID occurs when a person's gender identity differs from their biological sex causing distress (gender dysphoria). This is a joint study between the British Paediatric Surveillance Unit and the Child and Adolescent Psychiatry Surveillance System. Clinicians reporting a case meeting case definition criteria will be sent a brief questionnaire (taking approximately 20 minutes to complete) to establish basic clinical details about the child or young person concerned. A follow-up questionnaire will be sent at 1 and 2 years post-notification. This study will provide important population-level data about the incidence, clinical presentation, co-morbidities and stability/persistence of gender dysphoria at one and two years. These data will inform service provision for and clinical management of this vulnerable group of patients.

Principal Investigator

Dr. Sophie Khadr, Academic Clinical Lecturer, UCL Institute of Child Health, 30 Guilford St., London WC1N 1EH

Tel: 0207 905 2190

Email: s.khadr@ich.ucl.ac.uk

Co-Investigators

Professor Russell Viner, Dr. Polly Carmichael, Dr. Vicky Holt, Dr. Edna Roche

Website

www.rcpch.ac.uk/what-we-do/bpsu/current-studies/GID

Background

GID is an important condition where a person's gender identity differs from their biological sex. Some describe this as feeling they are in the wrong body or that their gender and body do not match. Children and adolescents with GID experience significant distress, particularly with the physical changes of puberty. There are increased risks of self-harm, suicide and eating disorders. While a psychological condition, concerns about possible hormone abnormalities and inter-sex conditions can prompt initial referral to Paediatricians. After diagnosis, Paediatric Endocrinologists are involved in the medical management of GID including pubertal suppression and treatment with cross-sex hormones.

Population-level data about the epidemiology, characteristics and outcomes of GID are lacking - information that is critical for optimising service provision and treatment options for individuals with GID. These debates are occurring without reliable data on the incidence, burden and natural history of childhood/adolescent GID, including whether GID in early adolescence is likely to be transitory or persistent.

Coverage

United Kingdom and Republic of Ireland

Duration

1st Nov. 2011 to 1st Dec. 2012 (13 months of surveillance). Follow-up until Dec. 2014

Research questions

Specific aims of the project are to determine:

1. The incidence of GID in children and young people aged 4-15 years inclusive (4-15.9 years) in the UK and Eire over one year.
2. The pattern of presentation to CAMHS services including the source of referrals.
3. The age, sex and family characteristics of children and young people who present with GID.
4. The clinical features of GID in affected children and young people, both medical and psychological.
5. The initial management of affected children and young people.
6. Outcomes at one and two years (persistence/desistence of gender dysphoria, referrals, treatment, co-morbidities)

**Case
Definition**

BOTH the following criteria (1 and 2) should be fulfilled:

1. A strong cross-gender identification for ≥ 6 months

(i) In children <12 years, this requires 2 or more of the following:

- a) In boys, preference for cross-dressing or simulating female attire; in girls, insistence on wearing only stereotypical masculine clothing;
- b) Strong preferences for cross-sex roles in make-believe play or fantasies of being the other sex;
- c) Intense desire to participate in stereotypical games/pastimes of the other sex;
- d) Strong preference for playmates of the other sex.

(ii) In adolescents ≥ 12 years, this requires 1 or more of the following:

- a) Frequent passing as the other sex (adopts clothing, hairstyle of the other sex)
- b) Desire to live and be treated as the other sex
- c) Belief that their feelings and reactions are typical of the other sex

2. a) Distress or unhappiness with his/her biological sex

(e.g. Stated dislike of/aversion to or self-inflicted injury to their primary or secondary sexual characteristics, request for physical intervention to alter their physical sexual characteristics to those of the other sex)

OR

b) Stated desire to be or belief that he/she is or should be the other sex

Exclusions:

- (i) GID cannot be diagnosed in children with known intersex conditions (disorders of sexual differentiation)
- (ii) Major psychotic disorder in which gender is one element of a wider delusional system.
Cases where gender identity is the *only* identified “delusion” should be included.

**Reporting
instructions**

Please report any child/young person aged 4-15 years inclusive (i.e. 4-15.9 years) meeting the case definition criteria below for the first time in the last month. If the clinician is uncertain or awaiting confirmation, the child should still be reported.

Methods

Using a monthly postal survey, clinicians will be asked to report any new cases of GID meeting the criteria above. Notifications will be followed up with a brief questionnaire about the young person's socio-demographic and clinical details. A brief follow-up questionnaire will be repeated at 1 and 2 years.

**Ethics
approval**

This study has been approved by London Bloomsbury REC (ref.11/LO/1512) and the National Information Governance Board (NIGB) under Section 251 (ECC 8-02(FT4)/2011).

Funding

Tavistock & Portman grant via the Advisory Group for National Specialised Services

For further information about the study, please contact:

Faye Sweeney: email f.sweeney@ich.ucl.ac.uk telephone: 0207 905 2190