BRITISH PAEDIATRIC SURVEILLANCE UNIT

WHAT IS THE BRITISH PAEDIATRIC SURVEILLANCE UNIT (BPSU)?

The aim of the BPSU is to encourage the study of rare conditions in children. It was founded in 1986 by the Royal College of Paediatrics and Child Health, the Health Protection Agency and the Institute of Child Health (London).

WHAT DOES THE BPSU DO?

It allows doctors and researchers to find out how many children in the UK and the Republic of Ireland are affected by a particular disease or condition each year - this is called epidemiological surveillance. Doctors can also gather information about all the cases of a particular rare condition so they can begin to understand what might have caused it and how to diagnose and treat.

On receiving the card, the BPSU informs the investigation team, who send the reporting doctor a short confidential questionnaire for more information about the affected child. BPSU researchers never contact families or children and surveillance studies don't ever affect a child's treatment. The purpose is ONLY to collect information to learn more about the condition.

HOW DOES THE BPSU WORK?

Each month the unit sends a distinctive orange card to over 3200 consultant paediatricians; the card lists the rare conditions currently being studied.
If a doctor has seen a child affected by one of these conditions they tick a box on the card and return it to BPSU.

WHAT HAS THE BPSU ACHIEVED?

PUBLIC HEALTH IMPACT

The BPSU has now helped to undertake surveys of over 70 rare conditions which may affect children. These have helped to increase understanding of why the conditions occur and can help to provide better diagnoses and treatments.

(From the BPSU Public Information Leaflet – 'Investigating rare childhood conditions for the future health of the nation')

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BRITISH PAEDIATRIC SURVEILLANCE UNIT & CHILD AND ADOLESCENT PSYCHIATRY SURVEILLANCE SYSTEM

PUBLIC INFORMATION SHEET

GENDER IDENTITY DISORDER STUDY

TOWARDS BETTER TREATMENT AND MANAGEMENT OF CHILDREN AND YOUNG PEOPLE WITH GENDER IDENTITY DISORDER

WHAT IS GENDER IDENTITY DISORDER?

Some people describe this as feeling they are in the wrong body or that their gender and body do not match. Children and young people with GID experience significant distress that frequently increases in intensity when they go through the physical changes of puberty. There are increased risks of self-harm, suicide and eating disorders.

WHY DOES GENDER IDENTITY DISORDER DEVELOP?

- No single cause has yet been found for the development of a gender identity disorder.
- There is some evidence that it can occur in young people with an autistic spectrum disorder.
- Most young people who experience gender dysphoria in childhood find these feelings decrease after puberty.
- In a few, gender identity disorder continues into adulthood and they may want to discuss undergoing a sex change
- More information is needed to help us understand why gender identity disorder decreases for some young people and continues for others.

Gender Identity Disorder Study, public info leaflet, Version 3, 16th January 2012
REC Ref. 11/LO/1512

How Will Affected Children be Treated?

Children and young people with a diagnosis of GID often experience significant distress and isolation, both in relation to their feelings about their gender and the reactions of others to their predicament. National and international guidelines for the management of GID recommend a multidisciplinary team approach including specialist psychological, psychosocial and endocrine (hormonal) support. Many children and young people with gender dysphoria are referred to the Gender Identity Development Service (GIDS), a national specialist service based in London. We do not know how many young people are managed locally by other services and what kind of support they receive.

The GIDS is a multidisciplinary team including both mental health and medical professionals experienced in assessing and managing gender dysphoria. The aim of the GIDS is to promote understanding and exploration of the young person's feelings about their gender. The service works closely with local professionals involved in a young person's care to support their social, emotional and developmental needs.

In appropriate cases, young people can be assessed by a paediatric endocrinologist working with the multidisciplinary team and prescribed hormonal treatment to suppress pubertal hormones. The aim of this treatment is to reduce distress associated with pubertal development.

The Gender Identity Study

We do not know how common GID is in children and young people in the UK and Republic of Ireland, how long it persists and what is the best management for this condition. The National Commissioning Group funds a specialist GID service in London and is commissioning a satellite service in northern England. This study will provide important information to inform health service planning for this vulnerable group.

The British Paediatric Surveillance Unit (BPSU) and the Child and Adolescent Psychiatry Surveillance System (CAPSS) are supporting this study, as well as the National Commissioning Group (NCG) and the Mermaids support group (www.mermaids.org.uk Tel: (0208) 1234819.

What Will This Mean For Children With GID?

Medical doctors caring for children and young people with probable GID will send us some information about the development of their condition. Individual children will not be identified. Through this information we hope to increase our understanding of when Gender Identity Disorder develops, the difficulties that children and young people with this diagnosis experience and improve access to appropriate treatment.

Where Is This Study Happening

The study will be taking place in all hospitals and child and adolescent mental health services across the United Kingdom, Republic of Ireland and the Channel Islands.

How Long Will It Go On For?

The study will continue for three years.

What are the possible risks and benefits

The care and treatment that children and young people with Gender Identity Disorder are receiving will not change during this study. However we hope that by learning more about Gender Identity Disorder, diagnosis and care will improve in the future. The information collected will not identify individual children and patient confidentiality will be maintained at all times.

Who Should Be Contacted If I Have Any Questions About This Study?

Please contact the study investigators Sophie Khadr (s.khadr@ich.ucl.ac.uk) or Faye Sweeney (f.sweeney@ich.ucl.ac.uk) or the BPSU (see over page for address) if you wish to know more about the study.