

# Improving the experience of children, young people and families visiting Great Ormond Street Hospital

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*Meeting the duties of the Equality Act 2010*

*March 2018*

## **Summary report for Trust Board**

The Equality Act 2010 (the Act) simplifies equalities law into one single source of Statute. In addition to the Act, the statutory Equality Duty came into force in April 2011 which is applicable to all public sector bodies. As a Trust, we are legally required to demonstrate that we comply with the Act and are meeting the Equality Duty through the work we do, the Trust Board's involvement in this work and through publishing a range of equalities data annually.

To comply with the first specific duty of the Act, the Trust is legally required to annually publish equality data relating to both service users and staff. A copy of the latest edition of this report will be available on the GOSH website at [www.gosh.nhs.uk/about-us/equality-and-diversity/](http://www.gosh.nhs.uk/about-us/equality-and-diversity/). The second part of the specific duty requires the Trust to prepare and publish equality objectives, setting out progress towards meeting the objectives.

### ***Equality objectives relating to children, young people and families for period 2016 to 2020/21:***

The following objectives were selected previously in conjunction with children, young people, families and staff members and continue to provide the main focus for the Family Equality and Diversity group at GOSH.

#### **Objective 1: Achieve Accessible Information Standard within timescale**

The Accessible Information Standard sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss. This objective was time-limited as NHS England had required the Standard to be met by the end of July 2016.

The 'additional needs' tab on the Trust's Patient Information Management System (PiMS) enables staff to record these requirements. A handful of requests have been received during 2018, including one for large print information and two requests for telephone contact rather than letters.

Negotiations with the team implementing the Electronic Patient Record system have been successful in transferring this functionality as well as expanding it to record additional needs of all who hold Parental Responsibility for a patient.

The range of Easy Read information has also increased and a set of Easy Read information sheets to support the 'Growing Up Gaining Independence' (GUGI) programme (see objective 3) has been developed in association with the Improvement Manager for that project. The range of information sheets to support the GUGI programme will continue to expand as the programme is evaluated by young people and their families.

The Family Equality and Diversity group will continue to monitor compliance with this standard, in terms of usage levels of the additional needs tab and provision of communication and information support on request.

## **Objective 2: Publicise support for families including support organisations**

There are a wide range of support mechanisms for families both within and outside GOSH. However, families tell GOSH, in surveys and other encounters, that these are not always promoted as well as they could be. While many excellent support organisations exist, families may not always be aware of their existence so work is ongoing to support clinical staff in providing this information more systematically. Recording of information given will become easier following the introduction of the Electronic Patient Record.

The Patient Advice and Liaison Service (Pals) has developed a new service in conjunction with the Volunteers Service. The Pals Outreach Project, known as "Popping" was launched in September 2018 and is designed to meet patients and families face to face on wards and in outpatient clinics to promote access to GOSH information on health and GOSH services. Many people find accessing information through the internet quick and convenient but others struggle to access information in this way. Navigating the hospital website can be a challenge for those with limited reading skills, those with a learning disability or those who might be looking for information in other languages. The Popping service supports parents and young people in accessing information by providing face to face support.

Provision of information trolleys outside the Pals Office, supplying information sheets about support, details of organisations that can help and benefits advice, continues to be popular (evidenced by monthly monitoring of the information sheets supplied). The associated costs of stocking the trolleys are also being monitored to ensure that it is sustainable and worthwhile.

A wide variety of support organisations visit GOSH on a regular basis to promote the services they offer to children, young people and families. These range from umbrella organisations such as Contact (previously known as Contact a Family) to condition specific groups such as Young Epilepsy. This is in addition to therapeutic and entertainment volunteers, such as Therapy Dogs and Spread a Smile. Families can also access support through the Citizens' Advice Bureau.

### **Objective 3: Support on-going work to improve transition to adolescent or adult services**

The information and support needs of young people and their families have been prioritised by building on the previous year's work to develop the 'Growing Up Gaining Independence' (GUGI) framework. The framework clearly explains the life skills relevant to all young people, particularly those who will transfer to adult healthcare.

This is a major component of enabling a young person to become as independent as possible in managing their health, for instance, taking medicines, preparing for appointments and understanding the impact of lifestyle issues on their particular conditions.

Various clinical teams have been working with the Improvement Manager to develop condition specific information to prepare for the transfer to adult services, including multiple sclerosis, complex epilepsy and congenital hyperinsulinism. In most cases, an Easy Read information sheet is being developed alongside to meet the needs of young people with learning disabilities.

### **Family Equality and Diversity (FED) Group**

The Family Equality and Diversity Group has continued to meet during 2018. Presentations were received from:

- Andrew Pearson, Clinical Audit Manager – the Learning Disabilities Mortality Review (LeDeR) Programme
- Dr Elaine Clarke, Neurodisability Consultant – working with and supporting children and young people with autism spectrum disorder
- Representatives from the Electronic Patient Record team – components of the EPIC (supplier) system pertinent to equality, diversity and inclusion, such as demographic data, learning needs and education assessment and the After Visit Summary.

In addition, regular data reporting has improved with the development of an automated report showing data from the Friends and Family Test, broken down by gender, ethnicity and additional need to measure parity. This data is reviewed regularly and did not highlight any concerns as where there was a difference in percentage to recommend, this was usually from a very small number of responses so not deemed to be statistically significant.

GOSH continues to be represented on the Pan London NHS Equality and Diversity Leads Network, with the aim of learning from successful initiatives at other Trusts and sharing what we have learnt at GOSH. The two GOSH departments with overall responsibility for delivering against these objectives (Nursing and Patient Experience via the Health Information/Language Manager and Human Resources and Organisational Development) also meet more regularly to plan joint working such as improvement of equality analysis and coordination of reporting.