

# Meeting the duties of the Equality Act 2010

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*January 2016*

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This report details how Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) is meeting the requirements of the Equality Act 2010 in terms of service delivery to patients and families. It complements the report detailing how our Human Resources department is meeting staff requirements.

The Equality Act states that public authority must, in the exercise of their functions, have due regard to the need to:

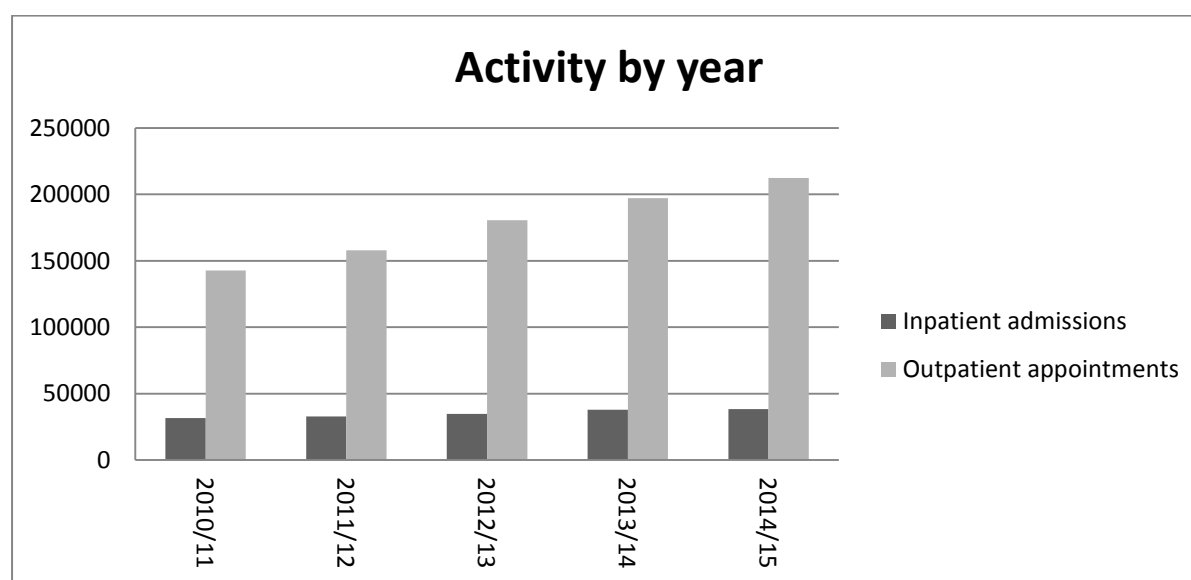
- Eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act
- Advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it
- Foster good relations between persons who share a relevant protected characteristic and persons who do not share it

The protected characteristics or groups defined by the Equality Act 2010 are age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex, sexual orientation and marital status.

GOSH is an acute NHS Foundation Trust providing a full range of specialist health services exclusively to children and young people. This report demonstrates our compliance with the general equality duty across our services in relation to children and young people who share a protected characteristic.

## Background

Activity at GOSH has increased again over the last year – both inpatient admissions and outpatient appointments. We have the widest range of health services for children and young people on one site in the UK – a total of 50 specialties and subspecialties.



We also host a number of highly specialised services, commissioned nationally, namely:

- Autoimmune paediatric gut syndromes service
- Bardet-Biedl syndrome service

- Beckwith-Wiedemann syndrome with macroglossia service
- Bladder exstrophy service
- Complex childhood osteogenesis imperfecta service
- Complex tracheal disease service
- Congenital hyperinsulinism service
- Craniofacial service
- Diagnostic service for rare neuromuscular disorders
- Epidermolysis bullosa service
- Extra corporeal membrane oxygenation service for neonates, infants and children with respiratory failure
- Heart and lung transplantation service (including bridge to transplant using mechanical circulatory support)
- Lysosomal storage disorder service
- Paediatric intestinal pseudo-obstructive disorders service
- Pulmonary hypertension service for children
- Severe combined immunodeficiency and related disorders Service
- Stem cell transplantation service for juvenile idiopathic arthritis and related connective tissue disorders
- Vein of Galen malformation service

In many cases, GOSH is the only paediatric centre in the UK offering the service or one of only a few centres.

## **Understanding our patient and family experience**

Our mission is to deliver world-class clinical care to the children and young people we treat and to consistently provide an excellent experience that exceeds the expectations of children, young people and their families.

We use a number of ways to help us engage effectively with our patients and their families to fully understand their experience and hear their feedback. In addition to the Friends and Families Test offered at the point of discharge to inpatients and day patients and to those attending outpatients, each year, we routinely consult patients and parents/carers both on a Trust-wide basis, and also at a service-specific level.

We have an active Members' Council with parent and patient representation and a thriving Young People's Forum, which represents the voice and perspective of children and young people. The forum allows our patients, ex-patients, their siblings and friends mutual support, an opportunity for dialogue and a platform to express their views to help shape services and drive improvement. In addition, there is a range of committees, project boards and steering groups which include parent/public representation, including the Family Equality and Diversity Group and Patient and Family Engagement and Experience Committee.

### ***Trust-wide surveys***

In autumn 2014, patients at GOSH participated in the first ever national Care Quality Commission (CQC) children and young people's inpatient and day case survey. It was the first time children and young people across England and Wales had been surveyed on such

a large scale. It allowed the Trust to compare its performance, in relation to patient experience, against that of other children's hospitals and services.

The most recent Trust-wide survey – the *National children's inpatient and day case survey 2014* – recorded some demographic detail about the 253 respondents. Fifty six per cent were male, compared to 55 per cent male for our overall population. However, the ethnic group of respondents is quite different to the data recorded about our overall population – for instance, 68 per cent of respondents described themselves as 'white', compared with 38 per cent of our overall population. Non-white respondent demographics were more broadly similar, with eight per cent of respondents 'Black or Black British' compared with five per cent of our overall population and 10 per cent Asian or Asian British compared with 9 per cent. It is not clear what arrangements were made to survey non-English speaking children, young people and families. Detailed response data is not available so further analysis to discover if non-white families have a similar experience to white families is not possible.

GOSH children and young people scored their overall experience as 8.5 out of 10, while parents rated their experience as 8.7 out of 10. This is comparable to other children's hospitals but lower than the best performing Trusts who achieved up to 9.4 out of 10 for each.

Our strengths according to the children and young people

- Do you feel that the people looking after you were friendly? 95 per cent said yes.
- Did you feel safe on the hospital ward? 94 per cent said they always felt safe with us.
- Did staff do everything they could to control your pain? 94 per cent said yes.

Parents also identified a number of strengths

- Did staff explain what would be done during the operation or procedure? 98 per cent said yes.
- Did staff tell you before the operation or procedure, what would be done? 97 per cent said yes.
- Did staff answer questions about your child's operation or procedure, in a way you could understand? 96 per cent said yes.

Where we could be better

- 85 per cent of parents and carers said the hospital did not change the admission date.
- 85 per cent of parents and carers said members of staff caring for their child worked well together.
- 73 per cent of children and young people said someone at the hospital talked to them about any worries they had.
- 54 per cent of children and young people said they liked the hospital food.

Quotes from the survey

*"Great Ormond Street Hospital is one of the greatest hospitals in the world offering wonderful support and care. Excellent staff, excellent services and excellent, experienced doctors. You are doing a great job, thank you."*

*“Overall, excellent care, but limited communication between specialties means that no one has a good overview of our child’s needs and treatment.”*

## Next steps

As many of you know, we have already started working on the areas for improvement. We have the Access Improvement Programme to give parents more choice of admission dates. To help staff communication we have been piloting Situation Awareness for Everyone (S.A.F.E) huddles across the Trust, as well as electronic patient status at-a-glance boards.

We’ve also had massive changes to our menus, such as the introduction to the one-week menu, food tasting with parents and patients, and we will shortly be bringing in protected mealtimes.

We need to focus our efforts on making time to talk to children about their worries and fears. To help us do that we will be trialling a new innovative toolkit that was developed at GOSH, called ‘Me First’. To find out more, please visit the website [www.mefirst.org.uk](http://www.mefirst.org.uk)

## Friends and Family Test (FFT)

The FFT is a simple, comparable patient experience indicator which asks patients and/or their parents/carers whether or not they would recommend the ward they have stayed on or service they have visited to friends or family if they needed similar care or treatment.

The FFT was released nationally by the Government in 2012 as a measure to identify best performing hospitals in England. At GOSH, the FFT was introduced for patients that stay one night or more in April 2014. To date, we have had over 16,100 responses and of these, 95 per cent of respondents said that they were extremely likely or likely to recommend GOSH as a place for care or treatment.

GOSH has expanded the FFT to include outpatients and day cases. To ensure that all patients at GOSH are offered the FFT, an age appropriate feedback form for inpatients, outpatients and day cases has been adapted to encourage younger patients to participate in FFT.

In the FFT guidance, which was updated in March 2015, it recommended that the FFT should include demographic questions, for example additional questions about sex, age, ethnic group and disability. We have reviewed the demographic questions and have adapted some of the questions specifically for the context of GOSH. It is expected that demographic questions will form part of the FFT in future system developments which will roll out across the trust in 2016.

Hello!

We would like to know what you think about your outpatient visit today.

If someone you knew had to come to an outpatient clinic, would this be a good place for them to come to?

Please colour in the face that shows what you think

Yes Don't know No

What clinic did you visit today?

What was the name of the Doctor / Nurse that you saw today?

How old are you?

(Please turn over)

Write or draw what you think was **good**

Write or draw what you think was **bad**

(Please post this card in the post box on the ward. Thank you!)

## Members' Council

In March 2015 we celebrated our third year as a Foundation Trust. We continue to develop a thriving and engaged membership community whose views are reflected by their representatives on the Members' Council. The Members' Council also provide a steer on how the Trust will make a difference to the future health and wellbeing of its patients.

In February 2015 our Members' Council entered its second three year term of office. The election was held for 22 of the 27 councillor seats.

Councillors have continued to actively engage with the hospital and membership community and have been involved in a variety of Trust working groups from redevelopment to strategy. They have fulfilled their statutory obligations, queried reports, key performance indicators, governance and financial figures with the aim of ensuring that Trust members and key stakeholders are represented.



## Trust Annual Plan 2015/16

The Members' Council received presentations and updates at their Members' Council Meetings. The Membership and Engagement Committee were consulted and had input into this year's membership Annual Plan Survey. This survey was disseminated to the wider membership via their FT Get Involved email and was available on the Trust website. Feedback on the results of the survey were presented at the January 2016 Members' Council Meeting.

## Young People's Forum

The Young People's Forum (YPF) have had another active year, advising the Trust on all matters related to adolescents and young adults. They had an induction and training programme and have continued to work in collaboration with a variety of teams across the Trust, including:

- They were involved in designing the Friends and Family Test cards and advised on how the results should be displayed.
- They continued to be involved in advising on the re-design of the GOSH Teens pages on our website and suggesting new content including a regular 'blog'.



- The YPF also worked with our Consultant Nurse for Learning Disabilities to help him improve patient experience for children and young people with learning disabilities.
- During one of their regular meetings held at GOSH, the YPF created a pledge for all new members to sign up to and agreed the processes for registering and inducting new members.
- They were consulted on the Lead Consultant role being developed at GOSH.
- They explored how the YPF can support the communication and engagement with more young people at GOSH.

The YPF continue to work with the Patient Experience team to develop a programme of activity for the coming year.

### ***Our 'always' values***

Over 2,500 people helped us define our 'always values' – 1200 children, young people and families as well as 1444 members of GOSH staff.

During 2015, we have continued to work very closely with our parents to help launch and embed Our Always Values. We have parents who sit on the values operational delivery group as well as on our steering board. Our initial phase of work has focussed on making our staff familiar with, and using, the values and their associated behaviours. Our next phase of work will focus around how we communicate the values to patients and families.



### ***Planning new services and buildings***

Ideas, insight and inspiration from across the hospital community are being used to develop a design brief for a new building at Great Ormond Street Hospital (GOSH) building.

GOSH has been constantly evolving since it opened in a 17th-century townhouse. We are currently halfway through an ambitious 20-year redevelopment programme to rebuild two-thirds of the hospital site. After Phases 2B and 3 (see below), our next goal is Phase 4, a new signature building on Great Ormond Street itself. Phase 2B is the Premier Inn Clinical Building, the second part of the Mittal Children's Medical Centre. It is due to open in 2017. Phase 3 is the Zayed Centre for Research into Rare Disease in Children. Construction on this building will begin at the start of 2016, and it is scheduled to open in 2018.

Although we are many years from breaking ground, work has already started in earnest to develop a business case and design brief for Phase 4. Early engagement with building users is central to good design, so discussions with staff, patient and family representatives are well underway.



## Workshops with young people

At a workshop in October, members from the Young People's Forum worked side by side with GOSH staff to develop creative ideas on four design aspirations that have emerged in discussions to date:

- magical spaces
- community, connection and a warm welcome
- the comforts of home
- alive with technology.

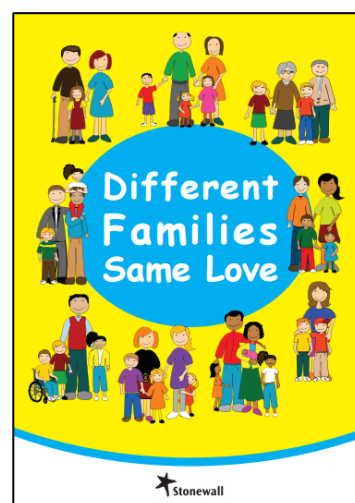
Participants took inspiration from their own favourite places and from a fascinating talk on the effect buildings have on patient experience from former patient Sophie Talib. Using various creative activities, from 3D modelling to drawing and collage, the young people developed ideas on tackling fear and isolation, improving the transition between home and hospital life, and promoting wellbeing. They also collated a range of written phrases, stories and language cues, demonstrating their aspirations for the building.

At another creative session, some of our younger patients and their siblings produced bold and beautiful collages and models demonstrating a delight in the magic of fairies, unicorns and superheroes. They also showed an interest in real-world wonders, including music, animals, cityscapes and the beauty of nature. The rich, creative input collated during these sessions will be analysed and incorporated into the Phase 4 design brief along with a range of other materials. This will help develop the design team's insight into the needs of our patients, families and staff, and keep their priorities at the heart of the design process.

## Diversity at GOSH

It could be argued that some of the protected characteristics (as defined by the Equality Act 2010) may be less relevant to children and young people. Our aim is to meet the needs of all children, young people and their families who need to use health services at GOSH.

We recognise that children and young people live in families or with carers in communities where all of the protected characteristics are important. To this end, posters produced by Stonewall have been circulated to all wards and departments for display during the previous year.



## Age

In the main, GOSH treats children and young people aged less than 18 years, although in some circumstances, older patients are treated. Some services offer antenatal care and genetic advice for the entire family.

## Transition to adult health services

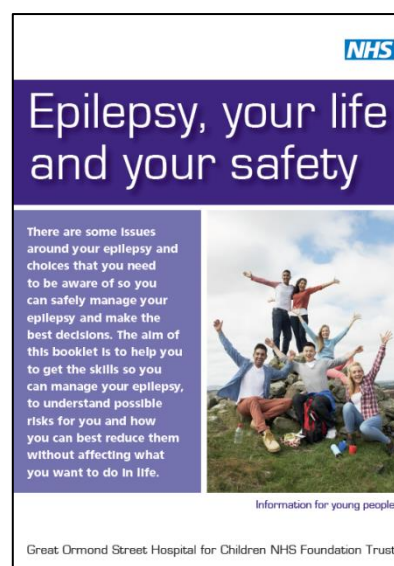
A number of services have been reviewing their transition processes recently, both to make sure the administrative process of handing care on to a relevant adult health service



happens in a streamlined fashion but also to ensure young people themselves are able to take as much control over their health as they feel able. The Children's Complex Epilepsy Service has worked with young people themselves to design a transition booklet covering topics pertinent to being a young person with epilepsy.

This includes information on staying safe, avoiding peer pressure, contraception, drugs and alcohol. It emphasises the potential to balance managing epilepsy with continuing as normal a day to day life as possible.

Other services such as Craniofacial Surgery and Cystic Fibrosis have also been reviewing their transition information and processes in the past year or so.



## ***Disability***

A high proportion of the children and young people seen at GOSH fall within the statutory definition of 'disabled'. In the most recent inpatient survey, 42 per cent responded that their child has special needs or disabilities. This is slightly down on previous years, where 44 per cent reported that their child has special needs or disabilities.

In previous Trust-wide surveys, respondents were asked 'to what extent do you agree or disagree that the hospital understands these [additional] needs and puts arrangements in place to meet them'. Unfortunately, the latest inpatient survey (a UK-wide survey from a different supplier) did not include questions about additional needs and arrangements to meet them, so it is impossible to provide a comparison with the 80 per cent tending to agree or strongly agree with this statement in the previous year.

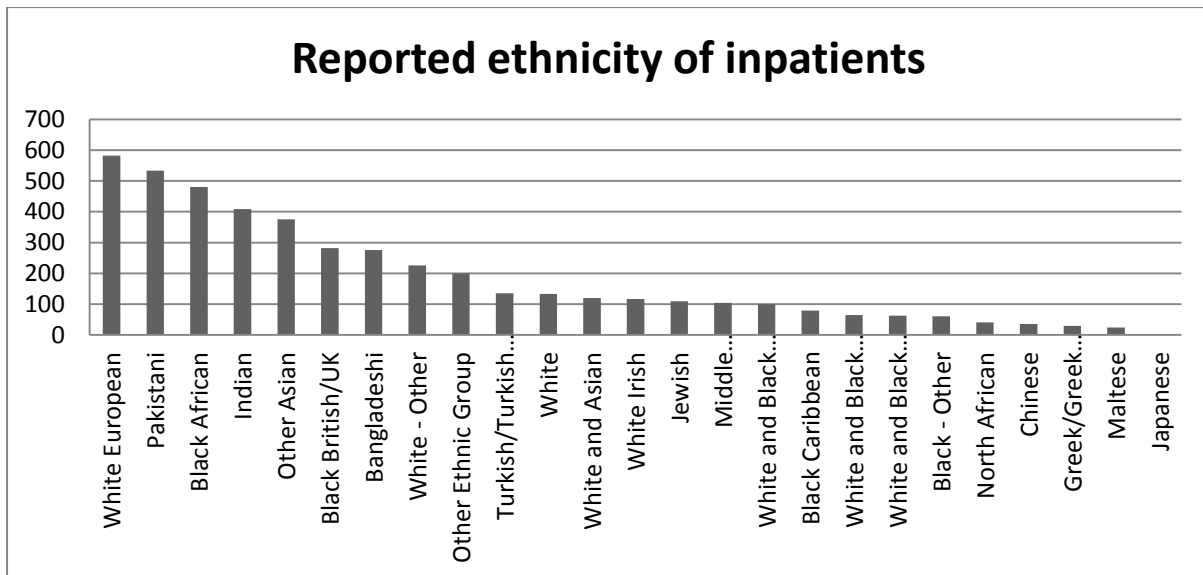
## **Improving services for children and young people with learning disabilities**

Work to improve services for children and young people with learning disabilities has continued with drop-in sessions for parents being held regularly. Items or queries raised at these sessions are fed back to the LD Steering Group for further action as required. Communication has remained the focus of the group – a subgroup has been using the results of an audit completed to steer future development, including discussions with the Makaton® charity and the design of guidance posters for staff.

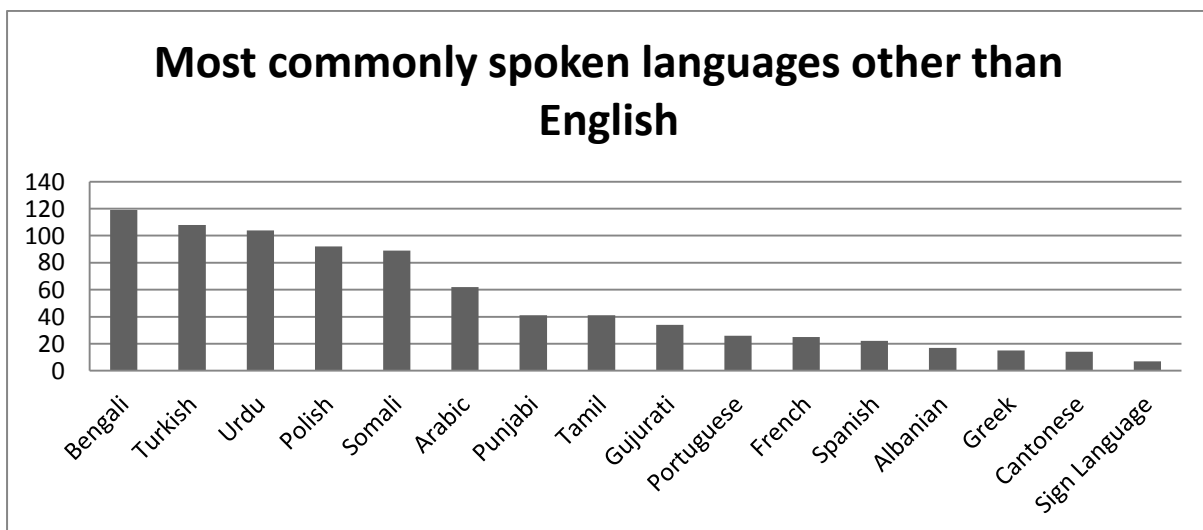
In addition, two clinical audits have been completed, looking at staff confidence in working with children and young people with learning disabilities and also at the reasonable adjustments made to meet their needs. Children and young people with learning disability can now have an 'alert' added to their medical record so staff are aware of their needs but the process of applying this alert is currently being fine-tuned.

## ***Race***

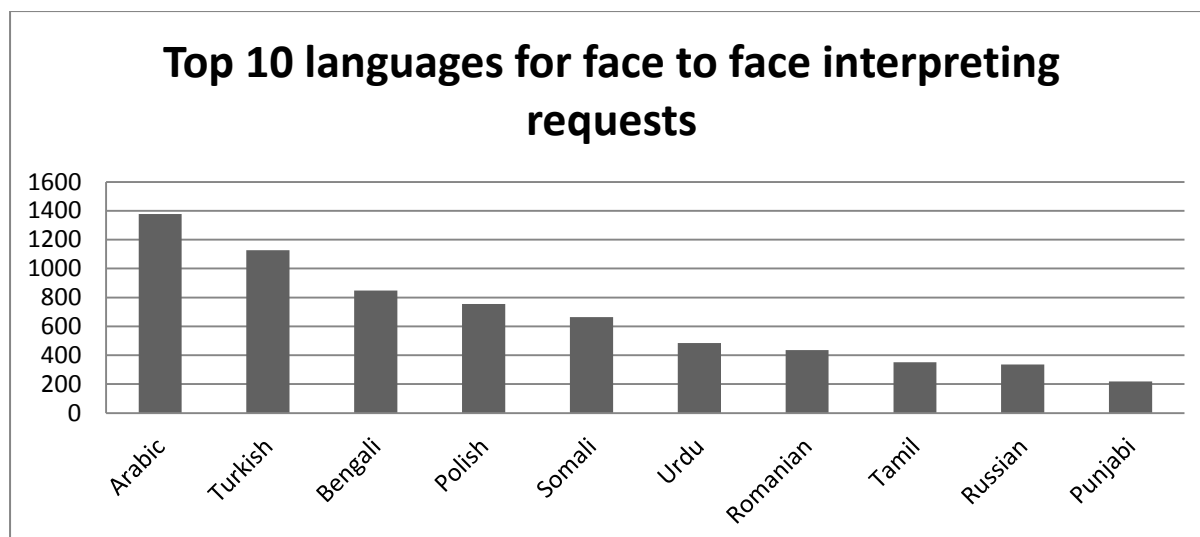
Thirty two per cent of inpatients report that they are White British/UK, a drop of three per cent on the previous year. A total of 42 per cent were either 'not asked' or 'not specified'. Fewer than one per cent refused to give their ethnic group.



We are concerned that a major barrier to equality of opportunity is the inability to speak English. We routinely record the patient's and family's mother tongue on registration and endeavour to provide appropriate language support whenever the patient is admitted or attends an outpatient appointment.

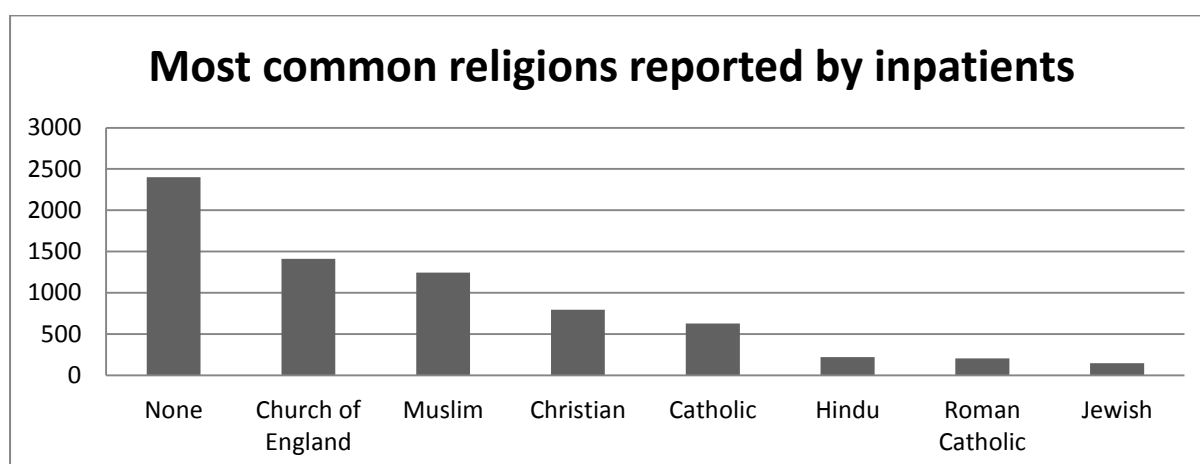


Language support, in the form of face to face interpreting, telephone interpreting and written translation is available in all languages seen at GOSH. A total of 8676 bookings were made for face to face interpreting during the past year – covering 64 languages from Albanian to Yoruba.



### ***Religion or belief***

GOSH treats children and young people from a wide variety of religious or faith backgrounds. The number of patients and families 'not asked' their religion or it is 'not specified' has increased from 53 per cent in 2013/14 to 58 per cent in 2014/15. Not knowing the religion or faith of over half our population has a great impact on the culturally competent services we can provide. Previously interventions to increase reporting have had little impact so we will continue to have this as one of our equality objectives.



Various faith festivals have been held throughout the year including Hannukah and Purim for our Jewish families and Ramadan and Eid for our Muslim families.

### **Sex**

The proportion of male to female patients remains broadly similar to previous years for inpatients, with 45 per cent females and 55 per cent males. In certain clinical divisions, there is a larger male patient population largely related to higher prevalence of many congenital disorders in males. Wherever possible, we offer our patients the choice of sharing a bay with other patients of their own sex, although this is not possible in intensive care units or high dependency areas for instance. More recently developed clinical buildings offer mainly single room accommodation for patients, although high dependency bays are mixed.

## Equality objectives

### *Selection of new objectives*

This year saw GOSH work towards developing new objectives for the next three-year period. FED undertook a number of initiatives, some of which were joint initiatives with the Staff Equality and Diversity Group. The Equality Delivery System 2 (EDS2) was mandatory this year and formed the basis of these initiatives – an electronic survey was developed and circulated to over 80,000 followers of the hospital on Twitter.



**GOSH** @GreatOrmondSt · 21h

Help us to define the hospital's equality objectives for the next three years: [surveymonkey.com/r/EqualityDive....](https://surveymonkey.com/r/EqualityDive) Survey closes 28 September.

A three-day event was also held in the Lagoon Restaurant on site – both to ask children, young people, families and staff to help grade us against the EDS2 objectives and also to ask for suggestions for the forthcoming equality objectives and vote on the most popular.



The suggestions and voting were then discussed at the November FED meeting, at which we arrived at our three objectives as described below. Progress against previous objectives as well as plans for meeting these was reported at the January Trust Board meeting.

### **Achieve Accessible Information Standard (2015-2018 objective)**

The Accessible Information Standard (SCCI1605) 'directs and defines a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents, where those needs relate to the disability, impairment or sensory loss'. By July 2016, the Trust will have 'core' information titles available in alternative formats suitable for people with visual and/or hearing impairment, such as British Sign Language (BSL). We will also have investigated methods for 'flagging' children, young people and families with visual and/or hearing impairment.

Measurement: Availability of information titles in alternative formats

Baseline measure: Currently, we have no BSL signed videos online. Children and young people with visual and/or hearing impairment can be tracked on PIMS but there is currently no facility to flag their parents' needs.

Target: Ten core information titles have been identified with help from the Patient and Family Engagement and Experience Committee. In addition, suitable video podcasts have been identified for production of BSL signed versions with video transcripts. By July 2016, these titles will be available in alternative formats.

Background: This objective is a requirement for all health and social care organisations. GOSH currently provides a wide range of information about medical conditions, procedures, treatments and medicines, but currently this is only translated into alternative formats on a basis of clinical demand and funded by individual departments. A bid to GOSH Children's Charity has been submitted to fund this work.

### **Improve publicity about support for children, young people and families (2015-2018 objective)**

This objective was identified as the most popular during our engagement with children, young people and families to identify key areas of equality and diversity work. There are a wide range of support mechanisms for families both within and outside GOSH but these are not always promoted as well as they could be.

Measurement: Number of hits for support services webpages at <http://www.gosh.nhs.uk/parents-and-visitors/clinical-support-services>

Baseline measure: 210 hits during December 2015

Target: To increase traffic to this set of pages

Background: Families of children and young people with rare medical conditions such as those seen at GOSH often have feelings of isolation, compounded by the lack of knowledge of the condition in the community. While many excellent support organisations exist, families may not always be aware of their existence so we should be promoting them in the course of our clinical contact.

### **Support on going work to improve transition to adult health services (2015-2018 objective)**

This objective was also popular during our engagement – transition to adult services has been a key priority for GOSH in the past, but now work needs to focus on the needs of children and young people with additional needs.

Measurement: Evidence of transition planning in medical notes

Baseline measure: In the most recent clinical audit of transition held in April 2015, 64 per cent of notes reviewed contained evidence of transition planning.

Target: Increase the proportion of young people having evidence of transition planning in their medical notes.

Background: Transition to adult services from GOSH can often be a complicated matter – children and young people may have been attending GOSH from early childhood so preparing to move on to an adult-focused service can be difficult. The Clinical Nurse Specialist for Adolescence has developed a transition pathway to enable all children and young people are prepared for transition but use of this needs to be promoted further so everyone can benefit. There are also plans to develop a ‘life skills’ training for all over 12 year olds, regardless of whether they will transition or be discharged from GOSH.

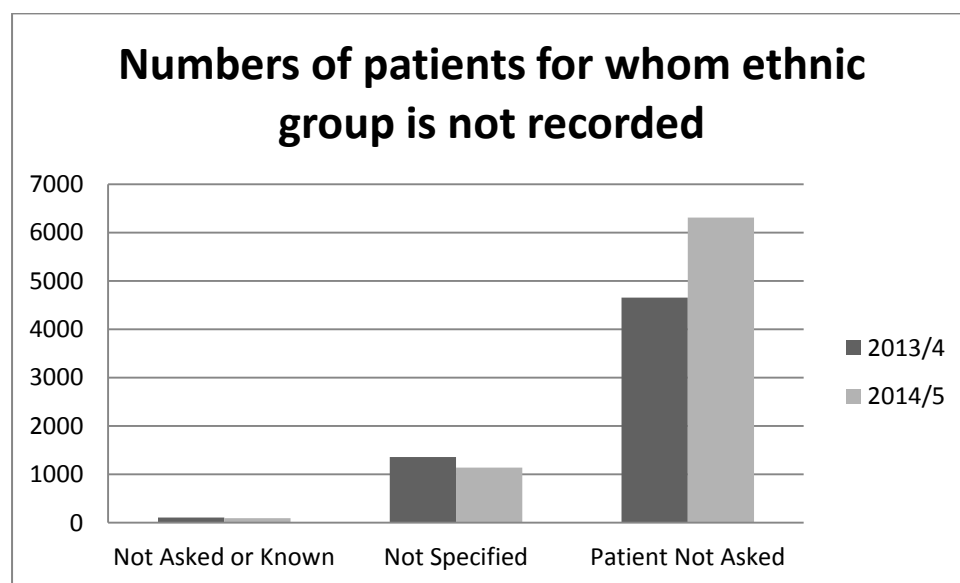
### ***Continuing progress against previous objectives***

#### **Reduce the number of patients for whom ethnic group and religion is not recorded (2012-2015 objective)**

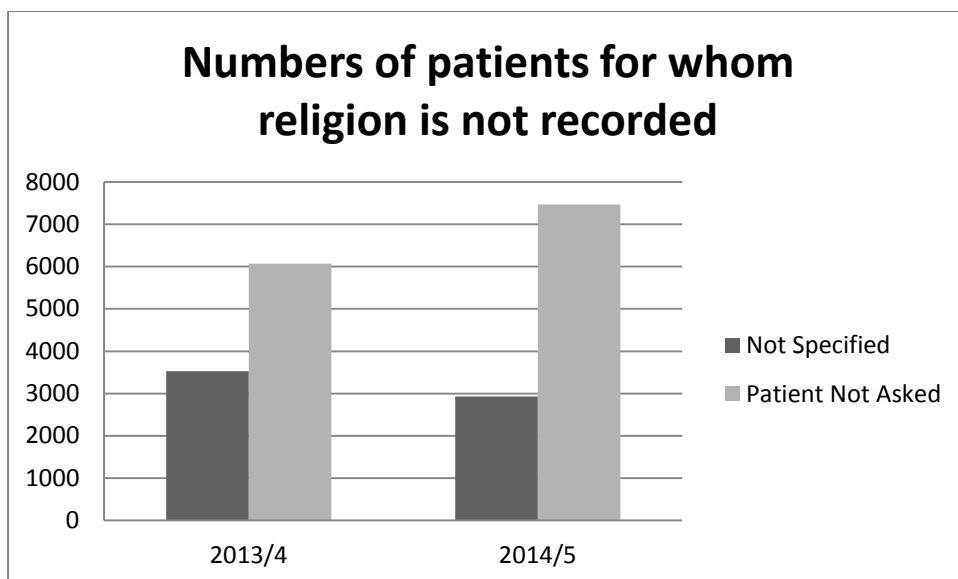
This objective forms part of a wider plan to revisit data collection and usage at GOSH, which will enable more meaningful analysis and action in future.

Measurement: Proportion of patients for whom ethnic group and religion is not recorded

Baseline measures: In the previous report, 31 per cent of patients were either ‘not asked’ their ethnic group or it was ‘not specified’ but this proportion has increased greatly to 42 per cent. The reason for this increase is not clear.



Similarly, the proportion of patients for whom their religion is not recorded has also increased, but to a lesser degree than ethnic group. In the previous report, 55 per cent of patients did not have their religion recorded, and this rose three per cent to 58 per cent for the current period. Again, the reasons for this are not known.



**Target:** Decrease the proportion of patients for whom ethnic group and religion is not recorded. Further explorations are planned to try to increase reporting, reviewing documentation used to collect these data and processes to ensure this information is added to the patient record.

**Background:** Having missing data for our patients clearly has a potential impact on the services we provide. For instance, not knowing a family's religious affiliation can lead to delays in providing spiritual care and support. Recording of ethnicity is a more complicated matter as, since these data no longer have to be reported to central NHS government, there is a perceived lack of need for them to be recorded.

**Increase the percentage of respondents stating that they agreed that the hospital understands their additional needs and put arrangements in place to meet them (2012-2015 objective)**

A high proportion of the children and young people seen at GOSH fall within the statutory definition of 'disabled'.

**Measurement:** Proportion of families who, when surveyed, feel that GOSH understands their child's additional needs and puts arrangements in place to meet them.

**Baseline measure:** In a previous inpatient survey, 42 per cent responded that their child has special needs or disabilities. This is a decrease of two per cent from previous surveys. Respondents were asked 'to what extent do you agree or disagree that the hospital understands these needs and puts arrangements in place to meet them?' Eighty per cent tended to agree or strongly agreed that the hospital did understand these needs and put arrangements in place to meet them. This proportion is one per cent lower than on the previous inpatient survey.

**Target:** Increase the proportion of families who feel that the hospital understands their child's additional needs and puts arrangements in place to meet them. Unfortunately, the latest inpatient survey (a UK-wide survey from a different supplier) did not include questions about additional needs and arrangements to meet them, so it is impossible to provide a comparison. It is also unclear whether future surveys will include these questions so



alternative methods of understanding the experience of families where a child has additional needs is required.

## **Family Equality and Diversity Group**

The Family Equality and Diversity Group has continued to meet during the year and has had input into a number of projects at GOSH including:

- Contributing to development of wayfinding kiosks to ensure that they are accessible to wheelchair users as well as those for whom English is not their first language.
- Promoting the use of an add-on to Microsoft Outlook so that staff are aware of the major faith festivals in the UK.
- Carrying out an audit of equality analyses completed for Trust-wide policies, following review and update of the policy itself.
- Supporting the Chaplaincy in the development of a new Muslim Prayer Room to replace to outdated and impractical current Multi-faith Room.
- Providing information to the Care Quality Commission on children and young people with visual and/or hearing impairment.
- Reviewing provision of BSL interpreters following a complaint raised – all BSL interpreters used at GOSH are now registered with their professional body.

## **Conclusions**

Progress in meeting the General Duty of the Equality Act 2010 will continue to be monitored by the Family Equality and Diversity Group, as will movement towards meeting our Equality Objectives above. Leadership of the Family Equality and Diversity group has changed during this period, moving from the responsibility of the Medical Director to that of the Chief Nurse. Changes in personnel in the latter role may lead to different directions of travel in future years. Two new staff members have been recruited to join FED but we are still advertising for parent/public members. Links with the London Equality and Diversity Leads group continues with several meetings attended and useful links made.