

# Meeting the duties of the Equality Act 2010

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January 2017

## Contents

|   |    |
|---|----|
| Background.....   | 2  |
| Understanding our patient and family experience .....   | 3  |
| Trust-wide surveys .....  | 4  |
| Friends and Family Test (FFT).....  | 4  |
| Listening event .....   | 5  |
| Members’ Council.....   | 5  |
| Young People’s Forum.....   | 6  |
| Our ‘always’ values.....  | 7  |
| Planning new services and buildings.....  | 7  |
| Diversity at GOSH .....   | 8  |
| Age.....  | 8  |
| Disability .....  | 8  |
| Race and ethnicity .....  | 10 |
| Religion or belief.....   | 11 |
| Sex .....   | 12 |
| Equality objectives.....  | 12 |
| Current objectives .....  | 12 |
| Achieve Accessible Information Standard.....  | 12 |
| Improve publicity about support for children, young people and families.....  | 13 |
| Support on going work to improve transition to adult health services .....  | 15 |
| Continuing progress against previous objectives.....  | 15 |
| Reduce the number of patients for whom ethnic group and religion is not recorded (2012-2015 objective).....   | 15 |
| 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) ..... | 17 |
| Family Equality and Diversity Group .....   | 17 |
| Conclusions.....  | 18 |

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. This data – and all figures included in this report – are taken from our Patient Information Management System (PiMS).

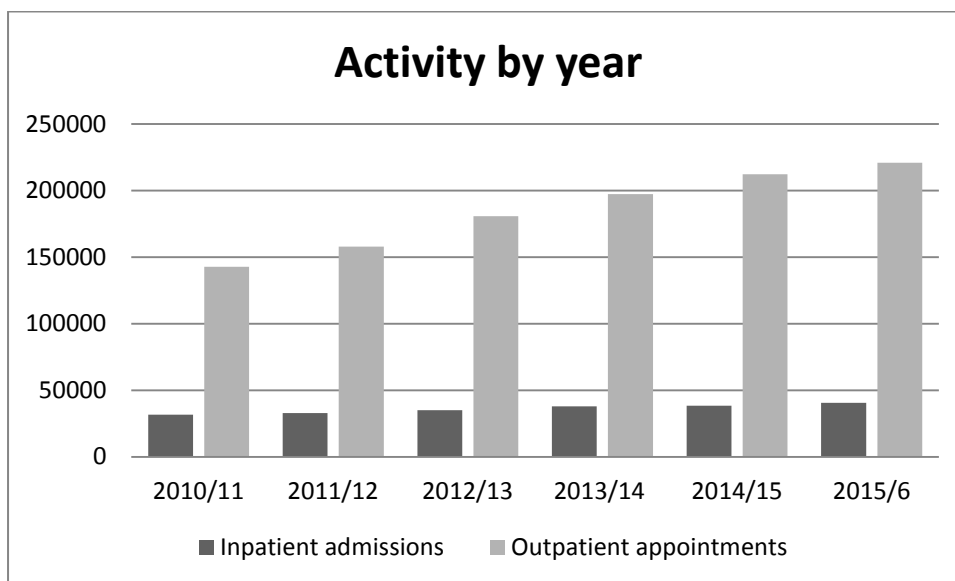


Figure 1 Data taken from PiMS

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, 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

GOSH took part in the 2016 national outpatient survey, administered by the Picker Institute. A total of 848 patients and their families were contacted with a printed survey instrument in May 2016 but only 82 patients and families returned their responses, giving a 9.7 per cent response rate, even lower than the average response rate for Trusts which was 16.4 per cent. Of those who responded, 72.8 per cent described their child's ethnic background as White, 9.9 per cent as Mixed, 9.9 per cent as Asian, 6.2 per cent as Black and 1.2 as any other ethnic background. A total of 82.5 per cent reported that the main language spoken at home was English.

The survey instrument asked about various aspects of the outpatient experience, such as booking of appointments, the facilities available, what happened during the appointment and awareness of next steps following the appointment. Overall, 82 per cent of child respondents felt they were looked after very well during their appointment and 16 per cent fairly well. This compares with the responses from parents of which 95 per cent rated their hospital experience as excellent, very good or good.

Various areas of the outpatient experience were rated better than in other Trusts including:

- Access to suitable food and drinks
- Health care professionals (other than doctors) giving clear answers to questions

Areas for improvement included:

- Waiting time to receive an appointment
- Booking in process
- Late start to appointments

However, due to the low number of respondents, the results may not be statistically significant.

## 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.

The National Target FFT response rate is 25 per cent for Inpatients; currently there is no set target for outpatients. The GOSH target response rate is 40 per cent. The Trust is currently achieving an average of 25 per cent (November 2016). The percentage to recommend score was 99 per cent (November 2016) which is above the GOSH target of 95 per cent.

The image shows a portion of a survey form with a light blue background. It contains three sections: 'Gender/Sex (please tick one)', 'Disability (please tick one)', and 'Ethnicity (please tick one)'. Each section has several radio button options and a text input field. The 'Gender/Sex' section includes 'Prefer not to say', 'Boy', 'Girl', and a text box for 'I think of myself as:'. The 'Disability' section includes 'Do you have a disability that affects your everyday life?', 'Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?', and 'Prefer not to say', 'Yes, it stops me doing a lot of things', 'Yes, it stops me doing a few things', and 'No'. The 'Ethnicity' section includes 'Prefer not to say', 'Asian or Asian British Bangladeshi', 'Asian or Asian British Indian', 'Asian or Asian British Pakistani', 'Any other Asian background', 'Mixed White and Asian', 'Black or Black British African', 'Black or Black British Caribbean', 'Any other Black background', 'Mixed White and Black African', 'Mixed White and Black Caribbean', 'Any other mixed background', 'Chinese or other Ethnic Group', 'White British', 'White Irish', 'Any other ethnic group', 'Any other White background', and 'Other, enter below' with a text box.

FFT responses are currently collected on paper and via the Patient Bedside Education and Entertainment System. The FFT database and feedback cards have recently been updated to include patient and parent demographic information which includes gender, age, disability and ethnicity. This will enable further analysis to identify any inequity in the services we provide.

## **Listening event**



On Saturday 19 November, the Trust held a space-themed Listening Event entitled *Let's make GOSH out of this world*. It offered patients, parents and carers the chance to meet staff and discuss the Trust's services and plans, and to hear their suggestions on what GOSH should focus on in the future. The day was centred on topics discussions which were chosen via social media campaign which asked patients and parents what they would like to focus on during the event by completing an online survey. The key areas chosen for discussion were: communication, food, transition, and outpatients.

Feedback and ideas collected at this event will help guide the Trust's priorities for 2016/17 to make meaningful changes. These will be shared in due course and formulated into an action plan for consideration at the Patient and Family Engagement and Experience Committee.

The Trust took the opportunity to show off new projects or updates on plans already underway, a market place was set up in Weston House and featured the following teams: GOSH Charity, Electronic Patient Records, Foundation Trust, GO! Create, Consultant Nurse Intellectual (Learning) Disabilities, Patient Advice and Liaison Service, Redevelopment, Research, Hospital School, Sustainability, Young People's Forum, Website Team and Volunteer Services. The event also enabled the Trust to raise awareness of other feedback mechanisms such as the Friends and Family Test.



## **Members' Council**

In March 2016, we celebrated our fourth year as a Foundation Trust. Our membership community has grown and developed and their views are reflected by their representatives on the Members' Council. The GOSH Members' Council is made up of 27 councillors. Of these, 22 are elected representatives for patients, parents, carers, staff and the public and five are representatives for appointed organisations. The duration of appointment for all elected and appointed councillors is three years.

Our Members' Council provide a steer on how the Trust will make a difference to the future health and wellbeing of its patients. Their active involvement ensures that the views of the wider hospital community are heard and reflected in the Trust's strategy.

Councillors attend five official Members' Council meetings a year, provide input on Trust work through various committees and working groups, and get involved in specific projects where their expertise or perspective is valuable. They are active in the hospital, and attend events in the community, key Trust and other engagement events. The Members' Council is a critical guardian of Our Always Values.

Councillors represented the interests of their members and the public by providing:

- input to the development of the Trust's new Electronic Patient Record Programme
- feedback on facilities and service provision to the Patient and Family Engagement and Experience Committee

- feedback and working collaboration with the Trust’s Redevelopment Team
- a perspective on the review of design brief structures for the Trust’s Redevelopment Programme committee
- initiating a process for representing members, by making presentations of individual case studies at the Patient and Family Engagement and Experience Committee and the Members’ Council
- feedback for consideration in the development of the Trust’s Annual Plan, from face-to-face and online Annual Plan consultation surveys

This year, councillors have continued to work with the Board and have an open invitation to attend and observe Trust Board meetings and Board Assurance Committee meetings. For more information on the Members’ Council visit [www.gosh.nhs.uk/about-us/foundation-trust/members-council](http://www.gosh.nhs.uk/about-us/foundation-trust/members-council)

## ***Young People’s Forum***

The Young People’s Forum (YPF) have had another active year, taking part in trust activity and advising on matters affecting young people within the Trust. The group have enjoyed an increase in membership by 60 per cent from January 2016 and now has 40 members, including a good representation of more current and recent patients. The diversity of the forum has also improved with representatives from non-White British backgrounds and those with long-term conditions.

They continue to work in collaboration with a variety of teams across the Trust and externally, including:

- Advising on the Patient Bedside Education and Entertainment system
- PLACE inspections
- Electronic Patient Records
- ORCHID research
- Redevelopment
- Catering
- Sustainability day
- Disney Garden consultation
- Student Nurses open day
- Recruitment and selection
- Play team – initial consultation
- Trust Listening Event

Key highlights of the year have been:

- Welcoming representatives from the London South Bank University to discuss and join in consultation regarding a new Curriculum for Children’s Nursing.
- Hosting a conference at GOSH on behalf of NHS England to share good practice on involving children and young people in healthcare. The conference, called ‘Cooking up a youth voice’ aimed to promote to NHS colleagues the benefits of patient engagement and the variety of ways to involve CYP. Four young people also received training from The Reporters Academy to plan, film and produce a film of the event.



**YPF members having a tour of our new clinical building**

- Children’s Commissioners Takeover Challenge – 30 young people took part in the Takeover Challenge, and took over a selection of teams, including Pharmacy, Quality Improvement, Chief Nurse Juliette Greenwood and Development and Property Services. The event gives young people the opportunity to go behind the scenes and learn about how and why decisions are made in the hospital.
- The YPF have been successful in ensuring that teenagers are catered for at Trust parties, planning teenage areas for the Queen’s Birthday Party and the Halloween Party.

The YPF have also had representatives attend several events, including the Commonwealth Service, RBC Race for the Kids and have also spoken at events such as the GOSH Foundation Trust Annual General Meeting.

### ***Our ‘always’ values***

Our Staff Friends and Family test results consistently show us that we have fantastic recognition by our staff of the four GOSH Always Values – Always Welcoming, Helpful, Expert and One Team. During 2016, we have been working with teams through facilitated sessions to encourage them to think about how they can make their service even more aligned to the values. This will continue across 2017, as we will be focussing on the One Team value. We also launched the SHOW (Smile, Hello my name is, Offer to help, What’s your name) campaign which supports the welcoming value and specifically incorporates the NHS campaign of #Hellomynameis.

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

GOSH is halfway through an ambitious programme to rebuild two thirds of the hospital site. The current phase involves constructing a new facility called the Premier Inn Clinical Building, which will be the second part of the Mittal Children’s Medical Centre. This new building will allow the hospital to provide state-of-the-art surgical and in-patient facilities. The Charity has also commenced building The Zayed Centre for Research into Rare Disease in Children, a brand new research and outpatient facility for childhood rare diseases.

The Redevelopment team want to make GOSH the best children’s hospital in the world so they invited input from our children, young people and families. The team held several events in 2015 including a workshop with the Young People’s Forum to develop design concepts for Phase 4 at GOSH based on visualisation of key themes the young people thought were important to children and families. Results from the event have been written up and published as the design brief for this exciting development on Great Ormond Street. Bidding design teams have been invited to respond and the outputs of their work will be on public display in March 2017. The YPF will also contribute to the selection of the successful design team.



## 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.

### 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.

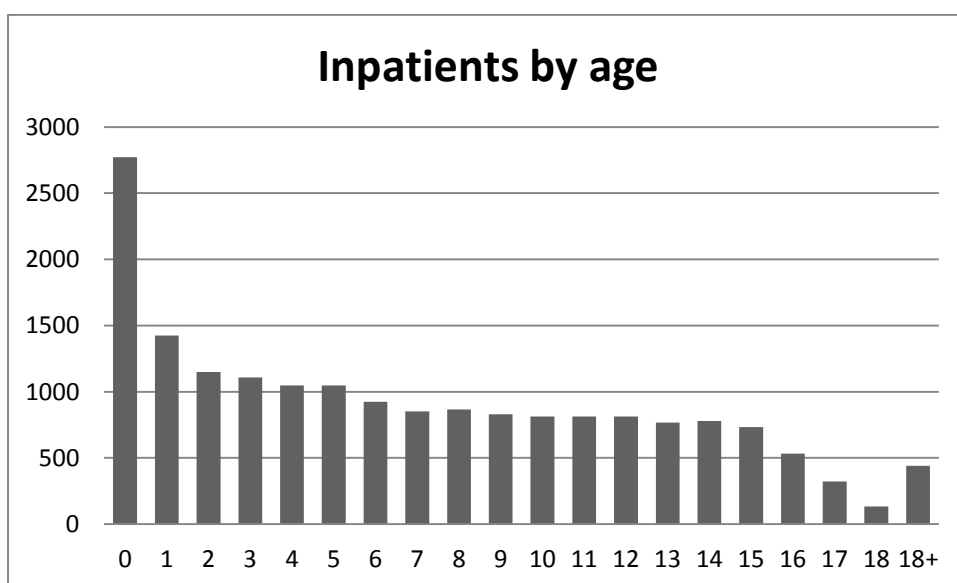


Figure 2 Data taken from PiMS

As with previous years, our biggest group by far is children aged less than a year – a quality improvement project to review care of this population has recently commenced, concentrating initially on improving clinical tasks, such as newborn blood spot screening, jaundice monitoring and ensuring sufficient hydration. These initial priorities are due to be delivered in Summer 2017.

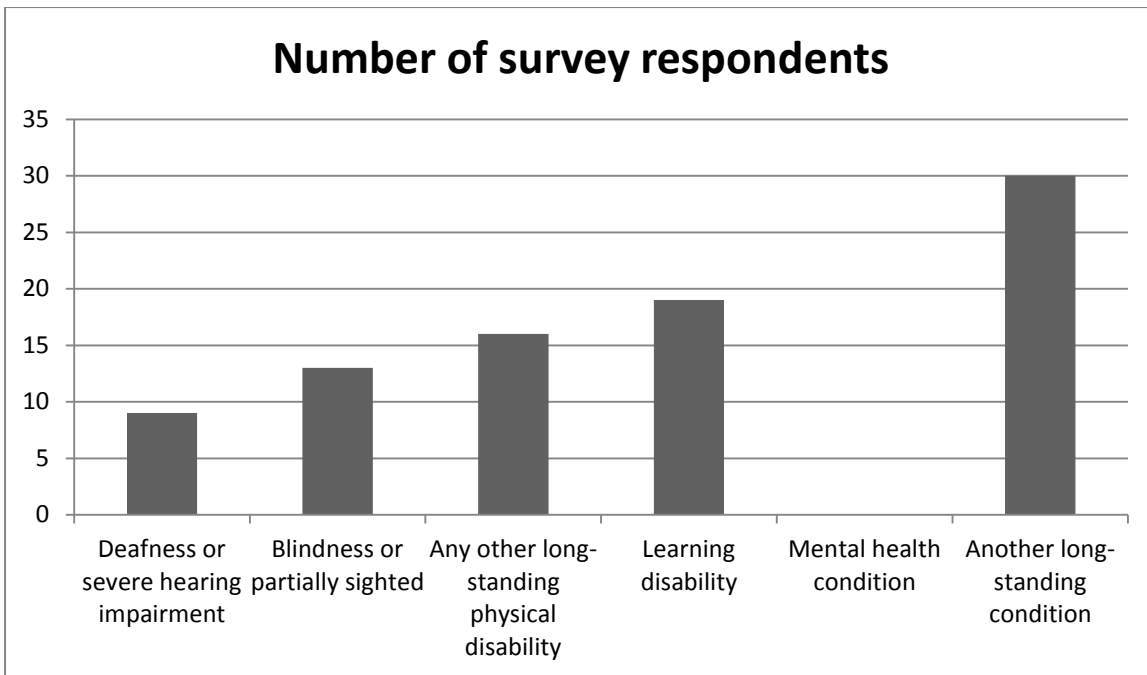
### Transition to adult health services

Transition for our young people has gained a higher priority this year for GOSH with the appointment of a Transition Improvement Manager to review the processes in place throughout the Trust and to share good practice. NICE Transition Guidelines were published in February 2016 and these are being used as the basis for the improvement work. Transition – particularly for those with additional needs – also forms one of our equality objectives (see later in this report for more detail).

### Disability

A high proportion of the children and young people seen at GOSH fall within the statutory definition of 'disabled'. Under the Equality Act 2010, this means that our children and young people have 'a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities'. In the most recent outpatient survey (carried out in 2016), for instance, 70 of the 82 respondents reported that their child had a long-term condition as shown below.





**Figure 3 Data taken from 2016 Outpatient Survey responses**

Unfortunately, the survey used this year did not include any specific questions relating to disability or long-term conditions and the reasonable adjustments required for a good experience.

A major hurdle to providing consistently good care with all reasonable adjustments made remains our lack of facility to record centrally any additional need experienced by our patients. This is being addressed as part of our work to meet the Accessible Information Standard – see later in this report for details.

One priority for the year has been the development of a simpler method of informing families about the support available for children and young people with additional needs. This formed one of our equality objectives so is reported in more detail later in this report.

We have also been working hard to develop an information sheet for families of young people with additional needs, explaining not only the process of transition but covering other aspects of growing older, such as financial and legal considerations. This has been widely reviewed with very positive feedback and should be ready for upload and circulation early in 2017 in alignment with the Transition Improvement work.

While developing this information sheet, it became clear that there may be a lack of knowledge around the legal aspects of growing older, such as consent. In conjunction with the Legal team, a number of posters are in development to highlight these changes to families.

In November, GOSH staff were honoured to receive a visit from Alex Brooker, host of The Last Leg television programme, who shared his experience of being a patient at GOSH throughout his childhood. He also described his career to date and the impact of disability both personally and societally. A write up of his interview with Peter Steer is available for staff on GOSWeb.



**Alex Brooker in conversation with CEO Peter Steer**

## Race and ethnicity

Twenty nine per cent of inpatients and 27 per cent of outpatients report that they are White British/UK, a drop from previous years. However, data collection around race and ethnicity continues to be a challenge with 47 per cent of inpatients and 49 per cent of outpatients ‘not asked’ or ‘not specified’ on our systems. This continues to concern the Family Equality and Diversity Group so the previous equality objective for 2012-5 has been extended for the next three years – details of action planned and progress later in this report.

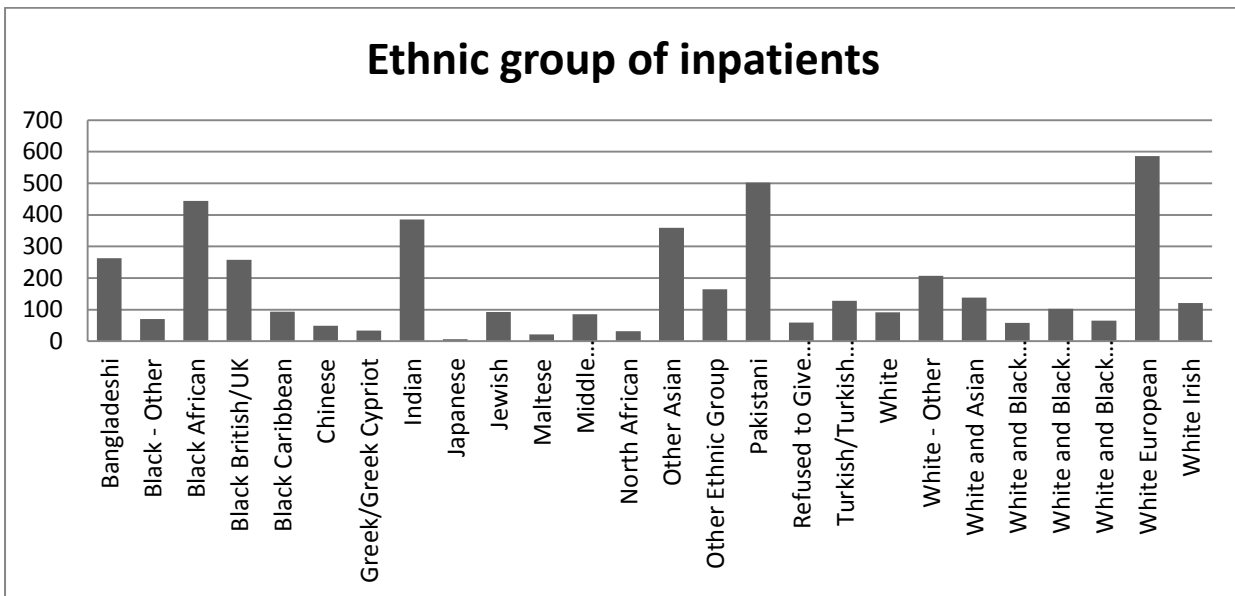


Figure 4 Data taken from PiMS

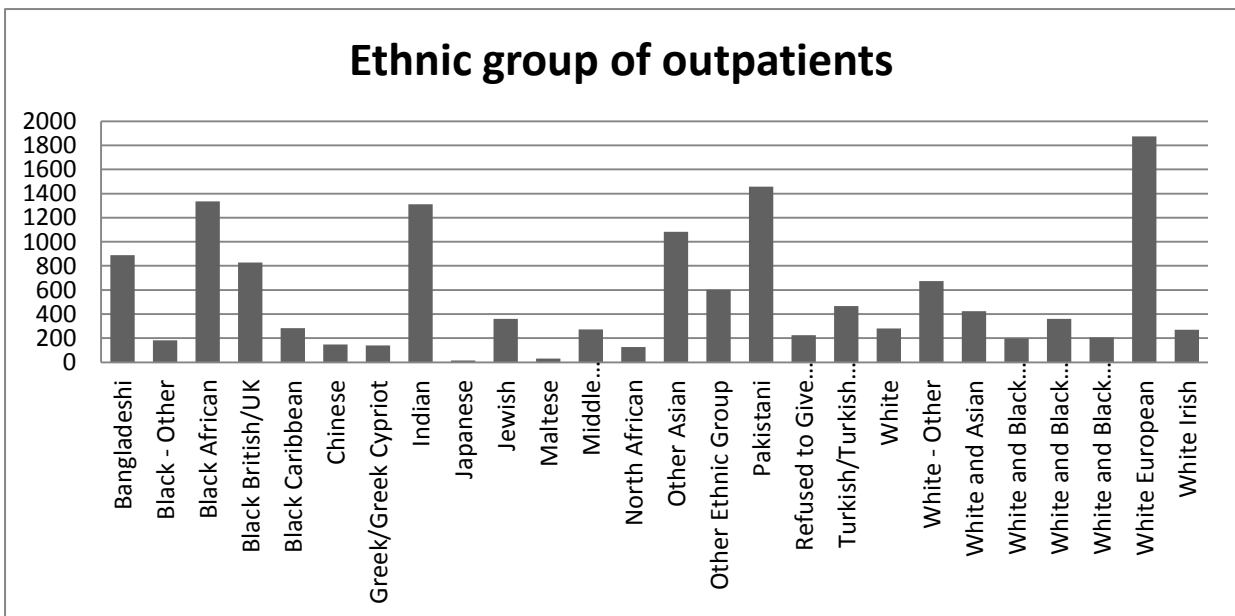


Figure 5 Data taken from PiMS

GOSH celebrated Black History Month with an event held in October 2016. Although primarily aimed at our staff, it attracted interest from many families too, with a sing-a-long session of African and Caribbean folk music followed by a short musical performance from one of our porters. The success of this event has

spurred on the organising team to aim higher next year, with a greater emphasis on including children, young people and families.

We are also aware 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.

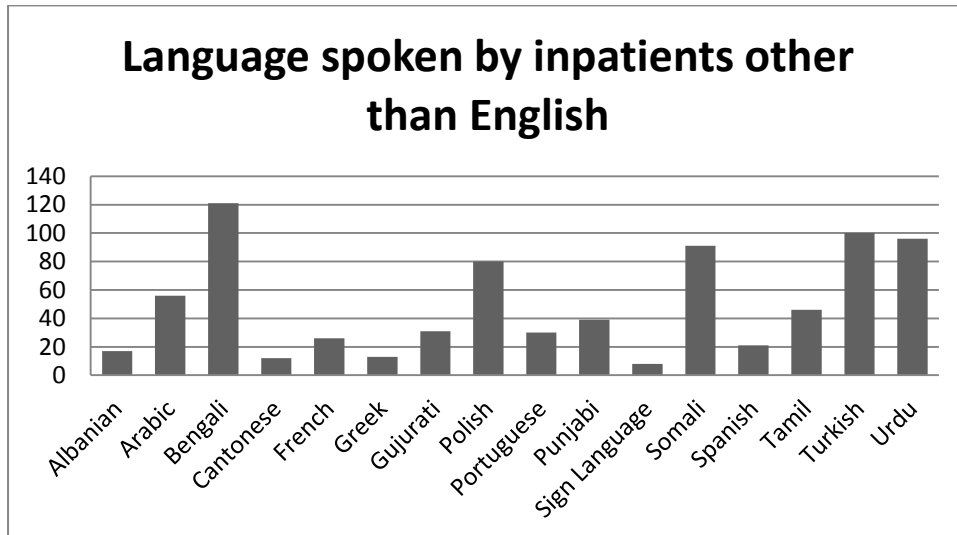


Figure 6 Data taken from PiMS

Language support, in the form of face to face interpreting, telephone interpreting and written translation is available in all languages seen at GOSH. Newer methods of communication, such as video-based British Sign Language interpreting, continue to be investigated for feasibility and value for money.

**Religion or belief**

GOSH treats children and young people from a wide variety of religious or faith backgrounds, the most common of which are illustrated below.

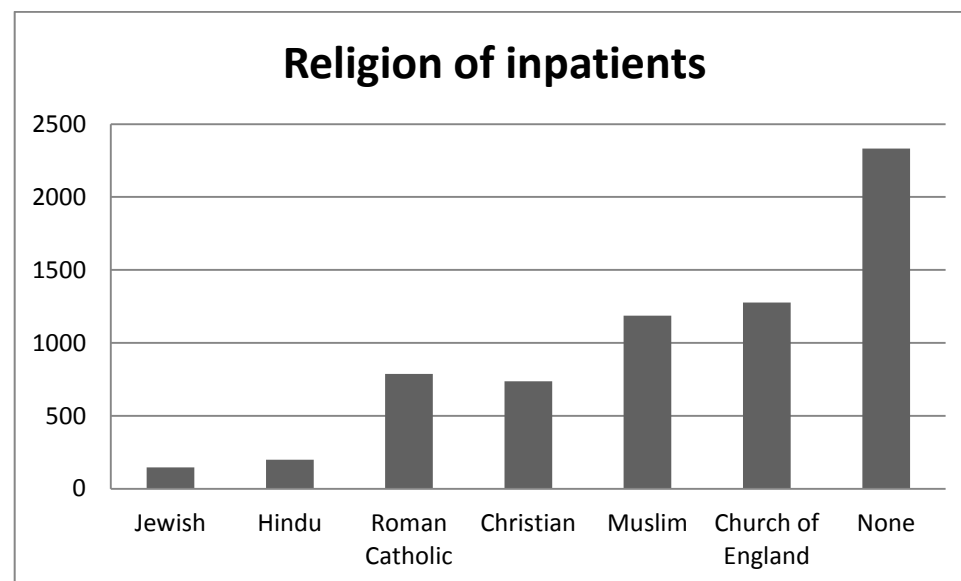


Figure 7 Data taken from PiMS

The quality of data recording about patient religion with regard to lack of data is decreasing. The number of patients and families not asked their religion has increased again to 61 per cent of inpatients and 65 per cent of outpatients. Not knowing the religion of three-fifths of our population has a great impact on the culturally competent services we can provide. As with ethnicity, this continues to concern the Family Equality and Diversity Group so the previous equality objective for 2012-5 has been extended for the next three years – details of action planned and progress later in this report.

Once more, we have celebrated major faith festivals throughout the year, including Hanukkah and Purim for our Jewish families, Ramadan and Eid for our Muslim families and, for the first time, Diwali for our Hindu families.



Henna tattoos to celebrate Diwali

## Sex

According to our PiMS data, the proportion of male to female patients remains broadly similar to previous years with 46 per cent females and 54 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

### **Current objectives**

#### **Achieve Accessible Information Standard**

This objective was time-limited as NHS England had required the Standard to be met by the end of July 2016. We can now supply information in alternative formats on request. Recording and flagging of communication and information need remains a challenge within the constraints of our current computer systems. 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'. Guidance from NHS England received in summer 2016 clarified that we were not required to produce every piece of information in every additional format; rather we should be responsive to the needs of our children, young people and families.

**Measurement:** As stated above, the measure identified in last year's report is no longer relevant to meeting the standard. We will instead record the number of requests received and the time taken to fulfil the request.

**Progress against objective:** A guidance sheet for staff has been developed and circulated widely – setting out the Hospital's responsibilities under the Standard and the method for ordering and obtaining alternative versions of information sheets. The *Producing information for children, young people and families* operational policy has also been updated to reflect the requirements of the standard.

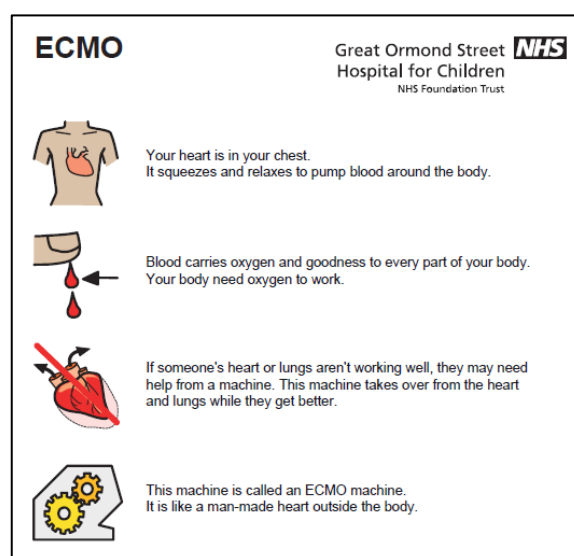
To support delivery of the Standard, and facilitate appropriate recording of any additional needs children and families may have, proposed changes to the Patient Information and Management System (PiMS) have been identified and a paper outlining these developed and consulted on widely. The paper is scheduled to be presented to the PiMS Improvement Group for consideration by April 2017. Until this facility is available, clinical teams remain responsible for recording additional needs locally. Compliance will be audited in the next two months to provide assurance until the changes to PiMS have been approved.

Since implementation, three requests for information in alternative formats have been received, all of which requested large print versions of our documents. These were supplied in hard copy within 24 hours. A 'large print' appointment letter template has also been designed and loaded to the hospital's Patient Information Management System (PiMS).

Although the hospital is not required to produce alternative formats of information 'just in case', we decided that it was important to have key videos, such as the Welcome to GOSH video, on our website subtitled and with sign language. These have been produced by the GOSH Charity web team in collaboration with ITV.com and will shortly be available on our website at [www.gosh.nhs.uk/parents-and-visitors](http://www.gosh.nhs.uk/parents-and-visitors)

**Next steps:** In addition to the proposed changes to the PiMS system, additional activities are planned, such as testing the responsiveness of selected teams using 'mystery shopping'. Compliance of local teams recording additional needs of children will also be audited by April 2017.

The range of Easy Read information is also being increased. For instance, Easy Read information sheets are available for all radiology procedures carried out at GOSH. A minimum of 10 extra information sheets in this format will be produced by the end of June 2017.



Example of recently produced Easy Read information sheet

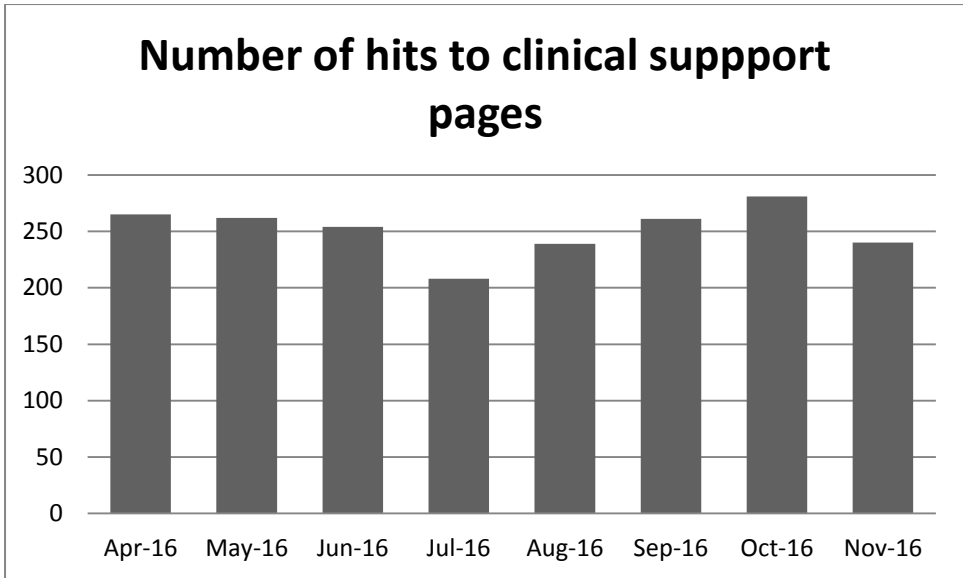
The hospital is now represented at a subgroup of the London Equality and Diversity Leads Network to share learning and experience of the Accessible Information Standard with other Trusts within London.

### Improve publicity about support for children, young people and families

There are a wide range of support mechanisms for families both within and outside GOSH but families tell us, 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 we should be promoting them in the course of our clinical contact.

**Measurement:** Number of hits for support services webpages at [www.gosh.nhs.uk/parents-and-visitors/clinical-support-services](http://www.gosh.nhs.uk/parents-and-visitors/clinical-support-services)

**Progress against objective:** As shown below, the average number of hits to the clinical support services pages has remained steady at average of 251 hits per month. This is an increase on the baseline measure from December 2015 which was 210 hits.



**Figure 8 Data from Google Analytics**

**Next steps:** In addition to increasing traffic to these pages through advertising, a number of other improvements have been carried out to increase the knowledge of support mechanisms for families.



**Information trolleys outside the Pals Office**

These include the provision of information trolleys outside the Pals Office, supplying information sheets about support, details of organisations that can help and benefits advice. In addition, the organisation Contact a Family – an umbrella organisation of support groups in the UK – now attends GOSH weekly with a stand in the Lagoon, again providing information for families on sources of support. Feedback on the use of this stand will be requested to evaluate how useful this is proving to our families.

A new set of web pages (see below) have been developed to highlight the reasonable adjustments that GOSH can make under the terms of the Equality Act 2010 as well as individual pages highlighting services that can help for particular additional needs, such as visual impairment or motor difficulties. With little specific advertising, these pages average around 100 hits per month.

Home > Parents and visitors > Coming to hospital > If your child has additional needs

|  |   |
|--|---|
| Travelling to GOSH   | <b>If your child has additional needs</b>   |
| Coming to hospital   | We want every child and young person to have the best experience possible when visiting or staying at Great Ormond Street Hospital (GOSH). We will always try to make 'reasonable adjustments' for children and young people with additional needs – for example, considering a child's needs when allocating single cubicles, finalising the theatre list order or planning outpatient appointments.   |
| <b>If your child has additional needs</b>                              | Following are just some of the reasonable adjustments we make for children and young people with additional needs:  |
| Children and young people with a hearing impairment                    | <b>Access</b> – All clinical areas at GOSH are accessible to people in wheelchairs, many of our reception desks have lowered sections and there are a number of accessible toilets throughout the hospital.   |
| Children and young people with a visual impairment                     | <b>Play</b> - The Play department provides everyday play and specialist play preparation for children and young people in outpatient clinics and on the wards. Some of our play specialists have developed expertise in play for children and young people with additional needs. For further information, please visit their <a href="#">website</a> or call them on 020 7829 8849.  |
| Children and young people with language and communication difficulties | <b>Information</b> – GOSH provides a wide range of information on <a href="#">medical conditions</a> , <a href="#">procedures</a> and <a href="#">treatments</a> and <a href="#">medicines</a> . All of these can be provided in alternative formats on request. For instance, our PDF information sheets can be converted to large print by enlarging and printing on A3 paper instead of A4 size. Please contact the <a href="#">Pals</a> team if you require alternative versions of information. Our website is fully enabled for text-to-speech synthesiser software. Easy Read information sheets for many procedures and treatments are also <a href="#">available</a> . |
| Children and young people with learning disabilities                   | <b>Hearing induction loops</b> – These are available at all reception desks, in our Pals Office and the majority of clinic rooms. In addition, we have a number of portable induction loops.  |
| Children and young people with motor difficulties                      |   |

**New web pages for families of children with additional needs**

## **Support on going work to improve transition to adult health services**

NICE guidelines on transition, published in February 2016, recommend that all applicable young people should have a Transition Plan in place to support their move from children's to adult services. Work has already commenced at GOSH but has been prioritised as a quality improvement work stream with the appointment of a Transition Improvement Manager.

**Measurement:** Documented evidence of transition planning. In addition, the release of NICE guidelines as above will enable us to measure GOSH against the associated standards and highlight areas for improvement in the future.

**Progress against objective:** A phased approach is being taken with this objective. Our initial focus has been on ensuring appropriate young people aged over 16 years have a Transition Plan in place. We are working towards identifying which young people still require a Transition Plan. We will have a clearer view by the end of March 2017.

Alongside this, we continue to work with clinical teams to develop and improve their transition planning capability and capacity. The Young People's Forum at GOSH have been consulted throughout this process and continue to be a vital partner.

We also regard it as important to understand the experience of our young people during and after transition so we are actively collecting patient stories to enable future comparison. These stories will also form a major part of the education package for clinicians being developed currently.

With assistance from the Family Equality and Diversity group, a separate information sheet for young people with additional needs is in development, which will sit alongside the service information pages described earlier.

**Next steps:** Once we have improved the transition process for young people aged over 16 years, our priority will shift to the preparation of younger patients and their families for their eventual move to adult services. Further engagement with young people and their families will be essential and this consultation with the Young People's Forum is in the planning stages.

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

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

As described earlier, the quality of data on the ethnicity and religion of our patients continues to be a challenge to the Family Equality and Diversity Group. While we continue to address known sources of inequality, it is frustrating to be unable to demonstrate clearly the benefits of what we are achieving. As we cannot use our data to any great degree due to its lack of completeness, we therefore cannot prove the usefulness of collecting it to our staff.

Not having complete data about our patients means that planning services effectively is a challenge, ensuring that there is equitable access for the children and young people who need our help – for instance, it is more difficult to plan Chaplaincy and Spiritual Care support if we do not know the religion of our inpatients.

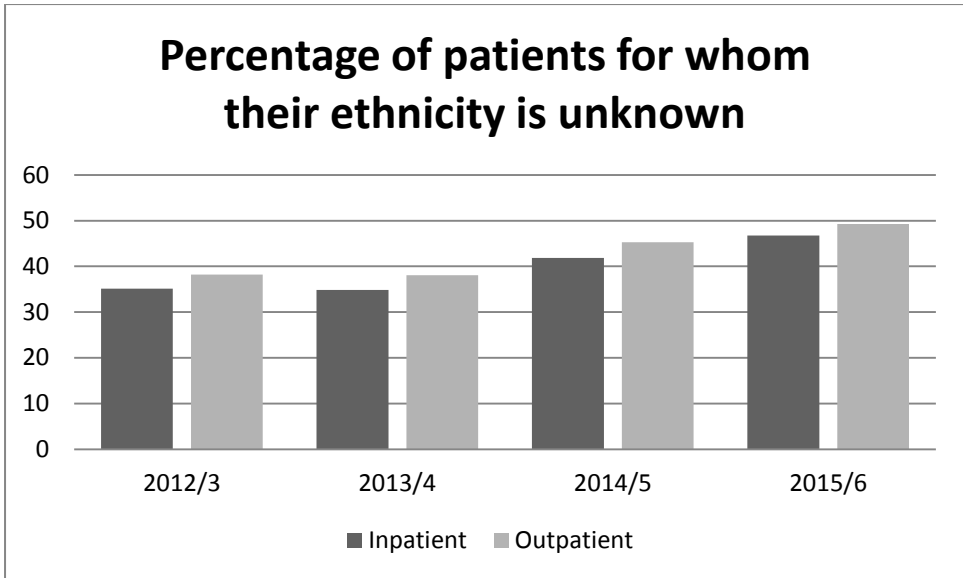


Figure 9 Data taken from PiMS

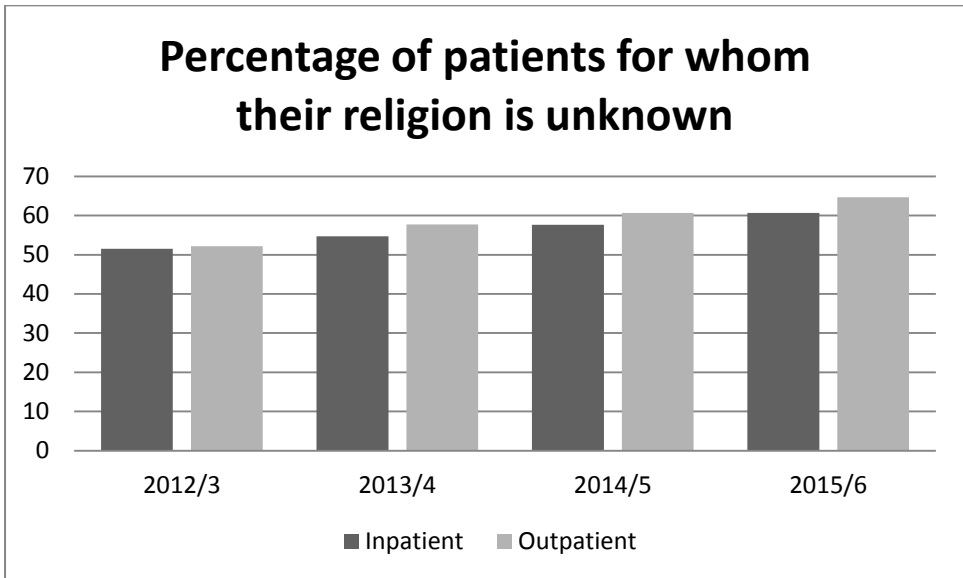


Figure 10 Data taken from PiMS

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

**Progress against objective:** As the figures above show, the percentage of patients for whom we are missing crucial data continues to increase year on year, despite efforts to improve this by a number of staff members.

**Next steps:** The Family Equality and Diversity Group has now decided to take multiple approaches during the same time period including holding a ‘census’ week where members of the group visit each clinical area to update or complete our records. This will tie in with publicity to our staff on the importance of collecting this data and potentially training to help ask questions that are perceived as ‘awkward’. A review of documentation used to collect and share this information is also planned.



## **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)**

We know that a great many of our patients have additional needs, but currently have no way to record these systematically, although a paper to propose a way of recording this is out to review. In previous years, our Trust-wide survey (developed with Ipsos MORI) contained specific questions to measure the experience of these families. Unfortunately, the national survey now used does not contain such questions so no direct comparison is possible. While we provide copies of our Hospital Passport to families of children with primarily learning disabilities, these are held by the family so we have little way of monitoring uptake and use.

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

**Progress against objective:** We know that 70 of the 82 respondents to this year's outpatient survey consider their child to have a disability or long-term condition. However, as the survey did not contain any specific questions for this subset, no comparison against previous years is possible.

**Next steps:** As so many of our children and young people have additional needs of various kinds; we need a way of collecting their experience. The revised Friends and Family Test contains basic demographic data, including disability status, so that we can track experience of those with a disability and compare it with those who do not. This will enable us to look at experience in specific wards and departments over time, which will enable the group to highlight areas for improvement and whether this method is sufficient for monitoring progress against this objective.

## **Family Equality and Diversity Group**

The Family Equality and Diversity Group has continued to meet during the year – on occasion the group has not been quorate according to the Terms of Reference, but on review, the group feel that they are still working effectively and delivering against objectives. We have also gained two new staff members with a strong interest in equality and diversity issues. Highlights of the previous year include:

- Support of cultural competency e-learning toolkit developed by Katie de Freitas (QI Lead)
- Development and use of a new equality analysis audit tool
- Consideration of how we can measure equity jointly with the QI analyst team
- Review of outpatient letters for clarity and succinctness
- Support of proposal for academic research into health equity at GOSH
- Contributed to development of Standard Operating Procedure for registering new patients
- Receiving updates on plans to improve Muslim Prayer Facilities

The group is looking forward to new initiatives at GOSH such as the Electronic Patient Record and the Real Time Feedback systems – both of which have received representation to include equality and diversity issues – so should enable greater analysis and improvement in future.

In addition, two members of the Family Equality and Diversity group now attend the Staff Equality and Diversity group regularly to ensure that there is cross-fertilisation of ideas and duplication of effort is

reduced. The two Operational Leads for Equality and Diversity also meet more regularly to plan joint working such as improvement of the annual equality analysis audit and coordination of reporting.

## **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. 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.