

Meeting the duties of the Equality Act 2010

January 2015

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Introduction

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

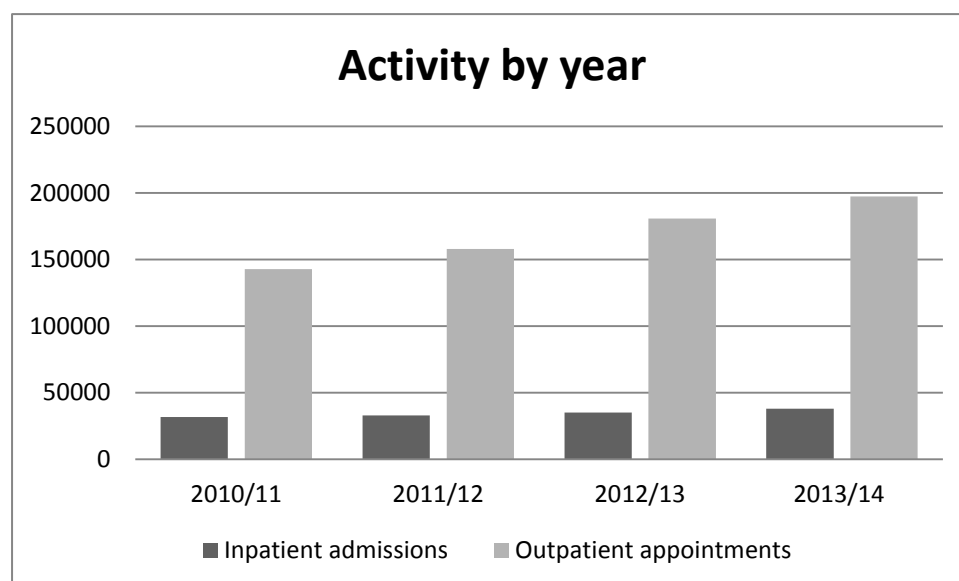
- Eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act
- Advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it
- Foster good relations between persons who share a relevant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

GOSH has 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 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 Public Involvement and Patient Experience Committee.

We commission external organisations to conduct regular surveys of GOSH patients and ensure the results represent the known demographic profile of GOSH patients at the time of admission or visit. This demographic profile includes the patient's age, gender and ethnicity but not the other protected characteristics covered by the Act. The staff who undertake the

survey are also specifically trained to interview non-English speaking patients and parents, as part of the survey. However, the sample is not weighted to include a specific proportion of non-English speakers.

The most recent telephone survey of outpatient experience, carried out by Ipsos MORI, found that overall satisfaction with last visit to GOSH remained steady at 95 per cent, with 97 per cent of children and young people surveyed expressing satisfaction. The most recent telephone survey of inpatients showed that 94 per cent of respondents (97 per cent children and 93 per cent of parents) were satisfied overall with their visit to GOSH. The proportion very likely or fairly likely to recommend GOSH for care and treatment remains steady at 97 per cent – a similar proportion to that elicited through the Friends and Family Test.

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 2000 responses and of these, 97 per cent of respondents said that they were extremely likely or likely to recommend GOSH as a place for care or treatment.

We want to include all areas of the Trust, so GOSH is currently expanding the FFT to include outpatients and day cases. To ensure that patients at GOSH are also offered the FFT, work has been undertaken to adapt an age appropriate feedback form specifically for inpatients and day cases. An adapted FFT question has been tested with approximately 70 current inpatient and day case patients ranging in age from six to 19 years. Development of an age appropriate FFT question for outpatient attendees is also currently being undertaken.

In the FFT guidance, which was released in July 2014, 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.

Members' Council

The Members' Council reflects the views of the Trust's members, promotes and supports the Trust's strategy and holds the Board's Non-Executive Directors to account. There are 27 councillors who make up our Members' Council. Seventeen are elected by our Foundation Trust's public, patient or carer members and five are elected by staff members. There are also five appointed councillors who are nominated by stakeholders such as the local authority, commissioning groups, or other organisations. Councillors have had a busy year contributing to a number of workstreams across the Trust.

Trust Annual Plan 2014/15

Members' Council received presentations and updates at official meetings. Results of a membership Annual Plan Survey were presented to the Council which then held an open feedback session in March 2014 to discuss the key priorities and give feedback.

New Centre for Research into Rare Disease in Children

The Council received a presentation on the development of the Centre. A representative from the Redevelopment team attended the Membership and Engagement Committee to give regular updates. It was agreed that the Council would delegate responsibility to the Membership and Engagement Committee to refine the consultation process. A working group of councillors from this committee gave further consultation providing advice as family-friendly advisors to the redevelopment team. The Members' Council also attended the exhibition for the new building which gave them the opportunity to be consulted further.

Trust Quality Report

Consultation was held with Members' Council in June/July and September to inform next year's report and quality priorities and the selection of indicators for auditing the report

Trust Always Values

Councillors were consulted on these and some councillors then joined a working committee to provide further feedback.

International Private Patient (IPP Strategy)

The Members' Council were provided with an update on the plan to review the strategy. It was agreed to develop a working group of Councillors to discuss the GOSH two year operational plan 2014-16.

Changes to staff membership constituency

Members' Council were consulted on changes to the staff constituency for election purposes.

Further information about Members' Council is available at www.gosh.nhs.uk/about-us/foundation-trust/membership/

Young People's Forum

In February 2013, the Government pledged that

Children, Young People and their Families would be at the heart of decision-making, with the health outcomes that matter most to them taking priority.

The NHS Outcomes Framework, NHS Mandate and Business plan commits to addressing this. The Regional Office North, Patient and Information Directorate in association with Changemakers / Foyer Foundation organised an event based on Children and Young People services in the North, in York. The purpose of the event was to bring together service users, service providers, and community and voluntary sectors who work with children and young people providing them services to improve their health and drive up standards of care.

This event was attended by members and coordinators from GOSH Young People's Forum (YPF), where members presented the achievements of the forum and met other young people involved in similar work. Delegates had the opportunity to listen to service providers where engagement has proved successful, how young people have had the opportunity to engage and to also listen to the young adults themselves on how they would like to help shape the services provided to them.

In January 2014, we asked members why they wanted to participate in the YPF:

“The ability to make a change, to be heard as a patient and a young person”

“That I get to use my own experience to help others in the hospital”

“Having a voice, an opportunity to make a difference”

“...teens want to be heard and noticed more....”

This year, we set ourselves the task of working more closely with our children and young people to help us improve their experience of being in hospital and accessing healthcare. This has been championed through a number of initiatives and the input of the members of the Young People’s Forum. They have focused on looking at the five priority areas, outlined below:

- transition to adult services
- the provision of age-appropriate information
- the provision of an age-appropriate environment
- ensuring staff receive training to communicate effectively with young people
- increased involvement of young people in service evaluation

Further information about the GOSH YPF is available at

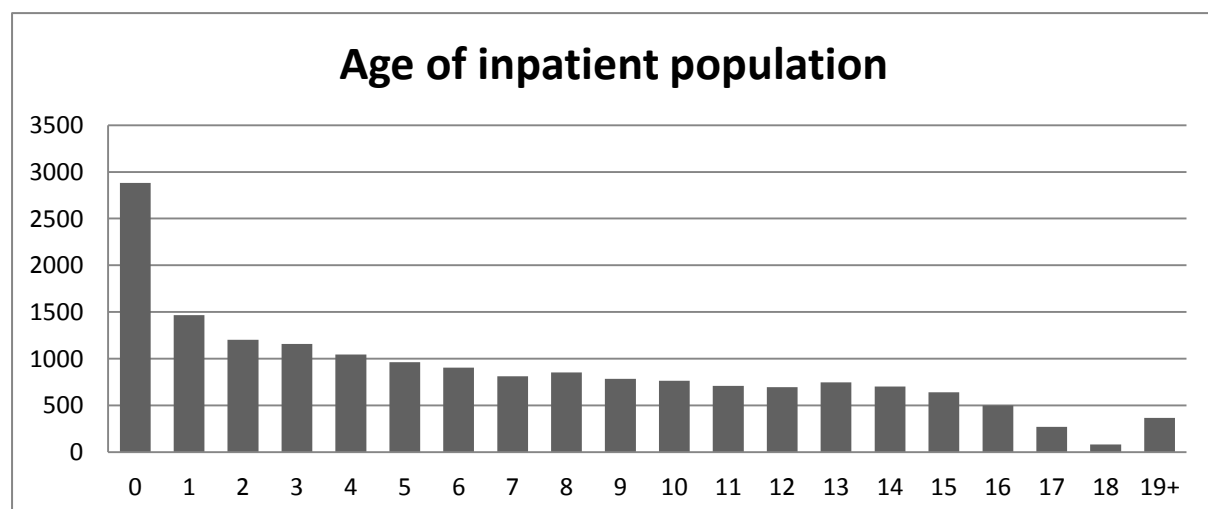
www.gosh.nhs.uk/teenagers/teengosh-community/young-peoples-forum/

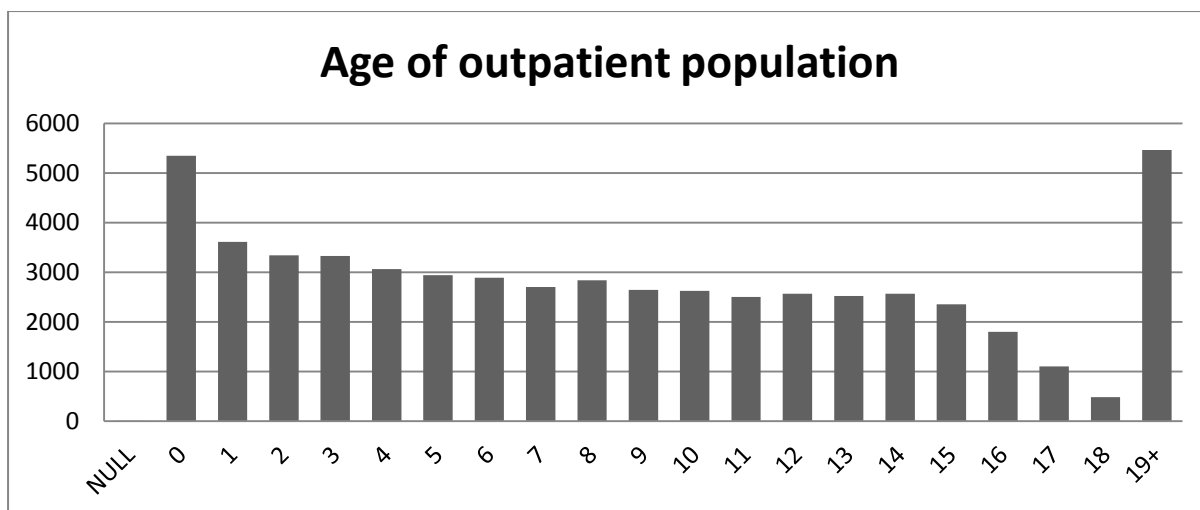
Diversity at GOSH

It could be argued that some of the protected groups (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.

Age

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





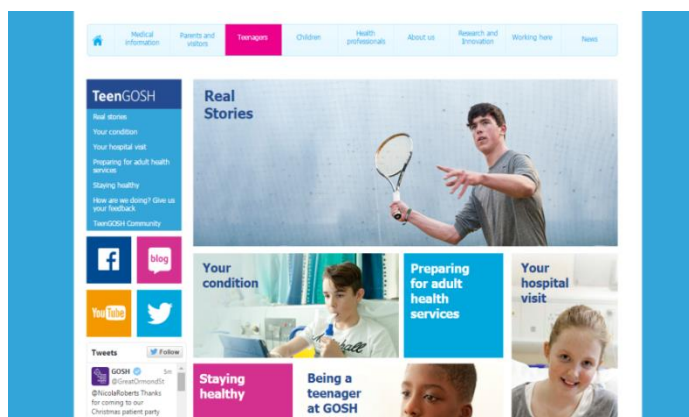
Transition to adult health services

Improving transition to adult health services continues to be a priority for the Trust. During 2014, the Adolescent Medicine team engaged with 15 clinical specialities to support them to ensure young people, where appropriate, are on a transition pathway. The team have previously developed an Integrated Care Pathway for clinicians to use to support a young person through the process of moving into adult services.

From our audit data we learnt that 36 per cent of patients in the 15 specialities engaged in the work had some evidence of transition planning. The Adolescent Medicine team are working to promote and further encourage teams to plan transition in 2015. We are also working with the Care Quality Commission to develop national standards for transition from child to adult services. Several specialties have very effective transition programmes and their good practice is being shared throughout the Trust. An important part of this work is both to learn from patients themselves and to provide effective information for young people about the process and what to expect – again, we are building on existing good practice to develop information for other specialties.

Improving the teens' section of our website

In September 2014, a redesigned section of the hospital website for teenagers was launched, in close consultation with current and former teenage GOSH patients. During initial audience research, patients highlighted the look and feel of the pages and the inclusion of more age-appropriate information as key areas to improve. They also wanted the pages to connect them to other young people at GOSH, so patients visiting the hospital for the first time would feel part of a wider 'TeenGOSH' community.



Members of the Young People's Forum fed back on draft designs for the new pages in workshops, along with teenagers on the Mildred Creak Unit and at the Hospital School.

Visit the new pages at www.gosh.nhs.uk/teenagers

Comments received about the original section included:

There's nothing that catches your eye. It looks too simple and too young. It needs to look more modern.

I want to find someone with the most similarity to me, I want to know how to deal with my condition and how to cope in the future.

Following the re-design and re-launch of the section, the Young Peoples' Forum said:

It is much easier to navigate and provides very clear information. I really like the ways to get involved section and the inclusion of social media

It's colourful and bright and accessible - everything we said we wanted!

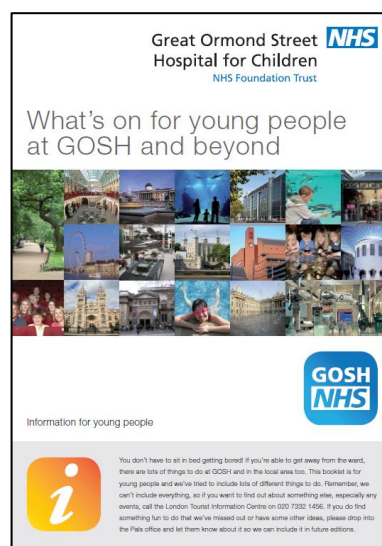
Publications for young people

The Child and Family Information Group have increased the number of publications for young people in the past year. A guide to activities within GOSH and further afield has been developed with input from the Young People's Forum.

I think the document is brilliant ... and will be extremely useful for children, young people and parents alike.

YPF member

Information packs for young people with chronic fatigue syndrome (CFS) and Tourette syndrome have also been revised and updated.

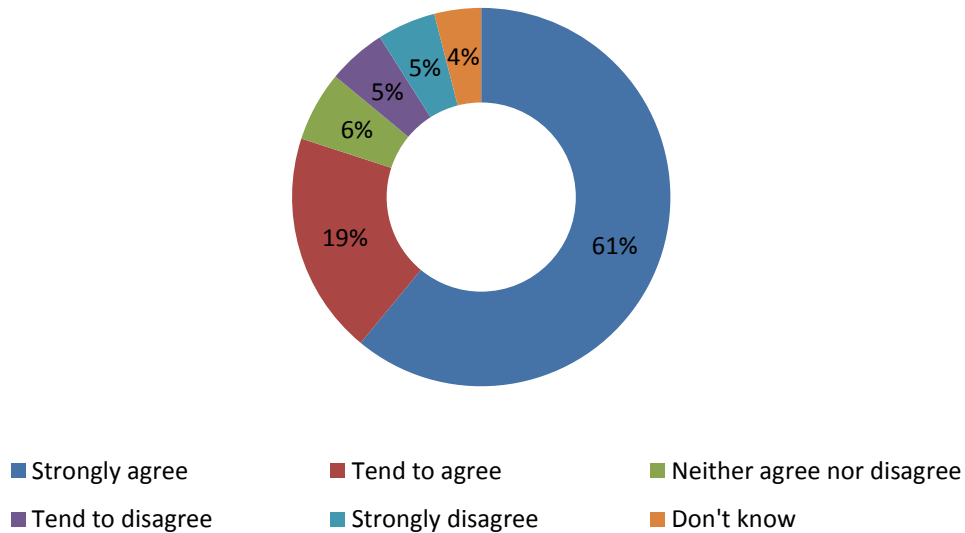


Disability

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.

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' with the following responses.

Arrangements put in place to meet special needs



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 is slightly down on the previous inpatient survey (81 per cent).

In addition, the survey showed that parents of children with special needs were less likely to be satisfied overall with their stay – 88 per cent of respondents with children with special needs were satisfied (65 per cent very satisfied and 23 per cent fairly satisfied) with their stay at GOSH compared with 97 per cent of other respondents (78 per cent very satisfied and 19 per cent fairly satisfied).

Planning new services/buildings

The Redevelopment team have held a workshop for children and young people to gain their views on GOSH 2030 as part of the Development Control Plan process and the public consultation for the Phase 3A Centre for Research into Rare Diseases in Children.

Wayfinding and signage at GOSH

The results from the wayfinding and signage survey conducted by the Redevelopment Team in 2013 highlighted the desire from patients, families, visitors and staff to “introduce interactive signage” that was “more engaging” and “visually exciting and interesting” to help people find their way across the hospital.

The Redevelopment Team are working with a software supplier to introduce a 3D interactive and patient wayfinding system. This is an electronic wayfinding system where users are shown a ‘photo-real’, 3D walkthrough of their chosen journey, from a first-person point of view through GOSH – as illustrated above. To use the system, the user chooses their destination and is shown their route, factoring in temporary or permanent route closures or requested stop-off along the way. During the journey, a character (Peter Pan) will appear pointing out artworks and at key junctions to help the user remember their way.

Due to the wide range of ethnicities and languages spoken by our patients, families and visitors to GOSH, the system is available in 10 other languages. These are Arabic, Bengali, Greek, Polish, Punjabi, Romanian, Somali, Tamil Turkish and Urdu – our most commonly spoken languages. The questions “where do you want to go” are shown in the chosen language but ward names and departments will remain in English, consistent with signage in the hospital and appointment letters.



The system will be accessible via kiosks located in key entrances in the hospital and also online to allow the user to preview their journey before coming into the hospital. The system is due to be implemented early in 2015.

Back care advice

We have long been concerned that our parents are putting themselves at risk of health problems through the day to day care they give to their children. The Back Care Advisor has worked with the Child and Family Information Group to develop a booklet showing how to safely manoeuvre their child in a variety of activities.



Improving services for children and young people with learning disabilities

Our Nurse Consultant in Learning Disabilities has been working to raise awareness of the particular needs of families with a member with learning disabilities. A Hospital Passport has been developed so that families can carry pertinent information about their child. This, along with a wealth of other information to support families is available on our website at www.gosh.nhs.uk/parents-and-visitors/clinical-support-services/intellectual-learning-disability/

A survey to measure staff awareness, originally carried out in 2013, has been repeated to assess the impact of introducing information and support to the wards. Understanding of the Mental Capacity Act – of vital importance to older children and young people with a learning disability has increased overall.

- 100 per cent felt that people with a learning disability can have capacity
- 98 per cent acknowledge that people can regain capacity
- 95 per cent understand that a best interest decision can be made for an individual assessed to lack capacity
- 97 per cent are aware that decisions are time, issue and situation specific
- 57 per cent realise that a parent or carer cannot consent on behalf of a person over 18 years old

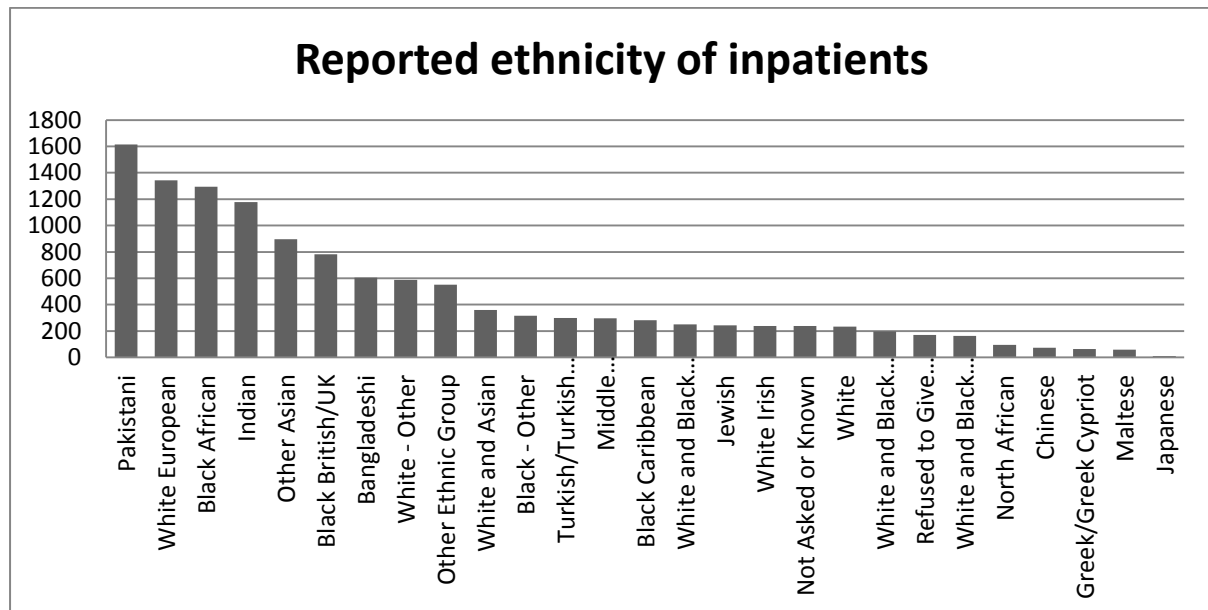
There is clearly a lack of understanding about consent for over 18 year olds but this is being addressed through a project to revise and improve consent forms Trust-wide.

In general, staff surveyed seem to have increased awareness of the interventions introduced to improve services for children and young people with learning disabilities. In particular, the following interventions had been noticed:

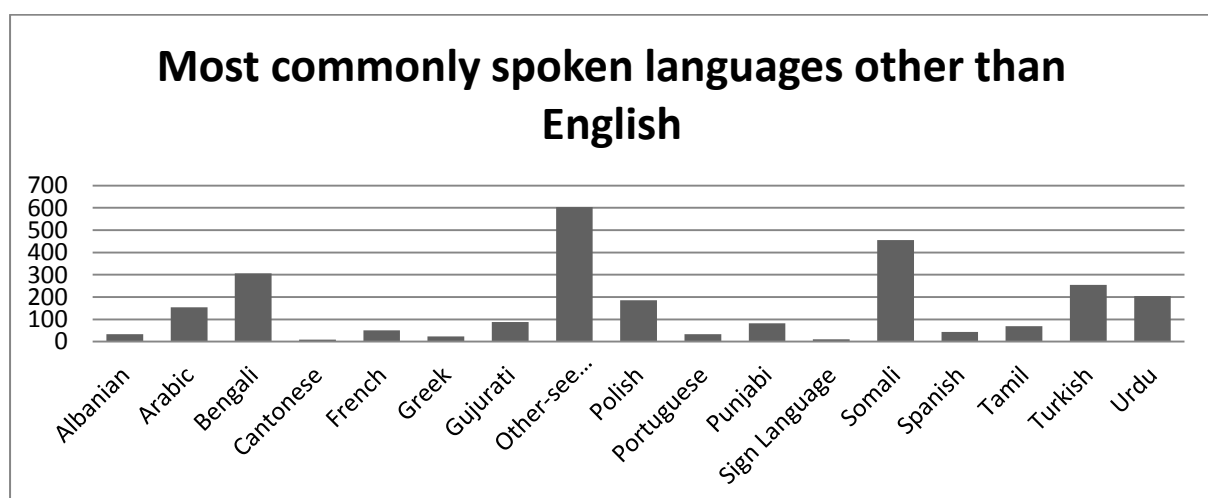
- Hospital passport
- Communication packs
- Flagging and alert system
- Trust Intranet and Internet pages

Race

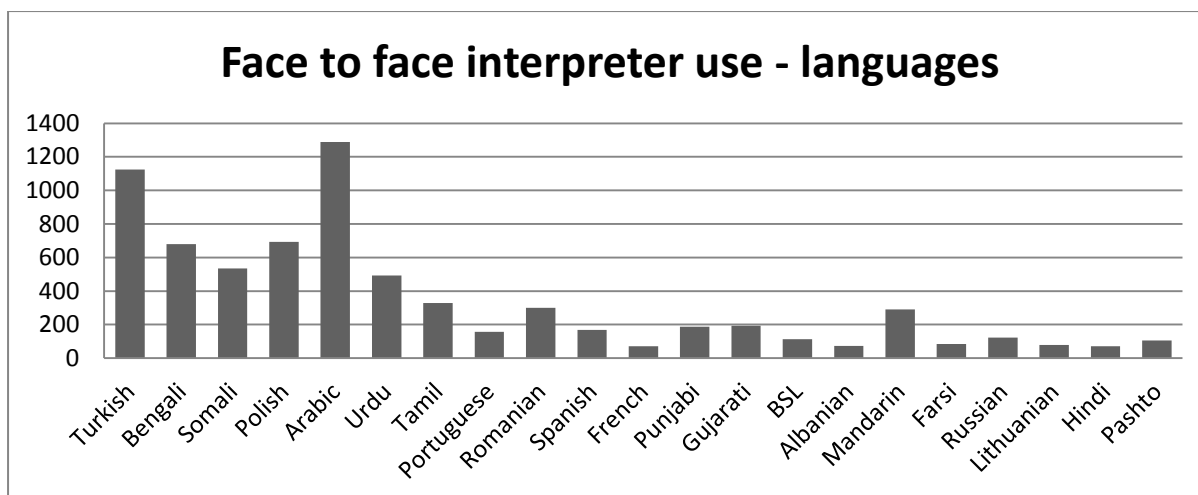
Thirty five per cent of inpatients report that they are White British a drop of 2 per cent on the previous year. A total of 31 per cent were either 'not asked' or 'not specified' – an improvement of 3 per cent on the previous year.



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 thereafter.



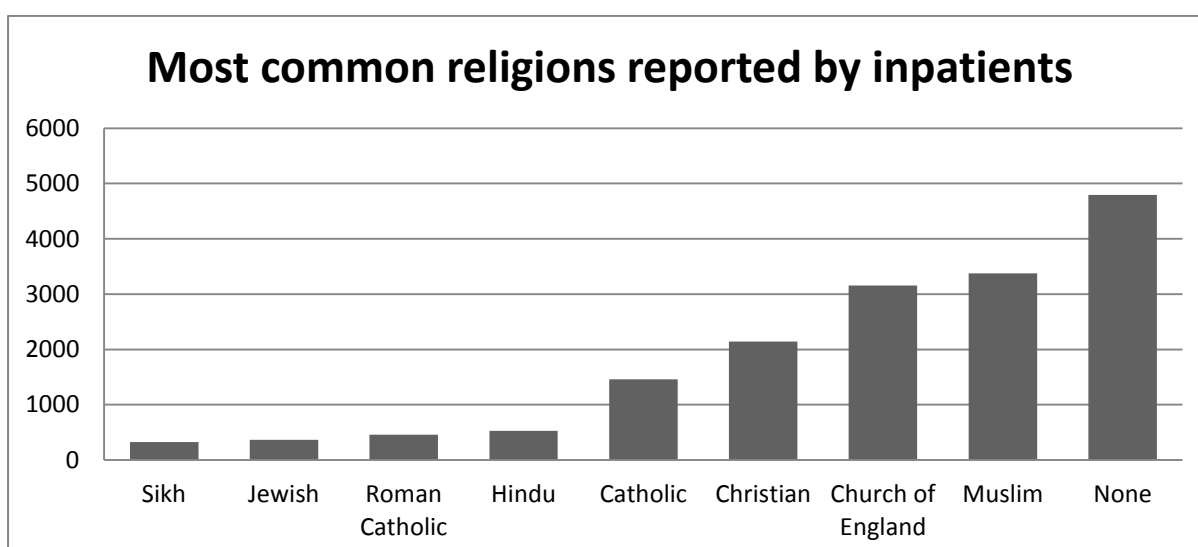
Language support, in the form of face to face interpreting, telephone interpreting and written translation is available in all languages seen at GOSH, the most common of which are illustrated below.



The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) is carrying out a research project looking at the experiences of non-English speaking patients and families. They acknowledge that people who do not speak English (NES) tend to be excluded from research projects so we need to gain a better understanding of their experiences. The initial plan was to look at the top five languages spoken at GOSH but this has now been reduced to one language (Turkish) for a pilot study to test the methodology and practicalities of bilingual focus groups. In addition, they have held a focus group and a number of interviews with staff who work with interpreters and also a focus group with interpreters working at GOSH. They have recruited a Turkish speaking community outreach worker to facilitate the families' focus group. Findings from this research will be shared with the FED group and published in the next year.

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 to 53 per cent, up one per cent from previous years. Not knowing the religion of over half of our patient population has a great impact on the culturally competent services we can provide, so improving recording of religion (and also race) is one of our two equality objectives leading up to 2015.



Jewish Families Working Group

The group, which was a mix of GOSH staff, external rabbinical and lay members and representatives from a number of Jewish charities, has successfully completed its tasks. Key topics addressed included:

- the provision of appropriate Kosher food for patients and families,
- Sabbath information, facilities and food – the new Shabbat room was opened in April 2014. Furnishings were provided by Ezra U'Marpeh charity.
- minimally invasive post mortems and suitable support for post death religious requirements
- Festival celebrations – events in the Lagoon for Purim and Chanukah in 2014
- Staff training – work in progress to increase awareness and understanding
- Support and internal accreditation of charitable groups volunteering their services – Camp Simcha, Shmeichel and Ezra U'Marpeh
- Recruitment of Jewish lay Chaplains to support families and the work of the Jewish Chaplain
- Provision of appropriate psychosocial and education/activity services
- Information for staff and families about the provision of suitable food, facilities and services.

The working group achieved its aims and plans to review provision six monthly to ensure progress is maintained.

This has been a wonderful forum for networking services, sharing ideas / information and promoting sensitivity and awareness of Orthodox Jewish culture and practices.

Member of Jewish Families Working Group

Ramadan support

Ramadan is the most important time of year for Muslims. This year the Lagoon did not feel it was sustainable to stay open beyond their normal hours to enable people to break the fast, as so few families had used this provision last year. Instead, Halal meals and snacks were available in the vending machine. This was not ideal and we would want to review this provision next year.

The Chaplaincy team feel that:

Over the last two years we have tried to find creative ways to cater for the needs of our Muslim community, but do not feel we have got it right yet.

Each ward and Muslim family was provided with an information booklet with prayer times and other appropriate information. All Muslim children in the hospital were given gifts donated by a Muslim charity at the end of Ramadan to celebrate Eid-ul-Fitr.

Sex

The proportion of male to female patients remains broadly similar to previous years for inpatients, with 47 per cent females and 53 per cent males. The sex split is similar for our outpatient population, with 48 per cent female and 52 per cent male. 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.

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, as follows:

Objective 1: We aim to reduce the number of patients for whom ethnic group and religion is 'not asked' by ten per cent year on year.

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. The latest report shows that 31 per cent of patients were either 'not asked' or 'not specified' – an improvement of 3 per cent of the previous year. While this improvement is gratifying, we have still fallen short on our aim. The proportion of patients whose religion was 'not asked' or 'not specified' has risen by one percentage point to 53 per cent.

Having inaccurate data about 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. A leadership project is being carried out by a member of the Chaplaincy team to investigate ways that religion can be better recorded in future. The recording of religion for our inpatient population is the initial priority as this is where the greatest impact could be demonstrated.

The admission processes – during which religion and other relevant data is collected – for several wards is being reviewed along with the documentation used to capture this data. This will enable identification of further interventions to increase reporting. Potential staff reticence about asking such 'sensitive' questions will be tackled by providing hypothetical scenarios of where knowing a patient's religion early in admission can save hurried arrangements being made at times of crisis.

Recording of ethnicity is a more complicated matter as, since this data no longer has to be reported to central NHS government, there is a perceived lack of need for it to be recorded. It could be argued that knowing other data, for instance, language spoken or socioeconomic need, could have a more practical use at GOSH. This having been said, further explorations are planned to try to increase reporting, reviewing documentation used to collect the data and processes to ensure this is added to the patient record.

Objective 2: We aim to increase the percentage of respondents stating that they agreed that the hospital understood these needs and put arrangements in place to meet them year on year.

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 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 put arrangements in place to meet them. This proportion is one per cent lower than on the previous inpatient survey. While members of the Family Equality and Diversity (FED) group felt that 80 to 85 per cent was a reasonable rate of agreement with the statement, further work is needed to understand why we are not meeting the needs of 15 to 20 per of respondents. Unfortunately, there is not the facility with the inpatient and outpatient surveys to gain more detailed insight, so other mechanisms, for instance, Pals enquiries and Friend and Family Test responses will be examined instead. Understanding the shortcomings perceived by those who do not agree that we understand these needs and put arrangements in place to meet them will enable us to introduce targeted interventions in the coming year.

Family Equality and Diversity (FED) Group

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

- Receiving progress reports on work to improve services for children and young people with learning disabilities.
- Receiving progress reports from the Jewish Families Working Group
- Advising on a research project with non-English speaking families and interpreters
- Increasing the range of information available for young people and contributing to the re-design of the teens section of the GOSH website
- Development of a back care advice booklet for families of children and young people with mobility problems
- Advising on future developments in real-time feedback to ensure that the system selected has the functionality to encourage feedback from all protected groups
- Advising on the functionality of wayfinding kiosks to ensure that they are accessible to wheelchair users and non-English speakers
- Contributing to a study day at GOSH on female genital mutilation
- Reviewing results of telephone surveys to ensure that no statistically significant differences in experience is found between different ethnic groups, age groups and non-English speakers