

Improving the experience of children, young people and families visiting Great Ormond Street Hospital during 2019

Meeting the duties of the Equality Act 2010
March 2020



Contents

Equality objectives relating to children, young people and families for period 2016 to 2020/21	2
GOSH in 2019 – an overview	5
Experience at GOSH.....	5
The patient population at GOSH	7
Other initiatives	13
Conclusions and next steps.....	14

This report details how Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) met the requirements of the Equality Act 2010 in terms of service delivery to children, young people and families during 2019. It complements the report detailing how our Human Resources and Organisational Development department is meeting staff requirements.

The Equality Act 2010 (the Act) states that a 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 Act are age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex, sexual orientation and marital status.

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

The following objectives were selected previously in conjunction with children, young people, families and staff members and continue to provide the main focus for the Family Equality and Diversity group at GOSH. Building on the achievements to date, new objectives will be identified and agreed in 2020.

Objective 1: Achieve Accessible Information Standard within timescale

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

Progress to date and future plans

We developed the facility to provide information and communication in alternative formats in 2016, but have found the consistent identification and recording of individual family's needs to be more of a challenge. Until April 2019, the Patient Information Management System (PiMS) administrative system was the main



location for recording this information but, despite a great deal of work with frontline and other staff, found that the 'additional needs' tab was not be used routinely.

In April 2019, GOSH went live with an entirely new electronic patient records system called EPIC. This too has the facility to record individual need but also includes a module – MyGOSH – allowing access to certain parts of the record to those with Parental Responsibility but also to young people over the age of 12 years themselves. This, plus another module called My Fingerprint, will enable capture of information regarding individual needs (and other vital data) more efficiently in future.

To date, alternative formats for information and communication have been made on a basis of clinical need – that is, in response to a patient or family's individual needs rather than in a more widespread 'just in case' way. Various requests have been fulfilled in 2019, including preference for telephone communication for families with literacy problems and large print information resources for those with a visual impairment.

However, we are concerned that families may be missing out on opportunities to communicate effectively and have information in a suitable format. It is our intention that a 'core' set of information will be made available by 2021, not only in alternative formats but translated into our most common community languages. This will then be made freely available online or to pick up in the hospital without the need for staff intervention.

GOSH has used the Widgeit™ system of symbols for producing resources for children, young people and families with learning disabilities for many years now, expanding each year the range of titles for which there is a separate 'Easy Read' version available. Currently, 54 separate Easy Read information sheets are available online at www.gosh.nhs.uk/parents-and-visitors/coming-hospital/if-your-child-has-additional-needs/easy-read-information-sheets. During 2019, we decided to routinely include an Easy Read version as an integral part of every procedure information sheet produced, with the aim of increasing access. Over 200 titles are in production currently, covering a wide range of clinical specialties. This continues to be developed and has proved popular for the titles produced to date.

The advent of MyGOSH will also offer us the facility to 'push' information to families as well as receive it from them. Already over 9000 people have signed up to have MyGOSH and this is expected to increase in line with increased functionality. Access to MyGOSH will enable us to tailor information and communication to meet the needs of patients and families and ensure it is made available (and recorded as such) to access from any mobile or home device.

Objective 2: Publicise support for families including support organisations

There are a wide range of support mechanisms for families both within and outside GOSH, including Social Work and a Citizen's Advice Bureau, Pals and Psychology. However, families tell GOSH, in surveys and other encounters, that these are not always promoted as well as they could be. While many excellent support organisations exist, families may not always be aware of their existence so work is ongoing to support staff in providing this information more systematically.

Progress to date and future plans

The five Pals Poppers – outreach volunteers who visit clinical areas – introduced in 2018 are going from strength to strength with a new volunteer recruited and trained to expand the service further into outpatient clinic areas at GOSH, Royal London Hospital for Integrated Medicine and the Zayed Clinical Research Centre, alongside an external organisation Contact (previously known as Contact a Family).



With assistance and guidance from the Poppers, the range of information available has been expanded and updated to give more practical support and advice to families visiting the hospital. Ten further information sheets giving advice on coping with a hospital stay are in production.

An accompanying initiative to increase access to non-clinical information about services available at GOSH and further afield through information trolleys outside the Pals Office in main reception also continues to be popular. The range of information has expanded to include suggestions for what to do in the local area, services at GOSH as well as other support information to help cope with a hospital visit.

We work with 42 external organisations to support and entertain children, young people and families at GOSH. This includes 'condition-specific' organisations, such as Young Epilepsy and the Migraine Trust, faith organisations such as Ezra U'marpeh and the Mothers' Union. All these representatives undergo initial training with Volunteer services followed by regular update training.

As part of the review of written information available for children, young people and families, it is now standard that each information sheet includes details of 'further information and support', which may be available within GOSH or via an external support organisation. Where no support organisation exists, families are directed to Contact (previously known as Contact a Family) who can often put individual families in touch with each other.

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

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

Progress to date

Transfer (or transition) to adolescent or adult services continues to be a priority for GOSH. The Transition Improvement project came to an end during 2019 but work continues with clinical services by the Adolescent Clinical Nurse Specialist. The end of project evaluation showed that the suite of information is highly valued by young people and their families, and clinical teams using it also liked how it gives them a 'programme' of topics to follow to ensure young people are ready for adolescent and adult health services. The GUGI folders are widely available in clinical areas throughout GOSH. In addition, a number of other organisations within the UK are in negotiation to adopt and adapt the resources for their own areas.

GOSH Arts and the Young People's Forum also carried out a joint project during 2019 to look at the emotional impact of transition – many young people have attended GOSH all their lives so moving on to another health organisation can be difficult. Families often struggle to 'let go' having had so much input in their child's health. Following a workshop, the team produced a 'Transition workbook' which passes on tips and tricks from young people who have already moved on, as well as exercises to promote mental well-being at what is already a period of change.

Future plans

Work to improve transition will continue into the future, with a greater emphasis on using MyGOSH to 'push' information and activities to young people facing transition to adolescent and adult services.



Clinical services will also continue to develop relationships with relevant services in the adult sector to ensure a smooth transition – this will be easier for some conditions than others so inevitably some specialties will need to develop more than others. The Young People's Forum will carry on advising as 'experts by lived experience' to ensure that future projects reflect what young people need and want.

Another area that will become increasingly important is the extension of work looking at the needs of older patients who lack capacity to manage their own health. We have already started to inform families of the legal and financial aspects of their child growing older and will expand this to cover other aspects. For instance, a range of posters have been developed to highlight the change in Parental Responsibility once a young person has their 18th birthday.

GOSH provides 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.

Note about data sources

The data quoted in this report is taken from the EPIC electronic patient record system which was introduced at GOSH in April 2019. Data reported is for the calendar year 2019 from April to December. Unfortunately, data from the first three months of 2019 – stored on the previous administration system – is no longer available for analysis.

GOSH in 2019 – an overview

During 2019, there have been 222,975 outpatient appointments, 30,318 day case admissions and 13,604 inpatient admissions. The number of day case and inpatient admissions remained steady, despite reducing planned admissions during the introduction and first few weeks of using the EPIC system. Outpatient clinics were also reduced during this period. A total of 63 specialties are based at GOSH – the widest range of services for children and young people in the UK. A number of these provide highly specialised services, commissioned on a national basis, for rare diseases and conditions. In many cases, GOSH is the only (or one of a few) paediatric centre in the UK offering the service.

Experience at GOSH

Seeing the world through the eyes of children, young people and families can help us to remember that they should be at the centre of everything we do. We use various methods to seek and hear experience of GOSH – highlights from 2019 follow.

Online and paper feedback

Early in 2019, an online feedback tool was introduced to complement our existing feedback cards. This enables all children, young people and families to feedback at a time convenient to them and also improves our responsiveness – the time taken to respond to individual comments has reduced to two days. The online tool can also be used by those with additional needs – the display size can be enlarged and text to speech has been enabled. As with the cards, some demographic data is collected along with comments and feedback – for instance, ethnicity and additional needs. Unfortunately, detailed analysis of this data has not been possible but individual comments with an equality, diversity and inclusion aspect continue to be monitored and reported to the Family Equality and Diversity (FED) group as well as in the Integrated Quality Report.



One of the key measures is how many people would recommend GOSH as a place for treatment – our results have consistently been high – around 96 per cent – and comparable to similar organisations elsewhere in the UK.

Feedback Friday has been introduced to share positive comments received both inside GOSH and also on Twitter – these have proved extremely welcome and demonstrate how much we value feedback from children, young people and families. Feedback is consistently positive with patients and families commenting effusively about the care offered by our nursing staff. Typical comments shared include:

“Our stay here has been a rollercoaster of emotions but the staff have been outstanding they have been a great source of comfort to us as a family and to our son who has been here with them. They have laughed and stayed strong and positive for our son and it’s made it more bearable to cope with the journey we are continuing on when we leave here. I can’t thank you all enough” – Chameleon Ward

“Always provided with a BSL interpreter during GOSH visits. This has proved very useful for two profoundly deaf parents who has a child with a heart condition. GOSH is a very welcoming place”.
Cheetah Ward

Work to develop a new system to encourage children and young people to give their own feedback continued during 2019 – this involved various workshops with the Young People’s Forum throughout the development process. Programming and integration of the system will continue during the coming year.

Planning for the future

In July 2019, the Patient Experience team held an open day to ask children, young people and families their views on GOSH in 15 to 20 years’ time. A total of 43 people took part in discussions about GOSH in the future. 20 of those were parents and other family members, 23 were children and young people. The average age of the children and young people were 10.8 years old and the youngest participant was 5 years old. The majority of participants were from the South of England, which is reflective of the patient population.

As well as talking to staff about future plans, attendees could meet with services offering support. Compared to previous Listening Events, attendees were from more diverse ethnic and socioeconomic backgrounds, therefore giving a more representative view of future developments. There was also a separate area for those with additional needs so that they felt welcomed and could give feedback and share experience in a way that was comfortable for them.



A separate event was held with the Young People’s Forum, attended by 35 young people. The average age of the YPF member at this meeting was 15.3 years old. Various methods were used to understand the views of young people attending, including setting up a model of a hospital to stimulate views about face to face visits compared with other ways of having consultants. Emoji stickers and sticky notes were given to attendees so they could show how they felt about each operational model proposed, plus explain why they felt that way.



The overwhelming response from attendees at both sessions was that 'GOSH should stay the way it is'. However, there was an appetite for increased use of technology in the future, particularly from younger attendees. There was little appetite for GOSH developing an Emergency Department and opinion was split as to whether GOSH should expand service provision outside the UK. The use of technology at home to enable access to GOSH is a key part of future plans so will be developed further in the coming years. This will inevitably impact on families with additional needs of all kinds as technology can reduce disruption and increase access to the services in which GOSH specialises.

Patient stories

These are identified and collected by the Patient Experience team and then shared widely through a variety of mechanisms include presentation at meetings and used in training.

Patient stories presented during 2019 included:

- Josephine about her experience of the epilepsy service at GOSH
- Alfie about his experience with cleft lip and palate
- Sophie about her experience at GOSH with her young baby
- Kai about his experience of cardiac services at GOSH
- Families' experience of introduction of new Electronic Patient Record
- Hannah about her experience as the sister of a GOSH patient

Issues highlighted are then addressed through action planning, coordinated by the Patient Experience team. One patient story involved a mother from the Traveller community. A number of issues were highlighted – as a result, the mother is now telephoned about appointments and admissions rather than sending a letter that she cannot read, and a visual cribsheet of her child's medicines was developed to increase compliance and clarify the complex treatment regime needed.

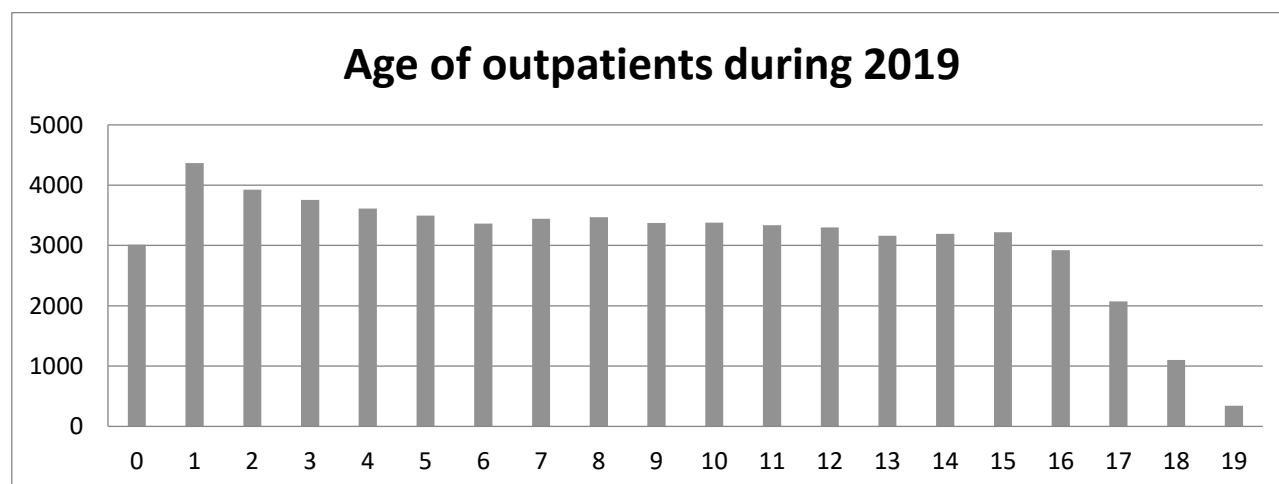
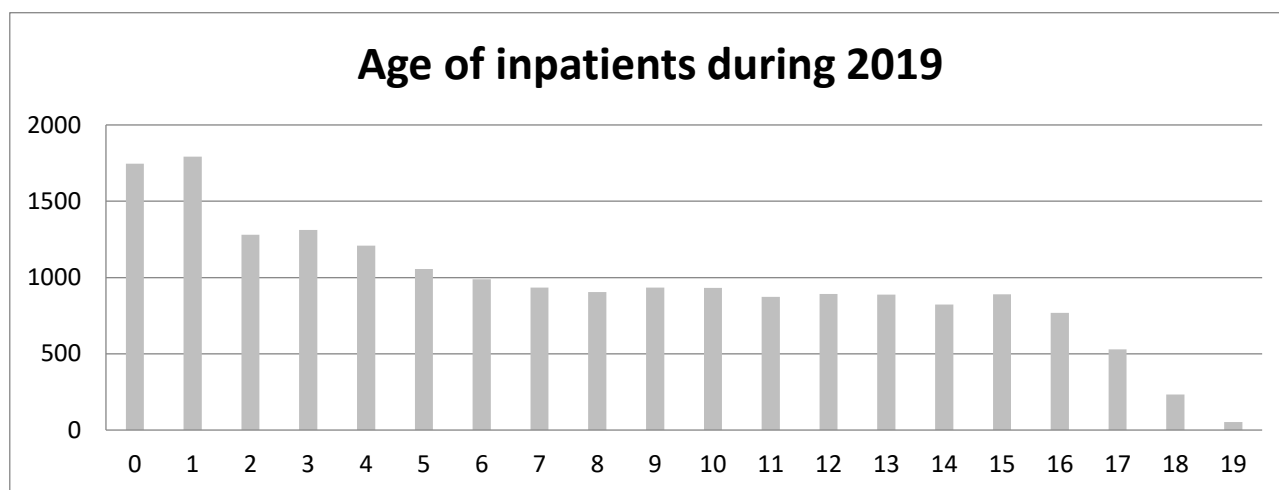
The patient population at GOSH

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. However, our aim is to review the experience and outcomes for more of the protected characteristics, so that we can 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, while others offer a lifetime diagnostic scanning service for children, young people and adults. This is why over 5000 patients aged 20 years or more were registered as having an outpatient appointment during 2019, as well as 270 inpatients or day case patients aged 20 years or more. The breakdown of our core groups of patients is as follows:





As in previous years, our biggest age group is toddlers aged one year, with a smaller proportion being older teenagers as many have moved on to adolescent and adult health services.

Transfer (or transition) to adolescent or adult services continues to be a priority for GOSH and is also one of our Equality Objectives (see Summary Report for Trust Board section). The Transition Improvement project came to an end during 2019 but work continues with clinical services by the Adolescent Clinical Nurse Specialist. This is a core component of all clinical services at GOSH.

Disability

Unfortunately, with the introduction of the electronic patient record system EPIC, access to data around disability has been more challenging than previously. Regaining access to this data is a priority for the coming year as it is vital to monitor access to and experience of services at GOSH.

The Play team now includes a member of staff who is qualified in Makaton™, the sign language used widely by children and young people with additional needs. As well as face to face teaching, a series of videos have been produced showing commonly used signs.

We realise that being in hospital and/or living with ill health can impact on a person's emotional and mental health. An initial research study involved the setting up of a Mental Health and Psychological Wellbeing



Drop-In Centre, known as the ‘Lucy booth’, in the main reception area of the hospital. This proved to be successful so it has continued to offer support to families by trained support volunteers.

In 2019 GOSH was officially recognised as a Centre of Clinical Excellence by Muscular Dystrophy UK. This means that the hospital provides comprehensive services for people with muscle wasting conditions and the high number of dedicated neuromuscular clinics the hospital provides.

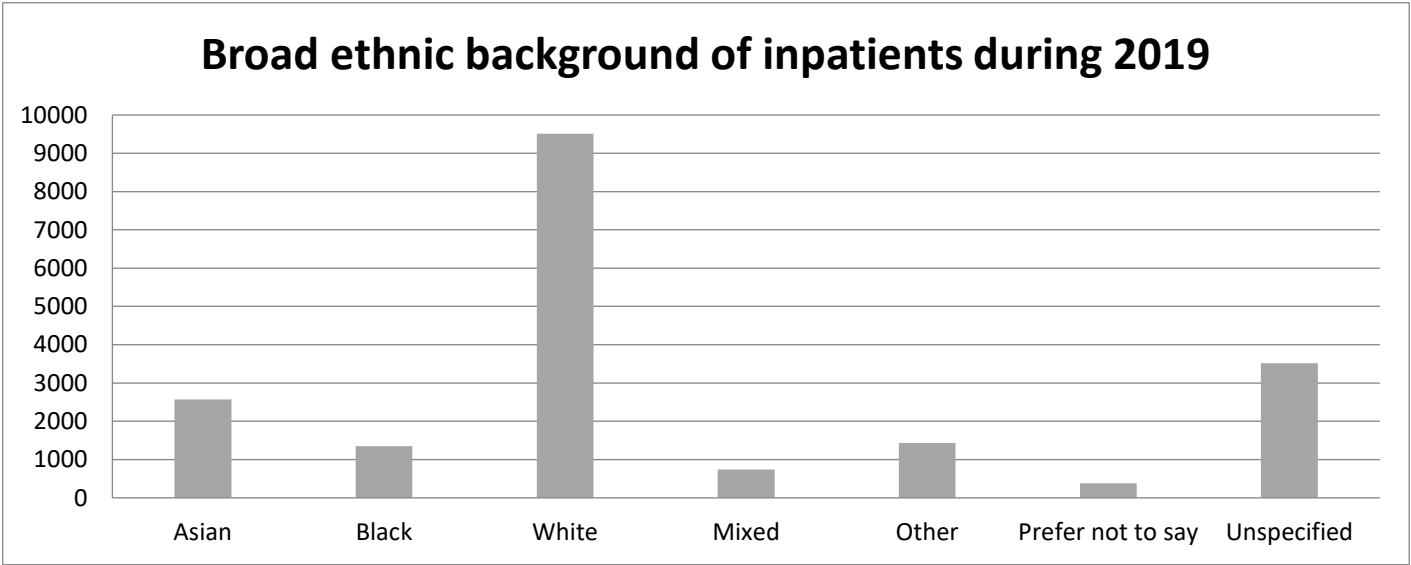
Learning disabilities

The Learning Disability team at GOSH now comprises a Nurse Consultant supported by a Clinical Nurse Specialist. There are 12 LD-qualified nurses in inpatient areas and one in outpatients. In addition, a Practice Educator for LD has recently been appointed. Simulation training continues to be delivered with input from people with learning disabilities and is highly valued by staff in increasing their confidence in nursing children and young people with a variety of additional needs.

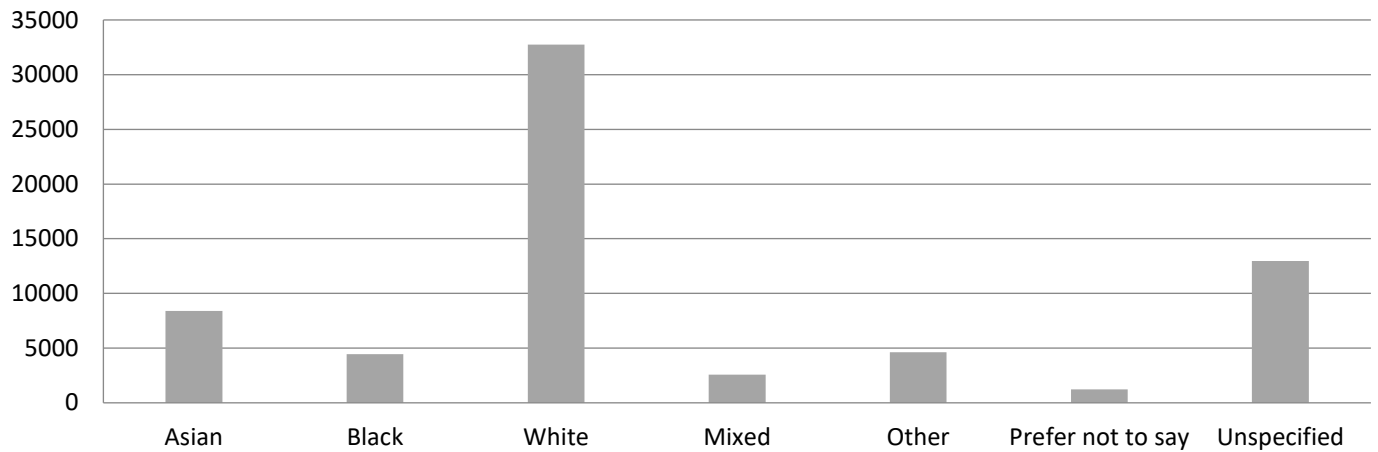
Race and ethnicity

Children and young people from a white background continue to be the largest group (49 per cent) both in inpatients and outpatients. After those for whom we do not know their ethnicity, children and young people from an Asian background are the next largest group. Only 2 per cent of patients would ‘prefer not to say’ when asked their ethnic background.

We do not know the ethnicity of 18 per cent of our inpatients and 21 per cent of our outpatients. This is an improvement of previous figures captured in our previous patient administration system and may be due to easier recording within EPIC.



Broad ethnic group of outpatients during 2019



A major barrier to equality of opportunity is the inability to speak English. The Trust routinely records the patient's and family's mother tongue on registration and endeavours to provide appropriate language support whenever the patient is admitted or attends an outpatient appointment. On average, we provide face to face interpreters on around 700 occasions each month. Telephone interpreting is still used in an emergency but usage has reduced year on year.

The most common languages for which interpreting is used are:

- Turkish
- Romanian
- Bengali / Bangla
- Arabic (Modern Standard) Middle Eastern
- Polish
- Urdu
- Somali
- Albanian
- Bengali / Bangla (Sylheti)
- Spanish
- Gujarati
- Arabic (Modern Standard) North African
- Tamil
- Bulgarian
- Punjabi

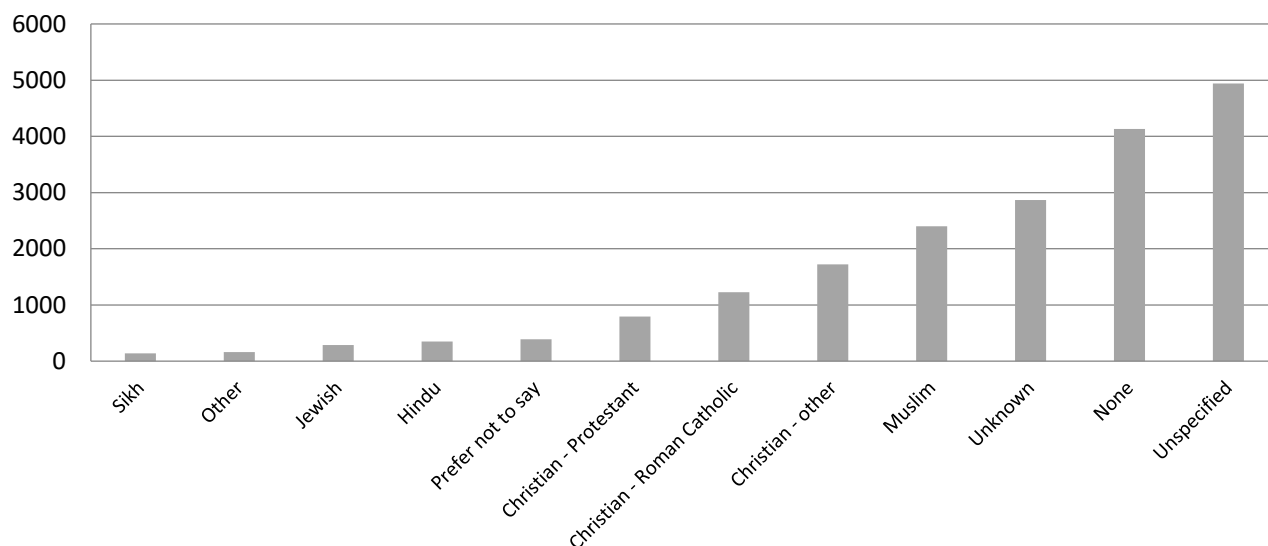
This is broadly in line with previous years and will guide provision of our 'core' set of information translated into languages other than English.

Religion or belief

GOSH treats children and young people from a wide variety of religious or faith backgrounds. The Chaplaincy and Spiritual Care team represents Church of England, Roman Catholic, Muslim and Jewish faiths, with other faith leaders on call if required. Information about the religion or faith of patients and families is requested on checking in to clinic appointments or as part of the ward orientation for inpatients. This data is stored on the patient record and weekly reports are run to enable members of the Chaplaincy and Spiritual Care team to tailor their visiting. In addition, families can request involvement from the Chaplaincy and ward staff can also request input. Unfortunately, data quality is patchy as we do not ask and therefore cannot record the religion or belief of 25 per cent of inpatients and 29 per cent of outpatients.



Most common religions for inpatients during 2019



The Chaplaincy and Spiritual Care team continue to support children, young people and families (as well as staff) through difficult times – in addition to the everyday support offered, they have carried out 42 baptisms and six funerals. They also carried out a wedding so that a seriously ill child could attend their parent's wedding. The team have also led 12 memorial events as well as the Trust-wide Annual Memorial Service, which was attended by 350 people affected by the death of a child.

The increase in Muslim children, young people, families and staff both in the UK as a whole and also at GOSH has led to a review of the services provided to this group. An Imam has been recruited to lead Friday prayers and there continues to be an on-site Muslim chaplain throughout the week supported by an out of hours on call service. A short pilot of having a Humanist volunteer chaplain was also completed during 2019 but further work is needed to refine the requirements of this role.

Once more, the Trust has celebrated major faith festivals throughout the year, including Hanukkah and Purim for Jewish families, Ramadan and Eid for Muslim families, and Easter and Christmas for Christian families.



Sex

According to our data, the proportion of male to female patients remains broadly similar to previous years with 54 per cent male and 46 per cent female for inpatients and similar figures for outpatients. In certain clinical divisions, there is a larger male patient population largely related to higher prevalence of many congenital disorders in males, for example in Urology. The launching of the Women's Forum will enable us to consider wider issues than currently, for instance, supporting working mothers of patients at GOSH.

Sexual orientation

The LGBT+ and Allies Forum for staff and volunteers has been in operation throughout 2019, with a mixture of educational events and speakers, promotional and awareness-raising events for non-members, as well as



more social occasions. The Forum has played a vital role in raising awareness and increasing visibility at GOSH, with the Rainbow flag flying for LGBT History Month and Pride, backed up with a large rainbow painted by our main entrance.

The Forum has also introduced rainbow badges for staff and volunteers. The aim of these badges, as well as to promote the Forum, is to encourage children, young people and families to feel welcomed regardless of their sexual orientation and/or gender identity. Anecdotal evidence shows that families value seeing the badges as it proves that GOSH is welcoming to all family set ups.

GOSH has also been represented at events outside the hospital, with our largest ever contingent taking part in Pride and Black Pride. Initial discussions around joint working with the local Police Station have also taken place with a view to holding joint events in the future.



GOSH does not record sexual orientation of patients currently but is aware that we may be called upon to do so in the future – particularly for our young people aged 16 years old or over. Members of the LGBT+ and Allies Forum will be asked to advise how we can best do this as well as evaluate new training resources and information.



Gender reassignment

While gender re-assignment is primarily regarded as a medical or clinical issue at GOSH, the Family Equality and Diversity Group, Patient Experience team and LGBT+ and Allies Forum are keen to increase awareness of 'gender fluidity' as a concept rather than just 'gender reassignment' as identified as a protected group by the Equality Act 2010. Consequently, all surveys wherever possible include the option of 'I think of myself as' under gender. Further work to spread the use of the trans training package trialled by our Play team is planned in conjunction with the GOSH Learning Academy.

Other protected characteristics

Everyone at GOSH encourages breastfeeding (or expressing breast milk) for all babies – we have a Neonatal Advisor who is available to help initiate or restart breastfeeding and several wards have dedicated breastfeeding/expressing rooms. These rooms are variable in quality and suitability so the Redevelopment team are reviewing them with a view to introducing improvements, standardised across all inpatient areas.

Other initiatives

GOSH has worked with the local community, including local schools, to hold several 'play street' events. This involves closing Great Ormond Street to traffic and laying on numerous activities open to children and young people at GOSH as well as in the wider community. This enabled children and young people who have never experienced street play and also mixing with other from the local community.



A Music Therapist (in addition to our volunteer musicians) now works with children and young people especially those with additional needs using music to encourage, comfort and empower them, as well as bring joy directly and indirectly.



Zayed Centre for Research into Rare Diseases in Children

This opened at the end of 2019 and is used to hold many outpatient clinics, including Respiratory, Immunology, Cardiology, Inherited Cardiology, Paediatric Genetics, Dermatology, Infectious Diseases, General Surgery, Endocrine and Rheumatology. As well as clinic rooms and investigations suits, a separate sensory room is available for children and young people who find traditional outpatient waiting areas too noisy and over-stimulating. There are also interactive artworks within the Centre offering distraction and entertainment. During the development of this building, children and young people were very involved in planning not only the look and feel of the Centre but also new ways of working. In due course, evaluation will be completed to inform future development plans at GOSH.

Sight and Sound Centre

This new facility is also nearing completion and will offer a totally new environment for children and young people with visual and hearing impairment. A variety of workshops have been held to date both with existing patients and the local community to inform the design of the facility including new artworks and installations.



Children's Cancer Centre

This will provide a national resource for children with rare and difficult to treat cancers, offering holistic, personalised and coordinated care, across the child's entire cancer journey. Development of the design started at the end of 2019, involving children, young people and families in workshops and presentations. Further events are also planned to involve the local community, as the project continues.

Conclusions and next steps

Although 2019 has been a challenging year with various changes in personnel, there is still much to celebrate. The introduction of staff forums will make a real difference to children, young people and families as well as staff and volunteers, raising visibility of minority groups at GOSH and ensuring that everyone who uses our services feel welcomed and valued. The introduction of the new Electronic Patient Record EPIC has also brought challenges, but the introduction of MyGOSH and My Fingerprint modules will enable us to be far more responsive to individual patient/family needs. Services offered to children and young people with additional needs, such as learning disabilities and/or mental health will be expanding so will undoubtedly form a priority area, as will the continuing development of ways to encourage everyone to raise concerns and give feedback about their experience. Children, young people and families continue to give positive feedback about their experience at GOSH – we will build on this in 2020 to ensure our services meet the needs of all who need them.

