Improving the experience of children, young people and families visiting Great Ormond Street Hospital during 2018

Meeting the duties of the Equality Act 2010

March 2019

Summary report for Trust Board

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

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

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

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

Objective 1: Achieve Accessible Information Standard within timescale

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

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

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

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

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

Objective 2: Publicise support for families including support organisations

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

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

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

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

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

The information and support needs of young people and their families have been prioritised by building on the previous year's work to develop the 'Growing Up Gaining Independence' (GUGI) framework. The

framework clearly explains the life skills relevant to all young people, particularly those who will transfer to adult healthcare.

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

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

Family Equality and Diversity (FED) Group

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

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

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

GOSH continues to be represented on the Pan London NHS Equality and Diversity Leads Network, with the aim of learning from successful initiatives at other Trusts and sharing what we have learnt at GOSH. The two GOSH Operational Leads for Equality and Diversity also meet more regularly to plan joint working such as improvement of equality analysis and coordination of reporting.

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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 2018. 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.

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.

Data sources

The data quoted in this report is mainly taken from our Patient Information Management System (PiMS). In previous years, the submission date for this report was January 31st so the previous financial year's data was reported. In 2018, the submission date was changed to March 31st enabling GOSH to report more up to date information for the previous calendar year.

Background

Activity at GOSH has increased again over the past year – both in terms of inpatient and day case admissions (3.3 per cent increase) and outpatient appointments (3.1 per cent increase).

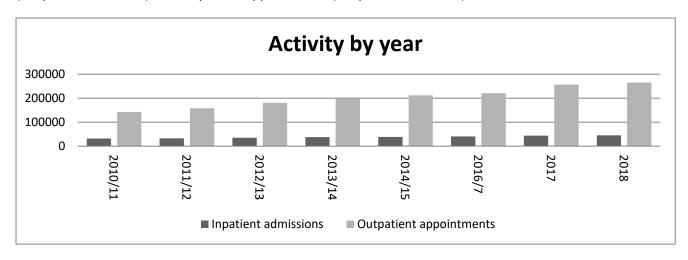


Figure 1 - Data taken from PiMS

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. These include:

- Bardet-Biedl syndrome service
- Beckwith-Wiedemann syndrome with macroglossia service
- Bladder exstrophy service
- Cardiothoracic transplantation 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
- Lysosomal storage disorders service
- Paediatric intestinal pseudo-obstructive disorders service
- Pulmonary hypertension service for children
- Severe combined immune deficiency and related disorders service
- Vein of Galen malformation service
- Ventricular Assist Devices (VADs) as a bridge to heart transplantation or myocardial recovery

A number of European Research Networks are also based at GOSH, which aim to:

encompass the principles of better access for patients to highly specialised, safe care of the highest quality, support European co-operation on highly specialised healthcare, knowledge pooling, improving diagnosis and care in medical domains where expertise is rare.

The Networks currently based at GOSH include:

- Rare craniofacial anomalies and ENT disorders
- Rare endocrine conditions
- Rare and complex epilepsies
- Rare kidney diseases
- Rare inherited and congenital anomalies
- Rare and undiagnosed skin disorders
- Rare neuromuscular diseases
- Uncommon and rare diseases of the heart
- Rare congenital malformations and rare intellectual disability
- Rare hereditary metabolic disorders
- Paediatric cancer (haemato-oncology)

Whether these Networks will continue in the same format after the UK has left the European Union is currently unclear, but it is likely that informal networks between expert clinicians will continue. Further information about all of these specialised services and networks is available from NHS England at www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2018/12/Highly-Specialised-Services-2018-v2.pdf.

Understanding the GOSH experience

At GOSH, we are always trying to improve the experience of children, young people and families who use our services. It helps us to understand what they experience when they come to GOSH – seeing what we do through their eyes can show us things that we might miss as members of staff.

Trust-wide surveys

GOSH takes part in the national surveys conducted on behalf of the Care Quality Commission. As the current children's inpatient national survey is still ongoing, the results cannot yet be reported.

Topic-specific surveys

Play provision in Outpatients

The Patient Experience team have supported two surveys with the Play Service during 2018 – one looking at Outpatient play provision and the other looking at access to ward play rooms including sensory equipment. The Outpatient survey arose from confusion about what play support was provided in which of the six main outpatient areas at GOSH. Prevention of infection in outpatient play areas was also a priority. Following review of the results the number of play volunteers has increased and become more visible within the departments and more specialist support has been strengthened in areas such as phlebotomy. New processes have been introduced to improve infection prevention within these areas.

The access survey showed that most wards kept their play rooms open during evenings and weekends, although some wards had unfortunately had to lock away valuables due to theft. Provision of sensory equipment is patchy with four wards having entire sensory rooms but five wards having no access to sensory equipment. The Play Service are working with the Family Equality and Diversity Group to lobby for greater equality of access to sensory equipment in future.

Radiology

The Radiology department again asked the Patient Experience team to assist in gathering evidence for their Imaging Service Accreditation Scheme. Following development of the survey last year, this was reviewed and improved to capture data in 2018. Unfortunately, only 60 responses were received but these contained a great deal of helpful information that will allow the Radiology department to focus their improvement efforts on the aspects of care that really matter to children, young people and families. Highlights include:

- An increase (70 to 77 per cent) from the previous survey in the proportion of respondents who felt
 the appointment letter told them everything they needed to know before the x-ray, scan or
 procedure.
- Almost all found the information or explanation about the x-ray, scan or procedure quite or very easy to understand.
- Over 85 per cent of respondents could access all the facilities they needed while in the Radiology department.

The learning from the survey has been reviewed and the Radiology Department will be implementing 'You Said, We Did' boards in March 2019 to improve communication with children, young people and their families/carers. Following feedback from the survey, the Radiology department is reviewing the information sent to patients before their scans to improve communication; this will include easy read information sheets and electronic information sheets.

Friends and Family Test1

The Friends and Family Test has been used as the GOSH baseline feedback tool since 2014. Each month, 1500 to 2000 pieces of feedback are received which are reviewed and escalated for further action if required. In June 2018, the Patient Experience team launched the online feedback form – Your opinion matters – allowing children, young people and families to feedback at their convenience. This online form also allowed us to ask families some additional questions about their experience and respond to feedback in real time.

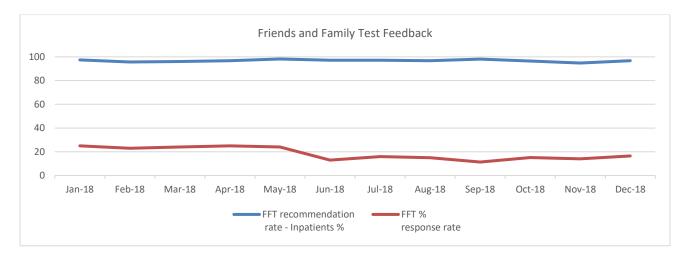
Having revised the feedback cards in 2017 to collect disability status, ethnicity and sex of responders, additional analysis has been carried out in 2018 to compare the experience between these groups. To date, there has been no statistically significant different in the likelihood to recommend GOSH (the key FFT question) or in the positive, neutral and negative comments received. This analysis will continue to be carried out and reviewed.

Some of the comments received include:

"Pleasant staff. Very supportive while I'm here with a severely disabled child. At ease. Thanks."

"From contacting the hospital to arrange support for our appointment to arriving on the day, I cannot praise [staff name] (who organised support) and [staff name] (who assisted on the day) enough. This service is a life saver to ourselves as parents and our son [child's name]. To have someone by our side who understands and empathises with his needs is like a dream come true. We cannot thank you enough for this fabulous service."

Both FFT response and recommendation rates are monitored closely and any negative feedback is followed up with appropriate teams. Average response times vary between 11 days (for paper feedback cards) and 2 days (for online submissions).



¹ The Friends and Family Test (FFT) is a national patient feedback mechanism that supports the fundamental principle that people who use NHS services should have the opportunity to provide feedback on their experience. FFT asks people if they would recommend the services they have used and offers a range of responses. When combined with supplementary questions, the FFT provides a mechanism to highlight both good and bad patient experience to inform improvement.

Patient stories

Patient stories are shared at each Trust Board meeting and represent a range of families' experiences across the hospital. The stories, presented either in person or filmed in advance, ensure that the voice of patients and their families is heard and that action is taken to improve aspects of a service and patient experience. Stories look at what is important to patients and families, and both positive and negative feedback. One issue highlighted related to the importance of reasonable adjustments including staff reading letters to a family member, the use of colour coding for medication, information shared using images and increased 'Easy read' leaflets and materials.

Young People's Forum

The Young People's Forum (YPF) is a group of current patients and siblings aged 10-21 who meet six times a year to discuss topics on which they think the hospital should be taking action. The YPF uses its voice to improve the experience of patients at GOSH, particularly the teenage experience. The YPF use their own experiences to guide and support the hospital, voicing opinions and making suggestions on a range of topics and issues. As well as providing feedback the YPF are a stakeholder group in key decisions and projects that around the hospital such as executive recruitment and redevelopment.

In 2018 YPF members highlighted concerns about employability, expressing worries that missing school and having long-term medical conditions may prevent them from pursuing certain careers. The GOSH Teens Careers Festival was established in conjunction with GOSH Charity. The YPF told us what advice they needed and the industries that they wanted to meet. Using this as a starting point several GOSH corporate partners were invited to showcase their companies and careers. We also offered interactive sessions and workshops including CV writing, confidence building, interview skills and alternative routes to entering a career.

There was also a panel of ex-patients who took part in a Q&A session to talk about the careers that they have gone on to do. The Careers Festival was open to all young people aged 13-21 with a connection to GOSH and feedback from the first event was overwhelmingly positive.

Abdullah, 14 said: "Before this I thought there wasn't that much I could do, but after attending this it's made me think there's lots more that I could do in the future."

Grace, 16 said "I found it helpful to hear different people's experiences, and to learn that you don't need to be perfect. There are lots of different ways to get to where you want to go, and even if there's a bump in the road, you can get round it."

We also received feedback from the companies, all of which said that they would recommend and take part again. When asked about the impact that the GOSH Teens Careers Festival had on the company the response from one was:

"Help[ed] us to re-think everything we are doing to tackle all barriers to entry for disabled colleagues."

Planning new services and buildings at GOSH

The Built Environment Programme at GOSH is creating new facilities appropriate for world-class paediatric care and research and more space to meet the growing demand for our services. GOSH has been constantly evolving since it opened in an 18th century townhouse in 1852. The aim of the programme is to replace out of date buildings and plan for the future so GOSH can provide the best care and treatment for more children in safe, spacious surroundings. The Built Environment strategy, known as the GOSH Masterplan, maps out the key phases of development to the year 2030. A key tenet of the strategy is the involvement in children, young people and families in the development and design of future facilities, often through the use of workshops.

Evaluation of the Premier Inn Clinical Building

As part of redevelopment of the GOSH site and associated fundraising for new buildings, the Patient Experience team worked with GOSH Children's Charity to assess the impact of the Premier Inn Clinical Building (PICB) since opening compared with the wards in the Morgan Stanley Clinical Building (MSCB), opened in 2012, as well as with the much older wards elsewhere on the site.

- In terms of accessibility, 90 per cent of children and young people (and 100 per cent of adults) responding agreed that the PICB wards were easily accessible for people with additional needs.
- A total of 85 per cent of children and young people felt they could have privacy when they
 wanted it. This is very similar to the responses about the MSCB wards and interestingly, the
 older wards as well.

Learning from the development of both buildings has been reviewed so it can be incorporated in future design of inpatient buildings.

Zayed Centre for Research into Rare Diseases in Children

The Zayed Centre for Research (ZCR) will be a world-leading centre of excellence that will tackle some of the most challenging scientific questions, enabling scientists and clinicians to more accurately diagnose, treat and cure children and young people with rare diseases. Locating researchers alongside clinical activity in the outpatient department is intended to reduce the 'bench to bedside' time, enabling new discoveries to be translated into cutting edge treatments more quickly.

As with many GOSH buildings, children, young people and families attended a number of workshops to help finesse the design of the new building. Construction is nearly complete and throughout the process, there have been many events with children and young people from neighbouring areas.



Figure 2 Artist's impression of the Zayed Centre for Research into Rare Diseases in Children

Children's Cancer Centre

The Children's Cancer Centre is proposed to be located in a brand new building that will be constructed along the frontage of the Great Ormond Street site, replacing the Paul O'Gorman and Frontage Buildings. The building will provide 22,000 square metres of space including five inpatient wards, an outpatient and day care centre for cancer services and a new pharmacy department including manufacturing facilities for intravenous medication, parenteral nutrition and chemotherapy.

A new imaging department will include a PET MRI scanner. This hybrid technology produces very detailed images of the inside of the body and will allow our clinicians to accurately diagnose conditions and determine the most effective treatment plan. A new Hospital School and Activity Centre will improve accessibility to education for our long-stay patients and provide much-needed extra capacity in the classrooms and play spaces.

This scheme will see the public face of our hospital completely redeveloped and the main entrance will be moved forward to the pavement. Better public space will be created and the arrival experience for our children and families will be dramatically improved.



Figure 3 - Artist's impression of the Children's Cancer Centre

The Design Brief for the Children's Cancer Centre was developed around work undertaken by the YPF with the creation of a series of pictures that represented how the new building should feel to move around in. Work on this project in 2018 extended our understanding of the needs of patients through further workshops with young people on the bedroom and the creation of a palette of colours. It is hoped that construction can commence in mid-2022.

Sight and Sound Centre

Refurbishment of the Italian Hospital on the corner of Queen Square has started, with the aim of creating an exemplar outpatient and day case environment for hearing impaired and visually impaired children.

The design team has been working alongside GOSH staff and families who formed an Expert Patient Group to develop a design concept to restore original features and create a welcoming, home-from-home environment for some of the busiest clinics at GOSH. This includes Ophthalmology, Audiology, Ear, Nose &

Throat (ENT), Speech and Language Therapy (SLT), Craniofacial and Cleft Lip & Palate. Construction is expected to be complete in early 2020 and the first clinics should be held in the building next summer.

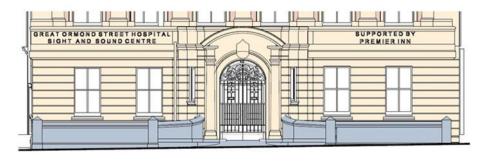


Figure 4 - Proposed frontage of the Sight and Sound Centre

Considering equality, diversity and inclusion in decision making processes at GOSH

GOSH has an equality analysis review process to ensure that all policy and decision making is carried out in a fair and equitable manner. This applies to all policies, strategies, formal consultations, guidelines, service improvements and business cases produced under the aegis of Great Ormond Street Hospital (GOSH).

It is clear that staff sometimes struggle to carry out an equality analysis, so in addition to the written guidance available, a PowerPoint session has been developed to explain why equality analyses should be used and what should be considered as part of one. This is now sent to all staff requesting help with equality analysis to enable them to develop an initial analysis, before a review is completed. The following policies (and associated equality analyses) were approved in 2018:

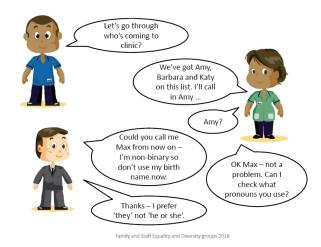


Figure 5 - Example slide from equality analysis PowerPoint

- Blood Transfusion Policy
- Cancer Access Policy
- Clinical Audit Policy
- Countering Fraud, Bribery and Corruption Policy
- Dignity at Work Policy
- Disciplinary Policy and Procedure
- Equality at Work Policy
- Equality Policy
- External Images Policy
- Health and Safety Policy (Camelia Botnar Laboratories)
- Managing Pressure and Wellbeing Policy
- Medical Cover for Private Patients Allocated to Non IPP Wards Policy
- Mixed-Sex Accommodation Policy
- Non-medical prescribing policy
- Nurse Rostering and Safe Staffing Policy
- Observations and PEWS Policy
- Patient Property Policy
- Pay Protection Policy
- Play Equipment safety policy
- Preceptorship for Newly Registered Practitioners policy
- PREVENT Policy
- Recovery of Salary Overpayments Policy
- Recruitment and Selection Policy
- Research Declarations of Interest Policy

- Safety Standards for Invasive Procedures (SSIP)
- Security Policy
- Staff Travel and Other Expenses Policy
- Very Important Persons (VIP) and Celebrities Policy
- Ward naming and signage Policy

The diversity of the GOSH patient population

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 the reason why over 10,000 appointments in 2018 were attended by adults aged 19 years or older.

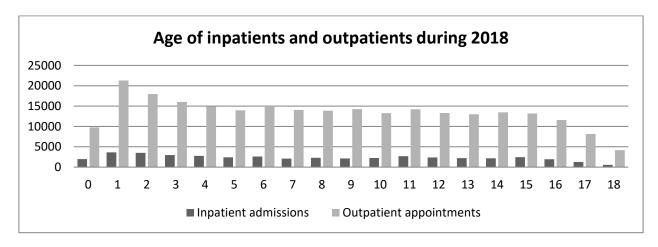


Figure 6 - Data taken from PiMS

The biggest age group at GOSH continues to be toddlers aged one or two years, with a steady proportion of older children until the age of 14 or 15 years when many start to move on to adolescent or adult services.

Transfer (or transition) to adolescent or adult services

This 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 Manager has developed the Growing Up, Gaining Independence (GUGI) framework for organising transition to adolescent or adult services.

GOSH aims to encourage and support young people to become as independent with their healthcare as they can. Young people have told the Trust how important it is to have time to learn new skills, practise them and gradually take on more responsibility. They have a lot to learn, often from their family who have managed their health up to now, so GOSH relies on them to help pass on experience to help gain independence.

Having worked with the Young People's Forum to develop an overview of the sort of information they need to support them in becoming independent, a series of Easy Read information sheets for young people with learning disabilities have been developed and uploaded to the GOSH website. This range is now being expanded for young people with capacity to make their own decisions.

Great Ormond Street Hospital for Children NH5 Foundation Trust Keeping organised and safe As you grow older, you learn new things. You might start to do things on your own, without your parents being there. This is called becoming independent (said: inn-dee-pen-dent). When you do things on your own, you need to keep organised. This means having your stuff in one place and keeping it lidy and up to date. Your parents will know all about this, so ask for their help. If you have a mobile phone you could use this to keep organised. You could use the calendar to know when you have an appointments. You could take a photo of every letter you get and store in a folder on your phone.

Figure 7 - Example of Easy Read information sheet for the GUGI programme

Disability

Having achieved the facility to record additional needs on PiMS, work has been ongoing to make sure this functionality is not lost when the electronic patient record system goes live in April 2019. Following negotiations with the relevant design leads and clinical information officers, not only will the current functionality be kept, any additional needs of the people with Parental Responsibility will be recorded as well.

We know from talking to families that many need to use accessible toilets and changing places, either for themselves or for their child. While information about general accessibility has improved, it is still quite difficult to know where facilities are located so an information sheet available to pick up from outside the Pals Office in the main reception area has been developed.

The AccessAble (previously known as Disabled Go) information on the GOSH website has been updated to include the wards in the Premier Inn Clinical Building. The process for ensuring this information remains up to date has also been agreed.



Figure 8 - Information sheet about changing and toilet facilities at GOSH

Learning disability

With a change in personnel mid-way through 2018, the emphasis has been on reviewing the services provided to date and identifying any gaps in provision. For instance, the 'definition' of children and young people supported by the service has now been widened to include children with autism spectrum disorder, who previously were not formally offered support. A parent of a child with learning disabilities was included throughout the recruitment process for the vacant Nurse Consultant for Learning Disabilities role.

In addition, ways of improving communication between families and staff are being reviewed, including the use of a hospital passport or similar and ward-based communication strategies. Training continues to be delivered to staff, with a number of simulation sessions planned (involving actors with learning disabilities from the Baked Bean Theatre Company) following the success of the pilot session held in 2018.

Race and ethnicity

Of those inpatients whose ethnicity we know, 46 per cent record their broad ethnic background as white as shown in the graph below. Despite efforts to improve the recording of ethnicity, we still do not have a record of the ethnicity of 21.7 per cent of inpatients in 2018, although this is a good reduction on the 37.7 per cent without ethnicity data seen in 2017.

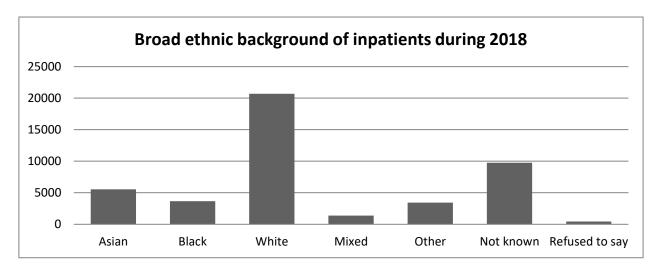


Figure 9 - Taken from PiMS data

The broad ethnic background of children and young people attending an outpatient appointment is similar, with 46.0 percent reporting their broad ethnic background as white. The overall recording of ethnicity in outpatients has also improved – in 2017 43.2 percent did not have a recorded ethnicity, but this reduced to 21.0 per cent in 2018.

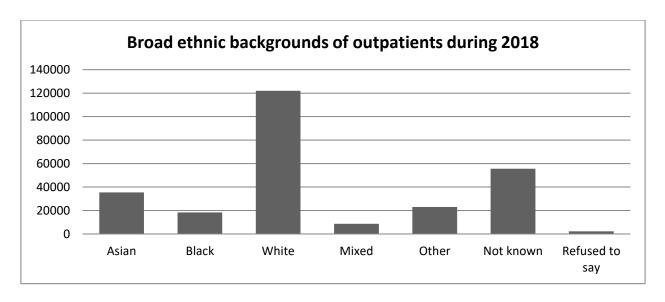


Figure 10 - Taken from PiMS

Further analysis shows that our largest non-white populations attending outpatient services at GOSH are Pakistani and Middle Eastern/Arab States, followed by people of Black African and other Asian origins.

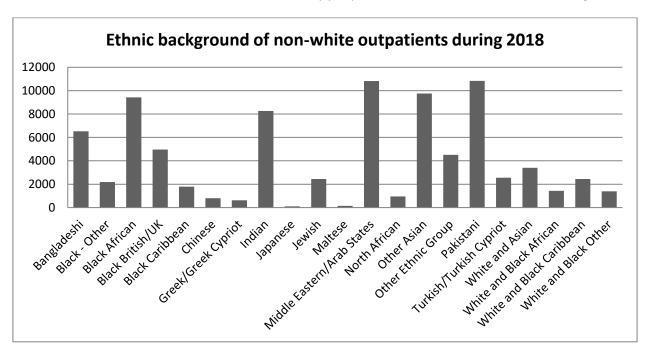


Figure 11 - Taken from PiMS

When considering inpatient admissions, children and young people with a Middle Eastern/Arab States background form the largest group followed by those of Black African or other Asian backgrounds.

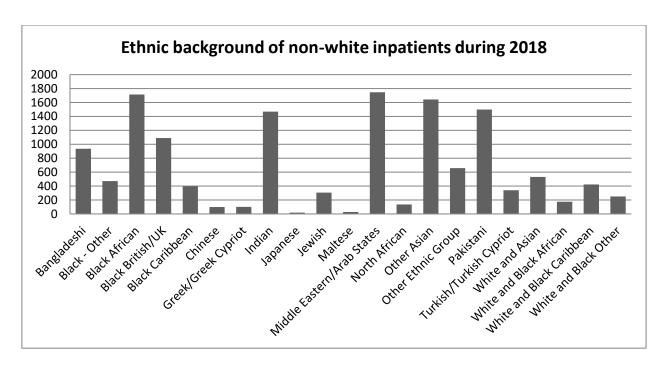


Figure 12 - Taken from PiMS

Primary language spoken

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.

The most commonly spoken language at GOSH after English remains Arabic (as would be suggested by the ethnic background data shown above), followed by Bengali and Polish. The 'other' column records any languages other than those included in a drop down list but cannot be examined further as it is a free text field.

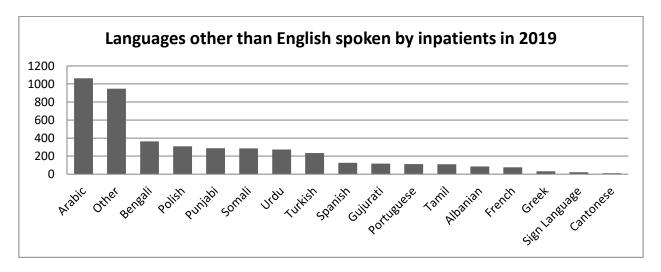


Figure 13 - Taken from PiMS [Other refers to languages other than English not available in the drop down list]

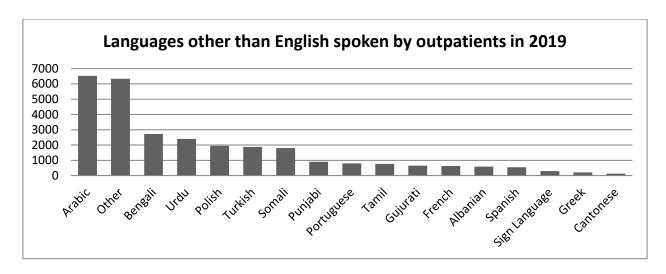


Figure 14 - Taken from PiMS [Other refers to languages other than English not available in the drop down list]

Language support, in the form of face to face interpreting, telephone interpreting and written translation is available in all languages seen at GOSH. During 2018 there were 10,105 face to face interpreting sessions and 1,545 telephone interpreting sessions. Newer methods of communication, such as video-based British Sign Language interpreting, continue to be investigated for feasibility and suitability for families.

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.

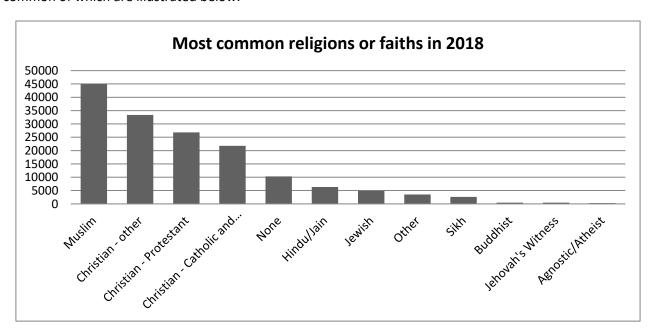


Figure 15 - Taken from PiMS [Other relates to religions not included in the drop down list]

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. Naming and other ceremonies can be celebrated by the Chaplaincy and Spiritual Care team either in the Chapel or at the bedside if needed.

The Chaplaincy and Spiritual Care team has traditionally been based in St Christopher's Chapel, with its non-denominational lobby area, but there is now a Shabbat Room for Jewish families (supported by the charity Ezra Umarpeh who provide food and supplies for the Sabbath), a non-denominational quiet room which can be used for meditation or reflection, and a large Muslim Prayer Room with ablution facilities opened in 2018.





Figure 16 - New Muslim prayer room with ablution facilities

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, Diwali for Hindu families and Easter and Christmas for Christian families.

Improved Muslim prayer facilities

With the growth of the Islamic faith within the UK, the previous facilities for Muslim prayer were not fit for purpose – every day prayers were held in a small multi-faith room with no ablution facilities and Friday Jumah prayers were held in two sittings in the Charles West Room (boardroom).

The improved Muslim prayer room was opened in June 2018 and comprises a large prayer area with sanctified carpet (negating the need for individual prayer mats) with a separate section for females. Separate ablution facilities for each sex have also been provided. The area is managed by the Chaplaincy and Spiritual Care team in association with a user group of worshippers.

Sex

According to our data, the proportion of male to female patients remains broadly similar to previous years with 52 per cent male and 47 per cent female for inpatients and outpatients. A total of 62 patients either did not have their sex recorded or were reported as indeterminate. 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.

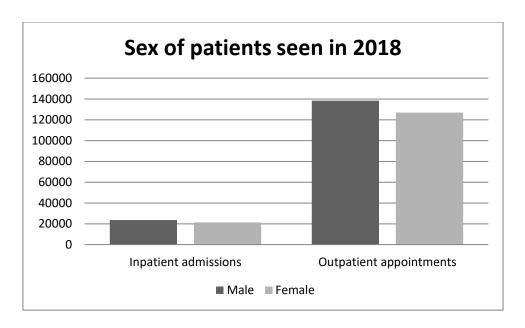


Figure 17 - Taken from PiMS

Mixed sex accommodation audits

The area where the sex of the patient has the biggest impact is in bed allocation, although this may become less important in future years with the move towards single occupancy bedrooms for the majority of children and young people. Where a child or young person has to share a room, we clearly indicate how we will allocate beds, as below.

If your child is in a shared bay, we will ask if your child has a preference for being with other children of their own age or gender and will try to meet this request where possible. Please note that there are some circumstances where requests cannot be met, for instance, in high dependency or intensive care areas. Your child's safety will be our utmost priority at all times.

Information about Chameleon Ward

In addition, monitoring of bed allocation for young people aged 18 or older continues on a monthly basis.

Sexual orientation

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. In a similar way to recording additional needs, further exploration is needed to identify how staff can be encouraged to check and then the response recorded centrally to avoid repeat questioning.

In 2018, the LGBT+ and Allies Forum for staff was convened. Although it is aimed at staff, a survey carried out in early 2018 identified some inappropriate behaviour and communication by and towards same sex parents, both from fellow families as well as staff, so clearly work is needed to address this.

Having the LGBT+ and Allies Forum will enable the Family Equality and Diversity Group to work with experts through lived experience to develop and improve services at GOSH. Already the Forum has circulated posters from Stonewall celebrating the diversity of family set ups and has also displayed the rainbow flag outside the hospital for the first time.

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.



Figure 18 - The rainbow flag flying for LGBT+ History Month

Consequently, all surveys wherever possible include the option of 'I think of myself as' under gender. Training for staff has also been explored, with a number of staff groups having undertaken the online training provided by the Gender Identity Research and Education Society (GIRES) to help them care for gender non-conforming young people. This is due to be more formally evaluated by Forum members, with a view to rolling it out to all members of staff in the future.

Conclusions and next steps

This report gives just a flavour of the many strands of work ongoing at GOSH to improve inclusion and recognise the diversity of children, young people and families who use Trust services. 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 part of the Public Sector Duty.