

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

Meeting the duties of the Equality Act 2010

March 2018

Contents

Background.....	2
Understanding the GOSH experience.....	4
Trust-wide surveys	4
Topic-specific surveys.....	5
Friends and Family Test.....	7
Young People’s Forum.....	8
Fulfilling our potential and our ‘always values’	9
Planning new services and buildings at GOSH	9
Zayed Centre for Research into Rare Diseases in Children	10
Phase 4 building.....	10
Sight and Sound outpatient facility	10
Considering equality, diversity and inclusion in decision making processes at GOSH.....	11
Advice and training.....	11
Quality checking policies	11
Improving the quality of data held about children and young people	12
The diversity of the GOSH patient population	13
Age.....	13
Disability	14
Race and ethnicity	16
Religion or belief.....	17
Sex	17
Other protected characteristics	18

Progress against Equality Objectives at GOSH	19
Current objectives	19
Continuing progress against previous objectives	21
Family Equality and Diversity Group	21
Conclusions and next steps	22

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 2017. It complements the report detailing how our Human Resources department is meeting staff requirements.

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

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

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

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

Data sources

The data quoted in this report is mainly taken from our Patient Information Management System (PiMS) for the calendar year 2017, although previous reports have been based on data from a financial year. Where data is taken from sources other than PiMS, details will be given in the caption below each chart.

Background

Activity at GOSH has increased again over the past year – both in terms of inpatient and day case admissions (7 per cent increase since financial year 2016/7) and outpatient appointments (16 per cent increase).

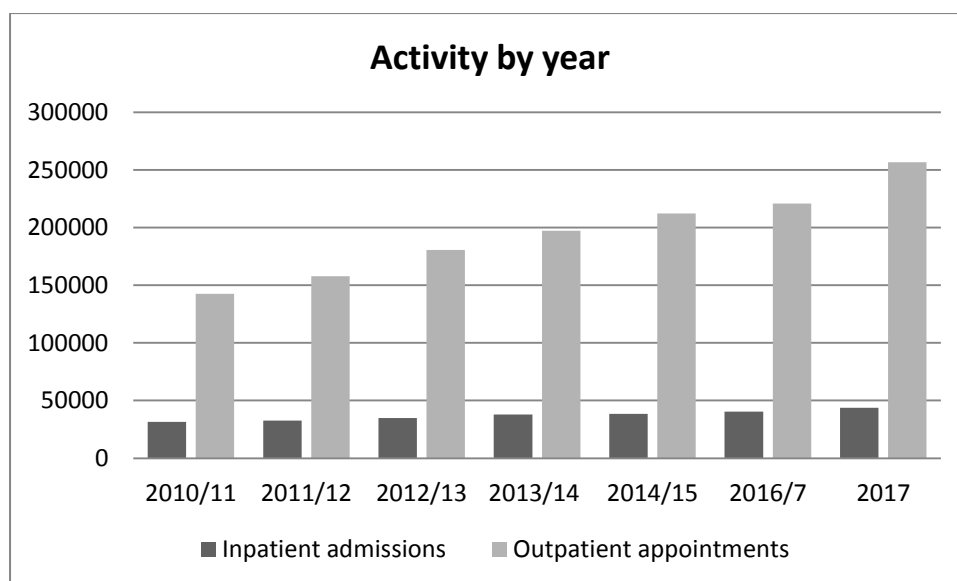


Figure 1 - Data taken from PiMS

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

Equality analysis of the delivery of these services and associated outcomes were analysed by NHS England and published in February 2018. This report is available online at www.england.nhs.uk/wp-content/uploads/2018/03/highly-specialised-services-17.pdf

Understanding the GOSH experience

What children, young people and families experience when they come to GOSH matters. The Trust aims to provide the best experience possible during what must be a difficult time in their lives. However, this is only possible by understanding what happens when a child and young person comes to GOSH so a range of ways are used to capture this information. The best way to learn how to improve what the Trust does and how it is done is to listen to children, young people and families. Seeing GOSH services through their eyes can highlight areas we may miss as members of staff.

Trust-wide surveys

GOSH took part in the national Inpatient Survey conducted on behalf of the Care Quality Commission, and although the survey asked about experiences of services during late 2016, the results were not received until November 2017 so will be reported here. The survey was sent to a sample of 1250 patients and families and a total of 372 responses to the survey were received, giving a response rate of 30 per cent which is broadly in line with the expected response rate for postal surveys.

In terms of who completed the survey, 47.8 per cent were completed by just the child or young person, 22 per cent by just the parent and 30.2 per cent by both child and parent. Long-standing conditions of respondents were also reported, with the most common condition being a long standing condition (38.2 per cent) and any other long term physical disability (29.7 per cent) – in both cases, these were far greater proportions than respondents from other organisations. The most common ethnicity of respondents was 62.3 per cent White British (lower than for other organisations) followed by White Other with 7.2 per cent (higher than other organisations).

Responses to individual questions are reported as a score out of a total of 10 – scores to questions follow in brackets. Areas where GOSH scored highly included:

- Able to ask questions of staff and receive an answer (9.7/10 and 9.8/10)
- Talking to a doctor or nurse on their own (9.7/10)
- Staff introducing themselves (9.6/10)
- Parents feeling listened to and given explanations they could understand (9.4/10 and 9.5/10)
- Parents given enough information to be involved in decisions (9.2/10)
- Parents having confidence and trust in staff (9.4/10)
- Parents knowing what to do if concerned after going home (9.4/10)
- Parents' view of overall experience (9.0/10)

The main areas for improvement identified by respondents were:

- Ensuring parents have a choice of admission dates, where possible
- Improving the hospital food
- Ensuring children and young people feel involved in decisions about their care and treatment
- Having enough things for children and young people to do while in hospital
- Ensuring staff are aware of patients' medical history

Comparison with other hospitals was provided from the responses received, with GOSH performing 'better than expected' for respondents aged up to seven years and 'as expected' for respondents aged between 8 and 15 years of age. In general, a higher proportion of younger children reported a positive experience

compared with the older age group. There were no questions where GOSH compared poorly with other hospitals taking part in the survey.

Topic-specific surveys

In addition to nationally mandated Trust-wide surveys, the Patient Experience team also carries out a number of topic-specific surveys each year. Surveys carried out during 2017 include:

Food

Feedback about our catering services via the Friends and Family Test is continually monitored and as a result the following changes have been introduced:

- Child size portions in the Lagoon hospital restaurant, for example, half-sandwiches
- Regular food tasting by the hospital's Young People's Forum
- Working with an outside contractor to improve our catering services and training available to our staff
- Increased vegetarian and vegan options
- Theme days every Thursday in the Lagoon hospital restaurant
- Increased healthy food options in vending machines and on main till points in the restaurant



Figure 2 - Healthier food in the Lagoon

Accommodation

In 2016, a number of aspects of parent accommodation which could be improved were identified. Families were then re-surveyed the following year to see whether the experience of staying in parent accommodation had improved. Results showed:

- More people had received information about accommodation in their admission letter.
- Cleaning standards of accommodation have improved
- All beds are now made up before arrival
- Decor within accommodation has been refreshed with cleaning and re-painting
- Inventories have been developed for shared kitchens to identify what cutlery and equipment should be available.

However, there is room for improvement so in the coming months, the Accommodation Service will be:

- Encouraging staff to attend customer service training provided in-house
- Investigating potential funding for free tea and coffee provision in parent accommodation



Figure 3 - Photograph of Morgan Stanley House accommodation opened in October 2017

Radiology

As part of their submission for the Imaging Service Accreditation Scheme, the Radiology departments asked the Patient Experience team to develop and carry out an experience survey. This asked 207 children, young people and families attending the Radiology department about various aspects of their experience, such as waiting times and play facilities.

An equal number of responses were received from families of male and female children and around 60 per cent were from a White British/UK background. Just under half of respondents' children had a health condition or disability that limited their day to day life to some extent. Mobility and coordination problems were most frequently reported, followed by long standing illness and learning disability.

Around 70 per cent of respondents felt the appointment letter contained enough information about the scan or test to prepare. Just under half of respondents also received a written information sheet as well as the letter, which they found easy to understand. Over 80 per cent of respondents were not asked when checking in whether their child had any additional needs.

Nearly three-quarters were not directed to facilities in the waiting area but over 90 per cent of respondents found the temperature of the area just right. Overall, 75 per cent of respondents felt that they spent an appropriate length of time in the waiting area. During the scan or test, 85 per cent of respondents felt their child was treated with dignity and respect and 92 per cent had confidence and trust in staff from the Radiology department. The overall rating for their experience in Radiology on that occasion was 7.5 out of a maximum 10.

The Radiology management team are focussing on improving information about services initially alongside reviewing processes for sending information with appointment letters. As well as reviewing existing information for families, a range of Easy Read information for people with learning disabilities is also being produced in conjunction with the Health Information/Language Manager.



Figure 4 - One of our MRI scanners

Impact of buildings

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 find out the impact of current buildings before the opening of the Premier Inn Clinical Building. Thirty seven responses were received from children and young people and 83 from family members – both groups has equal responses from those staying in older ward facilities and more recently built ones.

Around 65 per cent of family respondents reported that their child had a health condition or disability that had an impact on their daily life, with 75 per cent of children and young people responding the same. Long term conditions problems were most common, followed by mobility or coordination, learning disability and communication problems. More males than females took the survey, with 43 per cent of respondents coming from a White British/UK background.

In many ways, the responses to this survey confirmed what was suspected – that wards in the older building (Southwood Wing) were not as spacious as ones in the Morgan Stanley Clinical Building (opened in 2012), had less storage space, less suitable décor and were not as accessible to those with additional needs. The survey will be repeated once the wards in the Premier Inn Clinical Building have been in use for six months or so.

Other projects with which the Patient Experience assisted:

- Project Identity – reviewing the GOSH 'brand'
- Information needs of families attending the Neurodevelopmental Assessment Clinic
- The experience of patients needing serial casting

Friends and Family Test

The Friends and Family Test has been used at GOSH since its national launch in April 2013. Since that time, our percentage to recommend has remained consistently above 95 per cent.

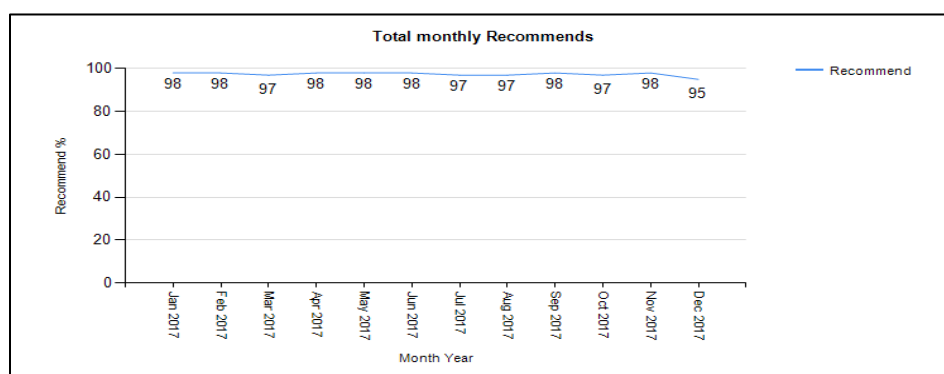


Figure 5 Run chart showing consistent recommendation levels

In spring 2017, the Patient Experience team revised the Friends and Family Test feedback cards to include the facility for collection of sex, ethnicity and disability status of respondents – for each, there is also a 'prefer not to say' option.

This has enabled comparison of experience between different groups at GOSH, for instance, those with a disability and those without. The first few months' worth of

FRIENDS AND FAMILY TEST: INPATIENT AND DAY CASES

We would like you to think about your most recent experience of our service. How likely are you to recommend our ward to friends and family if they needed similar care or treatment? (Please tick)

☐ Extremely likely ☐ Likely ☐ Neither likely or unlikely ☐ Unlikely ☐ Extremely unlikely ☐ Don't know

Please tell us more about your response to the question above:

All comments provided will be used to improve our services, however please tick here if you do not wish your comments to be published

Are you: ☐ A patient ☐ A parent/carer Your age: _____

Gender: ☐ Male ☐ Female ☐ I think of myself as _____

Disability: ☐ Prefer not to say ☐ Yes, limited a lot ☐ Yes, limited a little ☐ No

If yes, please select the relevant category/categories

☐ Communication ☐ Hearing impairment ☐ Learning disability ☐ Long-standing illness, such as heart disease, diabetes, epilepsy ☐ Mental health ☐ Mobility or coordination ☐ Visual impairment ☐ Other health problem or disability (please state): _____

Please complete your details if you are happy to be contacted. Otherwise please leave blank.

Name: _____ Contact number/email: _____

When you have completed this card, please put it in the feedback box on the ward or request it back to us. Thank you for your help.

Figure 6 - Revised inpatient FFT card

data shows that the percentage to recommend does not alter significantly when both groups are compared. In time, as more data is collected, there will be a clearer view of whether the experience of GOSH differs between groups of respondents.

Young People's Forum

The YPF helps to improve the experience of teenage GOSH patients. The hospital asks them for their thoughts and ideas about important issues that affect young people, both as inpatients and outpatients. The YPF also develop their own projects to make hospital life better for patients and families.

Membership of YPF has increased again in 2017 to over 70 members, with around 30 members attending each meeting. They met five times during 2017, received presentations and discussed many topics including:

- Tour of operating theatres
- Review of plans to celebrate Clean Air Day at GOSH
- Design and development of temporary tattoos
- Presentation from Estates and Facilities team on food provision and bedside television system
- Evaluation of designs for the new Phase 4 building
- Q&A session with Chief Financial Officer and Chief Information Officer
- Contributed to the NHS England review of critical care and specialised surgery
- Presentation about the work of the Clinical Ethics Committee at GOSH
- Tour of garden and outdoor spaces at GOSH
- Contributed to reorganisation of GOSH website
- Presentation on the history of GOSH
- Input into discussions around visiting times at GOSH

In October 2017, GOSH also coordinated the first ever joint meeting of Young People's Fora from the UK entitled 'The Big Meet Up'. Attended by more than 80 young people, the aim was give forum members the opportunity to 'share and steal' ideas about improving services in their hospitals: such as practical and emotional aspects of staying in hospital. In addition, attendees identified the following themes for further discussion and action:

- Everyday mental wellbeing is everyone's responsibility
- Communication and two way conversations should be between equal partners

These results have been forwarded to the NHS England Youth Forum which works with the Department of Health to work on national issues.



Figure 7 Temporary tattoo designed by YPF member

Fulfilling our potential and our 'always values'

In spring 2017, the Strategy and Planning Team worked with staff and Members' Councillors to refresh the GOSH strategy (now called Fulfilling Our Potential). This assessed the issues and opportunities faced by the Trust, as well as considering the vision for the future. In particular, the following priorities were identified:

- GOSH will achieve the best possible outcomes through providing the safest, most effective and efficient care
- GOSH will attract and retain the right people through creating a culture that enables learning and thriving
- GOSH will improve children's lives through research and innovation
- GOSH will transform care and the way it is provided through harnessing technology
- GOSH will use its voice as a trusted partner to influence and improve care
- GOSH will create inspiring spaces with state-of-the-art equipment to enhance care delivery and learning
- GOSH will provide timely, reliable and transparent information to underpin care and research
- GOSH will secure and diversify funding so all the children that need care can be treated.

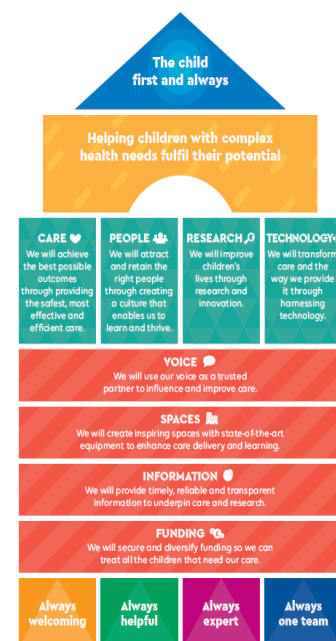


Figure 8 GOSH 'Strategy House'

These priorities are presented in a 'strategy house' along with the mission, vision and Our Always Values. Together, they form a framework for staff and leadership teams to use to plan and make decisions.

Planning new services and buildings at GOSH

This year saw the opening of the Premier Inn Clinical Building (PICB), the final part of the Mittal Children's Medical Centre at GOSH – part of an ambitious programme to re-build two-thirds of the hospital site.

The PICB has been operational for some months now, with the majority of ward areas now occupied giving spacious new facilities for children, young people and families.

As part of the moving process, information about each of the new wards was produced along with a guide to each room, available on the bedside television system. The Patient Experience team assessed the experience of the current buildings (see page 7) and plan to repeat this exercise some months after full operation of the PICB.



Figure 9 Artist's impression of the Premier Inn Clinical Building including Disney garden

Zayed Centre for Research into Rare Diseases in Children

The Zayed Centre for Research into Rare Diseases in Children will be a research and outpatient facility on Guilford Street. It is a building in which scientists and clinicians can work together to care for children and young people with rare diseases, learn more about what is making them unwell and discover new ways to help them get better.

As with many of 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 10 Artist's impression of the Zayed Centre for Research into Rare Diseases in Children

Phase 4 building

This will provide a new clinical building on Great Ormond Street on the site of the Frontage and Paul O’Gorman Buildings. GOSH held a design competition facilitated by the Royal Institute of British Architects (RIBA) to select the team who will partner with the Trust to design and build the scheme. After comprehensive analysis and debate the John Sisk & Son with BDP team won the design competition. Partly this was because of the quality of their concept design, which was really popular among the GOSH community (children, young people, families, staff and neighbours) when the design proposals were anonymously exhibited side by side.



Figure 11 Artist's impression of the new clinical building on Great Ormond Street

Just as important was the strength and depth within the team, who clearly demonstrated a deep understanding of the GOSH values, creativity, expert clinical planning and a robust commercial proposition. The ‘four houses’ concept responds to the domestic scale of Great Ormond Street and the imaginative ‘lily pad’ winter gardens with embayment spaces between them will enhance the inpatient experience, offering views of nature from every bedroom window.

Sight and Sound outpatient facility

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

The design team is now working alongside GOSH staff and families 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 including Ophthalmology, Audiology, Ear, Nose & Throat (ENT), Speech and Language Therapy (SLT), Craniofacial and Cleft Lip & Palate.

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

There has long been a process to be followed at GOSH to ensure that all policy and decision making is carried out in a fair and equitable manner, which applies to all policies, strategies, formal consultations, guidelines, service improvements and business cases produced under the aegis of Great Ormond Street Hospital (GOSH).

Advice and training

It is clear that staff sometimes struggle to carry out an equality analysis, so in addition to the written guidance available, a teaching session is being developed explaining why equality analyses should be used and what should be considered as part of one. This is now out for review and should be available in the next two months.

Quality checking policies

Another part of ensuring that our policies are fair and equitable is to review policies and their associated equality analyses for completeness and quality. An audit tool and scoring system has been developed and is now used to review all policies presented to the Policy Approval Group for ratification.

Equality analysis assessment tool			
Policy name:		Policy author:	
Ratification group:		Ratification date:	
Policy reviewer:		Date reviewed:	
Protected characteristic	Grade (see Key)	Score	Notes
Age			
Disability (including learning disability)			
Gender re-assignment			
Marriage or civil partnership			
Pregnancy and maternity			
Race			
Religion or belief			
Sex			
Sexual orientation			
TOTAL SCORE		0	
Action required		Needs review immediately	

Key

Good - 3 points
All potential issues (including if no issues present) identified and actions needed described
All relevant stakeholders engaged and results reported fully

Satisfactory - 2 points
Some issues and actions described but further examples identified by reviewer
Limited stakeholder engagement reported

Weak - 1 point
Some issues identified in body of document but not in equality analysis or vice versa
Little or no stakeholder engagement reported

Not completed - 0 points
Forms contains no issues or actions but examples have been identified by reviewer
Little or no stakeholder engagement reported

Figure 12 Audit tool for quality of equality analysis

While the occasional policy is still presented to the Policy Approval Group with no equality analysis whatsoever (one to the November meeting), the majority do now contain one although the quality of the analysis is somewhat variable.

The hope is that the teaching session described above will improve this situation but in the meantime, auditing of all policies and giving feedback to authors will continue.

Improving the quality of data held about children and young people

The quality of data held about children and young people attending GOSH continues to be a concern, and it has been frustrating to be unable to demonstrate clearly the benefits of what has been achieved. As we cannot yet use our data to any great degree due to lack of completeness, we therefore struggle to promote the usefulness of collecting it to our staff.

For example, it is difficult to identify any differences in outcome by ethnic background if we do not know the ethnicity of a large proportion of children and young people. Equally, it can be more difficult to change our services when we have incomplete data – for instance, being able to prove the increase in Muslim children, young people and families has strengthened the requirement for improved prayer facilities.

However, members of the Family Equality and Diversity Group carried out a range of improvements in 2017 with initially promising results. Members of the Quality Improvement and Chaplaincy teams developed a short teaching session to deliver to front line staff in Outpatients to help them feel more confident in asking for demographic details at the check in desks. During May 2017, this was delivered to 36 members of Outpatient staff who all evaluated the session as useful and reassuring.

Alongside this, a leaflet for families explaining the importance of holding this data and what we do with it was produced. This is nearing sign off and will be widely available on paper and online in the coming months.

As a component of the improvement process, it was important to measure whether a difference had been made or not. To this end, the Quality Improvement team developed a series of dashboards to demonstrate this. As shown below, there was an improvement in our success in capturing ethnicity and religion in Outpatients following the teaching session, which gradually dropped off again as time passed. The chart is showing an improvement again, now that the Data Quality team in Information Services is taking over leading this piece of work.

- Ethnicity, religion and additional needs may impact the way which individuals:
 - Think and view the world
 - Make judgements and decisions
 - Understand health and illness
 - Take up health care and treatment options
 - Use strategies to cope with illness or loss

How to ask

- Suggestions for words to use include:
 - “How would you describe your child's ethnic background?”
 - “Do you identify with a particular faith, religion or belief?”
 - “Does your child have any additional needs that you want us to know about?”
- We do not need to ask for confirmation at each encounter but you do need to ensure that the fields are completed and updated.

Figure 13 - Slides from revised teaching session for staff



Figure 14 - Information for families about data collection

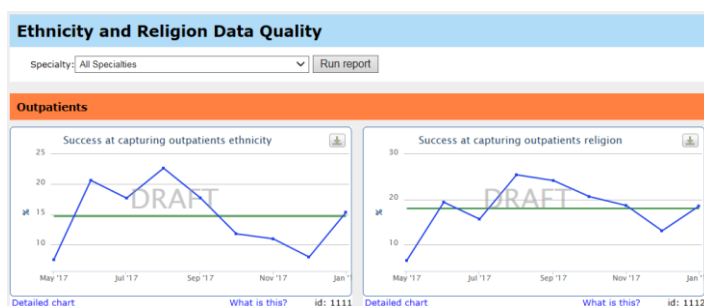


Figure 15 - Run charts showing progress in capturing ethnicity and religion for outpatients – data taken from PIMS

Another step towards improving the data we hold about children and young people at GOSH has been achieved in 2017. The Family Equality and Diversity Group has long made representation that there should be the facility on our PiMS system to record additional need and as a result, a new tab has been added to the patient record making this possible. Additional need is defined by family members rather than on a diagnostic basis but it should still enable us to carry out more meaningful analysis.

The teaching session and information leaflet have been refreshed to take this into account and new 'downtime' forms have also been developed to make capturing this information easier. This has now been passed to the Data Quality team to take forward.

Figure 16 - New tab on PiMS to record 'additional needs' of all kinds

The same question has been built into the screening form within the Anaesthetic Pre-Assessment Clinic which will also increase the number of children and young people for whom this is recorded. It is also being included in other registration or assessment forms to further increase its use.

It is hoped that this data can be pulled through in some form to the electronic Patient Status at a Glance (ePSAG) boards available on all wards to highlight if a particular patient has an additional need about which staff should be aware.

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 in due course, 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.

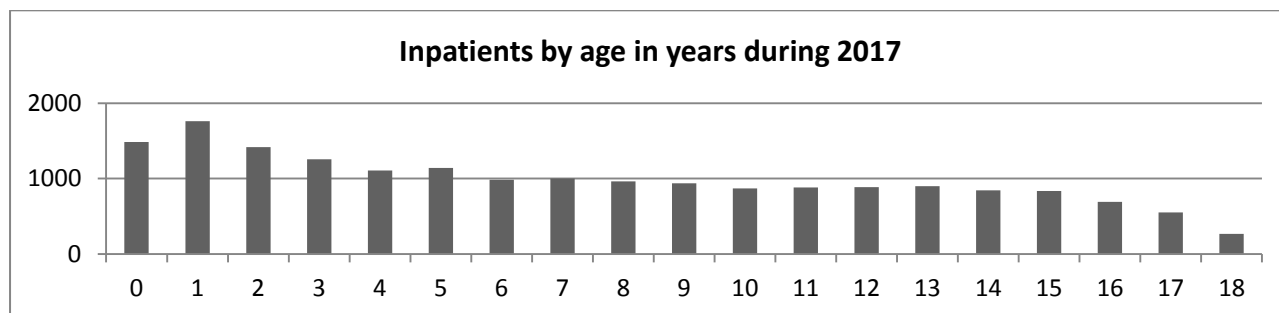


Figure 17 - Data taken from PiMS

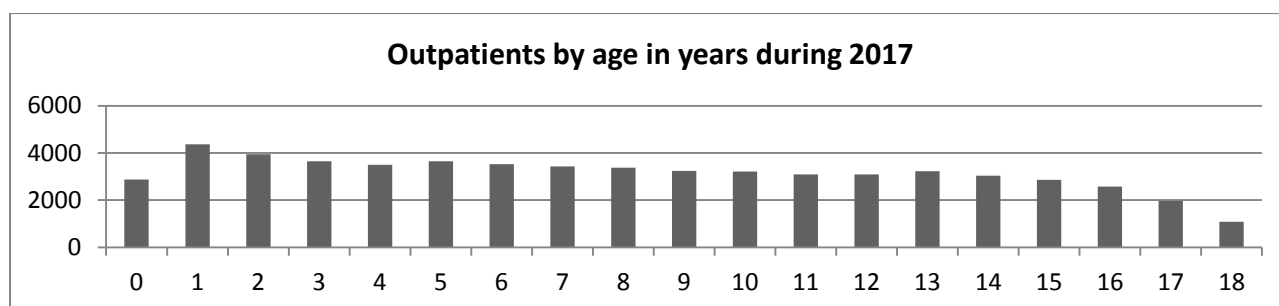


Figure 18 - Data taken from PiMS

The biggest age group 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.

Transition

This continues to be a priority for GOSH and is also one of our Equality Objectives (see page 19). 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.

The GUGI framework outlines the generic skills, knowledge, understanding and information needed to have a successful transition, in addition to the more specialty-specific topics that should be covered. Young people with additional needs will be supported throughout the GUGI framework to become as independent as possible before leaving GOSH.

Neonatal care

At any given time, approximately 5 to 10 per cent of our inpatient population are neonates (defined as less than four weeks old). Following 2016 audit data, several areas have been identified where the provision of care could be improved to better meet the needs of this population. A working group was established focused on developing a care bundle and pathway for neonates, involving standardisation of revised procedures and guidelines, development of a training package encompassing the identified areas of improvement, and updated information for families.

Disability

As described above, there is now the facility to record the additional needs (including disability) of children and young people coming to GOSH. This will enable better planning for an appointment or admission, making 'reasonable adjustments' where needed.

GOSH re-entered into a contract with Disabled GO to provide accessibility information about our facilities in

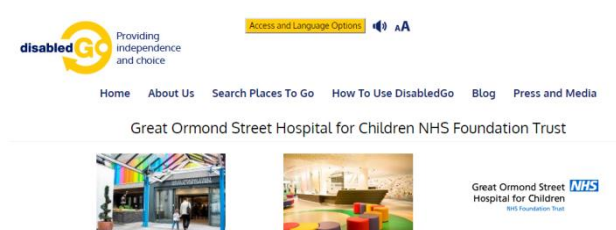


Figure 19 - GOSH section on DisabledGO

2017. The entire site (at that time) was surveyed and detailed information is available online about each ward and department, accessibility of its facilities and support available. Analytics showing how many times this information is access and for how long will be monitored during the next year or so to ensure that the information is meeting the needs of families.

A poster showing some useful Makaton™ signs has been developed and distributed to the wards. A large proportion of children and young people sign using Makaton™ so learning a few keys signs can help staff to communicate better. The helpfulness of these posters will be checked within the next year using spot checks carried out on the ward to check retention of sign knowledge.

The range of Easy Read information for children and young people with learning disabilities continues to increase, with an Easy Read version in development for every scan and diagnostic test carried out at GOSH. These are currently being finalised before clinical approval and will be uploaded to the website over the coming year.

The Learning Disabilities team expanded in 2017 and now comprises a Clinical Nurse Specialist for Learning Disabilities in addition to the Nurse Consultant. Learning disabilities support is now monitored under the aegis of the Family Equality and Diversity Group instead of by a separate steering group, as the issues and solutions needed are broadly similar across all additional needs.

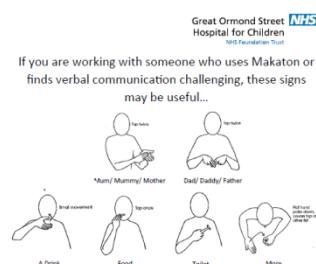


Figure 20 - Poster of useful signs. Makaton line drawings of signs copyright © The Makaton Charity 2017, makaton.org

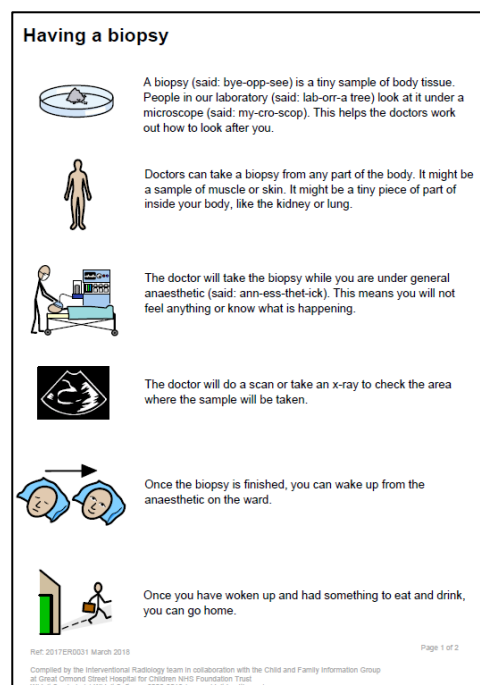


Figure 21 - An Easy Read information sheet produced using Widgit symbols

Race and ethnicity

Of those inpatients whose ethnicity we know, 32.4 per cent describe their ethnic background as White British/UK. The percentage for outpatients is 29.4 White British/UK. Although the efforts to increase recording of ethnicity as described on page 11 are showing some success, 43.2 per cent of outpatients do not have their ethnic background recorded. For inpatients, it is 37.7 per cent.

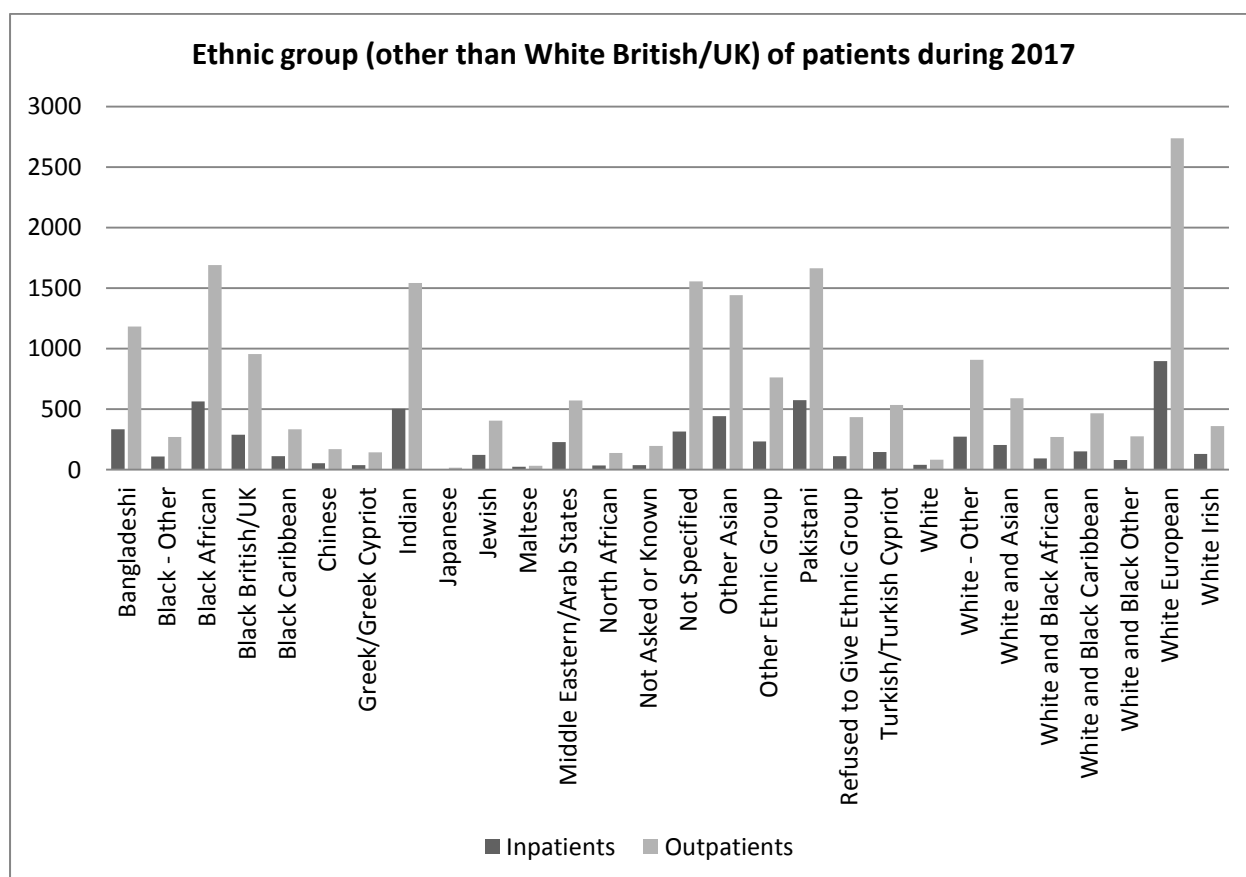


Figure 22 - Data taken from PiMS

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.

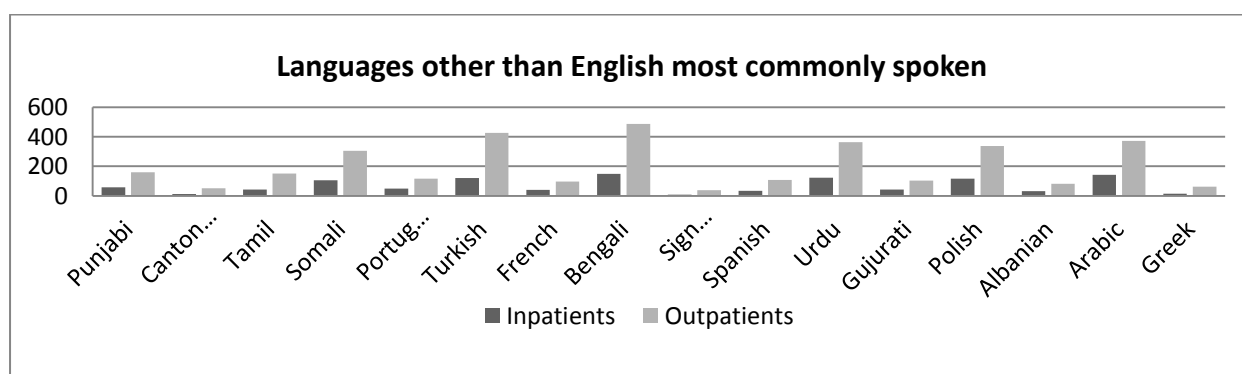


Figure 23 - Data taken from PiMS

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

Religion or belief

GOSH treats children and young people from a wide variety of religious or faith backgrounds, the most common of which are illustrated below. During 2017, agreement for increasing the space available for Muslim prayers was agreed and planning is underway. This facility will provide a segregated space for children, young people, families and staff to carry out prayer routines including ablutions. As well as facilities for Muslim prayers, a non-denominational reflection space will be included.



Figure 24 - Examples of faith facilities information sheets

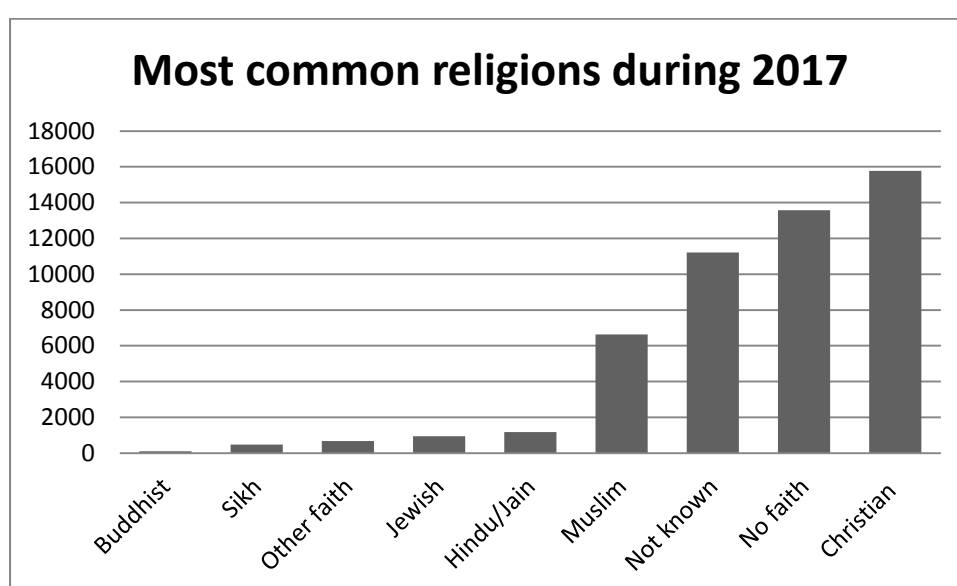


Figure 25 - Data taken from PiMS

As part of efforts to ensure everyone with a belief or faith can be supported at GOSH, the Chaplaincy and Spiritual Care department have helped produce information sheets for each major faith group seen at GOSH. As well as highlighting food options provided and support available within the hospital, details of churches, temples and synagogues are also included. Once all information sheets have been completed and approved, they will be made widely available on paper and online.

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

Sex

According to our PiMS data, the proportion of male to female patients remains broadly similar to previous years with 54.1 per cent of inpatients recorded as male and 50.6 of outpatients. In certain clinical divisions, there is a larger male patient population largely related to higher prevalence of many congenital disorders in males.

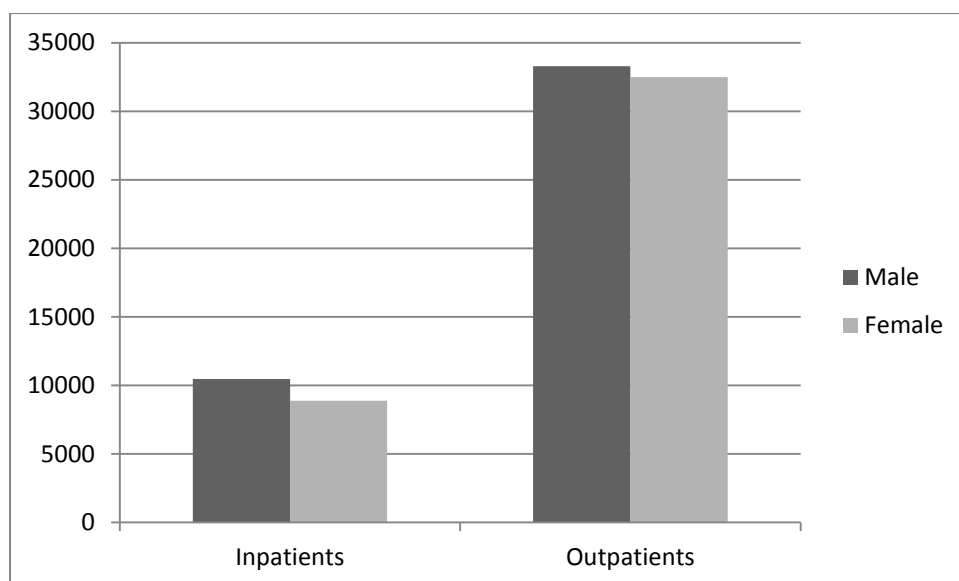


Figure 26 - Sex of patients during 2017

Monitoring of bed allocation for young people aged 12 or older continues on a monthly basis.

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

Other protected characteristics

In addition to the characteristics reported above, GOSH also aims to improve the experience of children, young people and families from the following groups in a number of ways.

The Trust has a legal duty to check that each female patient is not pregnant before carrying out treatment. There has been some reticence in staff asking questions to check so to remove any judgement calls, all females aged 12 years or older are asked about their periods or any chance they could be pregnant. Systems are in place to ensure privacy and identify any safeguarding issues as a result of pregnancy testing.

While gender re-assignment is primarily regarded as a medical or clinical issue, the Patient Experience team is trying to increase awareness of 'gender fluidity' so all experience surveys (including the Friends and Family Test) now offer the option 'I think of myself as' under sex/gender. While this is occasionally answered with 'unicorn' or 'tired', cards have been received from children, young people and family members who identify as 'non-binary'.

Gender/Sex:

☐ Prefer not to say

☐ Male

☐ Female

☐ I think of myself as _____

Figure 27 - Answer options on Friends and Family Test card

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 more. 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.

Progress against Equality Objectives at GOSH

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

Current objectives

The following objectives are for the period 2015 to 2018.

Achieve Accessible Information Standard

This objective was time-limited as NHS England had required the Standard to be met by the end of July 2016, with systems in place to record centrally any communication and information support needed as well as meeting these needs.

GOSH can now supply information in alternative formats on request. The inclusion of the additional needs tab on PiMS finally allows staff to record communication need and preferred information format centrally. It is now feasible to advertise the capacity to provide information in alternative formats more widely and this will be a priority in 2018.

Measurement: Having the facility to record additional need now enables the Trust to monitor completion rates for these fields as well as any requests for communication and information support received.

Progress against objective: The 'additional needs' tab on PiMS has had great impact to date, with records being updated as part of routine clinical contact. The Quality Improvement team have also developed a mechanism for monitoring the number of records updated and which additional needs are selected, which can now be reported to the Family Equality and Diversity Group. Revision of Trust-wide data collection paperwork is underway to enable all staff to collect data about additional need.

The range of Easy Read information has also increased and draft versions are now available for each diagnostic procedure used at GOSH. As part of radiology patient experience improvements, the sheets are now being checked for accuracy by clinicians. A small selection is currently being evaluated with Project Search students.

Next steps: 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.

Improve publicity about support for children, young people and families

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

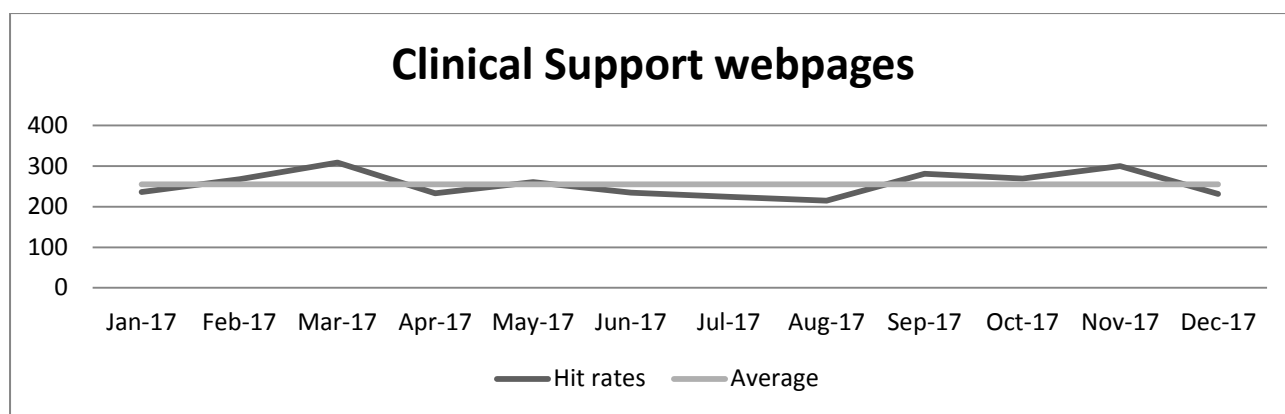


Figure 28 - Data from Google Analytics reports from 2017

The average number of hits to the clinical support services pages has remained steady at average of 255 hits per month. This is an increase on the baseline measure from December 2015 which was 210 hits.

Progress against objective: 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.

Next steps: It is unclear how the current re-organisation of the GOSH website will impact on progress. It is clear that the information will remain but the level of visibility on the site may increase or decrease depending on the location chosen by the Web team.

Support ongoing work to improve transition to adult services

Following publication of NICE guidelines on transition, work has continued at GOSH by the Transition Improvement Manager with the aim that all applicable young people should have a Transition Plan in place to support their move from children's to adolescent or adult services.

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

Progress against objective: This year has seen the development of the Growing Up Gaining Independence (GUGI) pathway which clearly shows what tasks need to be completed as part of transition planning. A major component of this is to enable the 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.

Next steps: To continue to work with clinical services to advise introduction of the GUGI pathway, developing information for young people to enable them to understand their health. Adaptations to the pathway for young people with a learning disability are also being developed, alongside specific information for parents and Easy Read information for the young person.

Continuing progress against previous objectives

The Family Equality and Diversity group continues to monitor progress against objectives for the period 2012 to 2015.

Reduce the number of patients for whom ethnic group and religion is not recorded

Although improving the quality of our data continues to be a challenge, the Family Equality and Diversity group is confident that progress has been made during 2017. Short teaching and discussion sessions have proved popular with frontline staff, giving them an understanding of the use of data at GOSH as well as the opportunity to explore suitable phrases for collecting this information.

The Family Equality and Diversity group continues to monitor completeness of ethnic group and religion recording using the run charts shown right. Now that the resources have been handed over to the Data Quality team, monitoring will continue.

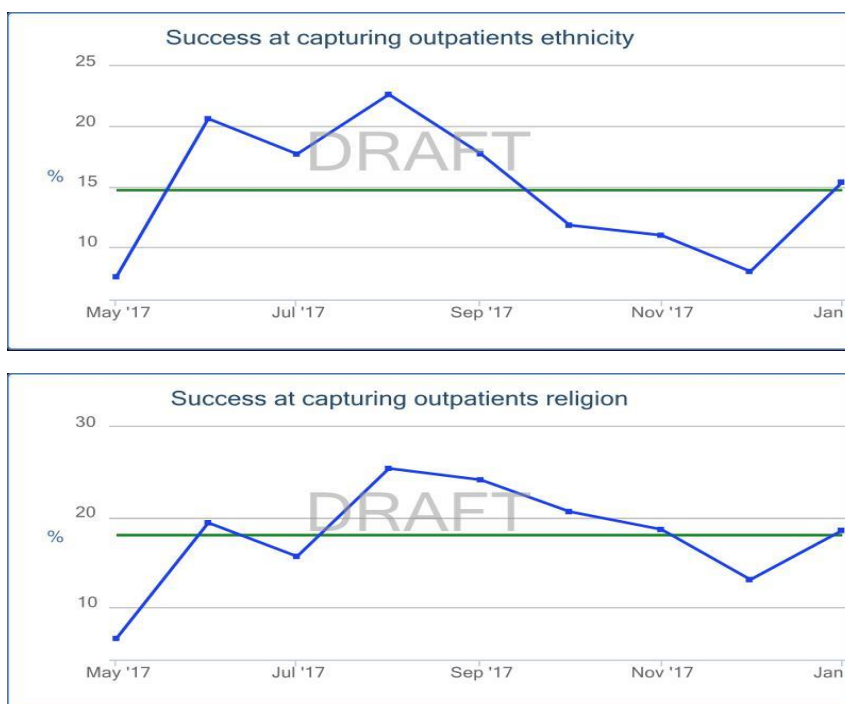


Figure 29 Outpatient ethnicity and religion recording

Increase the percentage of respondents stating that they agreed that the hospital understands their additional needs and put arrangements in place to meet them

In previous years, the Trust-wide survey (developed with Ipsos MORI) contained specific questions to measure the experience of these families. Unfortunately, the national survey now used does not contain such questions so no direct comparison is possible. However, the real-time survey and feedback system currently in development has been amended to include this question so in future monitoring how well reasonable adjustments are made for children and young people with additional needs will be possible.

A proxy measure for this objective could be the Patient Lead Assessment of the Care Environment (PLACE) inspection. This was carried out in March 2017 and showed an improvement from 73.5 to 93.6 per cent in the 'disability friendliness' score of the wards visited.

Family Equality and Diversity Group

The Family Equality and Diversity Group has continued to meet during 2017. In September, the group welcomed members of the Learning Disabilities Steering Group – as the aims and objectives of both groups are so similar, it was felt to be more efficient for all equality and diversity issues affecting children, young

people and families to be considered by one working group. As part of this, the Terms of Reference were revised with members feeling that they are still working effectively and delivering against objectives.

Highlights of the previous year include:

- Presentations received from Redevelopment and GOSH Arts
- Launch of revised Disabled Go information about GOSH
- Support of improving Muslim prayer facilities
- Development of teaching and information resources around equality data
- Reviewed several nationally published reports for consideration of issues at GOSH

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

GOSH is now 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.

Conclusions and next steps

Progress in meeting the General Duty of the Equality Act 2010 will continue to be monitored by the Family Equality and Diversity Group, as will movement towards meeting our Equality Objectives above.