Great Ormond Street Hospital for Children NHS Trust

Meeting the duties of the Equality Act 2010 in our function as a healthcare provider

This report details how Great Ormond Street Hospital (GOSH) is meeting the requirements of the Equality Act 2010, in particular to publish information supporting the general duty of the Act regarding public organisations[1].

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[1] (1) A public authority must, in the exercise of its functions, have due regard to the need to—
(a) eliminate discrimination, harassment, victimisation and any other conduct that is prohibited by or under this Act;
(b) advance equality of opportunity between persons who share a relevant protected characteristic and persons who do not share it;
(c) foster good relations between persons who share a relevant protected characteristic and persons who do not share it.

Introduction

Great Ormond Street Hospital (GOSH) provides specialist care at a tertiary referral level, that is, children are referred to GOSH for treatment from another healthcare organisation, such as a local hospital. As such, we have care purchasing agreements with over 150 primary care organisations, and children are referred to us from all parts of the UK and beyond. We also have a thriving International and Private Patients (IPP) Division, treating patients from many areas of the world, but predominantly the Middle East. An overview of our function as a healthcare provider and how it might affect equality and diversity follows along with associated data.

Data collection at GOSH

Information about our patients and families is collected in numerous different ways and at various stages of the patient journey. Data collection methods have developed in a piece meal fashion since the introduction of our Patient Information Management System (PiMS) in the mid 1990s and currently are recorded both electronically and on paper in the medical notes.

On referral, families are asked to complete and return Family Form 1, which comprises basic contact details, members of the healthcare team, a statement of parental responsibility, ethnic group status and entitlement to NHS treatment. This is inputted on receipt into PiMS and forms the basis for all future communications to the family until updated. Being held in a database, the data is readily searchable and completeness of collection is good.

Before admission, families are asked to complete Family Form 2. This gives the opportunity to record the child's activities of daily living, including details of mobility, toileting, feeding, play and pain assessment. The content of this form is used by nursing staff on admission to collate a care plan for the admission, but is not recorded on PiMS so is not so readily searchable.

The Patient Assessment Form (PAF) is essentially a medical clerking form and is completed by the doctor or nurse assessing the child on admission or at appointments. The form contains prompts to record information about disability status, general health and family issues. The PAF is filed in the medical notes rather than held electronically.

Other sources of data include Pals enquiries/complaints. The Pals and Complaints team attempt to record information about the complainant but there are occasions when this is not possible or could intrude on the enquiry/complaint process. All enquiries/complaints are registered on the Datix system, which until recently did not have the functionality to pull data across from PiMS so it had to be added manually. Both teams compile an annual report, from which the data in this report is taken.

As a provider of many National Commissioning Group and other specialised services, GOSH contributes clinical data to a number of registries. This data has not been accessed for this report, but mechanisms to so do for future editions will be investigated further.

In addition, GOSH surveys its patients and families regularly – all surveys and involvement exercises are overseen by the Patient/Public Involvement and Engagement Group. For the most recent inpatient survey conducted by Ipsos MORI, quotas were set and weighting applied to ensure the results represented the known demographic profile of GOSH patients at the time of treatment (1st June to 31st August 2010). This demographic profile included the patient's age, gender and ethnicity but not the other protected characteristics covered by the Act.

Until recently there has been no standard demographic sheet available to ensure that we are surveying a representative group of patients/families or to breakdown data by protected characteristic. A standard sheet covering more protected groups is in development with the aim that it will be included in all survey work in future. It is currently being tested with our rapid response survey, with initial results being available in the coming months.

Departments at GOSH already carry out a great deal of data analysis both to monitor our current service delivery and to develop and measure improvements. It is intended that this current analysis is

examined further to see whether deeper analysis by protected group is feasible. This work is ongoing and will hopefully be available for inclusion in future reports.

In summary, in preparing this report, we have had to rely mainly on information held in PiMS, Pals/Complaints and on survey work. Data held only on paper – while rich in relevant material – has not been contributed to this report.

Protected groups at GOSH

As a children's hospital, GOSH is in a rather different position to most other hospitals in that it could be argued that several protected groups are not relevant to children aged less than 16 years. An additional challenge is that in order to fully understand our service provision and its suitability for our users, we additionally need to consider the protected characteristics of our patients' parents. Currently, we do not collect much data about our patients' parents so this will be considered more fully in the coming year.

Age[2]

Overall patient population

GOSH is a paediatric hospital and as such our patient population is, in the main, aged less than 19 years. The median age of inpatients is five years while the distribution of ages of outpatients is more even and includes a number of adults – there are a small number of departments, whose patients are adult, for example, genetics for prenatal diagnosis and genetic counselling.

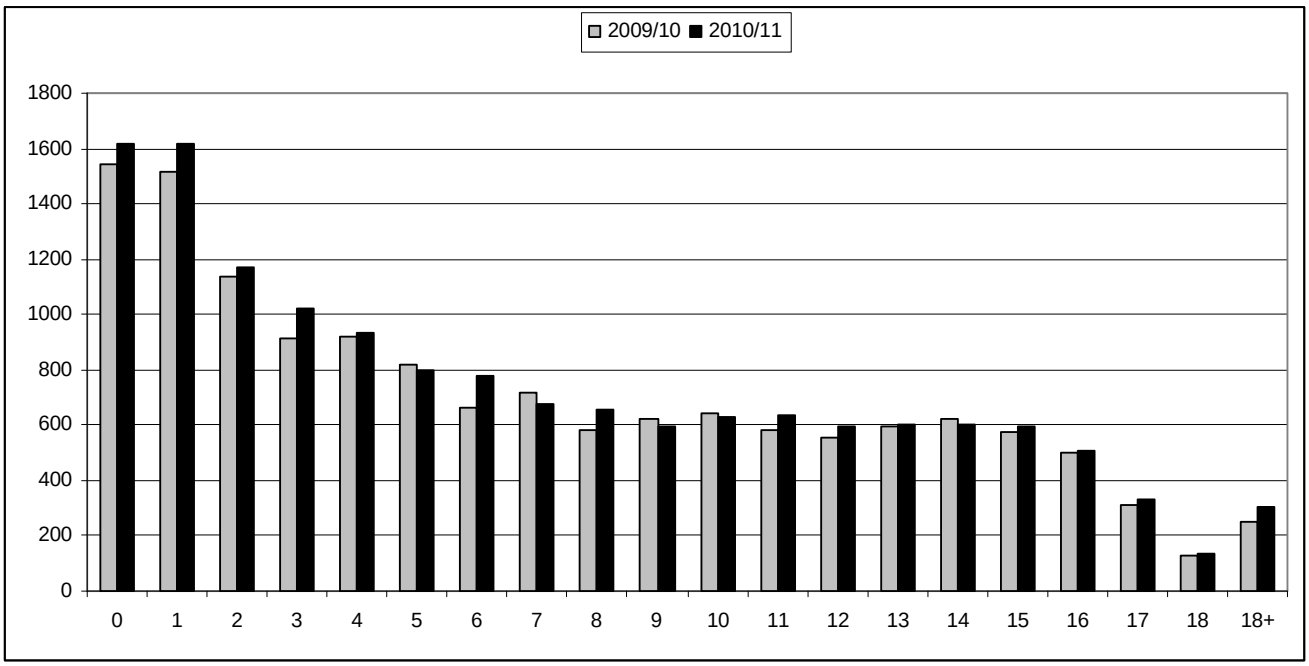


Figure 1 - Age of inpatient population - 2009/10 and 2010/11

[2] Note: For this section, the x-axis for each graph should be understood to represent chronological age. For instance, children included in the category '1' are those who have had their first birthday but have not yet reached their second.

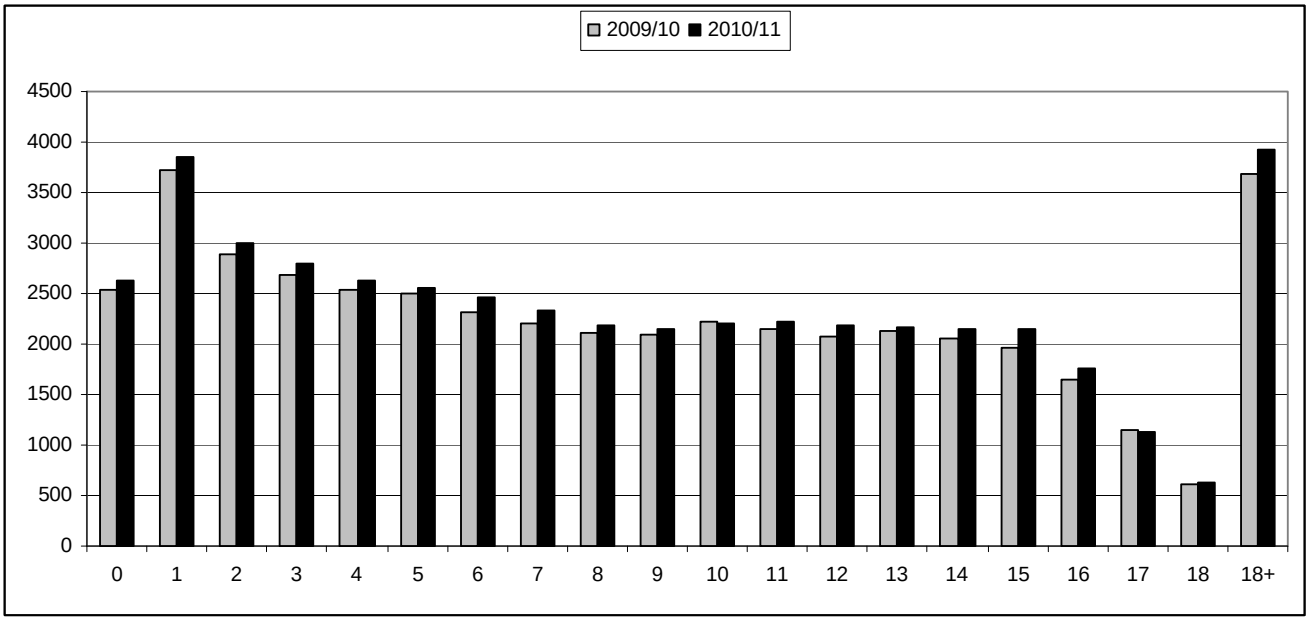


Figure 2 - Age of outpatient population - 2009/10 and 2010/11

Play support is available for all of our patients, either as a distraction or in use to prepare children and young people for procedures. Every ward has a well-stocked play room with activities for all ages and a bedside television system is being introduced that will give children and young people easy access to educational as well as entertainment content.

In addition, the Hospital School and Centre offer education and activities throughout the year, including a room dedicated to our teenage patients with age-appropriate games and pastimes. In recent years, services for our older patients, aged 11 and older, have been improved, with the appointment of a clinical nurse specialist for adolescents who has improved processes for transition from children's services to adult services.

Our adolescent clinical nurse specialist also carries out regular consultations on privacy and dignity – a concern for our teenage patients. In our latest survey, 13 out of 15 respondents said that their privacy was 'always' or 'usually' respected by staff. Following the survey, there has also been discussion about same sex accommodation for teenagers, who state that they would often prefer to share with someone of the same age than gender.

Our most recent survey of inpatients experience was carried out in February 2011 by Ipsos MORI. Our key indicators of service quality are: 'overall satisfaction with last visit to GOSH' and 'likelihood of recommending GOSH to a friend or relative'. Wherever possible, children and young people were interviewed as well as their parents/carers – 750 interviews were carried out overall, with 612 interviews with parents of inpatients and 138 interviews with the inpatients themselves. The responses from all age groups of children and young people were broadly similar, showing between 94 and 98 per cent satisfaction with last visit. The likelihood of recommending GOSH was also similar for all age groups, ranging from 93 to 100 per cent.

Average length of stay

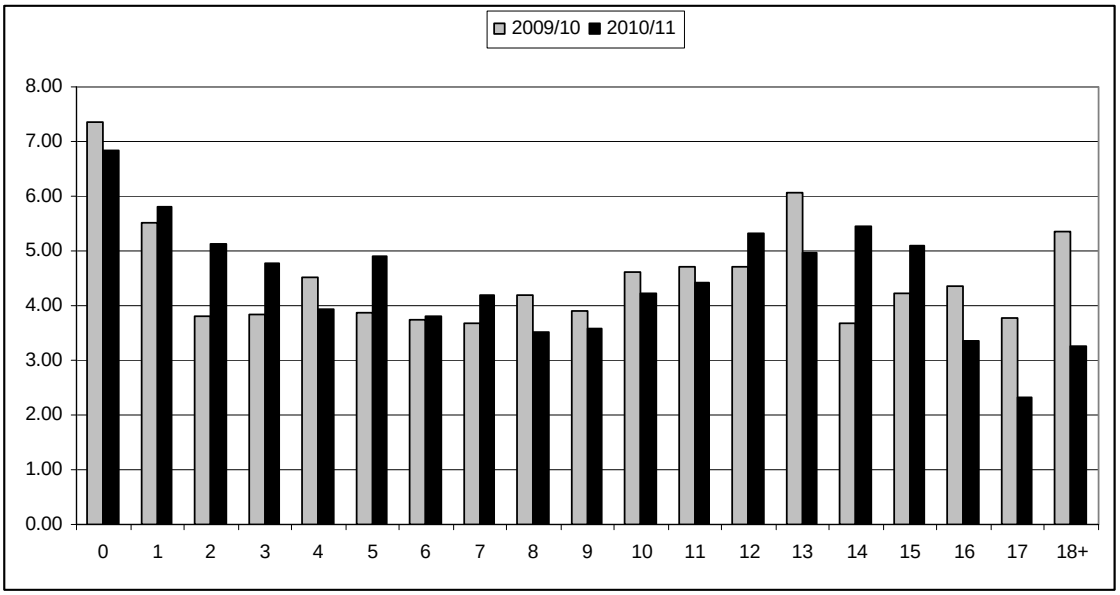
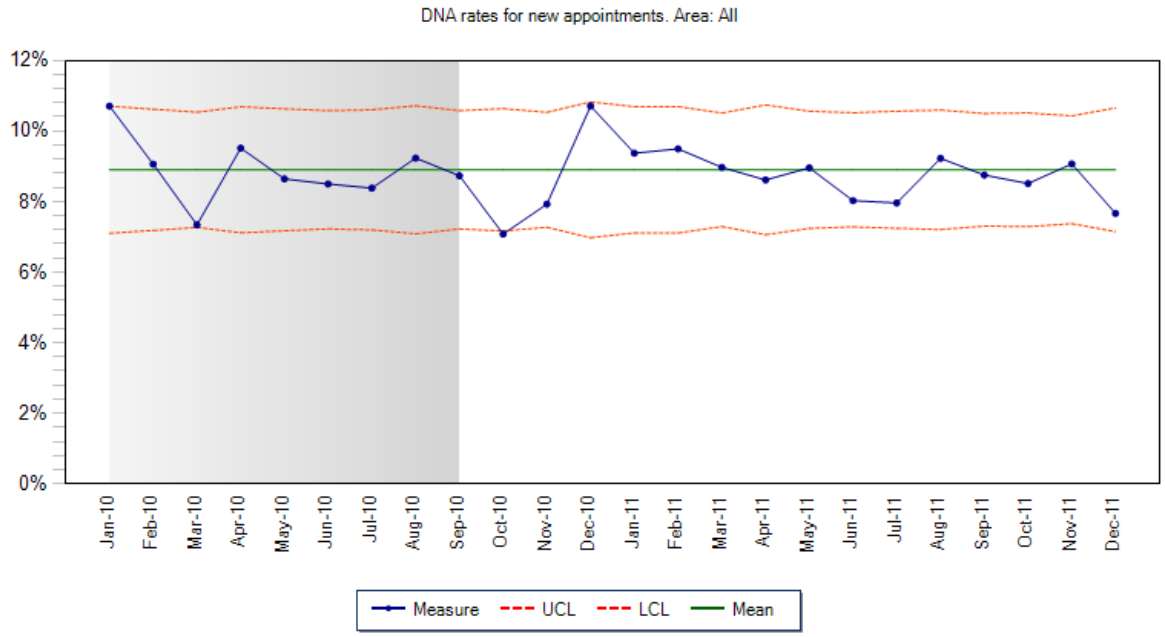


Figure 3 - Average length of stay by age of patient - 2009/10 and 2010/11

Our average length of stay at GOSH is five days. Unsurprisingly, babies admitted in the first year of life tend to have a slightly longer length of stay, usually because they need a period of stabilisation before treatment can be started. Additionally, newborn babies are more complex clinically so may require a longer recovery time. In 2010/11, teenagers also seemed to have a longer than average length of stay although the reasons for this are not clear.

'Did not attend' rates for outpatient appointments

The proportion of outpatient appointments which were 'not attended' is not currently analysed for all protected characteristics. However, the SPC chart below shows that our overall DNA rates for new appointments are within expected limits and are starting to decrease over time. The feasibility of analysing this data in greater detail will be investigated in coming months.



Disability

It is known that a high proportion of the children and young people seen at GOSH, by virtue of their medical condition, fall within the statutory definition of ‘disabled’. The recording of perceived disability status has proved difficult in the past, but is now collected via our new patient documentation, which is stored in medical notes rather than in our Patient Information Management Solution (PiMS). As well as recording disability status, this documentation elicits information about patients’ religion, language spoken and activities of daily living.

Individual patients are provided with support from our teams of occupational therapists and physiotherapists to ensure that they are enabled to carry out activities of daily living as far as possible during a hospital stay. The teams can also advise families on adaptations for home to encourage independence. We are also improving the availability of equipment such as hoists which will be available in all rooms within our new building, due to be opened in the spring of 2012. Psychological and practical support is also available to all patients through Psychosocial and Family Services.

In the past few months, a full audit of the accessibility of the hospital site has been carried out. The results of this audit are not yet available but are expected to highlight areas for improvement such as visual contrast between doors and walls, accessibility of departments and door widths in some of the older parts of the site.

Following attendance at the Camden Health Scrutiny Committee in 2010, at which there was a presentation and discussion around service provision to d/Deaf people from the local Camden Deaf Focus Group, further discussions are planned to identify areas for improvement at GOSH. In addition to this, the use of webcam technology to improve response times for British Sign Language (BSL) interpretation is being investigated.

After submitting evidence to the Care Quality Commission, we have commissioned a baseline audit of our services to children and young people with learning disabilities and the policies that support delivery of these services. While the audit identified clear pockets of good practice throughout the Trust, such as the Hospital School and Wolfson Neurodisability Service, further work is planned to spread these practices further throughout the organisation.

During 2012, a number of focus groups are planned to look at the experiences of patients and parents from several groups, such as patients with an Austistic Spectrum Disorder or from a particular faith group. When completed, the results from these groups will be made available to clinical units to enable future planning.

Gender re-assignment

As a children’s hospital, GOSH does not carry out gender re-assignment as such. However, a small proportion of our patients are born with a disorder of sex development. The teams (predominantly the Urology, Genetics and Endocrine departments) work with the family to assign gender and then carry out the treatment necessary. Psychological support is available at all points of the patient journey through to transition to adult services.

Marital or civil partnership

As a children’s hospital, it is unlikely although not impossible, that any of our patients are married or in a civil partnership. More relevant perhaps are the pressures of caring for a child with a long term or life threatening condition which puts enormous strain on marriage and partnership and that many of our patients are cared for on a day to day basis by a single parent. In recent years, we have also had a number of enquiries to our Patient Advice and Liaison Service (Pals) from separated fathers who are not always receiving copy letters about their child. We are now aiming to investigate collecting data on parents’ marital or partnership status in the coming year.

Pregnancy and maternity

GOSH does not have a maternity or obstetrics service. However, in 2010 we did safely deliver our first baby when a mother of a patient went into labour unexpectedly.

Pregnancy testing before treatment

You may hear us referring to 'girls of childbearing age' – what does this mean?

What will you ask me?

Will everything I say be kept private?

Figure 4 - Information for young people

GOSH carries out a great deal of prenatal diagnosis with pregnant mothers, both from a genetic standpoint and to confirm suspected diagnoses from routine scans in secondary care. The Cardiac Fetal Screening Unit diagnoses many children with a congenital heart defect each year, which then informs planning of surgical repair at the optimum time after birth. We also offer a prenatal urological/renal diagnosis service to identify potential problems that will require correction soon after birth.

We make a point of checking the menstrual history and potential for pregnancy of our female patients' aged 12 or older, before all x-rays and invasive procedures. Accompanying information is provided to the girl as illustrated above. If one of our patients were to become pregnant, this would be recorded in the medical notes and appropriate action taken.

Race

Overall patient population

GOSH treats a diverse population of children and families. Around half of our inpatient population considers themselves to be White British/UK. Figure 5 below shows the ethnic group reported by the remainder of our population. The next biggest group within our inpatient population is those who 'did not state or were not asked their ethnic group' or 'not specified' at 12 per cent. This proportion has increased from 2009/10 where 10 per cent fell into this category.

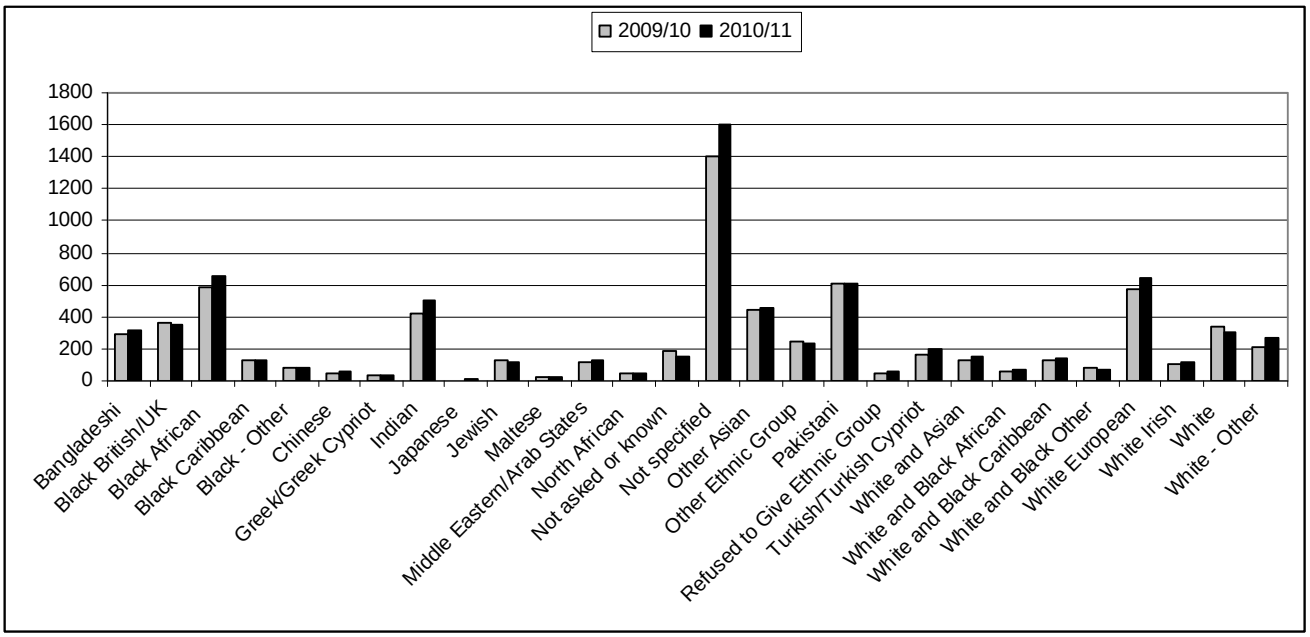


Figure 5 - Reported ethnic group of inpatients - 2009/10 and 2010/11

The picture is broadly similar for our outpatients, 46 per cent of whom described themselves as White British/UK. Figure 6 below shows the ethnic group reported by the remainder of our population. Again, the proportion of those who 'did not state or were not asked their ethnic group' or 'not specified' is the next biggest group standing at 18.5 per cent for 2010/11, similar to the position in 2009/10. Further investigation is needed to better understand these categories and how they are being used by staff – currently we are not clear how many patients recorded as 'not specified' were not asked or refused to give their ethnic group.

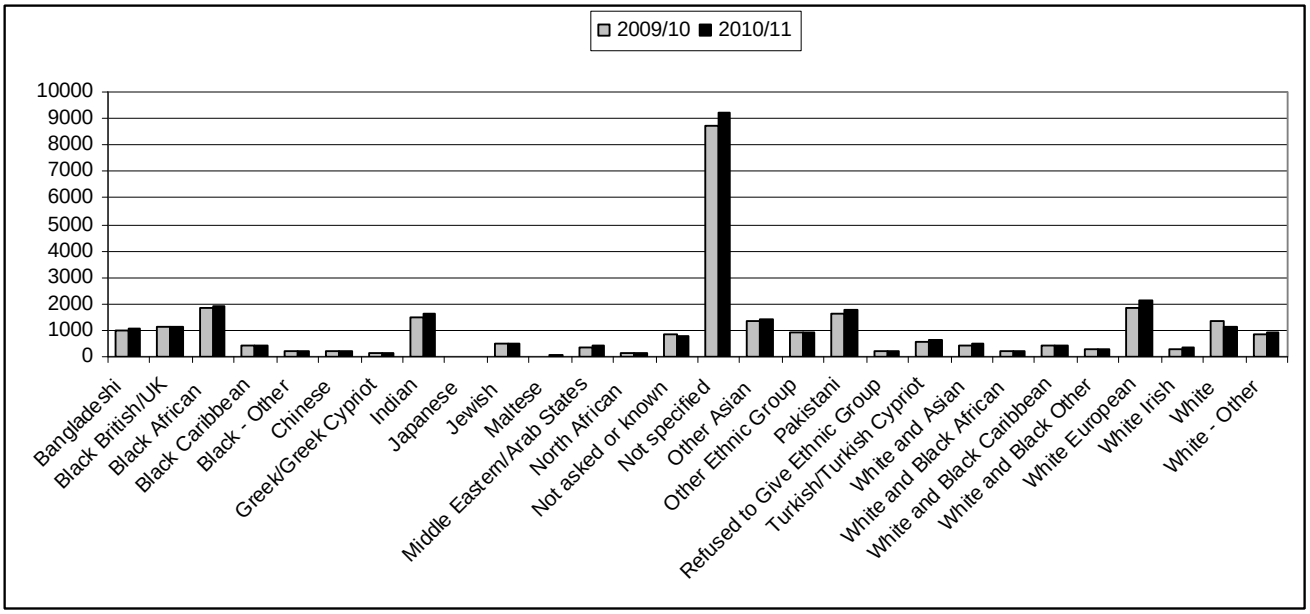


Figure 6 - Reported ethnic group of outpatients - 2009/10 and 2010/11

The results from the 2011 Ipsos MORI inpatient survey were broken down by ethnic background, into 'white' and 'non-white'. Ninety-six per cent of respondents with a white background were satisfied with their last visit, as were 97 per cent of non-white respondents. Similarly, 95 per cent of white respondents were likely to recommend GOSH and 99 per cent of non-white respondents.

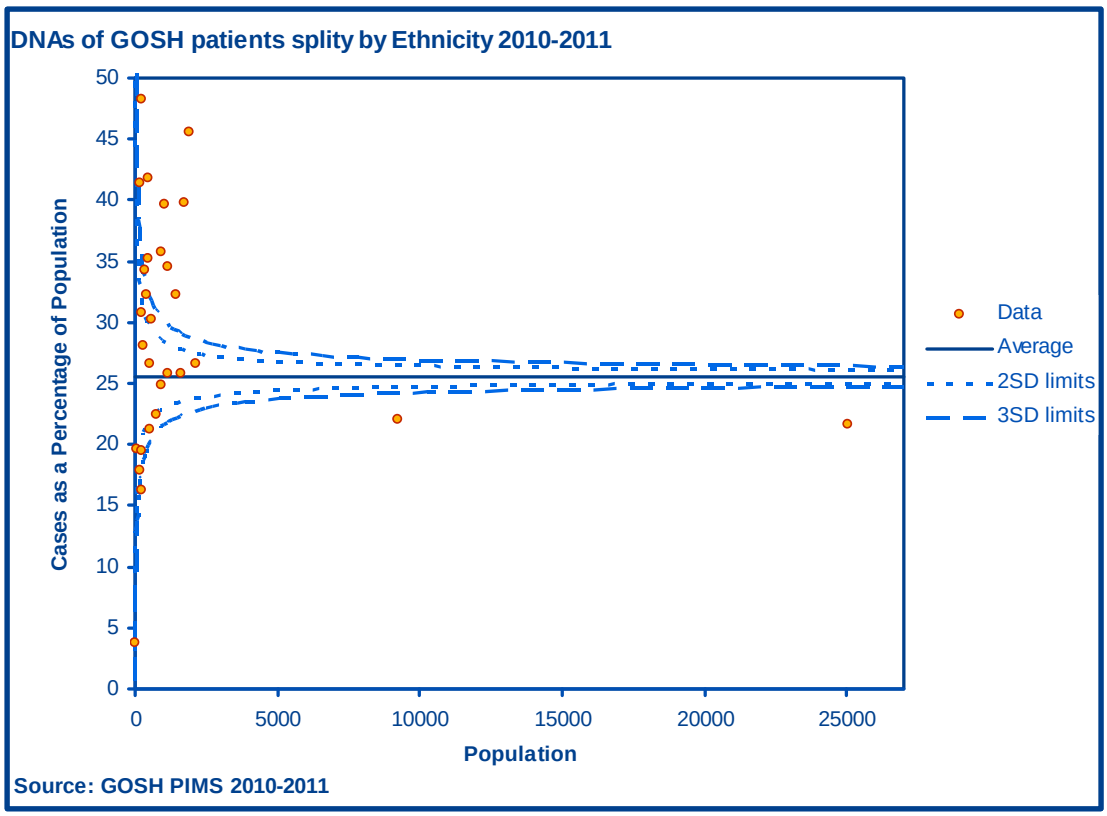
Clinical outcomes are being developed for many specialties at GOSH, the majority of which are also investigating outcome by protected group, especially ethnic background. Specialties currently developing outcome measures include our Child and Adolescent Mental Health Service, Endocrinology and Chronic Fatigue Syndrome teams.

The Metabolic and Dietetic departments recently looked at outcomes of children with phenylketonuria (PKU). Children with PKU are identified through newborn blood spot screening and their condition is managed with a special diet. Looking at test results to identify patients' and parents' control of the special diet identified that control decreases with age and that patients from an ethnic minority background do worse than their white counterparts. There are a large number of Turkish patients treated by GOSH so the department has started to hold clinics dedicated to Turkish patients, so that cultural aspects of the special diet and language needs can be considered with the aim of improving outcomes for these patients.

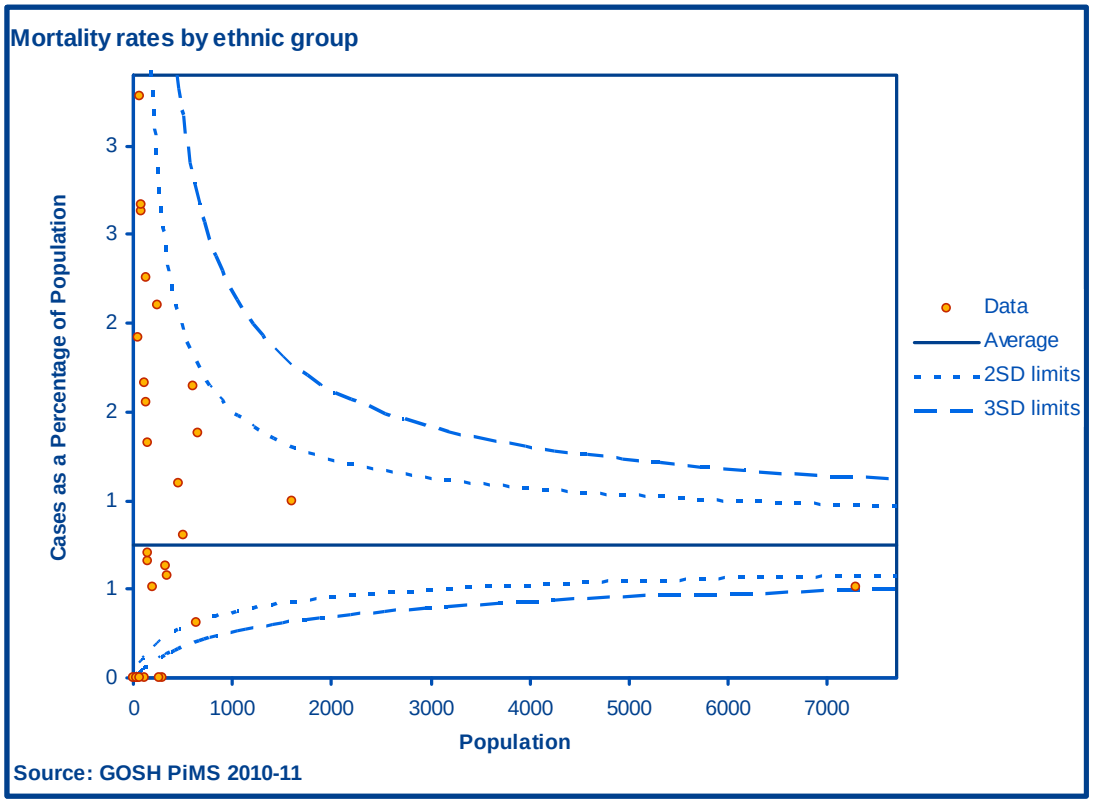
Did not attend (DNA) rates for outpatient appointments[3]

All appointment letters are currently sent out in English, although telephone interpreting can be used to confirm or re-arrange appointments when required. As shown in the funnel plot below, several groups of patients are showing significantly higher DNA rates – the data points above the upper 3SD limit – these include all Black ethnic groups, Bangladeshi, Other Asian, North African, White/Black Caribbean, White Irish and Other ethnic group. It is not clear whether language difficulties are the basis for these differences but further investigation will be carried out to ascertain this. Similarly, the reason for significantly low DNA rates for White British/UK and Not specified groups – the data points below the lower 3SD limit - will be looked at in more depth.

[3] If a patient had more than appointment and did not attend each appointment, they will be counted more than once



Mortality rates



As shown in the funnel plot above, there are no highly significant differences in mortality rate by ethnic group.

Enquiries to Patient Advice and Liaison Service (Pals) and complaints

Wherever possible, the ethnic group is recorded of anyone making an enquiry to our Pals service, as illustrated below. There are some circumstances where it is not possible to record this data, for instance in enquiries made by telephone. Where ethnic group is recorded, it is broadly in line with our overall patient population. Equally, whenever a formal complaint is made, an attempt is made to record the ethnic group of the person making the complaint. In the past year, 28 per cent of complaints have been made by people recorded as White British and 20 per cent from other ethnic groups. For the remainder, the ethnic group of the complainant is not known.

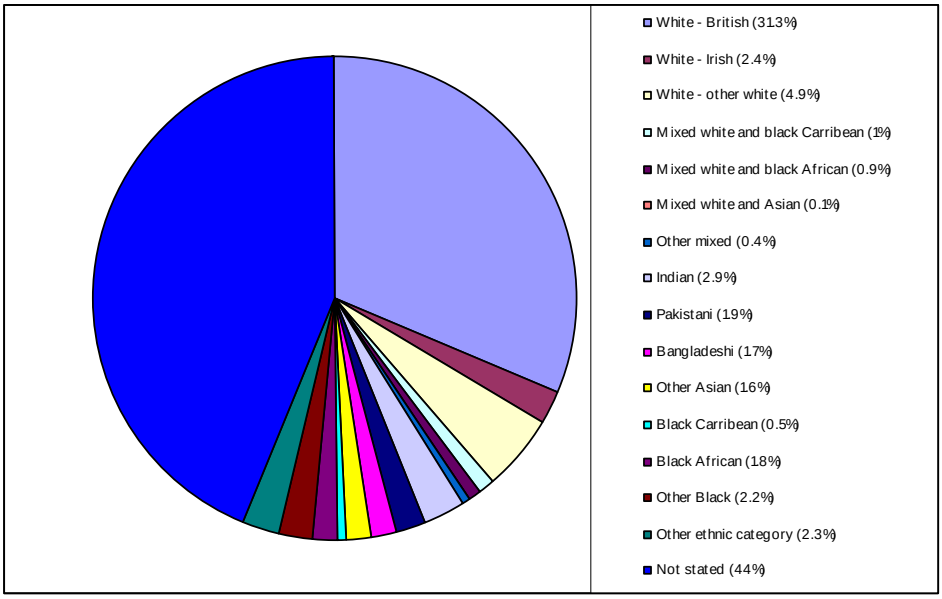


Figure 7 - Enquiries to Pals by ethnic group 2010/11

Religion or belief

Religion is included in the new patient documentation in more detail than previously so may improve reporting figures, particularly if staff reticence about asking questions is the cause of low reporting rates.

Overall patient population

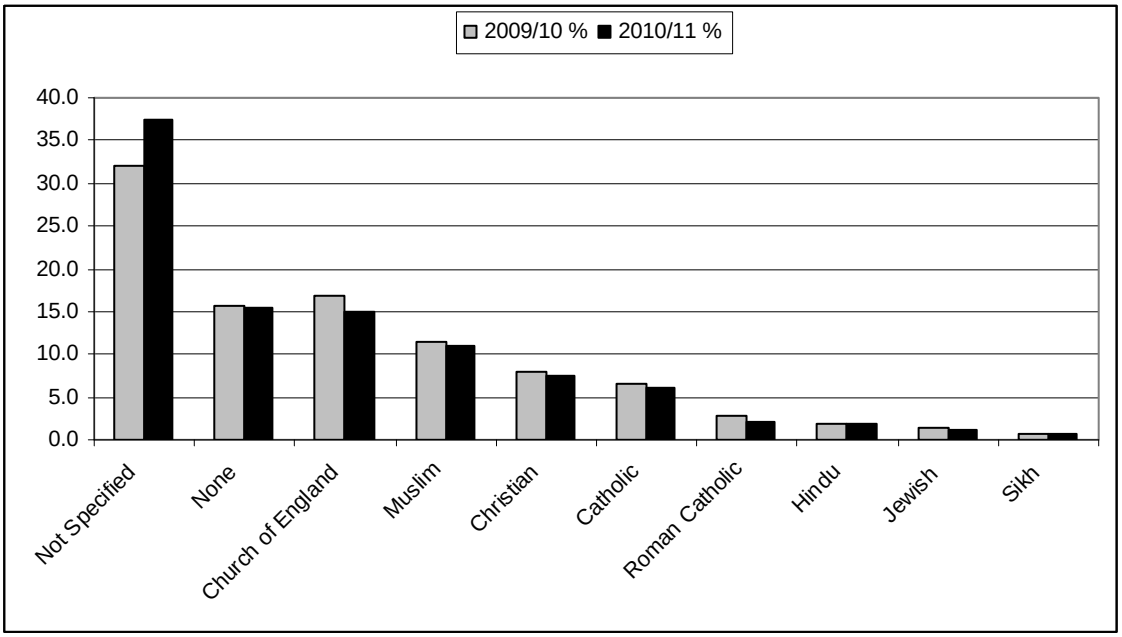


Figure 8 – Ten most common religions reported by inpatient population - 2009/10 and 2010/11

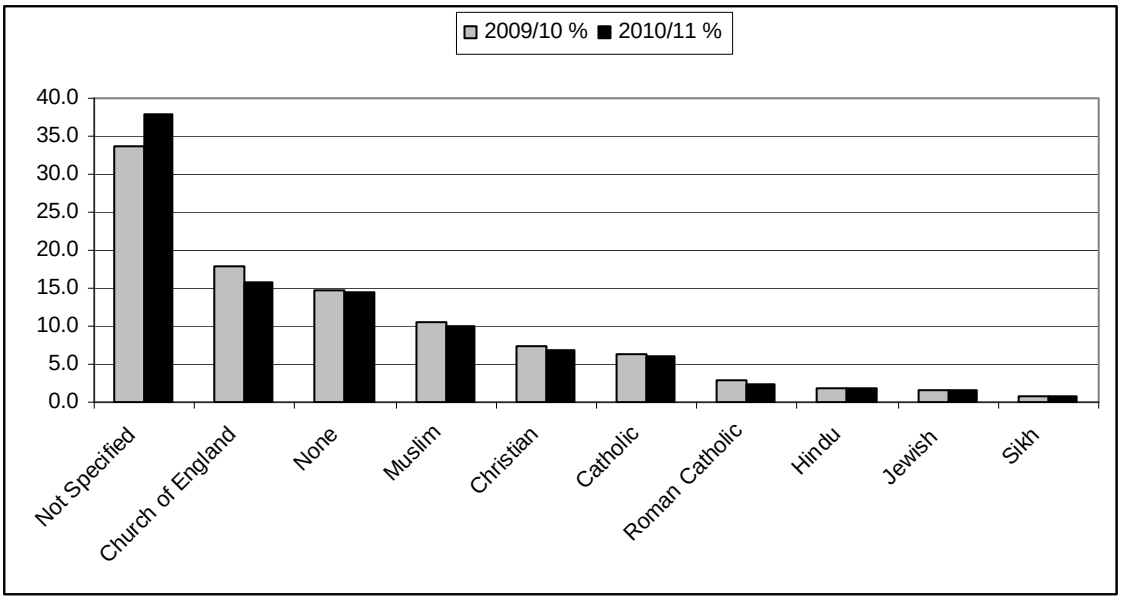


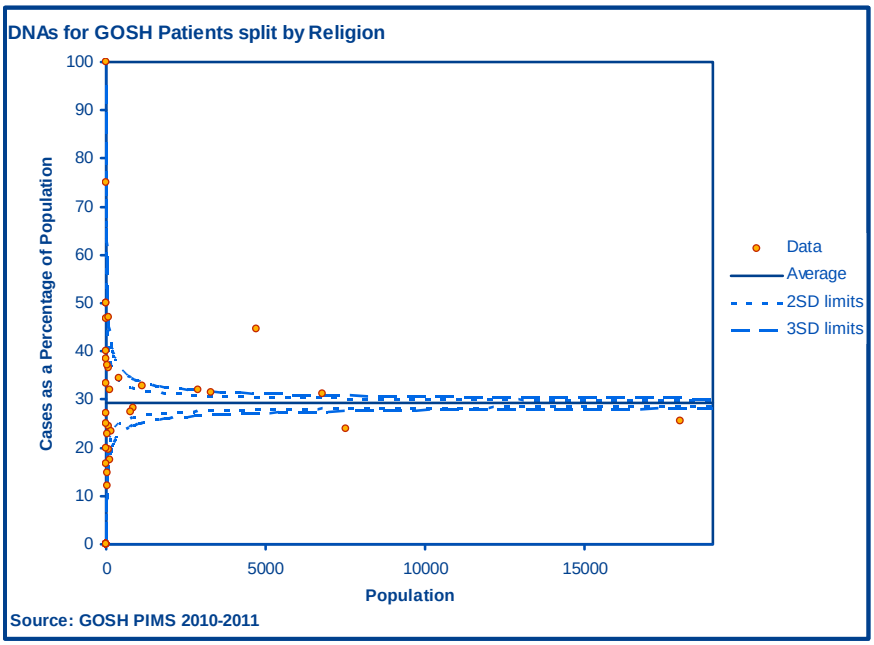
Figure 9 – Ten most common religions reported by outpatient population - 2009/10 and 2010/11

Our chaplaincy and spiritual care team have representatives from the Church of England, Roman Catholicism, Judaism, Islam and the Greek Orthodox Church and local faith representatives can be called in if required.

In the past year, our Multifaith Room has been refurbished so that it is better suited for our Muslim patients and is now being more heavily used than previously. Likewise, our Shabbat Room for Jewish families is valued highly. Special arrangements are put in place for major faith festivals, such as Ramadan, with additional facilities available for breaking of fast for instance. On a day to day basis, a wide range of specialist diets, such as Kosher and Halal, can be accommodated at GOSH, both for our patients on the wards and in our eating facilities for parents, visitors and staff.

Did not attend (DNA) rates for outpatient appointments[4]

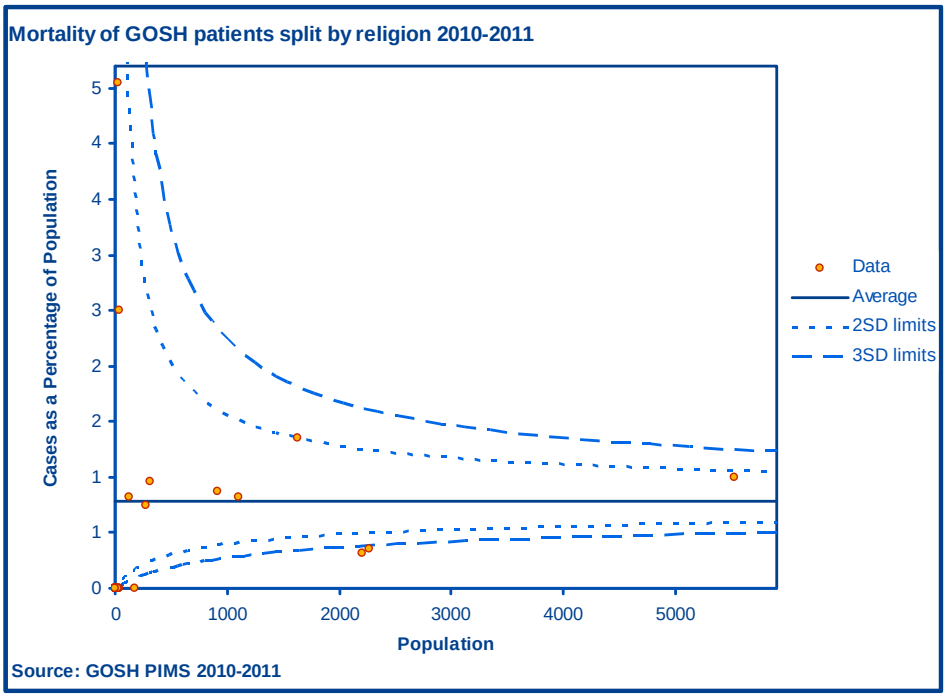
As stated earlier, all appointment letters are currently sent out in English, which may impact on the DNA rates shown in the funnel plot below. Patients reporting the following religions show highly significant difference to the average DNA rate: Catholic, Christian Scientist, Muslim, Non-conformist, No religion and Plymouth Brethren, although there are low numbers for some of the groups.



[4] If a patient had more than appointment and did not attend each appointment, they will be counted more than once

Significantly lower DNA rates were seen for Church of England and Not specified groups, although again the reasons for this warrant further investigation.

Mortality rates



As shown above, there are no significant differences in mortality rates for specific religions.

Sex or gender

Overall patient population

As shown in the graphs below, overall activity has risen from 2009/10 to 2010/11 but the proportion of male to female patients remains similar. In certain clinical units, there is a larger male patient population largely related to higher prevalence of many congenital disorders in males.

Wherever possible, we offer our patients the choice of sharing a bay with other patients of their own gender, although this is not possible in intensive care units for instance. This is less likely to be an issue in future, with the move towards single bedded rooms for the majority of patients leaving multi-bedded bays for higher dependency care. Accommodation for parents is mainly by the bedside, although a Mothers' Unit is available for female-only accommodation.

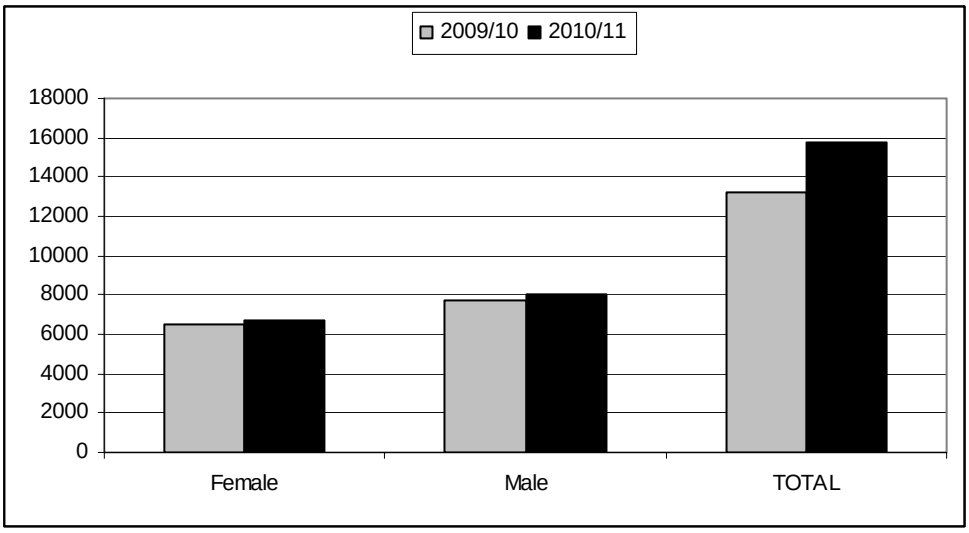


Figure 10 - inpatient population by gender – 2009/10 AND 2010/11

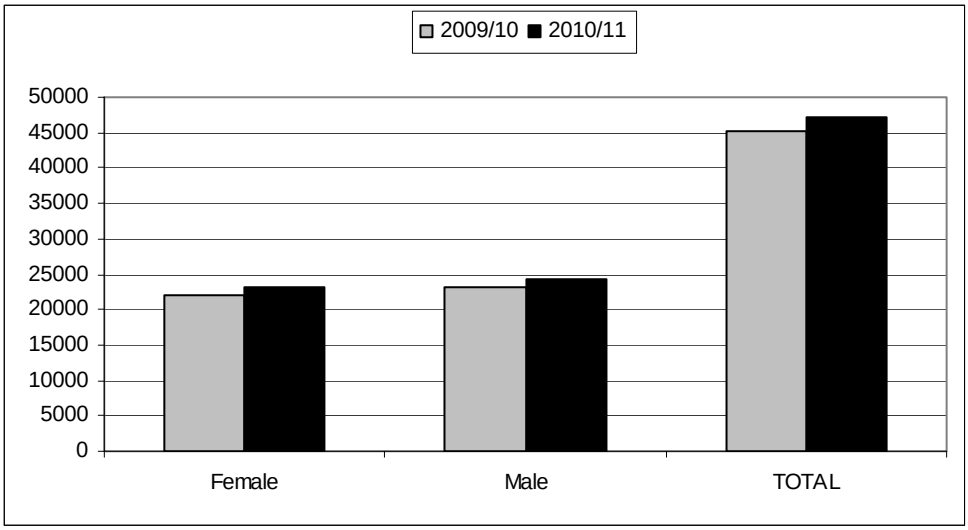


Figure 11 - outpatient population by gender - 2009/10 and 2010/11

Average length of stay

As stated earlier, the average length of stay for patients at GOSH is five days. When considering length of stay by gender, it is interesting to note that in 2009/10, male patients had a shorter than average length of stay of 4.81 days compared with females 5.24 days. In 2010/11, this situation reversed with males having an average length of stay of 5.11 days compared with 5.09 days for females. However, these differences are not regarded as significant.

Did not attend (DNA) rates for outpatient appointments[5]

Table 1 - DNA rates by gender

Gender	2009/10 %	2010/11 %	% overall outpatient population
Female	48.6	47.7	48.7
Male	51.4	52.3	51.3

As shown in the table above, there is no significant difference in DNA rates between male and female patients.

Sexual orientation

As a paediatric hospital, we do not enquire of our patients' sexual orientation and indeed do not have the facility for recording this information outside of the medical notes. If our young people wish to discuss issues of a sexual nature, there are several members of staff, including the Clinical Nurse Specialist for Adolescents, available to do so.

Other characteristics not covered by the Act

Language

Overall patient population

Although not one of the protected groups covered by the Equality Act 2010, we have long believed that the inability to speak English can lead to discrimination and lack of equality of opportunity. While language spoken can be seen as a component of a person's race or ethnicity, we believe that it warrants separate recording. We routinely record the patient's and family's mother tongue on registration and endeavour to provide appropriate language support whenever the patient is admitted or attends an outpatient appointment thereafter.

[5] If a patient had more than appointment and did not attend each appointment, they will be counted more than once

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

Note: Due to the limitations of PiMS, only the most common languages are available as a 'drop down' option – all other languages are recorded separately in the 'other patient comments' field so are not available for analysis. We know from previous years, however, that GOSH provides interpreters in upwards of 45 languages each year.

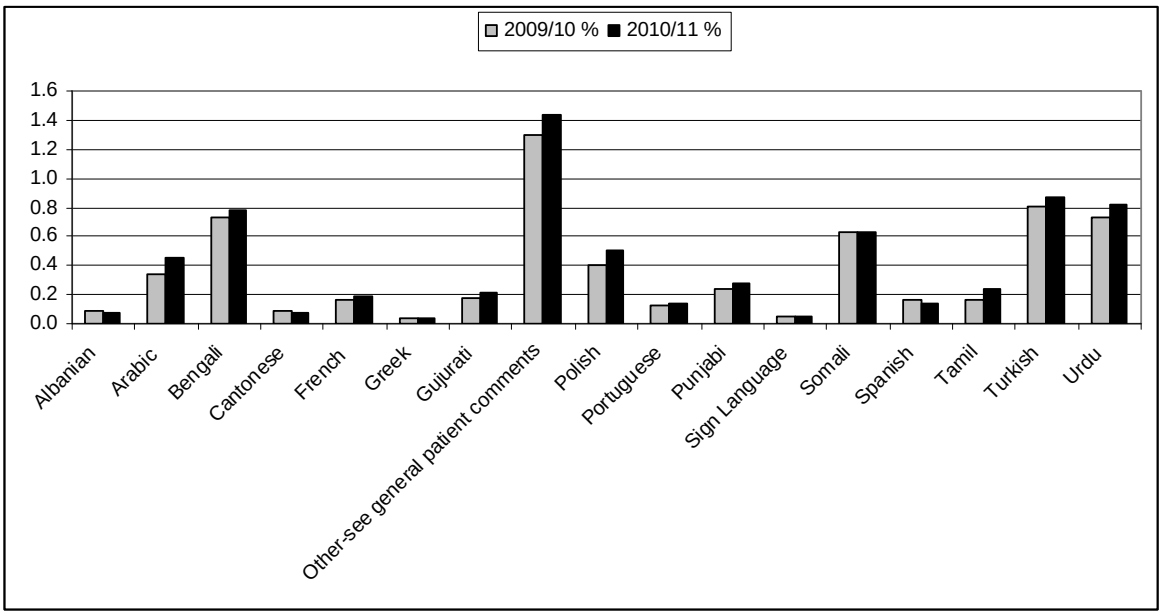


Figure 12 - Inpatient language requirements

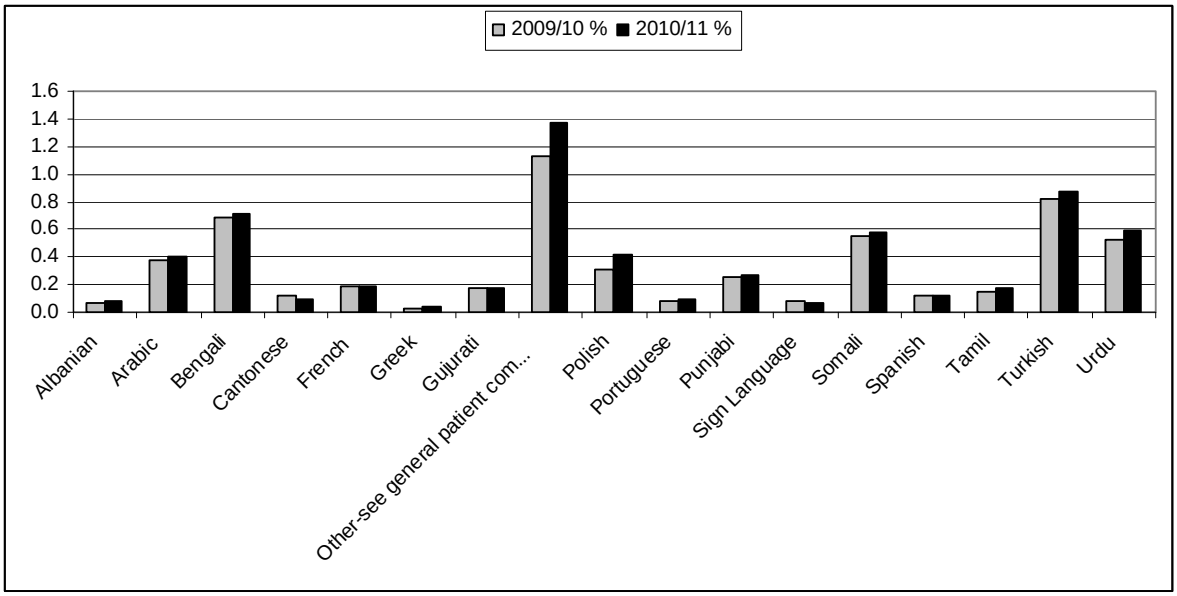


Figure 13 - Outpatient language requirements

Professional interpreters are used rather than family members or bilingual members of staff. Key documents are routinely translated into our core languages and others are translated on request. Face to face interpreting, rather than telephone interpreting, is booked for outpatient appointments and admissions where diagnosis, treatment options, outcomes or consent are being discussed.

The Ipsos MORI survey was predominantly administered to English speaking respondents, but a number of interviews were carried out in Turkish, Urdu, Polish and Bengali. The number and language of non-English interviews was dependent on availability of bilingual staff at the survey

organisation. The most recent survey included sufficient Urdu interviews to be able to draw basic comparisons, with 87 per cent of Urdu interviewers stating satisfaction with their last visit and 100 per cent likely to recommend GOSH to a friend or relative.

Average length of stay

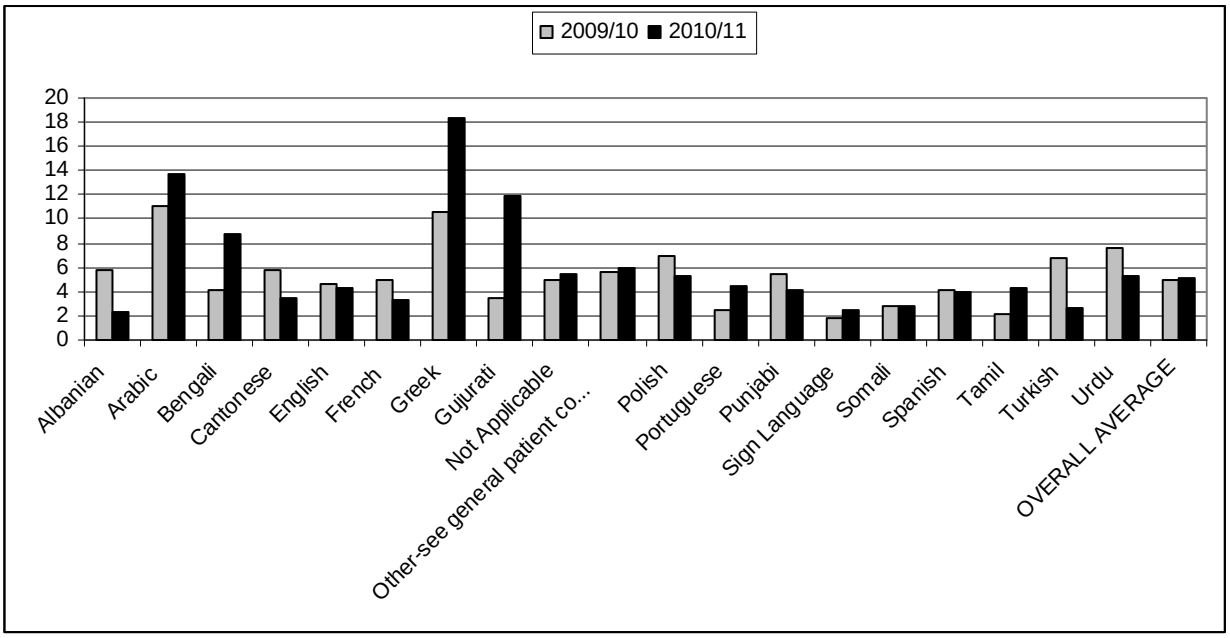
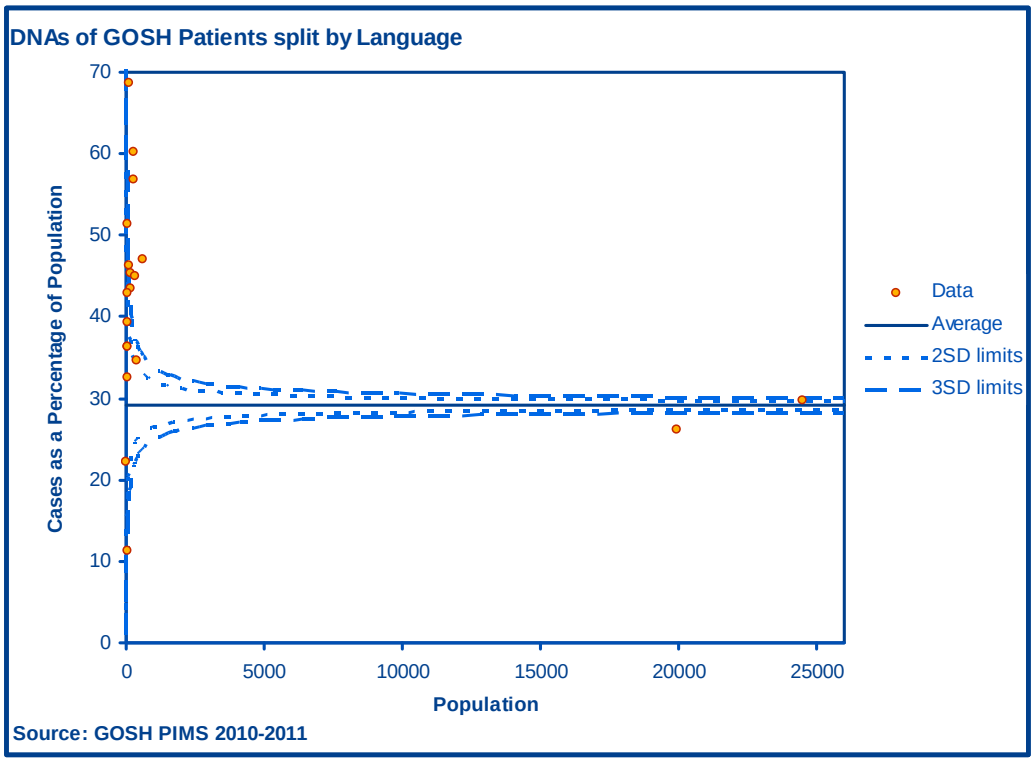


Figure 14 - Average length of stay by language - 2010/11

Greek- and Arabic-speaking patients tend to stay in our International and Private Patients Division and tend to need a longer recovery time due to the lack of an organised secondary care sector as we have in the UK. The reasons why other groups, such as Bengali, Gujarati, Turkish and Urdu speakers, are experiencing a longer than average length of stay will be investigated further.

Did not attend (DNA) rates for outpatient appointments[6]



[6] If a patient had more than appointment and did not attend each appointment, they will be counted more than once

As stated earlier, all appointment letters are provided in English, with telephone interpreting available to confirm or alter an outpatient appointment. It is not clear whether the significant differences in DNA rates for Arabic, Bengali, French, Punjabi, Somali and Urdu speakers is due to language difficulties but this will be investigated further. Unsurprisingly, significantly low DNA rates are recorded for 'Not applicable', that is, English speakers and those who do not require an interpreter.

Socio-economic deprivation

In addition to monitoring our patient population by the characteristics above, we are also keen to look at socio-economic deprivation as, like language, we feel that this could lead to discrimination and lack of equality of opportunity. The most widely used instrument in social and health domains is the IMD (Index of Multiple Deprivation) which emerged as a product of the 2000 census and ranks postcodes by deprivation. Further work is needed to investigate the feasibility of assessing our patient population by this means so a small scale pilot will be carried out initially focussing on our Trust Membership.

Conclusions

While much has been achieved over the previous 10 years in terms of equality and diversity, such as improving accessibility of our hospital, provision of appropriate food to patients, staff and visitors and provision of interpreters for non-English speaking families, there is still much to do. Priorities for the coming years include:

- Improving reporting rates for demographic data, especially in the IPP Division
- Investigating ways of understanding the patient experience of non-English speaking families
- Continued improvement of services for adolescent patients
- Following our baseline audit of services for learning disabilities, further work is needed to improve our education and training for staff and provision of Easy Read information
- Increased representation of people from protected groups as we move towards Foundation Trust status
- Development of clinical outcomes for each specialty, including analysis of outcomes for each of the protected groups where possible

The introduction of the Equality Delivery System (EDS) will of course impact on our objectives and a consultation is planned to deliver our equality objectives for the coming year and beyond. The Family Equality and Diversity (FED) Group will continue to encourage and monitor improvements in equality and diversity matters, with the help of our public members, to ensure that we continue to meet the general and specific duties of the Equality Act 2010.