Factsheet on the UK: Inequalities and Multiple Discrimination in Access to Healthcare – a study in 5 EU countries

Legal protection of the right to access healthcare

Article 35 of the Charter of Fundamental Rights of the European Union recognizes the right of every person to access healthcare under the respective national laws.

Evidence has shown that how healthy a person is, and whether they have access to health care, can strongly depend on the class, ethnicity, age, gender, disability and migration status of that individual. Persons at the intersection of these lines can be particularly susceptible to discrimination on more than one ground, or what is known as multiple discrimination.

The European Union is committed to fighting discrimination on grounds of gender, age, race and ethnic origin, religion, disability and sexual orientation. However, EU-level protection from discrimination on each of these grounds does not currently apply to access to healthcare. Discrimination on multiple grounds is also not legally protected.

The study

Against this background, the European Union Agency for Fundamental Rights (FRA) has launched a study on inequality, and multiple and intersectional discrimination in access to health care in the EU. The project was coordinated by the Middlesex University (UK) and conducted together with partners in 5 countries (Austria, the Czech Republic, Italy, Sweden and the United Kingdom).

Aims and outcomes

The aim of the study was to inform policy measures in order to tackle multiple discrimination in access to healthcare. Specific objectives are:

- mapping law and policy developments;
- identifying barriers to accessing health care experienced by healthcare users;
- mapping the ways health professionals address the needs of vulnerable groups.

Methodology

In the five countries studied, 142 interviews were conducted with health professionals, policy makers and other stakeholders, and 172 interviews with health service users. To find out about particular vulnerabilities of persons at the intersection of ethnic origin, age and gender the study focused on three groups of health service users: elderly migrants/minority group members, migrant/minority women with reproductive health needs, and young migrant/minority adults with intellectual disabilities.

Further information

Please visit the FRA website: http://fra.europa.eu/, or contact: information@fra.europa.eu for further information. This factsheet was produced by Middlesex University
Results in the UK

In the UK the research was coordinated by Middlesex University. Regarding health service users, the team focused on two broadly defined ethnic groups: African and African Caribbean and South Asians, which included East African Asians in Leicester. These are the two largest minority ethnic groups. Research was conducted in London and Leicester. Table 1 gives an overview of the number of interviews conducted in the UK.

### Overview of interviews conducted in the UK (EK)

<table>
<thead>
<tr>
<th>Interview category</th>
<th>Women</th>
<th>Men</th>
<th>Total number of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Legal experts</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Ombuds</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Advocacy organizations</td>
<td>6</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Health providers</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Policy maker</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Migrant interviews</th>
<th>Women</th>
<th>Men</th>
<th>Ethnic/national background</th>
<th>Total number of interviews</th>
</tr>
</thead>
</table>
| Women with reproductive health needs | 11    | ----- | Somali 7  
African Caribbean 2  
South Asian 2 | 11   |
| Elderly migrants         | 7     | 6   | East African Indian 3  
Mauritian 1  
South Asian 10 | 13   |
| Young adults with intellectual disabilities | 10    | 2   | Bengali 3  
Other South Asian 5  
African 4  
Caribbean 4 | 12   |

The health system and entitlements

The health system in the UK is funded through general taxation and is free at point of access. Private health care is sometimes funded by employers as part of a benefits package to employees though it is mostly the larger companies that do so. Insurers also market policies directly to the public. Most private care is for specialist referrals with most people retaining their NHS GP as their point of first contact. It was estimated in a consumer survey of 1477 adults 18 years and over that just over a quarter have some form of private health insurance, ranging from comprehensive to more selective (dental, optical).  

People who come from abroad and qualify as ordinarily resident in the UK (including those given leave to remain in the UK and those coming to work or study in the UK), and who are accepted for NHS treatment, may claim help with health costs in the same way as other residents (see exemptions below). Living lawfully in the UK means that one has permission from the UK.

---

1 Mintel, Private Medical Insurance and Health Cash Plans, August 2011
Government to live here. For example, those with a UK or EU passport, indefinite leave to remain, a current visa (also known as ‘leave to remain’). Generally, those without indefinite leave to remain or who have not entered for the purposes of settlement, as with family reunification migrants, are not eligible to apply for public funds. They can claim for health care and community care but will, however, be excluded from receiving social benefits such as severe disablement allowance, disability living allowance and carers allowance.

In relation to failed asylum seekers, the UK Court of Appeal held in ‘R (YA) v Secretary of State for Health’, (C1/2008/108) 30 March 2009) that unsuccessful asylum applicants were not ‘ordinarily resident’ due to their lack of status, and thus were not entitled to free medical care (secondary) regardless of the length of their residence in the UK. However, the judges also ruled that hospitals have the discretion to provide free treatment to such individuals if they cannot afford to pay for it. Primary and emergency healthcare must still be provided for them.

There have been a number of problems concerning pregnant women who are not ‘ordinarily resident’ in the UK and who may be asked to pay for maternity care. Maternity care is classed as ‘immediately necessary treatment’ and cannot be refused for any reason so a pregnant woman must not be refused care even if one can’t pay.

General practitioners (primary care) have discretion to register people as patients but they must have reasonable grounds to reject them which do not relate to their race, gender, social class, age, religion, sexual orientation, appearance, disability or medical condition. However a practice must offer treatment to everyone if in the opinion of the doctor it is treatment that is ‘immediately necessary’.

In terms of hospital or secondary treatment, The National Health Service (Charges to Overseas Visitors) Regulations 2011 (2011 No. 1556) which came into effect in August 2011, stipulate who may receive free treatment and the conditions under which charges should be made. No charge may be made or recovered in respect of any relevant services provided to an overseas visitor who has resided lawfully in the United Kingdom for a period of not less than 12 months immediately preceding the time when such services are provided or to those taking up permanent residence. Examples are family migrants or those who have been granted temporary protection, asylum or humanitarian protection under the immigration rules made under section 3(2) (general provisions for regulation and control) of the Immigration Act 1971 or those who have made an application, to be granted temporary protection, asylum or humanitarian protection under those rules but which has not yet been granted.

<table>
<thead>
<tr>
<th></th>
<th>Is this group entitled to access healthcare?</th>
<th>Please add relevant legal provision</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Asylum seekers</td>
<td>Yes</td>
<td>Court of Appeal 30 March 2009</td>
<td>Failed asylum seekers not entitled to free secondary care</td>
</tr>
<tr>
<td>Migrants with a permit to stay</td>
<td>Those ordinarily resident entitled to use primary and secondary</td>
<td>National Health Service (charges to overseas visitors*) Regulations 1989</td>
<td>Many without permanent residence fall into the categories permitted to use secondary services</td>
</tr>
</tbody>
</table>

The NHS has fixed charges for certain items and treatments such as prescriptions, dental treatment and eye tests but some people, such as those aged 60 or over and under 16 or between 16 and 18 years in full time education, or are pregnant or have had a baby in the past 12 months, are exempt from paying.

---

2 Maternity Alliance, Entitlement to free NHS maternity care for women from abroad, May 2010
Relevant anti-discrimination legislation

The UK has no written constitution, but the Human Rights Act 1998 has incorporated the European Convention for the Protection of Human Rights and Fundamental Freedoms into national law. The anti-discrimination legislation is contained in the Equality Act 2010, which covers nine protected characteristics (see below). The Act does not contain any reference to multiple discrimination nor are there any provisions for claims to be taken on more than one ground or for enhanced compensation when more than one ground of discrimination is present. There was a provision for dual discrimination in the Act, which would have allowed claims for direct discrimination to be made on two grounds (and not more than two grounds) but the Government has decided not to bring this provision in force because of possible costs it might impose on businesses.

Grounds of discrimination covered by national legislation

<table>
<thead>
<tr>
<th>Relevant piece of legislation</th>
<th>Grounds covered</th>
<th>Sectors covered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equality Act 2010, in force since October 2010</td>
<td>Age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion or belief; sex; sexual orientation.</td>
<td>Access to health care is covered for race, disability, sex and age.</td>
</tr>
</tbody>
</table>

Main barriers to access healthcare

There was considerable consistency between users who were older, people with learning disabilities, women of reproductive age and people from minority ethnic groups. Although often expressed differently, the provider and advocacy group interviews supported the views expressed by users. Service users highlighted lack of awareness of services amongst their peers, language problems both for non-English speakers and for those who experienced an inability to make themselves understood. Many users were unfamiliar with health and social services in general or the range of facilities or benefits to which they might be entitled.

Language and communication barriers: Advocacy groups in particular commented on barriers created by the concept of “open door” access which assumed that because everybody was welcome, services were accessible and there was no need to promote services in different languages or formats or target minority ethnic communities proactively. As in other countries, limited and patchy provision of interpreters was a problem and, although there was no evidence of using children to translate, there was an expectation among health professionals that adult family members or friends would accompany the patient for translation purposes and as such these services were not routinely offered. Even interpreters could be problematic where private and sensitive issues were being discussed, for instance as with infertility treatment, as in the case of several Somali women who were worried about the risk of information reaching the community and being stigmatised for not being able to bear children.

What was equally evident was the unwillingness of many, but not all practitioners, to speak slowly, use simple language or gestures to communicate. User, provider and advocacy interviews consistently reported on the inflexibility of services and the general unwillingness of practitioners to adapt ways of working to meet the needs of people who were old, disabled or from minority communities and particularly where all these elements intersected. Nobody denied how busy and constrained services were, but there was considerable criticism of the unwillingness to consider different ways of doing things. The impact of this inflexibility was that users and their carers were not listened to, given explanations in ways they could not understand and often felt a nuisance at best, or inappropriately cared for at worst. This may have contributed to drop-out from treatment.
or in some cases reliance on folk medicine or paying for private healthcare, sometimes in their home country. Several informants highlighted the impatience of health practitioners when language, speech or communication difficulties impacted on consultations. Several of the interviewees complained about the fact that the sight of a woman wearing a headscarf was interpreted by health professionals as meaning they needed an interpreter. In one case a university-educated respondent was turned away by a hospital doctor saying he couldn’t treat her without an interpreter.

**Cultural barriers**: Policy makers and advocacy groups highlighted a number of factors which were barriers to access. For some, cultural concepts of illness and help seeking meant that sometimes illness was not defined in western medical ways and as such, dealing with it happened in the family, using lay remedies, self-medication with herbs or over the counter medicines or even treatment from folk healers and/or religious persons. Certain conditions such as dementia were not recognised and others such as mental illness, TB and HIV were stigmatising for some groups and thus not referred to doctors until late in the illness. Some cultures had a preference for same sex professionals and many groups, particularly refugees and asylum seekers were suspicious of any type of authority.

The tendency to care for people with intellectual disabilities from minority ethnic groups within the family was seen by professionals and advocacy groups as a cultural barrier to access. Lack of information about available services, stigma or concern about their appropriateness meant that many people with intellectual or physical disabilities did not access the full range of support and care available to them.

**Information barriers**: The absence or at best shortage of translators/interpreters was a widespread problem which impacted on all interactions between clients and professionals. Having to book an interpreter or wait for one impacted on appointments and meant that practitioners could not give information, or did so in a rushed manner.

There is insufficient information about services or health promotion materials in different languages or media formats. Although providers attempted to provide appropriate information, rapid population changes with newer migrant groups in some areas were difficult to keep up with. Increasingly the closure or restriction of libraries facilities disadvantaged the poorest who cannot afford access to the internet. Providers and practitioners often assumed that ethnic minority families did not welcome the help of external agencies and thus did not provide information about what help they might be entitled to in order to care for an elderly relative or somebody with a disability.

Literacy in the home language is a barrier for certain groups such as Bengali’s and in other groups, such as Somalis, the absence of a written language or reliance on an oral rather than a literary tradition limit the ability to convey information. Policy makers and advocacy groups highlighted the neglect of effective communication strategies to provide information through community or faith groups to reach those who are less likely to proactively seek it.

Two policy/advocacy representatives highlighted the tendency of health promotion messages and campaigns to focus ethnocentrically on the white middle class family, thus neglecting people from other cultural groups who might not see a health issue as relevant to them.
**Physical barriers:** There appeared to be fewer physical barriers which probably reflects recent legislation requiring authorities to provide wheelchair ramps, lifts, and benefits to improve mobility and accessibility. However, the need to travel to different parts of a hospital for blood tests or x-rays or even to attend specialist clinics in different hospitals, sometimes in distant parts of the city, was a real barrier to people with a physical, visual, hearing or intellectual disability. Having to change buses or trains or the need for an interpreter usually required a relative to accompany them, often taking time from work to do so. Although travel might be free for the patient, it was costly for the person accompanying them and physically and emotionally exhausting for both.

Five older people were unhappy because they were not given the help they needed to remain mobile. One woman paid for a walking cane because it took too long and was too complicated to have one provided. Two older men were dissatisfied because their applications for a badge entitling them to park in restricted areas or adapt their cars had been rejected. Other older people were either waiting to have home adaptations undertaken or had paid privately to enable them to continue to be independent.

**Financial barriers:** Generally speaking, financial barriers were not an issue since services were free at point of access. However health users stated that the cost of travel to appointments for users and those accompanying them for safety or translation reasons and in some cases payments for prescriptions were considerable. Providers and practitioners did not appear to understand the human and material cost of several consultations with different professionals often at disparate sites across large cities like London.

It is important to note that barriers to services impact at different levels. If people do not know about services, believe them to be insensitive, inappropriate or in some way ‘not for’ them, they will not use them. However barriers also exist when people try to use services which are not sensitive to language, communication, disability, social circumstances or cultural needs. Some of the obstacles are at the level of individual practitioners but the majority relate to organisational structures, policies and procedures developed for a fairly homogeneous indigenous population. While the pressures on staff are widely recognised, it is evident that a need exists to review policies and practices to ensure they are able to cater for the ageing, multicultural and multiply disabled demographic that is Britain today.
**Experiences of discrimination**

Many users were satisfied with their care or if not, they blamed any shortcomings on lack of staff or practitioners who were under pressure, possibly because of restricted budgets. With a few exceptions, users tended to have a sense of injustice rather than perceiving they had been discriminated against. They felt their experience was common to other people. However many went on to describe unfairness or injustice related to their ethnicity, age, disability or any combination of all these vulnerabilities. Users were reluctant to be seen as conforming to wider negative images of immigrants making (illegitimate) demands on the welfare system. They emphasised their hard work, the contributions they had paid, in contrast to “others” who wanted to “grasp” everything and users were often resentful of recent migrants whom they perceived had contributed nothing but got everything. Lack of awareness or denial of discrimination does not mean it doesn’t exist because wider social discourses impact on peoples’ perceptions of themselves or to what they are entitled.

The data provides a small number of examples of direct discrimination or events which the users perceived as discrimination. Five of the older people felt they had experienced some discrimination and they tended to think it was related more to their age than their ethnicity. The interviews demonstrate that policy makers, providers and advocacy groups were more in tune with discrimination, especially that which is incorporated advertently or otherwise into systems, structures, policies and procedures. A few informants felt their symptoms had been trivialised by practitioners and some had observed non-English speaking patients being ignored or refused medication by nurses who believed they were making a fuss or had a low pain threshold. For example, a British born Asian woman aged 50-59 years reported that, whilst in hospital giving birth to her daughter, she heard nursing staff speaking disrespectfully of an Asian lady in the same ward who was crying for pain relief and saying that, “they always make a fuss...Asian people have a low pain threshold... Nothing really the matter with her”.

In each of the categories, there were instances of malpractices and mistreatment with serious consequences. Amongst Somali women there were complaints of poor treatment in relation to infertility treatment and miscarriages. One woman in her 30s had agreed reluctantly to having her circumcision reversed as part of her treatment for infertility only to find they had given her the wrong medication resulting in damage to her womb and permanent infertility. Her husband subsequently left her. An African Caribbean woman had a hysterectomy which was actually a mistake. When she went to PALS (see pg 9) her notes had disappeared. She is also the carer of a 19 year old daughter with intellectual disability. A number of years ago the daughter had been in a respite home when her arm was broken. The mother was advised by a social worker to take legal action but when she tried to get her to put it in writing; she said she had never told her to do so. She said she felt it was because of “her culture and her skin”. In the case of an older Tamil-speaking woman without any English, she was unable to communicate with anyone after her cataract surgery which had gone wrong but her daughter was told everything was OK when she came to pick her up. Her GP was also not notified of the accident until a subsequent visit to the consultant surgeon at a specialist unit in the hospital told them about it and corrected the damage. In the meantime she had experienced pain and reduced vision in the eye that had been operated on.

However the providers and advocacy groups focused more on organisational and structural factors predisposing to discrimination. They consistently commented on organisational policies and practices such as ten minute appointments or having to travel across hospital sites or even cities for investigations or consultations, which discriminate inadvertently against people who are older, disabled or from migrant communities.

According to policy makers, advocacy groups and service users, those responsible for implementing services do not understand the needs of those who use them, do not know how to bring about change and are not committed to institutional change. Policy makers, providers and practitioners
often do not understand the complexity of equality and believe that if everybody is treated the same, inequalities will be addressed. The Deputy Ombudsman commented:

“There is also sometimes a refusal to do things differently in the belief that if I apply a blanket approach to everybody, then all will be treated equally .......... failure to do things differently to make things easier for the patient with learning disabilities for example”

The providers and advocacy groups highlighted how ethnocentric approaches to health and healthcare excluded people who had higher levels of need related to age, physical or learning disability or belonging to a migrant / ethnic minority group. Despite significant legislation, several participants, such as a former policymaker in the Department of Health, highlighted the reluctance to talk about racism in health care settings. They were agreed that existing race relations legislation had a part to play in bringing about some change but that legislation alone was insufficient. A different approach was needed, to challenge old ways of thinking and address the ethnocentric practices which unconsciously discriminated against certain vulnerable groups. Participants were generally critical of equality training believing that it was more about ticking boxes rather than embedding and internalising positive attitudes and behaviours. Policy makers and advocacy groups also felt that although there had been considerable investment in mandatory equality training in health and social care services, the quality of training and its impact on practice was questionable. Realistically, a single day or a short course of training cannot be expected to change attitudes, challenge stereotypes or address the ethnocentrism in practices and procedures. Too often training is about needing to show that training has been undertaken, rather than improving practice.

Policy makers and advocacy groups highlighted the lack of leadership in the NHS in relation to equality issues, believing that current and previous governments were not interested in addressing inequality. There was a tendency towards a “one-size-fits-all” approach to policy, as a Chief Executive of an advocacy group noted. There is also an absence of targets or measures to evaluate progress on addressing inequality. The lack of leadership at government level cascades down to trust boards and senior managers, who lack the will, confidence or skills to guide and direct good practice or to manage that which is poor. However training is mostly focused on staff in lower grades and those in senior positions rarely see the need to develop their knowledge or expertise in this area.

Experiences with using complaints mechanisms

Key Characteristics of the British Healthcare Complaints System

Under the NHS Constitution (Department of Health, 2010)\(^3\), patients have the following rights:

- to have any complaint made about NHS services dealt with efficiently and to have it properly investigated;
- to know the outcome of any investigation into the complaint.
- to take the complaint to the independent Health Service Ombudsman, if the complainant is not satisfied with the way the complaint has been dealt with by the NHS.

In addition, The Health Act 2009 places a duty on all organisations operating within under the NHS (including external contractors) to “have regard to the NHS Constitution”. Since a structural reorganisation of services was undertaken in April 2009, the primary route for making Health and Adult Social Care related complaints in England has been through a single integrated system. This process is governed by The Local Authority Social Services and National Health Service Complaints (England) Regulations 2009. The regulations cover complaints made against Local Authorities, NHS hospitals, Primary Care Trusts (including General Practitioner practices) and independent providers (the ‘responsible body’) with the Regulations specifying that each responsible body must make

arrangements for dealing with complaints. Each responsible body must have designated staff, who ensure compliance and management of the complaints procedure (S4). Under S16 of the Regulations, each body must also make information available to the public in relation to arrangements for dealing with complaints.

The initial step to making a formal complaint consists of approaching the organisation or person concerned and only if the complaint cannot be resolved informally, will it be investigated. An explicit expectation exists that complaints procedures will be completed within six months or that an explanation for the delay will be provided by the responsible body and that the case will be dealt with as soon as ‘reasonably practicable’. Although unable to hear appeals against the decisions of responsible organisations, the (independent) Parliamentary and Health Service Ombudsman can investigate complaints referred to them which have been through the organisational complaints procedure and which (generally) are not subject to legal proceedings. A complaint must be made to the Ombudsman within 12 months of the date of the relevant event unless there are special reasons for the delay. If a fault is found the Ombudsman has a menu of remedies which can be applied, including requiring an apology, financial compensation loss, inconvenience or worry or repayment of money due, for example, tax or benefits, better facilities for patients, better administrative procedures better training and instructions for health care staff. However, as the Deputy Ombudsman stated, about complaints reaching the PHSO, if it is demonstrated that they have been dealt with according to procedure, have been investigated and viewed independently, have been admitted an apology has been issued and strategies put in place to put right, the case will not be taken even if the complainant is still unhappy.

Although not legally binding, the Ombudsman’s recommendations are almost always followed. The Ombudsman’s Office publishes an annual report providing information on the type of cases reviewed. The House of Commons Health Committee (2011) report on the NHS complaints and litigation process reported that since the introduction of the new Regulations in 2009 “Satisfaction with the outcome of local resolution has increased over the last four years, with over 70% of clients happy with the outcome in 2009/2010 compared to 45 –56% in 2006/2007”. (2011:7) However they “found it difficult to establish which organisation monitors the performance of the NHS against complaints standards and can see potential for failing organisations to be overlooked”(2011:3) noting too that the culture within the NHS was too often defensive and failed to be open to dealing with patients’ concerns and complaints.

In addition to the ‘internal complaints route’ and referral to the Ombudsman, the Equalities and Human Rights Commission (EHRC) undertakes official inquiries and formal investigations (for example in relation to disability related harassment and the human rights of older people receiving home-based care) and takes on a limited number of legal cases each year, focusing on those cases which are likely to establish a point of law pertaining to equality of treatment. The legal expert from the EHRC mentioned that if a person does not get access to medical treatment, they often do not know why but do not see it as discrimination. Discrimination in health care appears not to be mentioned although health inequalities and inequalities in health expectancy do exist. Some cases have been taken for refusal to make reasonable adjustments. However, in medical cases, negligence is often the preferred route as it is evidentially easier, but the EHRC does not deal with negligence.

The main gateway to raising an initial complaint is through the Patient Advice and Liaison Services (PALS) found in all Hospital Trusts. PALS is a service which provides information and advice, and can support a patient through the complaints procedure. The national PALS network has published a series of reports on its activities, and recommendations for good practice. In addition, advice on making complaints is readily available through a number of agencies and charities such as Citizens’

---

4 See on this the Health Service Commissioners Act 1993 and www.ombudsman.org.uk
London: TSO downloaded 10/11/11 available at:
http://www.publications.parliament.uk/pa/cm201012/cmselect/cmhealth/786/78602.htm
Advice Bureaux; Age Concern UK; Independent Complaints Advocacy Service (ICAS); MIND; MENCAP and the Patients’ Association.

Awareness and experiences

Despite the wide number of information sources available to service users, interviews with both patients and professionals bore out the consistent research literature findings that refugees, asylum seekers, minority ethnic groups, older people and people with learning disabilities were less likely to complain either informally or formally about poor quality treatment. Respondents overwhelmingly painted a picture of service users having a generally limited knowledge of the complaints process; and a significant reluctance – often related to gendered and cultural approaches to dealing with ‘authorities’ – to complain, even where abundant cause for concern existed. Professionals indicated that a sense of ‘gratitude’ for receipt of care can act as an inhibiting factor as well as language barriers; concerns about ‘repercussions’ if they complain about staff; and exhaustion and confusion when faced with the bureaucratic demands of long-winded formal complaints processes.

Complaint mechanisms used and motives behind complaint. Accessibility of complaint mechanisms in the country

In several cases evidence was found of advocacy groups working with service users to convince them of the need to complain about treatment. In one case - where a highly traumatized young woman asylum seeker with mental health problems who had been the victim of gang rape in her home country was treated with gross insensitivity by staff who expected her to speak to a male staff member about her experiences despite her hysterical panic and attempt to flee the office on seeing a man – the health worker made a formal complaint against her peers as she felt her patient experienced significant harm as a result of her treatment under NHS care. Respondents with learning disabilities and their families and older people (as well as staff working with these groups) reported that a general sense existed that people in these categories were powerless and would not be believed if they complained. In one case, a professional who complained on behalf of her patient noted that she did not receive a response from the hospital concerned and that, if even she could not enforce compliance, it was understandable that many individuals with less resources would feel that there was no point in complaining. Where service users did complain, (a very few cases, predominantly women of reproductive age, or on behalf of a child with learning disabilities) the most common route was an informal complaint to the agency concerned, although those who did utilise formal complaint routes referred to delayed responses, consistent barriers to resolution and generally expressed a lack of satisfaction with the outcome. Two women interviewed spoke about feeling duty bound to complain should the need arise again, in part as a way of helping other people (for example elderly patients) and avoiding them having similarly poor experiences.

Despite the fact that the review of complaints mechanisms available at the national level point to several routes by which service users and their families may complain about poor treatment, we found clear evidence that significant barriers exist to doing so. In addition, there is a lack of appropriate advocacy services across the country and within health and social care agencies (where most complaints arise) so as to militate against certain groups being able to complain effectively, thus ensuring that when they do complain, they are often not listened to or taken seriously, creating a vicious cycle whereby it was felt that their voices were not heard.

Women in reproductive health

Responses in relation to direct questions about discrimination varied. Whilst a number of interviewees described instances of overt discrimination, unfair treatment or failure to be treated with dignity in cases of infertility treatment and miscarriages, especially amongst Somali women; more commonly women reported feeling an unease that if they were white British they might have been seen faster or treated with greater care and consideration or had their concerns taken seriously.
Whilst a number of women reported that they did not feel discriminated against on grounds of ethnicity, they also told us that they felt that women doctors would be more sensitive to gynaecological issues than male staff, who often failed to recognise cultural barriers and the impact of concerns over modesty in discussing gynaecological matters. On the whole, however, there was not a problem in accessing female staff. Two Somali felt there was excessive concern with female circumcision which had led to insistence on the reversal of circumcision (see experiences of discrimination) and of another case where the woman was lectured to about it after giving birth which the interviewee was inappropriate and poorly timed. An African Caribbean Muslim woman also complained about the negative comments made by her doctor about her son’s circumcision.

Some interviewees reported that the objectification of patients and lack of personalised treatment created barriers to appropriate care, with one woman noting that she believed her poor experiences were less to do with her ethnicity than poor communication or a lack of ‘people skills’ amongst medics (“they treat us like animals”). In contrast, other interviewees reported hearing health workers characterising Asian women as ‘having low pain thresholds’ and thus ‘making a fuss’ about gynaecological pain, or being subjected to stereotypes by health professionals who failed to understand and behave empathically towards women who wished to have larger families or who do not conform to expectations (e.g. through marriage to a man from a different ethno-cultural background) as to how a minority ethnic woman should behave.

### Young adults with intellectual disabilities

The single strongest message, found across all ethnic groups, which emerged from the interviews with young people (and in a few cases from interviewers with carers), was the consistent lack of respect shown to people with learning disabilities. Nobody used the term discrimination, but young people with intellectual disabilities and their family carers were very clear that they had been treated unfairly. Almost overwhelmingly, interviewees (including carers) reported that it was the person who came to a health appointment with a young person (often their carer but not always) whose opinions were asked, and who was spoken to by health staff, even when the young person was more than capable of expressing an opinion, providing information about their needs or providing informed consent.

A Caribbean woman in her 30s with intellectual disability, epilepsy and a paralysed arm describes how health professionals ignore her and talk to her carer as though she isn’t present “with people with learning difficulties they blank you out”. In addition, some carers appeared to give little credence to the notion that young intellectually impaired people were capable of exercising autonomy, further diminishing their sense of self-respect and dignity.

A number of participants reported being asked deeply intrusive and embarrassing questions by health staff about contraceptive use even when they were not sexually active. Only one participant (a Caribbean woman) felt able to challenge such behaviour “I say it’s none of your business you’re supposed to be my GP not asking me about [personal life]”.

Most interviewees did not identify discrimination on grounds of ethnicity, but as a result of their intellectual impairment. They frequently did not understand why they were kept waiting in a clinic, because staff did not explain what was happening or explain it in a way they understood. When accessing preventative health checks, the dialogue was often directed towards their carers. Much of the dissatisfaction related to hospital experiences where they were ignored, pain not relieved, informed consent to treatment not obtained or procedures adequately explained. For example, one young woman did not know how to order food in hospital and was left hungry for several days. Staff were generally unwilling to make adaptations to the needs such as speaking more slowly, explaining things in simple language, using symbols or drawings to explain, allowing time to deal with the physical impairments a number experiences in addition to the intellectual disability.

Although interviewees were very clear that their treatment was often unacceptable, most felt that their intellectual impairment was the cause of their poor treatment, rather than their ethnicity.
However dissatisfaction was not universal and the same person might have a satisfactory experience in one organisation or department and a very poor one in another. Caribbean service users and their carers generally had a better experience by virtue of their engagement with the “Lambeth People First” self-advocacy programme. The experience in Leicester was generally more positive. There is a large Asian community and significant emphasis on equality, rights and partnership working between service providers and community.

Interviewees of Bengali background in East London were more likely to report significant levels of disrespect and insensitivity especially in hospital settings. Young adults were more likely to be cared for at home, within the family and without accessing external services. Instead of striving for independence, families tended to be over-protective and girls were particularly disadvantaged in not being allowed out to engage in activities which might enhance their skills and develop their independence.

Almost no interviewees had any idea of how to make a complaint and almost without exception they (and their carers) felt complaining about poor treatment would not make any difference to their treatment.

<table>
<thead>
<tr>
<th>Main data sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>EU-SILC database gathers comparative statistics on income distribution and social exclusion from the 25 EU member states, Norway and Iceland. It provides cross-sectional and longitudinal data pertaining on socio-economic indicators observed periodically over a four years period.</td>
</tr>
<tr>
<td><strong>The Labour Force Survey (LFS)</strong> is a quarterly sample survey of households living at private addresses in Great Britain, providing information on the UK labour force which includes details on health</td>
</tr>
<tr>
<td><strong>The Health Survey for England (HSE)</strong> is an annual survey series which examines the health of people who live in England. Although each year a number of core questions are</td>
</tr>
<tr>
<td><strong>The UK Census</strong> (every 10 years) It includes, among the others, statistics about: population size; demographic characteristics; ethnicity and country of birth; Health (for example general health condition, long-term illness, disability, caring responsibility).</td>
</tr>
<tr>
<td><strong>The Citizenship Survey</strong> is a household survey covering a representative core sample of 10,000 adults in England and Wales each year, has discrimination details.</td>
</tr>
</tbody>
</table>