EQUALITY

Inequalities and multiple discrimination in access to and quality of healthcare

EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS

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This report addresses matters related to human dignity (Article 1), non-discrimination (Article 21) and healthcare (Article 35) falling under the Chapters I 'Dignity', III 'Equality' and IV 'Solidarity' of the Charter of Fundamental Rights of the European Union.

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Foreword

During the past 30 years the European Union (EU) has put in place legislation to respect, protect, promote and fulfil the right to equality and non-discrimination, which is also enshrined in the Charter of Fundamental Rights of the European Union. Legislation against sex discrimination is in place since the 1970s; in 2000, the EU enacted an additional layer of anti-discrimination laws prohibiting race and ethnic discrimination (*Racial Equality Directive*) and established a general framework for preventing discrimination in employment on the grounds of religion or belief, disability, age and sexual orientation (*Employment Directive*). Existing equality and anti-discrimination legislation, nevertheless, protects against discrimination only on single grounds.

Individuals are, however, complex; they share a number of characteristics that expose them to possible discrimination, including sex, ethnicity, age, disability, sexual orientation and any combination of these grounds. When people are denied equal treatment because of a failure to consider all the relevant facets of their individuality, they can be said to suffer multiple or intersectional discrimination. The theoretical debate exploring the intersection of multiple discrimination grounds is on-going and established equality law has not yet adequately addressed this phenomenon.

Even more significantly, existing EU secondary law provides wider protection against discrimination on the grounds of race or ethnic origin and on the grounds of sex than on other grounds, such as religion and belief, disability, age and sexual orientation, resulting in an artificial 'hierarchy' among grounds. This differentiation in scope also makes it difficult to deal with multiple discrimination. In July 2008, the European Commission introduced a proposal for a directive extending the material scope of the provisions against discrimination beyond the area of employment for the grounds of religion and belief, disability, age and sexual orientation. Adoption of this proposal would reduce the current asymmetry in the protection of different grounds and facilitate efforts to handle multiple discrimination cases.

This report, based on qualitative social research and legal analysis in five EU Member States, is a first effort to explore the nature, context and effects of unequal treatment based on ethnicity in combination with one or more protected grounds (age, sex and disability) in the area of healthcare. It improves the understanding of the operation of multiple grounds of discrimination, particularly concerning healthcare, and provides policy makers with evidence to assist them in improving protection against discrimination in the EU.

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Director

Contents

FOREWORD....3

EXECUTIVE SUMMARY....7

OPINIONS....11

INTRODUCTION....13

1 MULTIPLE DISCRIMINATION: THE LEGAL SITUATION....19
  1.1. The knowledge base at European Union level....19
  1.2. At the crossroads of the right to equal treatment and the right to health....20
  1.3. Awareness of multiple discrimination at the international level....22
  1.4. Multiple discrimination under the European Convention on Human Rights....24
  1.5. National legislation: a patchy panorama....25
  1.6. Multiple discrimination in national case law....27
  1.7. Lack of legal certainty about multiple and intersectional discrimination....29

2 INEQUALITIES AND MULTIPLE DISCRIMINATION: DATA AVAILABILITY AND EXISTING EVIDENCE....31
  2.1. Availability of intersectional data on health conditions and use of health services....31
  2.2. Inequalities in health status....33
  2.3. Inequalities in access to and use of healthcare services....40
  Conclusions....45

3 BARRIERS AND INDIRECT DISCRIMINATION IN ACCESS TO HEALTHCARE....47
  3.1. Communication and language barriers....47
  3.2. Lack of information about healthcare services and entitlements....51
  3.3. Financial barriers....53
  3.4. Organisational barriers and accessibility....55
  3.5. Working conditions, living conditions, care responsibilities....57
  3.6. Cultural and psychological barriers....59
  Conclusions....62

4 EXPERIENCES AND PRACTICES OF DISCRIMINATION....63
  4.1. Awareness of discrimination....63
  4.2. Experiences of discrimination....65
  Conclusions....78

5 SEEKING REDRESS: OBSTACLES AND STRATEGIES....79
  5.1. Standards and challenges in EU law....79
  5.2. Availability of complaint mechanisms....80
  5.3 Challenges in addressing discrimination and multiple discrimination in healthcare....83
  5.4. Underreporting and underuse of complaint mechanisms by patients....90

CONCLUSIONS....97

REFERENCES....99

APPENDIX: METHODOLOGY....107

Figures and tables

Table 1: Grounds of discrimination covered by national anti-discrimination legislation on healthcare, by EU Member State 21
Table 2: Share of foreign-born population perceiving their health status as good, fair or poor 34
Table 3: Disability/strong limitations in daily activity (%), by sex 36
Table 4: People with limitations and strong limitations in activities due to health problems (%), by EU Member State and country of birth 37
Table 5: Unmet need for medical examination or treatment 41
Table 6: EU-27 – Unmet health needs by 'disability' and sex, EU-27 (%) 42
Table 7: Discrimination in the past 12 months 44
Table 8: Overview of health and equality bodies 81
Table A1: Fieldwork sites, by EU Member State 107
Table A2: Age and category of user interviewees 108
Table A3: Gender and category 109
Table A4: Migrant/minority groups in five EU Member States 109
Table A5: Professionals by category 111
Table A6: Professionals by sex 111
Table A7: Diversity of professionals 112

Figure 1: Life expectancy gaps between high and low educational attainment at age 60, by sex 38
Figure 2: Horizontal, vertical and diagonal comparator in multiple discrimination cases 86

Executive summary

The EU's key anti-discrimination legal instruments, namely the Employment Directive (Council Directive 2000/78/EC) and the Racial Equality Directive (Council Directive 2000/43/EC), explicitly acknowledge in their preambles the existence of multiple discrimination and note that women are often its victims. Nevertheless, while the anti-discrimination directives do not forbid claims on more than one ground, EU secondary law as currently in force provides better protection against racial and sex discrimination than against discrimination on the grounds of religion or belief, disability, age and sexual orientation. This difference in the level of protection makes it difficult to deal with cases of multiple discrimination. When it comes to healthcare, EU law provides: protection against racial discrimination; less developed protection against sex discrimination; and no protection against discrimination on the grounds of religion or belief, disability, age and sexual orientation.

At the international level, the most recently adopted convention, the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), is the first international treaty to explicitly recognise multiple discrimination in the text of the convention itself. All EU Member States have signed and 24 have ratified the CRPD. With respect to an Optional Protocol to the CRPD, which allows persons with disabilities to make individual claims including for multiple discrimination to the CRPD Committee, 23 EU Member States have signed it and, by January 2013, 19 have ratified it.

At national level, currently only six EU Member States address 'multiple discrimination' or 'discrimination on more than one ground' in their legislation. In some countries, a finding of multiple discrimination can be taken into account when awarding compensation. However, the legislation rarely gives a definition of multiple discrimination or any further guidance on how to deal with it. The lack of legal clarity is compounded by the lack of case law, at both the national and European level. The only courts which seem to deal with multiple discrimination are labour courts at national level and there is no case law concerning multiple discrimination framed as such in the area of healthcare. The five EU Member States examined in this research prohibit discrimination in healthcare on the grounds of racial or ethnic origin, sex and disability, or three of the four grounds covered in this study. However, the fourth ground, age, is not covered in regard to healthcare in Italy and Sweden, which means that in these EU Member States a claim for discrimination in healthcare on the ground of age cannot be made.

There is an absence of EU-level statistical data on multiple inequalities in health and, in particular, a lack of data that would describe the intersection of different grounds. While sex and age are systematically recorded, data on ethnicity and disability (such as how societies accommodate different impairments, as per the 'social model' of disability) are rarely collected systematically in national surveys or their samples are not large enough to allow for further breaking down of the data (disaggregation).

The fieldwork research for this report found that respondents had experienced unequal or unfair treatment in relation to access and quality of healthcare. They experienced this either directly as a form of alleged direct multiple discrimination on the basis of more than one ground or as a barrier to accessing healthcare, when they were treated equally but inappropriately for their specific situation.[1]

Some of these barriers are: communication and language barriers, lack of information on healthcare entitlements and services, organisational barriers and accessibility, working and living conditions, cultural and psychological barriers. While these barriers have a recognised impact on all groups that are specifically protected by anti-discrimination law, individuals who share more than one protected characteristic, such as age, sex, disability and ethnicity, face additional complex challenges.

Proper healthcare delivery is often hampered by inadequate or non-existent interpreter services. Those with a migrant background, for example, may be treated in the same way as a country national, but, in practical terms, if they cannot properly communicate because of language difficulties there is a risk that the treatment they receive may not be adequate. The research found that while language barriers are particularly relevant for new migrants, they also apply to older migrants and migrant women. Migrant women sometimes have more difficulties in learning the language, especially if they interact less with mainstream society, for example because they are only engaged in housework. Older migrants who have learned and spoken a second language for decades can lose this ability due to particular health problems, such as a stroke or dementia. The findings indicate that in cases of more complex health issues, such as intellectual disability or psycho-social disability,[2] language barriers can make it extremely difficult to diagnose and treat them.

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[1] FRA (2010a).

[2] In the first FRA disability-specific project, 'Fundamental rights of persons with intellectual disabilities and persons with mental health problems', the FRA adopted the term 'mental health problems' after careful consultation with partner organisations representing these groups of persons. From now on, the latter will be replaced by the term 'psycho-social disability', in line with the terminology of the CRPD.

Financial barriers, while affecting more generally people with lower economic resources, disproportionately affect older migrants or those with a disability, who, in some countries, might not be eligible for specific allowance schemes unless they hold a permanent residency permit. Their inability to work and exclusion from social protection schemes means they face major financial barriers in accessing healthcare.

The results of the field research suggest that another factor that can discourage service use is lack of consideration for and accommodation of the cultural practices of specific intersectional groups. In this report the term 'intersectional group' refers to individuals who share more than one protected characteristic. Migrant women, and especially Muslim women, for example, can feel uncomfortable with male health professionals and male interpreters. Sweden appears to be the only EU Member State of those studied which routinely accommodates this need. In the other EU Member States examined, the research found that there were often not enough female staff or that there was an unwillingness to satisfy users' preferences in this respect.

Specific 'professional bias' on the side of health professionals emerged in relation to lack of medical and cultural competencies which impact specific intersectional groups: for example, when treating minority ethnic women with female genital mutilation (FGM) health professionals might defer gynaecological treatment because they do not know how to treat this condition, ultimately causing a delay in treatment.

Another important research finding is that incidents of multiple discrimination can take place at different levels: members of the majority population can discriminate against members of a minority population; discrimination can also occur within minorities. An example of multiple discrimination within minorities was mentioned in relation to Muslim women who might not be allowed to take part in physiotherapy without their husbands' permission or presence. A combination of actions by minority and majority members may result in discriminatory treatment. The research found, for example, that in certain migrant minority ethnic communities families of children with intellectual disabilities may try to shield them due to the stigma attached to their condition. This could even result in failing to seek help from health professionals. On the other hand, health professional or social service providers may not offer support to these children because they assume that they are being well looked after by their families or simply because they have not been approached to provide assistance. Hidden in their own communities such children are doubly discriminated against: by their family and by authorities who wrongly assess that all is well.

Healthcare users and providers also reported several incidences of alleged direct discrimination, including delay of treatment; refusal of treatment; experiences of undignified treatment and stereotyping perceived as discriminatory; malpractice; harassment and lack of informed consent, including involuntary treatment. The interviews showed, however, that most healthcare users perceived such incidents as infringements of their rights as patients rather than as discrimination.

More than any other form of discriminatory practice, healthcare users have emphasised that lack of dignity and respect might be experienced when meeting, communicating and interacting with healthcare staff. Recurrent stereotypes linked to specific intersectional groups, compounded by failures in communication and trust between patients and medical staff, surfaced in different countries. For example, Muslim women, women with a migrant/ethnic background, including those with disabilities in the context of reproductive health, and older migrants are the groups who most often reported experiences of humiliating treatment and cultural stereotyping across all five EU Member States examined. In most of these countries, interviews with both health professionals and respondents showed that older members of migrant or ethnic minorities are often suspected of feigning their health problems in order to receive benefits. Such prejudice could influence the outcome of medical assessments for claims, such as for disability or invalidity and early pension.

Intersectional discrimination on the grounds of sex, ethnicity and disability emerged in relation to the violation of informed consent and more specifically of involuntary treatment of different groups of women, often linked to the parallel violation of sexual and reproductive rights. Examples include sterilisation of Roma women and women with disabilities; forcing women with disabilities to have abortions and forcing gynaecological examinations on young Muslim women in school settings to check if they have undergone FGM.

Lack of provision of adequate information to specific groups in the context of informed consent emerged as affecting Roma healthcare users and Muslim women specifically, who are sometimes considered too poorly educated to be able to understand and communicate their health problems.

The interviews show that healthcare providers are quite aware of barriers in healthcare, especially of structural and language barriers. They also show, however, that healthcare providers are often reluctant to talk about these barriers in terms of discrimination – especially direct discrimination – insisting that everyone is treated equally as professional ethics, expressed in the Hippocratic oath, prevent health professionals from treating anyone differently because of their sex, age, disability, ethnic or national origin. Nevertheless, those healthcare providers who did acknowledge the existence of discrimination as an issue agreed that certain groups of healthcare users are more vulnerable due to a combination of characteristics, such as socio-economic status, ethnicity, migrant status, sex, age and disability; however, only a few interviewees[3] were able to provide examples of this or suggest ways of tackling the problem.

Most of the healthcare users who had experienced unfair or unequal treatment believed that they had been discriminated against on one single ground. While ethnicity or migration status is the most commonly mentioned reason for discrimination among women and older people, persons with intellectual disabilities perceive disability as the clearest reason for discrimination. However, a small number of healthcare users who were interviewed believed they were themselves subject to multiple discrimination, particularly among women respondents in Sweden. More generally, healthcare providers and lawyers commented on the difficulty for individuals to understand that they might be experiencing discrimination in health due to the technical competence required, the lack of comparators and the belief that healthcare providers are there to help and thus cannot discriminate.

The report also shows what happens in practice when people attempt to seek redress by using courts or non-judicial bodies. Legal experts identified various challenges when dealing with discrimination and multiple discrimination in healthcare. For instance, several legal experts interviewed referred to the difficulties in offering judges proof of discrimination, with particular respect to proof of 'less favourable treatment' and choice of a comparator. Sometimes 'multiple comparisons' cannot be made under applicable law and judicial practice. Additional challenges in addressing multiple discrimination cases are found in the low awareness of discrimination on multiple grounds among complainants, lawyers and judges. In addition, proving that a discriminatory act or practice has taken place due to the intersection of two or more grounds is a time-consuming task and lawyers might perceive it as unnecessary, especially in those countries which do not provide higher compensation for such cases.

The research showed that due to the difficulties in bringing cases of (multiple) discrimination in healthcare to court, legal professionals often decide not to frame such cases in terms of discrimination but instead use other procedures that are easier to prove and can lead to higher compensation: particularly, medical negligence or malpractice. In doing so, however, the incidence of (multiple) discrimination remains hidden and unchallenged.

The research results point to a widespread perception of lack of effectiveness of the anti-discrimination redress mechanisms when it comes to (multiple) discrimination in healthcare. Very few respondents said that they had filed an official complaint even if they thought they had been discriminated against. Such widespread reluctance to file a discrimination complaint, which leads to underreporting of discrimination, is the result of several factors which often occur simultaneously. For example, a lack of knowledge about the available complaints procedures among healthcare users; the complexity of parallel, but distinct, complaint bodies which leave healthcare users unsure about where to address their complaints; the widespread belief that complaints have little or no effect and that they are generally not 'taken seriously'; the fear expressed by some respondents of retaliation by healthcare staff or immigration authorities after making a complaint; the lack of accessible redress mechanisms, both in terms of language barriers for migrants and lack of support for persons with disabilities, where the decision to file a complaint is usually left to the carer's goodwill.

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[3] The term 'interviewee(s)' is used interchangeably with that of 'respondent(s)' in this report.

Opinions

European Union law

EU secondary law as currently in force results in a 'hierarchy' of discrimination grounds, with the level of protection differing from ground to ground. Providing equal protection against discrimination on the grounds of religion or belief, disability, age and sexual orientation in areas beyond employment, including healthcare – as envisaged in the European Commission proposal for a Horizontal Directive[4] – is the first step to take in combating the phenomenon of multiple and intersectional discrimination. The ground of sex, though, would remain protected under separate legislation with a narrower scope.

In its amendments to the European Commission proposal for a Horizontal Directive, the European Parliament suggested introducing legislative provisions to prevent and combat multiple and intersectional discrimination.[5] This would more accurately reflect the experiences of victims, ensure that complainants can raise all aspects of a multiple discrimination claim in a single procedure and could also assist in raising awareness of this phenomenon. Nevertheless, claims of multiple discrimination involving the ground of sex might still be problematic under EU law because of the narrower scope of current gender equality legislation. It would therefore be advisable to tackle multiple discrimination in a consistent way throughout EU secondary law in order to enhance legal clarity. EU Member States, however, should not wait for harmonisation at EU level but should instead tackle multiple discrimination, including multiple discrimination involving sex, at national level in an efficient and encompassing way.

Due to low compensation awards in discrimination cases, alleged victims of discrimination in healthcare often initiate other types of legal actions, such as tort actions on grounds of medical negligence. Compensation awarded in discrimination cases should be dissuasive and proportionate to the damage suffered, including in the area of healthcare. Generally, providing for higher compensation in multiple discrimination cases would constitute an incentive for victims and their lawyers to pursue multiple discrimination claims before courts and hence render anti-discrimination law more efficient.

Institutionalising multi-dimensional equality in the healthcare system

EU Member States should adopt measures to further the right to health on an equal basis: free linguistic assistance – including translation and mediation services for those who do not speak or understand the language as well as 'signed' languages and other forms of support for people with sensory or intellectual impairments – should be made available in healthcare settings and when providing health information. Linguistic assistance is crucial in the context of informed consent (protected by Article 3 of the Charter of Fundamental Rights of the European Union); unequal treatment on the basis of language can easily result in indirect discrimination based on nationality (covered by the Cross-border Healthcare Directive) and/or ethnicity (covered by the Racial Equality Directive).

EU Member States should encourage positive actions for persons belonging to groups at risk of intersectional discrimination, as provided for by both the Racial Equality Directive and Employment Equality Directive. To do so, they should: accommodate the needs of women belonging to ethnic minorities who wish to be treated by female healthcare professionals; fund community-based mobile outreach programmes targeting different ethnic communities and groups among them – including elderly people, women and persons with a variety of disabilities – to promote healthcare and raise awareness of entitlements and available health services; and allocate more time for medical consultations with persons belonging to these groups due to their special needs.

EU Member States should find appropriate ways of guaranteeing that all healthcare users are treated equally, and with dignity and respect. Training on discrimination and multiple discrimination, cultural competence and understanding disabilities should be provided to healthcare professionals, possibly in a mandatory fashion.

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[4] European Commission (2008).
[5] European Parliament (2009).

Access to justice

EU Member States should take the necessary steps to increase healthcare users' awareness of the existence and functioning of the available complaint mechanisms, both for healthcare and discrimination issues. Complaint bodies should facilitate access to the complaint system for healthcare users who have specific linguistic needs and for those who have a disability. This can be done through the enhanced provision of information in different languages, in braille and easy-to-read format.

A fragmented system with a number of different equality bodies responsible for single grounds can contribute to undermining awareness of multiple discrimination as a legal approach to tackling discrimination. One equality body dealing with a variety of grounds of discrimination can, therefore, be an asset in efficiently fighting multiple discrimination. Furthermore, referral mechanisms between equality bodies and health complaint bodies and awareness of anti-discrimination legislation among health complaint bodies should be enhanced.

Improving data collection

Addressing health inequalities requires the collection and use of disaggregated data by the various individual grounds of non-discrimination and by those grounds in combination. There is a lack of reliable health statistics giving the full picture of the intersection of different grounds. In order to better reflect the monitoring of equality in EU cross-national surveys, data on ethnicity (recording both migrant status and ethnicity, where legal) and disability (taking into account the 'social model of disability') should be included in periodic national surveys. In order to capture multiple inequalities and disadvantages, survey sample sizes should be large enough to allow for further disaggregation.

Introduction

EU secondary law as currently in force provides comprehensive protection against discrimination only on the grounds of racial and ethnic origin and sex, although the EU enjoys far-reaching competence to legislate against discrimination in a number of sectors and across a variety of grounds.[6] Discrimination on the grounds of religion or belief, disability, age or sexual orientation is prohibited only in the context of employment. EU law does not currently protect against discrimination on more than one ground: a woman with a disability who is discriminated against in access to healthcare on the grounds of disability and ethnicity can claim only ethnic discrimination.

Multiple and intersectional discrimination recognise the complexity of discrimination against vulnerable groups and seek to obtain justice where a single ground might be insufficient. There is no commonly agreed definition for these concepts. In this report, multiple discrimination is understood as a phenomenon that can manifest itself in two ways. First, there is *additive discrimination* where, for example, a migrant woman might be discriminated in the work place because of her sex and when accessing healthcare because of her ethnicity. Second, there is the subject of this report, *intersectional discrimination*, where two or more grounds interact in such a way that they are inextricable. A young woman may, for example, face discriminatory treatment from her employers because she is seen as likely to interrupt her employment to have children. She is discriminated against, not just because of her age – this is not a problem affecting all young people. She is discriminated against, not just because of her sex – this is not an issue affecting all women. She is discriminated against precisely because she is both young and a woman. While this example refers to the intersection of age and sex, there are other vulnerable intersections of grounds, such as the intersection of religion, sex and ethnicity.

Intersectional discrimination applies where two or more grounds interact in such a way that they are inextricable. There are many possible intersections, such as: sex and age; or religion, sex and ethnicity.

The proposed Horizontal Directive would extend protection from discrimination beyond the area of employment[7] on the grounds of age, disability, sexual orientation and religion or belief, thus allowing for multiple discrimination cases to be brought also in sectors other than employment. In addition, the European Parliament called for national legal procedures to make it possible for a complainant to raise all aspects of a multiple discrimination claim in a single procedure.[8]

The comparative research conducted so far on multiple discrimination includes three EU-funded projects. A first explorative study, carried out in 2007, was based on a review of existing literature as well as on interviews with 'stakeholders' and a 'legal expert review' in 10 EU Member States and three non-EU Member States (Australia, Canada and the United States).[9] The report recommended more research, awareness raising and new legislation to define the concept. In 2009, the European Commission therefore requested the European Network of Legal Experts in the Field of Gender Equality to provide a complementary report to cover not only 10 but 30 countries and to focus on legal problems related to gender equality and multiple discrimination. The legal review shows that the term multiple discrimination is not used in legally binding EU legislation and there have been only a limited number of cases before the Court of Justice of the European Union (CJEU) and national courts. The report recommends "more research combining social sciences and legal approaches [...] or other methods through which barriers to and the practical effects of acknowledging cases of multiple discrimination can be assessed" and that changing the EU legal framework "seems most urgent in relation to those elements that have proven to be barriers for judges and equality bodies in addressing cases of multiple discrimination".[10] Finally, the project GendeRace tried to capture intersectional discrimination based on two grounds (sex and race) through a review of case law and interviews conducted with men and women belonging to ethnic minorities in six EU Member States, with a focus on employment. The report finds that while "[t]heoretically, multiple grounds [...] might be possible to claim in the area of employment, [...] practice demonstrates that these grounds, in most cases, will be argued separately".[11] The report recommends that the new European directive makes explicit reference to multiple discrimination as a form of discrimination that particularly affects the most vulnerable.

This report adopts a different perspective. Reflecting the lack of clarity surrounding the ways multiple discrimination manifests itself and whether there is a need to make adjustments in how the laws are formulated or applied, this report relies on fieldwork

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[6] See Treaty on the Functioning of the European Union (TFEU), Art. 10 and 19 (1).
[7] European Commission (2008).
[8] European Parliament (2009).
[9] European Commission (2007a).
[10] Burri, S. and Schiek, D. (2009), p. 23.
[11] GendeRace (2010), p. 96.

research conducted through interviews in an effort to give a voice to different groups of people at risk of multiple discrimination due to the interplay of age, sex, ethnicity and disability. In the example of healthcare, it illustrates how individuals (termed healthcare users) feel affected by the structures or the people they come into contact with when seeking help for their health; it also gives voice to those who serve them as clients (termed healthcare professionals), or those (termed legal professionals, encompassing lawyers in private practice, staff of equality ombudsmen and of patient complaint bodies) helping them seek (legal) redress for the (discriminatory) treatment they felt they received. This approach advances the understanding of the legal context because the stories of those concerned, both as healthcare users or professionals working in the field of equality or patients' rights, shed light on how multiple vulnerabilities work in practice and where some barriers in redress mechanisms can be found.

The FRA decided to select healthcare for this research both because there is a lack of research on how discrimination and multiple discrimination manifest itself in this important sector and also because healthcare is a particularly sensitive area, where unequal treatment, however rare, must be systematically and effectively tackled. The effects of unequal treatment and discrimination on health and its determinants, including access to healthcare services, are still not well documented across the EU. In this context the European Commission, in its Communication on *Solidarity in Health*, invited the FRA "[...] to collect information on the extent to which vulnerable groups may suffer from health inequalities in the EU, particularly in terms of access to adequate healthcare, social and housing assistance".[12] Discrimination and equal treatment in healthcare are not well documented in European countries.

Data from EU-MIDIS – the first EU survey on the discrimination experienced by ethnic minorities conducted by the FRA in 2008 – provided a quantitative insight into the reality of multiple discrimination.[13] The findings revealed that one fourth of the people of ethnic minority background interviewed indicated that they had felt discriminated against on at least two protected grounds in the last 12 months. 'Visible' minorities, such as Roma and African people, feel discriminated against more often and across a larger range of grounds than other ethnic minorities. The survey found that out of the nine domains of everyday life it examined, discrimination by healthcare personnel was one of the least significant areas in relation to ethnic and immigrant origin. Nonetheless, visible minorities, such as Roma and North Africans, reported some of the highest perceptions of discrimination in healthcare in the EU. There is little understanding, however, of the meaning of discrimination and multiple discrimination in healthcare: it is necessary to identify how exactly it plays out for individuals accessing and using healthcare.

Article 35 of the Charter of Fundamental Rights of the European Union states that "everyone has the right of access to preventive healthcare and the right to benefit from medical treatment under the conditions established by national laws and practices". EU Member States are responsible for the organisation and delivery of health services and medical care. Article 168 of the Treaty on the Functioning of the European Union (TFEU), however, gives the EU limited legislative competence in the field of public health.[14] Addressing health inequalities and equity in healthcare is a key action of the EU Health Strategy (2008-2013)[15] which identifies *equity in health* – defined as the absence of systematic differences in health status between social groups, including differences that occur by sex, race or ethnicity, education or income, disability, or living in various geographic localities – as a fundamental value. Inequities in health systematically put groups of people who are already socially disadvantaged at further disadvantage with respect to their health. It is increasingly recognised that such inequities may be avoidable, and are largely attributable not to natural factors alone, but are instead significantly associated with inequality or inequity of the 'social determinants' of health, including life chances and living conditions, residence, accessibility of services, health promotion services, public policies influencing the quantity, quality and distribution of these factors and socio-economic status. It is also affected by exposure to discrimination or harassment in different areas of life.[16] The European Commission's Communication acknowledges that vulnerable and socially excluded groups, such as individuals from migrant or ethnic minority backgrounds, persons with disability or the homeless, experience particularly poor average levels of health and face barriers in accessing healthcare.[17] In addition, patient's rights in cross-border healthcare have been enhanced by a recently adopted directive that EU Member States must transpose into national law by 25 October 2013.[18] The Directive on cross-border healthcare sets out the right of patients to seek healthcare in another EU Member State. Whilst Article 4 forbids discrimination with regard to nationality, point 21 of the Preamble specifies that Member States should

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[12] European Commission (2009a).

[13] FRA (2010a).

[14] Ex Article 152 of the Treaty establishing the European Community (TEC).

[15] European Commission (2007b); similarly, the EU commitment to reduce health inequalities was expressed in other policy documents including Council of the European Union, Employment, Social Policy, Health and Consumer Affairs Council (EPSCO) (2011) and European Commission (2010a).

[16] Braveman, P. and Gruskin, S. (2003).

[17] European Commission (2009a), p. 3.

[18] Council Directive 2011/24/EU, OJ 2011 L 88/45.

take into account the principles of universality, access to good quality care, equity and solidarity. Member States must further ensure that healthcare providers provide the information patients need to make an informed choice.

By examining how specific groups of healthcare users experience intersectional discrimination and barriers, the report will shed light on one of the factors that underlies inequalities in access to healthcare, which, in turn, contributes to health inequalities. This report aims to complement on-going and future EU health projects and actions funded by the European Commission targeting the health status of migrants or ethnic minorities.[19]

The research

This report seeks to understand how multiple discrimination affects equal access to healthcare services because of the interplay of age, sex, ethnic origin and disability. Based on qualitative research in five EU Member States – Austria, Czech Republic, Italy, Sweden and the United Kingdom – it explores the barriers, the needs and the experiences of (multiple) discrimination faced by different groups of healthcare users at the intersection of sex, age and ethnic origin when accessing the health system; the evidence collected though the fieldwork is analysed on the background of the existing legal instruments in place at the international, European and national, level to address multiple discrimination in healthcare. The report also identifies promising policy initiatives and measures undertaken by the five Member States and the European Union to enable and improve access to health services and quality of health for persons belonging to vulnerable groups at the intersection of gender, age and ethnic origin and in terms of disability.

These five EU Member States were chosen because their health systems and the way they address multiple discrimination in their national legislation differ. They also have very different histories of immigration and migrant or ethnic minority populations and stages of development of anti-discrimination legislation. Within each of these countries, two significant groups of nationalities or minority ethnic groups were selected.[20] In Austria, they were drawn from Turkish and ex-Yugoslav populations; in the Czech Republic, from the former USSR Republics and Czech/Slovak Roma (a non-migrant group); in Italy, North Africans and sub-Saharan Africans; in Sweden, from the Middle East and Africa; and in the United Kingdom, African and African-Caribbean and South Asian ethnic minorities. As noted above, the Roma and North Africans have some of the highest perceptions of discrimination in healthcare in the EU. Respondents were asked to participate if they defined themselves as members of a particular migrant or minority ethnic group. This report focuses on legally residing migrants, however other recent FRA reports also explored the situation of irregular migrants when accessing healthcare.[21]

The FRA carried out fieldwork in two sites in each EU Member State. With the exception of Italy (Bologna and Naples) one of the sites was the capital city. In Austria, Sweden and the United Kingdom, the second site was a major city with a large migrant minority ethnic community (Graz, Malmo and Leicester). In the Czech Republic, the second site was a rural area outside of Prague with many Roma residents. In-depth interviews were conducted with 172 users of healthcare services in total.

The methodology applied in this research does not aim to provide statistical data on the prevalence of multiple discrimination and its distribution in the population. Instead the in-depth interviews and case studies provide a better insight and deeper understanding of the experiences of multiple and intersectional forms of discrimination by members of multiply disadvantaged groups when accessing healthcare, including information on the contexts, the reactions, and the impact of this specific form of discrimination.

Interviews were conducted with three different groups of healthcare users with migrant/ethnic background: women with reproductive health issues between the ages of 18 and 50 years, older people (over 50 years), and young adults between 18 and 25 years with intellectual disabilities.[22] Furthermore, a number of young adults with intellectual disabilities and many of the older people also had various health problems and physical and sensory disabilities.

These three groups were identified as especially vulnerable to multiple discrimination in healthcare. In specific, older persons belonging to migrant or ethnic minorities

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[19] For instance, see the EQUI-HEALTH project, launched in 2012, which aims to foster health provision to migrants, Roma and other vulnerable groups in the EU; and a future call for tender, included in the 2013 European Commission work plan for the health programme, on 'Training packages for health professionals to improve access to and quality of health services for migrants and ethnic minorities'.

[20] The United Kingdom alone collects data on ethnicity. Elsewhere the data used relies on nationality and country of birth (see Chapter 3 on evidence).

[21] FRA (2011c). See also the projects co-funded by the EU public health programme, Health Care in NowHereland, available at: www.nowhereland.info/ and AVERROES–HUMA, available at: http://ec.europa.eu/health-eu/news/2012/8/news_20120907_avveroes__en.htm.

[22] According to Article 1 of the CRPD, "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".

where chosen due to the increasing aging population and the little research conducted so far on discrimination experiences of older people and more specifically older migrants in healthcare. The results will improve our understanding of how to further equality and inclusion in healthcare for older persons, which was one of the objectives of the 2012 European Year for Active Ageing and Solidarity between Generations. Younger persons with intellectual disabilities were recently identified by several international organisations as one of the groups at higher risk of discrimination and neglect,[23] also due to limited access to health services, including routine medical treatments, leading to health inequalities unrelated to their disabilities.[24] Finally, young women with a migrant or ethnic minority background are especially at risk of multiple discrimination when it comes to sexual and reproductive care.

Interviewees were recruited through a wide range of contacts including migrant and ethnic minority non-governmental organisations (NGOs) and migrant friendly health services, disability organisations and mainstream and specialised healthcare services. They were asked to identify persons who belonged to one of the three target groups and had health needs that required frequent utilisation of healthcare services, including persons that were likely to have experiences of discrimination although they may not have made any formal complaints. In some cases interviewees referred to experiences of discrimination they had witnessed happening to others. For young people with intellectual disabilities, specialist organisations and social services were approached.

The interviews were designed to obtain a detailed account of the barriers health service users face in accessing healthcare, their needs, access to and use of health services and preventive measures, information about and consent to treatment, experiences of discrimination in healthcare and knowledge and use of complaints mechanisms. The interviews lasted between one and two hours. In the context of healthcare, instead of the term discrimination interviewees mostly preferred to speak about unfair, unequal, delayed, refused or poor treatment. They also referred to their right to dignity and respect in treatment by health professionals and the right to reasonable accommodation. The CRPD defines reasonable accommodation as "necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, […] to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".[25]

One of the main research challenges was to recruit young adults with intellectual disabilities and belonging to a migrant or ethnic minority. While there is no widespread agreement on a definition of intellectual disability, FRA's recent research in the area of disability used a definition proposed by two leading EU umbrella organisations in this area: "a person with intellectual disability has life-long development needs. Intellectual disability is a condition of slow development, where medication has no effect".[26] In the United Kingdom, the preferred term is 'persons with learning disabilities'.[27] In all the EU Member States studied, with the exception of the United Kingdom which has an established minority ethnic population born in the country, it proved difficult to make contact with young people in this category.[28]

In addition, for the research project interviews were also conducted with 142 health providers, policy makers, advocacy groups, health ombudsmen, equality bodies and legal experts in the five Member States collecting their views on the barriers, needs, and policies towards vulnerable groups, as well as their understanding of (multiple and intersectional) discrimination in relation to these groups. In particular, legal experts were asked whether they were familiar with cases of multiple and intersectional discrimination, especially in healthcare, and the potential contribution of this approach to dealing with unequal treatment. Throughout the report, the terms 'interviewee' and 'respondent' are used interchangeably.

The report is based on five country reports that served as background. These country reports were partly based on desk research (legal review of (multiple) discrimination legislation and case law on health; review of health entitlements and health policies targeting vulnerable groups; review of evidence of inequality and discrimination in healthcare) and also presented the key results of the interviews with health providers, advocacy groups, policy makers and equality and ombudsman bodies, as well as with the selected health service users.

The present report is divided into five chapters. Chapter 1 reviews the legal context of existing measures to address multiple and intersectional discrimination with specific focus on the healthcare sector and the right to

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[23] See the European Declaration on the Health of Children and Young People with Intellectual Disabilities and their Families, an initiative that aims to ensure that all children and young people with intellectual disabilities are fully participating members of society, living with their families, integrated in the community and receiving healthcare and support proportional to their needs; see World Health Organization (WHO) and United Nations Children's Fund (UNICEF) (2010a).

[24] European Commission (2010b).

[25] UN, CRPD (2006), Art. 2.

[26] Inclusion Europe and Mental Health Europe (2004). See also, FRA (2010b), p. 7.

[27] See: www.nhs.uk/Livewell/Childrenwithalearningdisability/Pages/Whatislearningdisability.aspx.

[28] As a result, interviews with this group were conducted only in three EU Member States: Austria, Sweden and the United Kingdom.

health. Chapter 2 discusses the availability of evidence on health conditions and access to healthcare both at EU level and within individual countries and explores the feasibility of intersectional analysis by gender, age, disability and ethnicity. Chapter 3 highlights the diverse barriers in accessing healthcare services, such as communicational, informational, financial, organisational and cultural barriers identified by the social research. Chapter 4 presents the practices and experiences of discrimination (including multiple discrimination) discussed by the health providers and users in the five EU Member States studied. Chapter 5 then addresses specific aspects of access to justice, including knowledge and use of the complaint system and barriers in bringing discrimination and multiple discrimination cases in healthcare. The Appendix provides further detail on the methodology applied. An online Annex provides additional information on patients' rights, health outcomes and access to healthcare in the five EU Member States covered by the research.[29]

The FRA completed this report based on the research and analysis conducted by a group of external contractors with Middlesex University, London, United Kingdom, coordinating the work carried out by expert institutions in Austria (International Centre for Migration Policy Development and the Research Institute of the Red Cross), the Czech Republic (Gender Institute, Prague), Italy (Centre for International Health, Bologna) and Sweden (Research and Development Centre for the Care of Older and Differently Abled People, Stockholm).

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[29] See FRA's website at: http://fra.europa.eu/sites/default/files/inequalities-multiple-discrimination-healthcare-annex_en.pdf.

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Multiple discrimination: the legal situation

This chapter illustrates the legal situation surrounding multiple discrimination by putting equality, multiple discrimination and the right to health in their legal context. It shows an acknowledgment of multiple and intersectional discrimination at the UN and EU levels. Understanding of the phenomenon has evolved over recent decades as has the awareness that more needs to be done. There is a fundamental lack of clarity about how existing law functions in practice, and which results it can deliver to people who feel aggrieved. The lack of legal understanding of the phenomenon also leads to a lack of clarity about which legal or structural adaptations might be needed. The chapter highlights some promising developments and examples of good practice.

It should be read in conjunction with the last chapter of this report, which focuses on perceptions of the effectiveness of legal and non-legal redress systems by users, staff members or professionals in private legal practice. It looks at some of the barriers to redress that were identified and alternative, informal strategies deployed to overcome them.

1.1. The knowledge base at European Union level

Both those experiencing and legal professionals alike are concerned with what happens when a person experiences less favourable treatment on more than one ground. Previous academic thinking, including a number of reports at the European level,[30] have addressed the situation, sometimes from a comparative legal perspective.

The *Multiple discrimination in EU law*[31] report describes, from a legal perspective, problems with the EU-wide "transplantation of specific national models". It highlights the contradictory values informing the various conceptual layers used in addressing equality, such as "enhancing transnational competition between individuals, supporting individual mobility and engendering European employment markets, protecting against social exclusion, furthering group identities and numerous others". Contradictory values "will sometimes lead to clashes of norms within the field", the report says, but it could not report any case law from the Court of Justice of the European Union (CJEU) addressing the issue. "[T]he reluctance of the EU's highest court to engage with intersectional gender discrimination indicates the need of more reflection on the problem from an EU law perspective," it concludes.

The *Multiple discrimination in EU law* report finds that the situation at national level is diverse, ranging from lack of information to lack of awareness, to some acknowledgement of multiple discrimination. Case law at national level includes employment-related cases, such as sexual and racist harassment, refusal to employ or promote or even the dismissal of a woman perceived as minority ethnic, or detrimental working conditions for groups of migrant women employed as cleaners or domestic workers. Beyond employment, experts report cases in which women perceived as belonging to a minority were denied adequate protection against domestic or institutional violence, as well as cases of involuntary sterilisation of Roma women. Age and sex combine unfavourably especially in the context of different statutory pension ages for women and men, which can lead to the early compulsory retirement of women. Sex and religious discrimination are also in evidence, particularly with respect to the wearing of

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[30] European Commission (2007a); Burri, S. and Schiek, D. (2009).

[31] Burri, S. and Schiek, D. (2009), p. 7.

dresses and garments.[32] Overall, the report finds that multiple discrimination against women is not easy to address in *any* legal system: sometimes discrimination is not acknowledged at all; in other cases, it is acknowledged but better dealt with through other means than multiple discrimination claims. Despite these difficulties, the report concludes that "addressing such discrimination seems necessary to do justice to all women suffering discrimination".[33]

The present report reviewed in detail the legal system of the five EU Member States selected for this project. A summary of the findings is presented later in this chapter, with more detailed information on patients' rights, health outcomes and access to healthcare in the Annex to this report. Against this legal background, the experience of multiple discrimination documented through in-depth interviews with healthcare users, health professionals and legal experts contribute to understanding whether there is a need to adjust how the laws are formulated or applied.

1.2. At the crossroads of the right to equal treatment and the right to health

Equality in (access to) healthcare manifests evident specificities. Equal treatment and health are protected *as rights* by national and often international legislation. Each person is thus entitled to *both* the right to equal treatment and the right to health. These two rights are inextricably interwoven: the right to health can be violated by discriminatory rules or practices in healthcare, and this includes rules or practices which have an impact on classes of people who find themselves at the intersection of multiple factors of vulnerability such as sex, age, ethnicity and disability.

If a person feels that their *right to health* has been violated by some conduct which appears – subjectively, objectively or both – unfairly discriminatory, this person might want to have his or her right to health, rather than his or her right to equal treatment, legally enforced, or the latter in combination with the former. This report therefore analyses what the right to health entails, and which agencies and structures there are to enforce it, as far as these relate to practices perceived as discriminatory.

The issue clearly emerges of the interconnections between various patients' rights and the right to health on the one hand, and patients' rights and the right to equal treatment on the other. Are most situations protected by law? By which law? Are there variations among the five EU Member States analysed in this report? How is anti-discrimination law triggered to deliver full equality in practice?

In all national legal frameworks, the level of legal protection offered against discrimination changes according to both the area and the grounds involved. In the area of healthcare, anti-discrimination legislation in all five of the EU Member States researched covers racial or ethnic origin, sex and disability, the grounds studied in this research. However, age discrimination is not covered in the health sector in Italy and Sweden, which means that in these EU Member States a claim for discrimination in healthcare on the ground of age cannot be made. The following table explains which grounds are covered in healthcare in each of the five countries.

Patients' rights are fundamental to this analysis. Both international[34] and national legal instruments[35] have developed this notion recently, erecting a core of rights which must be guaranteed to healthcare users. Along with anti-discrimination legislation, patients' rights constitute an essential tool in combating discrimination in healthcare.

Since the 1948 adoption of the Universal Declaration of Human Rights, international agreements and national law have embedded the concept of patients' rights in the human rights protection framework. The declaration recognises the "inherent dignity" and the "equal and unalienable rights of all members of the human family". These concepts of a person, together with the fundamental dignity and equality belonging to all human beings, constitute the basis of the development of the notion of patients' rights. The EU and Council of Europe have, among others, adopted international agreements since 1948 to provide legal protection to the right to health and to develop patients' rights.

EU Member States, including the five countries studied, do not have common legislation on patients' rights. Table 1 in the online Annex shows for which patients' or health rights each of the five countries provide.[36] Austrian and Italian laws and regulations could be legislated at the regional level in addition to the national level and there are slight differences in practice among the United Kingdom's four nation states.

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[32] See FRA (2012a).

[33] Burri, S. and Schiek, D. (2009), p. 11.

[34] Council of Europe, Convention on Human Rights and Biomedicine (1997).

[35] See, for example, the British National Health Service's Constitution, available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113645.pdf.

[36] See FRA's website at: http://fra.europa.eu/sites/default/files/inequalities-multiple-discrimination-healthcare-annex_en.pdf.

Table 1: Grounds of discrimination covered by national anti-discrimination legislation on healthcare, by EU Member State

	AT*	CZ	IT	SE	UK
Sex	Yes	Yes	Yes	Yes	Yes
Race	Yes	Yes	Yes	Yes	Yes
Age	Yes, with exceptions**	Yes	No	No	Yes
Disability	Yes, with exceptions**	Yes	Yes	Yes	Yes

Notes: ** For Austria, the table presents anti-discrimination legislation at the provincial level. Legislation against discrimination at the federal level covers access to health only with regard to ethnic origin, sex and disability.*

*** At the provincial level, with the exception of Lower Austria, all provinces have chosen to guarantee the same level of protection in the employment and the non-employment field and have extended the grounds protected in the employment field to the non-employment field.*

Sources: *Austria: Equal Treatment Act (Gleichbehandlungsgesetz), Federal Law Gazette I Nr. 82/2005 last amended by BGBl. I Nr. 98/2008; Federal Disability Equality Act (Behindertengleichstellungsgesetz), BGBl I Nr. 82/2005, Federal Law Gazette I Nr. 82/2005; Czech Republic: Act No. 198/2009 Coll. on Equal Treatment and Legal Means of Protection against Discrimination and Other Laws (Zákon č. 198/2009 Sb., o rovném zacházení a o právních prostředcích ochrany před diskriminací a o změně některých zákonů (Antidiskriminační zákon)), 1 September 2009; Italy: Decree 215/2003, G.U. no. 186, 12 August 2003, Law 67/2006, G.U. no. 54, 6 March 2006, Decree 196/2007, G.U. no.261, 9 November 2011, S.O. no. 228; Sweden: Act on the prohibition of discrimination (Lag om förbud mot diskriminering), Lag (2003:307), 5 June 2003; Law amending the Act (2003:307) on the prohibition of discrimination, Lag (2005:453), 1 July 2005, Discrimination Act (Diskrimineringslag), SFS (2008:567), 1 January 2009; United Kingdom: Race Relations Act 1976; Equality Act 2010 (the age discrimination ban entered into force on 1 October 2012)*

The legal review considers the rights described by the 1994 World Health Organization's (WHO) Declaration on the Promotion of Patients' Rights in Europe.[37] National legislation in the EU Member States concerned also contains one or more horizontal anti-discrimination provisions which provide that the above mentioned rights are enjoyed without discrimination.[38] As mentioned above, the fieldwork research shows that most patients perceive that (multiple) discrimination impacts primarily on their rights as patients rather than on equality; they pursue redress strategies, if any, according to this perception. A report on multiple discrimination in healthcare, thus, cannot avoid examining the content of such rights and the available complaint mechanisms.

The right to healthcare encompasses a number of elements. The right to access care and treatment concerns the right for every individual to access the health services that his or her health needs require.[39] This couples up with the right to information, according to which "[p]atients have the right to be fully informed about their health status, including the medical facts about their condition; about the proposed medical procedures, together with the potential risks and benefits of each procedure; about alternatives to the proposed procedures, including the effect of non-treatment; and about the diagnosis, prognosis and progress of treatment."[40]

The right to an explanation appropriate to the patients' capacity of understanding means that patients must be involved in discussion about their healthcare, and that healthcare professionals must use understandable language appropriate to the person concerned.[41] The right to translation or interpretation support means that if patients do not speak the language used in the EU Member State where the healthcare service is provided, some form of interpreting should be available.[42] The right to informed consent means providing patients with appropriate information as to the purpose and nature of the intervention as well as its consequences and risks.[43] According to the right to free choice, everyone must be free to choose among different treatment procedures and providers on the basis of adequate information.[44] Under the right to privacy and confidentiality, "all information about a patient's health status, medical condition, diagnosis, prognosis and treatment and all other information of a personal kind must be kept confidential, even after death. The patient must give explicit consent to, or the law must expressly provide for, the disclosure of confidential information. Consent may be presumed where disclosure is to other healthcare providers involved in that patient's treatment."[45] The right to dignity implies that everyone has the right to be treated with dignity and respect, in accordance with his

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[37] WHO (1994).
[38] *Ibid.*, point 6.
[39] *Ibid.*, point 5.
[40] *Ibid.*, point 2.2.
[41] *Ibid.*, point 2.4.
[42] *Ibid.*, point 2.4.
[43] *Ibid.*, point 3. On the right to informed consent in the context of involuntary placement and treatment see also FRA (2012b).
[44] WHO (1994), point 5.6.
[45] *Ibid.*, point 4.

or her human rights.[46] Finally, according to the right to observance of quality standards, everyone must have access to high quality health services on the basis of the specification and observance of precise standards.[47]

1.3. Awareness of multiple discrimination at the international level

The principles of equality before the law and equal treatment irrespective of certain personal characteristics or grounds are cornerstones of modern EU democracies. The EU legal system prohibits discrimination on six grounds: sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation. Both the Treaty on European Union (TEU) and the Treaty on the Functioning of the European Union (TFEU) contain relevant provisions in order to combat discrimination at the EU level. In particular, Article 2 of the TEU establishes that equality is one of the founding values of the EU; Article 3 (2) of the TEU says that the EU "shall combat social exclusion and discrimination, and shall promote social justice and protection, equality between women and men, solidarity between generations and protection of the rights of the child"; Article 10 of the TFEU declares that "[i]n defining and implementing its policies and activities, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation"; and Article 19 (1) of the TFEU reads that the Council of the European Union, with the consent of the EU Parliament, "may take appropriate action to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation."

Furthermore, the Charter of Fundamental Rights of the European Union contains a number of fundamental rights among which are those of equality and non-discrimination. Article 20 declares that everyone is equal before the law, while Article 21 prohibits discrimination "on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation". However, the Charter does not mention multiple discrimination.

In regard to the right to health, Article 35 of the Charter states that EU Member States have to recognise that "everyone has the right of access to preventive healthcare and the right to benefit from medical treatment under the conditions established by national laws and practices. A high level of human health protection shall be ensured in the definition and implementation of all Union policies and activities".

There are also a number of EU directives containing prohibitions of both direct and indirect discrimination on the grounds of sex,[48] racial and ethnic origin,[49] religion or belief, disability, age and sexual orientation,[50] but the material scope of these directives varies and healthcare is not covered for all the protected grounds. None of these directives contain an explicit provision on multiple discrimination. Both the Employment (Recital 3 Directive 2000/78/EC) and the Racial Equality Directives (Recital 14 Directive 2000/43/EC), however, explicitly recognise the possibility of multiple discrimination and mention that women are often the victims of multiple discrimination, although the term does not appear in the binding part of these laws, and no definition is given.

EU legislation, at least, therefore acknowledges that victims of multiple discrimination may exist. There is little clarity, however, about who such victims are and what barriers and other specific issues they face. Consequently, although dealing with multiple discrimination does not appear to be barred, there is little indication of how to go about it. This report sheds some light on this problem.

Despite the lack of legal remedies on multiple discrimination, the EU has recognised the existence of multiple discrimination in a number of other binding secondary law instruments. The European Parliament, for example, established the European Year for Equal Opportunities for All in 2007 to, as its prime objective, raise awareness of the right to equality and non-discrimination and "of the problem of multiple discrimination".[51]

A review of existing UN treaties presented below shows a remarkably similar situation. There is clearly some awareness of the multiple discrimination which women may experience, and of the intersections between race

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[46] *Ibid.*, point 1.

[47] *Ibid.*, point 5.

[48] Council Directive 2004/113/EC, OJ 2004 L 373/37 (*Gender Equality Directive on Goods and Services*) and 2006/54/EC, OJ 2006 L 204/23.

[49] Council Directive 2000/43/EC, OJ 2000 L 180/22 (*Racial Equality Directive*).

[50] Council Directive 2000/78/EC, OJ 2000 L 303/16 (*Employment Equality Directive*).

[51] Decision No. 771/2006/EC of the European Parliament and of the Council of 17 May 2006 establishing the European Year of Equal Opportunities for All (2007) – towards a just society; reference is also made in the FRA Multi-annual Framework 2008; Commission Decision of 20 January 2006 establishing a high-level advisory group on social integration of ethnic minorities and their full participation in the labour market (2006/33/EC); Council Decision of 3 December 2001 on the European Year of People with Disabilities 2003 (2001/903/EC); Council Decision of 20 December 2000 establishing a Programme relating to the Community framework strategy on gender equality (2001-2005) (2001/51/EC); Council Decision of 27 November 2000 establishing a Community action programme to combat discrimination (2001 to 2006) (2000/750/EC).

and sex discrimination, but little indication as to how to attain a situation of greater fairness and justice. The structural legal problems are various, as the last chapter of this report details: to mention just one, the International Convention on the Elimination of All Forms of Racial Discrimination prohibits race discrimination only and does not cover sex; therefore, it is not possible to lodge an individual complaint to the monitoring committee on both sex and racial grounds.

A 'single ground approach', which descends from the conceptualisation of each ground of discrimination separately from all the others, thus informs UN law as well as EU law, and often characterises national law as well. There is, however, growing awareness that the single-ground approach might be too limited.

An example from outside the EU makes the problem of the single-ground approach clearer. Alyne da Silva Pimental Teixeira, a Brazilian national of African descent, was sixth months pregnant when she started suffering from nausea and severe abdominal pains. She turned to a private health centre for help but received poor quality care; her condition deteriorated, and she called a public hospital for an ambulance to be sent. The request was refused. Her family could not afford the costs of a private ambulance, thus Alyne did not receive the necessary emergency healthcare. She subsequently haemorrhaged and died in hospital.

Alyne's mother brought her case before the Committee on the Elimination of All Forms of Discrimination against Women, the treaty body of the 1979 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). The committee recalled the existence of discrimination against women, especially women from the most vulnerable sectors of society such as women of African descent.[52] It added that discrimination is exacerbated by regional, economic and social disparities. The committee noted that Alyne had been discriminated against not only because of her sex, but also because of her status as a woman of African descent and her socio-economic background. This was the first case in which the CEDAW Committee identified discrimination committed by a State Party on multiple grounds in healthcare, by failing to fulfil the obligations under Article 2 and 12 of the CEDAW to ensure access to healthcare. Moreover, in a recent concluding comment on the periodic state report of the Czech Republic, the CEDAW Committee voiced its concern regarding non-consensual sterilisations performed on, in particular, Roma women and women with mental disabilities. The committee noted the lack of implementation of the 2005 recommendations of the Ombudsman and urged the Czech government to "adopt without delay legislative changes with regard to sterilization, including a clear definition of free, prior and informed consent in cases of sterilization and to financially compensate the victims of coercive or non-consensual sterilizations performed on, in particular Roma women and women with mental disabilities."[53]

Thus the Committee recognises that "discrimination of women based on sex and gender is inextricably linked with other factors that affect women, such as race, ethnicity, religion or belief, health status, age, class, caste, and sexual orientation and gender identity".[54] The CEDAW Committee has forcefully called upon State Parties to legally recognise and prohibit intersecting forms of discrimination and their compounded negative impact on women.

Other treaty bodies have also affirmed the existence of multiple discrimination and the need to take measures to combat it. The General Comment No. 20 of the Committee on Economic and Social and Cultural Rights (CESCR),[55] adopted in 2009, recognises the existence of multiple[56] and intersectional[57] discrimination, and states that the specific impact these kinds of discrimination have on individuals "merits particular consideration and remedying". The CESCR has also voiced its concern about unequal access for all to healthcare in the United Kingdom: the committee stated that health inequalities widened among social classes, especially with regard to healthcare goods, facilities and services. The committee recommended the United Kingdom "to fulfil its commitment to reduce health inequalities by 10 % by 2010, measured by infant mortality and life expectancy at birth".[58]

According to the Committee on the Elimination of all Forms of Racial Discrimination (CERD), racial discrimination primarily affects women or can affect women in different ways or to different degrees than men. It intends to integrate a gender perspective and incorporate a gender analysis in its work.[59] It has called on States Parties to: "Take into account, in all programmes and projects planned and implemented and all measures adopted, the situation of women of African descent, who are often victims of multiple discrimination".[60]

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[52] UN, Committee on the Elimination of Discrimination against Women (CEDAW) (2011).

[53] UN, CEDAW (2010).

[54] *Ibid.*, para. 35

[55] UN, CESCR (2009a).

[56] *Ibid.*, para. 17: "Some individuals or groups of individuals face discrimination on more than one of the prohibited grounds, for example women belonging to an ethnic or religious minority. Such cumulative discrimination has a unique and specific impact on individuals and merits particular consideration and remedying."

[57] *Ibid.*, para. 27: "Other possible prohibited grounds could include [...] the intersection of two prohibited grounds of discrimination, e.g. where access to a social service is denied on the basis of sex and disability."

[58] UN, CESCR (2009a).

[59] UN, CERD (2000), General Recommendation No. 25.

[60] UN, CERD (2011), General Recommendation No. 34.

The 1989 Convention on the Rights of the Child (CRC) and the 2006 Convention on the Rights of Persons with Disabilities (CRPD) both prohibit discrimination. The CRPD, however, is the first international agreement which explicitly recognises multiple discrimination, also in the field of access to healthcare. All five EU Member States surveyed, as well as the EU, have signed and ratified it. The CRPD aims "to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity."[61]

The CRPD is significant for a number of reasons. It states explicitly, for example, that persons with disabilities have the right to the same level of health services as other people. The CRPD also enshrines a rights-based model of disability. Its definition reflects the marked evolution from a model of disability focused on individual limitations and medical support to one that emphasises the equal human rights of persons with disabilities and concentrates on removing the societal barriers which continue to impede equal opportunity. The Council of Europe's understanding of disability has undergone a similar 'paradigm shift' towards an approach that promotes the full rights and participation of persons with disabilities.[62]

This is especially relevant at the EU level, because the European Parliament[63] has suggested that 'disability' be understood in light of the CRPD in the proposal for a new EU anti-discrimination directive.[64] National legislation and national case law are also likely to follow this interpretation.

Most importantly, the guarantee of equal and effective legal protection against discrimination on all grounds, the explicit recognition of multiple discrimination and the attention to women and children with disabilities all suggest that the CRPD Committee will allow for persons with a disability to bring individual claims of multiple discrimination before it.[65] Whether this is indeed the case and how the committee's handling of such claims will influence national legislation and case law in dealing with multiple claims remain to be seen.

The CRPD might allow for persons with disability to make individual claims of multiple discrimination. This could be significant, because all 27 EU Member States are signatories to the convention and 24, including all five EU Member States in this research, as well as the EU, have ratified it.

1.4. Multiple discrimination under the European Convention on Human Rights

Both Article 14 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) and additional Protocol 12 on equality and non-discrimination prohibit discrimination on a large number of grounds, making a claim on more than one ground theoretically possible. However, the European Court of Human Rights (ECtHR) does not use the terms multiple or intersectional discrimination.

Furthermore, the ECHR does not mention healthcare in any of its provisions, although issues linked to healthcare might be subsumed under other relevant provisions. In general, however, a violation of Article 14 – which is a provision that can only be invoked when the matter falls within the ambit of another ECHR right – is difficult to claim in cases where access to healthcare is at stake. An analysis of case law primarily shows examples of cases where multiple discrimination was not used.[66] For example, no breach of Article 14 was claimed, nor was discrimination mentioned, in two cases where the individuals concerned claimed that if they were deported, they would not be able to receive the medical treatment in their home country that they were receiving in the United Kingdom. The *Bensaid*[67] case, concerning the deportation from the United Kingdom to Algeria of an Algerian national suffering from schizophrenia, invoked Articles 3 (prohibition of inhuman or degrading treatment), 8 (respect for private and family life) and 13 (effective remedy); and in *D. v. United Kingdom*,[68] a case where an applicant suffering from the advanced stages of AIDS was facing removal, Article 3 alone. The 2011 judgment in *Yazgul Yilmaz v. Turkey*[69] could be seen as a case where special guarantees were required due to age and sex, but again, no violation of Article 14 was claimed. The case concerned a Turkish national who, when she was sixteen years old, was subjected to gynaecological examination without her consent while she was in police custody – in order to ensure, according to the authorities, that she had not been assaulted – and the failure to prosecute the doctors who had carried it out. The ECtHR considered that such an examination could be especially traumatic for a minor and more so for a minor than for an adult. Authorities should have

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[61] UN, CRPD (2006), Art. 1.

[62] For a more in-depth discussion of the evolution in the concept of disability in international law, see FRA (2011a).

[63] European Parliament (2009).

[64] European Commission (2008).

[65] See also Hendriks, A. C. (2010), pp. 7–27.

[66] For more analysis of ECtHR's case law in this field please consult the *Handbook on European non-discrimination law*, FRA (2011b).

[67] ECtHR, *Bensaid v. United Kingdom*, No. 44599/98, 6 May 2001.

[68] ECtHR, *D. v. United Kingdom*, No. 30240/96, 2 May 1997.

[69] ECtHR, *Yazgul Yilmaz v. Turkey,* No. 36369/06, 1 February 2011.

obtained the consent both of the minor and of her representative for all parts of the examination, offered a choice of a male or a female doctor and informed the minor of the reasons for the examination. The Court found a violation of Article 3 of the ECHR.

Counsel for the applicants might have opted not to invoke the anti-discrimination clause of Article 14 in order to rely primarily on the violation of a substantive provision; the ECtHR typically examines the claim of the other articles first and, when it finds a violation of these other articles, it will usually not find it necessary to separately determine whether the facts of the case also give rise to a breach of Article 14.

A number of cases concerning the forced sterilisation of Roma women, which could potentially be framed as multiple discrimination cases, were brought before the ECtHR.[70] Three Slovak women of Roma origin, two of whom were minors at the time of the incident, claim that they were segregated in so-called ‘gypsy rooms’, and, while having caesarean sections, were sterilised without their knowledge or consent. The applicants allege breaches of Articles 3, 8 and 12 and also claim that their sterilisations were based on the grounds of sex, race, colour, membership of a national minority and ethnicity in breach of Article 14 in conjunction with Articles 3, 8 and 12 of the ECHR. These cases, which might have given the court an opportunity to clarify the application of Article 14 in relation to the use of medical procedures, were subsequently struck by the court because the parties reached a settlement.[71]

The ECtHR, however, has never used the term ‘multiple discrimination’, including in other recent cases of forced sterilisation of Roma women. In the 2011 case of *V.C. v. Slovakia,*[72] the ECtHR decided in favour of a 20-year old Roma woman who was sterilised in a public hospital without her informed consent, but the ruling mentioned neither ‘multiple discrimination’ nor ‘discrimination on more than one ground’. This judgment, the ECtHR’s first in a case of a forcibly sterilised Roma woman, found breaches of Articles 3 and 8. The court did not then find it necessary to determine separately whether the facts of the case also gave rise to a breach of Article 14 of the Convention, especially because “the objective evidence is not sufficiently strong in itself to convince the Court that it was part of an organised policy or that the hospital staff’s conduct was intentionally racially motivated” (paragraph 177). Similarly, in June 2012, the ECtHR delivered the judgment on *N. B. v. Slovakia,*[73] a case on forced sterilisation of a Roma woman at a public hospital and her subsequent failure to obtain redress. Even though the applicant complained that she was discriminated against on more than one ground (race/ethnic origin and sex), the ECtHR made no explicit reference in its judgment to discrimination or multiple discrimination; however, it stated that “the practice of sterilisation of women without their prior informed consent affected vulnerable individuals from various ethnic groups”.[74] It ruled that Articles 3 (prohibition of torture), 7 (no punishment without law) and 9 (freedom of thought, conscience and religion) of the ECHR had been violated.

There is, however, a discrepancy between ECtHR and EU law with regard to the evidence requirements to be fulfilled to prove discrimination. In the above-mentioned judgment the ECtHR used the expression “intentionally racially motivated”, thus implying that the plaintiff has to prove the discriminatory intentions beyond the perpetrator’s behaviour. In contrast, EU anti-discrimination legislation has been drafted explicitly excluding *intentionality* from the requirements. One of the main reasons for this is the difficulty of proving intentionality, and the resulting difficulty for victims of discrimination to win cases at court.

1.5. National legislation: a patchy panorama

The following section gives an overview of the national provisions in the five EU Member States studied, discussing provisions for and definitions of multiple discrimination, where available. All five countries are signatories of most of the above-mentioned international instruments; these have influenced and are influencing national law. They are all also Member States of the EU and are thus obliged to implement all EU directives in their national laws.

A more detailed examination of the patients’ rights protected under national law can be found in the Annex available online.[75]

1.5.1. Multiple discrimination provisions

According to the FRA Annual Report, in 2011 only six (Austria, Bulgaria, Germany, Greece, Italy and Romania) out of 27 EU Member States covered ‘multiple discrimination’ or ‘discrimination on more than one ground’ in their legislation.[76] In Poland, it is not clear whether it is covered by law. Among the six, two countries covered

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[70] ECtHR, *R. K. v. the Czech Republic (friendly settlement)*, No. 7883/08, 27 November 2012.; *Ferenčíková v. the Czech Republic (friendly settlement)*, No. 21826/10, 30 August 2011; ECtHR, *I. G. and Others v. Slovakia*, No. 15966/04, 13 November 2012.

[71] ECtHR, *R. K. v. the Czech Republic (friendly settlement)*, No. 7883/08, 27 November 2012; *Ferenčíková v. the Czech Republic (friendly settlement)*, No. 21826/10, 30 August 2011.

[72] ECtHR, *V. C. v. Slovakia,* No. 18968/07, 8 November 2011.

[73] ECtHR, *N. B. v. Slovakia,* No. 29518/10, 12 June 2012.

[74] *Ibid.*, para. 121.

[75] See FRA’s website at: http://fra.europa.eu/sites/default/files/inequalities-multiple-discrimination-healthcare-annex_en.pdf.

[76] FRA (2012a).

in this report, namely Austria and Italy, have explicit legal provisions on discrimination on more than one ground. The remaining three countries concerned do not explicitly provide for multiple discrimination in their anti-discrimination legislation or for claims to be brought on more than one ground, although the laws do not appear to preclude such claims.

Neither the Austrian Federal Equal Treatment Act nor the Equal Treatment Act provides specific rules on how to deal with cases of multiple discrimination. Following the amendment of the two acts in 2008, however, both mention that multiple discrimination must be taken into account when assessing the amount of damages.[77] The explanatory notes to the Acts state that cases of discrimination based on multiple grounds need to be assessed from an overall perspective and that the claims cannot be separated or cumulated by grounds. In the field of disability, multiple discrimination also has to be taken into account when assessing damages.[78] Among the five EU Member States, Austria is also the only one which explicitly provides for higher compensation for multiple discrimination. Section 9 (4) of the Austrian Federal Disability Act, for example, states that, in assessing the amount of immaterial damages courts must take into account: the duration of discrimination, the severity of guilt, the actual effect and multiple discrimination.[79]

Italian law explicitly recognises multiple discrimination only in the simplified form of double discrimination in which the ground of sex coincides with any of the other grounds of discrimination. The law provides that the implementation of the principle of equal treatment irrespective of race and ethnic origin, religion and belief, disability, age or sexual orientation as regards employment and occupation must be carried out from a perspective that takes into account the different impact that the same forms of discrimination can have on women and men.[80] In the area of access to healthcare, however, Italian law covers only discrimination on the ground of race and ethnic origin: only multiple discrimination on grounds of race and ethnic origin and gender is thus covered. Moreover, the provision containing the reference to dual discrimination is quite generic, and its practical implications have not yet been juridically clarified. There is also a procedural issue to take into account: Legislative Decree 150/2011 unified the rules of procedure applicable for discrimination claims.[81] It mentioned all of the laws covering different grounds of discrimination, except the one covering discrimination on the ground of gender. This means that, in principle, it is possible to bring a case of discrimination on grounds of, for example, disability and ethnic origin with a single procedure; however, if one of the grounds involved is sex, two separate proceedings will have to be pursued. Thus a Muslim woman who has been discriminated against in the healthcare sector for wearing a headscarf cannot seek legal redress, because she would have to use one legal proceeding for sex, and another for religion. As stated in a meeting of legal experts held at the FRA in February 2012, since no case law has been reported in this area to date, the legal implications of this issue have yet to be determined.

Although the Swedish Discrimination Act 2008 does not make any direct reference to the concept of multiple discrimination, Swedish legal doctrine considers and discusses this notion together with that of intersectional discrimination. Despite the absence of legal provisions, multiple discrimination claims are considered to be allowed under the Discrimination Act[82] – including in the area of access to healthcare – which is confirmed by case law.[83]

In the Czech Republic, neither the Anti-discrimination Act nor other pieces of legislation use the concept of multiple discrimination. No case law on multiple discrimination has been reported, and the topic is rarely discussed in theoretical and academic literature on equal treatment and protection against discrimination. The act does not, however, appear to preclude a discrimination claim being made on more than one ground, as a legal expert confirmed in an interview. Given that the Act contains an exhaustive list of discriminatory grounds, a claim would have to be based on grounds which the act explicitly mentions.

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[77] Austria, Federal Equal Treatment Act (Federal Public Sector) (*Bundes-Gleichbehandlungsgesetz*), BGBl. I Nr. 65/2004, Federal Law Gazette I Nr. 65/2004, Section 19a; and Equal Treatment Act (*Gleichbehandlungsgesetz*), Federal Law Gazette I Nr. 82/2005 as amended by BGBl. I Nr. 98/2008, Sections 12 (13), 26 (13), and 51 (10).

[78] Austria, Federal Disability Equality Act (*Bundes-Behindertengleichstellungsgesetz*), BGBl. Nr. 283/1990 as amended by Federal Law Gazette I Nr. 82/2005, Section 9 (4); and Act on the Employment of People with Disabilities (*Behinderteneinstellungsgesetz*), BGBl. Nr. 22/1970 as amended by Federal Law Gazette I Nr. 82/2005, Section 7j.

[79] Austria, Federal Disability Act (*Bundes-Behindertengleichstellungsgesetz*), BGBl. I Nr. 82/2005 (as amended), Section 9 (4); see also: Act on the Employment of People with Disabilities (*Behinderteneinstellungsgesetz*), BGBl. Nr. 22/1970 as amended by Federal Law Gazette I Nr. 82/2005, Section 7j; Equal Treatment Act (private sector) (*Gleichbehandlungsgesetz*), Federal Law Gazette I Nr. 82/2005 as amended by BGBl. I Nr. 98/2008, Sections 12 and 13; and Federal Equal Treatment Act (Federal Public Sector) (*Bundes-Gleichbehandlungsgesetz*), BGBl. I Nr. 65/2004, Federal Law Gazette I Nr. 65/2004, Section 19a.

[80] Italy, Decree 215/03, Art. 1 and Decree 216/03, Art. 1.

[81] Italy, Legislative Decree 150/2011, Art. 28.

[82] Burri, S. and Schiek, D. (2009), pp. 120–121.

[83] See, for example: Sweden, Labour Court (*Arbetsdomstolen*), A237/07, Dom nr 11/09, 21 January 2009; A268/09, Dom nr 91/10, 15 December 2010; A62/10, Dom nr 13/11, 16 February 2011; and A68/10, Dom nr 19/11, 23 February 2011.

In the United Kingdom, the Equality Act 2010 initially included a provision for 'combined discrimination: dual characteristics', which allowed a claim for discrimination on a combination of grounds, albeit only if a person claimed direct discrimination and only on two grounds. This Section of the Act, however, did not come into force with most other provisions in October 2010. In the April 2011 budget, the government of the United Kingdom announced that this section will not be brought into force. It said that although it had taken action to reduce the disproportionate cost of the regulations for business, there was still more to be done and that it would therefore not bring forward the dual discrimination provisions.[84]

Right to health and patients' rights

Most of the rights set out in the WHO's Declaration on the Promotion of Patients' Rights in Europe are covered by the national legislation of the five EU Member States surveyed. Sweden is, however, the only state to protect the right to translation or interpretation support, although it is up to local authorities to decide when and how to apply this right.[85] According to the WHO's declaration, however, this right is embedded within the right to informed consent, which is covered in all five countries surveyed.[86] In the Czech Republic and Italy the right to an explanation appropriate to the patients' capacity of understanding is enshrined only in non-binding code, while the other three countries included in the research provide for it in legally binding provisions. In the Czech Republic, the right to dignity is also covered only by a non-binding code. Austrian legislation does not protect the right to free choice (see Table 1 in the Annex).[87]

Some of these rights are guaranteed in constitutional or other legally binding instruments. Some are additionally, or exclusively, laid down in codes of practice. These codes of practice are soft law and thus not enforceable in a court of law. The National Health Service (NHS) Constitution for England,[88] for example, guarantees the right to drugs, treatment and vaccinations; the right to receive health services free of charge; and the rights to complain and to redress.

1.6. Multiple discrimination in national case law

Some acknowledgement of multiple discrimination can be drawn from cases reported in the employment sector in the five EU Member States studied.[89] Overall, however, there is very little articulation of this concept in either court judgments or the conclusions of legal arguments of non-judicial bodies.

The Swedish labour court (*Arbetsdomstolen*) considers claims on multiple grounds in some detail.[90] In 2010, for example, a court decided a case of multiple discrimination on the grounds of sex and age. The case concerned a 62-year old woman who had applied at the employment office for a job as a job-coach. She had the qualifications needed and solid work experience but was neither interviewed nor employed. Ten persons were interviewed, six women and four men, between the ages of 23 and 62. Two younger women, 27 and 36 years old, with poorer qualifications and shorter work experience got the positions. The labour court held that the employment office had discriminated against the woman in relation to sex and age by not interviewing her and in relation to age by not employing her.[91]

Another example is a case from 2011,[92] where the Equality Ombudsman claimed that the city of Helsingborg, Sweden had discriminated in the psychiatric care sector against two female employees from Bosnia and the former United Soviet Socialist Republic. The ombudsman claimed that one of the managers had harassed the employees by repeatedly calling them 'girls from the east' and other similar expressions. It was claimed that this was harassment on the grounds of ethnic origin and sex. The labour court held that the expression was clearly connected to the employees' ethnic origin. The court did not, however, find that the use of the expression was clearly connected to women in prostitution from Eastern Europe, and thus found no sex discrimination.

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[84] United Kingdom (UK), HM Treasury (2011), p. 53.

[85] Sweden, Administration Act 223/1986 (*Förvaltningslag*), para. 8.

[86] WHO (1994), point 2.

[87] See FRA's website at: http://fra.europa.eu/sites/default/files/inequalities-multiple-discrimination-healthcare-annex_en.pdf.

[88] UK, National Health Service (2012), first published in 2009.

[89] For an example from each EU Member State, see: Austria, Equal Treatment Commission, Case No. GBK I/166/09-M, 9 February 2010; Czech Republic, Supreme Court (*Nejvyšší soud ČR*), *Ing. M. Čaušević v. Pražská teplárenská a.s.*, Case No. 21 Cdo 246/2008, 11 November 2009; Italy, Constitutional Court (*Corte Costituzionale*), Judgment No. 252/2001, 5 July 2001; Sweden, Labour Court, A237/07, Dom nr 11/09, 21 January 2009; United Kingdom, Employment Tribunal, *Miriam O'Reilly v. British Broadcasting Corporation*, Case No. 2200423/2010, 11 January 2011.

[90] See, for example: Sweden, Labour Court, A237/07, Dom nr 11/09, 21 January 2009; A 268/09, Dom nr 91/10, 15 December 2010; A62/10 Dom nr 13/11, 16 February 2011; and A68/10, Dom nr 19/11, 23 February 2011.

[91] Sweden, Labour Court, A268/09, Dom nr 91/10, 15 December 2010.

[92] Sweden, Labour Court, A62/10, Dom nr 13/11, 16 February 2011.

The Austrian Supreme Court (*Oberster Gerichtshof*) dealt with a case of multiple discrimination in employment in 2010.[93] The Court recognised the existence of multiple discrimination against a young woman, whose employer did not allow her to wear the headscarf, called her by names other than her own so to hide her immigrant background and asked her to change her hair colour.

The Austrian Equal Treatment Commission (ETC) (*Gleichbehandlungskommission*) has handled a number of cases claiming multiple discrimination. In 2011, the ETC dealt with 14 cases on multiple discrimination, but none was brought to court. Moreover, when the plaintiff claimed multiple discrimination, the ETC often either found no discrimination or only discrimination on a single ground, and did not discuss the multiple discrimination and its effects.[94] In cases where sexual harassment was claimed in combination with one or more other grounds, the commission tended to withdraw claims regarding discrimination as soon as sexual harassment was proven and compensated. A case decided in 2011, for example, dealt with a woman with Columbian origins, who claimed that one of her co-workers had sexually harassed her because of her ethnic origin. The man, she said, touched and tried to kiss her, ignoring her requests not to. The assaults continued, the applicant informed the police. She was eventually dismissed from her post on the ground of poor knowledge of German. The ETC found sexual harassment and harassment because of the ethnic origin of the claimant, and discrimination based on the grounds of sex and of ethnic origin regarding the termination of the employment. The ETC said that multiple discrimination should be taken into account when deciding on compensation payments. However, the ETC analysed sex and ethnicity separately, without taking into account the intersection between the grounds.[95]

The ETC accepted a case of a young Muslim woman on a training contract that dealt with discrimination and harassment on multiple grounds – a combination of sex, ethnic origin and religious discrimination and harassment on the same grounds. Her employer told her not to wear a headscarf on her way to work or at work, forbid her to mention her Turkish origin to clients and harassed her. The employers dissolved her training contract with the argument that clients would not want to be served by a woman of Turkish origin. The ETC found discrimination on all grounds claimed and sexual harassment, and suggested a compensation payment reflecting the damage done to the woman because of multiple discrimination. [96]

Courts in the United Kingdom address discrimination according to the 'single-ground approach'. Claims can be made on more than one ground, but these are seen as separate claims and each has to be proven separately (see section 5.2.7.). In the case of *Bahl v. the Law Society*,[97] Dr Bahl claimed that she had been discriminated against in her job because she was a woman of Asian origin. The Employment Tribunal held that she could compare her situation to that of a white man, thus allowing a claim on the combination of race and sex discrimination. The Employment Appeal Tribunal and the Court of Appeal, however, both held that this was wrong and that each ground of the complaint had to be dealt with, proven and ruled on separately. Dr Bahl lost her case, because there was insufficient evidence to establish either sex or race discrimination. This case set a precedent in English law that must be followed in other cases, unless a Court of Appeal decision overrules it or the Supreme Court reaches another decision. The court also looked at two grounds separately and not in combination in the case of *Miriam O'Reilly*,[98] a presenter at the British Broadcasting Corporation (BBC), who claimed sex and age discrimination when the BBC dropped her from a programme when it was moved to a prime-time slot and replaced her with a younger female presenter. An older male presenter was retained. The Employment Tribunal found age discrimination but not sex discrimination.

In the 2010 case of *DeBique*,[99] however, the tribunal allowed more than one discrimination ground to be taken into account. Ms DeBique was a British army soldier from St Vincent and the Grenadines who had become a single parent. As the army encouraged single parents to invite a relative to share their service accommodation in order to help with childcare, she wanted to bring her sister to the United Kingdom. As a foreign national, her sister could only enter the United Kingdom as a visitor and remain for six months. The Ministry of Defence (MoD) would not intervene. The Employment Tribunal said that the MoD had applied a provision, criterion or practice (PCP) that required her to be available for duty 24 hours a day seven days a week.

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[93] Austria, Supreme Court, Ref. No. 8, ObA63/09m, 22 September 2010.

[94] See, for example, the following cases, mentioned in the Austrian background report: Austrian Equal Treatment Commission, GBK I/140/08-M; GBK I/175/09-M; GBK I/161/08-M; GBK I/155/08-M; GBK I/85/07-M; GBK II/79/09; GBK I/105/09-M; GBK I/153-08-M; GBK II/44/07; GBK II/95/05; GBK I/185/09; GBK II/44/07; GBK II/95/05; GBK I/185/09; GBK I/101/07-M; GBK I/166/09-M; GBK I/03-07-MG; GBK I/150/08-M; and GBK I/126/08-M.

[95] Austria, Equal Treatment Commission, GBK I/230/09-M.

[96] Austria, Equal Treatment Commission, GBK II/79/09.

[97] United Kingdom, England and Wales Court of Appeal (Civil Division), *Bahl v. The Law Society* [2004] IRLR 799, 30 July 2004.

[98] United Kingdom, Employment Tribunal, Case Nr. 2200423/2010 (ET), *Miriam O'Reilly v. British Broadcasting Corporation*, judgment 11 January 2011.

[99] United Kingdom, Employment Appeal Tribunal, *Ministry of Defence v. DeBique* [2010] IRLR 471 (EAT), 12 October 2009.

It held that women were particularly disadvantaged because they were more likely than men to be single parents with primary childcare responsibilities. This thus constituted indirect discrimination under the Sex Discrimination Act 1975,[100] but was held to be justified as the army needs to be in a state of readiness at all times. There was also, however, an immigration PCP under the Race Relations Act 1976, which prevented foreign and British Commonwealth soldiers from inviting relatives to help with childcare. The combined effect of the two PCPs put Ms DeBique at a disadvantage. The tribunal found that the MoD had not proved that the immigration PCP, either by itself or combined with the 24/7 PCP, was a proportionate means of achieving a legitimate aim. The Employment Appeal Tribunal dismissed the appeal by the MoD and considered that the nature of discrimination was often multi-faceted and could not always be compartmentalised into discrete categories.

The research found no court cases in any of the five EU Member States where multiple discrimination was claimed in healthcare. In addition, court cases on discrimination on a single ground in the five states were quite rare and were found only in Sweden. This leads to the conclusion that the existing anti-discrimination legal framework does not in practice have an impact in cases of discrimination in healthcare, according to the legal experts interviewed.

The rarity of court cases of discrimination in healthcare does not mean that: there is no discrimination or multiple discrimination taking place; that bias and discriminatory attitudes are not behind sub-standard care for certain groups; or that patients' dignity and equality are not violated. Rather, it implies that cases of unequal or unfavourable treatment, inappropriate or substandard treatment, delay in treatment and refusal of treatment or insufficient treatment are not lodged as complaints on the basis on discrimination. Chapter 5 discusses this in greater depth.

The absence of established case law on multiple discrimination means a lack of guidance on how to deal with this type of case. If cases are handled on one ground only, they will not set precedents or give interpretations which could guide lawyers and judges in future cases of multiple discrimination, nor will they increase awareness of the issue among the legal profession, the judiciary and the general public.

1.7. Lack of legal certainty about multiple and intersectional discrimination

Lack of legal certainty on multiple and intersectional discrimination is manifested in two main ways: there is a lack of legislation which provides for discrimination claims to be made on more than one ground in the Czech Republic, Sweden and the United Kingdom; and, even in those countries with legislative provisions on multiple discrimination, there is a lack of case law and thus a lack of interpretation and guidance on how to deal with claims on multiple grounds. Among the five EU Member States in this research, only Austrian and Italian legislation explicitly provides for such claims, while in Sweden and the United Kingdom they are allowed by the courts even though national anti-discrimination laws do not provide for them. There is no case law available in the Czech Republic.

Despite the inclusion of multiple discrimination in Austrian and Italian legislation, the fragmented nature of anti-discrimination laws complicates the bringing of claims for multiple discrimination. The situation in the area of health is even more complicated, because national anti-discrimination legislation does not always cover this sector or covers it only for some grounds of discrimination. Italian legal expects highlighted in their interviews the unsettled situation arising from a plurality of applicable rules. Similarly, an Austria legal expert interviewed felt that varying legal approaches to different discrimination grounds posed major barriers to multiple discrimination claims, a problem compounded by the differing legal situations at the national and provincial levels.

Aside from the scarcity of legal provisions on multiple discrimination, in all five EU Member States studied the research showed that there is a paucity of case law in which multiple discrimination has been claimed or framed as an issue. In this respect, the situation has evolved little from the time of the European Commission's Europe-wide report.[101]

There is an emerging acknowledgment of multiple discrimination as a social reality. Still, it is not possible to extract elements that can be distilled into an overarching legal principle, other than the general principle of equal treatment, from the national judgments and conclusions of the legal and quasi-legal official bodies dealing with it in the five Member States. A *tested* basis for an eventual European-wide legal formulation, therefore, remains lacking.

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[100] The Sex Discrimination Act 1975 and the Race Relations Act 1976 are now replaced by the Equality Act 2010.

[101] Burri, S. and Schieck, D. (2009).

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Inequalities and multiple discrimination: data availability and existing evidence

This chapter discusses available evidence on inequalities and discrimination on multiple grounds in healthcare. It reviews data – and specifically statistical data – on inequalities in health conditions, access to healthcare, and user satisfaction with the quality of healthcare at the EU and national levels for the five EU Member States covered by this research. In particular, it explores the feasibility of intersectional analysis on four equality grounds (sex, age, disability and ethnicity) in detecting significant differences between groups along these dimensions, for example low health status or low level of healthcare use among migrant men.

The chapter begins with a review of the availability of equality indicators on age, sex, ethnicity/migration and disability in EU and national datasets according to selected indicators of health outcomes and access to healthcare. This is followed by an analysis of EU and national data on these two dimensions, with a specific focus on intersectional groups. Finally, the section will review available evidence concerning healthcare users' views on respect and satisfaction with the quality of care, including experiences of discrimination in healthcare.

2.1. Availability of intersectional data on health conditions and use of health services

Understanding health inequalities is crucial to gaining an understanding of specific vulnerabilities and health needs of persons at the intersection of sex, age, ethnic origin and disability. The European debate on health inequalities and their monitoring started in the 1980s with the publication in the United Kingdom of the 'Black Report',[102] which raised awareness about the widening of health inequalities, defined as differences in health status or in the distribution of health determinants between different population groups,[103] and about factors which might contribute to these. The document prompted the collection and analysis of data in many EU Member States and at the EU level. The European Commission has also funded a number of relevant studies and reports on the subject in recent years. The Eurothine international research project, in particular, aimed at "increase[ing] our understanding of health inequalities in the European Union, and the possibilities to reduce these inequalities" with a set of descriptive and explanatory studies.[104] In 2005, the United Kingdom EU presidency commissioned a report on *Health inequalities: Europe in profile*[105] which reviewed evidence on socio-economic inequalities in health in the EU and its immediate neighbours; in 2008, the WHO Commission on Social Determinants of Health published a report on the priority actions needed to promote health equity.[106] The most recent report to elaborate on the subject is the 2011 report on *The state of men's health in Europe*[107] funded by the EU Directorate-General for Health and Consumers.

The evidence available in all EU Member States shows that health inequalities are systematically observed along a social gradient: the lower a person's social position, the worse his or her health. Research conducted in recent decades to unravel the determinants of health

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[102] UK, Department of Health and Social Security (1980).
[103] For a fuller definition by the WHO, see: www.who.int/hia/about/glos/en/index1.html.
[104] Erasmus MC (2007), p. iv. Other EU funded projects are Determine and INEQ-CITIES. A description of EU funded projects on health inequalities is available at: http://ec.europa.eu/health/archive/ph_determinants/socio_economics/documents/project_list_en.pdf.
[105] Mackenbach, J. (2006).
[106] WHO (2008).
[107] European Commission (2011a).

inequalities has shown that these are mainly caused by lower socio-economic group's higher exposure to a wide range of unfavourable material, psychosocial and behavioural risk factors.[108] The prevalence of smoking, one of the most common behavioural risk factors, for example, tends to be higher in lower socio-economic groups, particularly among men. Consequently, EU action has focused on reducing the gradient in health by addressing the role of socio-economic differences[109] as the main determinant of health inequalities. Less evidence is, however, available on the role of other strands of equality – such as disability and ethnicity – in explaining health inequalities. Because people with disabilities and people belonging to migrant or ethnic minorities experience worse socio-economic outcomes than the general population, they can be expected to have lower health status. There is evidence, though, that the health outcomes of some minority ethnic groups are even worse than their socio-economic circumstances alone would suggest, and that the direct and indirect experience of racism in everyday life is an important contributory factor.[110] A recent survey conducted in the United States found that the experience of multiple forms of discrimination is particularly associated with worse mental and physical health.[111]

The main EU-level datasets dealing with health-related issues are: the Health Interview Survey (EHIS), the Statistics on Income and Living Conditions (EU-SILC) and the Labour Force Survey (LFS), all coordinated by Eurostat;[112] and the Survey on Health, Ageing and Retirement in Europe (SHARE), coordinated by the Max-Planck-Institute for Social Law and Social Policy in Germany. In addition, the FRA has conducted specific surveys on discrimination in healthcare, albeit on an ad hoc basis and with smaller sample sizes.[113]

A review of EU cross-national surveys related to health suggests that there are a number of barriers to an intersectional analysis by equality grounds. All the surveys reviewed, for example, collect data on sex and age, and to some extent on socio-economic conditions, but none publishes data disaggregated by individual nationality or country of birth. In the few cases where this variable is collected, results are usually not released due to the inadequacy of the sample size or other technical limitations. In addition, data on ethnicity are not collected, nor is information indicating the country of birth of the parents, with the result that the only information on health available by ethnic background concerns first-generation migrants. Finally, these surveys are not generally in line with the human rights framing of disability enshrined in the CRPD, the so-called social model of disability, where disability "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".[114] This means that people with the same impairment can experience very different types and degrees of discrimination and inequality, depending on the context. The major surveys at the European and national levels incorporate concepts of disability which capture in different ways the degree of the impairment but not how this is accommodated by the social and environmental context, such as by the availability of transport, appliances and support. Some adopt various types of proxies, often joining disability with broader health issues; for example, phrasing it as the EU-SILC does as a "limitation in activities because of health problems".[115] Still, a number of surveys reflect a CRPD-compliant concept of disability. These include: the WHO's *World report on disability*,[116] disability surveys conducted in some EU Member States[117] and the recently launched European Health and Social Integration Survey (EHSIS) developed by Eurostat that is currently being conducted in all EU Member States, Norway and Iceland.[118]

Of the EU-wide surveys reviewed, EU-SILC is one of the few which collects information on the health conditions and healthcare access of people with a migrant background. Although EU-SILC does not include a specific question on disability,[119] it collects information on "limitation in activity because of a health problem",[120] which

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[108] See, for example, Mackenbach, J. (2006).

[109] For more information on EU policy in the area of health inequalities, see: http://ec.europa.eu/health/social_determinants/policy/index_en.htm.

[110] Nazroo, J. (2003).

[111] Grollman, E. A. (2012).

[112] The EU statistical office, Eurostat, gathers and provides access to a range of harmonised and comparable statistics on health status and, to a lesser extent, provides information on access to and use of healthcare services in EU Member States. These data are largely based on self-assessment via general population surveys; for more information, see: http://ec.europa.eu/eurostat.

[113] See, for example, FRA (2011c) and FRA (2012b). For other research on discrimination, see: http://fra.europa.eu.

[114] UN, CRPD (2006), Preamble (e).

[115] EU-SILC questionnaire, question PH030.

[116] WHO and World Bank (2011), p. 7.

[117] For instance, the Irish National Disability Survey conducted in 2006 defines disability as the outcome of the interaction between a person with an impairment and the environmental and attitudinal barriers s/he may face. The questionnaire investigated the role of barriers and facilitators of the following environmental factors: aids and appliances, help from other people, attitudes, transports and built environment accessibility.

[118] This survey will be the key source of data on disability defined in accordance with the CRPD. It was conducted in 2012 in all EU Member States, Norway and Iceland.

[119] It does, however, include questions on receipt of benefits, including disability benefits.

[120] EU guidelines recommended for implementing the question: "For at least the past 6 months, to what extent have you been limited because of a health problem in activities people usually do?" at national level define the variable (for the use of those administering the questionnaire) as: the person's self-assessment of whether they are hampered in their usual activity "by any ongoing physical or mental health problem, illness or disability".

international projects such as Measuring Health and Disability in Europe have identified as one of the most accurate ways to measure disability in self-reporting and observational studies. While keeping its limitations in mind, this variable can be used as an indicator of disability.[121]

In addition to the international data sources presented above, individual EU Member States carry out a diverse range of national surveys and ad hoc studies. The review conducted for this research indicates that information on health outcomes and access to healthcare disaggregated by sex and age is available in all five EU Member States surveyed, whilst data disaggregated by disability are generally not available or are available only for specific health outcome indicators (see Table 2 in the Annex).[122] In Austria, for instance, representative data on people with disabilities are rarely available due to legal restrictions on grounds of data protection – although some basic information is available through the *Austrian report on disabled persons*.[123]

Information on health outcomes and access to healthcare disaggregated by country of origin (or proxy) is available in all the EU Member States under review except the Czech Republic.[124] However, the specific proxy collected differs by country. The vast majority of EU Member States, with the notable exception of the United Kingdom, do not collect any statistics using variables such as 'ethnic origin', 'ethnic group' or 'race';[125] the main available proxies are variables such as citizenship and country of birth.

The diversity of variables collected across the EU allows for little comparison. Even when a certain variable, such as country of birth, is included, the sample may not be large or reliable enough to allow for a detailed breakdown or intersectional analysis. In Italy, for instance, the Multiscopo survey on *Health conditions and health service utilisation* includes data on country of birth and citizenship, although it uses the latter more often in reports.[126] With only 3,509 foreign citizens surveyed in 2005, the subgroups were too small to analyse the intersection of specific countries of origin, disability and sex. At the end of the 1990s, the Italian National Institute for Statistics implemented an information system to make existing data on disability from various sources publicly available. The most recently published data from this system do not, however, make reference to citizenship or country of birth.[127]

2.2. Inequalities in health status

This section presents data on inequalities in health status resulting from a FRA analysis of the EU-SILC 2009 dataset,[128] which it discusses in light of results from other EU surveys and national statistics. It presents some of the most widely used indicators of health status, such as general health conditions, disability rates, life expectancy and mortality rates, infant mortality, morbidity and specific health conditions and health-related lifestyle.

Before looking at these specific indicators, the health conditions and healthcare needs of the EU population need to be examined within the context of a demographic profile which has seen dramatic changes in recent decades. Most EU Member States have experienced a significant reduction in population growth, which is now primarily fuelled by migration. In 2008, for example, 71 % of the population increase was due to migrant inflows.[129] Although fertility rates have seen a slight overall increase in the last five years, the average figure for the EU is still 1.6 live births per woman, well below the replacement ratio of 2.1.[130] At the same time, life expectancy is increasing, resulting in the aging of the population.[131] Migration provides a temporary – though limited – respite, since most people migrate as young adults: looking at the resident population in 2010, 27 % of those aged 20-39 were nationals and 45 % were non-EU foreign nationals.[132] Overall, though, the EU population is growing older and more diverse.

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[121] For more information on ways to measure disability in self-reporting and observational studies by international projects, see the project Measuring Health and Disability in Europe, available at: www.mhadie.it/home3.aspx.

[122] See FRA's website at: http://fra.europa.eu/sites/default/files/inequalities-multiple-discrimination-healthcare-annex_en.pdf.

[123] Austria, Federal Ministry of Labour, Social Affairs and Consumer Protection (2009).

[124] In the Czech Republic no information on ethnicity – or any proxy – is monitored in standard healthcare registries and information on health status and access to services of people with minority backgrounds can be obtained only from ad-hoc research studies. In particular, see Nesvadbová, L. (2003) and the international comparative study SASTIPEN. For further information, see: www.fsgg.org/sastipen.

[125] Council of Europe, European Commission against Racism and Intolerance (2007).

[126] Italy, National Institute for Statistics (ISTAT) (2008).

[127] Italy, ISTAT (2007).

[128] This report follows Eurostat guidelines in terms of the reliability and publication of data: (i) an estimate should not be published if it is based on fewer than 20 sample observations or if the non-response for the item concerned exceeds 50 %; (ii) an estimate should be published with a flag if it is based on 20 to 49 sample observations or if non-response for the item concerned exceeds 20 % and is lower or equal to 50 %; (iii) an estimate shall be published in the normal way when based on 50 or more sample observations. For more information, see: http://epp.eurostat.ec.europa.eu/cache/ITY_SDDS/EN/ilc_esms.htm.

[129] Eurostat (2011a).

[130] See: http://epp.eurostat.ec.europa.eu/statistics_explained/index.php/Fertility_statistics.

[131] See: http://epp.eurostat.ec.europa.eu/statistics_explained/index.php/Mortality_and_life_expectancy_statistics.

[132] Eurostat (2011b).

2.2.1. General health conditions

A wide range of national and international surveys and studies as well as various registries use perceived or self-assessed health status as a proxy measurement of health condition. Although a subjective measurement, research shows that self-assessment usually correlates to actual morbidity and mortality rates.[133] Comparisons of subjective indicators across EU Member States should be made with caution; it is likely that some differences in the reporting of health problems relate to cultural differences. The definition of disability adopted in many surveys often does not differentiate between disability and self-assessed health, making it difficult to assess, for example, the perceived health status of persons with disabilities.[134]

A recent Eurostat report[135] presented EU-SILC data for most EU Member States[136] broken down for the first time by foreign citizenship and foreign-born population, both EU and non-EU, in thematic tables on 'perceived health status'. These data, summarised for the EU and four of the five Member States under review in Table 2, suggest that the great majority of the population, including the foreign-born population, is in good health. At the EU level, the proportions of people who perceive their health as being 'good', 'fair' and 'poor' are almost the same between foreign born and the overall population, with around 76 % of respondents reporting 'good health'. These figures, however, are average results across 21 countries. Looking at the individual EU Member States in this research shows very different levels of overall 'good health', ranging from over 80 % for the United Kingdom to less than 60 % in the Czech Republic. The percentage gap between foreign-born and total population is equally significant. In the Czech Republic and Italy, for example, foreign-born persons are more likely to report being in good health than the total population, with the gap between foreign born in good health and the total population at 12 and four percentage points, respectively. In Austria, in contrast, foreign-born persons were eight percentage points less likely to report being in good health than the total population. It is difficult to provide an overall analysis of these data which aggregate migrant groups in each EU Member State with very different characteristics and population sizes. It would also be important to review the data by age groups and time spent in the host country. Nonetheless, these data seem to confirm the 'healthy migrant effect':[137] immigrants are usually healthier than the national population.

Table 2: Share of foreign-born population perceiving their health status as good, fair or poor

	% of foreign born population perceiving their health status as…			Gap between foreign-born and total population (percentage points)		
	Good	**Fair**	**Poor**	**Good**	**Fair**	**Poor**
EU-27	**76***	**18***	**6***	**1**	**-1**	**0**
AT	68	21	11	-8	2	5
CZ	58*	28*	14*	12	6	6
IT	79	18	4	4	-2	-1
UK	87*	9*	4*	2	-3	0

Notes: ** Data not completely reliable due to sample size. Swedish data have not been included in the table because they are missing or unreliable.*

Source: *Eurostat, EU-Statistics on Income and Living Conditions (EU-SILC), 2009*

EU survey data and evidence available in some Member States suggests that the health of migrant populations deteriorates relative to that of native populations with age. Older migrants report worse health conditions in Austria[138] and Sweden;[139] older Roma report worse conditions in the Czech Republic.[140]. Data from the 2006/2007 Austrian Health Survey (*Österreichische Gesundheitsbefragung*),[141] for example, shows that whilst in all age groups, more non-migrant citizens than respondents from the two main migrant groups in the country, those with a Turkish or former Yugoslavian background, estimate their health to be 'good' or 'very good', this difference is particularly striking for people aged 55 or over. Among those with no migration background, 56.1 % of males and 52.5 % of females declared themselves to be in good or very good health, while among the two main migrant groups, the rates were substantially lower, at 30.1 % for males and 48.6 % for females.

This shows that even if migrants arrive in the host country in relatively good health, their health advantage appears to decline over time. This phenomenon, which is confirmed for most EU Member States by analysis conducted on the SHARE databases,[142] is still poorly

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[133] Kaplan, G. A., *et al.* (1996).

[134] Krahn, G. (2009)

[135] Eurostat (2011c).

[136] With the exception of Denmark, Finland, the Netherlands, Romania, Slovenia and Sweden, where the sample sizes were too small.

[137] Jasso, G., *et al.* (2004).

[138] Austria, Statistics Austria (2007).

[139] See: www.scb.se/Pages/Product____12187.aspx.

[140] Nesvadbová, L., *et al.* (2009), p. 70.

[141] Austria, Statistics Austria (2007).

[142] Solé-Auró, A. and Crimmins, E. M. (2008). The authors analysed health differences using a number of different indicators between immigrants and the native-born populations aged 50 years and older in 11 EU Member States countries. Among the 11, migrants generally have worse health than the native population. In these countries, there is a little evidence of the 'healthy migrant' at age 50 years and over.

understood and is usually attributed to the effects of socio-economic exclusion, poorer working conditions, changes in lifestyles and barriers to healthcare access.[143]

The data disaggregation also shows that sex is an important factor in perceived health status in Austria, Sweden and the United Kingdom. In Sweden, for example, (not included in the EU-SILC analysis presented above), data from the 2011 National Survey of Public Health show a particular disadvantage for migrant women: the proportion of women reporting 'good health' is 74 % among Swedish born, 64 % among those born outside of Europe and just 61 % among those born in other EU Member States. The percentage of men reporting 'good health' is more homogenous: 76 % among Swedish-born men, 74 % among men born in Europe and 71 % among men born outside Europe.[144] Conversely, the United Kingdom 2004 Health Survey for England,[145] which included a 'booster' sample[146] of people from several ethnic minority groups, showed that differences by sex varied according to ethnic group. Differences by sex were particularly large among Pakistani and Black Caribbean groups, with women 14 and 15 percentage points more likely than men to report poor health, respectively.

Finally, a report on structural discrimination in healthcare presented by a committee of inquiry in Sweden[147] as well as evidence from the United Kingdom[148] show that although socio-economic conditions are very important in explaining differences in health status, these alone do not paint a comprehensive picture. In the United Kingdom, analysis of the 1999 and 2004 England Health Surveys' results depicts a clear relationship between health and socio-economic circumstances across a large number of ethnic groups, including Bangladeshi, Black Caribbean, Chinese, Indian, Irish and Pakistani populations.[149] The findings suggest, however, that while lower socio-economic status plays a significant role in assessing the risk of poor health among these groups, health outcomes for poorer persons are often compounded when equality characteristics such as belonging to an ethnic minority are added. The relative deprivation faced by ethnic minority people, in other words, likely encompasses more than material disadvantage. Both the Swedish and the United Kingdom reports suggest that racial harassment and perceptions of discrimination have a considerable health impact.[150]

With regard to the health condition of persons with disabilities, the EU-SILC database allows for the possibility of intersectional analysis by disability, defined as 'limitation in activity', and health condition, as well as by sex. Results relating to the aggregated EU-27 dataset indicate a strong, positive correlation between disability and self-assessed general health conditions: people with limitations, and particularly those with severe limitations in their daily activities, are more likely to report a 'bad' or 'very bad' health condition (see Table 3 in the Annex).[151] Among those with severe limitations, for example, 23.7 % of females and 22.6 % of males report 'very bad health', while both males and females with no limitations reporting bad health comprise less than 0.1 %. This result is largely due to the definitions behind these two variables which, as previously discussed, overlap to a large extent. The results aggregated at the European level also reveal very little difference between males and females with disabilities in terms of self-assessed health status.

2.2.2. Prevalence of disability

Mapping the prevalence of disability within a population provides an indication of how many people are 'limited' in their ability to perform everyday activities and their need for assistance. Service registries, other surveys carried out in EU Member States and Eurostat information only rarely collect data on disability. The Labour Force Survey module 2002 was specially designed to fill this gap on an ad hoc basis. Results from this survey indicate an overall rate of EU residents with 'longstanding health problems of disability' of around 16.2 %. However, the rates vary considerably by EU Member State. For example, in Italy it is 6.6 %, in Austria 12.8 % and in Sweden, the Czech Republic and the United Kingdom 20 % or more. It is difficult to identify the extent to which the differences between countries correspond to actual circumstances as opposed to cultural differences in definitions and self-perceptions.

The EU-SILC database, based on a differently defined variable – 'self-perceived limitation in daily activity' – reports very different results. As can be seen in Table 3, the overall rate of persons in the EU reporting 'strong limitations'[152] is 8.1 %, with lower-than-average figures in the EU Member States surveyed such as the Czech Republic (6.2 %),

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[143] See, for instance, Noh, S. and Kaspar, V. (2003); Stronks, K. (2003); and International Organization for Migration (IOM) (2009).

[144] Sweden, National Survey of Public Health 2011, the data are available at: www.fhi.se/Documents/English/Highlights/HLV%202011/mental%20health.xls.

[145] UK, Joint Health Surveys Unit (2006).

[146] A booster sample makes it possible to focus on a small subgroup that wouldn't normally be adequately represented in a main survey.

[147] Sweden, Statens Offentliga Utredningar, SOU (2006).

[148] UK, Equality and Human Rights Commission (2010).

[149] UK, Joint Health Surveys Unit (2001); United Kingdom, Joint Health Surveys Unit (2006).

[150] For example, according to the EHRC (2011) report, those who had been verbally harassed had a 50 % greater chance of reporting fair or poor health compared with those who reported no harassment, while those who reported racially motivated damage to their property, or physical attacks were more than twice as likely to report fair or poor health.

[151] See FRA's website at: http://fra.europa.eu/sites/default/files/inequalities-multiple-discrimination-healthcare-annex_en.pdf.

[152] Possible answers were: 'yes, strongly limited'; 'yes, limited'; 'no, not limited'.

Sweden (6.3 %) and Italy (7.9 %), and higher-than-average figures in the United Kingdom (8.9 %) and Austria (9.7 %). The differences between the two surveys' results seem to confirm the limits of self-assessed measurements based on relatively general questions, as well as highlighting the need for standardised definitions across surveys to enable comparisons and trend analysis.

Looking at other equality grounds, females report a slightly higher prevalence of 'disability' than men: in none of the five EU Member States reviewed is the gap, either in the LFS or the EU-SILC, more than 2.5 percentage points. Similarly, initial results from the FRA/UNDP Roma Survey indicate that across all EU Member States more Roma and non-Roma women than men said that health problems limit their daily activities.[153]

Not surprisingly, an analysis of these data by age group shows an increased rate of limitations in daily activities for older people. The differences between the EU Member States become more pronounced among people aged 65 or over, with Austria reporting a rate of 'limitations' much higher than the EU average, and the United Kingdom and Sweden reporting considerably lower rates (for further details see Figure 1 in the Annex).[154]

Very little is known about the prevalence of disability among migrant or ethnic minorities; however, EU-SILC 2009 allows for an analysis of differences in disability rates among the migrant and non-migrant population (see Table 4). The five EU Member States under review report considerable differences in the prevalence of disability in the migrant and non-migrant population. In the Czech Republic, the rate of 'activity limitation' for migrants is over 26 %, compared to 17 % among native-born persons, whilst in the United Kingdom and Italy reported 'disability' rates are lower among migrants. In Austria, by contrast, there is no major difference in the assessment of migrant and non-migrant populations. Women report a higher rate of disability than men, both within the native-born and the migrant population.

FRA's large-scale survey of the Roma population in the EU,[155] which interviewed over 64,000 Roma and 20,000 non-Roma in 11 EU Member States, shows that, except in Slovakia and Spain, more Roma than non-Roma said that they are limited in their daily activities. In Italy seven times more Roma than non-Roma report limitations in daily activities due to health, while the differences are also elevated in the Czech Republic.

There is little country-level evidence on the prevalence of disability among different migrant or ethnic minority groups. In the United Kingdom, the data available points to contradictory results: although one study showed that 'South Asian' and 'White' populations have a similar prevalence of learning disabilities,[156] other studies have shown an increased prevalence of severe learning disabilities in 'South Asian' populations.[157] In Austria, the Austrian Health Survey, which distinguishes among different types of disability, points to specific disadvantages for certain intersectional groups depending on the type of disability.[158] Women with a migrant background, for example, report higher rates of physical impairment and restrictions in mobility when compared to migrant men and people of a non-migrant background. They report, however, lower-than-average rates of hearing impairments.

Table 3: Disability/strong limitations in daily activity (%), by sex

EU Member State	Disability (LFS)*			Strong limitations in daily activities (SILC)**		
	Total	Males	Females	Total	Males	Females
EU-27	**16.2**	**16.3**	**16.1**	**8.1**	**7.5**	**8.7**
AT	12.8	14.0	11.6	9.7	8.5	10.9
CZ	20.2	19.2	21.2	6.2	6.0	6.3
IT	6.6	7	6.3	7.9	6.7	9
SE	19.9	18.2	21.7	6.3	4.8	7.8
UK	27.2	26.7	27.8	8.9	8.3	9.4

*Sources: * Labour Force Survey (LFS) ad-hoc module 2002. Disabled persons are those who stated that they had a longstanding health problem or disability for six months or more or which was expected to last six months or more*

*** EU-Statistics on Income and Living Conditions (EU-SILC) 2009. Self-perceived limitations in daily activities (activity restriction for at least the past six months). New analysis of Eurostat datasets for the present report*

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[153] FRA (2012c).
[154] See FRA's website at: http://fra.europa.eu/sites/default/files/inequalities-multiple-discrimination-healthcare-annex_en.pdf.
[155] FRA (2012c).
[156] McGrother, C. W., *et al.* (2002).
[157] Azmi, S., *et al.* (1996); Azmi, S., *et al.* (1997).
[158] Austria, Statistics Austria (2007).

Table 4: People with limitations and strong limitations in activities due to health problems (%), by EU Member State and country of birth

EU Member State		Females		Males		Total	
		strongly limited	limited	strongly limited	limited	strongly limited	limited
AT	native born	10.80	18.58	8.71	17.82	9.78	18.21
	foreign born	11.30	19.46	7.30	14.95	9.44	17.35
CZ	native born	6.15	18.01	5.86	15.17	6.02	16.74
	foreign born	11.02	29.23	9.42	22.89	10.36	26.61
IT	native born	9.56	22.36	7.02	16.66	8.33	19.60
	foreign born	3.03	10.78	3.12	8.90	3.07	9.92
UK	native born	9.71	12.49	8.68	10.87	9.21	11.70
	foreign born	6.97	10.51	5.33	8.62	6.16	9.58

Notes: Swedish data have not been included in the table because they are missing or unreliable.
Source: EU-SILC, 2009 (New analysis of Eurostat datasets for the present report)

With regard to psycho-social disability, the existing literature shows that migrants, due to poor socio-economic conditions and inadequate housing, face a disproportionate burden of mental health issues. Separation from home and from familiar norms, loneliness, abuse and exploitation are also factors which can cause depression and anxiety.[159] Evidence available at the national level for Austria,[160] Italy[161] and Sweden confirm that women and especially migrant women are more often affected by psycho-social disabilities, compared to both migrant men and non-migrant women. In Sweden, for example, data from the National Survey of Public Health indicates higher levels of 'severe anxiety' (2011 dataset) and 'suicide attempts' of migrants (2009 dataset), and migrant women in particular.[162] At the same time, as a recent EU report highlights, the more frequent diagnosis of mental health issues among women hides the extent to which men, both migrant and non-migrant, suffer from these phenomena due to "men's difficulty in seeking help, health services' limited capacity to reach out to men, and men's different presentation of symptoms to women with higher levels of substance abuse and challenging behaviours".[163]

Promising practice

Counting people who use mental health and learning disability services

'Count Me In', the National Mental Health and Learning Disability Ethnicity Census, is the first census in the United Kingdom to record all in-patients in mental health services and in learning disability health services. It provides the first complete overview of mental health and learning disability services in England and Wales. It provides accurate information on the numbers and ethnicity of all in-patients using mental health and learning disability services in the National Health Service and independent hospitals. It encourages all mental health and learning disability service providers to keep accurate records of the ethnicity of all patients; and aims to supply information that helps providers take practical steps at the local level to tackle discrimination in these services.

The 'Count Me In' survey, started in 2005, makes it possible to highlight inequalities in access and outcomes that may affect in-patients from black and minority ethnic communities, or their carers; and studies how people's hospital stays are managed. By tracking, for example, whether those from black and minority ethnic communities are more likely to be detained under the Mental Health Act, or be subject to seclusion or restraint; the survey provides information that supports positive action and change at local level.

For more information, see: www.cqc.org.uk/sites/default/files/media/documents/count_me_in_2010_final_tagged.pdf

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[159] IOM (2009).

[160] Austria, City of Vienna (2004). In addition, a new calculation of the national Austrian Health Survey 2006/2007 show that in the middle age group, migrant women (with Turkish and ex-Yugoslavian background) are more often affected by chronic anxiety and depression than those without a migrant background.

[161] Italy, ISTAT (2008), which uses data from the Multiscopo survey.

[162] Sweden, National Survey of Public Health, the data are available at: www.fhi.se/Documents/English/Highlights/HLV%202011/mental%20health.xls.

[163] European Commission (2011a).

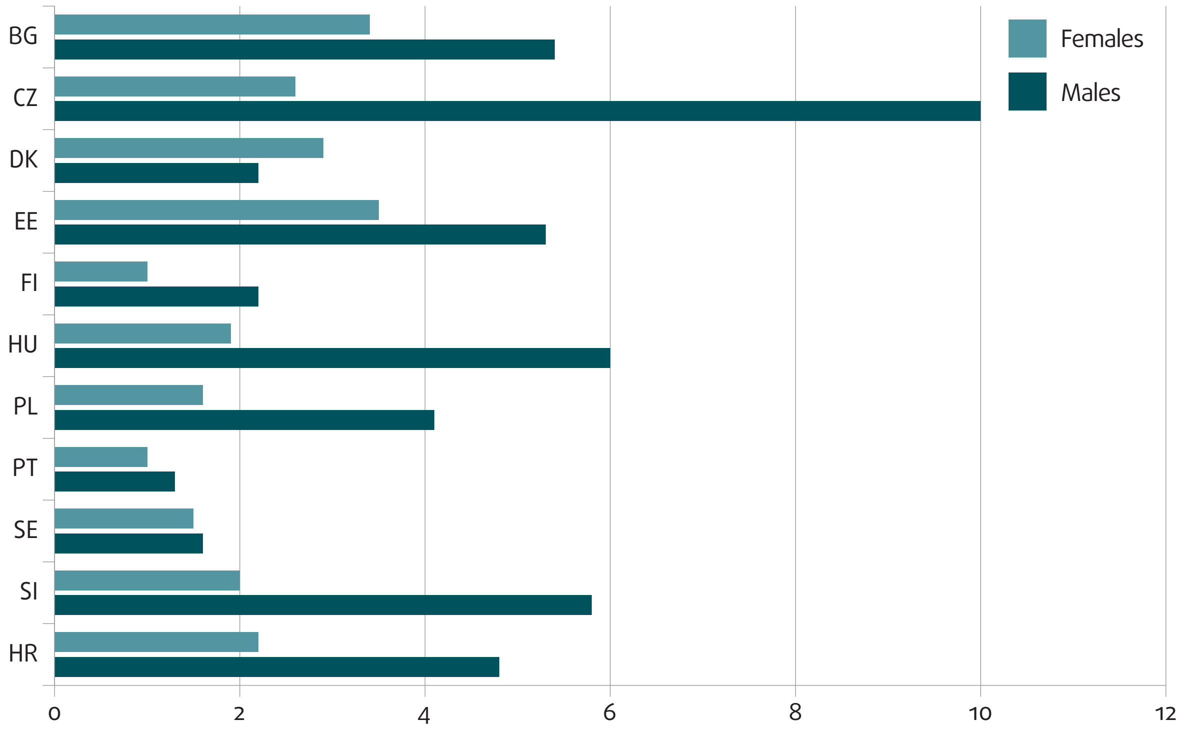
2.2.3. Life expectancy, mortality and infant mortality

Life expectancy, usually defined as the expected number of years of life remaining at a certain age, is one of the most common measures of population health in general. At EU level, life expectancy and mortality rates are usually calculated in terms of sex and age but not according to ethnic/migrant background or disability.

When it comes to sex, there are significant disparities in the life expectancy[164] rates of men and women. In 2009, the life expectancy at birth in the EU was 82.4 years for women and 76.4 years for men. The mortality rate in the EU-27 is higher for men in all age ranges, according to a recent report.[165]

The link between life expectancy and socio-economic conditions is particularly interesting. In 2011 Eurostat published estimates on life expectancy by sex, age and level of educational attainment for a selected number of EU Member States, based on 2008 data (see Figure 1).[166] The results confirm an inverse relationship between educational attainment (as a proxy for 'socio-economic status') and mortality, which is particularly significant among men. In the Czech Republic, for example, the gap in life expectancy between men with high and low educational attainment is approximately ten years, compared to less than three years among women.[167] These findings are likely to have a particular impact on migrant populations, which, in several EU Member States, are characterised by high levels of socio-economic inequality.

Figure 1: Life expectancy gaps between high and low educational attainment at age 60, by sex



Source: *Eurostat, 2010 (available at: http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=demo_mlexpecedu&lang=en)*

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[164] Life expectancy is an indicator of how long a person can expect to live on average given prevailing mortality rates. Mortality is the number of deaths for a given area during a given period, see Eurostat glossary, available at: http://epp.eurostat.ec.europa.eu/statistics_explained/index.php/Category:Glossary.

[165] European Commission (2011a).

[166] Eurostat (2011c).

[167] In the literature, it has been hypothesized that one of the reason why female mortality varies less across educational levels could be that in older cohorts in particular, women are less involved in the labour market. The material resources of these women are therefore less dependent on their own level of educational attainment than on their husband's educational level. In turn, material resources are a strong predictor of life expectancy. The lower impact of education on women's mortality might also be due to a weaker association between education on the one hand, and healthy lifestyle and health behaviour on the other. For instance, the prevalence of harmful behaviours, such as smoking and abusive alcohol consumption, is lower among women and less subject to educational level than in men. See Schumacher, R. and Vilpert, S. (2011).

Among the little data available on life expectancy and mortality rates among persons with disabilities, evidence from the United Kingdom suggests that people with intellectual disabilities have a lower life expectancy.[168]

Evidence on life expectancy and mortality rates among migrant or minority ethnic populations is available at the national level in all the EU Member States surveyed. These studies show two main results. First, no clear pattern emerges on the mortality rates of migrant groups compared to the rest of the population. Migrant mortality rates are: higher than the general population in Sweden[169] and in the Czech Republic among the Roma population; similar in Austria; and lower in Italy. In Austria, for example, the life expectancy of people with Turkish and former Yugoslavian backgrounds differed only marginally from the life expectancy of the Austrian majority population. Interestingly, women with a Turkish background exceeded the national average for females by 2.5 years, with a life expectancy of 85.3 years.[170] In the Czech Republic, there is little information available on mortality or causes of death based on ethnicity or other socio-economic indicators other than age and education. Research conducted in 2001, however, suggests that mortality rates among Roma people, especially children, are significantly higher than for the total population.[171]

Second, mortality rates differ significantly among national and ethnic groups. Mortality rates in Italy,[172] for example, are higher among Albanians and Moroccans, groups that tend to live in poorer socio-economic conditions. In the United Kingdom, analysis carried out on deaths occurring around the time of the 2001 census produced standardised mortality ratios which, when compared to the population of England and Wales as a whole, were significantly higher for men and women born in East Africa or West Africa, as well as for men born in Bangladesh and women born in India or Pakistan,[173] but lower for men and women born in China and Hong Kong.

In general, further research would be needed to understand if similar mortality rates between migrants and non-migrants are related to migrants returning to their country of origin when they grow older, which entails non-reported deaths by migrants in the country of destination and ultimately lower mortality rates. Or whether, alternatively, the similar mortality rates might be due to migration as a self-selective process, with migrants in better health than the average person.

The 'Reproductive Outcomes and Migration: an International Research Collaboration' project conducted a systematic review that linked migrant background to infant mortality and to children's health more generally. In Europe, non-European migrants are usually characterised as having the highest infant mortality rates, while refugees emerged as the most vulnerable group overall.[174] The adjustment of background factors, however, does not explain the higher mortality rate among migrants. The review also indicates that migrants often suffer from higher infant mortality rates due to disabilities related to congenital anomalies, perhaps due in part to restricted access to screening and to differing attitudes to screening and termination of pregnancy.

National data available in Austria, Italy[175] and the United Kingdom confirm higher infant mortality rates for specific, and in particular non-EU, ethnic/migrant groups, as well as poor health status among specific groups of migrant children. In Austria, for example, the overall perinatal mortality rate[176] in 2009 was 5.6 per thousand live births. For women with a Turkish background, however, and those from third countries, it was significantly higher at 7.5 and 6.5, respectively. In comparison, rates were significantly lower for women from former Yugoslavia at 2.9. Similarly, in 2010 in the United Kingdom, the perinatal mortality rate of migrant mothers was generally higher than the 6.9 of United Kingdom-born mothers, especially for mothers born in Western Africa (14.5), Pakistan (13.2) and Bangladesh (11.7).[177]

2.2.4. Morbidity and healthy lifestyles

With regard to morbidity, sex and age differences are key factors in most of the medical literature that analyses major diseases and health conditions.

In relation to cardiovascular diseases, stroke rates are higher in men. Women, however, are less likely to recover.[178] The evidence also highlights the underprescribing of recommended cardiovascular medications for some groups, including women, Black/African Caribbeans and older people.[179] Much of the research on cardiovascular disease has been based on long-term studies of men, so one broader issue is that the findings are not always applicable to women.

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[168] Emerson, E. and Baines, S. (2010); see also: McGuigan, S. M. *et al.* (1995).
[169] Sundquist, J. and Johansson, S. E. (1997).
[170] Austria, Statistics Austria (2007).
[171] Koupilova, I. *et al.* (2001).
[172] Italy, Ministry of Interior (2007).
[173] Wild, S.H. *et al.* (2007).
[174] Gissler, M. *et al.* (2009).
[175] Italy, ISTAT (2008); see also De Curtis, M. and Lucchini, R. (2010).
[176] The WHO defines the perinatal mortality rate as the number of stillbirths and deaths in the first week of life per 1,000 live births; see WHO definition, available at: www.who.int/healthinfo/statistics/indneonatalmortality/en.
[177] UK, Office for National Statistics (2011).
[178] Reeves, M. J. *et al.* (2008).
[179] Mathur, R. *et al.* (2011a).

Evidence increasingly suggests that, as a group, people with disabilities experience poorer levels of health than the general population. People with Down syndrome, for example, have a higher incidence of Alzheimer disease than the general population, while people with intellectual disabilities unrelated to Down syndrome have higher rates of dementia.[180]

Mortality registries at the national and local level are the most commonly used data sources to describe the non-communicable disease risk among migrant and ethnic populations.[181] A large-scale review of the availability of 'ethnically relevant data'[182] on mortality and morbidity from coronary heart disease, stroke and diabetes in EU Member States found that disease-specific registers recording data on ethnicity or migrant status were available only in England, Germany, Scotland and Sweden, although in Germany and Sweden data are registered by country of birth.[183]

A recent review of the literature shows that overall rates of cancer incidence and mortality are substantially lower among migrant than non-migrant populations, except with regard to stomach cancer and cancers related to infectious diseases.[184] Available data do not indicate any consistent picture of incidence and mortality for cardiovascular diseases with the exception of strokes: migrant populations appear to be at higher risk of strokes.[185] Diabetes mellitus shows a much higher prevalence among migrants than among the local population.[186]

With regard to communicable diseases, EU-level data from the European Centre for Disease Prevention and Control indicate that migrants from countries with a high prevalence of infectious diseases, or where prevention and checks are inadequate, are disproportionately affected by tuberculosis, HIV and hepatitis A and B.[187] The poor conditions in which many migrants live and work and their often limited access to healthcare services increase their risk of contracting a communicable disease. Transnational movements might also have an impact: children of migrants who periodically return to their family's country of origin, for example, appear to be among the most vulnerable to hepatitis A.

Several reports discuss the role of poor lifestyles on morbidity and life expectancy. A 2011 European Commission[188] report indicates that "poor lifestyles and preventable risk factors account for a high proportion of premature deaths and morbidity in men". In all EU Member States, men living in less affluent conditions are more likely "to eat less healthily, take less exercise, be overweight, consume more alcohol, be more likely to smoke, engage in substance misuse, and have more risky sexual behaviour".[189] In addition, the final report from the Assisting Migrants and Communities project[190] discusses the effects of lifestyle changes and acculturation on migrants' health. Rural to urban migration, for example, may lead to more 'Western' dietary habits and activity patterns which can increase the risk of obesity, diabetes and cardiovascular diseases.

Among the national surveys of the five EU Member States reviewed smoking rates are one common indicator of unhealthy lifestyles. In the Czech Republic, for example, smoking is significantly more widespread among the Roma population;[191] in Austria, smoking is more common among people with a migrant background, particularly male migrants.[192] Regression analysis, however, shows that factors other than a migrant background, such as job sector, unemployment and education, play a more important role in a person's decision to smoke. Moreover, data from the 2004 Health Survey England shows that it is important not to generalise, as factors related to a healthy lifestyle vary significantly across ethnic groups.

2.3. Inequalities in access to and use of healthcare services

Access to healthcare is a crucial component of a person's fundamental right to health. The right to the highest attainable health means that societies are obliged to provide accessible, appropriate and effective services to all inhabitants. The EU has made improving access to healthcare a priority in order to promote social inclusion and equal opportunities for all. There is, however, little evidence relating to inequalities in access to healthcare, and even less on inequalities in access faced by groups at the intersection of equality grounds.

In terms of sex, evidence shows that women are generally more aware of their health status than men and are more frequent users of healthcare services. Financial barriers can also affect men and women in different ways – with the latter possessing a lower-than-average income. More specifically, the increasing role

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[180] WHO and World Bank (2011), p. 57.

[181] Other sources include health-service based registries such as those for hospital admissions and general practitioners and from disease-specific registers (e.g. cancer).

[182] The term refers to data on ethnicity or – in most cases – proxies of ethnicity such as country of birth, citizenship or nationality.

[183] Rafnsson, S. B. and Bhopal, R. S. (2009).

[184] Bernd, R. *et al.* (2011).

[185] Mathur, R. *et al.* (2011b).

[186] Bernd, R. *et al.* (2011).

[187] European Centre for Disease Prevention and Control (2009).

[188] European Commission (2011a).

[189] *Ibid.*, p. 8.

[190] IOM (2009).

[191] Rambousková, J. *et al.* (2003).

[192] See Austria, Statistics Austria (2007).

of out-of-pocket payments may increase sex inequalities, since men are more likely to be covered by private insurance.[193] The sex dimension is particularly relevant in relation to access to long-term care, as women are more likely to be the users of such care, as they tend to live longer. Systematic evidence relating to healthcare access among populations with ethnic/migrant backgrounds is fairly limited.[194] Tables 4 and 5 present a summary of the analysis of two key EU-SILC variables, 'unmet needs for medical examination or treatment' and 'main reason for unmet needs'. Data are broken down by country of birth, including 'native born' 'foreign born' and for larger migrant groups, by 'country of origin'.

Table 5 indicates that the proportion of those reporting 'unmet needs for medical examination or treatment' is usually considerably higher among foreign-born than among native-born populations, although it varies dramatically by EU Member State. The Czech Republic and Sweden register the largest disparities among the selected countries. In several Member States, the highest rate of unmet medical needs is reported by migrants from other EU countries, rather than third-country nationals: in the Czech Republic the percentage reporting unmet needs among those born in Slovakia is almost three times higher than among native-born persons. This may reflect the large proportion of Roma among Slovak-born migrants, illustrating how data on country of birth often fail to capture ethnic identity.

Although in most of the EU Member States studied the difference between men and women reporting unmet needs is within one or two percentage points, there are cases where the gap is more significant, particularly among foreign-born people. In Sweden, for example, almost 18 % of foreign-born women report unmet medical needs against almost 14 % of native women and of foreign born-men. Similarly, in the Czech Republic migrant women report significantly higher unmet needs compared to both non-migrant women and migrant men.

The EU-SILC questionnaire asks each respondent to select one of eight possible reasons for their 'unmet need for medical examination or treatment'. New analysis conducted on the EU-SILC 2009 dataset suggests that in two of the three EU Member States where statistically significant results are available (France and Italy), the foreign-born population is significantly more likely than the native-born population to indicate an inability to pay

Table 5: Unmet need for medical examination or treatment

EU Member State		Female	Male	% answering 'yes'
AT	native born	2.12 %	2.35 %	2.23 %
	foreign born	3.22 %	5.17 %	4.13 %
CZ	native born	2.74 %	3.01 %	2.86 %
	foreign born	7.48 %	5.24 %	6.55 %
	Slovak Republic	8.68 %	6.59 %	7.81 %
IT	native born	8.32 %	5.94 %	7.17 %
	foreign born	8.35 %	7.87 %	8.13 %
	South America	13.57 %	16.74 %	14.80 %
SE	native born	13.58 %	10.27 %	11.97 %
	foreign born	17.65 %	13.75 %	15.74 %
	Middle East*	26.22 %	13.72 %	17.48 %
UK	native born	3.80 %	2.96 %	3.41 %
	foreign born	3.98 %	3.08 %	3.54 %

Note: ** Data not completely reliable due to sample size.*

Source: *EU-SILC, 2009 (New analysis of Eurostat datasets for the present report)*

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[193] European Commission (2009b), p. 7.

[194] See, for example: Austria: Statistics Austria (2007), Austrian Health Survey 2006/2007; Sweden: National Survey of Public Health, the data are available at: www.fhi.se/Documents/English/Highlights/HLV%202011/mental%20health.xls; UK: Allmark, P. *et al.* (2010); and Italy: ISTAT (2006).

as the main reason for an unmet need, with the figures in Italy at 68.7 % and 51.9 %, respectively. Differences in the same direction were noted in all the other EU Member States covered by this report but should be taken as indicative only due to the lack of statistical significance.

New analysis conducted on the EU-SILC 2009 dataset suggests that people with some or strong limitations in activities because of health issues are also more likely to suffer from unmet needs regarding medical examination or treatment (see Table 6). In particular, 14.7 % of women 'strongly limited because of a health problem' report unmet medical needs, compared to 5 % of women with no limitations. The situation is similar amongst men, although overall they report slightly lower rates of unmet needs.

People with a strong or some 'limitation in daily activity' are three to five percentage points more likely to report cost as the main reason for an unmet need for a medical examination or treatment. This result could relate to higher disability rates among people with lower income, including older people and some migrant groups.

2.3.1. Primary, secondary and emergency healthcare[195]

There are differences in access to primary and secondary healthcare by sex and ethnicity. A recent European Commission report on sex aspects of access to healthcare shows that despite significant differences between EU Member States, men access primary healthcare much less frequently than women: the gender gap ranges from five percentage points in Austria and the Czech Republic to 18 percentage points in Greece. [196]The factors behind such differences include services limited to traditional working hours; a perception that waiting rooms and other services are designed around women's needs; a lack of understanding of how to make appointments; and a lack of the vocabulary required to discuss sensitive issues. The report, though, does not take into account ethnicity and how it impacts access to healthcare.

Analysis of SHARE survey data suggests that older immigrants use health services more than native-born individuals with similar health needs in some EU Member States, including Sweden, but not in others, such as Austria and Italy (also Denmark, France, Germany, Greece, the Netherlands, Sweden and Switzerland). The results suggest that health differences between the native- and foreign-born populations alone do not explain the disparity in the use of medical care services, and healthcare usage disparities could be due to cultural background or the lack of a strong social network among migrants.[197]

The evidence on the use of emergency care is contradictory. Migrant and ethnic communities often use emergency care more than the rest of the population in

Table 6: EU-27 – Unmet health needs* by 'disability' and sex, EU-27 (%)**

		Limitation in activity because of health problems				
	Unmet need	**yes, strongly limited**	**yes, limited**	**no, not limited**	**n.a.**	**Grand total**
Females	yes	14.7	11.6	5.0	0.4	6.3
	no	84.7	88.1	94.6	3.2	81.1
	n.a.	0.6	0.3	0.4	96.4	12.6
Females total		**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Males	yes	13.3	11.0	4.5	0.2	5.3
	no	86.1	88.6	94.8	2.7	79.4
	n.a.	0.6	0.4	0.7	97.0	15.3
Males total		**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

*Notes: * Unmet need for medical examination or treatment.*
*** Self-perceived limitations in daily activities (activity restriction for at least the past six months).*
n.a. = not available
Source: EU-SILC, 2009 (New analysis of Eurostat datasets for the present report)

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[195] Primary healthcare refers to first-contact and coordinated care. As a rule it is provided on an outpatient basis and usually acts to coordinate other specialists (secondary healthcare) that the patient may need.

[196] European Commission (2009b).

[197] Solé-Auró, A. *et al.* (2009).

the EU Member States surveyed, such as Italy.[198] Austria presents a more complex picture, with older people with a migrant background the only group to report higher use of outpatient departments or emergency units.[199] The overuse of emergency room services has been explained by disparities in health, lack of knowledge about the healthcare system in the country of destination, as well as differing barriers with primary care including language, fear of discrimination and low satisfaction.[200] In some countries there is evidence that it is especially migrant men who use emergency healthcare services, a pattern which may reflect the greater risk of injury to which their working conditions expose them. In Italy, for instance, 5.7 % of foreigners used emergency care in the last three months, against 3.8 % of native-born. The difference is even more pronounced amongst males: 7 % of foreigners against 4.2 % of native-borns.

2.3.2. Preventive care and screenings

Preventive care programmes differ from country to country but usually include oncological screening and immunisation and pregnancy-related schemes. The 2009 European Commission report[201] contains evidence that sex-differentiated prevention programmes, as well as health education initiatives, mainly target women. Men, however, face stereotypes that obstruct their access to prevention programmes which should target both sexes. Osteoporosis, for instance, is still largely perceived as a female disease, and men are often excluded from prevention and screening programmes.

Evidence indicates a consistent preventive care pattern with respect to migrants: they have a much lower uptake of preventive health schemes than non-migrants. In Italy, in particular, the Multiscopo survey[202] indicates that the migrant population has lower access to screening programmes than Italian citizens. Foreign men have the lowest rate observed for diagnostic tests at 5.9 %, whilst Italian women have the highest rate observed at 11.1 %. Similarly, in Austria,[203] people with a migrant background – especially men – have a significantly lower uptake of preventive medical services than the majority population.

Evidence relating to breast cancer screening shows that, after controlling for socio-demographic factors, migrants from non-Nordic countries are more than twice as likely not to have such screenings as Swedish-born women.[204] In Italy and the United Kingdom, there is evidence that fewer migrant women attend cervical screenings than non-migrant women:[205] the uptake of cervical screening is 71.8 % among Italian women compared to 51.6 % among foreign women, with just 33 % and 37 % of African and Albanian women, respectively, taking up such screenings. Statistics show that this gap, which also concerns mammography, tends to increase with age.[206]

There is an absence of evidence on the take-up of health screenings among people with disabilities and especially people with intellectual disabilities. One study, however, suggests that this group lacks adequate health screening and preventive care.[207]

2.3.3. Sexual and reproductive health

Information related to the sexual and reproductive health status of ethnic or migrant groups is available only at national level. In Austria, women with no migrant background have a higher uptake of gynaecological healthcare: among women aged 35 to 54, 69 % with no migrant background and 54 % of migrants saw a gynaecologist in the last year.[208] Conversely, in Italy, 16.5 % of female Italian citizens consulted a gynaecologist in the public health service in 2005 compared to 57.6 % of women of foreign nationality.[209] This makes clear that there is a two-tier system for medical care during pregnancy: Italian citizens are generally wealthier and thus can afford to opt out of public gynaecological care – which they regard as poor quality – and pay for private care.

With respect to antenatal care, there is evidence in Italy and the United Kingdom that migrant women tend to begin antenatal visits later than non-migrant women, experience delays in access to screenings and have fewer visits during pregnancy. In Italy, 68.5 % of foreign nationals and just 48.4 % of Albanian women have their initial ultrasound scan during the first three months of pregnancy – compared with 88.3 % of Italian citizens.[210]

In the United Kingdom, qualitative research with healthcare professionals and users shows that Black Caribbean women with post-natal depression are less likely than others to consult practitioners. This is often because they lack familiarity with the problem, are reluctant to discuss mental health problems and tend to play down the level of depression and distress. They also cited negative experiences of contact with services, fears about confidentiality and the desire for services

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[198] Italy, ISTAT (2008).
[199] Austria, Statistics Austria (2007). For a discussion on the use of emergency care among migrants, see Bernd, R. *et al.* (2011).
[200] Norredam, M. *et al.* (2004); Puig-Junoy, J. *et al.* (1998).
[201] European Commission (2009b).
[202] Italy, ISTAT (2006). These results refer to the use of at least one diagnostic test in the month prior to the interview.
[203] Austria, Statistics Austria (2007).
[204] Lagerlund, M. *et al.* (2002).
[205] Webb, R. *et al.* (2004).
[206] Italy, ISTAT (2008).
[207] Lennox, N. G. *et al.* (1997).
[208] Austria, Statistics Austria (2007).
[209] Italy, ISTAT (2008).
[210] *Ibid.*

sensitive to their culture as other reasons for not accessing help.[211]

2.3.4. Discrimination, respect during treatment and level of satisfaction with healthcare

Inequalities in access to healthcare also relate to how practitioners treat patients and how these evaluate their experiences as healthcare users, including experiences of discrimination on one or more grounds. To establish this, the collection of evidence on user satisfaction and perceived mistreatment is essential.

The only EU-level source of information on perceived discrimination by healthcare services and personnel among ethnic minorities is the European Union Minorities and Discrimination survey (EU-MIDIS), conducted by the FRA. The survey's results (see Table 7) reveal a relatively low level of perceived 'aggregate group' discrimination in relation to healthcare compared with other areas of life, usually below 10 %. Roma represented the major exception: on average 17 % of the Roma population surveyed felt healthcare personnel (medical or other) discriminated against them.

When focusing on the national situation in EU Member States, North Africans in Italy emerge as the most discriminated against group with one in four indicating at least one incident of discrimination in the last 12 months. Africans in Malta have a 17 % perceived discrimination rate, Brazilians in Portugal 15 % and Somalis in Finland 14 %. A very similar picture emerges in relation to discrimination by social service personnel. Disaggregation by sex and age shows significant differences: in the Czech Republic, Roma women are more likely (21 %) to report discrimination by healthcare personnel than men (15 %). Such discrimination is also more often reported by young people and those over 55 than by middle-aged Roma. In comparison, for North Africans in Italy, perceived discrimination by healthcare personnel is higher among men (26 %) than women (20 %) and also higher for people aged 16–39 years than for those over 40.

Results from the World Health Survey conducted by the WHO show that in high- income countries, ill treatment against persons with disabilities in the healthcare sector is one of the most relevant barriers to healthcare: 39.6 % of the men and 20 % of the women interviewed reported not accessing care because they 'were previously treated badly'.[212]

The evidence on user satisfaction available at national level is sometimes contradictory. In Austria, for example, some sources indicate that people with a migrant background appreciate the Austrian health system and the high level of social security in Austria compared to their countries of origin.[213] The *Vienna Health Report*,[214] however, stresses that people with a migrant background, especially those with a Turkish background,

Table 7: Discrimination in the past 12 months

	Any discrimination (nine areas)	Discrimination by healthcare personnel	Discrimination by social service personnel
	Yes (%)	Yes (%)	Yes (%)
AT – ex-Yugoslav	3	0	1
AT – Turkish	9	2	2
CZ – Roma	64	18	21
IT – Albanian	37	9	9
IT – North African	52	24	22
IT – Romanian	29	10	8
SE – Iraqi	10	3	2
SE – Somali	33	7	9
UK – Central and East European	11	1	1

*Note: * Nine areas of discrimination including: discrimination when looking for work; discrimination at work; discrimination by housing agency or landlord; discrimination by healthcare personnel; discrimination by social service personnel; discrimination by school personnel; discrimination at a café, restaurant, bar or nightclub; discrimination at a shop; discrimination at a bank.*

Source: FRA, 2009

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[211] Edge, D. (2008); and Edge, D. (2010).

[212] WHO (2010b).

[213] Reinprecht, C. and Unterwurzacher, A. (2006).

[214] Austria, City of Vienna (2004).

report negative and discriminatory experiences during their treatment in health and social care centres.

In the United Kingdom, results from the 2010 General Practitioner Patient Survey[215] indicate significant variations in the overall level of satisfaction of people from different ethnic backgrounds. Most satisfied were 'White British' and 'White Irish'; with 58 % and 61 %, respectively, saying they were 'very satisfied'. Least satisfied were 'Bangladeshi', 'Chinese' and 'Pakistani' patients with only 28 %, 28 % and 29 %, respectively, saying they were 'very satisfied'. Minority ethnic groups are also the most reluctant to express an opinion about their local general practitioner: 14 % of Chinese patients and 13 % of Pakistani patients say they are 'neither satisfied nor dissatisfied', compared with 5 % of White British. More generally, as the Citizenship Survey 2009-2010 results show, Chinese and Black people stand out as least likely to report being treated with respect 'all of the time' or 'most of the time' when using health services[216]. Ethnic minorities reported similar levels of satisfaction with mental healthcare as the White British and White Irish population.[217]

Two studies in Sweden explored the association between perceived discrimination experienced in the healthcare sector, refraining from seeking required medical treatment and worse healthcare outcomes.[218] The findings indicate that experiences of frequent discrimination can result in persons being three to nine times more likely to refrain from seeking medical treatment and in worse mental and physical health. The authors conclude that public health policies should encompass strategies to tackle discrimination, particularly in national health services.

Conclusions

The review shows that the European cross-national surveys provide the main source for identification and measurement of health of the population at an EU level. While these surveys collect quantitative comparative data on the health situation and health system use disaggregated by sex and age, no data are available on individual nationality or country of birth, while ethnicity is almost never collected and data on disability are not always adequately collected. The lack of an adequate sample size also inhibits the possibility of further intersectional analysis.

With regard to self-perceived health status, despite differences across EU Member States, on average at the EU level the great majority of the population, including the foreign-born population, is in good health. The evidence available in some of the countries, however, shows that even if migrants arrive in the host country in relatively good health, this health advantage appears to decline over time.

EU data on healthcare use disaggregated by equality grounds are scarce. FRA analysis of EU-SILC data, however, shows relevant disparities concerning the use of healthcare services: for example, the proportion of persons experiencing unmet healthcare needs is considerably higher among the foreign-born population and those with disabilities compared to the native-born population and those without disabilities. For both groups, financial barriers are the main cause of this difference.

When it comes to users' satisfaction and perception of discrimination in healthcare, the EU-MIDIS survey is the only EU-level source of information. The survey revealed a relatively low level of 'aggregate group' perceived discrimination among ethnic minorities in healthcare, with the exception of visible minorities – Roma and North Africans – in specific EU Member States.

FRA opinion

Addressing health inequalities requires the collection and use of disaggregated data by the various individual grounds of non-discrimination and by those grounds in combination. There is a lack of reliable health statistics giving the full picture of the intersection of different grounds. In order to better reflect the monitoring of equality in EU cross-national surveys, data on ethnicity (recording both migrant status and ethnicity, where legal) and disability (taking into account the 'social model of disability') should be included in periodic national surveys. In order to capture multiple inequalities and disadvantages, survey sample sizes should be large enough to allow for further disaggregation.

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[215] Ipsos Mori (2010).

[216] See results of the Citizenship Survey 2009-2010, available at: http://webarchive.nationalarchives.gov.uk/20120919132719/http:/www.communities.gov.uk/publications/corporate/statistics/citizenshipsurvey200910race.

[217] UK, England, Department of Health (2003) and (2009).

[218] Wamala, S. *et al.* (2006); Frykman, J. *et al.* (2006).

3

Barriers and indirect discrimination in access to healthcare

This chapter discusses the barriers that healthcare users and providers perceive as impeding timely access to healthcare by migrants or ethnic minorities in the five EU Member States studied.

The concept of 'discrimination' is distinct from that of 'barriers'. Discrimination refers to cases where an individual considers that she/he has been unequally treated because of one or several protected characteristics. It is irrelevant whether the outcome in question is intentional or not; the issue is whether the complainant (or a legal mediator) believes there is a causal link between an identifiable set of practices and a penalising outcome for groups whose members share a protected characteristic. Barriers, by contrast, involve mechanisms or structures that impede or delay access to services or reduce their quality or effectiveness. Service costs applied in a uniform fashion may, for example, constitute a barrier, but they do not imply discrimination on the basis of one or more characteristics. A group may, therefore, encounter barriers but not discrimination, and vice versa. Still, some barriers may constitute indirect discrimination when an apparently neutral provision has a disproportionate effect on groups whose members share a protected characteristic.

Health professionals and advocacy groups often argue that 'colour-blind' or 'one-size-fits-all' approaches can give rise to barriers for minority groups and those sharing particular characteristics, such as migrants, older people or those with intellectual disabilities. They highlight that standardised services have the potential to generate inequalities, and that the 'universalistic' principle of many healthcare systems may have to be adapted to meet the needs of such groups.

This chapter analyses the nature and functioning of six barriers to access to healthcare, namely: communication and language barriers; lack of information about healthcare entitlements and services; financial barriers; organisational barriers and accessibility; working conditions, living conditions and care responsibilities; and cultural and psychological barriers. It analyses how these barriers affect the intersectional groups in the research and highlights the ways in which the interplay of disability, sex, age and ethnicity may increase the impact of a specific barrier.

3.1. Communication and language barriers

The research found that communication barriers are pervasive and their effects far-reaching, ranging from initial contact with services to diagnosis and receiving treatment. Language was the most relevant communication barrier mentioned by migrants in all the EU Member States surveyed. Evidence from this research, however, indicates that language barriers are particularly acute at the intersection of particular identities: they especially affect recent migrants, migrants with intellectual disabilities, elderly people with a migrant background and female migrants with care responsibilities. Specific communication barriers, sometimes linked to a lack of reasonable accommodation, were found among healthcare users with intellectual disabilities with migrant or ethnic backgrounds.

This section focuses on how communication problems affect the patient-healthcare relationship and the medical consultation. This research found numerous examples of communication problems that affect a correct diagnosis, the patient's compliance with treatment as well as the possibility for the healthcare user to understand information, to take and question decisions, and to build a trustful relationship between the patient and the health professional. This raises questions about the extent to which healthcare users are provided information in an accessible and understandable way.

The findings point to how language barriers affect a health practitioner's ability to assess effectively and diagnose correctly patients with a disability who have a migrant background. In particularly complex cases, such as intellectual or psycho-social disabilities, for example, language and communication barriers can make it difficult to find the root cause of health problems and discuss treatment options, possibly resulting in a number of different and unsatisfactory diagnoses.

Patients need to understand their diagnosis and prognosis, the nature and purpose of the intervention, as well as the alternatives, risks and benefits of treatment in order to express their wishes and make an informed choice. Healthcare users with a migrant background reported difficulties in explaining their symptoms, expressing their preferences, understanding what they were told, communicating consent and obtaining responses to their health needs. A healthcare user in Sweden, for example, went to a primary care unit for a blood test and, in the absence of an interpreter, had great difficulties in explaining what she wanted and in refusing an unnecessary flu injection. Such communication difficulties often arise due to language or medical terminology. Some healthcare users were, for example, unable to explain the exact nature of their health problems during the course of interviews, suggesting that they may not have fully understood what doctors told them.

Several health practitioners highlighted particular communication barriers deriving from the intersection of different characteristics, notably age, disability, socio-economic status and the amount of time spent in the host country. This reinforces the results of this research in Austria, the Czech Republic and the United Kingdom, which indicate that while language barriers are particularly relevant for migrants who have recently arrived, they also apply to older migrants. Older migrants who have learned and spoken a second language for decades can lose this ability when they develop dementia or suffer a stroke. A local policy officer in Sweden said: "even those who have learned Swedish might forget the language as they get older". Similarly, an interviewee in the United Kingdom stressed the vulnerability arising from the interplay between age and disability. The interviewee said that even non-migrant people with learning disabilities and older people, particularly those with memory or speech difficulties, may be unable to communicate that they are unwell or describe their symptoms to a practitioner:

> *"[...] when people don't have verbal communication, they may attempt to express they are not feeling well and this is interpreted as behaviour that challenges and they could go for years before someone thinks they are not very well."*
>
> *(Policy maker, male, United Kingdom)*

One area of particular concern is the impact of language barriers on persons with psycho-social disabilities and migrant background, as psychiatrists in Austria and Italy reported that psychotherapy can only be successfully done in the patient's mother tongue. The lack of translation also has severe consequences on children with intellectual disabilities. To assess the existence and severity of an intellectual disability, psychiatrists use cognitive tests. An Italian psychiatrist explained how the lack of such texts in the child's native language compromises the possibility of a correct diagnosis.

Among migrant women, language barriers were found especially problematic when booking gynaecological visits and while giving birth. The feeling that health professionals made no effort to listen and address their needs compounded the lack of language understanding:

> *"I have good relationship with my GP [General Practitioner]. But [...] there are other women, like me, who must find it difficult to access the system, because if you cannot pick up that phone and make an appointment for yourself, how would you feel? You need someone to make appointment for you – this is your private life!"*
>
> *(Healthcare user, female, migrant/ethnic background, United Kingdom)*

Women in Austria, the Czech Republic and Italy recounted how the lack of translation services prevented them from asking questions when giving birth:

> *"They told me I had to lie down all night and [...] that I must be quiet. And I didn't know how to explain that I have questions for them because, in general, the nurses didn't speak any English and were not interested in listening to me."*
>
> *(Healthcare user, female, migrant/ethnic background, Czech Republic)*

In addition, patients with a migrant background might fail to ask for clarifications, even if they do not understand what a professional has told them, due to shyness in front of a doctor (Italy) or shame about not being able to speak German (Austria).

In this context, the greatest problem for health professionals was how to adapt a standardised approach for providing information, and how to support and enable the patients to understand the information provided and comply with the treatment. Healthcare providers in Austria and Sweden and representatives of United Kingdom advocacy groups working with older people and those with intellectual disabilities also mentioned the communication challenges linked to older persons who become disabled. In such cases, it can be difficult, they said, to ensure that the patients receive all the information they need, as they might forget, or need information repeated on numerous occasions. Doctors often fail to communicate effectively with older persons with hearing impairments who do not have professional sign language, one Austrian doctor said:

"This is particularly obvious with another group, the hearing impaired. [...]. The communication in the 'non-hearing way', where the hearing impaired person writes down [a few] words, say: 'Fever since yesterday', and the doctor prescribes a medicine. That's really bad, because here it would be particularly important to ask [some] very basic questions. Sometimes that's not possible, because older deaf persons simply do not have professional sign language, they only have rudimentary signs, and then misunderstandings happen that never get resolved. Quite to the contrary, you hear things like: 'It's easy to work with the hearing impaired. They don't need so much time. They write it down anyway [...]'."

(Family doctor, male, Austria)

Communication difficulties may limit the exchange of information between patient and health professional, reducing the patient's ability to comply with the treatment. If misunderstandings persist, they can result in a public health threat, an Italian health professional said, recounting the case of migrant patients with tuberculosis who did not understand that treatment had to continue for several months. One consequence of the lack of and failures in communication is that some healthcare users in Austria, Sweden and the United Kingdom felt that doctors invested more time in consultations and made more effort with the non-migrant population that they did with migrants.

Both healthcare providers and representatives of advocacy groups also identified deficits in education, which they linked to socio-economic, migrant, age and ethnicity factors, as barriers that could make it difficult for healthcare users to understand the information provided and treatment options. Italian advocacy groups emphasised the low educational attainment of asylum seekers from many areas of Sub-Saharan Africa and the difficulties in explaining medical procedures and tests. According to a geriatric nurse in Austria, older first-generation migrant patients also often have not obtained higher degrees, having been recruited as so-called 'guest workers', which leads to a combination of vulnerability and potential discrimination factors including age, ethnicity, education and socio-economic status.

Two interviewees in Sweden, however, described how such assumptions can lead to intersectional discrimination towards Muslim women. One healthcare user described how others assumed she was uneducated, resulting in unequal treatment:

"[...] people here in Sweden they think that we who wear hijab, that our parents and family stop us from going to school and we don't understand, we cannot read, we cannot write and things like that."

(Healthcare user, female, migrant/ethnic background, Sweden)

A nurse similarly reflected on a tendency for some people to "look down on women from the Middle East":

"Perhaps [...] you have this perception [about women's oppression] and perhaps express something negative about them as a group."

(Geriatric nurse, female, Sweden)

While respondents described a range of communication and language barriers, one of the most common was the lack of translation services. The availability of translation services in healthcare settings varies: only in Sweden it is legally mandatory. In Austria, and in Italy and the Czech Republic in particular, interpreters and cultural mediators appear to be quite scarce. Hospitals in the Czech Republic are obliged to provide an interpreter within 24 hours, but interviewees reported that interpretation services are inefficiently organised. In the United Kingdom, the availability of professionally trained interpreters varies significantly: they were considered generally available in London but not in other areas of the country.

In some EU Member States it was reported that health staff did not necessarily use translation facilities even when they were available:

"[...] staff taking short-cuts and not using translators – GP [General practitioners] not wishing to wait for the very short time necessary to access (interpretation services) to assist clients whose English is limited."

(Health visitor,[219] female, migrant/ethnic background, United Kingdom)

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[219] In the United Kingdom system, health visitors are nurses or midwifes with further specialisation in community public health. They work within community settings and support families through the promotion of mental, physical and social well-being in the community.

Promising practice

24/7 telephone interpreting services, Language Line

Language Line Inc. is a commercial interpreting provider that was initially a charity. British social activist Michael Young noticed that language barriers were leading to substandard services for ethnic minorities at Royal London Hospital in London, England, so he obtained funding to provide free telephone interpreters starting in 1990. He later began serving corporate clients and converted the charity into a commercial service. Telephone interpreting is provided when an interpreter, who is usually based in a remote location, provides interpretation via telephone for two individuals who do not speak the same language. The telephone interpreter converts the spoken language from one language to another, enabling listeners and speakers to understand one another. It is especially useful in situations where some patients, for reasons of modesty and/or anonymity, prefer not to have another person, like an interpreter, physically present in the room, especially when discussing sexual health issues.

"[Now w]e can book the Pearl Linguistic time and use it at any time. Whereas in the past, we had to wait for the translators."

(Psychiatrist, male, migrant/ethnic background, United Kingdom)

Healthcare users and health professionals adopt different strategies to cope with a lack of translation services. In Austria, the Czech Republic and Italy, interviewees described relying on family members, often children, as informal interpreters. While facilitating immediate translation in the absence of formal services, this raises a number of difficult ethical and practical issues. Informal interpretation can create situations in which a young child must communicate a worrying diagnosis to a parent or translate intimate or embarrassing information. In other cases, a male partner might substitute for a woman in her interactions with a gynaecologist, raising similar issues. Healthcare professionals in the United Kingdom mentioned that they were reluctant to accept family members as interpreters because of problems with the informed consent procedure. They noted, however, that patients sometimes found informal translation more convenient than waiting for an appointment when an interpreter was available.

Healthcare providers in Austria and Sweden and representatives of United Kingdom advocacy groups also acknowledged the difficulty of having relatives translating for older people with a migrant background as disagreements about treatment could arise among family members. Relatives might, for example, be dissatisfied with treatment efforts because they did not fully understand the diagnosis, its consequences or the limitations of recovery, thus potentially leading to conflicts. Some relatives fail to understand that in geriatrics even small improvements can be seen as successes, a geriatric nurse in Austria said. Moreover, in situations where a lack of accessible information means family members play an important role in explaining the advantages of treatment, relatives may have trouble finding a balance between supporting the person's right to make an independent decision and having necessary treatment in their best interests. The mother of a Turkish healthcare user living in Austria reported that treatments she regarded as useful were discontinued because her daughter no longer wished to undergo them.

Another strategy is for health professionals to consult members of their staff or staff from other departments, as reported in Austria. According to the health professionals, however, this leads to organisational problems and team conflicts resulting from the ensuing absence of the temporary translators from their regular roles, often to the disadvantage of the translating staff member. Sometimes cleaners are engaged in translation. In other cases, providers consult specialised NGOs, although this can create issues regarding who will cover the resulting expenditure.

In Austria, Sweden and the United Kingdom it emerged from the research that family doctors themselves often have a migrant background. Where available, the presence of multilingual staff was clearly appreciated:

"I could ask my gynaecologist almost every question. Perhaps I was able to ask her so much because we were talking Bosnian."

(Healthcare user, female, migrant/ethnic background, Austria)

In Italy, cultural mediators and doctors who have frequent contact with migrants report that they are able to communicate effectively even with patients whose language they do not speak. They rely upon a wider register of communication, including gestures and nonverbal expressions, and have learned to interpret the gestures and expressions different immigrant groups use. Above all, their determination to understand and be understood – and their belief in their ability to do so – can be seen as a powerful resource. In Austria, a healthcare user with an intellectual disability described the similar use of non-verbal communication:

"We communicate with hands and feet (smiles). There [isn't] anybody accompanying us. We don't have a translator."

(Healthcare user, female, migrant/ethnic background, Austria)

More broadly, respondents described particular strategies in accessing healthcare which met their needs and preferences. Recommendations regarding 'good' doctors circulate by word of mouth within an ethnic community, and multilingual health workers disseminate information about migrant-friendly healthcare facilities. In Italy, the use of intra-community communication channels emerged as an 'organising principle' in relation to the flow of migrants through the healthcare service, resulting in an informal, 'parallel' healthcare service within the national system. Immigrants often access the healthcare system through specific immigrant health offices created inside Local Health Units (*Aziende Sanitarie Locali*, ASL) and through some voluntary centres that deliver health services specifically for immigrants. Migrants appear to use these 'migrant-friendly' services because they are more likely to be staffed by professionals with advanced language skills.

3.2. Lack of information about healthcare services and entitlements

Many health professionals believe that specific groups of healthcare users are less aware of available healthcare services and their entitlement to use them. This barrier was explicitly mentioned in relation to migrant status, ethnic background, age and disability, as well as a combination of these characteristics. Where migrants live, the amount of time they have been in the host country and their position on the socio-economic spectrum could exacerbate the barrier's impact. A number of respondents highlighted the intersection of these factors, indicating awareness that such barriers can result in indirect discrimination on multiple grounds.

Interviewees identified a number of specific reasons for low levels of awareness about healthcare entitlements and services, some reflecting the intersecting identities of the groups covered in this research. Some health professionals believed that first-generation migrants might be accustomed to healthcare systems that are radically different to those found in the destination country. The medical, bureaucratic and administrative systems that characterise the national health services in the EU Member States included in this report, are complex, culturally specific institutional forms, and all users have to be 'socialised' in order to use them in a culturally appropriate fashion. The research findings indicate that specific groups of healthcare users often do not know how to book a check-up with a doctor or identify a specialist. In the Czech Republic, lack of awareness was reported to have financial repercussions. Migrants did not know what kind of medical care specific insurance policies entitled them to receive. Hospitals and medical staff occasionally exploited this situation by charging higher fees for various services.

In the United Kingdom, an advocacy provider mentioned that high levels of mobility among asylum seekers resulted in lower awareness of healthcare services.

In some of the EU Member States surveyed, persons with intellectual disabilities belonging to migrant or ethnic minorities said that neither health professionals nor social services provided information on health entitlements. Questions of entitlement are especially important during the transition from childhood to adulthood. Social workers interviewed in Austria reported that many clients and their families are not aware that children are deregistered from their parents' health insurance when they reach the age of 18. They emphasised the importance of informing young adults and their families about the upcoming change to ensure continuous health insurance coverage. Health professionals in Austria felt that many patients with disabilities assume that the regular health provisions do not apply to them. One family doctor reported that hearing-impaired patients regularly assume that they cannot apply for provisions of the social and health systems. Lack of awareness of entitlements was raised also in relation to access to care and social protection schemes, as migrant families with children who had an intellectual disability appeared to be under-informed about support schemes for which they were eligible. In Austria, the mother of a young Turkish woman and the family of a young man with Down syndrome who has a migrant background, for example, were not informed that they were entitled to receive income support. A migrant woman in Sweden who cares for a brother with schizophrenia was never informed that she was entitled to municipal help and services.

Lack of information on entitlements might have particular consequences for persons with disabilities belonging to certain ethnic minority groups, given that some migrant communities relegate those with disabilities to the private domestic sphere and are unfamiliar with existing subsidised services for persons with disabilities because these do not exist in their countries of origin:

> *"In my experience, what happens in practice is that disability is an issue of the private space. Disability and accepting any help – in some migrant's communities, this is just not an experience that they have ever had. Disability is something women take care of at home, and something they have had to struggle with, but there is no tradition of governmental subsidies. So they would not approach such institutions, because they do not know anything about that. Even many Austrian citizens do not know that."*
>
> *(Family doctor, male, Austria)*

This research shows, however, that in several EU Member States health providers are often not informed themselves and, therefore, fail to inform their patients of support services for specific groups. A health professional in Austria, for example, mentioned that there was a lack of knowledge among health professionals with respect to asylum seekers who needed medical help for disability. More broadly, according to an Italian family doctor, health professionals take great responsibility for (in)adequately informing healthcare users:

> *"If I were to say which are the main barriers in access to healthcare, honestly I think that the main one is the fact that health professionals and we doctors in the first instance, are unable to inform patients. If you explain adequately to patients what they need to do, where they need to go and so on, access becomes much easier. Obviously this becomes more and more difficult if there is a linguistic barrier, too."*
>
> *(Family doctor, male, Italy)*

The Austrian, Czech, Italian and Swedish healthcare systems require a great deal of initiative on the part of patients which compounds these issues. In the Czech Republic, migrant women reported that general practitioners rarely volunteered cost-free preventive check-ups covered by their health insurance. The women needed to be proactive and request such check-ups:

> *"No, he didn't offer it. I went there and said that I hadn't been to a check-up for a year and I know that my insurance covers some annual check-ups. So I went there and said that I am entitled to it and that I want to have it done. No, […] nobody offers it, I have not seen a GP do that."*
>
> *(Healthcare user, female, migrant/ethnic background, Czech Republic)*

In some EU Member States, the lack of information on the time constraints to access available health services had a specific impact on migrant women of reproductive age. In the Czech Republic, finding a hospital in which to receive maternity care presented a problem for more than half of those interviewed, in part because they were not informed that hospitals had to be booked before the third month of pregnancy.

> *"I read on the internet that I must report to a maternity hospital in the 14th week of pregnancy. Almost every hospital website says that. As soon as I started my 14th week, I called the Motol hospital because I had had a good experience with them, and they told me they were full. That surprised me so I called other hospitals and they were all full because, as I later learned, although I was supposed to contact them in the 14th week in order to get in, I had to contact them earlier than that. They don't write that on any websites and when I learned it, it was too late."*
>
> *(Healthcare user, female, migrant/ethnic background, Czech Republic)*

In other cases, the information was available, but only in formats which might be inaccessible to particular groups. In the Czech Republic, for example, information about opening hours, the location of and contact details for healthcare facilities is now available primarily over the internet. This may have adverse consequences for migrants, and those with other or multiple characteristics associated with weaker socio-economic positions. The language barrier is also again of relevance, as even in EU Member States such as Sweden where translation services are mandatory, this applies only to appointments with healthcare professionals and not to information on available healthcare services.

In addition to the general impact on access to healthcare, interviewees identified several specific consequences of the lack of information regarding healthcare services and entitlements. They mentioned that in Italy and the United Kingdom low levels of awareness mean that migrants tend to visit accident and emergency units rather than making use of other available healthcare services. They may thus fail to seek or receive treatment during the early stages of a medical problem, posing potential risks to their health. Using emergency departments, often characterised by overcrowding and stressful working conditions, as the gateway to other services can cause irritation among healthcare providers.

Respondents also reported consequences linked to the structure of health services. Swedish healthcare system reforms since the 1990s[220] have aimed at increasing users' freedom of choice in providers. In 2010, the principle of freedom of choice became mandatory for primary healthcare services, which means that individuals can freely choose which provider they wish to visit. But available evidence shows that the prevalence of cognitive, physical and sensory problems among older and/or disabled people might prevent them from exercising their freedom of choice without appropriate support which, in the contemporary choice-based model, undermines their access to high-quality primary healthcare services.[221]

Finally, interviewees identified a number of strategies they use to overcome the lack of information about available healthcare services. In Italy, professionals and representatives of advocacy groups working with migrants reported that the task of providing information to migrants is implicitly delegated to the non-profit sector and informal networks. These networks may, however, transmit false information and make it difficult for migrants to receive assistance discretely, thus keeping them in a situation of dependence. Health professionals believe that routine attempts to improve this situation have been inadequate and that no concerted attempt has been made to provide accessible information.

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[220] For more information on the health policy reforms, see Glenngård, A. H., *et al.* (2005), p. 95.

[221] Meinow, B., *et al.* (2011). The results are based on a randomised study of 621 persons aged 77 years and older in Sweden showed that 90 % of the older persons in the sample were too ill to conduct an interview or a memory test, had problems understanding instructions or finding information, or were too physically impaired to visit a doctor who was not nearby.

Promising practice

Supporting access to information on healthcare

The Centre for Integration in the Regions in the Czech Republic offers migrants support in the area of access to information on healthcare, which several NGOs provide. Refugee Facilities Administration of the Ministry of Interior opened the Centres to support the integration of foreigners (CPIC) in several regions. The centres provide consulting and information services, legal counselling, Czech language courses, social and cultural courses, an internet point and library. Consultations include information about healthcare and health insurance. The centres often provide information to migrant women, especially those who have problems with their health insurance or with insuring a child. The centres were established within the framework of projects financed by the European Fund for Integration of Third Country Nationals.

Nevertheless, healthcare providers in all five EU Member States suggested that outreach strategies are crucial:

"Health promotion is not reaching Black and Minority Ethnic groups. Advertising does not reach the groups it should be reaching. There is a tendency to focus on the stereotypical white British family."

(Advocacy group, female, United Kingdom)

In Austria and Italy, respondents identified outreach through social workers, who may have extensive contact with some healthcare users, as particularly important for increasing awareness of specialised healthcare facilities, facilitating access to other support structures and relevant information. For example, a healthcare user with intellectual disabilities in Italy explained:

"[...] I did not even know about the existence of many things until someone, or the social worker, told me about them."

(Healthcare user, female, migrant/ethnic background, Italy)

Interviewees stressed that providing factual information is not sufficient, as trust must be built up within communities over time, and official information needs to be 'validated' by family or community knowledge. Information provided through formal channels may sometimes need to be reinforced, amplified or repeated by more immediate channels before it can start to alter established patterns of behaviour. Interviews with cultural mediators in Italy suggest that this role is often played by integrated, educated and informed members of migrant communities, particularly those working in healthcare services.

For families, access to parents' organisations can be a helpful resource for accessing information and services for children. Such groups, however, are often not accessible to migrant families who do not speak the local language. Information must therefore be provided in a form that is understandable and acceptable to users, explaining in concrete and simple terms what is being offered, rather than subsuming this under an abstract, general and perhaps stigmatising category such as 'social services' or 'mental health'. Health professionals in Sweden say that it would be good to have more written information in different languages, including general information about available healthcare services. New strategies should also take into account the linguistic practices of specific groups; healthcare providers in the United Kingdom pointed out that oral communication may be more effective with Somalis, for example.

3.3. Financial barriers

Financial barriers emerged as a fundamental and serious obstacle to healthcare for migrants or ethnic minorities in all five EU Member States surveyed, with the partial exception of the United Kingdom. User fees and dental care represent the two most frequently mentioned barriers in all five EU Member States surveyed. Financial barriers are intrinsically linked to socio-economic conditions, and particularly to employment status. Multiple or intersectional identities such as migration status, disability, age, long-term health issues or sex, which combine to reduce the likelihood of employment, are especially significant. Migrant status is another crucial factor as some Member States offer different entitlements to cost-free healthcare depending on status.

In addition, the disproportionate impact of the economic recession on lower socio-economic status groups is particularly relevant. Abolishing free services and increasing out-of-pocket charges for healthcare imposes a heavier burden on such groups. Although imposing disproportionate burdens on groups with lower socio-economic status is not against anti-discrimination legislation, it has indirect effects that could in principle be challenged under that legislation.

Financial barriers assume different forms depending on the specific EU Member State and its system for funding and organising healthcare. Financial costs of healthcare appear to be a particular barrier in the Czech Republic. The Czech system is based on public health insurance that excludes specific groups of migrants, such as those coming through a family reunification programme, who are more likely to be women. For third-country nationals not entitled to public healthcare, purchasing private health insurance can pose a major financial barrier. Moreover, commercial health insurance typically covers fewer treatments than public health insurance, thus ineligible treatments must be purchased separately. The challenges are particularly acute for migrant and Roma healthcare users, who face direct discrimination from healthcare professionals who refuse to register them for fear they are uninsured and will be unable to pay for treatment. When doctors accept an uninsured patient, they often require disproportionately high cash deposits.

In Italy, healthcare fees or insurance for consultations, tests and medications emerged as a relevant barrier, as well as the cost of private healthcare, due to lengthy waiting lists or the absence of public services. Other barriers mentioned were the cost of medications, equipment and devices which public schemes do not cover.

The Swedish national social insurance includes a high-cost protection scheme that covers costs for healthcare services that exceed a certain set sum for 12 months, including medical treatments, medical products, transport and assistive technology. After those 12 months, the individual must once again pay full charges. This resetting of the high-cost protection scheme causes difficulties for those on a low income. All costs are significant for asylum seekers, due to their low daily allowance, and for the unemployed and persons unable to work due to long-term ill-health. Financial barriers were less of an issue in the United Kingdom, as services are free at point of access. Still, healthcare users said that some prescription costs are considerable. Some also mentioned the cost of travel to appointments for users, and those accompanying them to assist them with translation.

In addition to the specific issues in each EU Member State, a number of recurrent issues emerged as financial barriers from the research, namely healthcare fees, insurance policies and the cost of medications. While these issues apply to all healthcare services users, the research indicates that such expenses are particularly problematic for certain groups, such as Roma, persons with disabilities and older people. The research found that even very low fees can deter individuals from using a service:

> *"Some of our (Roma) clients [are expected to] pay huge [amounts of] money for medicine, but they can't afford it, they live off the social minimum which is 2,200 CZK, and they should pay 1,500 CZK for the medicine, so they don't take the pills."*
>
> *(Social worker, male, migrant/ethnic background, Czech Republic)*

In Italy, to avoid paying increasing user fees, many migrants turn to dedicated 'parallel' services for undocumented migrants, skirting the user fees of the mainstream services to which their work or residency permits entitle them.

Of particular concern were treatments not covered by standard insurance schemes. Interviewees in all five EU Member States surveyed noted that dental care costs are not generally included in private or public insurance schemes. In some countries healthcare users who cannot afford dental treatment can access special dental clinics where treatment is offered for free. This can, however, mean the use of more cost-effective, but lower quality, treatment.

> *"Our clinic has three dentists, whose offices are unfortunately outside of Graz. The roundtrip ticket already costs €15. On the other hand, the treatment is for free. We also refer the patients, if it is very acute and we can't get them in and they can't afford the ticket, we refer them to the dental clinic. Then often the tooth gets pulled out. [...] Okay, you want to save the tooth, which of course someone who can afford that would get in any case, this is not possible here. In case of doubt, if there's nothing much to restore, I guess they'd make a filling, but in my experience they extract very quickly indeed. And this is very frightening. Among younger patients, we find very incomplete teeth, already in early years."*
>
> *(Healthcare professional, female, Austria)*

Insurance schemes may also exclude some types of preventive care, such as screening tests and oral contraceptives. In the Czech Republic, for example, health insurance covers biennial screening for breast cancer for women older than 45 but not for younger women. In addition, doctors and clinics sometimes charge an administration fee or ask for additional payments. After her sister was diagnosed with cancer, a young Roma woman was referred for a breast check, but she was unable to afford the screening. Moreover, health insurance funds sometimes do not or only partially cover psychotherapy and specific therapies for persons with disabilities. A representative of an advocacy organisation in Austria described a case of a child with a physical disability whose public insurer refused to pay for physiotherapy and other therapies to improve and maintain mobility because the insurer's healthcare staff did not consider them necessary treatments. *Lebenshilfe*[222] Graz brought the case to the Higher Regional Court which ruled that the public insurance system is responsible for covering measures which prevent health conditions from worsening.

Medication and treatment costs also act as a major barrier among older persons who are not exempt from prescription charges and live on a small monthly pension, respondents said. Migrants with psycho-social disabilities who need native-language psychotherapy face particular challenges as well. In Austria, for example,

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[222] *Lebenshilfe* is the biggest advocacy organisation of persons with intellectual disabilities in Austria. More information, in German, available at: www.lebenshilfe.at/index.php?/de/Ueber-uns.

most of the NGOs and support institutions that offer such treatments do not have contracts with the Austrian health insurance so the cost cannot be reimbursed. Representatives of women's and migrant-centred health providers stressed the need for such providers to secure contracts with health insurance companies in order to cover the costs at least in part. Health professionals noted that it would be more cost-effective for individuals to receive psychotherapy rather than be on sick leave, in hospital, or in need of other medical treatment for a longer time.

Interviewees also discussed the barriers created by third-country nationals' ineligibility for certain benefits. While not directly a barrier to healthcare, these restrictions particularly affect older migrants or those with a disability, who, in some of the EU Member States surveyed, might not be eligible for specific allowance schemes unless they hold a permanent residency permit. Their inability to work and exclusion from social protection schemes means they face major financial barriers in accessing specific care services and buying medicines. In Austria, third-country nationals in need of long-term care who do not receive a pension are not entitled to claim provincial long-term care allowance, with the exception of permanent residents in the provinces of Lower Austria, Tyrol and Vorarlberg. Third-country nationals are only eligible for minimum social protection if they are recognised refugees or have subsidiary protection, or if they hold a permanent residence permit. In the United Kingdom, migrants without indefinite leave to remain or migrants who have not entered for the purposes of settlement are not eligible to apply for public funds such as severe disability allowance, disability living allowance and carers' allowance. Similarly, in Italy, with the exception of refugees, third-country nationals who are not permanent residents are not entitled to disability allowances.[223] Despite several Constitutional Court and the Court of Cassation judgments,[224] the law has not been amended.

3.4. Organisational barriers and accessibility

Health professionals and advocacy organisations highlighted that different categories of healthcare users have different needs and situations, and the failure to take these into account both at the macro level – when financing the health system – and at the micro level – when deciding opening times, organising booking procedures and applying policies – has far-reaching consequences. While organisational barriers impact all healthcare users, the evidence from FRA fieldwork research indicates that they can constitute indirect discrimination by disproportionally affecting certain groups, particularly young migrants with an intellectual disability and migrant women of reproductive age.

The respondents described a number of supply-side barriers created by the absence or under-supply of particular treatment options or professional skills which more severely affect women and persons with disabilities belonging to migrant or ethnic minorities. Health professionals in Austria and the United Kingdom, for example, stressed how gynaecological treatment of women with FGM – a practice which affects women in specific ethnic communities – is often delayed because doctors face a situation in which 'normal' treatment is unsuitable or difficult.

"It is problematic when they [women with FGM] are never examined, or when they get an appointment but only in four weeks or when normal prenatal examinations are impossible, because, you cannot perform this exam on her anyway then she does not need to show up. This happens."

(Family doctor, female, migrant/ethnic background, Austria)

In the United Kingdom, health professionals' lack knowledge of FGM and its psychological consequences was also mentioned as a problem.

"The GPs are very pragmatic about this [clitoridectemy and infibulation] and do not understand the psychological implications. [...] There are specific areas where specialists need better access to screening knowledge or tools for use with particular groups of people from black and minority backgrounds, for example the impact of FGM on mental health, sexual functioning, attitudes and interpretation of what is domestic violence."

(Family doctor, female, United Kingdom)

Promising practice

Treating and counselling women subjected to FGM

A Stockholm hospital, *Södersjukhuset*, has since 2007 had a special centre for women subjected to FGM that provides both medical treatment and counselling. The centre is integrated into the hospital's other gynaecological health services and employs five gynaecologists and one therapist. The centre, called the 'Amel centre', is open for visits without referral from a physician for all women living in Stockholm county.

For more information, see: www.sodersjukhuset.se/sv/Avdelningar--mottagningar/Mottagningar/Mottagning-for-konsstymade

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[223] UK, Law No. 388/2000, Art. 80, c. 19.

[224] Italy, Constitutional Court (*Corte Costituzionale*), judgment No. 187, 28 May 2010; Court of Cassation (*Corte di Cassazione, sez. Lavoro*), judgement No. 14733/2011 dd, 5 July 2011; Court of Cassation (*Corte di Cassazione, VI sez. civ.*), judgment No. 4110, 14 March 2012.

In Italy, migrant women's ability to access cost-free ultrasound scans during pregnancy can be undermined by the booking procedures for such scans, one gynaecologist said. Ultrasound scans during pregnancy are free of charge when booked within a certain time limit, but if a woman seeks advice or treatment at a later stage, she may have to pay privately. Because migrant women typically have a non-medicalised approach to pregnancy, they tend to start antenatal care later.

More generally, for those with intellectual disabilities, delays can result from insufficient provision of particular services. In Austria and Italy, the lack of suitably trained professionals in the area of psychology and psychotherapy, the small number of multilingual professionals and, in Austria, the absence of such services from some health insurance schemes mean that some healthcare users experienced long delays in accessing treatment. Several healthcare users with intellectual disabilities reported being sent to three or four different doctors for the same health problem:

> *"This happened at the neuropsychiatry for children and juveniles. I got an appointment with a new doctor and she was a specialist for epilepsy. After I had explained our problems to her she told me to consult another doctor – Dr H. You cannot get an immediate appointment with her for she is always very busy but I should be able to get an appointment. Finally I was able to see her – Dr H. – but she seemed utterly incapable of managing the situation. We had two medications both of which were solutions. We had to switch from one to the other but she gave us a completely wrong dose rate – she did not do a measurement to fix the new dose rate. I tried to reach her for two months. During this time she never seemed to be at her office. Then I went to outpatient services again to ask what I should do about the dose rate."*
>
> *(Healthcare user, male, migrant/ethnic background, Austria)*

Low levels of awareness among health professionals and lack of available multilingual medical professionals can also result in difficulties obtaining a confirmed diagnosis. This in turn can create barriers to receiving treatment. In Austria, only a minority of interviewees with intellectual disabilities had certified medical diagnoses, and most did not know their medical history and could not give information on their diagnosis. The mother of a young Turkish-speaking woman living in Austria only learned about her daughter's intellectual disability when she was enrolled in school, although she had needed frequent hospital care as a young child. It was not until her daughter turned 18 that she found a Turkish-speaking psychologist, who she hoped might help her to find adequate and sustainable treatment. A migrant man in Sweden with Asperger syndrome and depression described how his attempts to receive proper diagnoses and treatment delayed therapies and other treatments. Doctors and psychiatrists he consulted repeatedly told him that they could not assist him because they were unaware of sufficiently qualified staff. He linked the barriers to healthcare he faced specifically to discrimination on the grounds of disability, in conjunction with his ethnicity.

Interviews with healthcare professionals in Sweden and Italy pointed to the complexity of assessing the impairments of children with intellectual disabilities belonging to minority ethnic communities. A Swedish healthcare professional suggested that intellectual disabilities amongst children with migrant backgrounds might be assessed differently than those of a Swedish child with similar problems, with certain behaviors attributed to cultural differences rather than learning difficulties.

Challenges which have more general consequences on persons with disability may occur when access to healthcare relies on coordination between different arms of the social security system. In Austria, affiliation for health insurance purposes is linked to registration either with the Austrian labour market service or the social services department as a recipient of minimum state benefits. The interviews conducted for this research, however, indicate conflicting competencies between the labour market service and the social services departments. Social services departments, for example, do not always accept a certification from the Labour Market Service declaring a person unfit to work, suggesting that the individual could participate in job training measures. As such, job trainers and social workers report that both institutions sometimes exclude their clients from accessing healthcare. This is particularly problematic in the case of persons with intellectual disabilities, as only a minority of healthcare users interviewed possess a diagnosis of disability – a medical confirmation of the degree of disability and thus the degree of required support – and proof of unfitness to work is difficult to obtain.

In the United Kingdom, a few healthcare users reflected on internal organisational barriers to the healthcare system that prevent quality care for people with learning disabilities. For example, a migrant woman with intellectual disabilities said that:

> *"What about the learning disability nurses who are supposed to help? Families don't know about them when they go to hospital. Why don't they make themselves known? There is no communication between sections. It is all down to people to find out and they can't. Doctors and nurses can't be held totally to blame, sometimes they may be too busy or too overworked to even know someone has a learning disability. It is not always clear. How can they help if they don't know? Also, the people who bring food, again, they are not necessarily aware or don't know what a learning disability is if they have never met the person."*
>
> *(Healthcare user, female, migrant/ethnic background, United Kingdom)*

Many respondents also mentioned accessibility and geographical distance as general barriers affecting people with disabilities when accessing healthcare. Accessibility has a specific meaning in the context of disability in line with the CRPD. Article 9 of the convention sets out a wide-ranging obligation for States Parties to take measures to ensure accessibility, including of medical facilities, for persons with disabilities.

In terms of physical accessibility, research findings showed that hospitals and particularly local doctors' surgeries in Austria, the Czech Republic and Italy were often not fully accessible for persons with certain impairments, such as wheelchair users and those with sensory impairments. Aside from physical accessibility, evidence from this research in Austria, the Czech Republic, Sweden and the United Kingdom revealed that unaccompanied people with intellectual disabilities often find information in hospitals inaccessible. The lack of easy-read[225] material made food menus particularly difficult to understand; two people in the United Kingdom would not have been able to select food to eat from the dietary sheet without their mothers' help:

> *"I don't understand this, there's no pictures or nothing, how was I supposed to understand?! There was nothing, there was just writing, I was like 'oh my word'."*
>
> *(Healthcare user, female, migrant/ethnic background, United Kingdom)*

Furthermore, in the Czech Republic, Italy and the United Kingdom, the absence or cost of accessible transport to health facilities emerged as a strong theme. In the United Kingdom, those with physical or sensory impairments, common medical conditions among older migrants, faced financial and logistical problems given the unavailability of accessible local transport and long complicated journeys to specialist hospitals.

Roma people living in isolated areas outside Prague, migrants in outer urban peripheries in Italy and asylum seekers with disabilities in remote areas also cited distance from specialist health services available only in big cities as a specific problem.

> *"Assume the asylum seekers are disabled and get assigned a place somewhere off-road, upper Styria, where there is no access to whatever they need for treatment. This can always be a problem. Then we write a letter, that they need access to certain therapeutic treatment. They can't finance the travel costs as they don't have much money. In the medical sense, there would not be any problem, well, if the infrastructure were available."*
>
> *(Healthcare professional, female, Austria)*

Interviewees in the Czech Republic also reported that ambulances may refuse to enter deprived areas where Roma settlements are located.

Lack of flexibility and reasonable accommodation in booking procedures and opening times of healthcare facilities might disproportionally affect specific intersectional groups. In the United Kingdom, an Asian wheelchair user described repeatedly being given Friday appointments when he would have been at mosque. The appointment times were only changed when an advocacy worker accompanied him to the hospital and raised the issue of the Human Rights Act and the CRPD.

> *"Practitioners and service providers are inflexible and fail to understand or lack the commitment to do things differently, with some flexibility, to make things easier for the patients with learning disabilities, for example. Flexibility would impact on the routine of the organisation. 'It is too difficult, its mucks up our routines, so we will treat everybody the same.'"*
>
> *(Legal expert (complaint body), female, United Kingdom)*

For many healthcare users with intellectual disabilities, the consequence of inaccessibility and the lack of reasonable accommodations is a reliance on support to access healthcare. Interviewees from Sweden and the United Kingdom explained that family members help them to make appointments, complete forms and go to the doctor. Others reported reliance on staff in group homes or day centres. This leaves them vulnerable to situations in which support persons are either unable or unwilling to facilitate access to healthcare:

> *"If you don't have the support you won't be able to do it [cope with health needs]."*
>
> *(Healthcare user, female, migrant/ethnic background, United Kingdom)*

Two mitigating factors to these difficulties are the close proximity of health services to the home and strong, trusting relationships built up with health professionals over a number of years. A few healthcare users with intellectual disabilities explained that they were able to schedule appointments and travel to doctors' surgeries they knew well on their own, particularly if they had formerly been accompanied while they learned the route.

3.5. Working conditions, living conditions, care responsibilities

The next set of barriers relates to the work, family and living conditions of migrants or ethnic minorities, as these influence both their health and their ability to access healthcare services. The most important issue regarding work is that these groups are often confined to secondary labour markets or the black economy.

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[225] Everyone has the right to information they can understand in order to be able to take informed decisions. For more information on what constitutes 'easy-read' material, see the 'Pathway' project of Inclusion Europe, available at: http://inclusion-europe.org/pl/icon-display-polityki/self-advocacy-and-accessibility/easy-to-read-project.

Several respondents in Austria and Italy, for example, pointed to the fear of losing their job if they went on sick leave for too long, or even took a morning off to have a check-up or test. Migrants working in sectors with little legal protection or with high rates of undocumented work, such as those performing casual agricultural work, or caring for an older person, may automatically lose income if they fail to report for work every day. Migrants who are not residing legally and those whose permit to stay is linked to a work permit, may perceive the risk of losing their jobs as greater than that of leaving health problems untreated.[226]

The cumulative effect over time of bad working conditions has a particularly negative impact on older migrants. Low use of healthcare services is coupled with a phenomenon referred to as 'exhausted migrant effect'.[227] As they grow older, people who were previously 'healthy migrants' may experience a rapid deterioration in health, often quite abruptly because of their poor living and working conditions. Not having previously paid sufficient attention to their health, due to the factors described above, they may experience early-onset rheumatism, arthritis, mental health problems, spine problems, the effects of repetitive strain injuries, stroke, depression, high blood pressure and other somatic symptoms. Several interviewees in Austria had applied for invalidity pensions or early retirement:

> *"At the age of 60 I do have higher cholesterol and triglycerides as well as other ailments I didn't anticipate. I do have arthritis; this may be a result of my way of life. Since 1992 when I came to Austria I had to take up every work possible to be able to survive, I wasn't prepared to do this. So this hard physical work did have some negative side effects on my health."*
>
> *(Healthcare user, male, migrant/ethnic background, Austria)*

Poor living and working conditions of migrants in the long term cause a deterioration in health; increased healthcare needs are, however, not matched by increased use of the healthcare system due to barriers created by working conditions.

Migrant or ethnic minority women's care responsibilities within the family, particularly in the case of sick children or family members with disabilities, may have the same effect of barring women from seeking healthcare when needed, generating health risks for them. This is often related to the socio-economic status and cultural practices of migrant or Roma families where, for example, the latter may be large, relatively poor and socially or geographically isolated, and the mother alone is expected to care for her family's needs. These barriers can take the form of intersectional discrimination, where Roma women are unequal both as a woman within Roma society, and as a Roma woman among other women. A Roma woman explained, for example:

> *"I came to the gynaecologist with three kids, my partner at work. It's also because we, the Roma women, have many duties and those like you [majority women] have everything neat and orderly, and lots of time, the husband does the cooking and cleaning, and you only care about how to wash your hair."*
>
> *(Healthcare user, female, migrant/ethnic background, Czech Republic)*

Care responsibilities also act as a barrier to migrant women, especially those who are single parents and have no family or support networks to mind a child during medical appointments. As health systems generally do not accommodate carers' needs by providing childcare, health mobile units or by allowing a disabled child to be hospitalised with the mother, many women lack the time and resources to look after their health, and may postpone accessing healthcare services until they go back to their country of origin. The impossibility of booking appointments in advance and the long waiting times in doctor's surgeries compound these problems.

For persons with intellectual disabilities, living arrangements can have a significant impact on the accessibility of healthcare.[228] In Austria, healthcare users in supported living arrangements tended to be better informed about the purpose of medical appointments they attend and their contacts to the health system, and were more independent in their decision making than persons living with their families. Social workers at a job training centre for young persons with intellectual disabilities reported that some of their clients' access to healthcare improved when they left the family context and moved into a supported living arrangement because their needs were more respected. In the United Kingdom, however, one healthcare user living in a group home explained that she refrains from asking for assistance with making medical appointments as the support worker is very busy and she does not want to "be a bother":

> *"Now I have to ask for help, I used to live with a carer but now the support workers have to arrange everyone's appointment: hospital, dentist, doctor, optician […]."*
>
> *(Healthcare user, female, migrant/ethnic background, United Kingdom)*

The need to address different working, living conditions and lifestyle factors emerges as a concern of health professionals. This involves the acknowledgement of multiple needs and that health should be approached

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[226] On the fundamental rights of migrants in irregular situations, see also FRA (2011d).

[227] Bollini, P. *et al.* (1995).

[228] For more information on the right to independent living for persons with intellectual disability and mental health problems, see FRA (2012d).

in a comprehensive way and cannot be separated from the patients' life context.

Promising practice

Addressing the needs of intersectional groups through 'community'

Social Action for Health (SafH) is a community development charity based in London, England, which works alongside marginalised local people and their communities towards equality and better health and well-being. In its outreach activities the charity's staff takes into account the needs of specific intersectional groups, such as migrant women and older people belonging to ethnic minorities. Because the staff themselves are predominantly from ethnic minority groups gives them privileged access to Somalis and Bengalis in Tower Hamlet. The group in Tower Hamlet is particularly active on cancer prevention and has achieved one of the lowest rates in the United Kingdom. One staff member said:

"'Social Action for Health' goes where the members of the ethnic communities meet instead of bringing them where the advocacy organisation is based. For example, in Tower Hamlets where there is a predominant Bengali and Somali community, the organisation reaches out to Somali men in cafés where they tend to meet and in mosques, where people gather five times a day. 'Social Action for Health' holds regular lunch clubs which elderly people attend. We go to homes where women meet anyway and do sessions around tobacco chewing speaking to them in Bengali. Bengali communities do the tobacco chewing, especially women instead of smoking, it's called paan in Bangladesh."

(Policy maker, male, migrant/ethnic background, United Kingdom)

For more information, see: http://safh.org.uk/

3.6. Cultural and psychological barriers

Cultural needs and practices are complex and varied and should not be dealt with by applying blanket knowledge to all individuals from a given country or ethnic group. FRA's fieldwork research indicates that a lack of knowledge of, or consideration for, cultural practices and customs can discourage service use:

"I think it is a lack of ethnic background knowledge. People [health professionals] have to make a little effort to know. Just because you are in Sweden [does not mean that] you are Swedish. You do not think Swedish […] you must show consideration for those things."

(Healthcare user, male, migrant/ethnic background, Sweden)

While respondents most often identified ethnic background or migrant status as the cause of such barriers, they also indicated an intersection with other protected grounds such as sex, religion and disability. Health professionals reflected on how cultural differences/barriers may imply a negative attitude towards certain groups, which in turn suggests a greater risk of discrimination.

The research in Austria, Italy, Sweden and the United Kingdom found migrant and especially Muslim women to be uncomfortable being attended to by male health professionals and male interpreters. One healthcare user in Sweden reported knowing veil-wearing women who avoid healthcare when they request a female doctor but the request is declined:

"Yes, for me it is totally okay, but I know women I work with […]. For example, they do not want to see male (gynaecologist) doctors when he will examine her […] they needed [the examination] very much but they did not want to."

(Healthcare user, female, migrant/ethnic background, Sweden)

A Muslim woman in Austria described a lack of sensitivity towards Muslim women's preferences and a reluctance to accommodate their needs:

"A Muslim girl is attended by [a male] doctor. For example, he says: 'Please undress. I have to feel your pulse.' He does not understand that one does not want to fully undress. He does not give any alternatives. He could go and fetch a female doctor. Or he could make use of his instruments in a way that renders undressing unnecessary. Instead he gives the feeling of him being the doctor and you being the patient who needs him. You are in Austria and you have to do what he tells you."

(Healthcare user, female, migrant/ethnic background, Austria)

This research indicates that the only country where this need appears to be routinely accommodated is Sweden, although in the United Kingdom providers seek to satisfy users' preferences or use alternative strategies, for example avoiding direct testing, turning to female health professionals for information and then making decisions. The shortage of female gynaecologists appears to be a structural problem in Austria, because of few female gynaecologists with an insurance contract with a public health fund. In Graz, for example, only one female gynaecologist has such an insurance contract, interviewees mentioned.

The specific needs of women with disabilities from specific migrant or ethnic minority groups were mentioned by a psychiatrist working on intellectual disability in the United Kingdom. The families of these women are unlikely to accept mixed-sex respite or in-patient care, which can jeopardise the service they receive. When the health service provider does not take this need into account, it could become indirect discrimination on more than one ground.

"Particularly south Asian families who don't tend to let their female children access [respite care or in-patient care], because of concerns about mixed-sex facilities. So that point kind of actually jeopardises the kind of service they receive. [...] I think the customer, it is their choice and that is a cultural need and if we don't provide services that respond to that cultural need, then it could become discrimination."

(Family doctor, male, migrant/ethnic background, United Kingdom)

Issues surrounding birth and motherhood amongst migrant or ethnic minority women emerged as a problematic area. Conflicting cultural ideas about appropriate behaviour can influence how services are provided. Sub-Saharan African women in Italy, for example, said that doctors put pressure on them to accept Caesarean sections, which they may refuse for cultural reasons, as they associate natural birth with their female identity. Cases were reported of women who left hospital during labour to avoid this procedure, which they believed to be unnecessary.

Different social norms about childcare may represent a source of tension between Roma women and the majority culture. In the Czech Republic, for example, Roma women are traditionally expected to take care of their families and children at home, even immediately after childbirth. This can induce them to leave hospital early, without informing staff, or to temporarily leave their newborn child in the hospital, which can increase the risk of the child being placed in care. Specific cultural practices can also contradict standard medical practice in the EU Member State concerned and this, in turn, can result in conflicts or insensitive remarks by healthcare professionals, as in the case of a Roma woman who reported a white female doctor shouting at another Roma woman for making her newborn baby tea.

Taboos regarding certain types of impairment among ethnic minorities may prevent persons with disabilities from accessing healthcare. According to a psychoanalyst in the United Kingdom, Muslim people with psychosocial disabilities sometimes have difficulty speaking about negative aspects of their mental health due to a belief that bad spirits cause depression. A psychotherapist in Austria mentioned that this can result in patients communicating general 'pain' instead of 'depression'. The president of an advocacy group for migrants in Italy explained that mental health services may be viewed as stigmatising, discouraging people from recognising they need help:

"But many African women here have psychological problems, not only women but also men. However, [...] they never go looking for a psychologist. Because when someone says: 'Go and see a psychologist', they say: 'but I'm not mad.'

(NGO, female, migrant/ethnic background, Italy)

The stigma associated with psycho-social disabilities among certain national/ethnic groups can in turn lead them to 'hide' family members with a disability, reinforcing their exclusion from society, as explained by a Swedish psychiatrist:

"Some of the families avoid seeking help for their children who have neuropsychiatric impairments or are born with functional impairments such as disabilities or such as functional impairments or cognitive impairments, such as ADHD [Attention deficit-hyperactivity disorder] or autism. Their upbringing shows that they are not normal. But in group-centred, shame-related cultures people try to avoid making the situation worse by seeking help, instead they isolate these children and they often do not go to the doctor or they go only after pressure from the environment, especially schools, when schools discover there is a problem. Often these parents come to us and are not convinced that the child is in need of help. They think that this is just because the child needs to adapt to Sweden or something; they try to trivialise the child's problem. In those situations we see that there is a need for more work, more information, more readiness to be able to reduce the unknown number out there."

(Psychiatrist, male, migrant/ethnic background, Sweden)

Psychiatrists in Italy and Sweden who treat children and young adults with migrant backgrounds mentioned that the children's parents sometimes deny that the child has an intellectual or cognitive disability and instead blame the school for being unable to meet the child's needs.

In Italy and the United Kingdom, health professionals reported mistrust among certain ethnic communities, and especially older community members, in Western medicine and reliance on traditional medicine. A health provider in the United Kingdom reported that the use of traditional remedies is most common among older people from African and South Asian communities. According to an Italian family doctor, because of this mistrust certain migrants, notably older Chinese, postpone seeking healthcare until they return to their country of origin:

"There are many situations where as a doctor you give up, because the patient is not compliant, he does not follow the doctor's indications. In the relationship with the migrant patient this can also be due to a cultural problem. [...] You realise this is the case in front of patients that you see very rarely, especially older migrants who show up very seldom, who do not seek healthcare. In these cases I really think it is an issue of lack of trust, lack of trust in our medicine and in the role of [Western] doctors specifically. These patients are often Chinese, they sometimes commute between here [Italy] and there [China] and seek healthcare when they are there."

(Family doctor, male, Italy)

Health professionals in Austria and the Czech Republic complained about the involvement of relatives or family members in consultations or decisions, including actions that undermine compliance. Several Austrian health professionals stressed the intersectional discrimination experienced by Muslim women who are often accompanied by family members. Turkish women are sometimes accompanied by their husbands who may be the primary interlocutor, a nurse said. A psychotherapist reported that Muslim women are sometimes not allowed to undergo therapeutic treatments or physiotherapy without the husband's permission or presence. The head of a health centre for girls and women mentioned courses of sexual education which Muslim girls do not attend. This health centre actively sought a staff member who wears the veil to facilitate access for religious groups.

Other cultural challenges not necessarily linked to specific intersectional groups emerged in the context of informed consent, time keeping and the role of relatives. In relation to the varying cultural understandings of the role and relevance of informed consent, some professionals suggest that different patients respond differently to questions about their views on different treatments or on being asked to consent. A general practitioner in Sweden recounted that some patients wanted her to make all the decisions and were surprised when asked what they thought or wanted. One psychologist in Italy underscored that the concept of informed consent related to a concept of self-determination, which typically comes from western societies. Migrants coming from cultures where unconditional trust in doctors and their experience is the norm find it difficult to understand this western meaning of consent. Patients sometimes sign a consent form based solely on the doctor's suggestion, repeating the same theoretical framework of unconditional trust in physicians, he added. A Swedish geriatric specialist said that 'immigrant patients' tended to be more 'obedient' than Swedish patients, and that the latter were more likely to question proposed treatments and were, in general, more demanding.

Another issue relates to problems with time-keeping. Health professionals in the various EU Member States researched highlighted the issue of patients arriving late or expecting to be seen without an appointment, which staff found frustrating and difficult to deal with. These problems may be attributable to unpredictable delays, where the service user has domestic responsibilities, for example, but they also result from different conceptions of time.

Health professionals also described situations where a large numbers of relatives visit a patient in hospital. Roma people in the Czech Republic consider health a family issue, prompting relatives to make hospital visits in large numbers and bringing in food from outside the hospital which causes problems for hospital staff.

Promising practice

Incorporating future patients' views in setting up a new hospital

Authorities in Göteborg, Sweden conducted a close dialogue with local inhabitants when establishing a new hospital in a suburb with a particularly large number of people with a migrant background. This dialogue involved meetings, interviews and focus groups with inhabitants, during which the locals were consulted on their experiences of and opinions on healthcare services and asked how the new hospital could contribute to improving the quality and accessibility of healthcare services. The dialogue helped improve healthcare services and continues on an on-going basis.[229]

For more information, see: www.angeredsnarsjukhus.se/sv/Angereds-narsjukhus1/Angereds-Narsjukhus/Om-Angereds-Narsjukhus/ANS-uppdrag/

Going beyond these cultural differences, many professionals and advocacy groups pointed to the existence of psychological barriers. They mentioned that fear often underlies a reluctance to seek help. Fear may relate to medical interventions themselves, which may be painful or undignified but may also be linked to stigma as well as experiences of institutions or discrimination and the fear of deportation. Understanding the determinants of (social) fear, on both sides of the interaction between migrants or ethnic minorities and health services, is therefore important.

Persons with intellectual disabilities, for example, often have long histories of serious medical interventions and regular contact with health or care services dating back to early childhood. Together with a low awareness of preventive health, this may prompt them or their families to avoid contact with the health system where possible:

> *"In the past I took her to the physician very often. Now we do not go to see the physician anymore. As long as she does not fall ill, I won't take her to the doctor."*
>
> *(Mother of healthcare user, female, migrant/ethnic background, Austria)*

Several groups of healthcare users, including asylum seekers and persons with disabilities, shared past experiences of institutionalisation which increased their fear of healthcare services.

> *"Often people that have been in institutional care are particularly frightened of using health services in general because they feel it is an institutional environment. Uniforms and white coats can be very frightening."*
>
> *(Policy maker, male, United Kingdom)*

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[229] See also Nasseri, A. et al. (2008).

This fear was felt to be particularly strong among members of minority ethnic groups because of high numbers of compulsory admissions into hospitals of black men, suggesting how intersectional identities combine to create specific vulnerabilities. A representative from a British NGO committed to reducing health inequalities among minority ethnic groups described how mistrust of healthcare settings among minority ethnic individuals is linked to personal or indirect experience of compulsory admission, seclusion or heavy medication in the care system:

> *"[…] the Caribbean community has not forgotten Rocky Bennett or Orville Blackwood [examples of deaths of Afro-Caribbean people in care due to stigma which were covered by the media]; there is still a lot of mistrust – even where there are staff from BME [Black and Minority Ethnic] communities."*
>
> *(Policy maker, female, United Kingdom)*

All these barriers may operate in isolation as well as interact in complex ways. Difficulties in registering with a family doctor may force a patient to seek treatment privately, which implies that an organisational barrier can give rise to a financial one. In a similar vein, resource constraints may exacerbate language barriers due to lack of staff, time constraints and the absence of interpreters, and the existence of stereotypes and prejudices may impede effective communication between health professionals and patients. When considering policy responses, therefore, it is important to be aware of these interactions and to adopt a holistic approach.

Training of health staff is considered crucial in addressing inequalities in access to healthcare. Such training should not consist solely of the provision of 'cultural information' about migrant or ethnic minorities, which may simply reinforce stereotypes. While conventional training has a place, according to some health providers, other approaches to learning are required to transform thinking and enhance sensitivity. Healthcare managers in the United Kingdom suggested that more use should be made of workplace activities such as mentorship or shadowing, case discussion and critical incident analysis. Learning sets, group training activities which focus on actual actions and practice, offer an approach to personal and professional development relevant to the reality of the individuals involved in everyday care work. Health professionals in several of the five EU Member States studied also stressed the importance of good management and strong leadership in facilitating quality services for people with different vulnerabilities and complex needs.

> *"Part of the problem with cultural competence is the inability of managers to challenge, direct and support good work – not to know everything. There has not been enough investment in management and supervision, not enough attention to providing good quality for all."*
>
> *(Policy maker, female, migrant/ethnic background, United Kingdom)*

Conclusions

Migrant or ethnic minorities face a variety of obstacles when accessing healthcare, including language barriers, lack of information about healthcare entitlements and services, financial barriers, organisational barriers, working conditions and other social determinants of access to healthcare; accessibility and cultural barriers. These barriers have different consequences according to the specific intersectional group affected. Most of these barriers can be considered examples of indirect discrimination, whereby an apparently neutral practice places persons of a racial or ethnic origin at a particular disadvantage. In treating people who have different needs as though they were same, routine organisational practices may disadvantage certain categories of users who have special needs, including persons belonging to migrant or ethnic minorities; especially women, older people and persons with intellectual disabilities.

FRA opinion

EU Member States should adopt measures to further the right to health on an equal basis: free linguistic assistance – including translation and mediation services for those who do not speak or understand the language as well as 'signed' languages and other forms of support for people with sensory or intellectual impairments – should be made available in healthcare settings and when providing health information. Linguistic assistance is crucial in the context of informed consent (protected by Article 3 of the Charter of Fundamental Rights of the European Union); unequal treatment on the basis of language can easily result in indirect discrimination based on nationality (covered by the Cross-border Healthcare Directive) and/or ethnicity (covered by the Racial Equality Directive).

EU Member States should encourage positive actions for persons belonging to groups at risk of intersectional discrimination, as provided for by both the Racial Equality Directive and Employment Equality Directive. To do so, they should: accommodate the needs of women belonging to ethnic minorities who wish to be treated by female healthcare professionals; fund community-based mobile outreach programmes targeting different ethnic communities and groups among them – including older people, women and persons with a variety of disabilities – to promote healthcare and raise awareness of entitlements and available health services; and allocate more time for medical consultations with persons belonging to these groups due to their special needs.

4

Experiences and practices of discrimination

This chapter presents and analyses the main experiences and practices of perceived discrimination identified by healthcare professionals and healthcare service users in the five EU Member States selected. The first section summarises healthcare professionals' and healthcare service users' awareness of discrimination in the healthcare sector. The second section describes the main forms of allegedly discriminatory practices emerging from the interviews and explores how they relate to patients' rights described in chapter two. Experiences of perceived discrimination and multiple discrimination are grouped into six categories: delay of treatment; refusal of treatment; lack of dignity and stereotyping; malpractice and poor quality of care; lack of informed consent; and harassment. The third and concluding section summarises the main results of the chapter.

4.1. Awareness of discrimination

This research shows that the term multiple and intersectional discrimination in healthcare is generally not familiar to either providers or users of healthcare services, both of whom were reluctant to define experiences, treatment, attitudes or behaviours as acts of alleged discrimination. Users generally qualified treatment or attitudes as unfair or disrespectful. Providers, in contrast, mentioned attitudes or behaviours as problematic or stereotyping, and acknowledged and identified indirect discrimination more readily than direct discrimination.

Several healthcare providers in each of the EU Member States studied were reluctant to talk about the existence of discrimination in the healthcare sector, emphasising the universalism of healthcare associated with the Hippocratic Oath. They felt that discrimination is not generally a problem because this universalism commits them to treating everyone on the basis of their health problems irrespective of other characteristics. Some healthcare users also cast doubt on whether discrimination is a problem in the sector. Other professionals argued that discrimination within the healthcare sector is not as much of a problem as it is in the labour market, the housing sector or social services. Several providers talked about health inequalities related to social determinants of health and socio-economic inequalities that affect ethnic minorities:

> *"The bigger problem regards the social aspects. Recently I read some publications that discuss the situation of the second, the third generation in terms of education, labour market opportunities, etc. In these areas there are massive problems. And it is beyond doubt that such a situation influences your health in a negative way."*
>
> *(Cardiologist, male, Austria)*

While healthcare providers and users rarely used the term multiple discrimination, many specifically highlighted the issue, describing situations in which multiple identities left certain groups of persons particularly vulnerable when accessing healthcare. Notably, this awareness also extended to the policy level in Sweden and the United Kingdom, where a legal expert for the National Health Service commented:

> *"It is not because of one or the other [discrimination grounds] but because of the whole package. Sometimes when a visible difference [e.g. skin colour or disability] is more evident, it tends to be targeted whereas something like sexuality may not be apparent."*
>
> *(Legal expert equality, male, migrant/ethnic background, United Kingdom)*

Other providers suggested that certain individuals – such as older ethnic minority women, disabled migrant women or homeless Roma – are particularly disadvantaged because of their multiple identities and/or socio-economic position. One gynaecologist in Sweden emphasised that women in general face more difficulties than men and that the combination of sex and disability, sex and ethnicity or sex and age particularly disadvantages women at the intersection of these positions. Other providers noted that discrimination on one ground adds to discrimination on another ground to create an added burden, an understanding of multiple discrimination known as 'additive'. A gynaecologist in Italy commented:

"The elderly are discriminated against, the disabled are discriminated against: if you put this together with the fact of being foreigner, [...] two plus two makes four."

(Gynaecologist, female, Italy)

In addition, several health professionals and policy makers associated multiple discrimination in healthcare with the extent to which an individual diverges from the 'norm'. A Czech health professional explained, for example, how multiple discrimination affects Roma when accessing healthcare services:

"Of course, when a decent Roma person comes, he is treated a little worse than a decent white person. But when a Roma person comes, drunk and homeless and maybe even a junkie, then, yes, I think the treatment is quite different. So, after all, yes, I think multiple discrimination exists. And it seems that everything is defined by the extent to which the other person is different from me."

(Internist, male, Czech Republic)

Though health professionals might be aware of and understand the principle of multiple and intersectional discrimination, this is not the same as recognising how the vulnerabilities interact or knowing how to counteract them in practice:

"The stereotype of the black woman in the wheelchair may be acknowledged but nobody knows how to deal with these multiple vulnerabilities."

(Policy maker, male, migrant/ethnic background, United Kingdom)

Similarly, a psychologist in Italy reflected on how the inability of services to recognise and take into account a person's various identities results in a process that simplifies a person's needs to only one feature, often the most problematic. A policy maker in the United Kingdom also attributed the challenges in addressing multiple and intersectional discrimination to a superficial understanding of the issues involved:

"Staff and policy makers understand multiple discrimination at a very shallow level. They try to deal with it efficiently, but they don't understand the complexity and don't know how to deal with it. It takes time to understand the complexity and being driven by economics and short-term goals it doesn't get addressed."

(Policy maker, male, migrant/ethnic background, United Kingdom)

More generally, national and local policy makers in Italy, Sweden and the United Kingdom mentioned that healthcare services often fail to meet the needs of people with multiple vulnerabilities because healthcare specialists frequently work independently and thus lack of an overview of the patient's needs and treatments.

The research finds that people have a wide range of views on the discrimination concept. Healthcare users' typically framed their awareness of discrimination within a discourse of unfairness. They generally referred to experiences of perceived discrimination as incidents that made them feel they were treated 'unfairly', 'harshly', 'indifferently' or 'disrespectfully'. The exception is women of reproductive age in Sweden and the United Kingdom, who most explicitly define their experiences of unfair treatment as discrimination.

The greatest recognition of discrimination on multiple grounds (sex and ethnicity; sex and disability; sex, age and ethnicity; sex, ethnicity and religion) was among women in Sweden, although healthcare users from the Czech Republic, Italy and the United Kingdom also said they felt discriminated against on the basis of multiple characteristics:

"[...] I think it was easier for her [the doctor] to behave like that when there was a woman sitting in front of her and because I am young. [...] So I think it would be a little more difficult for her to behave the same way when it comes to an older person and additionally a man. I think she [the doctor] has that attitude towards female migrants."

(Healthcare user, female, migrant/ethnic background, Sweden)

"It could be because I'm Asian, I'm timid, and I am a small woman as well. [...] There's a lot of ways that people are discriminated against, especially with my son [...] because he's got a label – he's autistic, that is negative for him and because he's Asian, that is negative for him."

(Mother of healthcare user, female, migrant/ethnic background, United Kingdom)

While women and older people mention ethnicity or migration status as the most common single ground for perceived unfair treatment, persons with intellectual disabilities point to disability. One theme emerging from the interviews with persons with intellectual disabilities is that, particularly where people are unable to verbalise alleged acts discrimination, their personal assistant and/or carer plays a key role in detecting such experiences.

Integration in general and the time the user had lived in the EU Member State were also linked to discrimination awareness. In the Swedish and United Kingdom samples, where one third and one quarter, respectively, of the women of reproductive age interviewed are second-generation migrants, there was a greater awareness of discrimination than in the samples of the other EU Member States where most women were first-generation migrants. Older migrants also showed greater awareness of discrimination. An older East African man in Italy entitled to all healthcare services referred to several episodes of perceived discrimination, including one where doctors tried to move him to a private hospital, a decision he attributed to his skin colour.

When looking at the triggers of unequal treatment or discrimination in healthcare, providers related discrimination to routines and stereotyping. They also linked it to providers' unwillingness to listen to a patient or to providers pretending not to understand a patient because of his or her origin, name, language, looks, behaviour or previous experiences:

"I mean there are people who do not want to understand if someone comes up to you and asks something in very broken Swedish, despite the fact that you can actually hear what they are saying, but they say it wrong, use the wrong words or something, who discriminate in that way. I don't understand what you are saying. You have to bring someone along who can explain what you are saying."

(Nurse, female, Sweden)

Another nurse in Sweden working in a nursing home for older people points to the fact that discrimination can be difficult to detect in healthcare as patients are often treated one-to-one and there are no witnesses to what happens. Although this research focused on discrimination of healthcare users, health providers in Sweden and advocacy groups in the United Kingdom noted that discrimination can take place in the other direction: health providers sometimes feel discriminated against or unequally treated by healthcare users:

"Many older people came from a culture where racism was acceptable, or at least more acceptable and common than it is today. Most care assistants (and many doctors and nurses) are not white. There is a difficult issue when a dependent older person, particularly one who is suffering from disinhibition through dementia, is racist. There is a duty to protect staff and a duty to support these vulnerable older people. This is a tension which is difficult to resolve."

(NGO, female, United Kingdom)

To take into account all possible discriminatory behaviours, healthcare systems must adopt a structural and organisational approach to discrimination.

4.2. Experiences of discrimination

This section discusses and analyses the six main practices of perceived discrimination in the healthcare sector detected in the interviews with health professionals and health service users in the five EU Member States studied, including delay of treatment; refusal of treatment; lack of dignity and stereotyping; malpractice and poor quality of care; lack of informed consent; and harassment.

These negative experiences affect future healthcare use and have important consequences which will continue to exacerbate racial and ethnic health disparities.

4.2.1. Delay of treatment

Charter of Fundamental Rights of the European Union

Article 21 – Non-discrimination

1. Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.

2. Within the scope of application of the Treaties and without prejudice to any of their specific provisions, any discrimination on grounds of nationality shall be prohibited.

Healthcare users and professionals in all five counties mentioned cases of delays in receiving treatment, which was often perceived to affect specific groups and not others. While the experiences varied, the main theme that emerged was long waiting times due to unequal treatment on different grounds at doctors' surgeries, in hospitals or when receiving emergency treatment. Several respondents felt that the delay was linked to a combination of their characteristics, particularly ethnicity and disability. Others focused on a single ground which they identified as prompting unequal treatment.

A number of cases concerned disparate waiting times for different patients. A Roma woman in the Czech Republic mentioned a typical example, describing how she and her grandson were made to wait while another woman was seen first, a delay which was due, she felt, to her being Roma.

Other healthcare users described similar experiences. A Somali woman in the United Kingdom mentioned an occasion when she was waiting to be seen by the doctor and they failed to call her for her appointment. When she asked why others had been called before her she was given a number of different reasons which left her feeling 'discriminated [against]', 'put off' and 'left out' and ultimately not willing to seek healthcare there any longer.

"The time that I feel that I was discriminated against was at an appointment. I had an appointment and I came for the appointment. I was waiting in the waiting area, expected to be called next, while other people went in. […] So I felt left out. […] When I asked the reception, […] the lady told me you are next in the queue, but when the doctor came in he called someone else and when I asked them they said they're running late. […] So that kind of a thing puts you off – puts you off to look for somewhere else, if you have the money."

(Healthcare user, female, migrant/ethnic background, United Kingdom)

When considering the reasons for delays in treatment, the carer of a young person with intellectual disabilities in the United Kingdom felt that it could relate to her ethnicity as well as to difficulties in communicating the pain she feels:

"You have to be insistent to get to the bottom of the problem. They [health professionals] never ever listen to you. You have to keep on repeatedly taking them [children with intellectual disabilities] back to the doctors. And even getting an appointment is not easy."

(Mother of healthcare user, female, migrant/ethnic background, United Kingdom)

However, she also attributed delays in getting a diagnosis to cultural factors linked to her African-Indian background:

"Our culture doesn't allow us to be rude, we [have] to be very patient […] because we're not insistent and don't have the habit of […] being, you know, on their backs. We feel that if a professional has given us an answer that means they are right but as a mother's instinct and a carer's instinct you always feel something."

(Healthcare user, female, migrant/ethnic background, United Kingdom)

A middle-aged African man in Italy said that, to get the nurse at reception to assist him, he must first get annoyed.

"When you go to ask, there is a woman who takes a number before you are seen [by the doctor]. When you go and ask, and you are black, she tells you that it is not the right time. It's no longer the time to pull a number. At the same time, Italians (pass ahead). When they arrive, she gives them a number, but when it's you, she doesn't give it to you. […] It's only when you get annoyed […]. She speaks to you, she goes and checks some things, and then she tells you 'OK, you can come back. […]' You see?"

(Healthcare user, male, migrant/ethnic background, Italy)

Healthcare providers also reflected on preferential treatment of particular groups regarding waiting times. A cardiac specialist in Austria explained that he was not sure who he would choose if he had the option of picking a patient with a typical German name or one with a foreign-sounding name.

"It is true that it happens from time to time that the last ones to wait have names such as 'Said' or 'Yilmaz'. That is true, but there are many reasons [such as communication issues and interaction] for this situation and it is not primarily a question of discrimination, although it is clear that one should always reflect whether on a latent level such a thing still exists. If I could choose between Mr Hofer and Mr Yilmaz, I am not sure, or I am sure, who is chosen first."

(Cardiac, male, Austria)

Interviewees also described delays in treatment following the initial contact with healthcare providers, including in emergency situations. A visually impaired migrant woman in Sweden described how she felt discriminated against on multiple grounds after the delivery of her son in 2006. After the birth, she was told that she would have a suturing operation at noon but instead had to wait with a severe open wound for more than 10 hours. Though she has since had an operation to correct the injury, she still has pain and suffers from faecal incontinence. She asked for her operation journals to see how the operation unfolded but the hospital said it had lost hers. She attributes these events to a combination of her migrant background and the fact that she was visually impaired.

"[…] I didn't know what had happened and I was very upset. […] They explained a little bit but that didn't help. Then I waited very long. […] I think [the treatment was delayed] because I was a migrant and I was visually impaired […]."

(Healthcare user, female, migrant/ethnic background, Sweden)

In more general terms, interviews in the Czech Republic and Italy indicate that the priority assigned to medical cases and their position in waiting lists, as well as the quality of communication and treatment, is linked to socio-economic status and the quality of social networks to which one has access, both in and outside the health service. If a powerful or well-placed actor within the service takes a pronounced interest in a service user, then preferential treatment is expected, and often obtained. Respondents often said that an academic title or a prestigious job calls forth more obliging behaviour on the part of both physicians and paramedics. While this affects all healthcare users, it may have a disproportionate effect on migrants who are less likely to have the relevant social contacts or to be employed in highly regarded professions. Such behaviour may also imply multiple discrimination, where the socio-economic condition of the healthcare user interacts with cultural stereotypes.

4.2.2. Refusal of treatment

Convention on Human Rights and Biomedicine

Article 3 – Equitable access to healthcare

Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to healthcare of appropriate quality.

Refusal of treatment often has certain distinctive national traits and thus has different expressions depending on the country-specific context. Nevertheless, the interviews with healthcare users and providers revealed a number of common themes. Respondents identified organisational factors including discriminatory elements of healthcare systems, the alleged refusal to register patients with a migrant background and perceived discrimination on the basis of legal status. They also described discriminatory behaviour on the part of individual healthcare professionals, including refusal of emergency treatment, being advised to return to their country of origin for treatment, false association of symptoms with pre-existing impairments and cultural stereotyping. Refusal of treatment is a complex process, which often results from the intersection of different forms of perceived direct and indirect discrimination, stereotyping and barriers. As such, the examples described in this section should be considered in conjunction with the discussion of barriers presented in the previous chapter as well as with the experiences of alleged humiliating treatment and stereotyping presented in the following section.

Refusal of treatment is often interwoven with how the social insurance system and the application procedures connected to healthcare entitlements are constructed. In Austria, a job trainer pointed to discrimination of young migrants in the system of minimum social protection. Applications by young migrants are more easily rejected than those of non-migrant applicants or granted for shorter periods, in his experience. He said that he had two clients with a similar degree of intellectual disability and the native Austrian client was granted protection for five years, while the migrant client received eligibility for just one year. Shorter eligibility entitlements increase the risk of exclusion from healthcare. In one case, the former counsellor of a young interviewee with an intellectual disability and migrant origin forgot to renew the application when his eligibility expired after one year. The Social Services Department thus cancelled the young interviewee's health insurance and he went without for six months. When he fell ill during this period, he had to go to a hospital that treats persons without insurance.

Respondents in the Czech Republic and the United Kingdom described general practitioners and specialists refusing patients, usually on the basis of full capacity. In the Czech Republic, this practice affects both the Roma population and regularly resident migrants with public health insurance. A Czech paediatrician explained how she referred a Roma family to a dentist who then allegedly refused to treat them:

> *"For example, I was recently involved in a problem of a Roma family, a mother with five children who could not find a dentist for her children. I told her that her children must see the dentist […] and she said she called there and that they did not want to see her. So I called [the] dentist [because I know she is] still accepting more patients. I spoke with her nurse and she confirmed this. The second day that colleague calls me back and scolds me, telling me never to do that again. Colleagues refuse to take those patients, to register them, so they go somewhere else, this is how we get too many patients because nobody wants them."*
>
> *(Healthcare professional, female, Czech Republic)*

An NGO representative working for Roma women, who is herself Roma, also described suffering ethnic discrimination at the hands of a dentist who refused to treat her:

> *"I went to see a dentist, who refused to see me. I asked why? Is it because I am Roma? They said, 'Yes'."*
>
> *(Policy maker, female, migrant/ethnic background, Czech Republic)*

A young migrant woman from Eastern Europe explained that she was refused healthcare because she was a 'foreigner', although she is a public health insurance holder.

> *"The first problem was that doctors didn't want to treat a foreigner. They weren't interested in the fact that I was employed in a regular job and that I had standard health insurance. They said, 'No, not foreigners!'"*
>
> *(Healthcare user, female, migrant/ethnic background, Czech Republic)*

A gynaecologist asked a pregnant woman to make co-payments for healthcare upfront in order to get treatment:

> *"I started bleeding and I didn't know why, so me and my husband went to a hospital in Prague at one o'clock at night and the doctor, a gynaecologist, did not respond to us and then, at one o'clock at night, she asked us to pay upfront. We paid about ten thousand crowns, if we hadn't paid, she wouldn't even have wanted to check what my problem was."*
>
> *(Healthcare user, female, migrant/ethnic background, Czech Republic)*

Refusal of treatment is often justified on the basis of full capacity. Under Czech law,[230] patients have the right to choose a physician but the physician may refuse to

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[230] Czech Republic, Act No. 48/1997 Coll, Section 11 on public health insurance, which concerns new patients' registration.

accept them on the grounds of full capacity. In addition, the Czech Medical Chamber code of conduct stipulates that a physician has the right to refuse healthcare for professional reasons, for excessive workload or if convinced that a necessary relationship of doctor-patient trust has not been established.[231] Though doctors who refuse treatment are supposed to recommend other doctors and ensure that the patient receives proper treatment by other providers, healthcare users as well as NGO representatives working for migrants in the Czech Republic mention that this rarely happens.

Lawyers and health professionals in the United Kingdom described how General Practitioners or hospitals often refuse migrants and especially asylum seekers' treatment because of confusion over eligibility rules and lack of appropriate documents. There are no eligibility criteria for access to primary healthcare in the United Kingdom: immigration status is irrelevant when registering with family doctors.[232] GPs can refuse to register someone on reasonable grounds, such as a patient living outside their catchment area or if their list is closed, but they cannot discriminate because of such issues as health status, race, sex, sexual orientation or social class. These cases are often dealt with through discrimination law and end up in settlements, as explained by a solicitor interviewed in the United Kingdom:

> *"I specialise in the denial of healthcare to people because of their immigration status and pretty much all of my cases settle. […] The discrimination cases all settle because they are quite strong. [Interviewer: So in a sense you would say if you pursue the discrimination claim it's because it is a very strong claim.] [Interviewee:] Yes, and the opponent doesn't want to fight it. […] I have had many, many cases where people [migrants] have been turned away by GPs, that is a clear and obvious discrimination, as there are no eligibility rules for primary care based on immigration status. They are told they can't register because they don't have the right papers or so on. So we threaten court action and they always back down."*
>
> *(Legal expert (health/equality law), male, United Kingdom)*

A healthcare worker with the Refugee Council explains that healthcare users might be refused registration because of a lack of appropriate documentation:

> *"The main barrier we encounter here is people being refused access for registration. […] So you are expected to have a passport, proof of identification, proof of address when registering for a GP. The bulk of clients do not have these documents."*
>
> *(Healthcare professional, female, migrant/ethnic background, United Kingdom)*

Moreover, practice managers and surgery staff often feel pressurised by immigration authorities to check the status of patients who might have overstayed their visas:

> *"West Africans are particularly discriminated against, being asked for passports because UK Borders Agency were contacting GPs and they were getting worried."*
>
> *(Health advisor advocacy organisation, female, migrant/ethnic background, United Kingdom)*

Immigration status is irrelevant for access to secondary healthcare, but here, too, people can be refused access due to healthcare providers' confusion over eligibility rules:

> *"[…] some health professionals don't know the difference between asylum seekers and refugees and economic migrants and without clear knowledge about the definitions some people can be refused or accused of not being entitled to healthcare."*
>
> *(Health visitor, female, migrant/ethnic background, United Kingdom)*

Healthcare providers in Austria also raised refusal of treatment due to legal status. They mentioned the vulnerability of asylums seekers with psychosocial problems, with external assessors in asylum cases sometimes ignoring asylum seekers' experiences of trauma, according to the deputy head of a healthcare centre for women and girls in Austria. Identifying experiences of trauma is crucial both for the asylum application and for access to psychological support, where available.

An Austrian social worker who regularly accompanies Muslim refugee women to public health services mentioned another case which concerned a refugee woman with intellectual disabilities who was verbally denied her right to asylum and refused specialist medical treatment by a neurologist because she did not speaking German. Learning German was challenging due to her disability and depression. The neurologist claimed that it would be better if she went back to Afghanistan, where she might recover more quickly.

Aside from organisational factors, many respondents described perceived discriminatory behaviour by individual healthcare professionals which had resulted in their being refused treatment. These examples, which often concern individuals who share a number of protected characteristics, endanger the health and well-being of the healthcare users and are examples of violations of patients' rights to care and treatment.

In the context of emergency care, a hospital doctor in Italy described the treatment a young black Swiss citizen received when he went to the accident and emergency department at a central hospital. After staff

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[231] Czech Republic, Czech Medical Chamber Code (*Etický kodex české lékařské komory*), Section 2, available at: www.lkcr.cz/doc/cms_library/10_sp_c_10_eticky_kodex-100217.pdf.

[232] UK, NHS Regulations 2004, para. 17, Schedule 6 and para. 16, Schedule 5.

members turned him away, he was put in contact with a 'migrant-friendly' public healthcare facility, where he received treatment for an infected foot wound.

"I was waiting for this Swiss patient to arrive and I thought 'Swiss, he must be tall and blond'. Instead, a guy comes who looks like someone Senegalese, with very dark skin. He had a wounded foot. We treated him. [...] What had happened when he first went to hospital was that he had been ill-treated because they thought he was African. [...] The patient said that he had been told to go back to his country."

(Internist, male, Italy)

The same doctor also mentioned a case of lack of emergency treatment of a Somali woman in a hospital in Naples that allegedly resulted in her death. The woman was left on a stretcher for more than 48 hours in a corner of the hospital courtyard. Medical staff at the emergency ward had apparently determined that she was drunk, although a proper medical examination was not carried out. After the woman started vomiting blood, she was brought to the operating theatre, where she died. A high-profile criminal lawyer in Naples has taken up a legal case.

Roma respondents in the Czech Republic specifically linked emergency ambulances and the refusal of treatment. This primarily concerns Roma living in marginalised communities or socially excluded parts of towns and villages, which emergency services vehicles refuse to enter, citing fear for their physicians' or paramedics' security.

"We even had a recent case where a physician did not respond to an emergency call coming from a certain location, and they had to arrange his transport in quite a complicated way. Of course, even worse cases happen, such as the one of a lady in labour. She called an ambulance but they refused to come to her area. And unfortunately I have to say that in most cases this concerns very poor families without a car to use to take the mother to the hospital."

(Social worker, male, migrant/ethnic background, Czech Republic)

An interviewee from Turkey gave another example of alleged refusal of treatment. Her family doctor referred her to a hospital specialist. A friends' daughter accompanied her to the appointment with the specialist to interpret for her as she could not speak German. The appointment had to do with a hip operation for the interviewee, but the doctors told her that this was not possible due to problems with her spine. When the friend's daughter clarified that they were there for the interviewee's hip not spine, the doctors did not accept this explanation and sent them away. The family doctor then recommended that the couple go to Turkey and have the surgery done there to avoiding misunderstandings and complications in Austria.

A Roma healthcare user with intellectual disabilities in the Czech Republic reported receiving only superficial medical treatment:

"When treating my Achilles tendon the doctor told the nurse to just patch me up, so that it just looked ok and to kick me out."

(Healthcare user, male, migrant/ethnic background, Czech Republic)

In another case, a doctor in accident and emergency verbally attacked him and said: "Who do you think you are, you gypsy?".

Respondents also described situations where health professionals ignored medical symptoms because they were seen as part of someone's disability, resulting in lack of treatment. Persons with intellectual disabilities in Sweden and the United Kingdom identified accusations of feigning illness and the association of intellectual or psycho-social disability with somatic health issues as a particular problem. A healthcare user from the United Kingdom, for example, described how doctors said she was "faking it" when she complained about post-operative pain, while another English-Bengali young woman mentioned that a health centre physician did not take her complaints seriously and accused her of faking pain. Other healthcare users explained that they had been treated unfairly and not received the treatment they required, often because doctors did not believe their descriptions of pain:

"I used to have a doctor, I always used to visit her and say that I have had a stomach ache. She did not believe me, and then she said: 'Well, you can write this down in a diary instead.' [...] So every time I went to her and explained that it hurts, she did not believe me."

(Healthcare user, female, migrant/ethnic background, Sweden)

One young Iraqi woman in Sweden suffered complications from a car accident but did not receive any rehabilitative treatment. She was told instead that her problems walking were psychological:

"[The health professionals] said it was mental. [...] That I thought was very ugly, to sort of put it at a mental level. That you [get a] mental explanation to something when you say: 'I cannot walk, can I have physiotherapy because I cannot, like, move.' [...] That I think is discrimination."

(Healthcare user, female, migrant/ethnic background, Sweden)

This experience left her with the view that one needs to be very demanding and in good health to exercise patients' rights in the Swedish healthcare system. Swedish healthcare providers and representatives of advocacy groups reinforced this perception, with several saying that the more established and demanding you are, the more you are ensured care and treatment.

Perceived discrimination and stereotypes resulting in the refusal of treatment were highlighted specifically in the context of disability-, ethnicity- and age-based discrimination. One healthcare user in the United Kingdom mentioned a case of alleged discrimination within minorities: she described changing her GP surgery four years earlier because she had had difficulties getting appointments and the practice had treated her with a lack of courtesy and support – treatment she attributed to the stigma attached to disability in some South Asian communities:

> *"The GPs just wouldn't listen, the doctors were all Indian, but because of the stigma of disability they didn't treat me well. [...] Disability is not really there in our culture, so, yes, they wouldn't treat me and did think of me as different."*
>
> *(Healthcare user, female, migrant/ethnic background, United Kingdom)*

However, she believes attitudes towards disability are evolving:

> *"Now I think the new generation has changed, people's attitudes are changing. With my new doctors it's really good. [...] My new doctors are very supportive. If I'm not well [...] my mum calls them and we get an appointment straight away, whereas before we couldn't ever get an appointment. At the new surgery they understand what I've got whereas in the old surgery they hardly even talked to me: When I went I never got proper treatment and normally they would talk to my mum."*
>
> *(Healthcare user, female, migrant/ethnic background, United Kingdom)*

A young, second-generation Turkish woman in Sweden described being refused treatment for a backache. Not only did the centre refuse treatment because she was not registered there, the doctor mocked her with gestures associated with stereotyping how particular groups of immigrants in Stockholm speak.

> *"Her attitude was like this that I said 'I am very much in pain' and then she mimicked me and said 'but you say you are in so much pain' in that way [like some groups of migrants in Stockholm speak]."*
>
> *(Healthcare user, female migrant/ethnic background, Sweden)*

Another issue mentioned in the interviews with health professionals in both Sweden and the United Kingdom concerns the cultural stereotype of migrants primarily from non-European countries as taking care of their own relatives, which is sometimes used as a rationale for denying older migrants their right to social care services. In Sweden, one representative of an advocacy group working for Africans mentioned a case of an older Somali woman who had been denied home help services because she had children and grandchildren who could assist her. This might constitutes direct discrimination as Swedish social laws do not take into account the existence of children and grandchildren in older people's right to help and support.

4.2.3. Lack of dignity and stereotyping

Charter of Fundamental Rights of the European Union

Article 1 – Human dignity

Human dignity is inviolable. It must be respected and protected.

More than any other form of discriminatory practice, healthcare users in all five EU Member States studied emphasised that they frequently felt they received undignified treatment when meeting, communicating and interacting with healthcare providers. This can take many forms, including those associated with insufficient communication and the absence of trust between healthcare users and providers and providers' stereotyping of healthcare users. These phenomena are often closely interrelated: the lack of thorough explanation of a health issue and potential treatment options can result in treatment experienced as lacking respect, while stereotypes based on ethnic, religious, migration or disability grounds can result in a lack of dignity. Undignified treatment was described most commonly by four groups of respondents: Muslim women, persons with disabilities, older people and women from migrant or ethnic minorities seeking reproductive care. These cases indicate that treatment perceived as lacking dignity occurred at the intersection of discrimination on different grounds.

Stereotypes, whether based on culture, sex, age, ethnicity, migrant background, religion or any other characteristic, can lead to unequal treatment of different groups of healthcare users. While health professionals' perceptions of particular groups change according to country-specific stereotypes, there are some recurrent stereotypes that this research found across all the EU Member States reviewed. These include those related to: appearance, particularly of Muslim women; disability; feigning illness, specifically among older people and persons with disabilities; cultural stereotypes and the association of migrant or ethnic minorities with HIV/AIDS.

Muslim women reported what they perceived as discriminatory experiences in four of the five EU Member States in this study, often associated with wearing a headscarf. They frequently specifically linked this treatment to the intersection of their sex and their religion or ethnicity, with age also mentioned as a factor. An Indian woman in the United Kingdom who felt her surgery was not properly followed up suggested that appearance, and particularly cultural or religious markers, make staff assume particular behaviours towards her:

"I think that I would have been better treated if I wasn't a Muslim and wearing a hijab. If I was a man or maybe younger or, you know, not wearing a hijab or niqab, maybe I would have been treated differently, I felt. I really felt let down."

(Healthcare user, female, migrant/ethnic background, United Kingdom)

Language difficulties can further exacerbate alleged discrimination associated with stereotypes of Muslim women, as described by interviewees in Austria:

"Austrians always pay attention if you dress yourself in a proper way or not, if you take the headscarf or not and if you know the German language or not. Then they behave differently."

(Healthcare user, female, migrant/ethnic background, Austria)

"If someone does not understand the second word, the doctor does not repeat it, but shouts or gets angry: 'Why can't you (understand)? You have to learn German! You are here, you are in Austria, you have to learn German!' [...] I wished the doctors would collaborate, that they would encourage the patients and not say such things that make the patients run away and never come back. And also because of the headscarf [...] I [ask] the doctors: 'Please do not say anything bad because of the headscarf!', or not assume it. If they see a headscarf or other clothing, then they do not examine closely or are not friendly with this woman. [...] I have noticed, if I go somewhere with a headscarf-woman and then I go there with a woman without headscarf, I have always noticed a difference."

(Social worker, female, migrant/ethnic background, Austria)

Stereotypes associated with disability were also identified as resulting in treatment that was felt to be disrespectful. The cases of perceived discrimination described by interviewees often cut across several grounds. Interviews with Roma healthcare users with psycho-social problems indicated undignified treatment in healthcare:

"Well, the family doctor sometimes has a strange look and sometimes does not behave entirely as he probably should when treating those patients."

(Healthcare user, male, migrant/ethnic background, Czech Republic)

People with intellectual disabilities in the United Kingdom claimed medical staff ignored them, left them unattended and neglected and that carers were expected to deal with their needs. One interviewee indicated that healthcare staff directed their attention towards the carer or family member:

"Why talk to the carer? She's not the one who is sick. [...] They have to talk to me, because you're the one, they have to, because the doctor told me to talk – the main thing is they do talk to me now."

(Healthcare user, female, migrant/ethnic background, United Kingdom)

Two healthcare users with intellectual disabilities also reported unfriendly and undignified treatment. A woman described asking for help from a nurse:

"I was sick and asking for a bowl and she said: 'Get it yourself'. She [the nurse] was really rude to me. My brother had told them I have a disability but she still just said: 'Get up and do it yourself'. [...] They pushed me really hard: they told me to go to the toilet myself, wash myself. I couldn't even get up, I was crying and they just ignored me."

(Healthcare user, female, migrant/ethnic background, United Kingdom)

In Austria, the Czech Republic and Sweden, respondents reported that older people and persons with disabilities with a migrant or ethnic minority background are often accused of feigning their problems in order to get benefits and also face unfair medical assessments for pension and invalidity claims. One doctor in Austria mentioned the situation of older migrants and former guest workers who face difficulties in receiving early retirement or disability pensions due to misunderstandings, their inability to explain their health problems and the stereotypes of health professionals who label them as unwilling to work.

"If people are applying for invalidity pension, a premature pension, it is often the case that there are barriers and also misunderstandings and the people are very often not able to objectivise their health problems and to display them. If in the examinations no pathologies are found, these people are simply labelled as unwilling to work. This is something I have seen various times and of course is related to misunderstandings, because these people cannot express themselves and this leads to the fact that these people are seen as unwilling to work and thus much is refused."

(Family doctor, male, migrant/ethnic background, Austria)

An older Turkish man with psycho-social disabilities reported that a psychiatrist he saw for many years accused him of feigning his health problems in order to receive a disability pension. He would have taken further steps if he had spoken German better.

"I said to him that he was a xenophobe; I phrased it just like that. If there had been a native Austrian in my place you wouldn't have treated her/him this way and talked to her/him like that. A native Austrian would have known how to deal with the situation and how to talk to you. As I am not able to talk in German my answers won't be sufficient. I may only express my answers through my behaviour, by showing you my anger. Of course, this might not satisfy you, but you are xenophobic."

(Healthcare user, male, migrant/ethnic background, Austria)

This case exemplifies how language difficulties can increase feelings of being misunderstood and not being treated with respect.

An older migrant woman in Sweden described how she once sought treatment from a doctor who assumed that what she really wanted was sick leave from work. The doctor's attitude left her feeling angry and ashamed. Similarly, a Roma woman in the Czech Republic mentioned that a doctor accused her of causing her own health problems to get sick leave benefits:

"The doctor told me that I was causing this [illness] by eating something bad and then I run to the doctor. [...] She said, basically, that she doesn't believe me and that I should go [back] to work. [...] I felt that [...] [she did it] because I was Roma and [because she thought] I wanted to avoid going to work."

(Healthcare user, female, migrant/ethnic background, Czech Republic)

Some older healthcare users and persons with disabilities in Austria confirmed this form of stereotyping. One woman recalled a doctor beginning the appointment by turning to the interpreter and saying:

"Please ask the lady why she does not want to work?"

(Healthcare user, female, migrant/ethnic background, Austria)

Women with an immigrant background in Austria, the Czech Republic and Italy and Roma women in the Czech Republic reported several incidents related to giving birth. In the Czech Republic both women from post-Soviet states and Roma women felt disrespectfully treated, describing medical staff as condescending, rude and insulting.

"When I was screaming with pain, those nurses [said]: 'If you have made it so far, you will manage everything and shut up.'"

(Healthcare user, female, migrant/ethnic background, Czech Republic)

One Russian woman described how staff failed to examine her when she arrived at hospital with labour pains. Instead, she was instead locked in a room with three other women and told to keep quiet. When she managed to get a nurse's attention, the nurse got angry and asked what was wrong with her.

In Italy, one Nigerian woman described being abandoned on her bed in hospital when pregnant, given only a basic examination and not offered any painkillers. When she screamed in pain, the nurses shouted at her. She summarised her experience by saying she felt as if she were something disgusting lying on the bed. A Romanian woman in Italy described how a doctor treating a friend found out that her friend's child had Down syndrome.

"When she was told that the child had Down syndrome, then [the doctor] made a gesture as [if that were] something disgusting. The girl took the child in her arms and ran away from the hospital."

(Healthcare user, female, migrant/ethnic background, Italy)

Healthcare users with a migrant background also described stereotypes and stigma leading to the assumption that they are HIV positive, as explained by the lawyer of an Austrian NGO:

"I know most of those [black people] who don't have a job. They are treated by their non-African environment, as being AIDS-patients and being treated with caution. In these countries there is a high rate of AIDS and the majority of the society knows about that. And there is a stigma that is of course causing caution, because one could get infected."

(Legal expert, female, migrant/ethnic background, Austria)

In Italy, this assumption specifically affects migrant women working as sex workers: two health professionals stated that there is reluctance on the part of health professionals to treat them, due to fears of HIV/AIDS infection.

A Sub-Saharan African woman in Italy describes how healthcare staff treats her differently now that she is married to an Italian:

"When I had my second child, and I was in labour, [...] I was going: 'Ah, it hurts, it hurts', and the doctor who was there, who wasn't my [regular] doctor [...] said to me: 'What is it, you're in pain? Why don't you shut up? Have you done a test for AIDS?' [...] As soon as he asked: 'Where is your husband?', I said: 'He has gone to call the doctor'. I said the name [note: the doctor the husband called is powerful and well-known], and as soon as he heard it, he got up and disappeared, so that I couldn't recognise him. The fact of being a foreigner, that is precisely why this happened."

(Healthcare user, female, migrant/ethnic background, Italy)

One theme addressed by many respondents, particularly health professionals, is the risk of 'culturalising' healthcare by projecting stereotypes on different groups of patients based on generalisations. Health stereotypes depersonalise the healthcare user and can result in insensitive remarks and comments by healthcare staff, as explained by one Asian healthcare user in the United Kingdom who overheard comments such as:

"[...] they make such a fuss. [...] Asian people have a low pain threshold. [...] There is nothing really the matter with her."

(Healthcare user, female, migrant/ethnic background, United Kingdom)

An Afro-Caribbean woman working as a nurse in the United Kingdom described a GP's reaction when she asked him about hair on her chin (hirsutism):

"'Yes, Black Caribbean, hirsutism is very common.' I saw this as: 'You're black, you're Caribbean, you put up with it.'"

(Healthcare user, female, migrant/ethnic background, United Kingdom'

Another healthcare user described feeling that she was put in a box marked 'Asian woman' based on assumptions about the causes of her symptoms.

Health professionals' perceptions of how life-style factors impact on patients' health may also result in harsh treatment deriving from multiple discrimination. One Roma woman in the Czech Republic, for example, mentioned that doctors and nurses implied that her family's health issues were her own fault and sometimes refused her help because of this. Another Roma interviewee with psycho-social problems also described being made to feel that his health issues were his fault:

"You did drugs, it is all your fault, your health is your problem and that's it, such treatment."

(Healthcare user, male, migrant/ethnic background, Czech Republic)

4.2.4. Malpractice and poor quality of care

In all five EU Member States, respondents reported alleged maltreatment and/or malpractice that at times involved perceived discrimination. While the experiences described varied widely, they generally shared a number of common features including: incorrect or insufficient medical examinations by healthcare professionals; medical errors or errors in treatment; and incorrect dosages. Many of the reported cases also involved a lack of information and explanation regarding treatment. In most cases, healthcare users reported that providers denied what had occurred and did not admit to mistakes. Many healthcare users who felt maltreated left without any information or explanation of what had happened.

In Sweden and the United Kingdom, interviewees specifically described feeling that the perceived malpractice was the result of discrimination on multiple or intersectional grounds, most notably sex and ethnicity, and ethnic background and disability. For example, one GP in Sweden explained the disadvantages faced by an elderly woman with an ethnic minority background:

"You have the whole spectrum there, then you are sort of at the bottom of the scale. You have to wait for a long time, and a longer wait for the next visit, and there are fewer tests, you receive cheaper medicines, you get a lot of psychological medicines. I mean there are a series of things just because you have precisely this combination of several [characteristics]."

(Family doctor, female, Sweden)

Two Turkish women in Sweden described poor treatment which they associated with intersectional discrimination on the basis of their ethnic background and sex. One woman recalled how, after her condition deteriorated in her condition, a gynaecologist from Turkey informed her that the operation she had to rectify a previous problem had damaged an internal organ. When she gave this information to a doctor in Sweden, she had additional operations, which failed to correct the initial mistake. She is yet to receive detailed information about what happened, and because of the injury cannot manage without a catheter and lives isolated in her apartment.

Several respondents also reported what they identified as malpractice linked to multiple discrimination on the basis of ethnicity and disability status. The director of an advocacy group in the United Kingdom described the situation of a patient with depression whose diabetes was not under control. The interviewee asked the person in charge, who replied: "She's fat and mad, what do you expect me to do?" A nurse in Sweden similarly explained:

"I got the feeling that it was her ethnicity amongst other things plus the fact that she was mentally ill then that was the reason [she did not receive appropriate help from doctors]."

(District nurse, female, Sweden)

Healthcare users in Austria, Italy and Sweden described how they felt they had been refused proper medical treatment due to inadequate examinations, particularly in relation to antenatal care. One pregnant Romanian woman living in Italy described how she went to a hospital gynaecologist to report the sudden lack of movement of her foetus but was not examined. Two days later, she went to a hospital in a nearby city, where she had emergency surgery. The delay in treatment, however, meant that the baby's brain had not received enough oxygen, resulting in permanent damage. Her son has an intellectual disability.

A woman from Eritrea living in Sweden described what she identified as discrimination on the grounds of ethnicity when, after an accident at work, she went to her company's occupational health service. The doctor referred her for a back X-ray but refused one for her knees, although she told the doctor she had hurt both areas. The woman sought private healthcare and after three months saw another doctor who said her knee problems were likely linked to the accident, but that it was too late to prove the connection. Following the incident, the woman went on sick leave for over a year and lost her job.

"Yes, what else can it be [but ethnic discrimination]? I cannot think of anything else but that. He does not know me privately. I have not acted strange against him."

(Healthcare user, female, migrant/ethnic background, Sweden)

Finally, respondents described malpractice relating to incorrect treatment or dosages. The migrant mother of a young man with intellectual disabilities reported that a doctor prescribed an incorrect dosage of medicine for her son. She tried unsuccessfully to get another appointment with the doctor over the next two months to fix the dosage.

"I went to the appointment and told the physician everything. When he saw the prescription he was astonished. He reckoned that the dose of the medication was totally wrong. He called up [the first doctor] immediately and she admitted that she had made a mistake. He had her on the telephone in only a moment whereas I had tried to call her for two months and they had always tried to get rid of me. There was absolutely no chance for me to talk to her."

(Mother of healthcare user, male, migrant/ethnic background, Austria)

4.2.5. Lack of informed consent

Charter of Fundamental Rights of the European Union

Article 3 – Right to integrity of the person

2. In the fields of medicine and biology, the following must be respected in particular:

– the free and informed consent of the person concerned, according to the procedures laid down by law [...]

Informed consent to healthcare is a complex issue involving the intersection of many different rights and healthcare practices. These all entail effective and careful communication: freely giving one's informed consent necessarily requires having been provided with comprehensive information in a format one can fully understand. This subchapter first discusses the lack of adequate communication including insufficient explanations of treatment and the failure to ask for consent; and second, alleged cases of compulsory treatment, where medical interventions are carried out in the absence of consent.

The first aspect of the lack of informed consent concerns the patient's right to be provided with adequate and clear information about his or her health status and possible treatments. This is linked to the right to an explanation appropriate to the patients' capacity to understand, and to the right to translation or interpretation support. Furthermore, according to the right to free choice, everyone must be free to choose among different treatment procedures and providers on the basis of adequate information. Many healthcare users in this research described information as being either too dense and inaccessible, or too poor.

Two Roma women in the Czech Republic recalled being provided with information in a manner they found incomprehensible. They felt that they were expected to understand expert medical terminology and that doctors were not willing to clarify their health issues and treatments in lay terms. Consequently, the women were not always aware of what treatment they were to receive. One woman perceived this unwillingness to explain her health issues as prejudice based on the perception that Roma are not educated and therefore not able to understand and communicate their health problems.

"They treat us like idiots. [They think] why would she need it, here she hears it and she will forget it as soon as she gets out."

(Healthcare user, female, migrant/ethnic background, Czech Republic)

Muslim women in Sweden mentioned that healthcare staff sometimes treat them as if they are illiterate and therefore do not provide them with adequate information or explanations about their health issues. A woman in the United Kingdom said she felt the pharmacist would have been more receptive to her queries about the strength of cholesterol medication had she not been an Asian woman.

Similarly, healthcare users with intellectual disabilities in the Czech Republic and the United Kingdom described not being given important information about their healthcare or it being presented in an inaccessible form. The same concern was reported in the Czech Republic and Italy by health professionals and advocacy groups. This frequently angered healthcare users and undermined their confidence in medical staff.

Another healthcare user in the United Kingdom was taking treatment for an infection without being informed of the full purpose of the medication or how long treatment should last.

In contrast, interviewees with intellectual disabilities from Austria reported positive experiences of doctors explaining the situation in terms they could understand. This was often attributed to their seeking clarification immediately if they did not understand information:

"I tell [the doctor] directly that I don't understand. [Then] he tries to say it more explicitly and that's very nice."

(Healthcare user, female, migrant/ethnic background, Austria)

A young man with intellectual disability from Eastern Europe, when asked what he likes about the Austrian health system, said:

"Austrian doctors really want to help the people and they also talk a lot to their patients. They ask for the people's problems."

(Healthcare user, male, migrant/ethnic background, Austria)

Several healthcare users complained of insufficient communication with health providers not seeking their consent before medical interventions. Most health professionals emphasised the importance of ensuring that consent is requested in their practice. Insufficient communication can be particularly problematic when healthcare users are alone and lack the support of relatives and friends. A Nigerian woman in Italy described an incident she observed concerning an African man who was in the same ward:

"This young man was on his own and didn't understand Italian, he didn't have a clue what was happening. He was just lying there, and they would say to him: 'No, we will operate tomorrow', or 'We will operate the day after tomorrow'. The doctors go over there, but they don't even touch him. I saw that he was crying one day. I asked him 'What's wrong?' He explained in English: 'Look, I have been here for such a long time, they don't even look at me, nobody looks at me, the doctor comes and he doesn't even look, they don't do the operation'."

(Healthcare user, female, migrant/ethnic background, Italy)

For healthcare users with intellectual disabilities, the patient's ability to give their informed consent can be undermined by healthcare professions when they direct information to parents, relatives or carers rather than to the patient themselves, even in situations where there is no formal loss of legal capacity. Several healthcare users in Austria, Sweden and the United Kingdom reported that healthcare personnel addressed their parents rather than them:

"I don't think doctors explain properly and sometimes like before, when I said to anyone here, the doctors don't look at you they look at your carer."

(Healthcare user, female, migrant/ethnic background, United Kingdom)

In some cases, family members also spoke on behalf of the patient:

"My family talk for me, they always talk for me, anything about my problem them talk. My mum would talk over me. She would say 'why you talk to her, she doesn't understand'."

(Healthcare user, female, migrant/ethnic background, United Kingdom)

One of the most serious violations of the right to informed consent is the practice of involuntary treatment. Compulsory treatment can violate several human rights, including the right to dignity and respect, the right to privacy, the right to informed consent and to an explanation and the prohibition of inhuman or degrading treatment.[233]

Respondents raised several allegations of involuntary treatment, including forced sterilisation, forced abortion and forced medical examinations of women with intellectual disabilities and women belonging to ethnic minorities, as well as forcible restraint. The interviews point to a severe imbalance in such cases: on the one hand people who in stressful and worrying situations and may have difficulties expressing themselves and, on the other hand, parents, doctors, and lawyers.

Forced sterilisation or abortion can involve the violation of several human rights encompassed under the umbrella of 'sexual and reproductive rights'[234] and protected in various articles of the Charter of Fundamental Rights of the European Union, including the right to privacy.[235] These practices can cause real damage to the patient's health and also violate the prohibition of torture, inhuman or degrading treatment, protected by Article 3 of the ECHR.[236]

While not covered in-depth here, involuntary treatment is often closely related to legal capacity. One of the cases described here concerns a woman with an intellectual disability and two concern minors, raising important questions about informed consent in cases where the patient's own opinions may not be legally recognised.

The head of the legal department of a disability organisation in Austria described how women with intellectual disabilities are allegedly sterilised at the request of family members.

"We are again and again confronted with the fact that disabled women get sterilised without their consent and partly at the insistence of their relatives, even if this is legally not permitted at all. We have been confronted with a case where a doctor did this at the request of the mother, and afterwards the concerned woman was told she had only undergone navel correction, and where both the doctor and the woman were convinced to have acted in the best of their knowledge, even if this in fact is illegal."

(Legal expert, male, Austria)

In this case, the Medical Chamber was consulted but it has not yet reached a decision.

In contrast, some Roma women interviewed in the Czech Republic struggled to obtain permission for voluntary sterilisation after a number of high-profile legal cases involving forced sterilisation. One reported that the Committee rejected her application for sterilisation after the birth of her fifth child in contravention of national legal standards. She was told sterilisation would be possible after the seventh child, whereas the eligibility criteria

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[233] ECtHR, *Storck v. Germany*, No. 61603/00, 16 June 2005, violation of ECHR Art. 5 (1) and 8; *Shopov v. Bulgaria*, No. 11373/04, 2 September 2010, violation of Art. 5 (1) and 8; *Fyodorov and Fyodorova v. Ukraine*, No. 39229/03, 7 July 2011, violation of Art. 3, 6 (1) and 8; see also FRA (2012b).

[234] "Reproductive rights rest on the recognition of the basic right of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so; Governments should prepare and disseminate accessible information designed to ensure that women and men, particularly young people, can acquire knowledge about their health, especially information on sexuality and reproduction, taking into account the rights of the child to access to information, privacy, confidentiality, respect and informed consent", see: www.unfpa.org/rights/language/right2.htm.

[235] ECtHR, *K.H. and Others v. Slovakia*, No. 32881/04, violation of Art. 6 (1) and 8.

[236] ECtHR, *V.C. v. Slovakia*, No. 18968/07, 8 February 2012, violation of Art. 3 and 8.

set by law is four children, or three if the woman is older than 35, in the absence of health problems.[237]

Several interviewees recalled being pressurised to have an abortion. In the Czech Republic a health insurance company and a doctor recommended two pregnant women have abortions. Abortion was presented as the only solution in their situation:

> *"[T]he doctor said: 'How many weeks?' I am in my eleventh week. 'And where have you been so far? This is too late. The only thing I can offer you is an abortion.'"*
>
> *(Healthcare user, female, migrant/ethnic background, Czech Republic)*

In the United Kingdom, an outreach health worker discussed attempts by family doctors to impose their own set of values or decisions regarding abortion on young unsupported woman from West Africa.

> *"When a young person is pregnant the GP will often want to push them to terminate. I'm not there to make moral judgements or decide – but at a young age – I have to say that I see a lot of young Caribbean and West African members of the population they enter into sexual relations without protection and then when they are pregnant the man goes off […] but GPs they don't always understand."*
>
> *(Family doctor, female, migrant/ethnic background, United Kingdom)*

Experts who work in the field of disability mention similar issues relating to the reproductive rights of women with disabilities. One described a migrant woman whose gynaecologist allegedly forced her into aborting her baby with Down syndrome and said that women with disabilities were not free to choose which gynaecologist to visit.

Respondents also described healthcare users being subjected to forced medical examinations, particularly in the context of reproductive and sexual health. A representative of an advocacy group for Somali women in Sweden described how staff suspected that a young woman had been subjected to FGM. Without asking the mother if that was the case or whether they could perform a vaginal examination, the girl was given a gynaecological examination by medical staff working at the school. The interviewee helped the mother and daughter to report the forced examination to the police but no further action was taken. Under Swedish law, all employees of authorities and agencies are obliged to report any suspicion that a child has been abused or subjected to illegal treatment to the municipalities' social administrative committees. The social administrative committee can initiate an investigation and take legal action to protect a child if there are suspicions that a child is at risk.[238] Initiating an investigation or taking legal action, however, requires solid and reliable information. The Swedish equality ombudsman took to court a similar case involving the forced gynaecological examination of a 10-year-old girl. The district court found that the municipality of Uppsala had discriminated against the family as the family's ethnicity was the only reason for the forced gynaecological examination of the girl.[239]

Aside from reproductive health, a legal expert in Italy reported another example of involuntary treatment. He mentioned the case of an unaccompanied foreign minor who told a police officer when stopped that he was under 18, but he was unable to produce an identity card. He was taken to hospital for a wrist X-ray to determine his age. No written record was kept and no consent was sought or obtained either verbally or in writing although, by law, the police are required to involve an interpreter and a tutor who can represent the minor's interests and obtain written consent before carrying out a medical procedure that has no health benefits. In its Communication on an *Action Plan on Unaccompanied Minors (2010-2014)*,[240] the European Commission highlights that in age assessment procedures "the guardian should be present at all stages of the procedure". The UN High Commissioner for Refugees, the UN Children's Fund and Save the Children recommend that "the procedure, outcome and the consequences of the assessment must be explained to the individual in a language that they understand. The outcome must also be presented in writing".[241] A recent FRA report on unaccompanied asylum-seeking children also recommends that, if medical examinations are considered essential, the child must give his/her informed consent to the procedure after any possible health and legal consequences have been explained in a simple, child-friendly way and in a language that the child understands.[242]

Lastly, several respondents recalled experiences of patients being forcibly restrained and anesthetised for treatment. The mother of a young woman with Down syndrome living in Austria explained how her daughter reacted violently to unpleasant treatment, resulting in several medical staff restraining her:

> *"She screams! If the doctors exactly do what she does not like! Then several people come and hold her and anesthetize her. They have to anesthetize her, because such children are very strong. She screams, she hits the doctors, she bites the nurses."*
>
> *(Mother of healthcare user, female, migrant/ethnic background, Austria)*

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[237] Czech Republic, Ministry of Health, Regulation LP-152.2.-19.11.71, 17 December 1971.

[238] Sweden, Ministry of Health and Social Affairs (2002), Social Services law (*Socialtjänstlag*) (2001:453).

[239] Sweden, Uppsala District Court, *Diskrimineringsombudsmannen v. Uppsala kommun*, case T 4350-07, 20 April 2010, available at: www.do.se/Documents/pdf/forlikningarochdomstolsarenden/dom_uppsala_t4350-07.pdf.

[240] European Commission (2010c).

[241] UNHCR, Unicef and Save the Children (2009).

[242] FRA (2010c).

Moreover, the same mother reported that when receiving dental treatment, her daughter had five teeth removed at once in order to reduce the number of treatment sessions. Whilst Article 25 of the CRPD recognises that medical care of persons with disabilities must be based on their free and informed consent, this case raises questions about how consent can be withheld, particularly by persons who use alternative communication methods. It is also closely linked to the issue of guardianship, and the balance between others making healthcare decisions in the 'best interest' of a patient and an individual's apparent reluctance to undergo particular treatment.

4.2.6. Harassment and privacy interference

Council Directive implementing the principle of equal treatment between men and women in the access to and supply of goods and services

Article 2 – Definitions

For the purposes of this Directive, the following definitions shall apply: […]

(c) harassment: where an unwanted conduct related to the sex of a person occurs with the purpose or effect of violating the dignity of a person and of creating an intimidating, hostile, degrading, humiliating or offensive environment;

(d) sexual harassment: where any form of unwanted physical, verbal, non-verbal or physical conduct of a sexual nature occurs, with the purpose or effect of violating the dignity of a person, in particular when creating an intimidating, hostile, degrading, humiliating or offensive environment.

Although relatively few cases of sexual harassment were reported compared to the other practices described in this chapter, some female interviewees said intrusive questions or what they perceived as healthcare professionals' inappropriate behaviour made them feel uncomfortable.

In Italy, the representative of an advocacy group recounted the experience of an African woman who was called in to see her GP only after all other patients had been seen. The doctor asked her to undress and started making sexual advances, prompting her to leave. She did not, however, make any complaint because she did not believe that any action would be taken against the doctor and was afraid that she would not be believed.

Other respondents indicated that they knew several female immigrants in Naples who had been harassed by healthcare staff. According to one cultural mediator, however, women usually do not report their experiences.

> *"When you send the woman up to the first floor to check in and book an examination, and she comes back in tears after two minutes and says: 'The man who is up there won't let me book and he started coming on to me', then you obviously get annoyed, and you go up there and start shouting at him, and you make a scene so that the others hear you as well […]. But they rarely come and tell you when it happens."*
>
> *(Mediator, male, migrant/ethnic background, Italy)*

As well as constituting discrimination, sexual harassment violates several patients' rights, such as the right to equal care and treatment, the right to dignity, the right to privacy and the right to observance of quality standards.

In Austria, a Turkish woman wearing the veil felt that some male doctors use appointments as an opportunity to exercise their power. She reported an incident when the doctor refused to let her enter his surgery without shaking hands. She felt he had the power to force her because she was on 'his territory'. The woman also reported that a male hospital doctor asked her to undress, although her daughter explained that this made her feel uncomfortable. She asked for a female doctor but was refused.

> *"The doctors said I had to undress. I said I would not because there were two [male] doctors present in the room. One of the doctors then insisted that I had to undress. He said: 'You came to the hospital and now you have to undress.' My daughter, who was with me in the same room asked if there was a female doctor around. The doctor answered: 'No. There is no female doctor; I have to do the examinations. Your mother now has to undress'."*
>
> *(Healthcare user, female, migrant/ethnic background, Austria)*

Moreover, a number of healthcare users said they were made to feel uncomfortable and their privacy invaded by inappropriate questions about their sex lives or reproductive health issues. A social worker in Austria mentioned that gynaecologists often ask the Muslim women she accompanies about the frequency of their pregnancies.

> *"At times at the gynaecologist, this happens at examinations in pregnancy, they ask: 'Why are you pregnant again?', 'Why do you have so many children? Now it's enough for you! You don't need this anymore!'"*
>
> *(Social worker, female, migrant/ethnic background, Austria)*

Several respondents with intellectual disabilities described being asked intrusive questions which were unconnected to their health complaint. One interviewee from Sweden described, for example, going to consult a doctor about a cough and having him ask about her menstrual cycle and when she last had sexual intercourse. She now feels uncomfortable seeing male doctors at her local primary healthcare centre:

"He was like: 'I'm a doctor, I have to know about these things, when did you have your period?' Why? Does this have anything to do with my cough? 'I am a doctor, I need to know. When did you have intercourse?' He asked me that kind of stuff. I said you don't have anything to do with that. He said: 'Yes, I have to ask.'"

(Healthcare user, female, migrant/ethnic background, Sweden)

A woman in the United Kingdom explained a similar situation involving intrusive questions about her sexual partner.

"My GP can sometimes butt into my business, ask me all these questions: 'Who are you sleeping with?'[...] I say: 'It's none of your business – you're supposed to be my GP – don't ask me about my [personal life]'."

(Healthcare user, female, migrant/ethnic background, United Kingdom)

Such questions can be experienced as undignified and a violation of a person's right to privacy, especially if women perceive that they are only being asked because of their disability.

Conclusions

Asked about experiences of discrimination and multiple discrimination in healthcare, healthcare users and professionals reported a number of practices and violation of patients' rights that affect both access and quality of healthcare – including delays in treatment, refusal of treatment, humiliating treatment and stereotyping, malpractice, lack of informed consent and harassment. Whilst these experiences were not always defined in terms of discrimination, they were often perceived to be motivated by ethnicity, age, sex and disability. In the majority of the EU Member States covered by the research, with the exception of Sweden (and to some extent the United Kingdom), there is little awareness of multiple discrimination among the alleged victims of discrimination.

Across the EU Member States covered in the research, some groups at risk of intersectional discrimination stood out more clearly, including Muslim women wearing headscarves (sex and religion/ethnicity); violation of informed consent in the case of ethnic minority women and women with intellectual disability (sex and ethnicity; sex and disability); older persons and persons with disabilities belonging to a migrant or ethnic minority accused of feigning their health problems to access social security benefits (age/disability and ethnicity). The role of visible markers of discrimination, especially appearance and language, was often mentioned as a trigger. There is evidence that discriminatory experiences are linked to foregone healthcare thus contributing to broader health inequalities. The research revealed that most health providers are reluctant to acknowledge the existence of discrimination, especially direct discrimination, in healthcare, and usually refer to language and organisational barriers that prevent specific groups from accessing healthcare. Whilst most health professionals understand the principle of multiple and intersectional discrimination, they usually do not recognise how the vulnerabilities interact or know how to counteract them in practice.

FRA opinion

EU Member States should find appropriate ways of guaranteeing that all healthcare users are treated equally and with dignity and respect. Training on discrimination and multiple discrimination, cultural competence and understanding disabilities should be provided to healthcare professionals, possibly in a mandatory fashion.

5

Seeking redress: obstacles and strategies

The first chapter of this report discussed how a single-ground approach to discrimination can have a major impact on how cases of multiple discrimination are handled. This chapter explores in more detail the legal intricacies that have emerged as possible hurdles to legal remedies and some of the views and practices of healthcare users, staff of relevant support bodies and lawyers in private practice.

The chapter begins by reviewing the standards set out in EU law, with an emphasis on the challenges and opportunities offered by what is one of the most advanced, if still incomplete, legal systems to protect against discrimination. It then provides an overview of available complaint mechanisms in the five EU Member States, and finds that enhanced referral mechanisms may be needed to improve coordination efforts across the various bodies. Finally, the chapter describes what happens in practice when people attempt to seek redress through formal mechanisms. This section interweaves the challenges identified by legal experts and the views of support bodies' staff, lawyers in private practice and healthcare users to present valuable experience of what works, what does not work and why. Only a few of those interviewed had filed formal complaints, so the chapter closes by examining the issues behind underreporting and the alternative strategies healthcare users have adopted.

The overall picture emerging from the research is a widespread perception of the lack of effectiveness of the anti-discrimination redress mechanisms in the five EU Member States included in the research. Legal experts, health complaint bodies and healthcare users all share this view.

5.1. Standards and challenges in EU law

Chapter 1 provided an overview of the main EU legal provisions to counteract discrimination. This section addresses the challenges that the existing legal situation presents and the opportunities it offers.

Legally speaking, the main barrier to bringing a multiple discrimination case is that EU anti-discrimination directives offer varying levels of protection to different groups of people ('grounds') in different areas ('scope'). In short, EU law establishes a hierarchy between grounds.[243] There are two main reasons for this: firstly, the material scope of the directives – the area which is covered by the prohibition – varies. With regard to healthcare, discrimination on the grounds of racial or ethnic origin[244] is clearly prohibited, while discrimination on the grounds of religion or belief, disability, age and sexual orientation is not. The status of discrimination on the ground of sex in access to healthcare is not very clear. The EU has had protection against sex discrimination in the area of employment in place since the middle of the 70s,[245] protection which subsequent

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[243] For more information on this hierarchy see, for example: Flynn, L. (1999); and Schiek, D. *et al.* (2007).

[244] The Racial Equality Directive (2000/43/EC) covers employment related areas; social protection, including social security and healthcare; social advantages; education; and, access to and supply of goods and services which are available to the public, including housing (Article 3 (1)). Therefore, healthcare is specifically mentioned as one of the areas in which discrimination on the grounds of racial or ethnic origin is prohibited.

[245] Equal Pay Directive (75/117/EEC) which was based on the principle of equal pay between women and men enshrined in Article 119 of the Treaty establishing the European Economic Community (EEC Treaty) of 1957 (now Article 157 TFEU).

directives[246] have further developed and strengthened. The prohibition of sex discrimination in access to goods and services was introduced much more recently by the Gender Equality Directive on Goods and Services.[247] There is no explicit reference to healthcare among the definition of 'services'; however, Recital 11 of the directive refers to Article 50 EC (now 57 TFEU) for the meaning of services, which might suggest that healthcare is not included. Conversely, although the Racial Equality Directive mentions healthcare separately from goods and services, it can be argued that it may fall under the scope of services, particularly where healthcare is private or where individuals are obliged to purchase compulsory sickness insurance to cover health costs. The CJEU has interpreted services in the context of the free movement of services to cover healthcare that is provided in return for remuneration by a profit-making body.[248] The second reason why a hierarchy is said to exist within EU anti-discrimination law is that the Racial Equality, Gender Goods and Services and Gender Equality (recast) directives impose a duty on EU Member States to designate a body or bodies for the promotion of equal treatment of all persons on the grounds of racial or ethnic origin and sex. There is no such duty in the Employment Equality Directive. Moreover, the Member States are free to create one body or different bodies covering race and/or sex discrimination.

This presents two problems in relation to multiple discrimination claims: if discrimination on one of the grounds claimed is allowed under EU law but the other is prohibited, then a claim on *both* grounds is likely to be adjudicated negatively; one could limit the claim to the ground covered by the scope of existing legal provisions (the 'dominant' ground), but this destroys the multidimensional aspect that is at stake. Under EU law a combined claim of, for example, race and age discrimination in healthcare is not possible, as age discrimination is not prohibited in healthcare. If a specialised body does not cover both grounds claimed, then again a claim to the body or with the assistance of the body will only be possible on one ground. A body designated to dealing with sex discrimination will thus not be suited to deal with a combined claim of, for example, sex and disability discrimination. Establishing one single body covering all grounds of discrimination in EU law would remedy the situation, although there is at present no duty to designate a body to cover the grounds in the Employment Equality Directive.

In July 2008, the EU Commission adopted a proposal for a Horizontal Directive extending the material scope of the provisions against discrimination on the grounds mentioned in the Employment Equality Directive to all areas covered by the Racial Equality Directive. The proposal would also require EU Member States to designate a body or bodies for the promotion of equal treatment, irrespective of a person's religion or belief, disability, age or sexual orientation (Article 12). Adoption of this proposal would embed protection against discrimination on the basis of religion or belief, disability, age and sexual orientation in the area of healthcare, and would decrease the chance that one ground is not covered in other areas. The possible problem with fragmented bodies dealing with equality on different grounds could be compounded, however, if different bodies are designated for each of the grounds covered in the proposal.

5.2. Availability of complaint mechanisms

All EU Member States have a structure in place to guarantee the rule of law through the interpretation, application and enforcement of existing legal rules. In addition to the ordinary court system two sets of complaint bodies address discrimination – including multiple discrimination – in health in the five EU Member States: equality bodies dealing with issues relating to equality and non-discrimination,[249] and health or patients' bodies/ombudsmen dealing with complaints in the health sector specifically (see Table 8). Their structure and functions will be briefly reviewed below. The fieldwork finds that the fragmentation within and between these bodies creates a barrier for those wanting to file claims of discrimination on one or multiple grounds in the health sector.

These bodies are non-judicial, meaning they lack the power to adjudicate formally a violation of the law, to award damages or to enforce their recommendations. They nevertheless have other important functions such as providing information and assistance, monitoring, supervision or mediation.[250]

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[246] Council Directive 75/117/EEC, OJ 1975 L 45/19; 76/207/EEC, OJ 1976 L 39/40; and 97/80/EC, OJ 1997 L 14/6. These have now been recast in one directive: Directive 2006/54/EC of the European Parliament and of the Council of 5 July 2006 on the implementation of the principle of equal opportunities and equal treatment of men and women in matters of employment and occupation (recast), OJ L 204/23.

[247] This applies to "all persons who provide goods and services, which are available to the public irrespective of the person concerned as regards both the public and the private sectors, including public bodies, and which are offered outside the area of private and family life and the transactions carried out in this context", Council Directive 2004/113/EC, OJ 2004 L 373/37, Art. 3 (1).

[248] See FRA (2011a) and CJEU, C-158/96, *Kohll v. Union des Caisses de Maladie*, 28 April 1998; CJEU, C-157/99, *Peerbooms v. Stichting CZ Groep Zorgverzekeringen*, 12 July 2001; and CJEU, C-385/99, *Müller Fauré v. Onderlinge Waarborgmaatschappij*, 13 May 2003.

[249] Some of the bodies have remits which also include human rights; see FRA (2010d) and FRA (2010e).

[250] See FRA (2011e).

All five EU Member States have judicial mechanisms which allow complainants to bring to court cases of discrimination in the healthcare sector on the grounds, at a minimum, of race and ethnic origin. In Italy, for example, Article 44 of legislative decree No. 286/1998 introduced a "civil action against discrimination", a procedure which is faster and less complicated than ordinary proceedings. With regard to access to healthcare, this action can be used only in cases of discrimination on the grounds of race, ethnic origin, nationality, religion or disability.[251]

5.2.1. Patients/health complaint bodies

Each state has one or more health complaint bodies which can be approached by patients who feel mistreated or who allege other sorts of grievances and wrongdoings by medical structures and personnel. There are two main types of health complaint bodies: 1) bodies which are established within, and often subordinate to, healthcare service providers, and 2) those which are independent from healthcare services. This is an important distinction, because lack of trust in internal or subordinate procedures may contribute to the underuse of such opportunities and the phenomenon of underreporting. Lack of knowledge about the existence of external, independent bodies, or the complexity of the structure also plays a role.

All five EU Member States included in this research have complaint mechanisms within their healthcare systems (see Table 8). These include official bodies of medical professionals which deal with complaints against their members and can undertake disciplinary measures, including expulsion in cases of grave error or gross misconduct. They also include bodies which oversee the functioning of the system, rather than individual performance. In Sweden, for instance, the National Board of Health and Welfare (*Socialstyrelsen*) supervises the health and social care services county councils and municipalities provide under the Ministry of Health and Social Affairs. Among other tasks, the National Board deals with healthcare complaints. The National Board may, either on its own initiative or because of a patient or care provider's report launch and conduct inquiries into healthcare providers. A 2011 system revision, which includes a new complaints structure, means it is not yet possible to assess the system's accessibility in practice, including how long it takes to pursue a complaint. The local Swedish complaint system also includes Patient Advisory Committees, which the statute requires regional and local public authorities responsible for health and medical care to establish.[252] These committees promote contacts between patients and medical staff and assist and support patients who are not satisfied with the care or treatment they receive.

In Italy, apart from the Medical and Dental Chambers which were established at a provincial level, each Local Health Unit must establish a public relations office (*Ufficio relazioni con il pubblico*),[253] mandated to receive complaints from healthcare users and initiate administrative proceedings to assess whether a health service provider under the Local Health Unit has violated a patient's rights, including the right to non-discrimination.

In contrast, of the five EU Member States studied only Austria and the United Kingdom have specific healthcare complaint bodies which are external to the healthcare system and deal specifically with issues related to access to healthcare. In Austria, for example, all provinces have an independent patients' Ombudsman

Table 8: Overview of health and Equality bodies

EU Member State	Patients/health complaint bodies		Equality bodies	
	Internal (within the healthcare provider)	Independent/External	Single, covering all grounds of discrimination	Many, covering various grounds of discrimination
AT	✓	✓		✓
CZ	✓		✓	
IT	✓			✓
SE	✓	✓	✓	
UK	✓	✓	✓	

Source: FRA, 2012

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[251] Italy, Legislative Decree No. 286/1998, Art. 44; Legislative Decree No. 216/2003; Law 67/2007.

[252] Sweden, Act 1998:1656 on patient committee activity.

[253] Each Local Health Unit is obliged to have a public relations office in accordance with Art. 12 of Legislative Decree of 3 February 1993, No. 29.

established by law which aims to secure the rights and interests of patients in all aspects of the healthcare system. Making use of the complaints procedure is free of charge and most cases are dealt with within two years. The Ombudsman has the right to handle complaints, to access all data and files necessary to deal with the complaint and to mediate in complaint cases. They do not, however, have the right to decide a case or to represent a claimant before a court. All public health funds also have institutionalised Ombudspersons, who may also handle complaints relating to the healthcare system, if the complainant is insured with them and the institution concerned holds a contract with the respective public insurance fund. These Ombudsmen have comparable rights and duties to the provincial patients' Ombudsman.

5.2.2. Equality bodies

All EU Member States have bodies tasked with helping make equality a reality for everyone in compliance with EU directives[254] requiring the setting up of such 'a body or bodies'.[255] While some EU Member States, including Austria and Italy, have chosen to set up a number of bodies to deal with each different ground of discrimination, others, including the Czech Republic, Sweden and the United Kingdom, have a single equality body.

Both Sweden and the United Kingdom have recently transformed their systems and established one single equality body (and a single equality act) covering multiple grounds of discrimination under one single mandate.[256] The British Equality and Human Rights Commission (EHRC) has a statutory remit to promote and monitor human rights, and to protect, enforce and promote equality across the nine grounds covered by law – age, disability, gender, race, religion and belief, pregnancy and maternity, marriage and civil partnership, sexual orientation and gender reassignment. Its mandate covers discrimination in access to healthcare. Because the EHRC can only take on a limited number of cases each year, however, it concentrates on those cases, known as 'strategic litigation' which are likely to establish a point of law or give an interpretation of a law. The EHRC thus does not deal with many individual cases. It does, however, fund other organisations which give advice and assistance to complainants in discrimination claims, such as Citizens' Advice Bureaus. The EHRC also supervises the public sector equality duty and has the power to launch official inquiries and formal investigations.

In comparison, both Austria and Italy have a number of bodies dealing with different areas of discrimination. For example, in Austria, a variety of equality bodies co-exist both at the federal and provincial levels with remits covering different grounds and/or sectors, including the Federal Equal Treatment Commission, the Equal Treatment Commission, the Ombud for Equal Treatment and specialised bodies dealing with disability.

5.2.3. Other relevant organisations

In the United Kingdom, the Care Quality Commission, which began its work in 2009, is the independent regulator of health and social care in England. It regulates and monitors care services provided by the National Health Service, local authorities, private companies or voluntary organisations and is responsible for issuing licenses, as well as for protecting the rights of people detained under the Mental Health Act. The Commission does not investigate individual complaints.

In all states examined in this report, charities and NGOs – such as mental health charities and charities for the elderly, for children, for people with disabilities, for women or for specific ethnic groups – play a key role in providing advice or assistance to victims of discrimination. The Italian NGO Tribunal for Patients' Rights (*Tribunale per i Diritti del Malato*), for example, is very active at the national and local level. It works together with lawyers specialised in health law to provide advice and assistance to persons who have been victims of malpractice and inequality when accessing the Italian health system. The Tribunal for Patients' Rights is currently promoting the introduction of chambers of conciliation specialised in health issues at local level.[257] The role of such chambers would be similar to those of the Austrian Equal Treatment Commission: they would facilitate agreements designed to avoid or to settle legal disputes, using their powers to issue advisory opinions or to settle disputes before proceedings are initiated.

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[254] Council Directive 2000/43/EC, OJ 2000 L 180/22; Directive 2002/73/EC of the EU Parliament and of the Council, OJ 2002 L 269/15; Council Directive 2004/113/EC, OJ 2004 L 373/37.

[255] See FRA (2011e), which provides added analysis on all countries tackled here, except for Sweden.

[256] Sweden previously had four ombudsmen, covering sex, sexual orientation, disability, and ethnicity and religion, which have now been integrated into the Equality Ombudsman (Act concerning Equality Ombudsman, SFS 2008:568); while the United Kingdom had three equality commissions, covering sex, race and ethnicity and disability, which have now been brought together under the Equality and Human Rights Commission Equality Act 2006 which covers all grounds of discrimination covered by the Equality Act 2010 (c 3).

[257] In the context of recent developments in the Italian Rules on Civil proceedings when Legislative Decree 28/2010 came into force.

5.3 Challenges in addressing discrimination and multiple discrimination in healthcare

This section shows how complaints of discrimination in healthcare are dealt with, and points out the most relevant challenges in dealing with such cases. Interviews reveal the motivation and the strategies healthcare users adopt to complain, and their level of satisfaction with available complaint mechanisms. This section also draws on information obtained through interviews with lawyers and staff of complaint bodies. A condensed legal literature review complements the assessment of the main legal obstacles in bringing cases of (multiple) discrimination in healthcare.

The last part of this section examines the extent to which complaint bodies are aware of discrimination in healthcare, and whether referral mechanisms exist between different types of bodies.

5.3.1. Experiences of healthcare users with complaint systems

In all five Member States covered by the research healthcare users reported cases of alleged malpractice, which they sometimes believed were motivated by discrimination. Very few healthcare users complained formally or informally[258] about the sector and all of those who did came from Austria, Sweden and the United Kingdom. None of the healthcare users interviewed in the Czech Republic or Italy had filed a complaint to a court or to any of the bodies reviewed above. This section addresses the experiences of those healthcare users who did approach the complaint system.

In Sweden, more than a third of the 34 healthcare users interviewed complained about the care and treatment they had received. Healthcare users in the United Kingdom filed only a few discrimination complaints, lodged predominantly by women of reproductive age, or on behalf of a child with intellectual disabilities. This research found occasions where healthcare professionals in the United Kingdom filed complaints against other colleagues on behalf of their patients. In one case, for example, staff expected a traumatised young female asylum seeker with psycho-social disabilities to speak to a male staff member, although the woman – the victim of a gang rape in her home country – fell into a hysterical panic upon seeing the man. In this case, one health worker made a formal complaint against her peers as she felt this treatment caused her patient significant harm. In Austria, this research uncovered only one case where a healthcare user complained before a complaint body, the Disability Ombudsman.

The research shows that users who decide to complain do so for a variety of reasons. Many complain, not to receive better treatment personally, but to improve the situation for other healthcare users, for their children or simply to prevent an allegedly incompetent medical professional from injuring others. Complaining becomes the only choice when there is no option to consult a different doctor, as mentioned by healthcare users in the Czech Republic and two carers of persons with intellectual disabilities in Austria.

Health system users reported the adoption of different strategies when complaining, ranging from directly approaching the head doctor of the health facility to filing a lawsuit. There is no discernible correlation between the complaint strategy and the level of satisfaction patients have with the result. In most cases, however, the healthcare users who had initiated formal complaint procedures felt that they had not received justice.

Directly complaining to doctors, supervisors or directors is the most common complaint strategy mentioned in the five EU Member States and is seen as more promising and less time consuming than filing a complaint with a specialised body or an ombudsman. About half of the complaints in Sweden were directed towards supervisors, the other half towards complaint bodies. Legal experts interviewed in the Czech Republic indicated that complaining within the institution would be the first choice, as all medical institutions had complaints procedures and it was easier to find remedies. Respondents also suggested filing complaints to the provider of the healthcare facility in question. Filing a complaint would ensure that the patient received a response, which might later be used as an argument in a dispute, as one Czech attorney explained.

> *"Well, [a] complaint to the manager is usually the first thing I recommend to patients, although when they come to see me this option has already been exhausted and therefore, theoretically, we might be able to file an action. Yet another way is to address the complaint to the provider of the healthcare facility. This is an option we have used several times. This especially concerns regional hospitals with the region as the provider. As a rule, the region forms an expert committee which decides if a failure occurred. And only after we fail at these two instances do we proceed to the court."*
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> *(Legal expert (health/equality law), female, migrant/ethnic background, Czech Republic)*

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[258] In this report, we refer to 'formal complaints' to encompass all complaints filed to those bodies which have a mandate to make a decision on the complaints they receive (e.g. courts and complaint bodies); 'informal complaints' are those addressed to bodies which do not have such mandate (e.g. NGOs, lawyers etc.).

The research shows that most of the users who complained were not satisfied with the outcome of the process. In Sweden, for example, healthcare users who filed a complaint expressed high levels of dissatisfaction. Seven persons made a written complaint to either the Patients' Advisory Committee, the National Board of Health and Welfare or the Equality Ombudsman and five complained directly to managing directors or similar. Out of the 12 who complained, the three users who filed a formal written complaint with the Patients' Advisory Committee received help with changing doctor and/or healthcare facility. All three are persons with intellectual disabilities. None of the healthcare users who complained of maltreatment to the National Board of Health and Welfare or of discrimination to the Equality Ombudsman felt satisfied with the help they received. This may reflect the institutions' status as national bodies which are obligated to conduct investigations according to special procedures. In order to prove discrimination, for example, the Equality Ombudsman must find a comparator or a comparative situation linked to the claimed ground for discrimination. The Board of Health and Welfare only opens cases of malpractice that threaten patients' security.

In the United Kingdom, where few healthcare users complained, the most common route pursued by complainants was filing an informal complaint to the agency concerned. Those who did use formal complaint routes referred to delayed responses, consistent barriers to resolution and a general lack of satisfaction with the outcome.

5.3.2. Hurdles in proving discrimination in healthcare

Interviews with legal experts, equality bodies and health ombudsmen indicate that proving that a discriminatory act has taken place is often challenging for plaintiffs and their lawyers. The research identified specific problems linked both to proving discrimination in the area of healthcare, and to proving discrimination on two or more grounds, irrespective of the sector in which it takes place.

Three major issues were raised in relation to proving discrimination in healthcare. First, producing the necessary legal evidence and medical experts' statements is costly, as it requires expensive professional expertise. A legal expert at the Discrimination Ombudsman in Sweden pointed out that medical knowledge is often required and that, as medical professionals make judgments based on their professional expertise and experience, it is difficult to show how particular treatment is the result of discrimination rather than a result of their professional judgement:

"Discrimination law makes certain demands, there are certain criteria that need to be fulfilled and I think that can be rather difficult. We find it unsuitable that […] some doctors perhaps are very fixated on 'oh, so you are Roma, is your husband also Roma?' I have a case where it comes through that [the doctor] attaches importance to that. But for us to be able to show that she has discriminated against this person we need to show that this has implied disadvantage, she has received inferior treatment or she has missed out on something. If you think of goods and services, it is much more obvious there, this disadvantage, e.g. been denied entry."

(Legal expert (complaint body), female, migrant/ethnic background, Sweden)

In Austria it was mentioned that people do not have enough understanding of the medical process and therefore cannot question their treatment. An interviewee in the Czech Republic pointed out that proving discrimination in healthcare is difficult because of the patient's right to privacy and because there are frequently no witnesses to communication between doctor and patient.

Legal experts also mentioned the so-called 'comparator requirement' which must be fulfilled to prove a discrimination claim under EU anti-discrimination law and national laws in the five Member States studied. The definitions of direct and indirect discrimination included in EU law both depend on an actual or hypothetical comparator, which means that equal treatment is a relative concept: equal treatment means treating people equally, but this could mean treating them equally badly as well as equally well. If everyone receives poor service from a doctor or in a hospital, there is no discrimination, because everyone is treated equally badly. A claim of discrimination would fail because there is no unfavourable treatment.

A final problem in establishing discrimination before a court, raised by legal experts in the United Kingdom, is that it is often fairly easy for the defendants – doctors or hospitals – to prove that the unequal treatment was objectively justified:

"In healthcare cases discrimination often isn't perceived as an issue because the judges are quite open to resource arguments and there is a very, very high obstacle of justification to overcome because the opponents don't really have to do much to show that their discriminatory behaviour is justified. They can say that it costs more money. I don't know if in other countries that would be different, because the NHS is purely publicly funded."

(Legal expert, male, United Kingdom)

A representative of the Patients' Ombudsman in Austria delineates a broader, contextual challenge: the interplay between discrimination law and tort law, which deals with civil wrongs, is often unclear. The burden of proof concerns a lack of documentation on the communication between patients and health professionals that is often connected with discrimination and harassment:

> *"In our work we apply tort law and in this sense there must be damage to physical integrity or psychological integrity. And especially in these cases of discrimination or in issues where it comes to ruthless treatment, it is difficult to claim damage and to prove what really happened. […] The communication is not always documented and it is also difficult to prove a damage coming from this evidence."*
>
> *(Legal expert (complaint body), female, Austria)*

In trying to find the best solution for their clients, lawyers identified a claim for medical negligence rather than a discrimination claim as the preferred approach. The following case from an Austrian health ombudsman illustrates this issue. A patient with a migrant background from former Yugoslavia had surgery and was asked to leave the hospital the following day. He told doctors that he was still in pain, but he was not taken seriously. According to the complainant, the doctors called it 'Balkan syndrome'. There was no further examination. Later in the evening, however, he was operated on to stop internal bleeding. Following this operation, the hospital cared for him properly. The patient complained about the delay in treatment, alleging that doctors had assumed that he was pretending or exaggerating because he was a foreigner. The Ombudsman requested a statement from the hospital. The hospital denied racist comments and said the bleeding was considered a typical complication without any fault on the hospital's part. The Ombudsman believed that the bleeding might have caused the pain and that therefore there had been a treatment delay, but there were difficulties in proving the exact time frame and the causal relation to the damage. The Patient's Compensation Fund (*Patientenentschädigungsfonds*) offered the patient compensation; discrimination, however, could not be proved.

Another case where discrimination could not be proved occurred when the UK Equality and Human Rights Commission handled a case concerning the definition of disability before the relevant legal provision was changed to include HIV-positive status. The general practitioner of a HIV-positive man refused to prescribe Viagra and sent him to a consultant instead. This case was fought on the grounds that this was less favourable treatment on the grounds of disability, but the case was lost because it could not be proven that HIV-positive status was a disability according to the Disability Discrimination Act 1995. The provision was later changed.

5.3.3. Specific challenges in proving multiple discrimination

Proving multiple discrimination in all areas where it may occur is particularly difficult. It presents two additional aspects which, according to the interviews with legal professionals, constitute a disincentive to initiating claims of discrimination on multiple grounds. As evidenced by legal literature throughout Europe, the first hindrance is the so-called 'single ground approach' laws or courts in many states have adopted.[259] This approach means that each ground of discrimination claimed must be proven separately, thereby increasing the burden of proof on the complainant. In intersectional cases the claim might even fail, because discrimination on any of the single grounds claimed cannot be proven.

Court cases of discrimination on multiple grounds have been reported in Austria, Sweden and the United Kingdom; however, the single ground approach tends to be the one judges adopt. This situation characterises not only those states with a number of different laws against discrimination; it can also be observed, for example, in the United Kingdom which has a single Equality Act. The need to prove each ground of discrimination separately is also a disincentive to bringing a claim on multiple grounds and a reason why lawyers make strategic decisions as to which ground to pursue. Legal practitioners in all five countries studied confirmed that they often opt to claim only the ground for which the evidence is strongest and which thus has the greatest chance of success. An Italian legal expert added that claiming discrimination on more grounds would double the burden of proof. In Italy, although legislation seems to allow claims on multiple grounds, no related case law has yet been reported, and one research respondent – an anti-discrimination lawyer – believes that at present it is impossible to say how judges will deal with such cases.

Linked to the 'single ground approach' is a second challenge in the area of evidence for multiple discrimination, namely the need for a comparator. The comparison that must be made according to the law makes a claim on more than one ground more difficult, because the more grounds that are applicable, the more complicated it becomes to find a comparator, even a hypothetical one.

Figure 2 shows how the comparison is made in a single ground approach. An ethnic minority woman can compare herself: to an ethnic minority man to prove sex discrimination; or to a white woman to prove racial or ethnic origin discrimination. Two comparisons can then take place, one horizontal, one vertical.[260] A comparison with a white man, and thus a comparison across the two grounds of ethnic origin and sex (a diagonal comparison in the diagramme) is normally not allowed, or can be very difficult to argue. If the grounds of discrimination are intersecting and the ethnic minority woman is discriminated against because of a combination of the two grounds, she would not be able to prove discrimination on one ground alone and thus her claim would fail.

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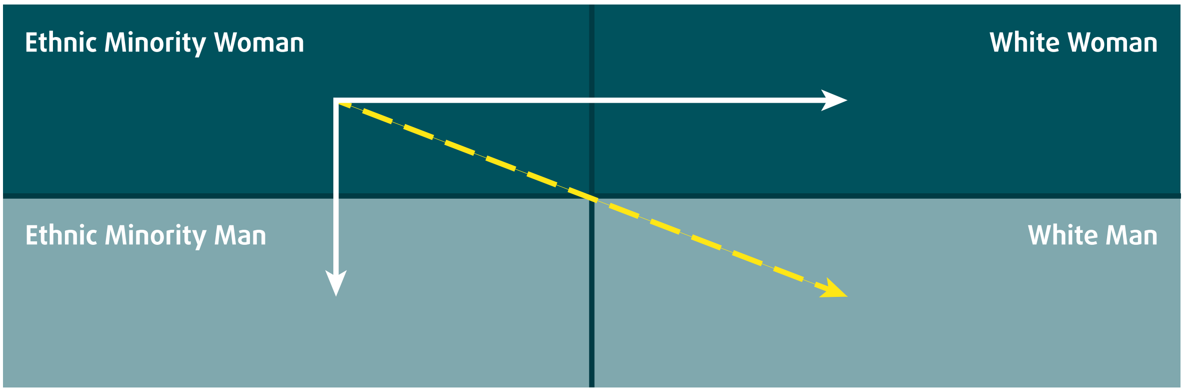
[259] See Fredman (2005); European Commission (2007); Burri, S. and Schiek, D. (2009); Schiek, D. and Lawson, A. (2011).

[260] On the problems with comparators, see also the Commissioner for Human Rights of the Council of Europe, who explained the problems with comparators in his opinion on national structures for promoting equality (Commissioner for Human Rights 2011).

Figure 2: Horizontal, vertical and diagonal comparator in multiple discrimination cases



Source: European Network Against Discrimination, 2011

One way to overcome the obstacles created by the burden of proof in intersectional discrimination claims would be to take into account the combined effect of more than one ground of discrimination, because it would allow a diagonal comparison. Due to lack of case law, it is not possible to ascertain whether the sharing of the burden of proof mechanisms foreseen by EU directives to ease the conditions that the claimant must fulfil would work in such a scenario. It is nevertheless important to keep in mind that, lacking a specific provision on multiple discrimination, the burden of proof typically operates within a 'single ground' definition of discrimination. It is possible, however, that the legal definitions are general enough that they do not prevent courts from moving beyond the single ground approach to take into account the combined effect of more than one ground of discrimination. It is in this context that the importance of raising awareness about multiple discrimination amongst judges, lawyers and general public becomes obvious.

5.3.4. Reports of low effectiveness of available remedies

In all five EU Member States included in this research healthcare users and legal professionals consider legal redress mechanisms in the area of anti-discrimination law as weak or ineffective, for three principal reasons: the low compensation awarded for discrimination claims, particularly in multiple discrimination cases; the fragmentation of competent complaint bodies; and specific issues related to healthcare user expectations.

As discussed, the research shows that lawyers do not usually consider the discrimination factor and the applicable anti-discrimination legal framework when assessing if, and how, to bring a case concerning healthcare to court, and instead frame cases using medical negligence or malpractice. What happens when medical negligence or malpractice can be ascribed to discriminatory views or conduct of the professional thus becomes important.

Legal respondents in Austria and Sweden reported several cases of alleged medical malpractice in conjunction with alleged discrimination, with the vast majority of cases concerning persons with disabilities or with an ethnic background. In most, the issue of medical malpractice was at the heart of the lawyers' or the ombudsmen's examination and discrimination was not raised. In the Czech Republic, damages caused by the sterilisation of Roma women without their informed consent were claimed for medical negligence or medical malpractice. Two of these cases were brought to the ECtHR in Strasbourg: in *R.K. v. the Czech Republic* only Articles 3 (inhuman and degrading treatment), 8 (right to private and family life) and 12 (right to found a family) of the ECHR were claimed, while in *Ferenčíková v. the Czech Republic* the plaintiff also claimed Article 14 (right to non-discrimination).[261]

Another factor that leads legal experts to avoid considering or framing claims from the angle of anti-discrimination legislation is that compensation for non-pecuniary damages is generally very limited while compensation for medical maltreatment is much higher. Thus, when the health of the complainant has been seriously damaged a claim based on medical negligence or medical malpractice is preferred. A Czech legal expert declared that compensation is too low to motivate people to take discrimination cases to court, while an Austrian legal expert added that compensation in discrimination cases is not enough if the complainant requires further (long-term) on-going medical treatment and/or needs care for a certain period of time, possibly for the rest of their lives because of the inadequate treatment or lack of treatment received. In contrast, malpractice allows for compensation for pecuniary damages due to income loss and out-of-pocket expenses. An Italian lawyer and expert in non-discrimination law stated that:

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261 ECtHR, *R. K. v. the Czech Republic*, No. 7883/08, 15 December 2009; ECtHR, *Helena Ferenčíková v. the Czech Republic*, No. 21826/10, 1 September 2010.

"We as lawyers try to go straight to the point, to find a solution to the situation of the client. Especially in health matters, if there is a mistake, a negligence, the possibility of claiming objective damage compensation because the doctors have erred, we don't 'lose time' trying to demonstrate that this victim was also black, gay, etc., because this would bring minimal added value. […] I would address the problem of discrimination only when there is urgency, but never in a regular lawsuit."

(Legal expert (health/equality law), male, Italy)

A legal expert in the United Kingdom confirmed this use of discrimination law, saying that when the aim is to get his/her client treatment rather than money – such as when GP practices refuse to register migrants or asylum seekers – then he would use general public law principles or human rights arguments to support the case, including discrimination.

In a claim for medical negligence, the (discriminatory) reason for medical errors is irrelevant: if there is negligence, it does not matter whether the doctor has acted in a racist manner. This may mean, however, that the discrimination remains hidden and unchallenged. A case discussed by the Swedish National Board of Health and Welfare, for instance, concerned a foreign-born man who had sought help at an emergency ward for severe pain. The doctor gave him a cursory examination but, when he could not find anything wrong, sent him home. That same night, the man repeatedly returned to the emergency ward only to be sent home each time. He later died without receiving help. In the inquiry into the case, the man was said to come from a culture where it was considered 'unmanly' to complain about pain; the doctor who had examined him therefore did not perceive that the man was in enough pain to warrant further examination. The inquiry did not address discrimination, because the expert who dealt with the case did not frame it from this perspective. The research respondent who recalled this case, however, claimed that discrimination was an element in the case.

Apart from considerations related to the amount of compensation awarded, the research showed the choice of legal redress is also dependent on what plaintiffs want to achieve. While some patients want compensation for the damage they have suffered, others may be satisfied with an explanation of what happened, and/or an apology from the health professionals, legal experts, in particular those from ombudsman's offices, said. Although some complainants might be advised to seek compensation to care for a child or relative damaged by a medical accident, monetary redress was secondary for most:

"In my case it's not for the money. I only want to know the truth. I have to know what really happened! I don't want any money but I want the doctors' explanation and that they finally come to admit their mistake!"

(Healthcare user, male, migrant/ethnic background, Austria)

Lawyers must take into account both their clients' wishes, and the legal feasibility and likelihood of success of a particular legal action. A Czech attorney said, for example, that claiming damages before a court was seen as the most appropriate reaction, since filing a complaint with the respective complaint bodies would not lead to comparable compensation.

Remedies such as apologies are often better obtained through institutions such as patients' or health ombudsmen or health complaints bodies, which are generally extra-judicial bodies, than through courts. Extra-judicial measures lead to better and more practical solutions for the individual, according to NGOs in Italy and Austria. Legal respondents in all five EU Member States surveyed, especially in Italy, however, raised doubts about their usefulness, particularly when (mal)treatment had caused a patient bodily harm and she or he was primarily seeking damage compensation.

A representative from the Disability Ombudsman in Austria said the focus on financial compensation deterred some people from making a complaint, particularly if their aim was to eliminate discrimination:

"Actually, this is one of the major claims of the disabled people's movement, to provide discrimination cases not only with the right to compensation, but with a demand for elimination. […] For example, if I complain about a ramp which is not there, and I cannot enter the General Hospital, I have gained nothing if I am given €1,000, if the next time I cannot enter either. This means, legal claims which are directed towards elimination or omission. Up to now, there is only a legal claim for compensation."

(Legal expert (complaint body), male, Austria)

When it comes to discrimination claims on multiple grounds, two specific elements compound the problems related to the low effectiveness of legal redress mechanisms in the area of anti-discrimination law. First, the fragmentation of competent complaint bodies constitutes a hindrance in bringing claims on multiple grounds to court. In Austria and Italy, for example, there are several equality bodies, each dealing with different discrimination ground(s). Combined with poor, or non-existent, referral and coordination mechanisms, this fragmentation makes it difficult to handle a claim for multiple discrimination. In the area of health, health-related bodies usually do not deal with cases as an issue of discrimination and there appears to be little cooperation with equality bodies, except in Austria and Sweden.

The fragmentation of competent equality bodies could in theory be remedied by establishing single equality bodies which cover all the grounds of discrimination that are prohibited by national anti-discrimination legislation. A single equality act would also help put an end to such fragmentation. But even with a single act and a single body two factors might still keep discrimination claims from being lodged on multiple grounds: first, a hierarchy of discrimination grounds based on differences in the scope of coverage of each ground, in both Sweden and the United Kingdom, for example age discrimination is not prohibited in the health sector; and, second, in the exceptions or justifications permitted for the various discrimination grounds.

The lack of advice and advocacy organisations compounds the complexity of the discrimination complaints mechanism, especially for lay persons. One interviewee in Austria mentioned that procedures before the Equality Commission are becoming more adversarial and this might stop people from claiming. A complainant might have to face representatives of an enterprise or institution with highly paid lawyers, giving at least the appearance of tilting the balance against him or her.

Promising practice

Collective actions

An Austrian interviewee suggested an improvement to the legal situation in relation to claims in healthcare: group or collective actions (*Verbandsklagen*) would make possible interventions without the involvement of a concrete claimant. This could be useful in combatting discriminatory guidelines and rules of procedure.

For more information, see: www.chancen-gleichheit.at/ChancenGleichheit/FAQ/default.htm

Secondly, the problem of the low compensation awarded for discrimination claims is more accentuated when it comes to discrimination claims on multiple grounds. Apart from Austria, no extra compensation is provided for such claims, meaning that lawyers, when taking a discrimination claim to court, might be discouraged from mentioning any extra grounds in the claim. If it does not make a difference to the outcome and a single-ground claim could be successful, then they may feel that there is no need to complicate the case by adding additional grounds, which usually require more evidence.

FRA opinion

Due to low compensation awards in discrimination cases, alleged victims of discrimination in healthcare often initiate other types of legal actions, such as tort actions on grounds of medical negligence. Compensation awarded in discrimination cases should be dissuasive and proportionate to the damage suffered, including in the area of healthcare. Generally, providing for higher compensation in multiple discrimination cases would constitute an incentive for victims and their lawyers to pursue multiple discrimination claims before courts and hence render anti-discrimination law more efficient.

5.3.5. Reluctance of health professionals to acknowledge discrimination

Another barrier to discrimination cases in healthcare is that health professionals and health bodies are often reluctant to admit that discrimination has taken place. Legal and equality body interviews in Austria, Italy and the United Kingdom all commented on this issue. Health staff fear criminal prosecution or the loss of their jobs, respondents said.

According to the interview with the representative of the Patients' Ombudsman in Austria, hospitals only rarely admit mistakes, and legal means for her to claim compensation or to enact changes are limited:

> *"If patients say they feel discriminated against, then we will of course inform the hospital about the allegations; we do this also with the thought that no such thing should happen again. We inform the director, who is the top manager in the hospital, from there it goes to the managing director of the department and further down to the doctor who performed the treatment. We hope that there is awareness raising about these aspects of treatment. [...] We have different outcomes. We get statements; the hospitals are obliged to give us statements. The outcome may be that the allegations of the patient are simply denied. [...] The outcome may also be that they say, 'I'm sorry how the patient understood it, we apologise, it was not meant that way.' Very rarely it happens that they say 'Yes this is the truth, we are sorry.' We were not there and we do not have the statutory mandate to arrange hearings of witnesses. This means we cannot call in the nurses or the doctor and simply put them under oath to tell us the truth. [...] If we had a legal basis, then we could resolve it and finally adjudicate on it, pass a judgment. But we have no powers to do that, we just have to leave things as they are."*

(Representative of the Patients' Ombudsman, Austria)

A legal expert in the United Kingdom pointed out that if discrimination is alleged, and subsequently investigated, this case can have a positive impact on subsequent discrimination claims. This is especially the case if the claim against the National Health Service is successful, because it would create a lot of publicity. Medical staff interviewed in the Czech Republic said that all complaints in the healthcare sector were futile and dysfunctional: hospitals generally do not take responsibility for maltreatment. Due to their negative experiences, advocacy NGOs in the Czech Republic have recently decided to try lobbying the Ministry of Health to reach a solution.

5.3.6. Lack of awareness of discrimination and multiple discrimination among health complaint bodies, and lack of referral mechanisms

The research shows that the staff of health complaint bodies are often unaware of the concepts of discrimination and multiple discrimination and how to deal with them, meaning that they do not frame cases in terms of anti-discrimination. This is also reflected in the low number of cases dealt with by those bodies which have used anti-discrimination law. Equality bodies, in contrast, specifically deal with discrimination cases but are not specialised in healthcare and are thus unable to address these issues properly. This problem is compounded by poor, or non-existent, cooperation and referral between health and equality complaint bodies.

In Austria, a representative of the Patients' Ombudsman reported that legal experts at the arbitration commission lack an understanding of discrimination:

> *"The legal experts sit there, in the arbitration commission, and they do not have the professional competence to recognise the problem. […] They have the responsibility to report on poor quality [category under which discrimination is addressed], but they do not see it."*
>
> *(Representative of the Patients' Ombudsman, Austria)*

Other Austrian legal respondents pointed out that, particularly in the health sector, there is little awareness that anything can be done legally and that, at public institutions and even at court, there is a lack of awareness about discrimination in healthcare.

One of the legal experts in the United Kingdom said that the Health Services Ombudsman does not frame cases using the anti-discrimination legal framework because the Ombudsman's own remit does not include legal issues. A Swedish interviewee mentioned that the Patient Advisory Committee in Stockholm only registers what the patients say and how they feel they have been discriminated against, implying that when the healthcare user does not identify and raise the discriminatory component, it is lost. The committees do not have a legal mandate to decide if a patient is discriminated against or not, but they do explicitly mention discrimination in mediation between the patient and the provider.

Awareness of multiple discrimination among complaint bodies, including equality bodies, is even lower than of discrimination on a single ground. Multiple discrimination arose as an issue for respondents only in those states where anti-discrimination law is relatively long-standing, such as in the United Kingdom and Sweden. In states where anti-discrimination laws are relatively new it was mentioned that the first priority is to establish the law and deal with discrimination or unequal treatment as such:

> *"Multiple discrimination is not an issue in the Czech Republic. There is a big problem of just establishing the issue of discrimination as such in the trials and complaints. There is no law theory that would deal with it, that would analyse the adjudications. So I personally see the multiple discrimination as one step beyond for us at the moment."*
>
> *(Legal expert, female, Czech Republic)*

Furthermore, having a single equality body does not guarantee that the body is aware of multiple discrimination. Even in those states, such as Sweden and the United Kingdom, where the single equality bodies are well aware of the existence of multiple discrimination, they still might not take a case on multiple grounds.

Secondly, lack of awareness goes beyond the equality and health bodies to include lawyers, courts and complainants, as mentioned in interviews in the Czech Republic, Italy and Sweden. Even where lawyers, complaint bodies, complainants and the courts are more aware of multiple discrimination, such as in the United Kingdom, the focus is on employment and bringing cases outside that area is considered low-profile. The lack of awareness leads to lawyers not taking cases on multiple grounds, and as few cases are taken, there is little awareness of the problem.

Furthermore, there is a significant fragmentation of competent complaint bodies in most of the five Member States surveyed. In the Czech Republic, Italy and the United Kingdom, there appears to be a lack of contact and cooperation between the equality and the health body or bodies which should make any necessary referrals to one another. Nonetheless, in some states, such as Austria and Sweden, references to the other bodies appear to be made. For example, in an interview in Sweden it was mentioned that, in cases where a patient complains about medical treatment and the Equality Ombudsman does not find sufficient basis for pursuing a discrimination case, the Equality Ombudsman frequently refers people to the National Board for Health and Welfare. Referrals from the Patients Advisory Committees to the Equality Ombudsman also take place, another interviewee said.

The co-existence of different bodies also leads to different 'cultures of cooperation'. A representative of the Patients' Ombudsman in Austria explained that the legal situation on the national and on the provincial level differs with regard to cooperation with her organisation. For example, the relation of the Patients' Ombud to the public Hospital Association KAGES, which runs hospitals and care institutions, is governed by provincial law, whereas federal law governs the relation to local practitioners in the community. This leads to a situation where hospitals are obliged to cooperate in the case of a complaint and would learn to cooperate and develop a 'culture of cooperation', but practitioners in the community would not.

FRA opinion

A fragmented system with a number of different equality bodies responsible for single grounds can contribute to undermining awareness of multiple discrimination as a legal approach to tackling discrimination. One equality body dealing with a variety of grounds of discrimination can, therefore, be an asset in efficiently fighting multiple discrimination. Furthermore, referral mechanisms between equality bodies and health complaint bodies and awareness of anti-discrimination legislation among health complaint bodies should be enhanced.

5.4. Underreporting and underuse of complaint mechanisms by patients

Interviews with healthcare users, legal experts and equality bodies in all five EU Member States surveyed confirm reluctance among complainants to file discrimination claims, especially in the healthcare sector. This section discusses the reasons reported by healthcare users for not filing complaints and the alternative strategies adopted by those who have experienced ill-treatment and discrimination in the healthcare system.

5.4.1. Lack of awareness of the complaint system among healthcare users

The most commonly mentioned reason for not complaining is a lack of knowledge about the complaints system. This finding confirms previous research conducted by FRA.[262]

Lack of knowledge about the complaints system was particularly the case in Austria, the Czech Republic and Italy, while in Sweden and the United Kingdom a higher proportion of healthcare users had some knowledge of complaint mechanisms. In the Czech Republic, for example, none of the seven women who felt discriminated against had filed a complaint; they lacked knowledge about available redress mechanisms or bodies. As an Italian psychologist underlined, culture, education, availability of information, familiarity with the legal system, knowledge of one's own rights in the host country in case of migrants and knowing someone who can provide necessary support are all crucial factors that affect a person's ability to access the complaints' system.

Experts in several Member States surveyed believed that foreigners have less awareness of the complaint system, as they do not know the language or their rights and tend to have little self-confidence. Two healthcare users with migrant backgrounds in the United Kingdom explicitly indicated that they would complain now that they are aware of complaints procedures and have built up their confidence:

> *"Now we know all about procedures, we can complain if we've been treated unfairly."*
>
> *(Healthcare user, female, migrant/ethnic background, United Kingdom)*

Low awareness of the complaints system was not only a patient's concern; with the exception of Sweden and the United Kingdom healthcare providers and doctors also often commented that they would not know how to handle complaints. In Sweden, where the majority of health professionals had some knowledge of the complaints system, different healthcare professionals suggested that they would deal with patients' complaints in different ways. A further deterrent might be found in the sometimes complicated and confusing co-existence of separate complaint bodies, as explained earlier. Most health professionals in Sweden knew only the specific complaint bodies for the health sector, but were not aware of the work of the Equality Ombudsman.

In Austria, another reason for the low number of complaints is that they are often initiated by self-help organisations which cooperate closely with the respective Ombudsman. Clients with a migrant background and

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[262] The FRA 2009 European Union Minorities and Discrimination Survey (EU-MIDIS) showed that awareness of redress mechanisms (for discrimination) is very low, in particular among vulnerable groups, such as minorities and immigrants; see FRA (2009). In May 2010, the FRA published a set of reports on how the architecture for the promotion and protection of human rights, in particular National Human Rights Institutions and Equality Bodies, could be improved in the EU; see FRA (2010d).

those with intellectual disabilities are often under-represented by such self-help organisations, which may not be well equipped to reach out to these groups.

5.4.2. Lack of belief in the effectiveness of complaints

There is a widespread belief among healthcare users, health professionals and NGOs in all five Member States surveyed that health complaints have little or no effect or are not generally taken seriously. Several healthcare users in Austria said that the power imbalance between patients and doctors – reinforced for migrant patients by the language barrier and lack of a resourceful social network – means that few complaints will be resolved to the satisfaction of the user. A Turkish woman stated that she knew a lot of people who were treated badly, but that no one had complained because they did not believe they would succeed. The doctor could always argue that the patient had misunderstood him or her. Another healthcare user argued that hospitals tend "to draw the curtain" if something goes wrong.

Migrant women in the Czech Republic said that complaints by foreigners are not taken seriously. NGOs and healthcare professionals also viewed the Czech Republic's system negatively, especially the way targeted institutions handle and assess the relevance of complaints:

> *"Well, officially you distinguish several types of patients, but in practice if you listen to the hospital staff you hear that for them a problematic patient is the one who may potentially file a complaint and whose complaint would potentially be taken seriously. This means that certainly they would not worry about a migrant whose opinion does not bother anyone."*
>
> *(Healthcare professional, male, Czech Republic)*

A general lack of confidence in the existing state structures may also keep persons from complaining. One healthcare user in Italy believed that migrants had no freedom of expression and that racism and discrimination are so embedded in the legislation that those who complain end up in trouble; foreigners learn that it is better to avoid all complaints.

NGOs and professionals often share a sceptical view of the effectiveness of the complaints system and they may even discourage victims from filing complaints. A social worker from an NGO working on Roma issues in the Czech Republic, himself with a Roma background, described that he had once opted against suing a health provider on the grounds of discrimination because of the widespread discrimination Roma face:

> *"I wanted to sue them, I wanted compensation and an apology from the hospital, but both my sister and my brother with whom I discussed it constantly told me that we would never win because we're just Gypsies. The hospital [would] destroy us, so what is the point of going to court. Apology? Who [would] apologise to Gypsies for not changing their mother's bed, or for performing some tests too late? It does not work that way in this country."*
>
> *(Policy maker, male, migrant/ethnic background, Czech Republic)*

A teacher and intercultural mediator working with migrant minors in Italy said that people working with health institutions usually were not trained to be aware of the complaints system. Although she saw situations requiring a complaint, she advised them against challenging a system unable to protect their rights, suggesting that they instead simply "bite the bullet".

According to an Italian lawyer working in the field of patients' rights, the effectiveness of the public relations offices as health complaint bodies is very low. Since they are dependent on their Local Health Unit, they are reluctant to investigate users' complaints, because this could lead to an admission of responsibility, with possible legal consequences.

5.4.3. Victimisation

Fear of retaliation or victimisation after using the complaints mechanism also emerged as a widespread reason for not complaining in all five Member States included in the research. In the Czech Republic, two Roma women did not seek legal redress because they were afraid of being seen as 'problem patients' which might make it harder to obtain good quality care in the future. Another Roma woman said her doctor had advised her not to complain. A Swedish interviewee mentioned that people might be afraid of the consequences of complaining, fearing, for example, that a complaint might lead to worse treatment.

Family members who are themselves fearful of the potential repercussions of complaints can also put pressure on healthcare users not to complain. One healthcare user with intellectual disabilities and a South Asian background in the United Kingdom said she had never complained about her treatment at hospital because she was worried about her sister's reaction:

> *"She would get even more angry with me. I don't lose my temper but she loses her temper. I didn't want them to kick me out of the hospital [...] she said people don't like [us] to complain, they keep it to themselves. This thing of being scared to complain."*
>
> *(Healthcare user, female, migrant/ethnic background, United Kingdom)*

Healthcare professionals in Austria confirmed that fear of victimisation can prevent patients from complaining and that this fear is well grounded:

"Many people are always afraid, because if they complain and they come back to this hospital, then they really get treated worse. And this continues. So if complaints go somewhere, then this always has consequences. I think this is something very typical which is known from many other institutional sectors, also the educational sector. I think this is a big problem […]."

(Healthcare professional, female, migrant/ethnic background, Austria)

Fear of revenge also dissuades health system users from complaining in the United Kingdom. A black executive director described how healthcare users approached him with complaints about services or treatment but were unwilling to be named:

"We have a very sophisticated complaints system but there is a large group of people, those classifiable as having protected characteristics, who will not put their heads above the parapet. The systems might be good but they do not assure them well enough that something will be done without any comeback on them."

(Policy maker, male, migrant/ethnic background, United Kingdom)

Fear of possible repercussions in other areas of life may also prevent complaints. Respondentsin Austria, Italy and the United Kingdom said migrants might be reluctant to initiate a discrimination claim because they fear that they will be reported to the authorities which could affect their legal status. A migrant woman in Italy said that she did not consider complaining when her doctor did not give her proper treatment for fear both that she would be separated from her children and that it would negatively influence her ability to stay in Italy, as she did not have a regular status at the time.

5.4.4. Bottlenecks in accommodating diversity

Several healthcare users with migrant backgrounds in all five EU Member States studied consider language to be one of the most crucial limitations when seeking legal redress, as they cannot navigate the complaint system without a good grasp of the host country's language. A migrant woman who felt unfairly treated when using the health system in Sweden, for example, said the main reason why she did not complain was her lack of Swedish and financial means. Several health system users in Austria suspected that their lack of knowledge of German would be perceived as a lack of intelligence and might be used against them if they were to complain:

"I don't know where to file a complaint. Whom should I tell […]? Who would listen to me? Also, I do not have the time to file a complaint. I cannot speak German perfectly. If you can't speak [the language], the Europeans think you are stupid. They consider you as stupid. What should I do?"

(Healthcare user, female, migrant/ethnic background, Austria)

A young Turkish woman also pointed to the lack of self-confidence associated with low language proficiency and the absence of knowledge of the complaint system.

In most of the cases of persons with intellectual disabilities in Austria, the Czech Republic and Sweden, the caretaker had to deal with the situation. Only in a few cases in Sweden did the patients themselves complain; however, they found it difficult as the complaint had to be filed in writing, which in these cases required help and assistance from others:

"I prefer like explaining my problem face-to-face. [It's] hard to write [the complaint] down in a sensible way, formulate well so others understand and such things. [I] often get distracted in the head when I try to write. Then I need help from somebody else, like, if it is necessary to write down the complaint […]."

(Healthcare user, male, migrant/ethnic background, Sweden)

Health providers in Sweden interviewed for this research suggested that the complaints system could usefully be less bureaucratic and more decentralised. The Equality Ombudsman is, for example, located in Stockholm and has no regional offices so people outside the capital may not be as informed about the possibility of complaining to the Ombudsman.

Promising practice

The Patient Experience Group in the United Kingdom

The National Health Service (NHS) created the Patient Experience Groups to improve the healthcare user experience. Specifically, the group meets regularly to ensure provision of choice in access and in treatment by providing a range of information accessible by the local population. The Patient Experience Groups are also designed to: monitor environments that promote dignity and respect for patients' needs review survey requests; deploy patient experience tools and monitor feedback from the tools. They are based on feedback to and from patients, carers and relatives on 'what actually happened' in the course of receiving care or treatment, both the objective facts and their subjective views of it. The groups are made up of representatives from inpatient and outpatient healthcare services and service users. They have procedures for processing complaints with set timescales, according to the chair of one group interviewed for this research. Most complaints concern staff attitudes. A patient liaison service provides support to healthcare users who wish to file a complaint.

For more information on involvement of patients, see: Section 242 of the NHS Act 2006; NHS Constitution

FRA opinion

EU Member States should take the necessary steps to increase healthcare users' awareness of the existence and functioning of the available complaint mechanisms, both for healthcare and discrimination issues. Complaint bodies should facilitate access to the complaint system for healthcare users who have specific linguistic needs and for those who have a disability. This can be done through the enhanced provision of information in different languages, in braille and easy-to-read format.

5.4.5. Other barriers

The interviews with healthcare users and professionals also highlighted additional obstacles in lodging complaints in the field of healthcare. Respondents in the Czech Republic, Italy and the United Kingdom mentioned that some ethnic and migrant groups might have cultural reasons that keep them from complaining and act as a further obstacle to seeking legal redress. As a South Asian healthcare user in the United Kingdom argued, she had been raised in a tradition where complaining leads nowhere and brings shame on the complainant. But second-generation migrants do not seem to share these attitudes: a British woman mentioned that her parents from Barbados would not have complained but she feels a duty to do so if there is an unresolved problem.

Sometimes healthcare users do not complain because they have the impression that health professionals are doing their best. One interviewee in the United Kingdom pointed out that, when people are not born and raised in the United Kingdom, they hold medical professionals in even higher esteem than the British-born population and thus feel a stronger reluctance to challenge a medical opinion.

The time and effort needed for issuing a complaint can also deter victims of discrimination, particularly people who have health concerns. A migrant woman living in the Czech Republic gave the following statement:

> *"Well, when a person complains about an institution, it's another story. It's hard. My nerves and my health are not strong enough for that."*
>
> *(Healthcare user, female, migrant/ethnic background, Czech Republic)*

Another issue is that in some cases the time taken to decide to file a complaint may exceed the time limit set by law. A healthcare user in the United Kingdom reported that she had considered filing a complaint, but only decided to do so more than 12 months after the discrimination had happened, which was beyond the legal time limits for health complaints.[263]

Finally, access to supportive persons or institutions raises the propensity to file a complaint: several users said that although they had not filed a complaint when first discriminated against, they would do so if the discrimination reoccurred, because since the first incident they had met a social worker, a lawyer or an NGO who could support them.

5.4.6. Alternative strategies by healthcare users

Instead of filing a formal complaint, healthcare users often resort to other strategies to improve their situation; the most common being to look for another doctor or facility. Some respondents also reported avoiding particular services, looking for healthcare in their country of origin or complaining to NGOs as alternative strategies. There is evidence that a large number of Czech doctors refuse to treat Roma, who thus are forced to look for a doctor who will accept them as patients.

Other healthcare users indicated that rather than complaining to their doctors, they would inform either their parents or their job trainers and social councillors.

A further strategy is the avoidance of particular health services. Several experts stressed that the detachment of specific groups of healthcare users from healthcare, or its limited use, can be attributed to their efforts to avoid interactions that might somehow involve discrimination. This could be considered participants' natural defence mechanism to preserve their dignity. Subsequent neglect of healthcare, however, may lead to a vicious cycle of growing marginalisation and social exclusion.

According to the interviews conducted in Austria and Italy, some migrants resorted to undergoing certain treatments, in particular dental treatment, in their country of origin. A few Turkish interviewees who complained about rude treatment and medical malpractice by their Austrian dentists opted for dental treatment in Turkey, where they could communicate well with the dentist and perceived the treatment as generally less stressful. This practice can, however, lead to follow-up problems, as dentists in the country of residence often

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[263] UK, Local Authority Social Services and National Health Service Complaints (England) Regulations 2009. Health complaint in the United Kingdom must be made within 12 months from the date when the matter complained about has happened or 12 months from the first date the complainant has become aware of it, but this time limit can be extended if it is unreasonable to expect a person to have complained in time.

decline to treat a patient with, for example, dentures fitted in another country.

A particular issue was mentioned in Austria: children with autism often had to wait a long time for therapy. Certain kinds of early intervention and therapy accepted as scientifically approved medical treatment in Germany are not accepted as such by health insurance funds in Austria and thus are not funded. Some parents decided to go to Germany to access this kind of therapy but have to fund it privately.

In Austria, the Czech Republic, Italy and the United Kingdom migrant respondents who feared that filing a complaint would impact negatively on their legal status indicated that they had turned instead to municipal and civil society associations. A British healthcare user reported a similar strategy. She went to a publicly funded programme for young children and asked them to pass on information to a General Practitioner who, in her opinion, had discriminated against her:

> *"And you're certainly not going back to that same doctor and have her tell me something [like:] 'Oh, well, maybe you've got too many children.'"*
>
> *(Healthcare user, female, migrant/ethnic background, United Kingdom)*

Another interviewee from the Czech Republic mentioned trade unions as possible go-to bodies in case of a complaint.

An Austrian health professional raised the option of reporting cases of discrimination anonymously, a service provided by the Vienna-based anti-discrimination NGO ZARA and in Graz by the anti-racism support centre Helping Hands. An interviewee in the Czech Republic said that, if the incident was serious, rather than making a complaint to the hospital or the GP, it would be more promising to take legal action, as only a court can award damages, provided a third-sector organisation or advocacy group could be convinced to support the cost. Marginalised or socially excluded individuals or groups need to find associations which give information, advice or support, and support them in filing a complaint.

A rudimentary form of complaint, described by several respondents in Italy, essentially involves "making a fuss". When faced with refusals or delays, the service user starts shouting, asks operators to call the police or presses doctors and nurses with questions and demands. This strategy appears to be effective in some cases, as providers may decide to find a solution in order to defuse the protest.

A Czech health professional and respondent from an advocacy group also mentioned contacting the media as a potentially successful strategy for fighting discrimination.

5.4.7. Possible law reform initiatives at EU level

Chapter one noted that there is growing acknowledgment of multiple discrimination as a social reality. National judgments and other legal or quasi-legal conclusions of official bodies, however, do not provide elements useful for distilling an overarching legal principle – other than the generic principle of equal treatment – that could be used as a basis for recognising multiple discrimination in a European-wide legal formulation.

This chapter highlighted the following:

1) A hierarchy of grounds embedded in secondary EU law.

2) Various practical challenges in addressing discrimination and multiple discrimination in healthcare, namely:

    a. low effectiveness of available remedies;

    b. persisting legal hurdles, especially with respect to proving discrimination;

    c. lack of awareness of multiple discrimination among all actors involved;

    d. underreporting and high use of alternative, informal strategies to seek redress.

One option for moving forward with effective action is to introduce new legal provisions expressly acknowledge multiple discrimination. The European Parliament has taken an initiative in this direction, proposing an amendment to modify the European Commission's draft Horizontal Directive. Parliament suggests amending proposed Article 1 to make it clear that the directive lays down a framework for discrimination, including multiple discrimination. Under its proposal, Article 1 (2) would read:[264]

> "2. Multiple discrimination occurs when discrimination is based:
>
> (a) on any combination of the grounds of religion or belief, disability, age, or sexual orientation, or
>
> (b) on any one or more of the grounds set out in paragraph 1, and also on the ground of any one or more of
>
> (i) sex [...]
>
> (ii) racial or ethnic origin [...], or
>
> (iii) nationality [...]"

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[264] European Parliament (2009), Amendment 37.

In Amendment 38,[265] Parliament proposes that the definition of direct discrimination should read: "[…] (a) direct discrimination shall be taken to occur where one person, or persons who are or who are assumed to be associated with such a person, is treated less favourably than another is, has been or would be treated in a comparable situation, on *one or more of the grounds* [our emphasis] referred to in Article 1".

Both these amendments could be transferred into the other Equality Directives (2000/43/EC; 2000/78/EC; 2004/133/EC and 2006/54/EC).

The advantage of having an explicit provision at EU level is that all EU Member States would then be required to transpose it. If, however, the EU does not institute this provision, the Member States could still use the above as an example to lay down protection against multiple discrimination in their national laws.

The introduction into the Horizontal Directive of the above-mentioned amendments, and the entry into force of this piece of EU legislation, would constitute a step forward in giving the concept of multiple discrimination more prominence and in making it more operational at the EU and national levels. Experts expressed some concerns, nevertheless, about a lack of clarity in the proposed amendments. First, because the proposed directive does not cover discrimination on grounds of sex, problems might arise when bringing claims based on sex intersecting with other grounds in sectors where 'sex' has less protection. Second, some legal experts worry that introducing a specific provision on multiple discrimination in the prospective Horizontal Directive could be interpreted as meaning that the existing non-discrimination directives do not allow claims on more than one ground. The Horizontal Directive should be clarified to ensure that a systematic interpretation of the entirety of EU non-discrimination law does not hinder the possibility of bringing claims of multiple discrimination under the other directives, and that Member States are not prevented from introducing explicit provisions to this end in their national legislation. While the concept of discrimination remains – both conceptually and practically – anchored to 'less favourable treatment' or 'disadvantage' *in comparison to* a control group, the Employment Directive offers an alternative. It defines harassment as "unwanted conduct related to any of the grounds referred to in Article 1 [taking place] with the purpose or effect of violating the dignity of a person and of creating an intimidating, hostile, degrading, humiliating or offensive environment".[266] This definition is based on the principle of respect for human dignity, not on a comparator. While it is clearly stipulated that harassment, so defined, is to be considered as a form of discrimination, this could provide a useful recourse for those who consider they have suffered from instances of multiple discrimination. While a test based on human dignity leaves the courts wide discretion in interpreting when this is violated and could thus lead to legal uncertainty, the same approach might be particularly useful in cases of (multiple) discrimination in healthcare because of the emphasis it places on the experiences of victims.

FRA opinion

EU secondary law as currently in force results in a 'hierarchy' of discrimination grounds, with the level of protection differing from ground to ground. Providing equal protection against discrimination on the grounds of religion or belief, disability, age and sexual orientation in areas beyond employment, including healthcare – as envisaged in the European Commission proposal for a Horizontal Directive[267] – is the first step to take in combating the phenomenon of multiple and intersectional discrimination. The ground of sex, though, would remain protected under separate legislation with a narrower scope.

In its amendments to the European Commission proposal for a Horizontal Directive, the European Parliament suggested introducing legislative provisions to prevent and combat multiple and intersectional discrimination.[268] This would more accurately reflect the experiences of victims, ensure that complainants can raise all aspects of a multiple discrimination claim in a single procedure and could also assist in raising awareness of this phenomenon. Nevertheless, claims of multiple discrimination involving the ground of sex might still be problematic under EU law because of the narrower scope of current gender equality legislation. It would therefore be advisable to tackle multiple-discrimination in a consistent way throughout EU secondary law in order to enhance legal clarity. EU Member States, however, should not wait for harmonisation at EU level but should instead tackle multiple discrimination, including multiple discrimination involving sex, at national level in an efficient and encompassing way.

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[265] *Ibid.*, Amendment 38.

[266] Council Directive 2000/78/EC, OJ 2000 L 303/16, Art. 2 (3). Council Directive 2000/43/EC has the same definition but limited to racial and ethnic origin.

[267] European Commission (2008).

[268] European Parliament (2009).

Conclusions

The research has shown that persons with certain combined protected characteristics may experience particular problems in accessing healthcare and receiving the same quality of treatment as others. These problems can be due to structural barriers, which in some cases might even amount to indirect discrimination, and/or their individual experiences of unfair or undignified treatment in healthcare, which were at times perceived to be motivated by the person's disability, ethnic origin, age, sex or a combination of these factors.

Key barriers can be the lack of translation and interpretation services for migrants or the lack of communication support services for persons with intellectual and sensory disabilities: these emerged from the research as the most urgent issues to address. In addition, members of migrant or ethnic minorities who were women, old or had a particular impairment encountered specific financial, organisational, cultural and psychological barriers. In addition to barriers, the research found that at times healthcare users belonging to groups at risk of discrimination or multiple discrimination may face unequal treatment in healthcare. Muslim and migrant women are the two groups who most often said they had been victims of multiple discrimination on grounds of ethnicity or religion and sex. It also found that healthcare users who think that they have been discriminated against may be affected in a variety of ways that can impact on their health, if, for example, they were to avoid using healthcare.

The findings of this research suggest that the health system might not be adequately equipped to address the needs of all its users who may face particular challenges in being treated equally not only because of one characteristic that is protected against discrimination in healthcare, such as sex and ethnic origin, but because unequal treatment may be the outcome of a combination of these characteristics. In addition, other characteristics, that may also intersect, such as religion or belief, age or disability, are not among the grounds protected against discrimination in the area of healthcare, at least in EU law.

Therefore it is important to raise the bar of the protection EU law affords against discrimination by extending protection to key areas of life, such as healthcare for all grounds. It is equally important to introduce positive measures promoting equal treatment through the provision of translation and interpretation services.

The evidence shows that unequal treatment in healthcare at the level of the clinical practice, whether in diagnosis or treatment is rare. Nevertheless, stereotyping as well as time pressure that can result in such inequalities must be avoided. Health professionals are on the whole reluctant to acknowledge that unequal treatment can be present in healthcare and tend to focus more on the role of social determinants of health or the role of societal discrimination in employment, for example, in generating health inequalities. The obligation to ensure equal treatment and respect for every patient is deeply embedded in key ethical codes such as the Hippocratic Oath[269] and health professionals might not easily recognise how sometimes practices and stereotypes can undermine the rights of particular groups of healthcare users, including those with disabilities and those with a migrant background. The results of this research call for better reflection on how existing equality law and international human rights instruments, such as the CRPD, are applied in practice across all levels of healthcare and how this can be improved through monitoring, regulation, training and accountability.

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[269] See the Declaration of Geneva adopted by the General Assembly of the World Medical Association in 1948 and its subsequent amendments.

At present EU secondary law outlaws discrimination in healthcare only on the ground of race or ethnic origin and, arguably, sex. The adoption of the proposed Horizontal Directive would constitute an important step towards combating discrimination on the grounds of age, disability and sexual orientation – including multiple and intersectional discrimination – in healthcare.

The recent adoption of the Cross-border Healthcare Directive – which provides basic rules for EU patients seeking healthcare in another EU Member State – is another important step for furthering equity and quality of healthcare. It calls on Member States to guarantee the provision of information on health treatments and services to patients of other nationalities and languages, to commit to non-discrimination and to ensure that mechanisms for seeking remedies in the event of harm are in place. It remains to be seen how the transposition at the national level will translate this directive into practice.

The research documents how alleged discrimination in healthcare often remains hidden and unchallenged either because patients are not well informed of their rights to complaint or because the available redress mechanisms are complex, and also because lawyers may prefer not to use the applicable anti-discrimination legal framework due to the low compensation usually awarded. In order to improve access to redress, compensation awarded in discrimination cases needs to be dissuasive and proportionate to the damage suffered; referral mechanisms between health and equality bodies should be enhanced; and ways should be found to feed healthcare users views, including complaints, into the 'quality assurance' processes of healthcare providers.

Finally, the findings can usefully contribute to the integration debate following the recent European Commission communication, *European Agenda for the Integration of Third-Country Nationals*.[270] They show that legally resident third-country nationals may face problems when accessing healthcare due to one or a combination of several characteristics, such as their sex, age and race or ethnic origin. In this regard comprehensive national integration strategies would more effectively tackle the specific issues and needs of people who share more than one of these characteristics by specifically recognising their particular vulnerabilities and taking the appropriate measures to support them.

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[270] European Commission (2011c), reference or comment on the resulting Justice and Home Affairs Council conclusions of December 2011 could also be made.

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Appendix: Methodology

Research design

The objective of the fieldwork research was to examine the views of both a range of health professionals and of different categories of healthcare users. Results from the fieldwork were used in the context of prevailing inequalities and relevant policy developments, established through the country reports.

Stakeholders at meetings for the five EU Member States studied, held at the beginning of the project (January to February 2011), gave advice and commented upon the research design (sites, nationalities/ethnic minorities, categories of healthcare user respondents) and made suggestions for contacts amongst health professionals and groups which might be able to assist the research teams in each country in accessing healthcare users.

The fieldwork was conducted from March/April, and once relevant ethical approval was obtained. This process was particularly rigorous in Sweden and the United Kingdom. Most of the interviews were completed by July with a few undertaken in September and October.

The FRA carried out fieldwork at two sites in each EU Member State (see Table A1).

Table A1: Fieldwork sites, by EU Member State

EU Member State	Site 1	Site 2
AT	Vienna	Graz
CZ	Prague	Rural Central Bohemia
IT	Bologna	Napoli
SE	Stockholm	Malmø
UK	London	Leicester

Source: FRA, 2012

In Austria, Sweden and the United Kingdom, the second site was a major city with a large migrant and ethnic minority population (Graz, Malmø and Leicester). In Italy, the two major cities represented regional health systems in the north and south of the country with different migration histories. In the Czech Republic, fieldwork took place in the capital and in a rural area outside of Prague which had a large number of Roma.

In two of the five EU Member States studied there were considerable differences between sites. In the Czech Republic, the isolated/socially excluded communities in Central Bohemia are unique because of their limited access to services. Certain areas are only inhabited by Roma people with migrants residing in other areas. A number of local people have low levels of education and many are unemployed. Their access to services is much worse than it would be in larger cities. With regards to healthcare services, however, the inhabitants might also make use of services in Prague.

In Italy, there are considerable differences between Naples and Bologna. Whilst Naples tends to attract more recent migrants and those without regular work and residency permits due to the demand for low-paid workers in the extensive black-market economy and the lack of rigorous policing. Bologna tends to attract those who are more fully integrated within the formal labour market and have obtained permission to live and work in Italy. This spatial distribution of foreign migrants has a number of consequences for health service use and represents a key dimension of variation within the sample.

In each EU Member State two sets of in-depth interviews were undertaken. The first set was with healthcare users, for whom three categories were selected – women with reproductive health needs, older people and young adults with intellectual disabilities. The second set was with health professionals, consisting of providers, advocacy groups, policy makers, legal experts, ombudsmen and equality bodies.

For each specific category of health professionals and health service users, a specific topic schedule was prepared (five for professionals and three for healthcare users). Interviews were transcribed in the original language and a factsheet with a summary of the issues produced in English. In a few instances, the interviewee did not agree to be recorded.

Healthcare users

In-depth interviews were conducted with 171 frequent users of healthcare services across three broad categories where research had revealed differential health outcomes according to migrant and ethnic origin and socio-economic status.

Besides belonging to one of the target three groups of healthcare users, experiences of problems and discrimination in accessing health services were emphasised in approaching individuals and organisations to help with access to respondents. The objective of the analysis was not to map the extent of discriminatory experiences but to gain a better understanding of the barriers and the practices which vulnerable groups at the intersection of age, sex and ethnic origin might experience when accessing healthcare.

Three different topic guides were drawn up for each of the groups. Whilst some of the questions were common for all three groups, others were specific. The three categories and the topic discussed are:

(i) Women with reproductive health issues between the ages of 18 and 50 years. Problems concerning access to abortion, infertility treatment, pregnancy, ante-natal, birth and post natal services were raised. A few of the women interviewed had physical and sensory disabilities.

(ii) Older people generally over 50 years of age. A large number suffered from various disabilities, including chronic long-term illnesses which had resulted in economic and social exclusion. Though not mentioned as a form of disability in the UN Convention, chronic long-term illnesses often result in diminished physical capacity, anxiety and depression, as a number of the respondents demonstrated.

(iii) Young adults between 18 and 25 years with intellectual disabilities. Some of those interviewed as part of this group only had learning difficulties (see below).

A number of young adults with intellectual disabilities and many of the older people also had various health problems and physical and sensory disabilities.

The interviews were designed to obtain detailed accounts of health service users' barriers to healthcare, their needs, access to and use of preventive health programmes and measures, information about and consent to treatment, experiences of discrimination and knowledge and use of complaints mechanisms. In relation to healthcare, since the notion of discrimination is little used amongst respondents, we sought to explain clearly the different forms of discriminatory practices which could include unfair, unequal, delayed, refused or poor treatment and medication but also the right to dignity and respect in treatment by health professionals.

Table A2 indicates the age breakdown of the sample. The main point to note, and which is likely to be linked to their longer histories of migration, are the higher number of older people in their 70s in Sweden and the United Kingdom. In Italy, the people classified as older, and who presented themselves with chronic diseases, were only in their late 40s.

Table A2: Age and category of user interviewees

		18-29	30-9	40-9	50-9	60-9	70-9	Total
AT	**R**	5	3	4	1			13
	O				9	3	1	13
	D	10						10
CZ	**R**	8	6	5				19
	O			1	11	2	2	16
	D		1					1
IT	**R**	2	11	3				16
	O			3	9	1		13
	D							0
SE	**R**	5	4	4				13
	O				5	3	4	12
	D	7	2					9
UK	**R**	1	6	4				11
	O				3	5	5	13
	D	7	5					12
Total		**45**	**38**	**24**	**38**	**14**	**12**	**171**

Notes: R = women of reproductive age; O = older persons; D = young persons with intellectual disabilities.

Source: FRA, 2012

As Table A3 indicates, amongst older people there were generally more women than men except for Italy where there are few older women in Naples. Amongst those with intellectual disabilities there were varying sex balances with many more women in Austria and the United Kingdom.

Table A3: Gender and category

	R	O		D	
	Female	Female	Male	Female	Male
AT	13	7	6	7	3
CZ	19	9	7		1
IT	17	4	9	-	-
SE	13	9	3	5	4
UK	11	7	6	10	2
Total	73	36	31	22	10

Notes: R = women of reproductive age; O = older persons;
D = young persons with intellectual disabilities.

Source: FRA, 2012

In each of the EU Member States studied, two significant groups of nationalities or minority ethnic groups were selected for the fieldwork among the health service users. Only in the United Kingdom are statistics collected by ethnicity (see Chapter 2), otherwise the groups were based on nationalities which were often regrouped in order to be able to obtain sufficient interviews in the chosen sites. For example, in Sweden the category of Middle Eastern includes a number of different nationalities, such as Iranian, Iraqi and Lebanese. In the United Kingdom ethnic categories, such as African or Asian, also encompass a wide range of nationalities with different migration histories and socio-economic situations.

The nationalities and ethnicities in each EU Member State covered by the research represented significant and large groups where inequalities in health outcomes were often known. The need for research on the selected groups was confirmed by participants in the national stakeholders meetings. Table A4 gives the distribution of the major groups for each of the five EU Member States studied.

Respondents included those who had been in the EU Member State for shorter periods (less than five years), those who had lived there for a long time and those who were born there. Most of the interviewees, especially in Austria, Sweden and the United Kingdom had been in that EU Member State for longer periods and had residence permits or were EU or national citizens. Details are given below of the sample for each of the EU Member States.

Austria: The sample focused on the two main migrant groups from third countries, persons of Turkish and former Yugoslavian origin (Bosnia, Croatia, Macedonia and Serbia). Within the group of respondents of young persons with intellectual disabilities, interviews were also conducted with two Polish and one Chinese/Vietnamese persons due to difficulties in finding interview partners.

In contrast to the other two user groups, all interviews with persons with intellectual disabilities are second-generation migrants, who were either born in Austria or attended primary and/or secondary schooling here. All respondents in the category of older persons have been living in Austria for more than 10 years, and most of them for more than 30 years. In the category of women with reproductive health needs the sample also includes three newcomers (residence less than five years). This group had the fewest number of persons with long-term residence or Austrian citizenship.

Table A4: Migrant/minority groups in five EU Member States

		No		No	Other	No	Total
AT	Turkish	14	Ex-Yugoslav	19	Polish Chinese/Vietnamese	3	**36**
CZ	Ex-Soviet Union	16	Roma	19	Macedonia, Morocco, Yemen	3	**38**
IT	Sub-Saharan African	16	North African	11	African-Cuban; African-Colombian; Romanian	4	**31**
SE	Middle East	23	African	10	Moroccan	1	**34**
UK	African and African Caribbean	14	Asian	21			**35**

Source: FRA, 2012

Czech Republic: The sample consisted of two subgroups: those of Roma ethnicity and migrants from the former Soviet Union. Roma people, who are Czech citizens, make up the largest ethnic minority in the Czech Republic. There were also four Slovak Roma. Evidence shows they face discrimination in all areas of life. A number of them live in isolated communities, where access to healthcare is extremely limited. Although Slovakians are the largest migrant group, they are EU citizens, hence it was decided to select as the second group migrants from different countries of the former Soviet Union (Armenia, Chechnya, Georgia, Kazakhstan, Ukraine, Uzbekistan and Russia) as well as one person from Macedonia who was the only young person with an intellectual disability.

Italy: Interviewees were drawn from two broad subpopulations, that of North Africans and Sub-Saharan Africans, both numerically important in Italy and in Bologna and Naples. There were several respondents were did not fall within these two populations – a Cuban African and a Colombian Africans and two Romanian women. Amongst the category of older people, three interviews were with those under 50 years whose working conditions engender a relatively high risk of early-onset chronic health problems. They tended to be migrants who had approached the health services for assistance with a chronic condition or other longstanding complaint. It should be noted that there are few female older migrants in the sample in Naples, due to the composition and recentness of migration. The majority had either permanent residency or EU/Italian citizenship. A small number were asylum seekers (2) or were waiting for their residency permits. None were second generation. The average duration of residence was nine-ten years in Bologna and seven years in Naples.

It was extremely difficult to find respondents for the category of young adults with intellectual disability due probably to the short history of migration, and the fact that children in this category may be left behind. Some who were approached in Bologna refused.

Sweden: The two main groups were first-generation migrants from Africa and the Mideast (Iran, Iraq, Turkey). These two groups are the largest migrant communities in Sweden and both were among the first migrant groups to arrive in the country.

Twenty-nine held Swedish citizenship while five were permanent residents who had been in the country for under 10 years, four of whom were amongst the women with reproductive health problems. Five were second generation, four of whom were women with reproductive health problems. Amongst the older group, all were Swedish citizens born abroad whilst amongst young adults with intellectual disabilities there was one permanent resident and one second-generation migrant.

United Kingdom: The two major groups consisted of African and African Caribbeans, on the one hand, and South Asians, on the other. These are the two largest groups but are both quite heterogeneous. Amongst the Africans interviewed, the greatest number were of Somali nationality, most of whom originally entered as asylum seekers and refugees. All of them interviewed within the reproductive health category. African-Caribbeans constitute one of the earliest post-war flows and now form a minority ethnic group of second and third generations. They were interviewed in the reproductive health category and amongst young adults with intellectual disability. The second broad groups of South Asian respondents comprised Bangladeshis, primarily in London, and East African Asians mainly in Leicester where many settled in the 1970s. In addition there are also some Indians who migrated directly from the subcontinent. They were interviewed in all three categories.

Health providers and legal experts

Interviews were also conducted with 142 professionals, including health providers, policy makers, advocacy groups and legal experts with a minimum of 25 per EU Member State studied across the following categories:

(i) Health providers. These ranged across specialist providers such as psychiatrists, gynaecologists, midwives, those working with people with older people and intellectual disability (specify types) as well as GPs, district nurses and health visitors. In Italy a number of cultural mediators and hospital doctors were interviewed.

(ii) Policy makers active in the health sector: at national, regional and local level (according to the institutional setting in each EU Member State). In the United Kingdom there is no regional level so interviews were held with those at the local and national level unlike in Austria and Italy where the regional level is very significant for the provision of healthcare. In Sweden, the interviews covered all levels.

(iii) Advocacy groups. These groups often represented particular ethnic or national groups, migrants more generally or with specific interests (dementia, migrant and Roma women, older people, people with disabilities) or drop-in centres for migrants.

(iv) Ombudsmen, equality bodies and legal experts. Legal experts worked in private firms, as experts in disability law, and in equality bodies and in ombudsmen organisations, hence there was also some overlap between these sub-categories.

Individuals and institutions were contacted because they had expertise or provided services in areas relevant to the three healthcare user groups under study. Groups, who had contact with service users in an advocacy capacity, or were involved in providing services or developing policy were interviewed to ascertain their views on issues concerning the barriers, needs, policies confronting vulnerable groups and their understanding of (multiple and intersectional) discrimination in relation to these groups. They were also a major source of contact for health service respondents.

A separate topic guide was developed for each group of professionals. For provider and advocacy groups the topic guides were fairly similar, asking them about usage and needs of users/patients; their barriers to healthcare; their understanding and experiences of multiple discrimination and unequal treatment; information and training and knowledge and experience of complaints mechanisms. Policy makers were particularly asked about their awareness of health inequalities, needs and barriers of users and patients, multiple discrimination and remedies; policies and targets and whether evaluations had been undertaken.

Health ombudsman and complaints bodies were asked about their awareness of health inequalities, barriers to healthcare and effective complaints systems, their knowledge of multiple discrimination, remedies and policies and targets. Legal experts were also asked whether they were familiar with cases of multiple and intersectional discrimination and the potential contribution of this approach and alternative approaches to dealing with unequal treatment in relation to access to healthcare.

Table A5 indicates the distribution of different kinds of professionals interviewed, by EU Member State.

Table A5: Professionals by category

Category	AT	CZ	IT	SE	UK
Legal	4	4	6	2	3
Ombudsmen & equality bodies	4	5	2	1	3
Providers	12	8	18	16	7
Advocacy	5	9	6	3	8
Policy makers	1	2	6	3	4
Total	**26**	**28**	**40**	**25**	**25**

Source: FRA, 2012

There was a majority of female interviewees, particularly in Austria, Czech Republic and Sweden. This also tended to be the case among providers and advocacy organisations.

Table A6: Professionals by sex

EU Member State	Female	Male
AT	16	10
CZ	22	6
IT	20	20
SE	19	6
UK	13	12
Total	**90**	**54**

Source: FRA, 2012

In terms of diversity of background, approximately 30 % of the professionals interviewed were of migrant or ethnic minority background. This was particularly the case amongst advocacy organisations. Legal experts and ombudsmen were all of non-migrant or non-ethnic background.

Table A7: Diversity of professionals

EU Member State	Migrant background or ethnic minority	Non migrant or non-ethnic background
AT	6	20
CZ	5	23
IT	7	33
SE	9	16
UK	8	17
Total	**35**	**109**

Source: FRA, 2012

Accessing interviewees

A wide range of contacts was used to access respondents: migrant or ethnic minority, specialist NGOs, cultural mediators and advocacy groups, clinics, GPs, migrant friendly health services, mosque associations, language course providers; disability organisations and job programmes for young persons with disability. They were asked to identify persons who belonged to one of the three target groups and had health needs that required the frequent use of healthcare services, including persons who were likely to have experiences of discrimination although they may not have made any formal complaints. In some cases respondents referred to experiences of discrimination they had witnessed happening to others. For young people with intellectual disabilities, specialist organisations were approached.

Challenges in recruiting appropriate individuals were also experienced. There were two issues at play here. For some of the participants in the United Kingdom the personal nature of the topics discussed and the potential for them to be stigmatised in their communities should knowledge of their health condition get out, meant that even organisations that worked with participants on a regular basis found it difficult to convince their users to take part in the interviews. In Austria, one contact person initially refused to help in finding interview partners, fearing the stigmatisation of 'difficult Turkish patients'.

Interview procedures, language issues and quality control

Interviews lasted on average about an hour to an hour and a quarter. They ranged from short interviews of about 30 minutes to some long ones of two hours. Generally, interviews were conducted at the n premises of NGOs, the offices of researchers and professionals as well as day centres. Most interviews were conducted face to face with a few professional interviews undertaken by telephone to suit the needs of the interviewee and the researcher. Female researchers (the team was mainly female) interviewed female respondents.

For migrants whose language ability was not sufficient to be interviewed in the national language, the interview schedules were not translated but interpreters were used. Some interpreters were professionally trained, others worked for the NGO through which the interviewee was contacted or as one part of their counselling or other duties.

For those with intellectual disabilities, either specialist or highly experienced researchers (Austria, Sweden, United Kingdom) were used. They had previously had training in working with persons with disabilities and had close connections with the organisations at which the interviews were conducted (Leicester, Vienna).

In all EU Member States studied, some interviews were conducted with others present. The choice of interpreter must be guided by the interviewee's wishes. In a few cases, the interpreter was a friend or family member of the interviewee to ensure the interviewee felt comfortable during the interview. With young adults with intellectual disabilities in particular a number of interviews were conducted in the presence of other people, be it the carer, a support worker or a friend or family member. In several instances, it was the carer who articulated the needs and experiences of the young person. This approach may carry the risk that the interviewee may not be able to speak freely about private issues in front of family and carers.

Quality control was undertaken in a number of ways.

- Initial stakeholder meetings commented on the design of the research, the groups to be included and made suggestions for advocacy groups, organisations and individuals who would be able to assist the teams in contacting relevant respondents amongst health service users.
- Topic guides for interviews were circulated and commented upon by national teams and the FRA.
- Pilot interviews were undertaken and circulated amongst team members.
- Regular meetings were held amongst team members and fieldworkers were personally briefed.

Intellectual disability

Except for Austria and Italy, where the term intellectual disability had a negative connotation, researchers first interviewed those who defined themselves as intellectually disabled and second those diagnosed with learning difficulties or a diagnosis usually recognised as an intellectual disability, such as Down syndrome, Attention deficit hyperactivity disorder (ADHD). Many of the respondents would be classified as having mild or moderate intellectual disabilities and therefore would have some capacity to work and live independently or in special accommodation for persons with intellectual disabilities, as in Sweden. Some of those interviewed in Sweden had learning difficulties, in particular severe ADHD (one of whom also had Asperger). In Austria, several had Down Syndrome. Those with more severe disabilities were interviewed with carers or with support workers.

Young persons with intellectual disabilities and with ethnic/migrant background proved the most challenging group to access, in particular for those individuals who do not use specialist centres or organisations. This group could not be accessed in Italy and the Czech Republic. For these two EU Member States, the interviews originally designed for this group were redistributed among the other two categories: women of reproductive age and older people with migrant/ethnic background.

Access to respondents was mediated by several stakeholders and associations in each EU Member States. This meant that the sample in each country was quite specific.

In Austria and the United Kingdom, all interviewees, except for one in the United Kingdom, were second generation. In Sweden there was only one second-generation person and all but one were citizens.

Austria: Finding interview partners with an intellectual disability was difficult due to several reasons: first, difficulties were met in finding young persons with a migrant background who had an intellectual disability through job training programmes or programmes offering occupational therapy: the informants have pointed to the fact that many migrant teenagers/young adults with intellectual disability often remain within their families and are therefore limited in their access to support structures. As not all of the respondents had a medical diagnosis and/or their trainers/counsellors were not aware of any, the experiences of trainers/counsellors with the respective persons was taken into account, as well as on a first face-to-face contact with the potential interviewee (prior to the actual interview appointment) where the project was presented.

To identify potential respondents, contacts were established with organisations working with persons with this kind of disability. These organisations included large Austrian organisations promoting training and labour market integration of young persons with learning difficulties and persons with intellectual disabilities, self-representations of persons with disabilities, advocacy organisations, migrant organisations, as well as health providers. Most of the organisations responded negatively, however, because they had no clients or members with a migrant background. Hence two main groups of persons regarding the degree of intellectual disability were interviewed: (i) young adults who were able to deal with matters of daily life independently. They also gave the interview independently. As far as FRA could learn, only a minority of them had a certified medical diagnosis, such as 'retardation', for example. Most respondents in this group, however, did not know their medical history and could not give information on diagnoses, for example. The information given in the interviews in some cases could be complemented and contextualised by talking to social workers or parents after the interview. The second group comprised young adults with different degrees of Down Syndrome who needed support in most aspects of their daily life. The interviews were conducted together with their parents, mainly the mothers.

Sweden: All interviews with persons with learning disability were conducted with the support of the Swedish Disability Federation (HSO). Nearly all of the interviews with young adults were done by two persons – one a manager of the project and another who has been a young adult with a disability. Despite using a wide range of strategies to access respondents, such as contacting all known organisations in this field, special schools and special healthcare facilities for intellectually disabled people in Stockholm and Malmø, difficulties were nevertheless experienced in accessing migrants and members of ethnic communities with intellectual disabilities due to several factors. Young adults with intellectual disabilities from African and Middle-Eastern countries, for example, very seldom live in special housing (so-called group living or group accommodations) for persons with intellectual disabilities, which Swedish-born young adults with mild to moderate intellectual disabilities often do. Young adults with intellectual disabilities from African and Middle-Eastern countries are also under-represented as patients at the healthcare clinics which work with intellectual disabilities and therefore it was not possible to access interviewees through these channels. Finally, young adults with intellectual disabilities from these countries are in general not known as users or members of Swedish disability organisations and very rarely as users or members in ethnic associations/organisations. As in Austria and Italy, they are mostly taken care of within the family and in general not let to live by themselves outside of the family.

The first to be interviewed were those who defined themselves as intellectually disabled followed by those diagnosed with a specific intellectual disability. This resulted in five with mild intellectual disability all of whom had attended special schools and four with learning difficulties, namely severe ADHD, of whom one also has Asperger.

United Kingdom: Accessing young adults with intellectual disabilities was much less difficult. In Leicester, for example, there is a very well established Black and Minority Ethnic (BME) (South Asian) led NGO which was established by a group of Asian parents unsatisfied with the mainstream services and support networks which were not culturally sensitive. The parents set up a support network within the community that now works across all the minority groups. One of the community facilitators conducting the interviews was the founder of the agency. Migrant or ethnic minorities in this case do use services and do not ''keep them (young adults with intellectual disabilities) hidden at home', because of the well organised service that works closely in partnership with the LPS (NHS Community 'Partnership' Trust responsible for mental health and intellectual disability services). They work collaboratively with third-sector organisations, to ensure that their services are well known and accessible, including outreach work and joint working.

Italy: according to several respondents, the failure to find young people with migrant/ethnic background and with an intellectual disability was due to the physical hardship that is often required when migrating (often illegally) from Africa to Italy, which creates a strong selection effect. The recent nature of migration to Italy means that ethnic minorities basically comprise first-generation migrants and (young) children. The weak and partial coverage of public welfare services for young people with this kind of disability imposes considerable financial costs and time constraints, which are often beyond the possibilities of the families of recent migrants, who may be more likely to send children with disabilities to be brought up in their country of origin. A number of organisations were contacted in cities outside the main areas. In several instances, where individuals were identified, they did not wish to give an interview or the NGO felt their family circumstances were too difficult. Eventually two Romanian women, who also had complaints about treatment during their pregnancies, spoke about their experiences with the health system and NGOs in dealing with their young children with intellectual disabilities.

Czech Republic: Finding respondents with intellectual disabilities was not possible, as among the migrants and especially Roma, such a situation is dealt with in the family. Therefore NGOs did not have contacts with clients with intellectual disabilities.

Annex: Supplementary data on patients’ rights, health outcomes and access to healthcare in five selected EU Member States

Table 1: Patients’ rights in five EU Member States

Right	AT	CZ	IT	SE	UK
Horizontal Antidiscrimination leg.	yes [1]	yes [2]	yes [3]	yes [4]	yes [5]
Right access to care and treatment	yes [6]	yes [7]	yes [8]	yes [9]	yes [10]
Right to information	yes [11]	yes [12]	yes [13]	yes [14]	yes [15]
Right to explanation appropriate to the patients capacity of understanding	yes [16]	yes [17]	yes [18]	yes [19]	yes [20]
Right to translation or interpreter support	no	no	no	yes [21]	no [22]
Right to informed consent	yes [23]	yes [24]	yes [25]	yes [26]	yes [27]
Right to free choice	no	yes [28]	yes [29]	yes [30]	yes [31]
Right to privacy and confidentiality	yes [32]	yes [33]	yes [34]	yes [35]	yes [36]
Right to dignity	yes [37]	yes [38]	yes [39]	yes [40]	yes [41]
Right to observance of quality standards	yes [42]	yes [43]	yes [44]	yes [45]	yes [46]

Notes:

1. *The Charter of Patients’ Rights (Vereinbarung zur Sicherstellung der Patientenrechte, Patientencharta), BGBl. I Nr. 42/2006, Art. 3.*
2. *The Charter of Fundamental Rights and Basic Freedoms, No. 2/1993 Coll. (2/1993 Sb., Listina základních práv a svobod), Art. 3 (1) and Art. 24; The Anti-Discrimination Act, Act No. 198/2009 Coll. (zákon č. 198/2009 Sb., o rovném zacházení a o právních prostředcích ochrany před diskriminací a o změně některých zákonů (antidiskriminační zákon), para. 2 (3).*
3. *The Italian Constitution (Costituzione della Repubblica Italiana, G.U. 27.12.1947, no. 298), Art. 3; Law 883/1978 on the Establishment of the National Health System (Legge 883/1978, Istituzione del servizio sanitario nazionale, G.U. 28.12.1978 no. 360 Suppl. Ordinario), Art. 1 (3); The Ethical code for physicians (Codice di deontologia medica), Art. 6 (2).*
4. *The Discrimination Act (Diskrimineringslagen, SFS 2008:567), Chapter 2, para. 13.*
5. *The NHS Constitution, Section 1 (1); available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113645.pdf.*
6. *The Charter of Patients’ Rights (Vereinbarung zur Sicherstellung der Patientenrechte, Patientencharta), BGBl. I Nr. 42/2006, Art. 4 (1); The Professional Qualification of Physicians and medical chambers Act (Bundesgesetz über die Ausübung des ärztlichen Berufes und die Standesvertretung der Ärzte, Ärztegesetz), BGBl. I Nr. 169/1998, Section 49 (1); The Health and Health Care Act (Gesundheits- und Krankenpflegegesetz, GuKG), BGBL. I Nr. 108/1997, Section 4 (1); The Federal Hospitals Act (Krankenanstalten- und Kuranstaltengesetz), BGBL. Nr. 1/1957, Sections 22 and 23; The Viennese Hospitals Act (Wiener Krankenanstaltengesetz), LGBl. 1987/23, Sections 30 (1) and 36 (4); The Styrian Hospitals Act (Steiermärkisches Krankenanstaltengesetz), LGBl. Nr. 66/1999, Section 29 (2) (3) (4).*
7. *The Charter of Fundamental Rights and Basic Freedoms, No. 2/1993 Coll. (2/1993 Sb., Listina základních práv a svobod), Art. 31; The Act on Health Care No. 20/1966 Coll. (zákon č. 20/1966 Sb., o péči o zdraví lidu), para. 9 (1); The Code of Patient rights (Práva pacientů ČR), Art. 1 and 7.*
8. *The Italian Constitution, Art. 32; Legislative Decree No. 502/1992 on the Reorganisation of the Legislation on Health Care, according to Art. 1 of Law 23rd October 1992, Art. 1 (1), and subsequent amendments (d.lgs 502/92, Riordino della disciplina in materia sanitaria, a norma dell’art.1 della legge 23 ottobre 1992 e successive modificazioni, n. 421, G.U. Serie Generale n. 305 del 30 dicembre 1992); Law 883/1978 on the Establishment of the National Health System (Legge 883/1978, Istituzione del servizio sanitario nazionale, G.U. 28.12.1978 no. 360 Suppl. Ordinario), Art. 19.*
9. *The Health and Medical Services Act (most recent version) (Hälso- och sjukvårdslagen), SFS 1982:763, paras. 3, 3b, 18 and 18b.*
10. *The NHS Constitution, Section 2a.*
11. *The Charter of Patients’ Rights (Vereinbarung zur Sicherstellung der Patientenrechte,Patientencharta), BGBl. I Nr. 42/2006, Art. 16 (1); The Federal Hospitals Act (Krankenanstalten- und Kuranstaltengesetz), BGBl. Nr. 1/1957, Section 5a (1); The Viennese Hospitals Act (Wiener Krankenanstaltengesetz), LGBl. 1987/23, Sections 17a (2) (e), 17a (4),17a (5) and 17a (6); The Styrian Hospitals Act (Steiermärkisches Krankenanstaltengesetz), LGBl. Nr. 66/1999, Section 6a (2).*
12. *The Act on Health Care No. 20/1966 Coll. (zákon č. 20/1966 Sb., o péči o zdraví lidu), paras. 23 (1) and 67b (12); The Code of Patient rights (Práva pacientů ČR), Art. 2 and 3.*
13. *Legislative Decree No. 502/1992 on the Reorganisation of the Legislation on Health Care, according to Art. 1 of Law 23rd October 1992, Art. 14 (4), and subsequent amendments (d.lgs 502/92, Riordino della disciplina in materia sanitaria, a norma dell’art.1 della legge 23 ottobre 1992 e successive modificazioni, n. 421, G.U. Serie Generale n. 305 del 30 dicembre 1992); The Ethical code for physicians (Codice di deontologia medica), Art. 33 and 42.*
14. *The Health and Medical Services Act (most recent version) (Hälso- och sjukvårdslagen), SFS 1982: 763, para. 2b.*

15. *The NHS Constitution, Section 2a.*
16. *The Charter of Patients' Rights (Vereinbarung zur Sicherstellung der Patientenrechte,Patientencharta), BGBl. I Nr. 42/2006, Art. 16 (2); The Federal Hospitals Act (Krankenanstalten- und Kuranstaltengesetz), BGBL. Nr. 1/1957, Section 5 (a); The Viennese Hospitals Act (Wiener Krankenanstaltengesetz), LGBl. 1987/23, Section 17 a (2) (h); The Styrian Hospitals Act (Steiermärkisches Krankenanstaltengesetz), LGBl. Nr. 66/1999, Section 6 a (2) (p).*
17. *In non-binding code: The Code of Patient rights (Práva pacientů ČR), Art. 3.*
18. *In non-binding code: The Ethical code for physicians (Codice di deontologia medica), Art. 33 (2).*
19. *The Health and Medical Services Act (most recent version) (Hälso- och sjukvårdslagen), SFS 1982: 763, para. 2b.*
20. *The NHS Constitution, Section 2a.*
21. *The Administrative Act (most recent version), para. 8.*
22. *Where the right to translation or interpreter is not explicitly mentioned in national legislation, it might be implied in the right to explanation.*
23. *The Charter of Patients' Rights (Vereinbarung zur Sicherstellung der Patientenrechte, Patientencharta), BGBl. I Nr. 42/2006, Art. 17 (1); Section 17 a (2) (f) The Viennese Hospitals Act (Wiener Krankenanstaltengesetz), LGBl. 1987/23, Section 17 a (2) (f); The Styrian Hospitals Act (Steiermärkisches Krankenanstaltengesetz), LGBl. Nr. 66/1999, Sections 6 a (2) (e) and 11 (3).*
24. *The Act on Health Care No. 20/1966 Coll. (zákon č. 20/1966 Sb., o péči o zdraví lidu), para. 23 (2); The Code of Patient rights (Práva pacientů ČR), Art. 4.*
25. *Law 883/1978 on the Establishment of the National Health System (Legge 883/1978 "Istituzione del servizio sanitario nazionale", G.U. 28.12.1978 no. 360 Suppl. Ordinario), Art. 33 (1) and (5); The Ethical code for physicians (Codice di deontologia medica), Art. 26 (2) and 35. Moreover, in its judgment No. 6464/1994, the Italian Civil Court of Cassation stated that if physicians do not provide their patients with appropriate information, the contract is nullum ab origine. Thus, a specific tort liability arises towards the physician. The Court also affirmed that, even though the health performance is carried out without mistakes, patients have the right to obtain a favourable judgment against the physician if she/he has omitted to ask them for an informed consent.*
26. *The Health and Medical Services Act (most recent version) (Hälso- och sjukvårdslagen), SFS 1982: 763, para. 2a.*
27. *The NHS Constitution, Section 2a.*
28. *The Act on the Public Health Insurance No. 48/1997 Coll. (zákon č. 48/1997 Sb., o veřejném zdravotním pojištění), para. 11.*
29. *The Italian Constitution, Art. 32 (2); Law 883/1978 on the Establishment of the National Health System (Legge 883/1978, Istituzione del servizio sanitario nazionale, G.U. 28.12.1978 no. 360 Suppl. Ordinario), Art. 19 (2), 25 and 33 ; Legislative Decree No. 502/1992 on the Reorganisation of the Legislation on Health Care, according to art.1 of Law 23rd October 1992, Art. 8, and subsequent amendments (d.lgs 502/92, Riordino della disciplina in materia sanitaria, a norma dell'art.1 della legge 23 ottobre 1992" e successive modificazioni, n. 421, G.U. Serie Generale n. 305 del 30 dicembre 1992); The Ethical code for physicians (Codice di deontologia medica), Art. 3, 16 and 27.*
30. *The Health and Medical Services Act (most recent version) (Hälso- och sjukvårdslagen), SFS 1982: 763, para. 3a.*
31. *The NHS Constitution, Section 2a.*
32. *The Charter of Patients' Rights (Vereinbarung zur Sicherstellung der Patientenrechte, Patientencharta), BGBl. I Nr. 42/2006, Art. 2; The Health and Health Care Act (Gesundheits- und Krankenpflegegesetz, GuKG), BGBL. I Nr. 108/1997 (as amended), Section 6 (1); The Professional Qualification of Physicians and medical chambers Act (Bundesgesetz über die Ausübung des ärztlichen Berufes und die Standesvertretung der Ärzte, Ärztegesetz), BGBl. I Nr. 169/1998, Section 54 (1); The Federal Hospitals Act (Krankenanstalten- und Kuranstaltengesetz), BGBl. Nr. 1/1957, Section 9 (1); The Viennese Hospitals Act (Wiener Krankenanstaltengesetz), LGBl. 1987/23, Section 17 a (2) (b) (c); The Styrian Hospitals Act (Steiermärkisches Krankenanstaltengesetz), LGBl. Nr. 66/1999, Section 6 a (2) (c) (l); The Criminal Code (Bundesgesetz vom 23. Jänner 1974 über die mit gerichtlicher Strafe bedrohten Handlungen – Strafgesetzbuch), BGBl. Nr. 60/1974, Section 121 (1).*
33. *The Act on Health Care No. 20/1966 Coll. (zákon č. 20/1966 Sb., o péči o zdraví lidu), para. 55 (2); The Act on the Protection of Personal Data No. 101/2000 Coll. (zákon č. 101/2000 Sb., o ochraně osobních údajů), para. 13 (1); The Code of Patient rights (Práva pacientů ČR), Art. 2, 5 and 6.*
34. *Law 883/1978 on the Establishment of the national health system (Legge 883/1978, Istituzione del servizio sanitario nazionale, G.U. 28.12.1978 no. 360 Suppl. Ordinario), Art. 27; Legislative Decree no. 196/2003 on the Data protection code (D.lgs 196/2003, Codice in materia di protezione dei dati personali", G.U. n. 174 del 29 luglio 2003 - Supplemento Ordinario n. 123), Art. 76 and 90; The Ethical code for physicians (Codice di deontologia medica), Art. 11 and 12.*
35. *The Public Access to Information and Secrecy Act SFS 2009:400 (most recent version), Chapter 25, para. 1.*
36. *The NHS Constitution, Section 2a.*
37. *The Charter of Patients' Rights (Vereinbarung zur Sicherstellung der Patientenrechte – Patientencharta), BGBl. I Nr. 42/2006, Art. 2; The Viennese Hospitals Act (Wiener Krankenanstaltengesetz), LGBl. 1987/23 of 24 March 1987 as amended by LGBl. 2010/56 of 22 October 2010, Section 17 a; The Styrian Hospitals Act (Steiermärkisches Krankenanstaltengesetz), LGBl. Nr. 66/1999, Section 6 a (2) (b).*
38. *In non-binding code: The Code of Patient rights (Práva pacientů ČR), Art. 5.*
39. *The Italian Constitution, Art. 32 (2); Law 883/1978 on the Establishment of the national health system (Legge 883/1978, Istituzione del servizio sanitario nazionale, G.U. 28.12.1978 no. 360 Suppl. Ordinario), Art. 1 (2); Law 883/1978 on the Establishment of the national health system (Legge 883/1978, Istituzione del servizio sanitario nazionale, G.U. 28.12.1978 no. 360 Suppl. Ordinario), Art. 33 (2); Legislative Decree No. 502/1992 on the Reorganisation of the legislation on health care, according to art.1 of Law 23rd October 1992, Art. 1, and subsequent amendments (d.lgs 502/92, Riordino della disciplina in materia sanitaria, a norma dell'art.1 della legge 23 ottobre 1992 e successive modificazioni, n. 421, G.U. Serie Generale n. 305 del 30 dicembre 1992), Art. 1; The Ethical code for physicians (Codice di deontologia medica), Art. 3 and 4.*
40. *In Preamble of Discrimination Act Chapter 1, para. 1 of Discrimination Act (Diskrimineringslagen), SFS 2008:567.*
41. *The NHS Constitution, Section 2a.*
42. *The Charter of Patients' Rights (Vereinbarung zur Sicherstellung der Patientenrechte,Patientencharta), BGBl. I Nr. 42/2006, Art. 7 (1) and (2); The Viennese Hospitals Act (Wiener Krankenanstaltengesetz), LGBl. 1987/23, Section 17 a (2) (d); The Styrian Hospitals Act (Steiermärkisches Krankenanstaltengesetz), LGBl. Nr. 66/1999, Section 11d; The Health and Health Care Act (Gesundheits- und Krankenpflegegesetz, GuKG), BGBL. I Nr. 108/1997, ,Section 14 (1); The Professional Qualification of Physicians and medical chambers Act (Bundesgesetz über die Ausübung des ärztlichen Berufes und die Standesvertretung der Ärzte, Ärztegesetz), BGBl. I Nr. 169/1998, Section 49 (1); The Federal Hospitals Act (Krankenanstalten- und Kuranstaltengesetz), BGBl. Nr. 1/1957, Section 5b (1).*

43. The Act on Health Care No. 20/1966 Coll. (zákon č. 20/1966 Sb., o péči o zdraví lidu), para. 11 (1).

44. The Italian Constitution, Art. 97; Legge 241/1990 Nuove norme in materia di procedimento amministrativo e di diritto di accesso ai documenti amministrativi, G.U. n° 192 del 18/08/1990, Art. 1; Legislative Decree no. 502/1992 on the Reorganisation of the legislation on health care, according to art.1 of Law 23rd October 1992, Art. 1 (2), 10 (1) and 14 (1), and subsequent amendments (d.lgs 502/92 "Riordino della disciplina in materia sanitaria, a norma dell'art.1 della legge 23 ottobre 1992" e successive modificazioni, n. 421, G.U. Serie Generale n. 305 del 30 dicembre 1992"); The Ethical code for physicians (Codice di deontologia medica), Art. 21 and 24.

45. The Health and Medical Services Act (most recent version) (Hälso- och sjukvårdslagen), SFS 1982: 763, para. 31; The Patients'Security Act (Patientsäkerhetslagen), SFS 2010:659, Chapter 7, para. 1.

46. The NHS Constitution, Section 2a.

Source: FRA, 2012

Table 2: Availability of systematic statistics on health outcomes and access to healthcare

Theme/Variables	EU Member State	Sex	Age	Disability	Ethnicity proxy**	Source
Mortality*	**AT**	YES	YES	NO	cob, nat	Death registers
	CZ	YES	YES	NO	cit	Death registers
	IT	YES	YES	NO	cit	Death registers
	SE	YES	YES	NO	cob	Death registers
	UK	YES	YES	NO	cob; ethn	Death registers
Health status	**AT**	YES	YES	NO	mig	Austrian Health Survey
	CZ	YES	YES	YES	NO	EHIS
	IT	YES	YES	YES	cit	Multiscopo
	SE	YES	YES	NO	cob	Swedish Living Conditions Survey (ULF)
	UK	YES	YES	YES	ethn	Census, HSE
Specific health conditions	**AT**	YES	YES	NO	mig	Austrian Health Survey
	CZ	YES	YES	NO	NO	EHIS
	IT	YES	YES	NO	cit	Multiscopo
	SE	YES	YES	NO	cob	ULF
	UK	YES	YES	YES	ethn	HSE
Disability	**AT**	YES	YES	n.a.	mig	Austrian Health Survey
	CZ	YES	YES	n.a.	NO	EHIS
	IT	YES	YES	n.a.	cit	Multiscopo
	SE	YES	YES	n.a.	cob	Swedish Living Conditions Survey (ULF)
	UK	YES	YES	n.a.	ethn	Census, LFS
Mental health	**AT**	YES	YES	NO	mig	Austrian Health Survey
	CZ	YES	YES	NO	NO	EHIS
	IT	YES	YES	YES	cit	Multiscopo
	SE	YES	YES	NO	cob	NSPH
	UK	YES	YES	YES	ethn	HSE
Health related lifestyle	**AT**	YES	YES	NO	mig	Austrian Health Survey
	CZ	YES	YES	NO	NO	EHIS
	IT	YES	YES	YES	cit	Multiscopo
	SE	YES	YES	NO	cob	NSPH
	UK	YES	YES	YES	ethn	HSE
Access to health care	**AT**	YES	YES	NO	mig	Austrian Health Survey
	CZ	YES	YES	NO	NO	IHIS, insurance funds
	IT	YES	YES	YES	cit	Multiscopo
	SE	YES	YES	YES	cob	Register
	UK	YES	YES	YES	ethn	HSE

*Notes: * Mortality and infant mortality.*

*** Ethnicity or main proxy, including Ethnicity (ethn); nationality/citizenship (cit); country of birth (cob) and 'migration background' – some groups only (mig).*

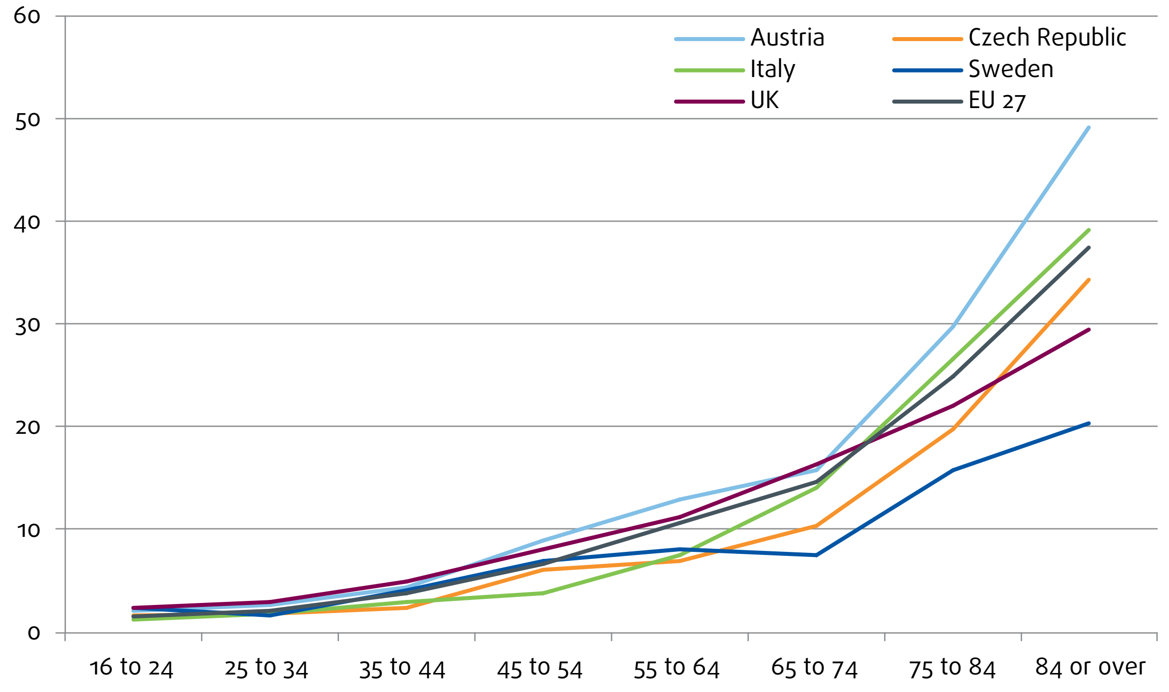
Source: FRA, 2012

Table 3: Health condition by 'disability'* and sex, EU-27 (%)

	General Health	Limitation in activity because of health problems				Grand Total
		yes, strongly limited	yes, limited	no, not limited	n.a.	
Females	Very Good	1.0	2.2	26.6	0.4	17.1
	Good	5.5	18.6	52.4	1.4	36.6
	Far	23.1	52.3	18.4	1.2	22.4
	Bad	45.4	24.2	1.7	0.2	8.6
	Very Bad	23.7	2.2	0.2	0.0	2.3
	N.A.	1.2	0.6	0.8	96.8	13.0
Females Total		**100.0**	**100.0**	**100.0**	**100.0**	**100.0**
Males	Very Good	1.4	2.7	29.7	0.3	19.9
	Good	6.7	20.9	52.0	1.1	37.3
	Far	24.2	52.1	15.5	0.9	18.7
	Bad	43.7	21.3	1.3	0.2	6.4
	Very Bad	22.6	1.8	0.1	0.0	1.7
	N.A.	1.5	1.2	1.4	97.4	16.0
Males Total		**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

*Note: * Self-perceived limitations in daily activities (activity restriction for at least the past 6 months).*
n.a. = not available
Source: EU-SILC, 2009 (New analysis of Eurostat datasets for the present report)

Figure 1: Self-perceived strong limitations in daily activities (%) by age



Source: EU-SILC, 2009 (New analysis of Eurostat datasets for the present report)

European Union Agency for Fundamental Rights

Inequalities and multiple discrimination in access to and quality of healthcare

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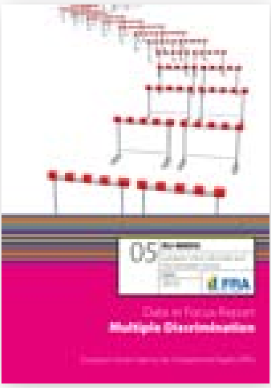
A great deal of information on the European Union Agency for Fundamental Rights is available on the Internet.
It can be accessed through the FRA website at fra.europa.eu.

This FRA report looks at multiple discrimination with regard to certain minority groups.



05

Data in Focus Report

Multiple Discrimination

EUROPEAN UNION AGENCY FOR FUNDAMENTAL RIGHTS

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HELPING TO MAKE FUNDAMENTAL RIGHTS A REALITY FOR EVERYONE IN THE EUROPEAN UNION

Certain people are seen as particularly vulnerable to unequal treatment, because they share a combination of characteristics that may trigger discrimination. A Roma woman sterilised without her informed consent, for example, has suffered discrimination not just because of her sex, as all women do not face this treatment, nor just because she is Roma, as Roma men may not face this treatment. The discriminatory treatment is based specifically on the intersection of her sex and ethnic origin. Although awareness of this phenomenon of multiple discrimination is on the rise, EU law has yet to adequately address it. Current EU law provides better protection against discrimination based on race and sex than on grounds of religion or belief, disability, age or sexual discrimination, making it difficult to tackle multiple discrimination.

This research project aims to shed light on the experience of multiple discrimination in healthcare. It looks at how 'multiple' discrimination is legally addressed and examines relevant case law with a special focus on healthcare. It also explores healthcare users' and professionals' views and experiences on how people of different gender, age, disability and ethnic origin experience discrimination and multiple discrimination when accessing the health system. It found respondents had experienced unequal or unfair treatment in relation to access to and quality of healthcare, discusses a number of barriers they face and points to possible improvements.

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