

Terms of reference

## ANNEX A.1

# DRAFT TECHNICAL SPECIFICATIONS

**D/SE/10/09**

“Inequalities and multiple discrimination in access to health”

## Terms of reference

### 1. Technical specifications

#### 1.1. Objective

The objective of the Technical Specifications is to provide the contractor(s) with all the necessary information that will allow them to develop a Technical Offer and a price offer.

#### 1.2. Title of the contract

“Inequalities and multiple discrimination in access to health”.

#### 1.3. Contracting Authority

The contracting authority is the European Union Agency for Fundamental Rights (hereinafter referred to as the FRA or the Agency). The Agency was established by Council Regulation No 168/2007 on 15 February 2007. Its objective is to provide the relevant institutions, bodies, offices and agencies of the Community and its Member States when implementing Community law with assistance and expertise relating to fundamental rights. In order to achieve this objective the Agency is required to perform a number of tasks, including data collection and research. The research commissioned through this Call for Tender is undertaken within the scope of the Agency's Work Programme 2010 available on its website.

### 2. Background information

The Multi-annual Framework for the European Union Agency for Fundamental Rights for 2007-2012 covers, among other areas, “discrimination based on sex, race or ethnic origin, religion or belief, disability, age or sexual orientation and against persons belonging to minorities and **any combination of these grounds (multiple discrimination).**”

The Treaty of Amsterdam granted the Community new powers to combat discrimination on the grounds of sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation. Since the Treaty of Amsterdam came into force in 1999 five Directives in the area of non-discrimination have been adopted: the Racial Equality Directive (2000/43/EC), the Employment Equality Directive (2000/78/EC), the Equal Treatment Amendment Directive (2002/73/EC), the Gender Directive (2004/113/EC), and the Gender Recast Directive (2006/54/EC). As a result of these Directives, equal treatment on the grounds of racial or ethnic origin and gender was introduced in the following areas: social protection, including social security and healthcare; social advantages; education; and access to goods and services, including housing.

**Multiple discrimination** is addressed in the Racial Equality Directive that states the need “to eliminate inequalities, and to promote equality between men and women, especially since women are often the victims of multiple discrimination”<sup>1</sup>.

Other EU official documents emphasise the need “to develop new practice and policy for combating discrimination, including multiple discrimination”<sup>2</sup> and “to promote measures to

---

<sup>1</sup> Recital 14 of the “Racial Equality Directive” (Directive 2000/43/EC), see also <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2000:180:0022:0026:EN:PDF>

<sup>2</sup> Recital 5 of the Community Action Programme to combat Discrimination (2001 to 2006) [2000] OJ L 303/23 see also <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2000:303:0023:0028:EN:PDF>

## Terms of reference

prevent and combat discrimination whether based on one or on multiple factors<sup>3</sup>. But no definition of multiple discrimination or indications on how to combat it is specified.

As part of the Renewed Social Agenda, in 2008 the Commission adopted a proposal for a new Directive on equal treatment prohibiting discrimination on grounds of age, disability, sexual orientation and religion or belief outside the employment sphere<sup>4</sup> (hereafter called “horizontal directive”). The proposed directive intends to reduce discrimination whether direct or indirect, and whether based on real or presumed criteria. In its current draft, the Directive would apply to social protection and health care, social benefits, education and access to goods and services, including housing.

The proposal for the new Directive builds upon the strategy developed since the Amsterdam Treaty to combat discrimination and to further the fundamental rights of citizens, in line with the provisions of EU Charter of Fundamental Rights. Within the context of the preparatory work of the European Commission for the proposal, attention was drawn to “the need to tackle multiple discrimination, for example by defining it as discrimination and by providing effective remedies”<sup>5</sup>.

In recent years, the phenomenon of multiple discrimination has been increasingly acknowledged, but to date little is known on the groups more likely to face it and the sectors concerned.

In its Communication on “Solidarity in Health”<sup>6</sup>, the Commission invited the Fundamental Rights Agency could, “within the limits of its mandate, 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 health care, social and housing assistance”.

This project aims to fill this gap. Building on previous analysis funded by the EU, this social research will look at **inequalities and multiple discrimination in access to health services**.

The right to health is a human right and the European Charter of Fundamental Rights specifies the following: the right to access preventive health care, the right to benefit from medical treatment and to working conditions which respect health<sup>7</sup>.

More specifically the project will explore access to health among vulnerable groups at the intersection of **age, gender and ethnic origin**.

The research will also include access to health among persons with disabilities<sup>8</sup> at the intersection of **age, gender and ethnic origin**. Promoting and protecting the rights of people with disabilities is a major objective in the European Union, but also internationally. People with disabilities often face difficulties when they try to use health services<sup>9</sup>. According to Article 10 of the Treaty on the Functioning of the European Union, in defining and implementing its policies and activities, the Union shall aim to combat discrimination, including discrimination based on disability.

<sup>3</sup> Article 2 on the objectives Community Action Programme to combat Discrimination (2001 to 2006) [2000] OJ L 303/23 see also <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2000:303:0023:0028:EN:PDF>

<sup>4</sup> The European Parliament has adopted the proposed directive in April 2009 and on May 2010 the Spanish Presidency issued a Progress Report on Council negotiations

<sup>5</sup> COM (2008) 426. <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:52008PC0426:EN:NOT>

<sup>6</sup> COM(2009) 567 see [http://ec.europa.eu/health/ph\\_determinants/socio\\_economics/documents/com2009\\_en.pdf](http://ec.europa.eu/health/ph_determinants/socio_economics/documents/com2009_en.pdf)

<sup>7</sup> Article 31 and 35 of the European Charter of Fundamental Rights

<sup>8</sup> There are different ways of defining disability. Throughout this document we will use the UN Convention definition of persons with disabilities as a frame of reference. It distinguishes 4 main types of disability (i) physical (ii) sensory (iii) intellectual (iv) mental

<sup>9</sup> For example, according to a report by the European Policy Evaluation Consortium (EPEC), throughout Europe “8.4 million of severely or very severely people with disabilities are estimated to face discrimination when accessing health services”.

## Terms of reference

The Charter of Fundamental Rights of the European Union reaffirms the right of non-discrimination and the principle of integration of persons with disabilities<sup>10</sup>.

The United Nations Convention on the Rights of Persons with Disabilities (thereafter CRPD or the Convention) and its Optional Protocol, clarify the obligations and legal duties of States to respect and ensure the equal enjoyment of all human rights by all persons with disabilities<sup>11</sup>. The European Community itself is a signatory to the Convention. Article 25 of the Convention states that “persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability, and shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive”.<sup>12</sup>

### 2.1. Inequality and multiple discrimination in access to health

**Multiple discrimination** describes a situation where discrimination takes place on the basis of several grounds operating separately. For instance an ethnic minority woman may experience discrimination on the basis of her gender in one situation and because of her ethnic origin in another. **Intersectional Discrimination** refers to a situation where several grounds operate and interact with each other at the same time in such a way that they are inseparable<sup>13</sup>.

From a legal point of view, the notion of multiple and intersectional discrimination has been deemed to be a useful tool to capture differences in treatment, or inequalities, that would otherwise not be fully captured under the realm of unlawful unequal treatment, which normally functions through a ‘single-ground’ approach. For example, Muslim women may encounter a mixture of sex, ethnic and religious discrimination not experienced by Muslim men or by white women. The logic of a single category being subject to inequalities is not sufficient to cover such experiences of social disadvantage. In addition, some legal systems would not be able to address these situations.

The notion of **intersectionality**<sup>14</sup> broadens the understanding of legally defined discrimination, insofar as it requires addressing issues of vulnerability and disadvantage at a group level. There are a number of individuals in society that are among the most *vulnerable* to inequalities based on the constellation of factors that mark their particular position in society. Globally speaking, being a woman or being a member of an ethnic minority is associated with a certain amount of vulnerability. Evidence of this vulnerability tends to be of a structural nature, including statistics on illiteracy, poverty, socio-economic situation, and so on<sup>15</sup>.

The association of socio-economic status, poor language competencies, immigration background, young or old age, etc., which may be compounded by disabilities, may produce vulnerability and inequalities that might not be captured under the notion of discriminatory treatment. To the extent that it does, discrimination law might play a role in ensuring a remedy, but to the extent it does not, other remedies should be sought, such as redistribution, welfare reforms, training, information, etc. **This research should try to capture both**

<sup>10</sup> OJ C 364, 18.12.2000, p. 1 see also <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:C:2000:364:0001:0022:EN:PDF>

<sup>11</sup> Convention on the Rights of Persons with Disabilities (CRPD), adopted by the UN General Assembly on 6 December 2006, entered into force on 3 May 2008, ref U.N. Doc. A/61/611, see also <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N06/500/79/PDF/N0650079.pdf?OpenElement>

<sup>12</sup> Article 25, UN Convention on the Rights of Persons with Disabilities, see also <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

<sup>13</sup> European Commission, “Tackling Multiple Discrimination: policies, practices and laws”, 2007, see also <http://ec.europa.eu/social/BlobServlet?docId=2026&langId=en>

<sup>14</sup> “Intersectionality” has become the most frequently used word in academic literature to capture the significance of the intersection of two categories or grounds of discrimination, more commonly referring to the intersection of gender and race. Official publications within the European Union which address issues that imply some form of **intersectionality** use the term **multiple discrimination**.

<sup>15</sup> Makkonen T. (2002) “Multiple, Compound and Intersectional Discrimination: Bringing the Experiences of the Most Marginalized to the Fore”. Institute for Human Rights. Åbo Akademi University.

## Terms of reference

**multiple and intersectional discrimination (legally defined) and inequalities (that do not fall under the law) in access to healthcare services.**

### 2.2. Existing research in the field

Evidence point to discrimination in access to healthcare, referring to both direct discrimination e.g. refusal to treat patient, denial of emergency care, verbal abuse and degrading treatment, segregation in special areas of hospital but also indirect discrimination e.g. absence of linguistic or cultural mediators that hinder ethnic minority individuals chance to access care. In addition, it includes discrimination people might not be aware of such as lower quantity and quality of care. Other recurrent problems that have been addressed in the literature are: private funding of healthcare which specifically impact on poorer groups; long waiting list that can be overcome just by people who have the economic means to access private care; low health literacy among specific groups.

#### 2.2.1 Research on Multiple discrimination

##### Work funded by the European Commission

At the level of the European Commission, the following research has been undertaken.

1. In 2007 the EU Commission published the report “Tackling Multiple Discrimination. Practices, policies, laws” in order to address the need to find “workable solutions to combat the existence of Multiple Discrimination”. The report was based on a literature review, stakeholder meetings and questionnaires that were sent out to ministries, National Equality Bodies and NGOs in 10 EU Member States. Generally, the document concludes that the EU anti-discrimination legislation recognizes that different protected grounds can intersect, “but there is no explicit prohibition of Multiple Discrimination. Specific prohibition of Multiple Discrimination would create a greater awareness of the problem... in turn providing more effective protection for individuals and groups experiencing Multiple Discrimination.” The report states that “in theory all EU Member States which have transposed EU anti-discrimination and equal treatment legislation could address Multiple Discrimination, at least in the field of employment. However as EU legislation does not include an explicit provision, most Member States do not address Multiple Discrimination<sup>16</sup>.”

The majority of Ministries, NGOs and Equality Bodies surveyed for this report do not have specific strategies targeting multiple discrimination. The study also highlights the existence of difficulties in taking into account the concept of multiple discrimination in anti-discrimination legislation. The report points to a lack of research and data collection in the field.

2. In 2009, following a request by the EU Commission, the European Network of Legal Experts in the field of gender equality published “Multiple Discrimination in EU Law. Opportunities for legal responses to intersectional gender discrimination?”. The study focused on legal problems related to gender equality and multiple discrimination. Experts from single MSs were asked to list cases of multiple discrimination including gender: the largest number of cases reported was on the ground of gender and ethnic origin.

3. The 2010 report of the European Commission “Ethnic Minority and Roma Women in Europe: a Case for Gender Equality?” presents the socio-economic conditions and

---

<sup>16</sup> The absence of such legal provisions is demonstrated by the aforementioned review carried out for this study by the European Network of Legal Experts at the beginning of 2007.”

## Terms of reference

perspectives of women belonging to disadvantaged ethnic minorities, with special attention to Roma women. The report recalls that existing evidence suggests that ethnic minority and especially Roma women are the most vulnerable to multiple discrimination and present higher risks of social exclusion and poverty than the women of the native population and minority men. The report also emphasises that there are differences in the social and economic conditions of women among and within ethnic minorities and across European countries.

4. The abovementioned studies are mainly 'mapping study' of the legislation in different Member States. The lack of empirical research has partly been addressed by Commission funded projects. The 7<sup>th</sup> Framework project Genderace is researching the experience of people who have lodged complaints on the grounds of gender and race in 6 EU member states. The 2 main hypotheses underlying the research are: 1) that women and men will use race equality law differently, and 2) that intersectional experience of discrimination based on race and gender is not recognised properly in legal frameworks based on a single ground approach. The research includes both a legal analysis on the multiple discrimination law and a primary research on victim's experience of access to law. The research focuses mainly albeit not only on the employment sector and the results are not yet available.

Apart from the above-mentioned initiatives, projects on discrimination funded by the 5<sup>th</sup>, 6<sup>th</sup> and 7<sup>th</sup> framework adopted mainly a single ground approach<sup>17</sup>.

### The work of the European Union Agency for Fundamental Rights

1. In 2008 FRA carried out the first European Union wide survey to ask immigrant and ethnic minority groups about their experiences of discrimination and criminal victimisation in everyday life<sup>18</sup>.

Among EU-MIDIS questions on discrimination, one explored respondent's actual experience of discrimination in the past 12 months. The respondent could indicate their experience of discrimination on more than one ground thus pointing to the experience of multiple discrimination. More specifically, the respondent could indicate if he felt personally discriminated against or harassed on the basis of at least two of the following factors: ethnic or immigrant origin, gender, sexual orientation, age, religion or belief, disability or another reason. The question formulation in the EU-MIDIS leaves open the interpretation if the discrimination experience on at least two grounds occurred simultaneously. According to the findings, 23% of the respondents reported they were discriminated against on a single ground in the past 12 months, whereas 14% reported being discriminated against on multiple grounds. The data don't allow us conclude in which sectors multiple discrimination occurs. Despite this, the results support the proposal to introduce the concept of multiple discrimination into the framework of horizontal directive to account for the fact that discrimination can occur on more than one ground.

2. In 2003 the EUMC undertook a project on Romani Women access to Public Health Care<sup>19</sup>. The report highlighted the specific constraints and the discriminatory practices Romani Women face in accessing health care in different MSs. These include refusal of assistance by general practitioners or health care institutions; segregation in health care facilities; degrading treatment and difficulty in accessing emergency care.

---

<sup>17</sup> See for instance "Religious Discrimination of Muslims in the European Union: experience of injustice, fight for recognition and implementation of equality in a plural society" 2005-2006 (6th Framework); The European dilemma: institutional patterns and politics of 'racial' discrimination XENOPHOB 2002-2006 on racial discrimination in 8 MSs; Racial and ethnic minorities, immigration and the role of trade unions in combating discrimination and xenophobia, in encouraging participation and in securing social inclusion and citizenship (RITU) 2003-2005; 4 member states;

<sup>18</sup> In total – 23,500 immigrant and ethnic minority people were surveyed in face-to-face questionnaire interviews in all 27 Member States of the EU during 2008. A further 5,000 people from the majority population living in the same areas as minorities were interviewed in ten Member States to allow for comparisons of results concerning some key questions.

<sup>19</sup> EUMC (2003), "Breaking the Barriers – Romani Women and Access to Public Health Care" see also <http://fra.europa.eu/fraWebsite/attachments/ROMA-HC-EN.pdf>

## Terms of reference

### Other research

Apart from above mentioned EU Framework research on intersectional discrimination has been conducted in single MSs and has mainly focused on discrimination in access to employment and education for groups at the intersection of ethnicity with other grounds (mainly gender or age) e.g. the discrimination faced by migrant women in the labour market or the condition of second generation migrants in schools<sup>20</sup>.

### 2.2.2 Intersectional research in health

#### Work funded by the European Commission

At the level of the European Commission, DG SANCO (Health and Consumers) is directly engaged with public health promotion. Its mission includes tackling social determinants of health inequalities through, *inter alia*, funding of different research<sup>21</sup> and community action<sup>22</sup> projects. These projects specifically addressed the following groups: adolescent, elderly, Roma and irregular migrants. DG EMPL (Employment, Social Affairs and Equal Opportunities) is working on discrimination and promotion of health in work settings.

We will briefly review projects that focused on health inequalities on one or more grounds including gender, age, ethnic origin and disability.

1. The 5<sup>th</sup> Framework project “Minority Elderly Care” (MEC) addressed the intersection of age and ethnic origin and focused on minority elderly health and social care across ten European countries<sup>23</sup>. In each country, elders from the three main ethnic groups were interviewed and their expectations and perceptions on the health care system assessed. Health and social care professionals and organizations were also interviewed in order to assess awareness of specific health problems, needs and access barriers by Black Minority Ethnic (BME) elders. Among the research findings were the information available on health services for each ethnic group, the barriers accessing health services encountered by specific groups, the request for cultural sensitive medical treatment; health professionals’ awareness of specific needs; inclusion of cultural information in health service design. For instance, the socio-economic situation of patients was considered the least important reason for BME elders’ special needs whereas many statistics point to the high negative impact of poverty on health and well-being. Thus a project recommendation is the need for a greater awareness among health professional of the role of socioeconomic status. Another relevant result was difference in expectations and perceptions with regard to health provision among users and providers of health services. Thus a specific recommendation is to design policies on issues that although not perceived by service providers as important, may be very important to some of their service users.

However, most EU funded projects focused on the collection of best practices or the review of relevant literature and included no actual data collection through fieldwork.

2. According to a report commissioned by DG Employment, Social Affairs and Equal Opportunities on women with disabilities<sup>24</sup>:

---

<sup>20</sup> See for instance OECD-PISA data on differences between ‘second generation’ immigrant families and the other students in school performance and drop out rates. Available at <http://www.pisa.oecd.org/>

<sup>21</sup> For a full list of funded projects see [http://ec.europa.eu/health/ph\\_determinants/socio\\_economics/documents/project\\_list\\_en.pdf](http://ec.europa.eu/health/ph_determinants/socio_economics/documents/project_list_en.pdf)

<sup>22</sup> For a full list of funded projects see [http://ec.europa.eu/health/ph\\_programme/documents/award\\_decision2009.pdf](http://ec.europa.eu/health/ph_programme/documents/award_decision2009.pdf)

<sup>23</sup> See, for example, Patel, N. and Traynor, P, *Developing Extra Care Housing for Black and Minority Ethnic Elders: an Overview of the Issues, Examples and Challenges*, 2006, PRIAE and Housing Learning and Improvement Network.

<sup>24</sup> EC, “Study on the situation of women with disabilities in light of the UN Convention for the Rights of Persons with Disabilities”, 2009. Available at <http://ec.europa.eu/social/BlobServlet?docId=4365&langId=en>

## Terms of reference

- women with disabilities face the "intersection" of gender and disability, which combines to create a distinct and particular experience of disadvantage and discrimination, not suffered by others
- Women with disabilities typically receive health services that are targeted at women in general or at people with disabilities in general, but rarely targeted specifically at them
- Social protection systems tend not to recognise gender differences and women with disabilities are not generally recognised as a legal term in that context.

3. In 2008 the report "Quality in and equality of access to healthcare services: HealthQUEST" was published, funded by the DG Employment, Social Affairs and Equal Opportunities. The report analysed barriers in accessing healthcare for people at risk of social exclusion and provided an overview of effective policy initiatives in 8 Member States to reduce these barriers. The analysis was conducted through a review of the literature and focused on 3 specific vulnerable groups: migrants, older people with functional limitations and people with mental disorders. Key findings were that although most countries provide health coverage, most of them exclude irregular migrants from non-emergency care; cost sharing requirements are common in many countries and they disproportionately affect vulnerable people who can't afford out-of-pocket payments.

4. According to a 2009 report on disability funded by DG Employment, Social Affairs and Equal Opportunities<sup>25</sup> "people with disabilities are sometimes prevented from accessing healthcare on an equal basis with others by the negative and discriminatory attitudes of healthcare providers. Such attitudes may be born out by the inappropriate assumptions about the quality of a disabled person's life. They also arise out of fear of how people with disabilities might behave or nervousness as to how to react to them". This attitude can result in less detailed examinations and in an unpleasant experience for the disabled person that might prevent him/her from seeking assistance in the future. Further, unfounded assumptions about the inadequacy of people with disabilities as parents or about their sexual behavior may result in unequal access to sexual and reproductive healthcare services<sup>26</sup>. According to evidence though, those with disability and women disabled in particular are likely to have more sexual partners than their non disabled peers. Extreme poverty and social sanctions against marrying a disabled person mean that they are likely to become involved in a series of unstable relationships<sup>27</sup>.

Other projects funded by DG Sanco that are of interest to this study are ENGENDERER<sup>28</sup>; MIGHEALTHNET - Information network on good practice in health care for migrants and minorities<sup>29</sup>, ITHACA - Institutional Treatment, Human Rights and Care Assessment.<sup>30</sup> Lastly, work done by the EuroHealthNet and its partner organisations, in particular Closing the Gap and Determine projects constitute useful sources of information and evidence<sup>31</sup>.

Finally in its 2009 Communication on health inequalities, the European Commission mandates the Fundamental Rights Agency to further collect evidence base in this area<sup>32</sup>.

### The work of the European Union Agency for Fundamental Rights

---

<sup>25</sup> European Commission, "Disability and non-discrimination law in the European Union. An analysis of disability discrimination law within and beyond the employment field", 2009. See <http://ec.europa.eu/social/BlobServlet?docId=4393&langId=en>

<sup>26</sup> Report by European network of legal experts on discrimination

<sup>27</sup> Groce E., "HIV-Aids and people with disability", The Lancet, vo. 361, April 2003

<sup>28</sup> The project objective is to create an inventory of good practice promoting gender equity in health.

<sup>29</sup> Its aim is to stimulate the exchange of knowledge on migrant and minority health through the development of a data bases in each of the participating countries. See [http://mighealth.net/eu/index.php/Main\\_Page](http://mighealth.net/eu/index.php/Main_Page).

<sup>30</sup> It identifies and disseminates best practice to improve the protection of human rights and the general health status of residents in health or social care institutions with mental ill-health, mental disabilities or dependency. It includes questions on access to healthcare. See <http://www.ithaca-study.eu/>.

<sup>31</sup> More information at: <http://www.eurohealthnet.eu> and <http://www.health-inequalities.eu>

<sup>32</sup> <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2009:0567:FIN:EN:PDF>

## Terms of reference

Since 2009 FRA is undertaking research on the rights of persons with intellectual disabilities and persons with mental health problems, including legal and social analysis of their situation. The main research focuses primarily on the rights to independent living, access to justice and legal capacity<sup>33</sup>.

### Other research

Other important research findings point to the role of health professionals inadvertently contributing to disparities in health care. As mentioned before, health professional practice and attitudes are very important in contributing to patient's wellbeing but to date little is known about how practising health professionals experience and perceive their work with patients from vulnerable groups such people with disabilities and diverse ethnic communities.

1. A research conducted in the UK in 2007<sup>34</sup> concluded that health professionals wrestled with considerable uncertainty and apprehension in responding to the needs of patients of ethnicities different from their own.

### 2.2.3 Research on access to health among people with disabilities

The UN Convention on the Rights of Persons with Disability (UNCRPD) defines persons with disabilities as "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".

There are many disability issues to think about in healthcare services. These range from the attitudes of healthcare staff to the accessibility of health information and buildings.

People with disabilities do not form a homogeneous group. For example, persons with mental health problems or with intellectual disabilities, the visually, hearing and speech impaired and those with restricted mobility all encounter different barriers, of different kinds, which have to be overcome in different ways<sup>35</sup>. According to a research conducted in the UK, people with mental health problems often feel that they are treated with less respect than other people at their GP surgery due to having a label of a mental health diagnosis.<sup>36</sup> There is evidence of less awareness of healthcare risks: for instance awareness of HIV prevention is lower among deaf and intellectually people with disabilities<sup>37</sup>.

Specific **intersectional groups** among disabled patients have specific vulnerabilities. In most countries the number of elderly people is increasing, and already in some as many as two thirds of people with disabilities are also elderly. Most of the conditions which cause their disability (for example, arthritis and deterioration in hearing and vision) are not common among younger people with disabilities and may require different forms of support services.

---

<sup>33</sup> More information available at: [http://fra.europa.eu/fraWebsite/research/projects/proj\\_disability\\_en.htm](http://fra.europa.eu/fraWebsite/research/projects/proj_disability_en.htm)

<sup>34</sup> Kai et al., "Professional Uncertainty and Disempowerment Responding to Ethnic Diversity in Health Care: A Qualitative Study", *Plos Medicine*, 2007, vol. 4, n.11

<sup>35</sup> Report from the UK Disability Rights Commission released in 2006. According to this research done on health inequalities among people with learning difficulties and people with mental health problems in the UK, people with mental health problems were more likely to have recorded health checks than the remaining population. The complete inverse, however, was found for people with a learning difficulty, who were far less likely to receive the health checks.

<sup>36</sup> The Sainsbury Centre for Mental Health, "A formal investigation into health inequalities experienced by people with learning difficulties and people with mental health problems", *Area Studies Report*, 2006

<sup>37</sup> Cambridge P., "How far to gay? The politics of HIV in learning disability", *Disability and Society*, 1997, 12, p. 427-453

## Terms of reference

In the UK evidence suggests that people with disabilities from minority ethnic populations may be less likely to formally report that they have a disability and are less likely to take up support services. Older Asian and black Caribbeans (aged 50–64) generally have considerably higher disability rates than the white population in the same age group<sup>38</sup>.

According to the EC 2009 report<sup>39</sup>, for many people with disabilities in Europe adequate healthcare provision is dependent on the possession of a healthcare insurance policy. There is evidence, however, that providers of such insurance are often unwilling to allow people with disabilities to participate in their scheme. And when participation is permitted it is often on terms less favorable and more expensive than those offered to non-people with disabilities. Evidence of differential access to insurance policy might be found according to gender, age and ethnic origin.

### 3. Contract Objectives and Expected Results

#### 3.1. Objectives

**The overall objective** of the research is to explore the particular vulnerabilities resulting from the intersection of ethnic origin, age and gender in access to health care and quality of care.

The research will focus on: access to health services and quality of health. This means that the contractor is expected to first focus on access to health services, defined as “the ease with which health care can be obtained” and address the different kind of access barriers people are likely to meet (geographical, financial, organization, cultural). Second, the research will focus on the quality of care, once access barriers have been overcome: namely, the take up of service and quality of service received, as experienced by health service users.

The contractor should use a right based approach to health; this should be reflected in the design of the fieldwork research, including any questionnaire. Such an approach takes into consideration on the one hand the **rights** and needs of persons with vulnerabilities and, on the other hand the **duty** of states to ensure that quality health care is available to and accessible by all.

**The specific objectives** of the research are:

1. To identify barriers of access to health care services and quality of health faced by people at the intersection of gender, age and ethnic origin;
2. to map the initiatives undertaken by Member States at policy level 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;
3. to identify the ways in which health professionals address the care needs of persons belonging to vulnerable groups at the intersection of gender, age and ethnic origin..

The fieldwork research will use in-depth interviews based on thematic guidelines with (1) persons belonging to vulnerable groups at the intersection of gender, age and ethnic origin, including such persons with disabilities, and (2) health professionals.

**In this research, intersectionality refers to at least two of the following grounds or axes of identity: ethnic origin, gender and age.** In this research disability is not considered as a ground but as an axe defining one of the target groups of the research.

<sup>38</sup> Purdam et al., “Disability in the UK: measuring equality”, *Disability and Society*, 2008, vol. 23, n.1, p. 53-65

<sup>39</sup> European Commission, “Disability and non-discrimination law in the European Union. An analysis of disability discrimination law within and beyond the employment field”, 2009, see also <http://ec.europa.eu/social/BlobServlet?docId=4393&langId=en>

## Terms of reference

The result of the current project should contribute to an understanding of the specific barriers persons belonging to vulnerable groups at the intersection of gender, age and ethnic origin, face in accessing healthcare and their experience of discrimination on one or multiple grounds. In this way the **research will contribute to a better understanding of how multiple identities translate into inequality in access to resources in the area of health.**

This research will supplement other thematic area of the Agency's work, in particular its work on non-discrimination. In addition, the inclusion of persons with disabilities in the target group shall contribute to the Agency's work on disability. The findings of the research should guide the development of recommendations to EU and national level policy makers how to improve access to healthcare for persons belonging to these groups.

### 3.2. Scope of Work

The research shall be carried out in the **five EU Member States** Austria, Czech Republic, Italy, Sweden, and the UK. In each country, the contractor will identify at least two urban metropolitan areas, where the fieldwork research will take place.

The work will entail desk research and fieldwork research. The purpose of the desk research is mainly to contextualise the findings of the interviews in the final report.

The research should cover the following areas:

- barriers in access to healthcare and quality of care;
- needs and perceptions of health service users and health service providers regarding access to health services and quality of health care;
- policy initiatives to tackle health inequalities for vulnerable groups at the intersection of age, gender and ethnic origin, including specific initiatives for those with disabilities in different areas, for example awareness raising, prevention, diagnosis and treatment, etc

The specific research activities are outlined in Section 2 below.

### 3.3. Target groups

Two main target groups will be the focus in this research:

1. People at the intersection of gender, age and ethnic origin accessing healthcare;
2. Health professionals.

Please see below in Section 2 (Activity 3-5) for further details.

### 3.4. Expected results

The research will start following the signature of the contract and will be completed within eleven (11) months. It consists of the following activities:

1. Desk research for each country;
2. One initial stakeholder meeting in each country

## Terms of reference

3. Development of one questionnaire for health service users and one questionnaire for health professionals common for all countries to enhance comparability;
4. Qualitative fieldwork interview research with health service users in each country;
5. Qualitative fieldwork interview research with health professionals;
6. Organisation of a peer review meeting to discuss preliminary results with main stakeholders;
7. Drafting and delivery of final report.

## 4. Specific Activities

### Activity 1: Desk research

**Geographical coverage:** 5 EU Member States (Austria, Czech Republic, Italy, Sweden, UK)

**Objective:** The desk research will provide an overview of existing research and data from 1990 onwards on health inequalities and discrimination that affect individuals at the intersection of gender, age and ethnic origin, including such people with disabilities. The desk research will also review relevant legal provisions, complaints mechanisms and health equality policies targeting such people.

More specifically, the desk research has **three** components:

1) **Literature review** composed of:

- (i) A general literature review for each country on data and information relating to inequality and multiple discrimination in access to health and groups affected. The main questions to be covered are:
  - Which are the main *findings* on inequalities and intersectional discrimination in access to health? And on intersectional discrimination faced by people with disabilities?
  - Which *methodologies* are used when studying multiple and intersectional discrimination in access to health? What is a right based approach when studying access to health?
- (ii) Review of evidence for each country on access to health among people at the intersection of age, gender and ethnic origin, including specific gaps and good practices in data collection at national level. The main issues to be covered are:
  - General health inequalities experienced by vulnerable groups at the intersection of gender, age and ethnic origin (e.g. mortality, morbidity);
  - take up of health services among vulnerable groups at the intersection of gender, age and ethnic origin;
  - evidence on quality of care for vulnerable groups at the intersection of gender, age and ethnic origin;
  - evidence on level of satisfaction with access to health services and quality of health for individuals belonging to such groups;
  - disability rates among the population broken down per age, gender and ethnic origin e.g. disability rates among elderly disaggregated per ethnic origin;

## Terms of reference

- health inequalities indicators and take up of health service among vulnerable groups of disabled persons at the intersection of gender, age and ethnic origin;
- level and kind of support in daily activities and supporting actors and institutions (family, public services, NGOs etc);

2) **Legal analysis:** the contractor should analyse legal provisions in each country. The main issues to be covered are:

- The extent to which existing legal instruments address the intersectional identities of people accessing health services (e.g. gender **and** ethnic origin, age **and** ethnic origin, gender **and** age);
- The existence and operation of complaints mechanism(s) in health services and institutions where complaints can be lodged;

3) **Policy analysis:** the contractor should review for each country barriers in access to health services (e.g. geographic barriers, economic barriers, long distance, opening hours, long waiting lists etc) experienced by vulnerable groups at the intersection of gender, age and ethnic origin. This analysis should take into account organisation and financing aspects and cover the main aspects of public health programmes e.g. population coverage under public programmes, scope of the health package under public programmes and cost-sharing arrangements. Specific access barriers that disproportionately affect people with disabilities should be taken into account.<sup>40</sup> An analysis of “good practices” at policy level to improve access to health services for vulnerable groups at the intersection of age, gender and ethnic origin should be included, justifying, as far as possible why they should be considered as “good”. The main questions to be covered are:

- To what extent does the national health system provide coverage to vulnerable groups of the population at the intersection of gender, age and ethnic origin?
- Which subgroups are the most likely to be excluded?
- Which are the most effective policy measures to ensure access to healthcare for the most vulnerable groups at the intersection of gender, age and ethnic origin, in general and among persons with disability?
- Is there a national (or regional, local) strategy targeting disadvantaged groups? Which groups are targeted?
- Which are the most effective practices to ensure access to healthcare among such groups?
- Are health programs that tackle root causes of well-being in place e.g. safe sexuality and to what extent do they target vulnerable groups at the intersection of age, gender or ethnic origin?

**Sources:** EU and national statistics on health, academic research, NGO reports and other similar sources, health authorities' documents and websites

---

<sup>40</sup> Lawthers and co. identified four major access barriers that disproportionately affect people with disabilities: (i) physical and transportation barriers; (ii) limited access to assistive technology and equipment ex. Wheelchairs; (iii) limited access to medications and specialists (iv) limitations in access to personal care attendants: for persons with major physical disability, access to high quality personal care attendants is a major issue. Personal care services allow the individual to regain independence and help reduce hospitalizations. Lawthers et al., “Rethinking equality in the contest of persons with disability”, *International journal for quality in healthcare*, 2003, vol. 15, n. 4

## Terms of reference

### Activity 2: One (1) stakeholder consultation meeting in each country

**Geographical coverage:** The selected five EU Member States

**Objective:** The stakeholder consultation on barriers in access to health care in each of the 5 countries will bring together relevant NGOs, providers of health services, representatives of the National medical associations and experts active in the field of healthcare and disability or providing general health services to vulnerable groups at the intersection of gender, age and ethnic origin. The meeting should include 7-10 participants in each country.

The meeting should provide an opportunity to the participants to provide feedback to the contractor as regards their experiences of multiple discrimination in access to health care; the population groups mostly concerned, main health barriers both from the supply and the demand side; an assessment of the public health service in this sector, possible remedies and best practices to fight multiple discrimination in access to health care, also focusing on people with disabilities.

The FRA will define the date of the meeting which is expected to take place within two to four weeks from the signature of the contract. The contractor should organize the meeting in agreement with FRA. The contractor is expected to provide a comparative report covering the meetings in all five countries to FRA. The report – together with the outcome of the desk research – will feed into the design of the questionnaires and the selection of the sample for **Activities 4 and 5**.

### Activity 3: Development of questionnaires

**Geographical coverage:** The selected five EU Member States

**Objective:** two (2) questionnaires will be designed by the contractor in consultation with the FRA to be used in the semi-structured interviews during the fieldwork. The questionnaires should be designed to best capture the views of both the people using health services and health professionals regarding access to health care.

The two questionnaires will have some common issues and some specific ones. The common issues to be addressed should contain, as a minimum, the following:

- barriers in access to health services (geographic barriers, economic barriers, organizational barriers and cultural barriers) for specific vulnerable health service users at the intersection of age, gender and ethnic origin;
- specific problems and needs of health service users belonging to vulnerable groups at the intersection of age, gender and ethnic origin;
- use and perception of general practitioners and specialist services among such groups;
- suggestions and best practices on how to improve access to health for vulnerable groups of health service users;
- Expectations and perceptions on different issues (e.g. staff of the same ethnic background or age, trust, respect, staff should understand patients cultural values...)

#### Questionnaire 1: Health service users

- Do individuals belonging to specific subgroups of the population at the intersection of gender, age and ethnic origin face problems with specific healthcare settings and

## Terms of reference

professionals (e.g. communication, treatment, visiting times, accessibility of building; gender of health professional, ethnic origin of health professional)?

- Do individuals belonging to such groups think some of their needs are not taken into account?
- What strategies do individuals belonging to such groups use to avoid problems? (e.g. change healthcare setting, use a private one, use an NGO instead of a public healthcare services, avoid using health services etc)
- How do individuals belonging to such groups perceive health care providers? Do they trust them? Are there differences according to health professionals (e.g. general practitioners and specialists)?
- Do individuals belonging to such groups believe women/ethnic minority/children/old people with disabilities have specific needs that should be addressed by the health system? If yes, which?
- Are there specific issues concerning hospitals (e.g. diet and food, culturally sensitive menu and menu written in brail)?
- Which are the experiences of discrimination in using health services and how did informants react to these experiences? What is their perception of the extent to which, ethnic origin, age, gender and/or socio-economic status influence the experience of discrimination?
- Are individuals belonging to specific subgroups of the population at the intersection of gender, age and ethnic origin aware of their rights and complaints mechanisms?
- Do individuals belonging to such groups believe health care providers should have a specific expertise or training to better take into account their needs (e.g. treatment advances, types of assistive technologies)? If so, do they believe health care providers usually have expertise and knowledge?
- Who helps them in their daily life and in accessing healthcare services? What is the support given by family members, public services and personal assistance etc? How does the interviewee value the support received?

The contractor should include questions to assess patient's disability and to understand patient's experiences of care with a wide range of health professions and services, including hospitals. This said, we are particularly keen to include questions on areas of primary care provision including dental services, midwifery etc.

### Questionnaire 2: Health professionals

- Do they address specific needs of vulnerable patients at the intersection of gender, age and ethnic origin? How? Are they aware of any good practice in addressing those needs?
- Do they address specific needs of people with disabilities? How? Are they aware of any good practice in addressing those needs?
- Did they have any patient with disability? And vulnerable patients among people with disabilities?
- Do they use any information system used to identify groups of service users? If yes, which ones?
- Do they think vulnerable groups at the intersection of age, gender and ethnic origin have higher/lower take up of health services? If lower, do they use any measure to encourage take up service among those groups? If not, why? Which measures do they think would best work? can they mention any best practice?

## Terms of reference

- Where do they face problems in dealing with specific groups at the intersection of gender, age and ethnicity among them? How do they react to these problems or how do they avoid them? (e.g. communication problems; making a right diagnosis)
- Did they observe racism on the part of health or social care professionals towards other vulnerable groups and specifically vulnerable groups among people with disabilities?
- Do they feel supported by their professional and political representatives in dealing with problems of diversity/intersectionality in general?
- What training activities concerning these issues have they followed? Which would they like to follow? (e.g. cultural diversity trainings, trainings on disability etc)
- Awareness of discrimination issues and in particular of multiple and intersectional discrimination

Two semi-structured questionnaires should be developed, one for each group. The contract should ensure that the questionnaires are proof-read by a native speaker in each of the official languages involved.

**Interview schedules:** All interviews should last at least one hour.

The contractor must ensure that the research complies strictly to national and EU data protection legislation, especially Regulation (EC) No 45/2001 and Directive 1995/46/EC, as well as Regulation EC No 322/97 on the processing of data for statistical purposes. In particular, complainant contact details and data collected during interviews carried out with individuals in respect of their personal experiences shall be processed anonymously in all the research deliverables/reporting, ensuring that individuals cannot be identified.

### Activity 4: Qualitative fieldwork interview research with health service users

**Geographical coverage:** The selected five EU Member States

**Objective:** To explore in depth the views, experiences, and perspectives of health service users.

This activity forms a central part of the research fieldwork, and every effort should be made to ensure that it can be successfully undertaken in the specific locations proposed by the contractor.

**Methodology:** Semi-structured, in-depth, face to face interviews based on the questionnaire for health service users developed under Activity 3.

The research should include the views of two groups:

1. people who need to use health services frequently due to chronic illness or other specific health needs;
2. people with disability: the contractor should select people with different experiences of disability and impairments and should include physical disability and other(s) kind of disability to be chosen by the contractor.

## Terms of reference

The number of interviews should be **at least 35 for each country**; half of the interviews shall be conducted with people with disabilities; the other half with people who need to use health services frequently. The number of interviews proposed is set as evaluation criteria.

A balanced sample should be used to ensure that people with a range of experiences of disability and chronic illness and of different gender, ethnic origin and age were included in the sample. The methodology adopted by the contractor should allow comparing the needs of different intersectional groups. The subject is multigroup and the method is comparative. Having three categories (age, gender and ethnic origin) requires an investigation of the multiple groups that constitute each category. For example, the incorporation of gender into the analysis means that two groups will be compared - men and women. Incorporating age, then gender must be cross-classified with age, which is composed of at least two categories. When ethnicity is incorporated into the analysis and it consists of at least two groups than the number of groups expands to eight. The contractor should follow the sample profile outlined in their technical offer upon agreement with FRA.

Given intersectionality is an 'open empirical question' that is articulated in different ways depending on the specific context considered we expect that each context will provide a specific configuration of intersectional inequalities and of groups to interview. This means – for instance – that each country should interview people from the most prominent ethnic backgrounds. This said, there is evidence that “visible” minorities, e.g. persons of Sub-Saharan or Caribbean origin, of North African or Asian origin, experience more discrimination and should be included where possible.

The contractor should also ensure a good mix of socioeconomic status.

For what concerns area of residence, all the interviews will be undertaken in at least two metropolitan areas in each country.

Where needed, interpreters and community researchers should be used when interviewing individuals from different ethnic backgrounds.

Contractors will identify and recruit the sample of persons who will participate in the fieldwork research and strategy to avoid biases e.g. the contractor should avoid just recruiting respondents via groups with a focus on disability because it is expected that those participating in such groups might be more aware and knowledgeable about health services and would therefore be atypical of the general population of people living with disability. Multiple sources should be used in order to identify and recruit the sample: community groups, specific diseases telephone help lines, hospitals, clinics and GPs.

At the same time, contractors should identify hard to find members of vulnerable groups, because they make little use of conventional health services.

The data collection should be appropriately documented, i.e. should be recorded. Agency staff may participate in the training of interviewers and that data collection stage.

All interview tapes, verbatim transcripts of the interviews or any other material relating to the fieldwork must be delivered to the Agency after the completion of the contract.

### **Activity 5: Qualitative fieldwork interview research with health professionals**

**Geographical coverage:** The selected five EU Member States

**Objective:** To collect the opinions of health professionals and caregivers in relation to specific needs of vulnerable groups at the intersection of age, gender and ethnic origin; to envisage the role they establish for themselves in meeting these needs, to define the training needed in supporting them in this role; to explore measures taken by health professionals to encourage

## Terms of reference

take-up services among specific groups, collaboration with vulnerable groups in the design of health services, service provision (e.g. the extent to which the share of vulnerable groups using their services reflects the share of vulnerable people in their area), experience of witnessing discriminative attitudes and behaviours in health settings, recommendations for improvement.

This activity should allow exploring differences in perceptions and expectations between health service users and health professionals

**Methodology:** Face to face, semi-structured, individual interviews and focus groups based on the questionnaire for health professionals and caregivers developed under Activity 3.

Health professionals working in primary and secondary care settings and GPs who most likely work with health service users of varying ethnic background, gender and age as well as specialists who deal with physical disability should be interviewed..

Participants should be sampled purposefully from a range of health service settings and networks and include, as far as possible, interviewees from different ethnic backgrounds and gender. The ratio of ethnic minority interviewee should be reflecting the ratio of ethnic minority health professionals as registered in national statistics, if they exist.

The fieldwork should be carried out through face to face interviews. The number of interviews should be outlined by tenderers in their Technical Offer and should be **at least 25 for each country**.

All interview tapes, verbatim transcripts of the interviews or any other material relating to the fieldwork must be delivered to the Agency after the completion of the contract.

### Activity 6: Peer review of the results

**Geographical coverage:** The selected five EU Member States

**Objective:** The objective of the peer review is to consult with the relevant stakeholders on the preliminary findings emerging from the preliminary comparative analysis.

**Methodology:** Peer review of results:

- The peer review could include representatives from government and academic institutions;
- NGOs and experts included in the first stakeholder meeting.

The review meeting will be held at the FRA offices in Vienna to review the preliminary comparative analysis. This meeting will be organised by the FRA (travel and accommodation expenses of participants, **but not of the contractor**, will be covered by the FRA).

### Activity 7: Analysing and presenting data and information

**Objective:** To analyse the data collected through the fieldwork and present the results in a comparative thematic report and in country fact sheets as described below in Section 5 (Deliverables).

## Terms of reference

In particular, contractors should bear in mind that the research requires rigorous scientific methodologies and analysis, which will lead to results that can feed into the development of practical outputs that are useful to policy makers. Thus the research, taking into account the complexity of the EU in terms of its diverse national contexts, should adopt a sociological approach that sufficiently can lead to findings with high policy relevance.

### 5. Deliverables

All deliverables must be submitted in English copy-edited by a native speaker. They must be written in a clear and unambiguous way, providing information and analysis that can be readily understood by a non-academic reader. The style should be balanced and contain no unsubstantiated statements. For detailed advice please see the FRA Style Guide.

The documents must be delivered in PC-compatible MS-Word electronic files. They should contain visual elements (for example graphs, boxes or pictures) to enhance readability. The size of each deliverable is defined in terms of A4 pages applying Times New Roman font 11pt, single spaced.

The Contractor must provide the Agency with the deliverables, respecting the deadlines mentioned below.

#### **Deliverable 1: five (5) country reports on stakeholder consultation meeting**

Within 2 weeks from the contract signature the FRA will convene five (5) national stakeholder meetings, each with 4-5 national experts and health NGOs working in the field of health, discrimination or/and disability. The contractor will draw up a report presenting the main outcome of the national stakeholder meeting; it will include suggestions for the design of the questionnaire.

**Size:** Each report should consist of 5 -10 pages

**Language:** English

**Linked to:** Activity 3

**Deadline:** The report is to be submitted to the Agency within 10 days after the stakeholder meeting

#### **Deliverable 2: draft questionnaire for interviews with health service users and health professionals**

Three (3) semi structured questionnaires. Each of the following groups shall be targeted by one questionnaire: health service users (as outlined in Activity 4) and health professionals (as outlined in Activity 5).

**Language:** English

**Linked to:** Activity 3

**Deadline:** The report is to be submitted to the Agency within 20 days after the stakeholder meeting

#### **Deliverable 3: 5 (five) background information reports**

## Terms of reference

The report should sum up the findings of each national desk review. The reports should be self-standing and offer good background information on the research, legal, policy and data collection framework regarding access to health among vulnerable groups as described in Activity 2. The report must be presented according to a template agreed upon with the FRA at the inception meeting.

**Size:** maximum 30 pages

**Language:** English

**Linked to:** Activity 2

**Deadline:** 2 months after signature of contract

### **Deliverable 4: Draft comparative report**

The country reports should summarize the main results of the desk research (Activity 1) and of the fieldwork (Activity 4 and 5). For what concerns the fieldwork, the report should present the results thematically, not by country. The report should include relevant quotes from interviewee narratives, a list of best practices stemming from the desk review and the fieldwork and recommendations for policymakers.

**Size:** The report should consist of max. 1020 pages

**Language:** English

**Linked to:** Activity 1, 2, 3, 5 and 6

**Deadline:** 8 months after signature of contract

### **Deliverable 5: 5 (five) thematic fact sheets**

The fact sheets are meant as a basis for discussion with different actors at a national and European level. They should provide an illustration of the main findings of the fieldwork in each country, a list of best practises encountered and recommendations at policy level. They should situate the national findings of the research with the overall results in the 5 Member States.

To the extent possible they should contain text boxes, pictures or other graphic elements to enhance readability. They should integrate background information which may be collected by the FRA independently.

**Size:** max. 5 pages per fact sheet

**Language:** English

**Linked to:** Activities 1-7

**Deadline:** 8 months after signature of contract

### **Deliverable 6: Report of peer review meeting**

## Terms of reference

One peer review meeting shall be organised by the contractor with a selection of representatives from the five Member States where the fieldwork was conducted. The FRA will cover the operational costs of the meeting, which will be held at the FRA's offices. A report covering the meeting will be drawn up by the contractor. The report should contain a summary of the conclusions of the meeting, a detailed protocol of the discussions, the agenda, the list of participants as well as any background materials used or referred to during the peer review meetings.

**Size:** 5/10 pages

**Language:** English

**Linked to:** Activity 6

**Deadline:** 10 days after peer review meeting

### **Deliverable 7: Final comparative report**

**Size:** The report should consist of max. 100 pages

**Language:** English

**Linked to:** Activity 1, 2, 3, 5, 6 and 7

**Deadline:** 11 months after signature of contract

### **Deliverable 8: Communications Material**

This material to be delivered by the tenderer should assist the FRA in its communication work related to this project. To this end, the contractor is requested to provide at least 5 photos from the five countries where the fieldwork was conducted. The photos should be illustrative of the issues covered by this research. The copyright of each photo has to be transferred to the contracting authority. Copyright costs are to be covered by the contractor. In addition, to the extent possible, a list of individuals who are willing to tell their story to the media or participate in related FRA events should be compiled by the contractor. Finally, an annex with meaningful quotes from the field work, which have not been used in the main deliverables, should also be provided.

**Linked to:** Activities 1-6

**Deadline:** 11 months after signature of contract

### **Deliverable 9: Dissemination Material**

Contractors are asked to provide the contracting authority with address material (list of e-mail addresses in MS Excel) for dissemination of project results covering the 5 countries and other important stakeholders in the other EU MS as well as at the European and International level.

**Linked to:** Activities 1-6

**Deadline:** 11 months after signature of contract

## Terms of reference

### 6. Project management

#### 6.1. Responsible body

The overall responsibility for executing the contract, including the implementation of all measures necessary to provide the Agency with deliverables of the highest quality on time lies with the contractor.

### 7. Logistics

#### 7.1. Communication and meetings

Communication between the contractor and the Agency shall be possible by phone during the Agency's working days and hours and through electronic and surface mail. Any written communication sent by the Agency shall be answered within five (5) working days.

The contractor shall submit weekly email reports concerning the progress of all stages of the project. This reporting mechanism will be used as an early warning system to identify any problems or potential problems in the progress of the research.

**Size:** maximum 1 page

**Language:** English

**Deadline:** weekly, starting the week following the inception meeting.

#### 7.2. Inception meeting

As soon as possible after contract signature the Agency will convene an **inception meeting** with the contractor to discuss various aspects of the research work, as addressed in the Technical Specifications and set out in the successful contractor's Technical Offer. The costs of participating to this meeting shall be covered by the contractor.

The aim of the meeting is to clarify specific points with respect to the research, in particular the methodology, the content of the deliverables, a final timeline and other issues that may arise.

Within 5 working days after the inception meeting, the contractor will submit a brief Inception Report to the Agency.

#### 7.3. Other meetings

During the course of the contract period **one (1)** additional meeting is envisaged between the Agency and the contractor in addition to the peer review meeting. This meeting will take place in Vienna at the Agency's headquarters.

## Terms of reference

### 8. Project team

Contractors should pay attention to the need to ensure that the research team fulfils the requirements listed below in terms of qualifications and experience.

#### 8.1. One Project Manager

*Qualifications and professional experience*

- University degree
- 3 years of proven experience as project manager in managing international research projects;
- Excellent knowledge of English (level C1)

#### 8.2. One Senior Expert Social Research

*Qualifications and professional experience*

- Advanced University degree in social sciences
- Minimum five years of experience in social research
- At least **five (5)** scientific publications related to social research. Publications can be in any EU language (e.g. article in peer reviewed academic journals or books or peer reviewed books by academic publishers). Titles, dates, type of publication, publisher, place of publication, ISBN number (if available) must be provided. A minimum of one such publication (abstract in English and full text in any EU language) must be provided.
- Experience in qualitative research, proven either by one publication or by participating in at least one research project using qualitative methods.
- Experience in social science in the area of health, proven either by one publication or by participating in at least one research project related to the area of health.
- Excellent knowledge of English (C1)

#### 8.3. One Senior Expert Legal Research

*Qualifications and professional experience*

- Advanced University degree in law
- Minimum five years of experience in legal research of which at least three in discrimination issues
- At least **five (5)** scientific publications related to law in the area of human rights or discrimination; publications can be in any EU language (e.g. article in peer reviewed academic journals or books or peer reviewed books by academic publishers). Titles, dates, type of publication, publisher, place of publication, ISBN number (if available) must be provided. A minimum of one such publication (abstract in English and full text in any EU language) must be provided.
- Excellent knowledge of English (C1).

## Terms of reference

In addition to the profiles listed above, a successful project team will be composed of an adequate number of research experts representing the following disciplines:

### 8.4. Research Expert in Policy analysis

#### *Qualifications and professional experience*

- University degree in political science/social policy
- At least **two (2)** scientific publications in any EU language (e.g. article in peer reviewed academic journals or books or peer reviewed books by academic publishers). Titles, dates, type of publication, publisher, place of publication, ISBN number (if available) must be provided. A minimum of one such publication (abstract in English and full text in any EU language) must be provided.
- Experience in policy analysis in the area of health, proven either by one publication or by participating in at least one research project related to the area of health.
- Excellent knowledge of English (C1)

### 8.5. Research Expert in social science with quantitative background

#### *Qualifications and professional experience*

- University degree in social science with a background in quantitative data analysis
- At least **two (2)** scientific publications in any EU language (e.g. article in peer reviewed academic journals or books or peer reviewed books by academic publishers). Titles, dates, type of publication, publisher, place of publication, ISBN number (if available) must be provided. A minimum of one such publication (abstract in English and full text in any EU language) must be provided.
- Excellent knowledge of English (C1)

## 9. Project Implementation Monitoring

The Agency will monitor the research in technical and administrative terms. The contractor should report immediately to the Agency in writing any problems they encounter during the implementation of the contract.

Bi-weekly progress reports will be delivered as brief e-mails to the Agency's project manager, and should document overall research progress. This should be supported by additional e-mail and telephone contact, whenever necessary.

Agency staff may during the duration of the research visit the contractor's offices and/or the site, where research is carried out to assess the quality of the work.