25 September 9:30-13:15

Event Report

Joint Equinet-EPHA-OHCHR Roundtable – Monitoring Effective Access to Quality Healthcare for Roma and Racialised Communities

Our health is impacted by much more than just the design of the healthcare sector. It depends on the inclusivity of the structures and systems our society is built on. This is why racism and discrimination are seen as fundamental determinants of health.

Health equity depends on inclusivity, and the European Union has a number of strategies at its disposal that are crucial for driving inclusion; the Union of Equality Strategies. Among them, the **EU Roma Strategic Framework for equality, inclusion and participation** is one of the longest-standing, with over two decades of development. As such, it can provide a wealth of good and bad practices for further improvement; lessons that have the potential to inform other EU inclusion strategies.

On 25 September 2024, **Equinet**, in partnership with the **European Public Health Alliance** (**EPHA**) and the **Office of the United Nations High Commissioner for Human Rights** (**OHCHR) Regional Office for Europe** – supported by the **DisQo Stakeholder Network** – held a roundtable titled '*Monitoring Effective Access to Quality Healthcare for Roma and Racialised Communities.*' A wide range of stakeholders discussed how health equity and monitoring frameworks could advance a true Union of Equality, particularly through the **post-2025 EU Anti-racism Action Plan** (EU ARAP). They did so by focusing on two questions:

- How have **equality bodies** and **civil society** contributed to the Roma Framework?
- How can their involvement improve **monitoring frameworks** for the EU ARAP?

Setting the stage

After an introduction by **Daris Lewis** from **Equinet**, the event was opened with a warm word of welcome from the two hosts. **Elena Kountouri Tapiero** opened on behalf of **OHCHR**, underlining that UN member states have already received a wealth of recommendations to act against racism and discrimination in health. **Anna Gaspard**, representing **Equinet**, added that equality bodies have been collecting evidence for decades, and that the post-2025 EU Anti-racism Action Plan and new directive on equality bodies show that the time for action is now.

No discussion on health in the EU ARAP is complete without mentioning **General Recommendation 37** on racial discrimination in the enjoyment of the right to health (GR37). **Tina Stavrinaki** contributed to its drafting on behalf of the **UN Committee on the Elimination of Racial Discrimination** (**CERD**). She

complemented Elena and Anna's points calling attention to three points to realise this: an **intersectional approach, inclusive decision-making,** and the importance of **improved** and **unbiased data.**

On that last point, **Andrey Ivanov** and **Jaroslav Kling** from the **European Union Agency for Fundamental Rights** (**FRA**) provided key insights on data collection by presenting their **Monitoring and Evaluation Framework**, currently applied only in the EU Roma Strategic Framework. Grounded in OHCHR's outcome-based indicators, this framework enables national-level tracking of policy impacts using surveys and national statistical data. On health for example, FRA estimates the current life expectancy gap between Roma and non-Roma to be around 10 years. This establishes a solid foundation for **expanding data-driven progress assessment** which **could be applied to all Union of Equality strategies**, on health and beyond.

Equitable access to healthcare: lessons from the situation of Roma in Europe

Against that background, the first panel – moderated by **Tomas de Jong** from the **European Public Health Alliance** – launched the discussion by tackling the first question from the health perspective; how have **equality bodies and civil society** contributed to the Roma Framework?

The first panellist was **Dănuț Nae** from **Cairde** in Ireland, a community health development organisation that combats health inequalities in minority ethnic communities. He shared the example of Cairde's **National Roma Infoline**, which provides essential information on accessing healthcare and other services. Dănuț testified to the importance of such initiatives based on his past experiences, and provided a recent account on how a Roma individual was initially refused a medical card stamp due to discrimination but was eventually assisted by Cairde's intervention. This shows how civil society initiatives can empower communities to overcome structural barriers to healthcare access.

Monika Čavlović on behalf of **the Ombudswoman of the Republic of Croatia** built on this by stating that such **community empowerment activities** require structural support to drive structural change. The Croation Ombudswoman was involved in developing Croatia's National Roma Inclusion Plan. Though it is comprehensive, at least 30 of its planned activities did not take place, illustrating the importance of **monitoring frameworks** with **strong indicators** and **robust data** collection. Based on this experience, Monika concluded that Roma inclusion strategies succeed only when truly supported by governments and implemented in a cross-sectoral way – a lesson that applies anywhere in Europe.

Providing that European perspective was **Giorgios Tsiakalos** from the **European Roma Grassroots Organisations Network** (ERGO). He recognised Monika's point which he noticed across Europe; National Roma Strategic Frameworks may be comprehensive, but action plans often lag behind. He illustrated the need for structural support and monitoring through the example of ERGO's **RIPE** (Roma Inclusion, Participation and Equality) **Index & Map**. By combining grassroots insights, national

authorities, and **participatory research**, RIPE creates a data-driven framework to map progress and guide concrete action on Roma inclusion measures.

In conclusion, despite the odds, equality bodies and civil society have provided tremendous value through their work on the ground and the data they provide. At the same time, these experiences show that initiatives taken by equality bodies and civil society cannot be a replacement for structural support and data collection.

Monitoring, indicators and equality data: accelerating effective action for a Union of Equality
After the break, the role of equality bodies and civil society was applied to data and accountability. This discussion was picked up through the second question; how can their involvement improve **monitoring frameworks** for the EU ARAP?

Sian Hughes from the **Equality and Human Rights Commission** (EHRC) in the **United Kingdom** kicked off this discussion by illustrating their **measurement framework**. The EHRC is the UK's equality regulator and national human rights institution established under the Equality Act. Using data collected by other parties in UK's 4 constituent countries, they monitor health inequities based on cross-sectoral indicators reflecting the **social determinants of health**. Unfortunately, current data systems are inadequate in providing the full picture. Sian concluded that designing a **flexible** framework with clear **limits**, taking a **wide societal** approach and adapted to the **needs of decision-makers** is the key to success.

With an understanding of monitoring frameworks, the second panel of the day explored how they can be put into practice through input from Commission policy makers with additional comments from OHCHR.

Vanessa Kabuta, representing the **Anti-racism team** at the European Commission, expanded on the EU Anti-racism Action Plan. Its soft law nature means it relies on other policy instruments, especially when it comes to health. Even so, the EU ARAP is significant in showing the EU's commitment to **intersectionality**. Based on this, she stated that **disaggregated data** is essential for addressing (health) inequities. The use of monitoring frameworks is critical to achieving concrete action, which is why a study is being conducted on the lessons from the current EU ARAP. Input from equality bodies and civil society will be crucial in ensuring those monitoring systems are robust post 2025.

Atanas Stoyanov, representing the **Roma coordination unit** at the European Commission, reinforced the importance of monitoring frameworks by highlighting how the EU Roma Strategic Framework incorporates both baseline and target indicators, including for health. This sets directions through a key objective of the framework to **halve the life expectancy gap between Roma and non-Roma** by 2030 – a goal increasingly out of reach. Atanas emphasised the need for higher-quality data to better

inform the framework to counteract this, pointing to the Eurostat Working Group on Equality and Non-discrimination as a vital initiative to strengthen data collection and monitoring efforts.

Mila Paspalanova, representing **OHCHR**, underlined the continuous lack of political will to collect disaggregated data, despite obligations under international treaties. Even so, the **OHCHR indicator framework** offers a robust tool to address these gaps, if done in collaboration with statistical offices and initiatives. This framework provides clear, cross-sectoral indicators, leaving no excuse for states to avoid data collection.

In conclusion, to drive progress, member states must commit to annual reporting on equality data through robust monitoring frameworks. The interventions show that frameworks supported by equality bodies and civil society **clarify actions**, foster **accountability** and **drive meaningful change**. **Outlining concrete steps to health equity**

To conclude the day, a **questions-and-answer session** was held, followed by conclusions by **Magdalena Maier** from **Equinet**, as well as Tina Stavrinaki and Tomas de Jong. The Q&A session highlighted the importance of tailoring data collection to national settings supported by strong data literacy within national statistical bodies and agencies. Equality bodies emerged as pivotal actors, not only in encouraging data collection but also in addressing discrimination and advocating for marginalised communities, in which the crucial role of women was highlighted.

In their closing remarks, the speakers emphasised the momentum behind current discussions on structural discrimination and racism as follows:

- Leverage the current **opportunity** and **momentum** to strengthen collaboration between policymakers and stakeholders
- Create **well-designed monitoring frameworks** to **empower equality bodies** to fulfil their role
- Remind **Member States** of their **responsibility** for strong anti-racism policy with concrete actions.

Experiences from the EU Roma Strategic Framework show that monitoring frameworks have allowed for **focus** and **purpose**. Within this, equality bodies and civil society drive **community empowerment**, **address discrimination directly**, and help **fill gaps in data collection**. However, this cannot be a replacement for structural support. The EU ARAP, just like the Roma Framework, needs **robust monitoring frameworks** and **inclusive data methodologies** to make policies more impactful. This requires **political will**, **consistent reporting**, and most importantly **strong collaboration** between EU institutions, member states, and strongly empowered and supported equality bodies and civil society.