

Organisations across sectors call for stronger action against racism and discrimination to achieve health equity

22 May 2023

Despite the increasing evidence showing that structural, institutional, and interpersonal racism and discrimination impact both physical and mental health inequities in multiple ways¹, the issue has gained too little attention in the public health domain thus far.

We, the undersigned organisations, working across sectors, commit to taking an active stance against all forms of racism and discrimination and call for decision-makers at all levels, including the European Commission, to follow suit.

Together, we have identified **five key priorities** for addressing the issue in a constructive, respectful, and participatory way:

- 1. Recognise racism and discrimination as fundamental determinants of health, equity and well-being**
- 2. Strengthen social participation of racialised and discriminated communities, and foster diversity, representation and anti-discrimination**
- 3. Increase clarity and consistency of key definitions related to racism, discrimination and health equity**
- 4. Collect more (health) equality data, disaggregated by indicators on multiple grounds of discrimination, and harmonise EU data collection**
- 5. Strengthen existing EU anti-discrimination legislation by breaking down silos and boosting policy mainstreaming, transparency, reparative justice and social participation**

This Joint Statement has been developed by people working for organisations that are members or supporters of the Thematic Network ‘DisQo – anti-discrimination & health equity’.²

A glossary with definitions of key terms being used in this document, such as structural and institutional racism, discrimination and health equity, is included in [Annex 1](#).

¹ [The Lancet 2022. The Lancet Series on racism, xenophobia, discrimination, and health](#)

² Thematic Networks are temporary networks of stakeholder organisations created in the [EU Health Policy Platform](#), which is hosted by the European Commission, DG SANTE.

1. It starts with recognition

Racism and discrimination are fundamental determinants of health, adversely impacting physical and mental health, and the accessibility and quality of health services, across the life course and across generations.³ Despite the overwhelming evidence, these systematic and avoidable health inequities have gained too little attention in the public health domain.

Recognising and naming unconscious biases, and interpersonal and internalised racism and discrimination, in the workplace, in communications, in research, and in interactions with others, including colleagues or patients, will advance understanding of the issue and will allow for further efforts to address it.

We recognise and support the actions of the current European Commission, including its anti-discrimination strategies, such as the EU Anti-racism Action Plan.³ However, we call for a stronger commitment, not only from the European Union Institutions but also from all leaders in and outside the public health domain, including our own organisations, to achieve wider recognition of racism and discrimination as fundamental determinants of health, equity and well-being.

To achieve wider recognition of racism and discrimination as fundamental determinants of health, equity and well-being

We commit to actions for the wider recognition of structural, institutional and interpersonal racism and discrimination as fundamental determinants of health, equity and well-being by:

- strengthening anti-racism and anti-discrimination policies and practices within our own organisations;
- integrating this recognition in our work/advocacy where possible;
- collaborating and partnering with organisations across sectors to create communities of practice and exchange learnings.

We call on the European Commission to explicitly recognise racism and discrimination as fundamental determinants of health, equity and well-being by:

- taking a leadership role to address this issue from the health equity perspective;
- including explicit mentions of the issue in hard and soft legislative and policy documents;
- prioritising the issue as an integral part of training curricula across different disciplines and as a key aspect of continuing vocational training; and
- prioritising the issue for research funding.

³ [EU Anti-racism Action Plan 2020-2025 \(European Commission, 2019\)](#)

2. It's about people

Too often, policies are developed without involving the people affected by these policies. Moreover, social participation in decision-making processes is more than engaging people in a tick-box exercise at the end of a process and should follow a 'human rights-based framework'⁴ that involves meaningful engagement of affected people and communities through the entire process, from diagnosis of the issue(s) to the planning, implementation and evaluation of the policy or intervention. It also includes providing the means to participate, people's capacity and empowerment where needed. WHO Europe recognises social participation as a *driver of health equity*.⁵ An important and related aspect of this is the lack of diversity and representation in positions of power, such as in the board rooms of public and private organisations and in advisory bodies. The diversity and representation referred to here include, but are not limited to, ethnicity, race, culture, nationality, gender, sexual orientation, gender identity, religion, age and disability. This lack of diversity is also observed in the current European Parliament where ethnic minorities in general and people of colour in particular are widely underrepresented.⁶

To strengthen social participation of racialised and discriminated communities, and foster diversity, representation, and anti-discrimination across all levels

We commit to actively promote meaningful social participation activities that are inclusive and in which those involved are given leadership by:

- Providing thought leadership, lived experience, and concrete solutions when engaged by decision makers in social participation activities for the design, development, and evaluation of hard and soft legislative initiatives;
- providing continuous feedback on how such processes can be improved; and
- advocating for diversity and representation at all levels, within both our own organisations and our work on (health) equity revolving around people from marginalised communities.

We call on the European Commission to strengthen its efforts to promote social participation and increase diversity across its organisational levels by:

- systematically incorporating and providing leadership to civil society stakeholders not only in the design, development and evaluation of hard and soft legislative initiatives, but also as a key source of expertise, following the [Better Regulation Guidelines](#); and
- fostering - in a non-tokenistic way (i.e., ensuring real influence) - diversity and representation in its advisors/advisory bodies, in its funded projects, and, importantly, across its DGs, at all levels of governance.

⁴ [Human Rights Factsheet. WHO, 2022](#)

⁵ [Participation as a driver of health equity. Copenhagen: WHO Regional Office for Europe; 2019](#)

⁶ [ENAR's election analysis: Ethnic minorities in the new European Parliament 2019-2025. European Network Against Racism, 2019](#)

3. Language matters

To enhance the quality of dialogue and discourse to effectively address racism and discrimination, concise and recognised definitions of key terms and concepts are needed, including for instance race, racism, racialisation, discrimination, anti-racism, anti-discrimination, health inequalities, and health equity. These are critical prerequisites for creating a common language, a common ground and a safe space for constructive dialogue, and ensuring the use of respectful and non-stigmatising language.

Existing definitions are fragmented across documents and websites of European Commission Directorate Generals (DGs) and Agencies. Moreover, multiple definitions exist for the same term, and definitions used by International Organisations, such as the United Nations, may also differ.

To increase clarity and consistency of key definitions

We commit to promoting respectful and inclusive language, and increasing the clarity and consistency of critical definitions by:

- creating safe spaces for inclusive and respectful dialogue in our own organisations; and
- providing thought leadership and active engagement in EU actions to harmonise definitions.

We call on the European Commission to take a leading role in increasing the clarity and consistency of critical definitions by:

- developing an overarching glossary webpage with definitions; and
- carrying out – or providing funding for – a harmonisation exercise to establish definitions for terms on which there is no current consensus, involving the relevant stakeholders, including civil society.

4. If you can't measure it, you can't fix it

Evidence-based policymaking and monitoring for addressing racism and discrimination and advancing (health) equity require good quality data (quantitative and qualitative) that allows for disaggregation by indicators on various grounds on which people may be discriminated against, including their race, ethnic origin, sex characteristics, gender, sexual orientation, disability, religion, belief, age and socioeconomic status. Moreover, data on self-reported or perceived discrimination are important as victims of discrimination tend not to report incidents of discrimination to the authorities for a number of reasons, including not knowing where to turn to and lack of trust in authorities.⁷ Such data would also allow an

⁷ [Guidance note on the collection and use of equality data based on racial or ethnic origin \(European Commission, 2021. High Level Group on Non-discrimination, Equality and Diversity, Subgroup on equality data\)](#)

intersectional analysis, showing individuals or groups that face multiple, interconnected discrimination. Importantly, the collection and use of equality data should follow the human-rights-based principle of *doing no harm*,⁸ and not create or reinforce existing discrimination, bias, or stereotypes.⁷ Moreover, anonymised data should be made publicly available. However, comprehensive systems or a coordinated approach to collecting and using good quality equality data is lacking in the EU, partially due to different approaches and rules whereby some of the member states prohibit data collection based on ethnicity for ethical, constitutional or historical reasons.

This includes equality data in the (mental) health domain, in which both the collection of data needs to be improved and more research, including long-term studies, on all forms of racism and discrimination, is required. A crucial element is the provision of training, not only for healthcare professionals but - more importantly - also for those staff members (assistants, receptionists, etc.) who are responsible for collecting the data, ensuring they understand the importance which they can, in turn, convey to patients. This includes interpersonal and culturally sensitive skills that create patient trust. Also, the European Commission's proposal on the European Health Data Space⁹ is a crucial piece of legislation that - if implemented thoughtfully - has the potential to increase transparency, give people control over their own health data and build trust in how data are used.

Although there are some legal considerations, most notably the EU General Data Protection Regulation (GDPR) and national data protection rules to protect citizens from any potential risks of misuse or abuse, the collection and processing of special categories of personal data are possible under certain conditions, including for statistical or research purposes. Finally, the lack of financial resources to carry out high-quality and frequent data collection surveys forms an important obstacle.

To collect more and higher quality equality data, disaggregated by indicators on multiple grounds of discrimination

We commit to pushing for better equality data by:

- advocating for higher quality equality data, including the appropriate resource allocation, at both EU and national level; and
- providing thought leadership and active engagement in efforts to harmonise the collection of equality data across the EU;

⁸ [Onarheim KH, Wickramage K, Ingleby D, et al. Adopting an ethical approach to migration health policy, practice and researchBMJ Global Health 2021](#)

⁹ [Proposal for a regulation - The European Health Data Space. European Commission, 2022](#)

We call on the European Commission to push for better equality data by

- taking a leadership role in the harmonisation of equality data collection in the EU, involving the relevant stakeholders, including those working with data (Eurostat, Eurofound, FRA, OECD, JRC, WHO, etc.) and civil society;
- developing further guidance for member states on the systematic collection of equality data, including in the area of mental and physical healthcare, improving its comparability and accessibility, and on training for people who collect the data;
- promoting a focus on intersectional data, ensuring that the collection of data reflects the diversity within the groups exposed to discrimination; and
- funding - and encourage member states to fund - projects that advance the harmonisation of equality data collection in the EU.

5. Breaking down silos and taking action

Tackling complex and deeply rooted issues like structural and institutional racism and discrimination, which cut across societies and generations, requires actions at different levels and collaborations and partnerships across different sectors. The latter calls for the breakdown of silos and operating outside of one's comfort zone and/or area of expertise, for which all the above points are crucial: recognition of the issue, a common language with clear definitions for understanding, participation, and leadership of affected people, and good quality data. It is crucial to recognise that silos exist across stakeholder categories, including the public, private, and civil society sectors, but also that within these silos there may be power dynamics and structures that sustain discrimination and/or exclusion.

The current European Commission has launched several *Union of Equality Strategies* in 2020-2021 that strive for equality on different grounds of discrimination, including racism and ethnicity, antisemitism, disability, gender, LGBTIQ and anti-Roma sentiment. These strategies are accompanied by a dedicated *Task Force on Equality* that works to mainstream equality in all policy areas.^[8] This Task Force operates horizontally across Commission Directorates and should thus reduce working in silos where that occurs. However, the Task Force is an internal service and not visible externally, hence its performance cannot be monitored. Moreover, transparency around resource allocation toward fighting inequalities would be favourable.

To strengthen existing EU anti-discrimination legislation by breaking down silos and boosting policy mainstreaming, transparency and social participation

We commit to breaking down silos and taking action by:

- increasing cross-sectoral collaboration with organisations outside of our usual networks; and
- actively engaging and providing thought leadership in participatory activities that focus on EU policy mainstreaming

We call on the European Commission to break down silos and take action by:

- strengthening its policy mainstreaming efforts through the Task Force on Equality, to identify fragmentation, improve coordination and increase (safe spaces for) dialogue among different levels;
- adopting an intersectional focus, acknowledging the diversity within the groups exposed to structural racism and discrimination, for an effective and comprehensive response to the particular needs of such groups at the relevant intersections; and
- increasing transparency and social participation to bolster policy mainstreaming, including on the Task Force on Equality and funding toward fighting inequalities;

The journey is ours

We, the undersigned organisations, recognise that achieving a true *Union of Equality* is and will be an ongoing journey, one that we wish to take together. Please consider this as a helping hand and a commitment from each organisation below to support wherever we can to go towards our common goal: just and equal societies.

Signatures

The undersigned organisations and Members of the European Parliament endorse this Joint Statement. Endorsements, questions or suggestions can be addressed to Raymond Gemen, Head of Policy at the European Public Health Alliance (EPHA) - Raymond.gemen@epha.org.

DisQo

anti-discrimination & health equity

Organisations

in alphabetical order



Africa Advocacy Foundation



AfroMedica vzw



AGE Platform Europe



Art.1 Midden Nederland



Association of Schools of Public Health in the European Region



Cairde



Cancer Prevention Research Group in Greece (CPRGreece)



Center for Community Research and Action at the University of Seville (CESPYD)



Centre for Global Health Inequalities Research



Eurochild



EuroHealthNet



European AIDS Treatment Group



European Association for Palliative Care (EAPC)



European Association for the Study of Obesity



European Cancer Organisation (ECO)



European Forum for Primary Care (EFPC)



European Hospital and Healthcare Federation (HOPE)



European Independent Foundation in Angiology/Vascular Medicine (VAS)



European Institute of Women's Health (EIWH)



European Midwives Association



European Network of Equality Bodies



European Psychiatric Association (EPA)



European Public Health Alliance (EPHA)



European Public Health Association (EUPHA)



European Society for Organ Transplantation (ESOT)



European Union of Medical Specialists



Eurordis



FEANTSA

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Fondazione LILA Milano ONLUS



Health Action International
(HAI)



Impact Epilysis



International Sports and
Culture Association (ISCA)



La Fragua Projects



Make Mothers Matter



Mental Health Europe (MHE)



MiHealth Europe



Nobody Left Outside (NLO)



Observatoire du sida et des
sexualités



Platform for International
Cooperation on Undocumented
Migrants (PICUM)



Research Center of Social
Inequality and Governance -
CEDESOG



Resilience Center of the Institute of
Psychology, at the Norwegian
University of Science and Technology



Robert Koch Institute (German
National Public Health Institute)



Romtens Foundation



Salud por Derecho



Social Platform



Terrence Higgins Trust



World Federation of Public Health
Associations (WFPHA)

Members of the European Parliament



Miguel Urbán Crespo
The Left Group



Milan Brglez
Group of the Progressive
Alliance of Socialists and
Democrats



Romeo Franz
Group of the Greens/European
Free Alliance