DisQo
anti-discrimination & health equity

The Right to Health of People of African Descent: Part 2 of the Racism, Discrimination and Health Series

Consultation report and recommendations for the post-2025 EU Anti-racism Action Plan

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Introduction

The European Public Health Alliance (EPHA) and the Office of the United Nations High Commissioner for Human Rights (OHCHR) in collaboration with Artikel 1 Midden Nederland and De Hofnar Present B.V., organised a two-day event on 26 and 27 June 2024 which brought together leading experts and stakeholders to address the pervasive issues of racism, racial discrimination, and their profound impacts on health, as well as access to healthcare services, with a specific focus on People of African Descent (PAD). The event is the second in a series organised by the EPHA-initiated DisQo network[1] in close cooperation with OHCHR, bringing together about 80 organisations focusing on anti-discrimination and health equity. They have joined forces in providing technical assistance and expert advice to the European Union (EU) in the integration of human rights-based approach to the design, implementation, monitoring and evaluation through indicators of anti-racism and equality policies.

Racism and discrimination are fundamental determinants of health, profoundly affecting physical and mental well-being. Addressing these determinants is crucial for achieving health equity and ensuring that all individuals have the opportunity to realise their right to health as defined in Article 12 of the International Covenant on Economic, Social and Cultural Rights to which all EU member states are party.

The consultation event took place in context of the EU Anti-racism Action Plan (EU ARAP) which is a pivotal policy instrument that addresses various forms of discrimination to differing degrees. The first cycle of the EU ARAP 2020-2025 is coming to an end and this report sets out to provide recommendations for the post-2025 EU anti-racism strategy. The EU ARAP is a first of its kind pioneering policy document and marks a significant step forward in addressing racism and racial discrimination across the EU. Even so, the plan has multiple areas of opportunity for improvement, particularly in its approach to PAD and its juncture with the right to health. Next to racism and racial discrimination's systemic harmful consequences, PAD often encounter significant disparities in access to healthcare services, quality of care, and health outcomes. Consequently, while the action plan represents a commendable and necessary initiative, it requires more robust measures to effectively tackle racism and racial discrimination and ensure equitable health rights and outcomes for all generations of PAD communities across the EU.

Recommendations

The recommendations resulted from a consultation of experts, victims, PAD, representatives of civil society organisations and EU stakeholders. They include a statement presented on 27 July by Dutch partners Discriminatie.nl, de Hofnar, We Promise To and Burundian Women for Peace. Further, they build upon the DisQo networks' joint statement which sets out key priorities to address racism and discrimination's detrimental effects on health in a constructive, respectful, and participatory way. Lastly, it integrates recent evidence on health disparities, drawing on insights from a webinar on cancer inequities and access to care co-hosted by EPHA and the European Cancer Organisation (ECO). These findings underscore the systemic nature of racial

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[1] The DisQo: anti-discrimination and health equity is a European Health Policy Platform Stakeholder Network which aims to address racism and discrimination as fundamental determinants of health on. It was established in 2022 by EPHA and brings together around 80 organisations https://epha.org/campaigns/disqo-thematic-network/

health inequalities, particularly in cancer prevention, diagnosis and treatment, and reinforce the urgency of the recommendations outlined below.

We urge the office of the Commission's Coordinator on combating racism, responsible for the development of the EU ARAP, to take the following 6 recommendations and action points into consideration for the development of the post-2025 EU ARAP. A cross cutting consideration for the post-2025 EU ARAP is the necessity to design it with strict adherence to international normative obligations of EU member states; guided by the understanding that the plan is aiming and promoting, protecting and guaranteeing human rights and has to be anchored in the principles of human rights based approach to policy and budgeting, as well as on the extensive body of international recommendations formulated to EU member states.

1. Recognising racism and discrimination against PAD as fundamental determinants of health

Health starts long before a person gets in contact with the healthcare system. Our health is shaped by broader determinants such as our social and economic environment, our physical environment, our education, gender and employment (General Recommendation No.37 & General Comment No. 14). Racism and racial discrimination affect and intersect with all of these determinants across the life course and across generations. Therefore, it is required to take a holistic approach on ensuring the fulfilment of the right to health for PAD. This recognises the justiciability of social rights and the necessity of the post-2025 EU ARAP to make specific reference to the penalisations in cases of racism, and racism in the health sector.

We call on the European Commission (through the EU ARAP) to explicitly recognise racism and racial discrimination as fundamental determinants of health, equity and well-being of PAD by:

- taking a leadership role to address racism and racial discrimination from the health equity perspective
- including explicit mentions of racism and racial discrimination in hard and soft legislative and policy documents
- focusing on racism and racial discrimination as an integral part of training curricula across different disciplines, and as a key aspect of continuing vocational training
- prioritising racism and racial discrimination for research funding in all funding calls of the European Commission
    - including research into the effects of prolonged exposure to discrimination and racism on physical and mental health, social mobility and participation in the EU and include transcultural care and trauma healing in standard or basic healthcare schemes
- dedicating a section in the upcoming EU ARAP to the area of physical and mental health and its determinants, including on access to health care services
- strengthening the Racial Equality Directive (2000/43/EC) in relation to the right to health
- naming racism as a health threat and racial health disparities as a consequence of systemic and structural racism
- acknowledging the disproportionate cancer burden faced by racialised communities, including:

  - significantly higher prostate cancer incidence and mortality rates among Black men
  - later-stage breast cancer diagnoses among women of African descent
  - disparities in access to timely screening and treatment

2. Meaningful involvement of affected communities, academics, experts, international organisations all other relevant stakeholders

Involving affected communities, civil society and grassroots organisations throughout the policy cycle is crucial for ensuring that health policies and all other policies that impact on health outcomes are holistic and equitable. For PAD in the EU, this participatory approach acknowledges their unique experiences and needs, fostering culturally competent and responsive healthcare. Inclusive policy making enhances policy relevance, restores community trust, encourages implementation success, and is recognised by World Health Organization as a driver of health equity.

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

- including civil society at the heart of the of the post-2025 Anti-racism Action Plan to assist with design, implementation, monitoring and evaluation
- 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
- 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
- including action points on empowerment or capacity-building of PAD regarding education, advocacy, and participation in consultative bodies in relation to the Right to Health and racial discrimination, as to ensure the principle ‘nothing about us without us’
- supporting and funding community-led cancer awareness and prevention initiatives that are co-designed with PAD communities to address specific barriers to early diagnosis and care, such as:
  - prostate cancer screening programs delivered through trusted community spaces like barbershops and places of worship
  - culturally adapted breast cancer awareness campaigns using community-preferred communication channels
  - peer navigation programs to guide PAD community members through screening and treatment processes
  - multilingual cancer education materials co-developed with community health workers

3. Respectful and inclusive language

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 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.

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 on key terms, in a broad participatory consultation with experts
- carrying out – or providing funding for – a harmonisation exercise to establish definitions for terms on which there is no current consensus, involving all relevant stakeholders, including civil society

4. Disaggregated equality data

Evidence-based policymaking and monitoring for addressing racism and racial discrimination and advancing (health) equity require good quality data that allows for disaggregation by indicators on various grounds on which people may be discriminated against. Currently, major gaps and challenges exist regarding the collection, availability, and comparability of equality data across EU member states.

We call on the European Commission to strengthen equality data collection by:

- taking a leadership role in the harmonisation of equality data collection in the EU, involving the relevant stakeholders, including those working with data[2] and civil society, making use of the common framework of indicators on human rights developed by OHCHR (Human Rights Indicators: A Guide for Measurement and Implementation)
- developing further guidance for member states on the systematic collection of equality data and data focusing on racial discrimination, including in the area of mental and physical health and healthcare, improving its comparability and accessibility, and on training for people who collect the data
- encouraging member states to develop national strategies for equality data ensuring integration of a human rights-based approach to data (A Human Rights Based Approach to Data).
- promoting a focus on intersectional data, ensuring that the collection of data reflects the diversity within the groups exposed to discrimination
- funding - and encouraging member states to fund - projects that advance the harmonisation of collection of equality data and data focusing on racial discrimination

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[2] Such as Eurostat, the European Union Agency for Fundamental Rights (FRA), the Organisation for Economic Co-operation and Development (OECD), Joint Research Centre (JRC), the World Health Organization (WHO), the European Centre for Disease Prevention and Control (ECDC) and the United Nations Statistics Division (UNSTAT).

- facilitating discussions on EU and national level, with the inclusion of civil society, on how to collect equality data and data focusing on racial discrimination in an ethical way that ensures it cannot be utilised to harm PAD
    - this should include the creation of exchange platforms on best practices and lessons learned on human rights indicators and data collection with partners from outside the EU (such as the International Meeting on Gender Statistics)
- supporting and validating community-led data collection (using the Afrozensus research project as a leading example) through funding
- exploring the creation of an EU working group of IT and data governance experts, legal and human rights experts, public health and academic experts as well as civil society to develop policy recommendations on (health) digitalisation and discrimination, particularly in relation to the European Health Data Space
- promoting the use of digital tools in the fight against racism and racial discrimination, such as the Dutch G4 analysis tool with an almost real time dashboard of reported incidents of racism
- exploring innovative technologies for secure and privacy-preserving data analysis
- addressing critical gaps in cancer-specific data by:
    - collecting and analysing ethnicity data across the cancer care continuum
    - ensuring research includes sufficient representation of PAD populations
    - tracking racial disparities in cancer incidence, stage at diagnosis, treatment access and outcomes

5. Breaking down silos and taking action

Tackling complex and deeply rooted issues like structural, systemic and institutional racism and discrimination, requires actions at different levels and collaborations and partnerships across different sectors. This 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 racial discrimination and/or exclusion.

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 all groups and individuals exposed to structural racism and racial discrimination, for an effective and comprehensive response to the particular needs of such groups and individuals at the relevant intersections
    - recognising that racism and racial discrimination intersect with other social categorisations and factors, including but not limited to sex, gender identity, sexuality, socio-economic status, religion, etc., creating overlapping systems of discrimination or disadvantage

- recommending member states to explicitly recognise and protect individuals who face intersectional discrimination in their national anti-discrimination action plans, human rights action plans and any other relevant policy
- increasing transparency and social participation to bolster policy mainstreaming, including on the Task Force on Equality and funding towards fighting inequalities
- promoting equal access to healthcare and social inclusion for all in EU funding programmes
- bridging communication gaps on the valuable tools that are provided by the EU institutions for the development of, and reporting on national action plans (such as the common guiding principles, monitoring checklist and reporting tool, etc.) for member states
- promoting best practices of member states (such as the appointment of National Coordinators against Discrimination and Racism)
- advocating for the coordination and standardisation of national anti-discrimination laws that are needed for the standardisation of equality data collection
- promoting and funding community-led initiatives that aim to address and improve the physical and mental health of PAD
- implementing multi-sectoral approaches to address cancer disparities through:
    - coordinated action between public health, community organisations and healthcare providers
    - Inclusion of cancer equity measures in anti-racism policies and programs
    - dedicated funding for interventions targeting racial disparities in cancer outcomes

6. Addressing racism and discrimination in healthcare and science

Within the healthcare field there is an urgent need for more knowledge on racism and health and the diversification of medical education, as well as a need to step away from underrepresentation in clinical trials and the healthcare workforce. Healthcare professionals need to be equipped with the knowledge, cultural awareness and skills to treat individuals from PAD communities, to tackle unscientific and biomedically irrelevant standards, often connected to erroneous beliefs about race, and ensure the fulfilment of the right to health. Furthermore, access to healthcare services is often seriously limited for PAD, risking either delayed or no treatment, causing health inequities. Additional focus should be put on the provision of holistic and culturally sensitive mental health services, as well as maternity services, obstetric violence and violence against women.

We call on the European Commission to address and combat racism and discrimination in the healthcare and science sector through:

- moving away from race-based to race-conscious medicine, while simultaneously considering biomarkers from a clinical perspective
- ensuring diverse representation in healthcare by moving away from the white-cis-male reference point in scientific trials, education materials, etc.
    - by integrating adequate representation in healthcare training curricula and enforcing binding guidelines for inclusive representation in all health research, including clinical trials of new medicines

- promoting adequate representation and diversity within all (health)care professions, including the healthcare workforce, particularly within managerial positions (General Comment No. 14)
- ensuring cultural knowledge and skills of the healthcare workforce through recommendations on guidelines on adequate training
- easing access to healthcare services for PAD communities through recommending member states with the sufficient provision of language and interpretation services, and administrative support
- eliminating racial biases in cancer care by:
  - diversifying representation in clinical trials and research
  - providing anti-racism and cultural competence training for oncology professionals
  - developing and implementing race-conscious clinical guidelines