

Use of ethnic identifiers to narrow health inequality gaps



Joshua A.N. van Apeldoorn,^{a,b*} Charles Agyemang,^a and Eric P. Moll van Charante^{a,b}

^aDepartment of Public and Occupational Health, Amsterdam UMC, University of Amsterdam, Amsterdam Public Health Research Institute, Meibergdreef 9, Amsterdam, the Netherlands

^bDepartment of General Practice, Amsterdam UMC, University of Amsterdam, Amsterdam Public Health Research Institute, Meibergdreef 9, Amsterdam, the Netherlands

The COVID-19 pandemic has brought ethnic health inequity to the forefront of public health. It has highlighted that health outcomes are generally worse for most ethnic minority groups across a broad spectrum of diseases.¹ Therefore, similar to sex and age, ethnic identity may be perceived as a distinctive phenomenon in diagnosis and treatment. Ethnicity is a self-identified and perceived identity reflecting common culture, shared traditions, history, language, and religion. Although often conflated with race based on physical characteristics such as skin colour and hair texture, ethnicity provides more contextual characterization.² Through ethnic identifiers in health care systems, the quality of care for minority populations, might be improved, facilitating detection and guiding interventions to reduce health disparities.

Over half of EU-27 countries collect ethnic data in official data sources, such as population censuses, whereas most others collect data that might serve as a proxy, i.e., country of origin.³ However, in health care systems, ethnic data collection is sparse and only legally mandated in Finland, the UK, and Ireland. Nevertheless, consistent registration and utilization of ethnic data are lacking, even within these countries.⁴ In most European countries, registration of ethnicity is met with restraint, motivated by fear of stigmatization, potentially worsened by measuring ethnicity only in high-risk populations, privacy concerns, perceived legal barriers, time constraints, fear of data misuse, and reluctance among majority and minority groups to talk about racial or ethnic origin.^{2,5} Furthermore, in a recent qualitative study, Irish general practitioners raised fundamental doubts about its clinical relevance for individual consultations.⁶ An additional reserve relates to the multifaceted concept of ethnicity, challenging sufficiently unambiguous operationalization.⁷ This may all add to the catch-22 in the

debate on health disparities: lack of clarity on the clinical relevance of ethnic identifiers impedes their further study, prohibiting in-depth understanding of their potential role in closing health disparity gaps.

Ethnic identifiers in health care systems help identify health disparities and provide opportunities to address them. For instance, in the US, where ethnic registration in health records is common, it has helped to guide multifaceted interventions targeting patient populations such as patients with poorly controlled diabetes, leading to improved control and decreased health disparities across several ethnic groups.⁸ In the UK, routine data collection from general practices on ethnicity was shown to differentially reclassify the 10-year cardiovascular disease risk across several ethnic minority groups and was incorporated in the QRISK algorithms now widely used in primary care.⁹ Recently, the COVID-19 pandemic demonstrated the need for collecting ethnicity data; countries like the UK could detect clear ethnic disparities early, which fuelled subsequent policy directives.¹

International organization and monitoring bodies, including The European Committee of Social Rights, emphasize collecting ethnic data.⁵ Such data provide information on a population's diversity and give direction to equity policies on educational levels and health conditions. The European Union General Data Protection Regulation (GDPR) prohibits personal data processing, such as ethnic origin, yet allows exceptions, specifically when collected with the data subject's consent.¹⁰ Furthermore, the European Union GDPR provides standards about data processing with subsequent penalties if not addressed correctly. Additionally, this regulation requires that only needed data should be collected, assuming adequate substantiation of their relevance. Hence, complex regulations on data protection and a lack of sound evidence on the benefit of ethnic identifiers to reduce ethnic health disparities may deny progression on narrowing this gap.

Altogether, ethnicity may be perceived as a distinct phenomenon in health and medical care, but the added value of ethnic identifiers is both questioned and overshadowed by concerns about stigmatization and data protection. We advocate a more consistent use of ethnic identifiers across primary, secondary, and tertiary care to avoid selective use that may inadvertently increase

The Lancet Regional Health - Europe
2022;18: 100411
Published online xxx
<https://doi.org/10.1016/j.lanepe.2022.100411>

*Corresponding author at: Department of Public and Occupational Health, Amsterdam UMC, University of Amsterdam, Meibergdreef 9, 1105AZ Amsterdam, the Netherlands.

E-mail address: j.a.vanapeldoorn@amsterdamumc.nl (J.A.N. van Apeldoorn).

© 2022 The Author(s). Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>)

stigmatization of ethnic minority groups. Only when appropriately used and studied we may learn how and where ethnic identifiers can contribute to improved health care. Standardized ethnic classification should be used alongside data on socioeconomic status and social determinants of health in general to facilitate analyses of the complex relationship between ethnicity and health. Simultaneously, barriers in clinical practice require exploration to acquire a well-balanced perspective on this complex subject and, ultimately, its contribution to reducing ethnic health disparities. Our societal responsibility is to acknowledge and bridge the ethnic health equality gap to advance to a healthy, multi-ethnic Europe.

Contributors

JvA conceptualized and wrote the original draft. CA and EMvC contributed by reviewing and editing.

Declaration of interests

We declare no competing interests and received no funding.

References

- 1 Kumar BN, Hargreaves S, Agyemang C, James RA, Blanchet K, Gruer L. Reducing the impact of the coronavirus on disadvantaged migrants and ethnic minorities. *Eur J Public Health*. 2021;31:iv9–iv13.

- 2 Lentini A. Europe and the silence about race. *Eur J Soc Theory*. 2008;11:487–503.
- 3 Villarroel N, Davidson E, Pereyra-Zamora P, Krasnik A, Bhopal RS. Heterogeneity/granularity in ethnicity classifications project: the need for refining assessment of health status. *Eur J Public Health*. 2019;29:260–266.
- 4 Hannigan A, Villarroel N, Roura M, et al. Ethnicity recording in health and social care data collections in Ireland: where and how is it measured and what is it used for? *Int J Equity Health*. 2020;19:2.
- 5 Farkas L. European Commission. Directorate General for Justice and Consumers. Analysis and comparative review of equality data collection practices in the European Union: data collection in the field of ethnicity. LU: Publications Office; 2017. <https://data.europa.eu/doi/10.2838/447194>. Accessed 18 June 2021.
- 6 Roura M, LeMaster JW, Hannigan A, et al. If relevant, yes; if not, no: General practitioner (GP) users and GP perceptions about asking ethnicity questions in Irish general practice: a qualitative analysis using Normalization Process Theory. *PLoS One*. 2021;16:e0251192.
- 7 Stronks K, Kulu-Glasgow I, Agyemang C. The utility of 'country of birth' for the classification of ethnic groups in health research: the Dutch experience. *Ethn Health*. 2009;14:255–269.
- 8 Calman NS, Hauser D, Schussler L, Crump C. A risk-based intervention approach to eliminate diabetes health disparities. *Prim Health Care Res Dev*. 2018;19:518–522.
- 9 Hippisley-Cox J, Coupland C, Vinogradova Y, et al. Predicting cardiovascular risk in England and Wales: prospective derivation and validation of QRISK2. *BMJ*. 2008;336:1475–1482.
- 10 Radley-Gardner O, Beale H, Zimmermann R, eds. *EU General Data Protection Regulation (GDPR): Regulation (EU) 2016/679 Of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing directive 95/46/EC (General Data Protection Regulation)*, OJ 2016 L 119/1. Hart Publishing; 2016. <https://doi.org/10.5040/9781782258674>.