Table 3 | A comparison between mass drug administration and indoor residual spraying or insecticide-treated nets

	Mass drug administration	Indoor residual spraying or insecticide-treated nets
Rationale	Reduce the infection source (reduce parasite biomass) through radical treatment Protect susceptible populations from contracting infections	Reduce vector capacity Protect susceptible populations from contracting infections
Outcome	Reduce morbidity Reduce transmission (indirectly)	Reduce transmission Reduce morbidity (indirectly)
Applications	Administer antimalarial drugs to populations	Household spraying Distribute insecticide-treated bed nets to communities
Effectiveness	Dependent on the therapeutic or prophylactic efficacy of drugs, the coverage, the rounds used, and the responsiveness of the targeted population to the drugs	Dependent on the characteristics of vectors, the efficacy and mode of action of insecticide, the coverage, the number of rounds used (for IRS), and the utilization by the population (for ITNs)
Use in China	Widely used in settings where the malaria vector could be *An. sinensis*, *An. minimus*, *An. lesteri* or *An. dirus*	Only in areas with *An. minimus* or *An. lesteri* as primary vectors; ITNs were used in areas with *An. dirus* as the primary vector

continued to decline until elimination was achieved.

China's success in achieving elimination was due to multiple factors including a sustained political commitment, economic and social development, community involvement, and an evolving health system aiming to provide universal health coverage. Underpinning the success was a problem-solving mindset that valued research and innovation. Beyond the success of drug development, which was coordinated at a central level, the capacity of regional governments and health systems was critical to generate and use data and adapt to local epidemiological and other contextual elements. Malaria was thus seen as a problem to be solved and not just a task to be performed. ❐

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Author contributions

X.L. and P.L.A. conceived the article and wrote the first draft. Y.T., L.T. and Q.G. critically reviewed the manuscript. All authors read and approved the final manuscript.

Competing interests

The authors declare no competing interests.

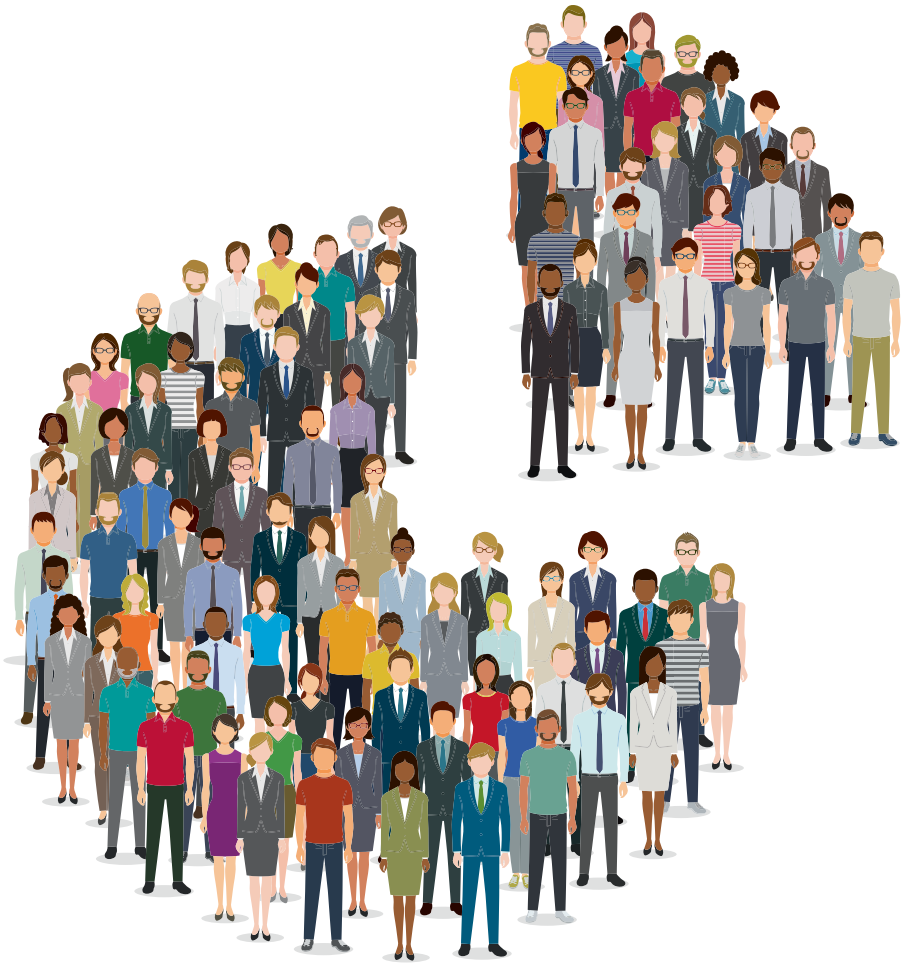
Check for updates

Strategies to record and use ethnicity information in routine health data

Ethnicity information is often missing from health data, impeding action on inequalities. Recording and using ethnicity data will require training, efforts at standardization, and policy changes, while engaging with patients and the public.

Ash Routen, Ashley Akbari, Amitava Banerjee, Srinivasa Vittal Katikireddi, Rohini Mathur, Martin McKee, Vahe Nafilyan and Kamlesh Khunti

With a few exceptions, health systems worldwide may collect data on people's age and sex, but few ask patients about ethnicity or race. There are many reasons, from historical abuses of data on race or religion in the early twentieth century, to simple inertia. Yet countries that collect these data comprehensively have shown that COVID-19 has been characterized by wide inequalities, with those from some ethnic groups



Credit: Viaframe / DigitalVision Vectors / Getty

disproportionately affected by the direct and indirect effects of the pandemic.

Data collection

To researchers who study ethnicity and health, these inequalities came as no surprise[1]. It has long been recognized that people from certain groups experience substantial barriers to accessing health care, as well as disproportionate rates of disease and its consequences, compounding their many other disadvantages in sectors such as employment, education, and housing, themselves risk factors for poor health[2,3]. Therefore, from a health equity perspective, the case for measuring and understanding variation in health and its determinants in different ethnic groups is obvious. Effective planning of health, social care and public health services requires data on ethnicity to ensure they are culturally appropriate, allocate resources equitably, and evaluate the impact of policy, with the ultimate aim to reduce variations in outcomes[4].

A lack of such data is a particular problem in research, where participants are often unrepresentative of those who will ultimately receive interventions being evaluated. This has been apparent throughout the COVID-19 pandemic, with many clinical trials failing to record or report results by ethnicity[5], in part because some countries prohibit the collection of data on ethnicity, citing concerns about privacy[6].

Ethnicity is a complex concept, incorporating notions of race (the classification of people based on physical appearance), religion, and culture, especially for individuals born into families with multiple heritages. When asked their ethnicity, a patient's first instinct may be to question why they are being asked. Their answer may differ according to their previous experience, especially if they have several possible identities, as is increasingly the case, and where they perceive that answering the question may place them at risk of discrimination or even violence, as described, for example, among Roma in central Europe[7]. There are also particular challenges in international comparisons, as context influences the response. For example, it may be quite different to be a Gujurati in India, Kenya, or the UK. Even where such data are collected, the quality may be variable. It has been suggested recently that inconsistencies in data on race (which is related to, but distinct from, ethnicity) in the USA delayed identification of groups at greatest need during the COVID-19 pandemic[8].

The experience in countries that collect ethnicity data shows its importance, with many examples from the UK, which is unique in that data on ethnicity are collected routinely in most interactions with public authorities. There is a legal requirement on the National Health Service (NHS) to do so, rather than, as in some other countries, limiting this to ad hoc research studies or using proxy measures, such as country of birth (which will miss second- and subsequent-generation immigrants), as in France.

Defining ethnic groups

The recording of ethnicity principally involves collecting data on an individual's membership of an ethnic group, but related information on primary language, religion and country of birth may also be collected, depending on the country and healthcare sector. In the UK, information on ethnicity is collected across a wide range of routine electronic health record data sources, primarily captured from patients within NHS systems at the point of care. These data are collected predominantly via self-reporting by patients and with or by health care practitioners.

Ethnic groups are socially constructed and distinct from genetic ancestry. Ethnicity is defined on the basis of a society's norms, attitudes and expectations, rather than being a readily measurable biological variable (like blood pressure) where there is widespread agreement on measurement[9,10]. For this reason, the categorization of ethnic groups can differ over time and place. In the UK, the broad ethnic group Asian largely comprises people from the Indian subcontinent, whereas in the USA the term often implies people from East Asia. Similarly, classifications often evolve over time, with the 'one-drop' rule defining a person as Black if they had any Black ancestry, which was used for the purposes of segregation in twentieth century USA[11]. Terminology reflects social factors such as experiences of migration and broader historical processes.

Box 1 | Common challenges of ethnicity data collection and recording in routine health data

- Healthcare professionals' lack of knowledge about the importance and use of ethnicity data, and understanding or confusion about ethnicity categories
- Healthcare staff reluctance to ask for ethnicity data and lack of confidence to be able to do this in a sensitive and culturally appropriate manner
- Pressures on healthcare staff and lack of time or opportunity to ask the patient about their ethnicity
- Lack of central supporting resources to provide training and appropriate data collection materials, such as the costs of translation into multiple languages, and data collection templates
- Variable processes for collecting patient ethnicity information, such as recording templates, within and between general practices and hospitals
- Lack of appropriate, or use of outdated, ethnicity codes in electronic health records

Box 2 | Recommendations to improve ethnicity recording in routine health data

- Embed ethnicity information collection within routine processes, such as during regular health checks within primary care.
- Create and adopt national standardized data collection protocols and standardized ethnicity categories.
- Develop comprehensive training to allow staff who collect ethnicity data in health and social care to be able to routinely ask about ethnicity in a sensitive manner, focusing on self-reported data collection.
- Ensure inclusion of minority ethnic communities throughout the development of staff training and the development of standardized data collection and reporting protocols.
- Facilitate linkage between primary and secondary care sectors to avoid repeated questioning of patients for ethnicity information.
- Ensure implementation of strict confidentiality controls, maintaining clear separation between data for health purposes from potential other uses, such as immigration controls.
- Regular reporting of data quality at regional, national and international levels, with cycles of improvement for both completeness and quality.
- Convey the value of data collection to the public in order to maintain public trust. This could involve a cycle of feedback and improvement between healthcare providers, data providers, and the public.
- Ensure the collection of wider determinants of health, which will include mechanisms for health inequalities between ethnic groups.
- Develop electronic health record minimum standards, professionalize informatics, and invest in electronic health record research.
- Raise the policy profile of ethnicity recording and associated research at national and international levels, as is being done by the UK Scientific Advisory Group for Emergencies (SAGE) ethnicity subgroup and Marmot reports.

Establishing meaningful ethnic groups to analyse health disparities is not a straightforward task. On the one hand, it is often preferable to study narrow ethnic groups lest important heterogeneity be masked[10,12]. On the other hand, some minority ethnic communities may be relatively small, which can prevent robust statistical analysis and raise concerns around maintaining confidentiality. It is increasingly appreciated that ethnicity intersects with other characteristics, such as gender, sex, or socioeconomic position[13]. There can be considerable value in adopting an intersectionality perspective, but this may again require a trade-off against studying more disaggregated ethnic groups. In the UK, a pragmatic classification of 18 ethnic categories has been chosen[14], which, where available, provides standardized categories across government and healthcare settings, allowing for the monitoring of inequalities across health, policy and social care spheres.

Patient involvement

Although information on ethnicity is typically collected through patient self-report, minority ethnic communities have rarely been involved in the design, implementation, collection, and use of routine healthcare data on ethnicity[15,16]. The active involvement of minority groups in the various processes of collecting and utilizing ethnicity data should be prioritized as a way to build trust in communities that are often hesitant to provide data due to wrongful use or past abuse of gathered information. The quality and accuracy of ethnicity data and the evolving relevance of ethnic categories will likely be improved by community members validating or sense-checking ethnic group coding standards[15].

Community members have been mobilized in some inclusive ethnicity data collection or design processes. For example, in the 2018 census in Colombia, the national statistical office undertook a wide-ranging consultative exercise with various indigenous and minority ethnic groups. This consultation resulted in revised question wording and ethnic group response options, to align with the consulted communities' needs. Such public involvement should be undertaken by all organizations collecting routine ethnicity information in health and social care systems, who should also work with ethnic minorities on governance of data repositories and ownership of data[17].

Boosting collection

One barrier to ethnicity data collection is healthcare professionals' lack of knowledge about the importance and use of the data, including a reluctance to ask for ethnicity data and a lack of demonstrated need for the collection of data (Box 1; ref. [18]). Experiences of providing ethnicity information within healthcare have been reported as acceptable, although in some studies, participants have expressed dissatisfaction about being asked to provide their ethnicity on repeat visits[19], and there needs to be a clear explanation from the healthcare provider as to why the data is being collected and how and what it would be used for[19].

At the organizational level, a comparison of self-reported ethnicity and Hospital Episode Statistics (HES)-coded ethnicity in England found that misclassification varied only by a small amount between ethnic groups, but varied by a greater degree between hospitals (the accuracy of coding of ethnicity across hospitals ranged from 67% to 100%)[20]. This suggests that processes within hospitals may influence coding accuracy, although whether this is driven by staff or organizational issues is unclear.

Incentives to record ethnicity can be effective. Ethnicity recording was introduced into UK primary care in 1991 and into Hospital Episode Statistics in 1995, but this was only financially incentivized under the Quality and Outcomes Framework (QOF) between 2006 and 2011. The completeness of ethnicity recording rose from 27% for individuals registered 1990–2012 to 78% for individuals registered 2006–2012, after it was incentivized, and the ethnic breakdown of Clinical Practice Research Datalink participants was comparable to the UK population[21]. Challenges remain, however, as while there is high accuracy for people who self-identify as white British (97% accurate), there is poorer accuracy for minority ethnic groups (59% accurate)[20].

Training and standardization

Two key factors that affect collection of ethnicity data are staff training and knowledge, and variation in data collection procedures[18,22]. Standardized data collection protocols and the use of standardized ethnicity categories that can be harmonized across sectors would reduce this variation. Harmonization across countries or continents may not be appropriate, as ethnicity is a social construct and varies significantly between countries.

Self-identification of ethnicity by the patient will avoid errors and emphasizes the value of an individual's lived experiences, as will self-completion of developed data collection forms. This will require comprehensive staff training to address barriers such as lack of time, or patient capacity for self-report, which can present in pressurized clinical situations[4]. Training should be developed with patients and public members to ensure that developed protocols are acceptable to patients, the reasons for collecting ethnicity information are clear and justifiable for both patients and staff members, and conveyed in appropriate languages and spoken or written formats[19].

Public involvement will avoid pitfalls. During the COVID-19 pandemic, the initial practice in the UK was to use the ethnic grouping Black, Asian and Minority Ethnic (BAME) for early data analyses on outcomes, until this was discontinued following public input and feedback that this was not an appropriate description, as BAME groups together disparate ethnicities[23]. Community members should also be involved when disseminating information to the public on the importance of data linkage and collection more generally, as well as communications on how health and ethnicity data in particular are used and interpreted.

As well as collecting ethnicity information, data on the wider determinants of health will help to understand inequalities. Most of the differences between ethnic groups in COVID-19 outcome analyses are due to wider structural factors, such as housing and intergenerational living, poor-quality employment and occupational exposure, and environmental support for health behaviours, that are imperfectly collected in electronic health records, if collected at all[24].

Policy and professionalism

Newly developed protocols, guidance and ethnic grouping standards will require support across sectors. Policy changes will be needed to enshrine regular reviews of guidance, as well as routine monitoring and publication on the quality of ethnicity coding data[4] (Box 2). There is an opportunity for ethnicity to be an exemplar for improving data quality overall; the power of ethnicity data will be increased if all data recording is also improved. Minimum standards for electronic health records should be introduced and health informatics, including the work of the Professional Records Standards Body and the Faculty of Clinical Informatics in these areas should be professionalized, and research using electronic health records increased.

Data quality should be regularly reported at regional and national levels, with cycles of improvement for both completeness and quality. In addition, ethnicity collection reporting could include cross-disease and cross-country comparison; there was little or no mention of ethnicity in the Global Burden of Disease studies and other similar inter-country or global data collection exercises[25]. Efforts to collate and improve comparability of ethnicity data globally are needed, as comparison of health inequalities data between countries is limited due to inconsistency in ethnicity data collection methods and variance in ethnic group categorizations. Addressing these issues will be complex as self-defined ethnicity will differ depending on the social and cultural context in which the individual is responding[26]. In addition, any international comparison analyses must be clear on the different experiences and cultural context of comparable ethnic groups between countries, such as how they are or are not minoritized.

Ultimately, funding is required for health care systems and researchers, with supporting policy to ensure continued implementation and monitoring. These are not new arguments, but they are receiving renewed attention following the impact of the COVID-19 pandemic. Action is required to ensure that existing health inequalities based on ethnicity are not maintained or exacerbated. Improving the collection and reporting of ethnicity information in routine health data should be one part of a wider process to tackle health inequalities. ❐

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Author contributions
All authors led on drafting, editing and revising the content. All authors approved the final version and are accountable for all aspects of this work.

Competing interests
K.K. is a director of the University of Leicester Centre for Ethnic Health Research, trustee of the South Asian Health Foundation, chair of the Ethnicity Subgroup of the Scientific Advisory Group for Emergencies (SAGE). S.V.K. was co-chair of the Scottish Government's Expert Reference Group on ethnicity and COVID-19 and a member of the Ethnicity Subgroup of SAGE. R.M. is a member of the Ethnicity Subgroup of SAGE.

Adverse effects of acquisitions in the pharmaceutical industry

Publicly funded research leads to the development of many new drugs, but the profits are largely reaped by big pharmaceutical companies through exclusive licensing deals, mergers and acquisitions, which can reduce competition and patients' access to medicines.

Melissa Newham and Kerstin N. Vokinger

Developing new therapies is a risky, lengthy process that requires substantial up-front investment. Governments are actively involved in supporting research and development (R&D). However, promising drug candidates often migrate from publicly funded research institutes and small biotech companies into the hands of big pharmaceutical manufacturers through a sequence of licensing agreements and acquisitions[1,2]. These deals are problematic for at least two reasons. First, they result in the private sector disproportionately reaping the financial rewards from drugs that often originate from publicly funded research. Second, these deals have the potential to be harmful to patients, and society at large, because they can provide manufacturers with an opportunity to kill the competition, leading to fewer therapeutic alternatives on the market as well as higher drug prices. Chimeric antigen receptor-Tcell therapy (CAR-T) for the treatment of certain hematological malignancies is a useful case study to highlight the challenges of these acquisitions.

Lessons from CAR-T therapies

CAR-T therapy is an innovative new treatment class for certain hematologic malignancies, such as B cell lymphoma, which uses genetically modified versions of the patient's own immune cells to attack cancer cells. Currently five CAR-T therapies are approved in the United States, European Union (EU) and/or Switzerland[3]. The development of approved CAR-T therapies can be traced back to research undertaken by academic institutions and research centers (Fig. 1). Technologies were then transferred from research centers and academic spin-offs to biotech companies through exclusive licensing agreements. Shortly before the approval of these therapies, in their late stages of development, all therapy candidates were acquired by large pharmaceutical manufacturers. Therefore, although numerous stakeholders have been and are involved in developing CAR-T therapies, three large pharmaceutical manufacturers now dominate the market for approved therapies. The pathway to big pharmaceutical companies cornering the market for innovative therapies is paved by three types of deals that transfer drug ownership from one entity to another: mergers, acquisitions and licensing agreements (Table 1).

The development history of axicabtagene ciloleucel illustrates the typical ownership trajectory of a CAR-T therapy well. Axicabtagene ciloleucel originated from research undertaken at the Weizmann Institute of Science in Israel. The scientist leading this research then founded a spin-off company, which entered an exclusive licensing deal with a small biotech, Kite Pharma, for patents related to CAR-T. Axicabtagene ciloleucel was also developed using technology invented by and licensed from the US governmental agency the National Institutes of Health (NIH) by Kite Pharma. Finally, Kite Pharma was acquired by the large biopharmaceutical company Gilead, while axicabtagene ciloleucel was under priority review by the US Food and Drug Administration (FDA).

Early public funding

Publicly funded research plays a crucial role in the development of new drugs, particularly in the early stages of research and development, and CAR-T therapies are no different[1,4,5]. The first approved CAR-T therapy (tisagenlecleucel) was primarily developed by researchers at the University of Pennsylvania with funding from the NIH, which has directed almost US$2 billion towards CAR T therapies. Similarly, in Europe, CAR-T research has been funded by the EU Horizon 2020 program and national funding bodies. Technologies invented and owned by the NIH were necessary for CAR-T therapy development, as indicated by the licensing deals between the NIH and biotech companies. Biotech