

Ethnicity and palliative care: we need better data – five key considerations

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Complete and valid ethnicity data are essential for monitoring racial and ethnic disparities but consideration needs to be given to collecting data well and using it responsibly. Palliative care could provide leadership in this field.

The COVID-19 pandemic has revealed the importance of good quality data for demonstrating the extent, nature and impact of ethnic and racial disparities within society.^{1 2} Where it has been available, data on race and ethnicity has long been used to highlight persistent inequalities in healthcare globally.³ Recent events of historical and political significance have also brought a renewed attention and momentum to these issues, for example, Black Lives Matter and Empire Windrush in the UK. There have been numerous calls for mandatory ethnicity data collection within routine health and social care, and on death certificates,^{2 4 5} which Scotland has already established.⁶ However, there has not been a parallel focus on how to get data collection right. Data are powerful, but can be misused. There are a number of practical, methodological and ethical issues which require addressing.

Holism is at the core of palliative care, in the approach to a person and their 'total pain'.⁷ Extending this framework to ethnicity data engenders a responsibility across both the collection and usage of data. We outline five key considerations informed by this framework relating to ethnicity data.

IMPROVEMENT OF ETHNIC GROUP CATEGORIES

Categories should be sufficiently granular to capture diversity, consistently applied and enable people to recognise their own identities.

Khunti *et al* have highlighted the inconsistent and simplistic ethnic group categories used in much COVID-19 research which hides intragroup variability.⁸ For example, the term 'South Asian' makes invisible heterogeneity in culture, behaviours and disease status between those of Indian, Pakistani and Bangladeshi heritage. Simplistic and crude ethnic group categories can also be a barrier to data collection. Good quality ethnicity data relies on self-report, so individuals need to see their own identity reflected.⁹

I have to state 'Other' as my ethnicity is not on the form, and I feel even now my origin is not widely recognised. (Punjabi participant)⁹

Most forms did not differentiate Asians, as Asian can be different groups, and not just Pakistani, not just Chinese. (Mirpuri participant)⁹

Ethnic group categories should reflect a granularity and diversity of experience for both research and

clinical understanding. Khunti *et al* suggest that all research and new datasets should collect and report ethnicity at a minimum of five levels, and where possible use nine.⁸

SENSITIVE, PROPORTIONATE AND TIMELY DATA COLLECTION

Questions about ethnicity should be clinically and societally sensitive, asked at non-intrusive times, and as infrequently as possible.

Asking about ethnic identity at the point of care could provoke feelings of concern and anxiety for some people. In particular, people from minoritised ethnic groups may be concerned due to historical and recent abuses of power, and personal experiences of discrimination or insensitivity within healthcare.⁵ A Canadian study found that some patients were concerned ethnicity data collection could lead to negative stereotyping, and could affect their treatment.¹⁰ One participant who identified as Indigenous was apprehensive about revealing his ethnicity:

I would feel insulted, offended, marginalized, targeted. I would wonder how this is going to affect my treatment, I would wonder how this would affect nurses', doctors' behaviour towards me.¹⁰

In a UK study, South Asian participants felt ethnicity data should be collected as infrequently as possible, and at a time when distress was minimised.⁹ For those receiving palliative care at the end of life these considerations are particularly important due to the high levels of emotional distress and symptom burden. Data collection needs to be sensitive to the individual's immediate clinical context, and to wider societal inequalities. Clinical encounters already involve complex power dynamics between doctor and patient. Collecting ethnicity data inappropriately could serve to reinforce wider structures of power, recreating and 'othering' non-white groups.⁹ Further research is

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required to develop sensitive and timely data collection methods.

SUPPORT FOR STAFF COLLECTING ETHNICITY DATA

Support for healthcare professionals and services collecting ethnicity data should be provided both in terms of resources and appropriate training.

Ethnicity data has been collected by the NHS in the UK since the 1990s. Over the last 15 years, policy and healthcare initiatives have sought to improve the quality of ethnicity data,¹¹ but despite some improvements, ethnicity data remains incomplete and largely unvalidated.¹² Collecting any data within healthcare settings is challenging due to lack of time, lack of training and lack of IT, administrative and financial support.¹³ The collection of ethnicity data is even more complex. It requires enhanced protections under the General Data Protection Regulation, and is a sensitive and personal issue for many people. In a hospice project to improve data collection on ethnicity¹⁴ healthcare staff demonstrated a heightened awareness of the cultural and political sensitivities around these topics and a lack of confidence in dealing with them:

If I ask the patient their ethnicity, they might think I'm being racist. (Healthcare professional).¹⁴

Moreover, a study of Irish GPs' views found that many were worried about the time constraints on collecting ethnicity data within primary care.¹⁵ Further research is required to help support staff collecting data, particularly within potentially emotive contexts such as palliative care.

BUILDING PUBLIC TRUST

Data collection must be part of wider reforms to build public trust in data and data security, and reduce discrimination in healthcare generally.

Public trust in data privacy is a longstanding issue. Failure to gain public trust has resulted in the collapse of data sharing programmes, such as NHS

England's 'care.data'. Trust for public institutions varies by ethnic group, these variations are the result of persistent structural racism, cultural racism and experiences of discrimination.¹⁶ Lack of trust can manifest itself in real world health outcomes, including greater levels of vaccine hesitancy.¹⁶ The trust deficit is particularly noteworthy for ethnicity data collection; ethnicity is self-defined and so relies on an individual answering on their own behalf. To do this they must trust that the data will be used, managed and stored securely and confidentially. In the rehearsal for the UK 2021 census, over 7% of respondents did not answer the question on ethnic background.¹⁷ This is indicative of a deliberate choice to not answer the question.

These concerns over ethnicity data and privacy are taken more seriously within Europe. The European Commission recommends the monitoring of ethnic equality data across all EU member states; however, only three countries (Ireland, Finland, UK) have placed a legal duty of data collection on public bodies.¹¹ The historical and political context of mainland Europe means that in many countries, data on ethnic origin is regarded as highly politically sensitive and potentially dangerous. Within some European countries there are legal prohibitions on ethnicity data collection, and groups such as Jewish and Roma communities who oppose ethnic data collection altogether.¹¹

Data security and confidentiality should be prioritised, and trust needs to be earned for the collection of data—particularly with people from diverse ethnic communities. Trust needs to be earned not assumed, with further research and collaboration with communities required to understand how trust can be built. This should form part of wider reforms to address racism and ethnic disparities in health and palliative care.^{5 18}

RESPONSIBLE AND CONTEXTUALISED USE OF ETHNICITY DATA

Data should not be 'cherry-picked' and must be understood and used within social, historical and political contexts.

Data that is presented without historical, social and political context can easily be misused or misinterpreted. For example, the UK government's Independent Commission on Race and Ethnic Disparities drew widespread condemnation for cherry-picking data to deny systemic racism in contemporary Britain. The findings were rejected by the United Nations (UN) and many of the groups who submitted contributions.¹⁹ When statistics are presented without a contextual understanding, the numbers themselves may appear to be the problem, and not a representation of the problems surrounding them. Cormack *et al* argues that by referring to ethnicity as a 'risk factor', those from non-white or indigenous backgrounds can be portrayed as 'health deficient'.²⁰

Community partnership working and patient involvement is crucial to understanding and using ethnicity data within research and for clinical purposes. Although it may be impossible to completely stop the misuse and misrepresentation of research findings, the whole research and palliative care community has a responsibility to safeguard data usage and draw attention to where it is misused.

CONCLUSION

Data are powerful. Good quality valid data on race and ethnicity is crucial for monitoring equality, and can be used to hold services accountable for disparities. Efforts to collect, store and use ethnicity data should be carefully and responsibly planned with 'bottom-up' community partnership and patient working to ensure appropriate data collection methods and data usage. Further research into these areas is required. 'Top-down' mandates for ethnicity data collection, without

consideration, could cause further harm and data misuse. Palliative care has not traditionally engaged with issues of race, ethnicity and racism,¹⁸ however, by extending its holistic approach to data collection, palliative care could provide leadership in this field.

Correction notice This article has been corrected since it was first published. Name of the author Jamilla Akhtar Hussain is now correct.

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