Gathering data on health inequalities

Reflections from the UK experience (advantages and potential issues with the systematic collection of socioeconomic, race, ethnicity data)

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Collecting ethnicity data

- Of 141 countries under study, 63 % incorporate some form of ethnic enumeration though question and answer schema vary along dimensions that suggest diverse conceptualisations of race/ethnicity/indigeneity/nationality (Morning 2008).
- Across Europe, only 5 out of 35 countries surveyed across Europe collected ethnicity data in the most recent census, of which the UK was one (Bhopal 1997).

Morning, A. (2008). Ethnic classification in global perspective: A cross-national survey of the 2000 census round. Population Research and Policy Review, 27, 239–272.

Bhopal R. Is research into ethnicity and health racist, unsound, or important science? Bmj 1997;314(7096):1751-6.

Models for ethnicity data collection

The census is one of the three institutions (alongside maps and museums) that states use to create a common imagination for its subjects (Anderson 1991: 163–164).

- *Counting to Dominate* - collectively identifying racialised others (Soviet Union)
- *Not counting in the name of national integration* - occurs when race or ethnicity is rejected either in the name of national integration (Western Europe, some African Countries)
- *Counting or not counting in the name of multiculturalism*, refers to Latin America's tendency to valorise racial mixing through the distinct practices of either not counting by race
- *Counting to justify positive action* invokes the pluralist models of Canada, the United States and Great Britain, all of which view racial enumeration as a tool in the fight against discrimination.

Rallu, J.-L., Piché, V., & Simon, P. (2004). Demography and ethnicity: An ambiguous relationship. In G. Caselli, J. Vallin, & G. Wunsch (Eds.), Demography: Analysis and synthesis. A treatise in population studies (Vol. 3, pp. 531–549). Amsterdam/Oxford: Elsevier/Academic Press.

Ethnicity and health inequalities

Value

- Deep understanding of intersecting forms of inequality, that can be used in order to design targeted interventions, investment and adapt care strategies (Mathur et al. 2013).

Critiques

- Statistics, and the census, don’t just capture reality, but create it – and might be used as instruments of the state to blame, define and control communities (Scott 1998).

The case of the UK

A brief history of ethnicity data collection

- *Colonial model* – 1841 question on parent’s place of birth.
- Census Act of 1920 which recommended that ‘race and nationality’ statistics be collected as part of the census for Great Britain in order to better understand the needs and circumstances of the population
- *Race Relations Acts* of 1965 and 1968 set up special bodies to deal with problems faced by immigrants in relation to discrimination, social welfare and integration.
- 1971 – General Household Survey - collecting data on a range of facets of life, interpolated with ethnicity, as defined by place of birth of household head, and inspection of interviewer as ‘White, Coloured or Unknown’.
- Haringey Affair 1979 - urged people not to answer the question on race or ethnicity; out of fear that this data may be used to ‘send them home’.
- 1981 census – inclusion of a specific question on ethnicity and language.
- 1991 census – enumeration of Mixed Race category, and addition of Black British and Asian British categories (links of race and citizenship)
- 2001 census – expansion of the ‘White’ category.

Mathur et al. (2013) Availability and use of UK based ethnicity data for health research. National Centre for Research Methods Working Paper 01/13

Sources: Data and health inequalities

- Primary care data – 98% GP registration allowing for interventions targeted by ethnicity and socioeconomic status.
- Ethnicity recorded in Hospital Episode Statistics, and in secondary care (since 1995).
- Census data sets - Samples of Individual Person-Level records (SARs) and the Office for National Statistics (ONS) Longitudinal study of England and Wales (LS).
- Data collected by para-governmental institutions – ONS, Public Health England, National Centre for Research Methods, ESRC grants.

Persistent ethnic disparities in Health

- In England, people from the Gypsy or Irish Traveller, Bangladeshi and Pakistani communities have the poorest health outcomes across a range of indicators.
- While the incidence of cancer is highest in the white population, rates of infant mortality, cardiovascular disease and diabetes are higher among Black and South Asian groups.
- Older people from ethnic minorities report poorer health outcomes even after controlling for social and economic disadvantages.
- Infant mortality rates are generally higher among ethnic minority groups. Infant mortality in 2015 –17 was highest among babies of Pakistani origin, followed by Black African and Black Caribbean groups. (refs in FEAM report)

Unequal impact of Covid-19

- People of black ethnicity have had the highest diagnosis rates, with the lowest rates observed in white British people.
- Data up to May 2020 show 25% of patients requiring intensive care support were of black or Asian background.
- An analysis of survival among confirmed COVID-19 cases showed that, after accounting for the effect of sex, age, deprivation and region, people of Bangladeshi ethnicity had around twice the risk of death when compared to people of White British ethnicity.
- People of Chinese, Indian, Pakistani, Other Asian, Caribbean and Other Black ethnicity had between 10 and 50% higher risk of death when compared to White British.

Fraught Political Climate

- This unexplained data on inequalities entered into a fraught political climate in the summer of 2020, when the BLM protests were ongoing.
- Our ethnographic research revealed ambivalent attitudes toward the data from minority communities; emergent folk explanations related to genetic disposition and ‘lifestyle’ (both factually grounded and grounded in eugenics); and a counter narrative that associated inequality with deprivation. Often manifest as stigma and blame for non-compliance.
- The SPI-B Ethnicity sub-group, ESRC Covid-19 grants, PHE and the RDU mobilized in different ways to better understand these inequalities.
- The backlash led to an inquiry on race and inequality in the UK that actively denied structural racism as a cause of inequality.
- Hence, efforts to address health inequalities and act on this data have been frustrated by the political climate.

How used in coronavirus response? Enduring Transmission and Mortality

Differential mortality high for all ethnic groups in second wave, but highest for Bangladeshi and Pakistani groups

- WHY?

Due to Amplifying Intersecting Effects of:

1. health inequities
2. disadvantages associated with occupation and household circumstances
3. barriers to accessing health care (stigma and unintended effects policies)
4. potential influence of policy and practice on Covid-19 health-seeking behaviour

- Social infrastructures of home, workplace, community taken into account
- Recommendations for interventions

Interpreting differential health outcomes among minority ethnic groups in wave 1 and 2, 24 March 2021

Paper prepared by the ethnicity subgroup of the Scientific Advisory Group for Emergencies (SAGE).

From: Scientific Advisory Group for Emergencies
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Documents

COVID-19 Ethnicity subgroup: Interpreting differential health outcomes among minority ethnic groups in wave 1 and 2, 24 March 2021

PDF, 813KB, 26 pages

Implications

- Advantage of collecting ethnicity data during Covid-19 has been the rendering visible of structural inequality and racism.
- This has allowed for the targeted investment in locally-led schemes such as Community Champions programs and vaccine uptake programs for minortised groups.

- Disadvantage of collecting ethnicity data is that ethnicity itself is analysed as the ‘exhaust’ of a range of other factors and cannot be grasped itself – leading to unstable assertions that cause social distress and divides.
- To remedy this, they must be complemented by qualitative, participatory and ethnographic methods to understand intersecting factors.

Credits

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Access to Healthcare

- Factors contributing to inability to access healthcare
  - a) inadequacy of the public resources invested in the health system;
  - b) fragmented population coverage;
  - c) gaps in the range of benefits covered;
  - d) prohibitive user charges, in particular for pharmaceutical products;
  - e) lack of protection of vulnerable groups from user charges;
  - f) lack of transparency on how waiting list priorities are set;
  - g) inadequate availability of services, in particular in rural areas;
  - h) problems with attracting and retaining health professionals; and
  - i) difficulties in reaching particularly vulnerable groups.

- “Stigma can cause health inequalities, drive morbidity and mortality, and undermine access to health services.”
- ”When services are not adapted to the needs and requests of marginalised communities, this can further increase distrust in the mental health system, and less likely for such groups to seek support.”

- “Without adequate investment in the health system, it is unlikely that inequality in healthcare will be addressed.”
- “A larger role could be played by patients and community members, contributing to a more comprehensive viewpoint on implementation of strategies to mitigate inequalities in healthcare access.”