

CanEth: Improving ethnicity data collection for statistics of cancer incidence, prevalence and survival in the United Kingdom – public and professionals perceptions

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Background

- Accurate 'ethnicity' data essential to inform officials of incidence, prevalence and outcomes of specific diseases in population subgroups
- Some ethnic minorities associated with increased incidence of diabetes, hypertension, stroke and certain cancers
- 4.5 million people (8%) from UK in 2001 defined as being from an ethnic minority group
- Immigrants from Pakistan, India, Bangladesh combined into South Asian group (figure 1)
- South Asians largest ethnic group in the UK (50% of non-white population, 2001)
- Reports suggest breast and colorectal cancer incidence lower in South Asian population; however this is rapidly increasing over time
- UK Government initiatives in place to collect ethnicity data since 1995 but limited to hospital admissions
- Data remains incomplete and has not improved over time



Figure 1: South Asia

Objectives

1. Evaluation of health care professionals' perceptions and experiences of collecting ethnicity data in primary/secondary care
2. Evaluation of consumers' perceptions, experiences and willingness to provide ethnicity data in primary/secondary care

Methods

1. Healthcare professionals survey

- 2-page questionnaire distributed through: Minority-Ethnic-Health jiscmail list, ALLSTAT jiscmail list, National Cancer Research Network, Race-for-health Primary Care Trusts
- Questionnaire was aimed all levels of healthcare professionals involved in data collection

2. Focus groups

- Focus groups formed from existing contacts with volunteer groups and facilitators to include main minority groups in local area
- Facilitators used a topic guide specifically developed to focus on the five areas of interest:

1. General opinions on the collection of ethnicity
2. Experiences of providing ethnicity
3. Categories used in practice (examples provided)
4. How should this information be collected
5. Closing comments

1. Healthcare professionals survey results

- Perceived importance of collecting ethnicity data

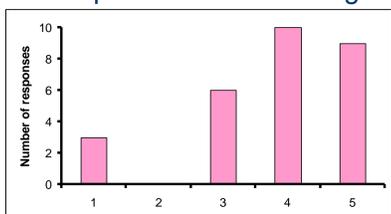


Figure 2a: Please rate how important you personally think the collection of ethnicity data is

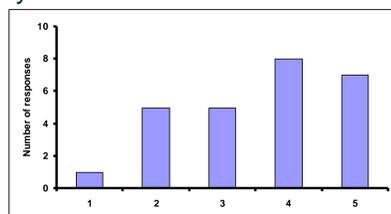
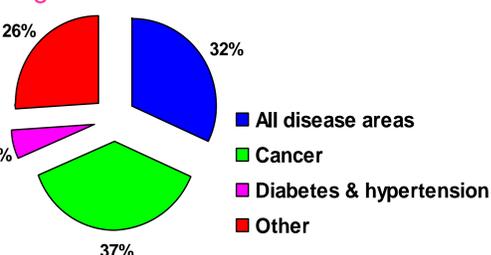


Figure 2b: Please rate the value of collecting ethnicity to your organisation

- Majority of respondents personally thought collection of ethnicity data was more important than their perception of its value to their organisation
- May be indicative of the organisations weak policies on and lack of training provision (figures 2a and 2b)

➤ Ethnicity data collection

Figure 3: Disease areas



Other includes: midwifery, all hospital registrations, contraception & sexual health

Table 1: Ethnicity data items collected

Data item	Yes	No	Missing
Census	16	3	3
Race	3	11	7
Religion	11	6	5
Patient name	8	8	6
Country of birth	6	12	3
Country of origin	3	13	4
Language	10	9	3
Other*	1	1	20

* Need for interpreter

- Ethnicity data routinely collected by 66% of respondents
- Most commonly collected for cancer (figure 3)
- Census, religion and language most commonly collected (table 1)
- Self-assessment most common method of data collection (n=22)

➤ Problems collecting ethnicity data

"We have been collecting data surrounding ethnicity etc for around 7 years. The main issue is the **patients lack of understanding of what ethnicity is**. Also practice **staffs lack of awareness of why we need to collect this information**. On the whole though there have been very few problems." (Profiling officer, Liverpool)

"People collecting the data may not realise that they have to ask the patient" (Informatics official, London)

"I feel this is a difficult area due to **fear of offending** anyone. Most of the younger generation are British, I would have thought." (Nurse, Birmingham)

"Clients have the **option of not stating** their ethnic origin so there will always be a gap in the data" (Service Development Officer, Sheffield)

"Existing data collection **systems are not made for it**. **Ethnic categories are not up to date**, follow old traditional immigration routes" (Information Analyst, Luton)

➤ Reasons for not collecting ethnicity data

"We have not to date regarded it as sufficiently important" (Gastroenterologist, Wales)

"Not relevant to care or treatment given to patients..." (Oncology Research Sister, York)

"Our data collection is poorly resourced as it is so we have to stay entirely focused on what is clinically relevant" (Oncologist, Birmingham)

"...Ethnicity data is difficult to collect because it involves asking the patient what they want it to be and they are not always available or willing to answer." (Informatics official, London)

"Not part of my job" (Radiographer, Gloucestershire)

Survey summary

- Self-assessed ethnicity is most common method of collection
- Data not collected due to a lack of 1) understanding 2) resources 3) training
- Lack of consistency at different levels of organisations
- No clear rationale for collection/use of data
- Data collected without training or explanation of its use

Focus group results

Group	Country of origin	Language	Males	Females	Total
1	Azad Kashmir	Mirpuri	0	5	5
2	Bangladesh	Bengali	8	0	8
3	Pakistan	Urdu	0	10	10
4	Pakistan	Urdu	8	0	8
5	India	Punjabi	2	3	5
Total			18	18	36

Selected quotes:

"They should explain why they collect the data; the reason behind it; what benefit there will be for people. Also, where the data will be used and how secure this data will be. It should be kept secret [confidential]" [Bengali focus group; all participants]

"Not routine; there is no need since these things don't change but once or twice is ok" [Mirpuri female]

"The information should be collected at the GP surgery as patients are already distressed in hospital" [Punjabi female]

Focus group summary

- No objection to providing data for healthcare purposes
- Explaining why data is needed and its use would increase willingness
- Ethnicity should only be collected once by GP or at first hospital visit
- There was a feeling data collected for 'statistical purposes' not used
- 'Ethnicity' information should include language, religion and country of birth to account for cultural differences

Conclusions

- Need more reporting of ethnicity data in the healthcare setting, in order to improve planning and delivery of services for ethnic minority groups
- Need training to raise awareness for patients and professionals:
 - Patients- why your doctor should know your ethnic group?
 - Professionals- how to ask/explain the importance of ethnicity data collection?
- Work towards a culture of routine data collection of ethnicity at GP level
- Need working groups to assess collection, completeness and validation

Contact details

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