ACCESS TO SERVICES
USER VIEWS OF ETHNICITY MONITORING
IMPLICATIONS FOR PRACTICE

This paper draws on user and decision maker views of the perceived harms and benefits of collecting ethnicity data, and links the findings to the development of informed practice.

1. USER AND DECISION MAKER VIEWS: SUMMARY OF FINDINGS & IMPLICATIONS FOR PRACTICE

HARMS AND BENEFITS: COLLECTING ETHNICITY DATA IN A CLINICAL CONTEXT

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A. RESEARCH QUESTION

- What are the implications of collecting ethnicity data in a clinical setting?

B. POSSIBLE BENEFITS AND GOOD INTENTIONS

Policy/decision makers anticipated group benefits

“If we can’t measure disparities in either their health status, access to services, types of treatment prescribed, health outcomes, it is an invisible problem” Decision-maker #6

Some patients anticipated benefits for individuals:

- genetically linked diseases
- food preferences
- language barriers

“I think it could be an advantage to ask… in terms of treatment for that person because, you know, like things like diet and such and religions and everything are different, okay, so this would be useful for a doctor to know so if you went to an emergency room unconscious then they would know how to proceed’” Patient #21

Some patients assumed good purposes

"I'm assuming they would use that information for good purposes" Patient #1

"[Asking about ethnicity will convey] that racism is being watched and monitored, and they will be held accountable for any wrongful action…" Patient #44

Anticipation of benefits was contingent on assumed actions

"I would readily give away where I am from if that would help the medical team resolve the problem" Patient #55

Patients drew on personal experience to evaluate

"I had a couple of doctors that did know native background… he asked me where I was from and automatically he knew what kind of [pause] he asked me these questions, like there's heart disease and arthritis, and there's a kind of blood type we get in this area" Patient #31

Patients drew on their personal ethnic identities to evaluate

"[*There is no benefit to me] because I'm part of the mainstream"* Patient #36

"For me specifically it probably won't benefit me that much, because I was born and raised in Canada, and so I am quite fluent in English" Patient #44

"I am a Canadian white guy, so it doesn't bother me at all" Patient #35

C. HARMS AND CONCERNS

Patients and community representatives overwhelmingly anticipated harms

"I would be [offended] if this was asked of me, I think it's just another means to divide" Patient #21

"Because it's, it's, it's not a good question, it's not a good question at all, it doesn't relate to my health, this sort of question, it makes me really angry" Patient #41

"[I have concerns] *because of how I'm categorized, how I'm viewed, how I'm judged, right, prejudged"* Patient #1

- **categorization**

"I feel I've been labeled or… classified into a category that I may not agree with… they're putting me into a category or giving me a certain label or list." Patient #1

- **stereotyping**

"if they just want to know if I'm Aboriginal, that would bother me…sometimes they look at natives as if we're only in here for the drugs and we're in here to get the attention or whatever" Patient #31

- **discrimination**

"I'd feel that they don't have any right to be asking what background I am, they treat me as a patient and the doctors are there to do their job no matter what race you are and I feel extremely highly discriminated towards by asking such a question" Patient #48

- **poorer care**

"A lot of us (Aboriginal people) have arthritis, and… are being put down from Tylenol 3's to Tylenol 2's, then to regular Tylenol because [the doctors] don't want to hand it out, they think we are selling them. In other words we have to go out and buy our medications off the street sometimes." Patient #31

4. CONCLUSIONS

- The potential harms to individuals engendered by collecting ethnicity data in a clinical context are considerable
- These practices must be evaluated in the context of increasing politics of fear, racial profiling and growing inequities

In the face of such concerns, how should practitioners strike a balance between HPA recommendations that:

- Standard systems should be improved to better capture information on country of birth, travel history, reason for travel and socioeconomic circumstances.
- Improved data on migration would be beneficial in analysing health trends in the UK.
- Further prevalence studies of disease in migrants would help inform policy development.

Good practice needs to:

- accommodate concerns and explain the motivation and outcomes of ethnicity data collection
- ensure that the data to be collected will be sufficiently detailed to identify needs, patterns and future work

“missing or incomplete data means that health service commissioners, providers and practitioners are working with one hand tied behind their back”

(Jacobson, 2008)

Jacobson, B. (2008) ‘An unequal race?’ *Health Service Journal*, 28 January, p. 21.

See the Barriers Links section for toolkits for staff training, community engagement and practical guidance around monitoring. Below is an example from the HRET Disparities toolkit.



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The ‘Response Matrix’ from the HRET Toolkit* gives suggestions of clear, plain English responses to difficult questions or reactions to monitoring. The full toolkit can be downloaded from: http://www.hretdisparities.org/

Patients response	Suggested response
“I’m English”	Would you like to use an additional term, or would you like me to just put ‘English’?
“Can’t you tell by just looking at me?”	I could get it wrong, so it is better to let people tell us. I don’t want to put in the wrong answer for you.
“I was born in Nigeria, but I’ve lived here all my life. What should I say?”	“That’s really up to you. You can use any term you like.”
A patient returning for care with a ‘unknown’ or ‘unable to provide information’ code.	Proceed by asking for information
“I’m human” “It’s none of your business”	If you prefer not to answer the question, I can just say that. That’s fine.
“Why do you want this information?”	We know that a patients’ race or ethnicity can influence the care they receive. We want to check that doesn’t happen – so we use this information to check everyone gets the best care possible and to plan better services that suit everyone.
“Who is going to see this information?”	The only people who see this information are registration staff, administrators for the hospital, and the people involved in quality improvement.
“Are you trying to find out if I’m a British citizen?”	No. The confidentiality of what you say is protected by law, and we do not share this information with anyone.

* The (HRET) Health Research and Educational Trust Disparities Toolkit team is proud to release this updated Toolkit. The Toolkit is a Web-based tool that provides hospitals, health systems, clinics, and health plans information and resources for systematically collecting race, ethnicity, and primary language data from patients.