

Continuing professional development

Making diversity count: equality and diversity monitoring

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Routine collection of more detailed data is key to improving knowledge. What is not recorded cannot be proven, and what cannot be proven cannot be addressed.

Introduction

A prerequisite for effective action in all social policy development is the availability of evidence. The introduction of any system of quality assurance or output management itself generates change. That which is measured can be aimed at; that which is left unobserved can be ignored. We live in an era of 'evidence-based practice', and collection of accurate and appropriate information has become more important than ever for the development of improved policies and practices in the health system. When dealing with the health and well-being of socially excluded and relatively powerless groups, access to such data assumes even greater importance.

In the USA, a crucial legacy of the Civil Rights Movement of the 1960s and 1970s was the introduction of ethnic record keeping and monitoring in all federally supported activities, in order to ensure contract compliance and the specifications of the 1964 Civil Rights Act. More recently, the US Department of Health and Human Services, under the authority of the Patient Protection and Affordable Care Act (the healthcare reforms signed into law by President Obama in March 2010), has published revised standards for data collection on race, ethnicity, gender, primary language and disability status (US Department of Health and Human Services, 2011). However, across most of Europe, and indeed the rest of the world, detailed, comprehensive and accurate information on the health of migrants, ethnic minorities or other 'vulnerable' groups is lacking (Rafnsson and Bhopal, 2009; Rechel *et al*, 2011; Kraler and Reichel, 2010; World Health Organization, 2011).

Equality and diversity monitoring can help to:

- build reputation
- improve productivity
- recruit and retain the best employees
- create awareness
- provide specific adjustments, training or interventions
- identify and address any inequalities
- avoid risk, including damaging and costly legal cases or negative publicity.

What needs to be measured?

The key dimensions of inequality, whatever they are deemed to be in a local or national setting, will need to be monitored. The precise factors will depend on local legislation and aspiration, but should include the protected characteristics laid out in the EU Treaties, Human Rights Acts or the local equivalent. Examples of categories or factors might include the seven strands of UK policy defined in the UK Equality Act (see below). In states where there are indigenous disadvantaged populations (e.g. Canada, Australia, the USA), groups should include 'First Nation' or Aboriginal status.

Effective monitoring is a legal requirement of the UK Equality Act 2010 (Section 149), which sets out a public-sector equality duty in relation to the following protected characteristics:

- age
- disability
- gender reassignment
- marriage/civil partnership status
- pregnancy and maternity
- race, including ethnic or national origins, colour or nationality
- religion or belief, including lack of belief
- gender
- sexual orientation.

Civil status and carer responsibilities are other possible themes to be considered.

What are the arguments against monitoring?

One of the most common arguments against monitoring is that the recording of data may breach human rights to privacy, or risk exposing minorities to the adverse effects of discrimination. It is also suggested that it may be illegal in some jurisdictions.

The European Data Protection Directive (Directive 95/46/EC 24.10.1995) regulations state (with good reason, in view of the experiences of the 1939–1945 Holocaust and more recent ethnic cleansing events) that ‘personal data must (only) be collected for specified, explicit and legitimate purposes.’ Furthermore, Article 8 makes it clear that:

Member states shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership and ... data concerning health or sex life.

(Directive 95/46/EC 24.10.1995)

Further sub-sections of the Directive go on to explain that data may be collected when the subject gives ‘explicit consent’, or where such data are necessary to ensure compliance with employment law, or when public interest (e.g. public health concerns) dictates that such data are necessary and assurance is available that the rights and safety of the individual will be safeguarded (see Johnson, 2008).

Other objections include the belief that it is discriminatory to ask such personal questions, or that people will refuse to participate and thus the monitoring may create barriers to service uptake. The cost and time involved in asking for additional information have also been suggested as reasons for not introducing equality monitoring (www.civitas.org.uk/press/prequalityimpact.htm), but there are no detailed analyses of the cost of introducing monitoring, which is usually added when other systems are revised. Consequently, the cost of gathering data for monitoring is likely to be minimal. There is indeed a business case for diversity and equality initiatives. Some major enterprises have reported a link between good diversity practice and overall business performance, including improved productivity (Procter and Gamble), cost savings (British Telecom), and better marketing through a more diverse team (Cadbury Schweppes) (Rutherford and Ollerearnshaw, 2002).

Some staff may be embarrassed to ask questions which they describe as ‘sensitive.’ All health services require very sensitive data on age, private behaviours and relationships, and the confidentiality and necessity of such data are seldom questioned. Once they are embedded in records, these data need not be requested again, except for occasional audit. Questions about

‘ethnicity origin’ can uncover the risk of certain inherited conditions, such as sickle-cell anaemia, which provides a clinical justification for them (Aspinall *et al*, 2003; Dyson *et al*, 2007).

How common and how effective is ‘ethnic’ or other diversity monitoring?

Despite a long tradition and legal mandate for such data in the USA, the levels of monitoring remain surprisingly variable. The Centers for Disease Control National Electronic Telecommunications System for Surveillance (NETSS) found that 59% of cases were missing race data and 40% were missing ethnicity data in Massachusetts. Data on gender and age, on the other hand, were complete in 95–99% of cases (Chen *et al*, 2003).

At present, in Europe, disease-specific population-based registers with data on ethnicity or migrant status are available only in Germany, England, Scotland and Sweden (for a limited number of conditions). Germany and Sweden register data only on country of birth, not on ethnicity. However, data on healthcare utilisation allowing for some identification of migrants at national or regional levels were found to be available in 11 of the 27 EU member states (Nielsen *et al*, 2009). In every case this included some utilisation data on hospital care, but only a few countries collected data on care in outpatient settings.

How and what do you ask?

The best indicator to collect is the one most closely related to the factors believed to drive inequities. Choice is often limited by political or ideological constraints, and one variable may have to be used as a proxy for another. Country of birth is often used as a proxy for ethnicity because it is conflated with nationality, but both may be very unreliable in former colonial powers such as the UK, France, Spain, Portugal, Belgium, the Netherlands or Italy. Members of colonial populations and the children of colonists born aboard may be entitled to citizenship and residence in the mother country even if they do not wish to take up these options. Patterns of migration are in a constant state of change, and the children of migrants may have dual nationality.

Labels may not be particularly helpful. For example, ‘Indian or British Indian (Asian)’ includes the possibility of membership of at least four major language groups (Punjabi, Hindi, Gujerati or Urdu), or many

minor language groups, such as Malayalam, spoken by more recent, 'high-skilled' workers, many of whom are also fluent in English, the lingua franca of India. 'Indian' people also belong to all of the world's main faiths (including Christianity, Islam, Sikhism and Buddhism, as well as Judaism), many but not all are vegetarian, and while some groups eschew alcohol, and others avoid tobacco, local cultural groups provide many exceptions to an 'ethnic stereotype.' Similarly, although the vast majority of people of 'Pakistani' or 'Bangladeshi' heritage in the UK are Muslim and speak Urdu (or a Kashmiri dialect thereof), or the Sylheti dialect of Bengali, respectively, there are many exceptions. What is required is some kind of agreed baseline (see Box 1).

Conclusion: key factors in equality monitoring

- The existence of 'Champions' (i.e. political leadership and ownership) along with support from communities, managers and staff is a key factor. Most important of all, however, is *political* acceptance of the value and necessity of the data.
- Agreement on the value of any data for clinical or policy purposes and the factors to be measured (whether migration origin, citizenship status, ethnicity, language or faith) is essential, and can be supported by reference to research.
- An understanding of the best place in the 'patient journey' to make the initial enquiry, and a way to record it so that data, while kept securely, can also

Box 1 A selection of recommended questions and categories used by the UK Civil Service

Age:

At the very minimum the age categories that should be used are as follows:

- 16–24
- 25–29
- 30–34
- 35–39
- 40–44
- 45–49
- 50–54
- 55–59
- 60–64
- ≥ 65
- Prefer not to say

Disability: defined in the UK as being when a person has a physical or mental impairment, and that impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

Do you consider yourself to be disabled?

- Yes
- No
- Prefer not to say

More detailed sub-categories have been suggested by the Employers Forum on Disability:

- (None)
- Hearing impairment
- Mental ill health
- Visual impairment
- Mobility
- Manual dexterity
- Progressive conditions
- Learning difficulties (e.g. someone who is dyslexic)
- Facial disfigurement
- Speech impairment
- Other
- Prefer not to say

Box 1 Continued

Note: In Europe, and increasingly elsewhere, the category 'intellectual disability' is used for many 'learning difficulties.'

Race: may be defined in various ways, including 'national identity' and 'ethnicity', and should be measured using local census or UK National Statistics categories.

Marriage/civil partnership status: this may be considered, and suggested categories are as follows:

Are you married or in a civil partnership?

- Yes
- No
- Prefer not to say

Religion/belief:

What is your religion or belief?

- No religion
- Christian (including Anglican, Catholic, Protestant and all other denominations)
- Buddhist
- Hindu
- Jewish
- Muslim
- Sikh
- Any other religion

Additional categories that are sometimes used in the UK include the following:

- Agnostic
- Atheist
- Bahai
- Humanism
- Jain
- Pagan
- Rastafarian
- Scientologist
- Shinto
- Zoroastrian.

Sexual orientation: a recommended question and categories are as follows:

What is your sexual orientation?

- Heterosexual/straight
- Gay woman/lesbian
- Gay man
- Bisexual
- Other
- Prefer not to say

It may also be desirable to add two further categories, namely 'intersex' and 'asexual.'

Note: In order to improve the accuracy of responses, it is advised that the question on sexual orientation should appear before the question on religion.

- be shared between relevant agencies so as to reduce the necessity for repeated requests.
- Standardised questions that can be utilised in and compared across national systems are desirable, and enable local data to be related to national or regional patterns.
- Data need to be tied to policies such as targets and expectations relating to equity or fairness and incentives, or penalties for non-compliance, and to action plans.

- Examples of good practice, or pilot projects which can be used to demonstrate both the feasibility and utility of the process, are needed.
- Finally, it is essential that once the data have been collected (even if they were initially flawed in terms of quality or coverage) they are analysed and used to make changes or justify policy actions, and to allocate resources to demonstrate their value (including the risks of non-collection).

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