ESRC Seminar 1st June 2005

Small group on patient profiling – to what extent could patient profiling help with assessing genetic risk?

Patient profiling implies collection (in primary care) of a more holistic minimum dataset to enable appropriate assessment of the social and cultural context of a person's illness and the potential barriers they may face in accessing care. Accurate and complete data about ethnicity, national identity, religious affiliation, country of birth, preferred written and spoken language, other communication issues, carer responsibilities etc allows practice based and between practice clinical audit to identify potential problems with equity of access to and outcomes of care.

In Lambeth PCT a project has been running for a number of years to encourage general practices to undertake patient profiling. This has become more formalised over the last year with an updated patient questionnaire in line with census questions and bids to local research funds (Guy's and St Thomas's Charity) to use the data to conduct research. Ethics approval has been granted to one project to look at differentials in diagnosis and treatment of schizophrenia between white British and African Caribbean populations. Although data are being collected on all patients the necessity to have adequate power has necessitated use of only the two largest population groups for the research itself.

In developing the project people involved have recognised that collecting quantitative data in this way will only give a partial picture. The PCT's public and patient involvement team have been invited to work with the project to develop a participatory element to the research.

Group discussion

Much textbook (eg Oxford Textbook of Medicine) and other information on genetic disorders is written in a "colour blind" way. Apart from well known groups that are at increased risk of some disorders such as people of Ashkenazi Jewish or black Caribbean descent there is hardly any mention as to whether incidence of genetic disorders is different across different ethnic groups.

The group suspected this was because western researchers and geneticists did not really consider this as a possibility. For this reason alone patient profiling might be useful as over time any differential incidence would be possible to discern. At the moment we are unsure whether much genetic counselling takes into account ethnic origin (apart from specific disorders) and primary care is not in a position to advise patients.

1. Development of a baseline epidemiological understanding of the distribution of disease between ethnic groups is therefore essential not just for genetic disorders.

2. If equity is to be achieved people need access to care on the basis of need. These data can be used to assess need for support (eg. language and interpretation) and to identify inequity in provision of care between different ethnic groups.

3. To account properly for the effect of socio-economic disadvantage and discrimination we also need to collect useful indicators that tell us about poverty

and social exclusion. Lambeth PCT has a separate project looking at potential indicators that could be asked at time of GP registration. Some research about social exclusion done for the Health Survey For England is on the DH website. *Social capital and social exclusion: development of a condensed module for the Health Survey for England*. Available on: http://www.dh.gov.uk/PublicationsAndStatistics/PublishedSurvey/HealthSurveyForEngland/HealthSurveyMethods/fs/en

4. We are already moving towards recording "lifestyle" risks for disease in primary care; BMI, smoking, exercise levels, sexual behaviour etc. Being able to assess some of these risks in particular ethnic and socio-economic groups allows constructive approach to designing interventions.

5. Need for genetic counselling and risk assessment might well differ between ethnic groups so this is a potential benefit of patient profiling. However we may need more detailed information as for sickle cell disorder where the ethnicity of the individual may need to be supplemented by a more detailed family history. This brings up the point that in many respects the concept of ethnicity used in the UK is a social construction not a biological one. Care needs to be used to understand what information is useful for what and we must not be simplistic about the relationship between self defined ethnicity and genetic risk.

6. This brings out the point that successful patient profiling and use of data relies on good relationships with communities and individuals. People have a right to know how data collected on them will be used and to have confidence that it is leading to improved care. Being transparent about how information is used and encouraging local people to take an active role in the development of information flows and research done on them is likely to be more relevant and successful in the long run. Another project mentioned in the discussion had used informal means to work with communities on patient profiling and to encourage local people to participate and complete primary care questionnaires.