

Background paper for the AMAC project

European research on migration and health

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A. Why is research on migrant health important?

In many parts of the world, particularly in Europe, an increased rate of immigration is confronting host societies with challenges and opportunities – the most familiar being in the labour and housing markets, inter-ethnic relations and the educational system. Until recently, however, much less attention has been paid to the consequences of migration for the health system.

This omission is hard to justify, because health is an extremely important factor in the lives of migrants² and their families. It is closely linked with *integration*:

Migrants who are burdened or handicapped by health problems are hampered in the task of integration. [...] Illness exacerbates marginalisation and marginalisation exacerbates illness, creating a downward spiral.

At the same time, integration is a prerequisite for effective health care delivery, which is often impeded by inadequate access. Access to effective health care should be seen as no less important than housing and education for the well-being, and thus the integration, of migrants.

(Ingleby et al., 2005, p. 1)

Access to good quality health care is thus an important aspect of the social inclusion or exclusion of migrants. Existing service provisions are the outcome of a long process of adaptation to the needs of the majority native population: it is only to be expected that they often fail to meet the needs of other groups (Watters, 2002). Most concern with migrant health therefore focuses on the topic of care provision.

However, health is not only determined by the quality of health care – far from it, in fact; most experts regard the environmental factors that influence health as even more important. Indeed, as the slogan “health in all policies” implies (Stahl *et al.*, 2006), almost all aspects of social life can have an impact on the health of citizens. Poverty and marginalisation are factors which often affect migrants to a disproportionate extent, and in the recently published WHO report on the Social Determinants of Health (WHO, 2008), particular attention is devoted to the health risks of migrants. Not only poverty, but also bad housing, discrimination and work-related health risks can have a serious negative impact on the health of migrants.

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² In this paper, the term “migrant” will be used in the broadest sense, to refer not only to those who change their country of residence voluntarily but also to asylum seekers, refugees and victims of trafficking. For reasons of brevity we will also use it to refer to the second and in some cases later generations, rather than using the lengthier expression “migrants and ethnic minorities”.

At the present time we can observe an increase in the level of activities aimed at improving the health of migrants and ensuring that they have good access to appropriate care. The amount of activity in a given country or region is related to the proportion of migrants in the local population, as well as to prevailing attitudes to migration. Where public opinion is hostile to migrants and a policy of assimilation prevails, only religious or charitable organisations are likely to get involved. Here, the dominant attitude is that migrants must learn to stand on their own two feet and the host society has no obligation to adapt to their presence. At the other end of the political spectrum, more ‘migrant-friendly’ attitudes are accompanied by greater willingness to accept the host society’s responsibility for the social conditions of migrants and to introduce changes that promote their interests (including their health).

Activities to further migrants’ health may be justified on broader humanitarian or human-rights grounds (“health as a fundamental human right” – cf. Pace, 2002), or on the more utilitarian grounds associated with public health policies since their inception in the nineteenth century (“health as a service of general (economic) interest” – cf. Huber, Maucher *et al.*, 2008). In a few countries, migrants and ethnic minorities have enough political influence to be able to insist that their interests are taken seriously. In Europe, policies and attitudes concerning migrants vary considerably between countries and are also liable to rapid change: this instability is reflected in the variety of approaches and attitudes to migrant health that can be found.

We have seen that the topic of migrant health comprises two main issues – on the one hand the state of health of migrants, on the other the quality and accessibility of health care provisions available to them. Obviously, any practical initiatives in these two areas need to start from a sound knowledge base. We need to know how healthy or unhealthy migrants are, and what special risks they are exposed to. Where do health services fail migrants, and what can be done to remedy these shortcomings? At a more general level, we need to know which strategies are effective for getting things changed. All this points to the fundamental importance of good research on migrant health.

The knowledge and insights generated by such research can be used at different levels:

- At the level of *policy-making* (by governments, health care authorities, or individual health providers), research is needed to inform decision-making. Politicians and managers must know where the problems are, how they can be remedied and how urgent they are.
- At the level of *service delivery* (by doctors, nurses, clinics, hospitals, public health agencies etc.), research is needed to inform health care workers about the special needs of migrants, so that they can provide more effective care.

Modern health care is increasingly dominated by the principle that all interventions must be ‘evidence-based’. It is not enough to have wisdom and professional experience: facts and figures are required, based on reliable and valid research data. However, these demands are hard to meet in the field of migrant health, where research is to a large extent still in its infancy. The lack of a sound knowledge base is one of the chief obstacles to progress in this area. Fortunately, at the present time many initiatives are under way to improve this situation. In some countries a substantial knowledge base has already been built up, and there has been a dramatic increase in the number of research projects at European level concerned with migrant health.

B. What kinds of research are needed?

In order to reduce a problem to manageable proportions, it is first necessary to break it down into its constituent parts. Ingleby *et al.* (2005) argued that in the field of migrant health, six main areas can be distinguished in which research is needed. We will examine each of these in turn.

1. Background information

This topic does not concern health data as such, but other information which is nevertheless indispensable for informed decision-making. It relates to such issues as the number and origin of migrants and their migration history; social and demographic characteristics of migrant populations; legislation governing immigration, integration, nationality and citizenship; public opinion and representations of migrants in the media.

Health workers and researchers need such information for two main reasons. Firstly, it is necessary to know the size and structure of migrant and ethnic minority populations in order to reach conclusions about their state of health. For example, general practitioners may have the impression that they see a lot of Turkish men with lower back pain. But how large is the proportion of Turkish men in the area they serve? What is the age structure of this group? In epidemiology, the denominator (the size of the relevant background population) is just as important as the numerator (the clinical data). All too often, information about the background population is simply not adequate for reaching reliable conclusions about migrants' state of health. As we shall see in the next section, this has proved a major obstacle to investigating migrants' state of health.

An additional problem here is that there is no international consensus about how individuals should be categorised in terms of their migrant status or ethnic background – or, indeed, whether they should be categorised in such ways at all. In many countries (e.g. France and Germany), there are severe legal restrictions on the collection and storage of such data. These restrictions are usually there for political reasons, e.g. the republican ideology (“all citizens are equal”) or a desire to make sure that nothing comparable to the ethnic cleansing and genocide practised by the Nazi's can ever happen again. Such considerations are by no means redundant today, in the light of the ‘moral panics’ that arise from time to time over such groups as Muslims or Roma. A further objection to laying down hard and fast categories of ethnicity or migration status is this: phenomena that are in essence shifting social constructions should not be treated as if they were timeless facts of nature. Fifty years ago, ‘ethnicity’ was regarded as an objective biological or demographic characteristic: nowadays, even in census data, it is treated as a personal choice.

A second purpose for which background information is important is to enable health workers to interpret migrants' complaints and to respond in an appropriate way. Philosophies of medical care are highly relevant to this issue. A purely ‘biomedical’ approach, in which the patient is reduced to a bundle of symptoms and causal mechanisms, will not encourage interest in the patient's living situation and cultural background, for such an approach treats only the disease – not the person who has it. A ‘biopsychosocial’ approach, by contrast, will insist on viewing the patient in their social context, in order to understand what their symptoms might be linked to and what treatment is appropriate. Another word for this approach is ‘holistic’: it says a lot about the state of modern medicine that this term is increasingly associated with the alternative circuit.

The recent spectacular advances of ‘high-tech’ medicine have tended to push biomedical approaches to the forefront. Medical anthropologists, however, emphasise that there is a crucial distinction between ‘disease’ and ‘illness’: ‘disease’ refers to the physiological processes that may underlie the patients’ complaints, while ‘illness’ refers to the experience of these complaints and their impact on the patient’s daily life. Only when ‘illness’ rather than (or as well as) ‘disease’ is the focus of concern, is the health worker likely to be interested in the social context of the patient.

The contextual information that we need in order to better understand the illnesses of migrants and minorities relates to the demographic, socio-economic, legal, political and historical factors influencing the conditions in which they live. What kinds of work do they have, if any? What education and qualifications do they have? How much hardship and deprivation do they experience? Do they have a valid residence permit? Have they claimed asylum, and what will happen to them if their claim is rejected? What is the climate of public opinion concerning their group – are they subject to discrimination? All these issues will be important in trying to understand migrants’ state of health, despite the fact that none of them, in themselves, are ‘medical’ data.

2. State of health

Information about the state of health of migrant and minority groups is needed for two main purposes:

- a) to identify problems that may call for special efforts in the area of health promotion and prevention;
- b) to give health workers insight into the kind of health problems that migrant and minority patients may be particularly prone to, as well as the factors which may underlying these problems.

Before going further, however, it is necessary to dispel two widespread misunderstandings about migrants’ state of health. One is that it is necessarily worse than other people’s. A contrary notion, the ‘healthy migrant’ concept introduced by Raymond-Duchosal in 1929 and often confirmed in later studies, suggests that migrants may start off with a health advantage compared with the host population, which they tend to lose over time. However, some of the data used to support this notion may simply reflect the fact that migrants tend on average to be younger than the host population. Another explanation could be that people with health problems have been excluded by immigration authorities. Even if there is, among some groups, a ‘healthy migrant effect’ at the point of arrival, most migrants will occupy an inferior socio-economic position in the host country, and this in itself will undermine their chances of staying in good health.

Nevertheless, there are certain respects in which migrants may enjoy a health advantage. According to McCormack *et al* (2008), “breast cancer incidence rates vary sixfold between industrialized and less-developed countries, and migrants from low-risk countries to high-risk countries have an intermediate risk”. Cultural and religious practices may offer health advantages over a modern Western life-style: for instance, Muslims who adhere strictly to the ban on alcohol exempt themselves from a wide range of alcohol-related diseases. These examples are sufficient to demonstrate that it is foolish to attempt any generalisations about the *general* level of health of *all* migrants. The answer will depend on the condition one is studying and the particular migrant group concerned. Sometimes, indeed, the findings will also differ between men and women, or between first- and second-generation migrants.

A second misunderstanding concerns the importance of health disparities for action on migrant health. Health disparities can indicate areas of special need where extra attention should be paid to research, prevention and health promotion. However, a major issue in migrant health concerns the provision of appropriate and accessible health care services, and to justify these it is not necessarily to argue that migrants have particularly severe or unusual health problems. Indeed, the association of migrants with 'special health problems' is often part of an older discourse with its roots in colonialism, in which the migrant is portrayed as in every way 'alien' or 'exotic'. More often than not, the health problems for which migrants seek help are common-or-garden complaints that anybody can suffer from.

As we will explain in the next section, research on the state of health of migrant and minority groups uses two main methods: clinical studies and population-based (epidemiological) surveys. The former generally take specific diagnoses as their starting-point, while the latter are usually confined to information that can be provided by informants themselves (self-report). Often, respondents are asked to make a subjective assessment of their general level of health. Such assessments often reveal striking differences, but it is difficult to know to what extent the self-ratings correspond to more 'objective' measures of health.

Investigations of migrants' state of health sometimes go further and attempt to explore the determinants of particular health problems. Stronks et al. (1999) put forward a model in which four basic contextual factors can underlie ethnic differences in health:

1. the process of migration
2. cultural factors
3. socio-economic position
4. social context

Specific determinants of health or illness which may arise in these contexts are:

1. genetic factors
2. lifestyle
3. physical environment
4. social environment
5. psychosocial stress
6. health care utilisation

3. Entitlement to health care

The next topic on which good research is important concerns the conditions under which migrants are entitled to receive health care. This question is usually subsumed under the topic of 'access', but we consider it sufficiently important and distinctive to deserve separate consideration.

Entitlement to care can be broken down into three components: 'coverage', 'health basket' and 'cost-sharing' (Huber, Stanciole *et al.*, 2008). 'Coverage' refers to whether a person's health expenses are paid for by a State or private insurance scheme. 'Health basket' refers to the range of services that are covered, while 'cost-sharing' refers to the out-of-pocket financial contribution which is required from the service user.

The entitlement of migrants to health care varies from country to country and according to the category of migrant concerned (employed, unemployed, asylum seeker, undocumented, etc.) The rules governing entitlement are often complex, fast-changing and poorly understood by migrants – and even by the people supposed to be applying the rules. Research is needed to clarify the situation in each country and its consequences for health.

4. Accessibility of care

We use this category to refer to obstacles to obtaining care other than problems of entitlement. In order to access care, a sick person (or someone in their environment) must first of all realise that they need it. This will depend on their level of ‘health literacy’, in particular their knowledge about the treatments available and the signs that they may be necessary.

It is sometimes said that health literacy tends to be low among migrants, but a more accurate analysis would probably be that knowledge about health is of different kinds, and the knowledge that migrants have is often different from that of the majority population. Particularly when a person has only recently migrated or has not had much contact with the host society, their knowledge about illnesses and health care is likely to reflect mainly the culture and health system of their country of origin.

Different cultures may have widely different ways of categorising, describing, assessing and responding to illnesses: Kleinman (1978) introduced the concept of ‘explanatory models’ to describe these culture-bound belief systems concerning health and illness. Health care systems also differ enormously across the globe, both in their formal structures and in the unwritten rules governing interactions between health care workers and patients. In this way it can easily happen that migrants are perceived by health workers as unaware of basic ‘facts’ about health, having ‘irrelevant’ expectations of the health system, behaving in ‘inappropriate’ ways, and so on – when all they are doing is drawing on their existing stock of health knowledge.

Nevertheless, although one can argue about the relative merits of different medical concepts and systems, it remains necessary for migrants in European countries who wish to use the regular health system to learn how people in the host society think about health, how the health care system is structured, and what the formal and informal ‘rules of the game’ are for both staff and patients. Indeed, everybody has to acquire this knowledge and keep it up to date: it is an important ingredient of socialisation and ‘health citizenship’.

A basic task for researchers in this area is to find out whether health care is being rendered less accessible for migrants by a lack of information. A crude indication of this is the level of ‘care consumption’: if fewer people are using a service than would be expected on the basis of the (assumed or measured) incidence of illness, this may be a sign that they need help in order to find their way to the service.

Another explanation, however, may be that they know perfectly well that the service is there, but have different views on what is wrong with them and what should be done about it. This is especially likely to be the case when Western medical views differ markedly from those prevailing in source countries.

In the West, the medical domain has expanded enormously in the last 50 years. This has been accompanied by a substantial increase in expenditure on health services – most notably in the USA, where total per-capita health spending, adjusted for inflation, has increased eightfold

during this period³. In West European countries, expenditure is currently less than in the USA (e.g. UK, 41%; Germany, 51%; France, 54%). In many of the countries that migrants come from, however, the corresponding percentage is far lower (e.g. Afghanistan, 0.4%; Pakistan, 0.7%; India, 1.5%; Morocco, 4%; China, 5%; Turkey, 9%; most African countries, below 1%)⁴. These figures show that in terms of the amount spent on health care, the contrast between sending and receiving countries can be very extreme.

Moreover, an increase in the amount spent on health care is accompanied by increased readiness to seek medical help and a broadening of the criteria for 'illness'. Conditions which were previously regarded as natural or inevitable, or not medical conditions at all, now qualify for diagnosis and treatment. The field of mental health is a prime example of this, with a massive increase in the number and variety of problems regarded as signs of 'mental disturbance'. In 1952, the Diagnostic and Statistical Manual of the American Psychiatric Association listed only 60 categories of abnormal behaviour; in 1994 this number had increased to 410. It is therefore understandable that migrants coming from countries where psychiatric provisions are few and primitive, catering only for the most extreme cases, may resist being told that they have a 'mental health' problem. The meaning of the term is for them quite different.

The medicalisation of ageing, or of pregnancy and childbirth, are further examples of this trend. People brought up to regard these as natural processes which should be allowed to run their course – a belief not confined to migrants, but shared by many Europeans – resist the idea that a pregnant or elderly person should live their lives under continuous medical supervision. Poor take-up of antenatal care and low compliance with medical advice may thus be more a result of differing health beliefs than of ignorance about what is available. In this connection it is important not to assume axiomatically that modern Western practices are preferable to other ones and that all that needs to be done is to educate migrants in 'good' health care attitudes. The massive investment in mental health care services in the West has not been accompanied by a commensurate improvement in the happiness of its citizens; this calls for appropriate modesty about the superiority of Western approaches. Though the USA spends more of its GNP on health care than any other country in the world (currently about 16%), many other countries enjoy better levels of health.

Besides divergent health beliefs, there may be practical barriers to using a particular health service (location, transport, opening hours), or social barriers in the form of stigma and fear of gossip (particularly in the case of mental health problems). One factor that may discourage migrants from using health care services may be a lack of consideration for cultural practises and customs (for example, concerning hospital food or contact between female patients and male doctors – although it is worth remembering that many European-born women sometimes prefer a female doctor.) In such cases we may speak of 'institutional discrimination', i.e. the failure to provide an adequate service to a group because of the procedures adopted by an organisation. Perhaps the most disturbing example of a barrier to access is the reluctance of undocumented migrants to seek essential health care because of the danger that they will be denounced to the authorities if they do so. As well as institutional discrimination, which is largely unconscious, health services for migrants can also be undermined by conscious, individual discrimination at any level from receptionist to consultant.

As we have seen, the concept of 'accessibility' is a very broad one, covering many aspects of the pathways to care. Research on accessibility sets out to find out, for example, whether migrants are adequately informed about illnesses and the health care system, and whether

³ This figure is based on data from Reinhardt (2002) and other sources.

⁴ The figures are for 2005 and were obtained from the WHO Statistical Information System (WHOSYS).

their ‘explanatory models’ and health beliefs conflict with those assumed by the health care system. A very important issue is the availability of information in different languages: health authorities require information about what information is needed and in which languages, and how it can be most effectively presented. Many studies have focussed on discrimination within the health system, though there is a lack of consensus among these studies as to what constitutes discrimination and how it should be measured. As well as identifying the problems, research can also help us to evaluate the effectiveness of the wide variety of measures that have been put forward as ‘good practices’ in the field of health education and service improvement.

Health education does not only concern what to do when one has become ill, but also (via ‘health promotion’) the question of how to stay healthy. Here, the challenge is to devise methods that are actually capable of changing people’s behaviour, which is notoriously intransigent when it comes to avoiding health risks. Research is needed to identify the methods which are likely to be most effective in persuading members of migrant and ethnic minority communities to take good care of their health.

5. Quality of care

While ‘accessibility’ refers to obstacles on the path to care, ‘quality’ refers to what happens in the care-giving situation. Some migration-related factors (e.g. language barriers, divergent health beliefs and discrimination) undermine both the accessibility *and* the quality of care. In order to improve the quality of health care for migrants, a wide range of interventions and methods have been put forward as ‘good practices’. The task of the researcher is (a) to find out when something is going wrong in the treatment situation, (b) to identify what it is, and (c) to evaluate the different solutions proposed for dealing with it.

To assess the quality or appropriateness of care, a number of measures can be used. *Subjective* measures set out to measure the degree of satisfaction of clients and their caregivers. This can be asked for directly, or estimated from levels of drop-out or compliance. *Objective* measures investigate the effectiveness of particular practices. Do the standard procedures lead to worse outcomes for migrant patients? Are particular ‘good practices’ capable of producing better outcomes? In order to evaluate a procedure or treatment method, researchers need ideally to carry out a ‘randomised clinical trial’ or RCT, in which patients are allocated at random to different groups (preferably without them or the researcher knowing which group they are in, i.e. ‘double-blind’). However, the practical and ethical obstacles to such research, which is usually very expensive, mean that RCT’s are hardly ever carried out to establish the effectiveness of treatments or ‘good practices’ for patients from migrant or minority ethnic groups.

6. Achieving change

Under this heading researchers examine all the activities that are undertaken to encourage the development of adequate health care for migrants. At the outset we can make a distinction between ‘structural’ and ‘incidental’ changes.

- ‘Structural’ improvements to health care services as those that are embedded in policy. Policy may be laid down at national, local or municipal levels, as well as by service providers or professional bodies.
- ‘Incidental’ improvements arise more spontaneously, as a result of the activities of individuals or NGO’s responding as they see fit to perceived needs.

However, the boundary between the two may shift overnight: an intervention may start out as a spontaneous individual initiative, yet because of its success receive the blessing of an institution or a ministry and become incorporated in official policy. The boundary between ‘structural’ and ‘non-structural’ provisions may also be blurred: in countries where there is little recognition by government of the health needs of migrants, services run by NGO’s such as *Médecins du Monde*, or religious organisations such as the Jesuit Refugee Service, may become virtually part of the landscape and even receive funding from central government. Nevertheless, there is increasing realisation that the structural embedding of measures in policy is essential for sustained progress (cf. the section “Why ‘good practices’ are not enough” in the report on Good Practices for the Portuguese EU Presidency Conference (Portugal *et al.*, 2007, p. 17)).

Under the heading of ‘achieving change’, researchers examine the wide range of activities that may be undertaken to lobby for migrant health, to bring together those interested in it, to form pressure groups, centres of expertise, research networks and ‘think tanks’. One of the most important of all these activities is *teaching* – educating students, professionals, politicians and the public about the importance of migrant health and showing how research findings can be applied.

C. Who carries out this research, what methods are involved, and what are the difficulties?

1. Background information

Much of this information is collected by national, regional or municipal authorities. As mentioned in the previous section, the amount of official information concerning such variables as (parental) place of birth, nationality, migrant status, ethnicity or religion can range from non-existent in some countries, to fairly detailed in others. Where official statistics are scarce, researchers have to try and remedy this hiatus as best as they can themselves.

In spite of the various legal and practical barriers to data collection, it is increasingly common for population data to be collected on people’s country of birth (and that of their parents), or their nationality, religion, or ethnicity. Unfortunately, the precise data available vary from country to country, making trans-national studies of migrants’ state of health very difficult. As far as demographic data on migration are concerned, Europe resembles a patchwork quilt.

Apart from data which is routinely stored on all citizens, many governments (national or local) conduct or commission surveys to collect specific types of information, including variables relating to migration or ethnicity, on a particular age cohort or sample of the population. Sometimes these surveys are longitudinal and enable conclusions to be drawn about the causal factors affecting people over the life course. The UK and Scandinavian countries have perhaps the most extensive collections of such data on their inhabitants. Thanks to this, and to the possibilities for linking different data sets with each other, these countries have been able to undertake some of the most extensive surveys on the health of migrants of ethnic minorities. In a review article (Ingleby, 2008) I have described Scandinavian and British studies published in recent years on the incidence of schizophrenia among migrants, which have revolutionised views on this topic with the help of databases covering millions of people.

Academic research in the area of ‘migration studies’ provides a copious source of data on topics such as education, housing, legislation, discrimination, public opinion, policy

making and (media) representations. To access this data it is necessary for researchers in the field of health to collaborate closely with their colleagues in the social sciences. Adam & Devillard (2008), reporting a study carried out by the IOM, have recently published a broad overview of immigration laws in the 27 EU Member States.

2. State of health

Two main types of research can be carried out to reach conclusions about the state of health of particular social groups such as migrants and ethnic minorities: *clinical studies* and *population-based studies*.

Clinical studies

These studies start from data generated in contacts with health service providers (family doctors, hospitals, well-baby clinics, etcetera). For example, the number of patients with a particular diagnosis or receiving a particular type of treatment may be recorded. This can either be done routinely, or at the special request of a researcher: if such data are collected routinely, existing clinical records will provide a wealth of information for the researcher.

However, the prevalence of a given condition among migrants or ethnic minorities can only be estimated from such data if (1) data relating to migration or ethnicity have been collected at the same time, and (2) information is available about the size of the underlying populations. Unless data can be collected from all the service providers in a given country, it will only be possible to estimate (2) if the background population can also be delineated in some way (e.g. by defining the catchment area for each service provider). Data on the underlying populations falls in our category of 'background information', and it will be immediately obvious that the best clinical data in the world is useless for estimating prevalence rates if good statistics are not available about the underlying population.

We can illustrate this point with an example. Consider – once again – general practitioners recording the number of male patients of Turkish origin reporting lower back pain. Suppose we have data from all the GP's whose catchment area falls in the city of Rotterdam (and not outside). We will only be able to estimate incidence rates from these data if, at the same time, data are available on the ethnic origin and gender of the inhabitants of Rotterdam. It will also be very helpful to have data about the *age structure* of different groups; if the Turkish inhabitants are older than average, this could be the reason for the higher incidence, because lower back pain is associated with ageing.

But there is yet another problem concerning the use of clinical data. Incidence rates in the clinic are only equal to incidence rates in the general population if access is perfect. In this example, it could be that access among Turkish men is limited, for all the reasons we have discussed above. Figures obtained from clinical practice shed no light at all on what is going on with the people who do not show up at the clinic. As Goldberg & Huxley (1980) point out, a number of 'filters' intervene between illness and treatment.

In general, we can say that the numbers of people who receive treatment will reflect two things: the proportion who are ill, and the proportion of these who succeed in getting into treatment. If (and only if) one of these variables is known, it is possible to estimate the other. However, if we know nothing about accessibility we cannot say anything on the basis of clinical figures about incidence; and if we know nothing about incidence, we can say nothing about accessibility. For this reasons, figures concerning the amount of 'care consumption' by different groups need to be interpreted with caution.

Many other problems surround the use of clinical data (for example, the reliability and validity of diagnoses), but it will be clear by now that the use of such data to shed light on the state of health of the migrant and ethnic minority population is fraught with difficulties. In many health care settings, information relating to migration or ethnicity is simply not recorded. Even when it is, the relevant catchment area may not be known, and there may be no information concerning the size of the migrant or ethnic minority populations in that area – let alone concerning gender and age. Moreover, access may vary between groups. Fortunately, however, there are other types of studies which can be used.

Population-based studies

For epidemiological purposes there are enormous advantages in collecting data on health from the general population, rather from the highly selected sub-sample which is found in clinical settings. By doing this, of course, one immediately loses the advantages of the clinical setting: there, a diagnosis is being made anyway, often with the help of very elaborate procedures. Outside the clinic, the information that can be collected is more basic in nature, and generally depends on self-report data from the respondent. Only when funds are available for medical screening of a group can population-based studies begin to match the sophistication of the diagnoses that clinical data is based on.

Population-based studies may concern very large populations, or may be quite small-scale; they may be focussed on a single health problem, or cover a whole range of topics. Increasingly, governments carry out large-scale surveys including questions about health in order to monitor the health needs of their citizens. For our purposes, however, such surveys are only useful if questions are also included about migration status or ethnicity. It may, however, also be possible to couple population data with health data obtained from special surveys.

The following indicators may be used to assess the general health of a group:

- The *mortality* of the group (i.e. the death rate). Such figures have to be interpreted with great caution. In the first wave of any migration, the people who migrate tend to be fit and healthy, ready to face the hazards of journeying far from home. Some migrant groups keep close contact with their home country, and return when they become sick or old. Their deaths are not recorded in the host country, so that official statistics on mortality rates may not give an accurate impression of the health of that group.

Inaccuracies may arise in several other ways. For example, if members of some ethnic groups are less likely than others to be accurately classified in a national census, but their origins are accurately recorded when they die, then the death rate of these groups will be overestimated. Conversely, if ethnicity is not correctly classified when a person's death is officially registered, then the death rate will be too low.

- A widely used indicator of general health is *life expectancy*, but this can also be difficult to interpret in the case of migrants. For instance, a Dutch study showed that life expectancy for Moroccan-born men is 3.5 years longer than for Dutch natives, while for Turkish and Surinamese-born men it is 1.5 years shorter. The explanation for these differences is very unclear (RIVM 2002). They, too, may be connected with the tendency of migrants to return home when they become old or sick.

- Another indicator that is often used in survey research is *subjective health*. When asked about their experienced state of health, 79% of the native Dutch population describe this as ‘good’ or ‘very good’, compared to 71% for first-generation Western immigrants and only 63% for first-generation non-Western immigrants (CBS 2004). Similar findings have been reported in the United Kingdom, e.g. by Dunnell (2008), and in Switzerland (Garbadinho et al. 2007). However, the cross-cultural validity of such self-report measures is unknown (Bruijnzeels, ed. 2004: 89).

Epidemiological research on migrants and ethnic minorities is in its infancy and most of the information currently available on their health is based on clinical studies – with all their attendant disadvantages. Bhopal (2007) gives an authoritative introduction to this area of research. Such studies belong to the domain of Public Health: they may be carried out by (large) health care providers, municipal authorities, national health research agencies, independent contractors, NGO’s and university-based researchers. However, the resources required for epidemiological research are usually substantial, so that only major organisations are able to fund them.

3. Entitlement

Research on the entitlement of migrants to health care is in its infancy, although Appendix A lists a number of comparative studies – mostly carried out on behalf of international agencies or NGO’s. The data required in order to study entitlement to health care consist essentially of documents relating to the policies of state health care schemes or health insurers. The answers to questions about who is covered, for what kinds of treatment, and how much money they have to contribute out of their own pockets, are all in theory laid down in black and white. Nevertheless, we cannot assume that theory and practice overlap perfectly when it comes to entitlement. Rules have to be *interpreted* (for example, regarding the definition of what constitutes ‘emergency care’) and different service providers may operate different definitions. Moreover, knowledge of the rules may be incomplete or out of date: for example, in response to the current confusion about the health care entitlement of asylum seekers and undocumented migrants in Britain, new guidelines and summaries follow on each other’s heels with alarming frequency.

Such ‘implementation gaps’ between policy and practice seem to be inherent to modern organisations (Hogwood & Gunn, 1984). Sometimes service providers will be more permissive than the rules allow; health workers quite often turn a blind eye to policy restrictions, out of a sense of professional responsibility or concern for human rights. Sometimes, however, they will be more restrictive, and will withhold information about clients’ rights because they disagree with the policy, or because of prejudice against the person they are dealing with. In this respect, a receptionist at the hospital’s front desk can wield more power than the rest of the medical hierarchy.

4. Accessibility

Research on accessibility often takes quantitative data as its starting-point and proceeds to investigate it qualitatively. Where there are signs that a given service is being ‘under-used’, research may be undertaken to find out what is holding people back from using it: generally, the best way to find this out is to ask them. In theory, quantitative methods such as postal questionnaires could be used, but there are doubts about the validity of data gathered in this way. If a person is mistrustful or not enthusiastic about a service, they will probably also be wary of a someone carrying out research on behalf of the service. Researchers often regard

migrants and ethnic minorities as difficult groups to investigate: because relations between them and the majority population are often strained, there may not be much willingness to cooperate if the researcher is perceived as representing ‘the authorities’ – or simply looks white and middle-class. Often, people are simply tired of being approached so frequently by researchers, and they may have misgivings about the use to which the data will be put. The researcher’s conclusions will then be based on those who *do* cooperate, whereas the opinions of those who *don’t* may be much more relevant. One way of overcoming some of these problems is to employ members of migrant or ethnic minority groups to carry out the research. A striking example of this is the book edited by Clarke (2005), reporting research on migrants entirely carried out by migrants.

Studies on the accessibility of health care for migrants and minorities are a fairly recent phenomenon and are typically small-scale in nature. Whereas epidemiological research is mostly large-scale and expensive, studies on accessibility are often small and commissioned by individual service providers. Many of these studies are classified as ‘grey literature’: because they are not generalisable, they do not make their way into mainstream scientific literature but instead enjoy only limited circulation. Hundreds of such studies have been undertaken by students for their final-year dissertations, and even these can provide highly useful data. In recent years, internet has provided possibilities for disseminating ‘grey literature’ cheaply and on a wide scale: local authorities and NGO’s are making increasing use of this medium to publicise their findings.

5. Quality

Who carries out research on quality and what methods are used? We have already mentioned the fact that in this era of ‘evidence-based medicine’, proof of the effectiveness of new procedures and treatment methods is required before they are introduced – the method of choice being RCT’s. However, such studies usually pay no attention to the possibility that effectiveness may vary between different ethnic groups. Worse still, members of minority populations may actually be *excluded* from clinical trials. Graham (1992) showed that 96 per cent of the studies published in the 1970s and 1980s in four leading journals of the American Psychological Association excluded African American subjects. There is, in fact, little hard-and-fast data available on differences in the effectiveness of treatments for different ethnic groups. However, some drug companies have begun to highlight this issue, in the hope of identifying products which can be marketed as specially appropriate for particular groups.

The lack of attention for the evaluation of supposedly ‘good practices’ was highlighted by Bhui *et al.* (2007), who examined 109 articles describing programmes for improving ‘cultural competence’ among health care professionals. Only 9 of these included an evaluation of the model described.

As noted above, most research in this area focuses on *satisfaction* or ‘procedural evaluation’, and much of it is qualitative in nature. Often, such studies are undertaken by the originators of the method and are thus far from impartial.

6. Achieving change

To find out what activities are being undertaken in order to improve health care for migrants and minorities, studies have usually been undertaken by national research institutions or by researchers in universities. Systematic surveys involve contacting service providers and asking them a number of questions about the measures that have been taken to improve the accessibility and quality of services for these groups. Alternatively, a qualitative overview of

initiatives taken may be made on the basis of literature reviews, Internet searches and ‘snowball’ sampling methods, in which one informant will suggest other informants.

Concrete examples of research in the above areas

A good impression of the ‘state of the art’ in the six areas we have discussed can be obtained from the extensive review undertaken by Philipa Mladovksy (2007) of the Health and Living Conditions Network of the European Observatory on the Social Situation and Demography, European Commission. Towards the end of 2008, detailed information from 17 countries will become available from the project MIGHEALTHNET, and this will be summarised as one of the outputs of the project.

D. Research at the European (or global) level

Thanks to the activities of bodies such as the WHO, the IOM, the European Commission, the Council of Europe and various international NGO’s, opportunities have arisen for carrying out international collaborative research on migrant health. In this section we will discuss the advantages of this kind of research and discuss some examples.

As far as Europe is concerned, perhaps it would be more appropriate to start by describing the *disadvantages* of confining research to the national level. Imagine what the state of research would be in the USA if each of the 50 states spoke a different language and there were no nation-wide arrangements for organising research, sharing knowledge and regulating professional organisations. Imagine also that few researchers moved from state to state. Yet this is the baseline situation in Europe. While not wishing to underestimate the richness of Europe’s enormous cultural and social diversity, the fact that health research is mainly carried out on a national basis is a great obstacle to progress. It reduces the scale of efforts and limits the possibilities for sharing data, methods and insights. For this reason, the emergence of health research at a European level is greatly to be welcomed – especially in relation to migrants and ethnic minorities.

Particularly important is the possibility of combining forces to increase the ‘critical mass’ of the research community. In each country, migrants and ethnic minorities form a small segment of the population whose interests easily get overlooked. As a result, research on migrant health often occupies a highly marginal position. On a European or international level, such research relates to far more people and can therefore claim more resources.

Apart from these advantages, cross-national comparisons of patterns of migrant health or approaches to health care can yield new insights into underlying factors and the nature of ‘good practice’. Are the higher rates of cardiovascular disorders among some Asian communities in the UK also found in the rest of Europe? What does their distribution tell us about the causes? What are the relationships between national health-care philosophies and provisions for migrants? Under what conditions are particular methods effective? Using data for different countries permits greater variation in the factors studied, making it easier to disentangle the influence of different factors.

In Appendix A a number of international collaborative research studies are described, together with a short description of their scope and (for completed projects) their results. The matrix of DG SANCO projects constructed by the IOM in the context of the AMAC project represents an important step towards obtaining an overview of current efforts.

E. Conclusions

Though research on migrant health has shown remarkable growth during the last decade, there still remain many ‘blind spots’ where research is urgently needed. To start with, we make here two suggestions – many more are possible:

1. An inventory needs to be made of legal barriers to the collection of data on migrant status or ethnicity in each country. The MEHO project (Migrant and Ethnic Health Observatory), co-financed by DG SANCO, has a special project on “Data sources and indicators”, but this will not investigate legal restrictions. A study is urgently needed which would clarify the situation and explore ways of overcoming the obstacles.
2. As noted above, ‘good practices’ to improve the accessibility and/or quality of health care delivery are seldom evaluated. More attention to this question is required. The methods used to do not have to be RCT’s – in fact in many cases it would be impossible or unethical to satisfy the conditions for RCT’s. Subjective measures of evaluation can be used instead.

We have seen that international collaborative projects are of great value in this area, and it is encouraging to note the substantial increase in funding for this type of project. However, as will be obvious from a study of Appendix A, these efforts suffer from a lack of cohesion and a systematic research policy. A rigidly centralistic, top-down policy would have perhaps even greater disadvantages: it would stifle creativity, innovation and diversity. Yet the philosophy of “let a thousand flowers bloom” can lead to wasting of scarce resources. At present, new projects arise in a fairly haphazard way: different agencies do not coordinate their efforts with each other and there is little synergy between different projects, with the result that efforts are not spread in a rational way. Moreover, knowledge does not seem to develop in a cumulative fashion: considering that the first studies were undertaken as long ago as 1983, there is a great deal of repetition of the same findings and recommendations – ‘reinventing the wheel’.

One illustration of the lack of a cohesive policy is the fact that it is often very unclear why certain countries get included in an international project while others are not. Probably the reason has to do with the international contacts that the proposer of the project happened to have in his or her address book. Especially noticeable is the fact that France, where the use of English is not encouraged, is conspicuously absent from almost all major projects. There may of course be other reasons for this under-representation – for example, the highly restrictive French legislation concerning the collection of data on ethnic minorities – but the dominance of English as a shared language in this research community is not an unmixed blessing.

Coordination of efforts is required not only within funding agencies, but also between them. For example, the European Commission’s DG SANCO and DG Employment, Social Affairs and Equal Opportunities have both commissioned pioneering studies in this area; yet there is no sign that efforts have been coordinated between these agencies. The same remarks apply to the lack of harmonisation between EC-funded projects and those initiated by the WHO, the IOM and some large private foundations.

In conclusion, we may observe that while diversity in research is a good thing, more attention should be paid to the need to develop shared approaches and to avoid unnecessary duplication of research effort. Projects such as the COST Action HOME (Health and Social Care for Migrants and Ethnic Minorities in Europe) can help to reduce the fragmentation of research efforts, but a more coordinated (‘joined-up’) approach by the EC and other international bodies is also urgently required.

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