Through a glass darkly: what should public health observatories be observing?
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Abstract

Background Eight regional public health observatories were launched in England in February 2000, to strengthen the availability and use of health information and to support efforts to tackle health inequalities at local level. This qualitative study was carried out by the Merseyside and Cheshire Zone of the North West Public Health Observatory to assess the needs of local users and producers of public health information.

Methods Semi-structured in-depth interviews were carried out with 42 representatives of three major groups in Merseyside and Cheshire: community groups, public-health-related professionals in the local statutory and academic sectors, and information specialists within the National Health Service.

Results Different groups of users and producers encountered different problems in accessing health information. Community groups had significant problems accessing and interpreting health information and were concerned about tokenism and the failure of professionals to recognize lay knowledge. Professionals experienced difficulties in accessing local information from outside their agency and had concerns over partnerships failing to work together to share information. The health information specialists stressed the danger of providing information without supporting intelligence, the difficulty of keeping track of the many local sources, and the importance of having access to local authority data sources. All three groups relied on their own networks in their search for information, and these should not be overlooked in any dissemination strategy.

Conclusion Information requires skilled interpretation to become policy-relevant public health intelligence. This research identified major problems in the communication of lay health knowledge and in the accessibility of public health intelligence.

Keywords: information, access, public health observatories, needs assessment

Introduction

As part of the Government’s Saving Lives national health strategy for England,1 eight regional public health observatories were launched in February 2000, to strengthen the availability and use of information about health at local level.2 There was a strong emphasis on tackling inequalities. Since then, a bewildering array of roles has been put forward for the observatories. The latest National Health Service (NHS) restructuring document, Shifting the balance of power, proposes that epidemiology, cancer registration services and advice on communicable diseases in each region should potentially rest with the respective observatory.3 Whatever roles the observatories eventually take on, it is clear that their work should involve a two-way process: gathering in and analysing information from many different sources (local and national), and disseminating that information, after careful interpretation, to local users who are trying to take action on health and inequalities. Information transformed in this way by adding interpretive and contextual material is termed intelligence. Whereas the National Strategy for Neighbourhood Renewal4 and the reports of its Policy Action Team (PAT 18)5 have focused attention on neighbourhood statistics and on the need to make good-quality, small-area information readily available, the specific problems faced by users and producers of public health information in accessing health information at a local, regional and national level remain under-researched.

Often, users are also producers of information, and for public health observatories to play a key role in designing an effective service with them there are a number of issues that need addressing: What do producers and users of public health information perceive as the main barriers or gaps they encounter when trying to obtain information? What service do they really need?

To shed light on these questions and to find out what role public health observatories could potentially play in improving the current situation, we carried out semi-structured in-depth interviews with three major groups of potential users and producers in the Merseyside and Cheshire Zone of the North West Public Health Observatory: community groups, public-health-related professionals in the local statutory and academic sectors, and information specialists within the NHS at various...
levels. In this paper, we report our findings from these three groups and draw out implications for what observatories should be observing in the future.

**Methods**

We carried out this study in our roles as members of the Merseyside and Cheshire Zone of the North West Public Health Observatory as part of a needs assessment initiative. Semi-structured in-depth interviews were carried out with 42 individual users and producers of public health information in Liverpool, Sefton, North Cheshire, South Cheshire and Wirral health authority areas. The following groups were represented:

1. members of voluntary and community groups active in the health and inequalities arena who use public health information to provide services and support to the local community;
2. health, local authority and academic professionals whose day-to-day jobs concern promoting the health of the public and who use public health information for many different reasons ranging from health care policies and strategies to urban regeneration;
3. information specialists in NHS trusts and health authorities who provide public health information and intelligence for the health community and to inform health care policies.

Interviewees were identified through purposive sampling of representatives from the main agencies involved in public health in each area (e.g. the health authority, local authority, Council for Voluntary Service, relevant community groups). This sampling method ensured the inclusion of a number of community and voluntary sector representatives. In addition, to ensure adequate coverage, each interviewee was asked to recommend one other person who should be interviewed. Results were then compared between areas and between organizations.

Interviews lasted between 40 and 60 minutes and were tape-recorded with permission. Interviews with information specialists were manually recorded at the time by the researcher. A semi-structured interview technique was used to allow the main issues to be explored in-depth, but also to allow flexibility within the interview and to allow the direction of the interview to be based on the responses of the interviewee. The interviews focused on personal experiences of accessing public health information from all sources including public health observatories, and participants were asked to reflect on: what public health information they needed and used, their experiences of gaining that information, the gaps in existing information and access issues. Additional discussions were based on the responses of the interviewee relating to their personal experiences of attempting to access public health information.

Initially, each transcript was analysed and thematic codes were applied specific to the individual respondent, focusing on the particular issues experienced by that individual. The codes were then analysed between transcripts from individual respondents from the same agencies in different health authority areas and then between all the agencies, to allow comparisons to be made. The issues of access to public health information introduced by the researcher raised specific issues for each of the groups interviewed. At the time of the study, March–June 2001, none of the professional or community respondents had had any experience of the North West Public Health Observatory. Although some had heard about the introduction of the observatories, none had had any direct experience of them. The information specialists, on the other hand, were aware of public health observatories and had used the website, but had had little influence over the observatory’s plans to disseminate health information. The findings are presented in terms of the main barriers to accessing information by community groups, the different problems of access experienced by health professionals and the concerns of information specialists.

**Findings**

All the respondents reported that they needed concrete public health information and intelligence for a variety of purposes in their day-to-day work. The two main reasons were to influence decisions about more effective service delivery to tackle the problems identified in and by the community; and to support funding applications such as bids for Single Regeneration Budgets and New Deal for Communities. The three groups encountered specific problems in accessing the information they required, as detailed below.

**Community group perspectives**

Three main barriers to accessing public health information emerged in interviews with members of voluntary and community groups. First, they had limited knowledge of what information was accessible and, even when they had some idea, they did not know where to go to obtain it.

‘Right now, it is a whole mystery to people. People don’t know where to go, don’t know how to use the information.’

Community group representative (C1)

‘I can see how community groups or people that weren’t in this business would be really daunted. You are phoning up and you are speaking to people who might talk to you in jargony terms and if you are a community person you would be like “what the hell are they talking about?”’

Community health worker (C2)

The problem was compounded by the fact that much of the information produced was presented through the medium of the worldwide web, but many community groups had few resources and little or no access to the internet. They tended to gain information from more informal, ad hoc sources, drawing frequently on personal contacts.
Second, members of community groups reported that they experienced difficulties in interpreting the information presented by statutory agencies. This meant that even once the required information had been obtained, there were further barriers to understanding it. Some made the point that the way in which information was presented by statutory agencies led to some sections of the community being excluded from essential knowledge:

‘Just accessing some of these data bases ... if you are not accustomed to researching, the set-up like that is fine if you are in the game and on the inside track, but if you are outside it is very, very excluding, you know? Just the way that things are referenced and the whole academic protocols around the appendices and this that and the other, it freaks people, frankly it does. There is a need to clean that information up if you like, and that is not in any way a patronising statement. I am not talking about dumbing it down. I am talking about removing some of the inner mystery about the way it is presented.’ Community group representative (C3)

Available information was often perceived as not readily usable for those who work in or with the community. Insufficient thought had been given to the main purposes to which public health information would be put, and therefore what practical format would be best to fit that purpose.

‘I think also it is not just about getting information to people, it is getting them to think about what it is that they might use it for. Information is nothing really. Information needs to be action. People should be able to utilize it or begin to take action in some way, to do something with it.’ Community health worker (C4)

Third, members of community groups voiced the view that information was presented by statutory agencies. This meant that problems would arise in trying to formalize these networks and replace them with web-based networks, because this would lose the importance of personal contacts and social networks.

Professionals in the statutory sector

Professionals in health and local authorities encountered a somewhat different set of problems. They tended to know where to go for general information and used technology, including the internet. They did, however, experience difficulties in accessing local information from outside their agency. For example, health professionals had problems in accessing information held by local authorities. In particular, they suspected that local authorities had valuable data about their local communities, but they did not know where or who to ask for that information. Networks and flows of information were not necessarily in place.

‘I think the main sets of information that it is difficult to find easily, without having to actually request it from somebody, is any data from the local authority. Which is a bit of a shame because a lot of (LA) information is of value to what I do. I don’t know what information they keep, what I could ask them for. I ring them up fishing usually, instead of knowing that they have got that and I can go there for it.’ Health Authority representative (P1)

From the local authority perspective, there was a realization that health professionals may be struggling to find out more about local authority information sources, but there was also some awareness that the health sector was not always forthcoming with the health information under its own control. Concern was expressed about the lack of communication between the main bodies involved in health-related decisions at a local level. With the advent of holistic approaches to health-related policymaking, greater flows of information were needed. People who should have been working to achieve the same aims and outcomes were not always working together across the agencies. Another criticism was that the health sector, when it was pursuing a new initiative, sometimes did not recognize that other local agencies may have been working on a particular issue for some time and already have valuable insights into it.

‘The other way round is that [health practitioners] are struggling to try and have access to information that we [LAS] might have about communities or about issues and there isn’t at the moment that two-way flow of information. It is almost as though they are working there and saying “this is our new initiative”.’ Local Authority representative (P2)

The professionals reported problems knowing what was being produced by different agencies and that this could lead to ‘reinvention of the wheel’. Several said they would like to know more about who is doing what, not just locally but regionally and nationally. Agencies identified the need to know what informa-
tion is out there and how it can be accessed and used for their own needs.

Although all the new local partnerships for health being set up under various government initiatives were supposed to involve local communities fully, it was recognized that they rarely did this in anything other than a token way. As with the community group interviews, some of the professionals identified the marginalization of lay knowledge and information as a key factor. Communities tended to be treated as merely consumers, rather than producers, of information.

‘I have to say as well that the partnerships are the worst offenders in a lot of that (undervaluing lay knowledge) because they are supposed to be the mechanism by which local people can have a voice. In reality most of the partnerships I have dealt with are far from representative of the views of the people that they are supposed to be consulting with, and seem to be far more dictated by bureaucracy than the council ever was.’ Local Authority representative (P3)

‘Unless local people and local organizations have an opportunity to have their say and influence what goes on then the partnerships aren’t going to be as strong as they could be.’ Voluntary sector representative (P4)

Information specialists

Information specialists reported that they spent a substantial proportion of their time providing individuals and groups with information about their local area. They acknowledged the value of the internet as a ‘one-stop shop’ for disseminating information to those groups who most commonly request it, such as health visitors, students and community groups. They perceived that a single point of access, provided by an observatory for example, could reduce their workload and make it possible for them to point people towards a trusted source of information. One specialist pointed out that:

‘How information is delivered is more important than where it comes from’. Information Specialist (S1)

Several stressed, however, the danger of providing information alone without supporting intelligence. On one level, it was vital that any information was accompanied by technical and other explanations (e.g. glossaries of definitions and abbreviations). These were needed to reduce the possibility of misuse or misinterpretation of the information (e.g. where the figures are based on small numbers of events). As such, the internet was perceived to have a potential role in helping new users to understand more about public health information, how it is collected and how it should be used. The information specialists emphasized, however, that the internet would only fulfill this potential for local users if careful thought was put into providing intelligence, not just loading websites with collections of data. On a much broader level, there was also a need for a more subtle type of intelligence, which drew on an understanding of the historical, social and political characteristics of the local area. This sort of intelligence was needed to put information in its proper context and was considered by the information specialists to be much more difficult to provide through an electronic medium such as the internet.

Information specialists from the health sector frequently commented on the importance of having access to local authority data sources. The view was that:

‘Making access to what’s there is better than adding a lot of new information.’ Information Specialist (S2)

However, there were wide variations in the extent to which local authorities were able to provide a joined-up information service, and information specialists tended to rely on their own networks of personal contacts. These networks were sometimes complicated when the health authority covered more than one local authority area (e.g. North Cheshire) or where the local government structure was multi-tiered (e.g. Cheshire).

Although they tended to deal mainly with routine national or regional data, information specialists were aware that this was only one part of the picture. They admitted to struggling sometimes to keep on top of all the local sources, particularly where this information had been gathered on an ad hoc, unpublished basis. Local information networks, such as the North West Public Health Information Group and the Merseyside Health Action Zone (HAZ) Information Group were mentioned as important in keeping professionals up to date with local developments in public health.

Discussion

All three groups needed and wanted more concrete information and intelligence to be readily available, so that they could influence the provision of better, more effective services to tackle the problems identified in and by the community. Information was also needed to support funding applications such as bids for Single Regeneration Budgets and New Deal for Communities. These are all areas in which public health observatories could offer more support and advice.

The findings of this study indicate a number of key messages for public health observatories and the restructured National Health Service. First, observatories need to think about multiple means of communication and dissemination, and not just the internet. The potential emergence of a ‘digital underclass’

19 without access to the internet means that verbal and paper channels of information provision should not be ignored by observatories and other NHS agencies when considering how best to disseminate the outcomes of their work.

Second, the ‘human’ as well as ‘electronic’ points of contact for advice and support are important. In particular, observatories need to become familiar with the existing personal networks of local users and how to make best use of them. A general improvement in the communication between partners involved in reducing health inequalities is needed, to address the needs.

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of the community adequately. One suggestion from our interviewees was that inter-agency training might generate new flows of public health information and provide opportunities for greater sharing of knowledge.

Third, much more could be done on a practical level to reduce the use of jargon and the inaccessible way public health information is sometimes presented. When developing channels of communication, the distinction between ‘information’ and ‘intelligence’ is paramount: observatories need to do much more than simply collect information and place it on a website. It needs to be digested, analysed and interpreted to turn it into useful intelligence, and this requires careful structuring, sensitive to the needs of users.

Fourth, observatories need to find ways of including and appreciating lay knowledge: information from local groups is often dismissed by the statutory sector as not meeting traditional quality standards. ‘Non-routine’ information from local communities should not be disregarded. In addition, it is rare for people working directly with communities from disadvantaged areas to be able to feed back their experiences to inform local policy-making; this needs to change.

Conclusions

The impending fragmentation of the public health function caused by the current restructuring of the NHS in England creates a high priority for the provision of accessible, good-quality public health intelligence. The results of this study indicate the need for a closely integrated network of agencies to provide the information conduit between locally focused bodies such as Primary Care Trusts, voluntary and community groups, and more broadly focused bodies such as local authorities and the new strategic health authorities. Acting in this way, the new public health observatories could ensure both that local bodies can access the information they need, and that the local intelligence gathered by such bodies can effectively influence policy and practice at regional and national levels.

References

19 Department for Education and Skills. 12,000 homes get wired up in £10m programme. Press notice 2001/0142, 16 March 2001.