Lay, Community and Worker 'Epidemiology' – An Integrating Strand in Participatory Research

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Introduction

Effective public health should be based on the World Health Organisation (WHO) principles of 'upstream' health interventions to prevent the development of avoidable diseases, rather than focus on 'downstream' medical interventions to treat preventable diseases. The achievement of such an approach should therefore rest on decision-making underpinned by the precautionary principle.

The precautionary principle depends as much on informed social, economic and political decision-making as it does on science and medicine. Indeed for the famous medical practitioner, Rudolph Virchow, medicine was 'applied politics'. Central to the approach is a need to assess the purpose and impact of any developments that might impinge on health in terms of environmental factors – be they personal, social or physical. In this context the first step in protecting public health should be the prevention of approval of dangerous substances or processes – be they in food, water, air, for domestic, leisure or workplace use. This should be achieved through rigorous toxicology or other scientific and technological testing.

In this context 'lay/worker/community' activity for the good of the public health has a part to play in the process of vetting substances, processes, materials, buildings, factories and other types of plant and installations. We have witnessed globally the over-confidence of scientists, regulators and politicians in the past when dealing with potential public health problems: their inability to deal with uncertainty, their failure to take data gaps seriously when carrying out risk assessments, their failure to go beyond very narrow risk assessments and skewed cost-benefit analyses which constantly favour capital over community and workers. Some communities live with the consequences of the failure of such approaches daily – whether in India and Pakistan, or Nigeria, China, the USA, the UK, Italy, Belarus, or Ukraine. Lay/worker/community action on public health issues can highlight these failures and bring important precautionary approaches to bear effectively on decision-making.

A case study – risk mapping on a grand scale

The Women's Environment Network (WEN) breast cancer survey with local community groups illustrates how communities themselves can explore possible health issues and look at ways to promote health supported by NGOs (WEN 1999). Appendix A contains some of the maps that the women developed. The UK has been top of the world league for several years on deaths from breast cancer in women. Local community groups have found in the east of England that they have some of the highest breast cancer mortality rates in the country, especially for women in younger age groups. The official response was to ignore these facts. The women themselves did not and organised a variety of means to investigate the problem and raise awareness of the disease – and the fact that perhaps at best only 40 % of all cases of the disease have established causes. They asked what role environmental factors could play in the disease and why so little data were available about environmental exposures and environmental risks related to breast cancer (Watterson 1995). The WEN breast cancer project has provided a community based means for such factors to be explored that may complement or possibly question some of the conventional tools used by epidemiologists.

These participatory studies now draw on Geographical Information Systems (GIS) approaches but their roots lie in the risk mapping activities of workers in a Fiat plant in Italy many years ago. The maps so prepared of course rely on worker/community knowledge of processes and procedures rather than managerial and 'expert' assessments that may sometimes reflect the theory rather than the real practice of processes and chemical usage. Appendix B shows risk maps prepared by Canadian factory workers.

WEN and other NGOs represent the prudent decision-makers, the precautionary principle advocates in the public health field, although this is only part of what can be a polarised picture on tackling environmental risks as Diagram 1 below reveals.

Diagram 1: Community environmental epidemiology and toxicology: models of environmental policy and practice

Technological optimists

1. "EXPERTIST"	-	White coat syndrome.
	-	Laws irrelevant.
(small pox	-	No freedom of information.
(asthma	-	"Paternalist".
(asbestos		
(endocrine disrupters		
(aluminium sulphate water pollution		
(lead in petrol		
(CFCs in fridges		
2. LEGAL	-	Science and law-led and operationalised by politicians "unholy alliance"?
	-	No need to enforce laws as experts solve problems.
	-	paradoxically often a non-enforced model.
3. PARTICIPATIVE MODEL - non expertist		
(uses community	-	Non jargonistic.
(environmental	-	Community as partners in (epidemiology and standard setting/vetting.
(toxicology.	-	Minimum legal standards.
	-	Right to information.
	-	"Maternalist".

[Source: Costanza 1992; Watterson 1994a]

Prudent decision-makers

These different philosophies underpin the different approaches to risk and to epidemiology. Prudent decision-makers who use lay epidemiology approaches are searching for public health data showing there are no major risks associated with hazards: the burden of proof lies with the manufacturer/government to show processes are 'safe'. The approach is informed but not dictated by science and scientific methods and recognises the limits of science. This is 'the prove it's safe' position.

Technological optimists rely on the 'scientific method' and on the null hypothesis. They look for evidence that a process or product is hazardous and with clear and calculated risks and assume no hazard and no risk often when data are lacking or limited. This is 'the prove it's dangerous' position The next section deals with how lay epidemiology has developed and how it engages with the technological optimists.

Origins of lay epidemiology
To determine the nature of 'lay epidemiology' it is first necessary to explore conventional epidemiology a little. Epidemiology has been defined as:-

> *'The study of the distribution and determinants of health and disease related conditions in populations. It is concerned with both epidemic (excess of normal expectancy) and endemic (always present) conditions…The basic premise of epidemiology is that disease is not randomly distributed across populations'.*
>
> (M Shenker in LaDou 1997)

Comprehensive epidemiology studies, if done on a large enough scale, over a long period of time and with designs that exclude bias may prove very effective ways of assessing disease causation in populations. This is, however, a very expensive process. It is also fundamentally limited because, although such studies may inform decisions – through exploring correlation between exposures and diseases, though not identifying individual disease causes - on other potential public health risks, they simply do not prevent diseases and disasters in the study being undertaken. Effectively they close stable doors after horses have bolted or shut the cage after the tiger has escaped. Toxicology and engineering are meant to be 'secure stables and cages' – we know that they are not.

Like most professional groups, epidemiologists do not like to discuss their failures in public. Some epidemiologists criticise commentators for using positive studies to dam materials and processes and point out that such studies are often not capable of proving something is not risky. However, such epidemiologists may be silent on the limitations of epidemiological studies that show no risks from a hazard exist. This is called 'negative epidemiology'.

Negative epidemiology
' "The prevailing view" is usually subjective in science' according to Hernberg. Hence the following basic problems sometimes occur in epidemiology to produce 'negative' results, but such results are effectively inconclusive and do not prove processes and materials are safe.

Table 1: Limits of 'negative' epidemiology
1. No studies carried out
2. Studies too small to have statistically significant results
3. Studies poorly designed and not sensitive
4. Problems with validity of control groups
5. Follow up periods insufficient for effects to materialise or materialise fully or follow up incomplete
6. Accuracy of exposure data needed
7. Wrong exposure categories are studied
8. Exposure is too low and/or too short
9. Measures of morbidity are crude
10. There are random errors
11. Wrong or irrelevant morbidity indicators are used

(Source: based on Sven Hernberg 1992)

The science of epidemiology, viewed as so critical to the development of 'academic', rigorous and high status public health medicine, has replaced clinical case studies as the most effective and credible science for sorting out disease clusters. The view of clinical cases is generally

that they are statistically limited sources of information. However, non-epidemiological data, linked to clinical cases or observations, have sometimes resulted in very effective actions. For instance the links between exposures to soot and cancer came from Percival Potts' clinical observations and case reports in the late 18th century. The links between exposure to vinyl chloride monomer and the rare liver cancer, angiosarcoma, came through primary care physicians near a US chemical plant connecting clinical cases. The 'Back to Sleep' campaign in the UK which cut 'sudden infant death' rates came from observational studies, not conclusive physiological studies that could explain mechanisms of mortality (DOH 1998:61).

In the 1920s and 1930s, Sir Thomas Legge who was an early user of 'sentinel' events to trigger investigations of health hazards, (Legge 1934:25-29) used observational data from workers to identify hitherto relatively unknown risk. For instance, he visited a docks site where the dockers themselves had linked work with a hard wood to ill-health cases in their members.

Trade union identification of workplace hazards

Workers have always used observations, knowledge of 'sentinel' events – sometimes single warnings or one worker presenting with an unusual or hitherto unnoticed disease – and varied data to make risk assessments of their workplaces and recognise occupational diseases, sometimes well ahead of medical and scientific investigators in those workplaces. The table below illustrates this clearly.

Table 2: Successful trade union recognition of occupational diseases

INVESTIGATOR	HAZARD `	ACTION
Alfred Greenwood, Glass Bottle Makers Secretary 1891 using social insurance records	cataracts in glass workers	1900s: compensation but no action on the process.
Local woodworkers trade union secretary observing workforce 1900s	Narcotic effects of African boxwood through slowing heartbeat	Substitution with safer woods as best available local exhaust ventilation still created dust inhaled by workers
South Wales Dockers Union secretary observed pitch dust exposure of briquette workers	skin cancer known for centuries in tar workers	1927 finally recognised as an industrial disease for briquette workers
Sheffield Occupational Health Project 1990	chrome ulceration	The project team found more cases in one small Sheffield factory than were recorded for the nation in official records
Local unemployed centre in Sunderland 1994	mucous membrane disease in engineering worker	The centre revealed gross under-reporting of the disease

[Sources: Legge 1934, Watterson 1999]

Rapid appraisal

One approach that now encapsulates much of lay epidemiology is 'rapid appraisal'. 'Rapid appraisal is primarily a methodology which provides timely, relevant information to decision-makers on pressing issues they face in project and programme setting (Kumar 1994 cited by Ong 1996:3). Hence it can be a diagnostic tool or an agent for change or both. It does, however, not necessarily draw on communities in the appraisal as lay epidemiology always would. Communities, whether geographic or workplace-based, should be public health decision-makers as well as the politicians and scientists. The methods that rapid appraisals deploy are very familiar to those engaged in lay epidemiology and might include a number of elements.

Table 3: Elements of rapid appraisal

Mixtures: mapping matrices, focus groups, time lines and trend analysis and faster than 'conventional methods'

1. Field work emphasis
2. Reliance on learning directly from local people
3. Semi-structured, multi-disciplinary, flexible , innovative approaches
4. Focuses on 'insights, hypotheses, best bets rather than final truths or fixed recommendations'

[Source: Ong 1996:2]

The key steps in the process would include those outlined below.
Step 1 defines purpose, identify target groups and agencies.
Step 2 identifies leader/team to conduct rapid appraisal.
Step 3 organises workshops.
Step 4 entails fieldwork, observation, secondary data collection, interviews.
Step 5 includes data collection and analysis.
Step 6 prioritises needs.
Step 7 feeds back to community and discusses possible actions.
Step 8 develop a programme of change.
Step 9 evaluates the work and, if necessary, redefine priorities.
Step 10 explores a second rapid appraisal or a view of future based on the first appraisal (Ong 1996:9)

Participatory research

This draws on lay epidemiology and rapid appraisal techniques to involve communities actively in the appraisals rather than simply being the passive subject of the appraisal. This entails opening up the research process to ensure communities and workers can influence any changes proposed as a result of the research undertaken.

Table 4: The benefits of participatory research

- exposing unrecognised levels of disease
- studying subjective symptoms in an effective way, for instance ME ,Chronic Fatigue Syndrome (CFS), MCS, syndromes, ULDs, asthma, occupational stress
- low cost way of identifying a wide range of exposures to possible disease causes and outcomes through interactive approaches able to deal with rapidly changing situations
- increasing capacity of communities and workers to involve themselves in public health
- recognising and using knowledge and experience of communities in identifying particular health risks
- new approaches to conceptualising knowledge
- enhancing the potential for action outcomes from research findings and raising awareness of policy-makers linked to an identification of key local concerns

(Source: adapted from Loewenson 1996)

Table 5 : Weaknesses of participatory research

- aim to identify community perspectives may mean no precise quantification of a particular problem occurs
- may provide inaccurate perspectives although there is major difference between lay perspectives and lay epidemiology eg malaria examples and CHD work.

Lay epidemiology

This should be a major strand of participatory research although it is often neglected as it sometimes appears too difficult to mount and potentially open to challenge by regulators and scientists. The uses of the technique are many and various and do not simply relate to the investigation of a health hazard and the scientific proof of correlations and causes of diseases. They also contain important community, individual, political and social elements (Watterson 1994b, Popay and Williams 1994 and 1996).

Table 6: Benefits of lay epidemiology

- Inform communities about public health problems and solutions
- Involve communities in public health policy and monitoring of solutions
- Sustain communities and individuals dealing with a common problem requiring community solutions
- Empower communities and individuals in an organisational and possibly social setting
- Change attitudes, approaches, sources of data, possible solutions to public health problems
- Educate professionals through lay groups about new or different public health perspectives and vice versa
- Campaign for positive change

Definition of lay epidemiology

'…the process by which lay persons gather statistics and other information and also direct and marshal the knowledge and resources of experts in order to understand the epidemiology of diseases.'

(Brown 1989)

Table 7: Principles of lay epidemiology - tools, mechanisms, techniques

These may include methods that:-

- appear 'easy' but are not in terms of data gathering
- sometimes observational – different types of data differently used
- generate similar data to that used by epidemiologists and toxicologists but perhaps more comprehensive, more up to date, more relevant, more current, better informed .
- are qualitative – records and histories that may be used in conventional epidemiology but given different weighting here. Problems exist already about recall, about job categorisation and about location and length of exposure and exposure levels in conventional epidemiology. Records of incidents, accounts of exposures, details of suspected adverse effects may all be more richly documented in lay epidemiology than some other sorts of epidemiological study.

The types of questionnaire that may be used in lay epidemiology studies are illustrated by the Vinatex study (see Appendix C) where the ex-workers organised, planned and partially implemented a study of workers exposed to PVC to try to track a range of health effects possibly linked to workplace exposures to vinyl chloride monomer (VCM), a gas used to make PVC. The workers themselves, in conjunction with an NGO, produced questionnaires, conducted interviews and gathered data. The questionnaires were modelled on those used by government departments and international agencies to protect the study from accusations of using 'subjective' data gathering methods. The results were analysed by a university in conjunction with the ex-workers group. The study has raised major questions about under-estimates of the ill effects of VCM exposure.

Data collection in lay, community and worker studies may also come in other forms, some of which would be readily recognised and accepted by conventional epidemiologists. These

approaches are illustrated, to some extent, by the Indonesian pesticide studies carried out recently on behalf of the FAO by Helen Murphy and her colleagues (Appendix D). These methods include recruiting local health workers and key community activists to gather data through observation and interviews using house, locality and body maps and also questionnaires comprehensible and quickly understood by the local population in which the study was being conducted.

Table 8: Strengths of lay epidemiology

- draws on qualitative and quantitative research methods for generating a rich mix of data
- relatively cheap to do, draws on local data, can relate to many people pooling knowledge.
- draws on a socio-participative/participative model
- transparency in study design, execution and analysis
- open
- inclusive
- empowering
- recognises uncertainty
- positive
- if wrong, 'will do no harm'
- relatively easy to do
- complements and may test other methods
- links in to current international and national agendas relating to WHO Charter on Environment and, involving locals communities in their health care. Health inequalities, warning of problems without waiting for disaster to occur
- links workers and communities

The approach offers, in some instances, a better way forward because:-

- it goes beyond the rhetoric of transparency and empowerment
- it may link with "health alliances" concept
- data may be more accurate and experiences and subjective symptoms may be more readily analysed

Table 9: A better way forward for lay epidemiology

- methodological difficulties
- resistance or ignorance of professional scientists
- may be restrained by lack of funds
- training and information issues
- lack of credibility
- lack of rigour
- too rough and ready
- lack of access to data
- lack of resources
- lack of tools tried and tested to analyse data
- size of sample and numbers and times of exposures
- visibility
- response from other groups
- associations not causes demonstrated (as for conventional epidemiology)
- problems of proving random/causal clusters (as for conventional epidemiology)
- lack of good data on exposures, effects etc. (as for conventional epidemiology)

Forms of conventional and lay epidemiology

Lay epidemiology may come in several and sometimes hybrid forms and is sometimes totally excluded from conventional epidemiology studies. For instance:-

1. Epidemiologists design, carry out, analyse and present the study.
2. Epidemiologists design, study and train and use lay staff to carry out survey.
3. Epidemiologists invite lay people to contribute to design of study protocol. Lay staff carry out questionnaire surveys and interviews.
4. Epidemiologists analyse and present data.
5. Epidemiologists invite lay people to contribute to study design. Lay people carry out surveys. Epidemiologists, with lay people, analyse and present results.
6. Lay people identify problem and invite epidemiologists to investigate the problem. Back to (1).
7. Lay people identify problems, involve epidemiologists. Joint protocol is drawn up. Back to (3) and (4).
8. Lay people identify problem, involve epidemiologists. Joint protocol. Lay people and epidemiologists jointly investigate problem and analyse results. Joint presentation of results.

The best approach is contained in number 7 above but this may also the most difficult to achieve because of resistance, apathy or ignorance from health professionals. Compromises along the way may need to be negotiated.

Ways forward

The benefits of lay, worker and community-led health studies are enormous. How can they be introduced more widely and supported more clearly? The following approaches may help the process. Strengthen the means available for social, economic or geographical communities to participate and indeed initiate lay/community epidemiology and toxicology projects both on suspect hazards and on industrial and other processes:

- by ensuring that 'no cost' freedom of information about disease and prevention are available at community level.
- by ensuring easy access to such information.
- by creating information systems that disseminate information rather than restrict information because communities do not know what information is available or are only given information if they ask very specific questions.
- by re-educating health workers in community epidemiology principles and techniques.
- by incorporating the need to involve communities in the monitoring, review and audit of pollutants into the new training of health and technical staff in public and private sectors.
- by all regional health authorities, trusts, local authorities, commercial bodies adopting the WHO Charter on Environment and Health with a commitment to implement its principles and practice (Appendix E). Public Health Medicine Departments in health authorities around the country should have a key role in this process as should community health councils.
- by central and local government and other funding agencies ensuring that lay/community epidemiology is built in as a requirement for any research grants or programmes which involve working on communities or health hazards affecting particular groups.

- by the adoption of cleaner production and toxics reduction methods, again based on community/worker input and audit on environmental hazards and the precautionary principle.

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