CLINICAL ETHICS

How should public health professionals engage with lay epidemiology?

P Allmark, A Tod

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“Lay epidemiology” is a term used to describe the processes through which health risks are understood and interpreted by laypeople. It is seen as a barrier to public health when the public disbelieves or fails to act on public health messages. Two elements to lay epidemiology are proposed: (a) empirical beliefs about the nature of illness and (b) values about the place of health and risks to health in a good life. Both elements have to be dealt with by effective public health schemes or programmes, which would attempt to change the public’s empirical beliefs and values. This is of concern, particularly in a context in which the lay voice is increasingly respected. Empirically, the scientific voice of standard epidemiology should be deferred to by the lay voice, provided a clear distinction exists between the measurement of risk, which is empirical, and its weighting, which is based on values. Turning to engagement with values, health is viewed to be an important value and is discussed and reflected on by most people. Public health professionals are therefore entitled and advised to participate in that process. This view is defended against some potential criticisms.

EMERGENCE OF LAY EPIDEMIOLOGY

The phrase lay epidemiology was coined in 1991 in an article that described the health beliefs and attitudes found in ethnographic research conducted in South Wales.¹ The authors of that article have since published several papers in which the concept is used,^{2–6} and several other writers have taken it up.^{7–11} In these articles, at least two distinct elements seem to make up lay epidemiology. The first is empirical: lay beliefs about the causes, course and management of illness. The second is values: lay beliefs about the place of health and risks to health in a good life. In almost all the articles, lay epidemiology is seen as oppositional to public health in one or both of these elements. The articles, however, differ in the way they view this opposition. To examine these accounts, we shall divide our discussion into the empirical and value elements of lay epidemiology.

Empirical element

On one account, lay epidemiology is in opposition to public health because it recognises that public health messages are sometimes false or exaggerated. On another account it is in opposition because it is itself based on partial or false beliefs. Let us take these in turn.

The originators of the term emphasise the veridical strength of the empirical beliefs in lay epidemiology in opposition to public health propaganda. At the heart of their position is concern over the prevention paradox in public health, first identified by Rose.¹² The paradox is that targeting the behaviour of the large majority of the population that are at medium or low risk for a particular illness related to a behaviour is effective at population level, but has little effect at the individual level. For example, a person whose dietary fat intake is about average is unlikely to gain from reducing it further. None the less, were the whole population to reduce their dietary fat intake, this would have far greater effects on the level of coronary heart disease than would simply targeting those whose dietary fat intake is particularly high. The problem is that it is difficult to persuade people to change their behaviour where it places them only at low to medium risk of a bad outcome. As a result, Davison *et al*¹ say that public health professionals have opted for “worthy dishonesty”: simple and untrue messages that exaggerate the risks of a particular behaviour and the benefits of changing that behaviour.

The problem with such dishonesty, aside from its ethics, is that lay epidemiology has cottoned on to the prevention paradox in at least two

This paper presents a new interpretation of and reflection on a theory that has been widely used in the discussion and development of public health policy. “Lay epidemiology” is a term used to describe the processes by which laypeople understand and interpret health risks. In doing this they use numerous empirical sources, such as the observation of cases known to them, newspaper reports and television dramas. Lay epidemiology is seen as a barrier to public health in at least two ways. Firstly, people do not always believe health messages that are issued from public health bodies. Secondly, people have cultural or individual values that undermine health messages—for example, health-threatening activities are viewed as “naughty but nice”. To be effective, therefore, public health professionals must engage with lay epidemiology. For various reasons, however, we may question the right of public health professionals to challenge the beliefs and values of people and communities. In this article, I defend the idea that public health professionals should engage with lay epidemiology. We begin by tracing the emergence and development of the concept.

See end of article for authors’ affiliations

Correspondence to:
Dr Peter Allmark, Samuel
Fox House, Northern
General Hospital, Sheffield
S5 7AU, UK; p.j.allmark@
shef.ac.uk

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ways. Firstly, the lay public sees the unwarranted survivals and anomalous deaths that run contrary to public health messages.¹³ Secondly, it notes the rarity of conditions that are associated by public health with common practices—for example, as malignant melanoma is associated with sun tanning.⁵ Furthermore, the lay public has become aware of the fickleness of health messages—for example, alcohol is damned and praised almost simultaneously for its health effects.¹⁴ As a result, lay epidemiology rightly “smells a rat” with public health messages.

In contrast with this “pro-lay epidemiology” view, others say that the task of public health professionals is to use information from standard epidemiology to correct the lay misapprehensions of the public.^{8 13 15} This correction may lead the public to behave in accord with public health messages. People’s behaviour, however, is a product not just of their empirical beliefs put also of their values. People will not give up smoking simply because they believe that it is injurious to their health; they must also believe that this risk of injury outweighs the pleasure of smoking. This takes us to the second element.

Values

When weighing up the potential benefits of public health measures, public health professionals view the outcomes for the health of the population to be of primary importance.¹⁶ If a change in population behaviour would result in a reduction of illness in the population, then it is desirable. In contrast with this, the lay public takes an “all things considered” view. As a result, there are subtle differences in the way of looking at behaviour that is deemed bad for health. At least three categories of “bad” health behaviour may be discerned.^{2 17}

1. *Bad because poisonous*: Such behaviour damages health and has little or no obvious pay-off—for example, eating foods that contain toxins, such as salmonella.
2. *Bad but desirable*: Despite being damaging to health, smoking, alcohol, illicit drugs, fatty diets and indolence all have rewards that may outweigh any health benefits gained from avoiding them.
3. *Bad in some ways, good in others*: As an example, some research suggests that people view the health risks of smoking as outweighed by its health benefits, such as reduction of stress.¹⁸

The public is likely to respond positively to messages about poisonous behaviour. Their attitude to messages about the other two types will be more ambiguous. Thus, the “all things considered” view of lay epidemiology may conflict with the health-oriented view of public health professionals.

This conflict is seen in the role of culture in lay epidemiology. Clearly, culture is a crucial factor in the values people have. In taking an “all things considered” view, people will be affected by culture in at least two ways:

1. Some cultures will place a high value on attitudes or activities to public health. Tod *et al*^{19 20} examined barriers to the uptake of services for coronary heart disease in a South Yorkshire working class community. These barriers included the cultural value placed on independence, strength and self-sufficiency. People put up with symptoms of coronary heart disease rather than be branded ill and in need of medical help.
2. Much of the public health message is conveyed in terms of risk. Cultural values will, however, affect how people weigh up behaviour as risky or not. If circumstances outside one’s control are such that life expectancy (in terms of morbidity and morality) is low, then this will

reduce the import of additional risk. For example, if we are likely to die or be miserably ill by the age of 50,²⁰ then smoking will not be seen as likely to rob us of much useful life. Similarly, anti-smoking messages will fail in those deprived communities where smoking may have a high value in an otherwise miserable existence.⁶

We are now in a position to set out the problem that lay epidemiology presents for public health.

THE PROBLEM FOR PUBLIC HEALTH

Effective public health measures will, among other things, require engagement with lay epidemiology. There are, however, reasons for being uneasy about doing so, in terms of both empirical beliefs and values. Again, we shall take these in turn.

We have seen the claim that lay epidemiology “smells a rat” in public health advice. In that this suggests that lay epidemiology is empirically correct (eg, in its belief that dietary change may have little effect on many people’s risk of coronary heart disease), there is no question that public health professionals should not seek to challenge it. Furthermore, as we noted earlier, values play an important part in our decisions on whether something is of high or low risk. Epidemiologists cannot simply say that, for example, smoking is highly risky to health. Smith²¹ takes this further: “This is the way the world is going. It’s called postmodernism. There is no ‘truth’ defined by experts. Rather there are many opinions based on very different views and theories of the world.”

Medical knowledge is no longer privileged; rather, it is one opinion to be weighed among others.¹⁵ Indeed, the real experts are those with the illnesses. In this climate, any attempt by public health professionals to correct lay views seems unjustified.

Ex fortiori, how can we justify challenging people’s values if we cannot even justify challenging their empirical beliefs? Indeed, given that the difference in values between people often reflects cultural differences, it would be disrespectful to attempt any such change.

Thus, we may argue that public health professionals should attempt to change neither the empirical beliefs nor the values inherent in lay epidemiology. How would public health professionals respond to this argument?

ENGAGING WITH EMPIRICAL BELIEFS IN LAY EPIDEMIOLOGY

The term “lay epidemiology” invites a post-modern interpretation. We are tempted to compare it directly with standard epidemiology (henceforth, simply “epidemiology”). The logic is that epidemiology is at the root of the public health view of health and risk, whereas lay epidemiology is at the root of the lay view. Lay epidemiology is, on this account, different but equal to epidemiology.

It is, however, worth noting in the first place that lay epidemiology includes the complete set of empirical beliefs and values relating to people’s behaviour on, and attitudes towards, risk. By contrast, epidemiology is purely empirical—the study of the occurrence and spread of illness in the population. As such lay epidemiology and epidemiology are not directly comparable. Furthermore, those who coined the term lay epidemiology had no postmodern intent. Their observation was that, although the lay public gathered empirical beliefs about health risk in a piecemeal way, many of these beliefs matched those in epidemiology and contrasted with the messages given by public health bodies. Hence, the term lay epidemiology was used to emphasise the correlation between lay and professional beliefs, not their opposition. The opposition is between both types of

epidemiology and public health messages that are seen as simplistic or even untrue. When used in this way, lay epidemiology is at odds with a post-modern view, because it relies on the idea of truth that post-modernism eschews.

If this is accepted, there is no reason to expect lay epidemiology to be better than epidemiology at discovering empirical facts. Epidemiology uses systematic research, whereas lay epidemiology develops its empirical beliefs in a partial and piecemeal manner. As noted above, lay epidemiology will err. Of course, epidemiology itself may err. This is shown particularly when observational epidemiological studies report findings that are subsequently not replicated in randomised controlled trials.²² None the less, epidemiology is less likely to err and more likely to correct its own errors. This gives purchase to the idea that lay epidemiology can stand in need of correction in its empirical beliefs.

What, however, of the concern that risk-related terms used in epidemiology are not straightforwardly empirical because our values determine, for example, what we perceive to be a high risk? Here, we should avoid being distracted by the way in which probability facts can be presented in several different ways.²³ All such presentations refer to the same fact; as such, this point does not support the concern. Nor should we be distracted by disputes in probability theory between, for example, Bayesians and Frequentists. Although their disputes are important, neither account is consistent with a post-modern view.

One serious argument remains in support of the idea that risk-related terms are not truly empirical: our perception of risk depends on our circumstances and values. This argument can be tackled by drawing a distinction between the measurement and the weighting of risk; in other words, we can distinguish between the precise level of risk and whether it is worth worrying about or acting on. In measurement terms, there are fairly precise ways of presenting risk. Many of us are familiar with taxonomies of risk presented in drug information sheets listing side effects. In weighting terms, however, whether a risk is worth acting on will be strongly dependent on values. Therefore, public health information can describe some behaviour as high risk and define this precisely, provided no weighting conclusions are drawn from this.

We can conclude, therefore, that a proper account of lay epidemiology does not support the idea that it represents an alternative to epidemiology; neither does it support a post-modern account of truth in medicine. As such, there is no problem in principle with the idea that public health professionals can challenge lay epidemiology on empirical grounds. Furthermore, it is possible for public health professionals to present epidemiological facts in ways that are true and meaningful. But what of the task of challenging the values inherent in lay epidemiology?

ENGAGING WITH VALUES IN LAY EPIDEMIOLOGY

To put this another way, what should public health bodies do if the public, once informed of an avoidable health risk, chooses not to avoid it? One response is to say that they should do nothing further, because the job of public health professionals is to inform the public, how the public responds is its business. We shall call this a libertarian response. It has *prima facie* plausibility. Also plausible, however, is the opposing view that we should sometimes challenge the values and attitudes of people and communities that leave them vulnerable to avoidable illness. To take a simple example, it seems right to challenge the suicidal behaviour of a young person determined on self-destruction after disappointment in love. Here, we shall develop and defend this idea.

In this context, values are the views people hold about what is worthwhile doing or having in a good life. Some of

these will be instrumentally worthwhile, such as money, and others intrinsically, such as independence or friendship. Some will be temporary, such as a brief infatuation with Sudoku, others fairly permanent, such as love of family. All will be weighted as worthwhile to a greater or lesser degree. Values will originate from a mixture of culture, personality, experience and reflection. As seen already, some working class communities in South Yorkshire place high value on strength and independence.²⁰

It is tempting to believe that there is no way of judging values and that it is wrong to do so; different people and cultures have different views on what is worthwhile and that's that; values are inaccessible to reason. This belief lies at the heart of libertarianism. At least two considerations, however, suggest that this belief is flawed.

The first consideration is that values and empirical beliefs interact. If we believe that there is little we can do to improve the course of our life, then we may be more inclined to value immediate pleasure over deferred pleasure. Changing the empirical belief may change the value in such cases. The second consideration is that some values seem to be widely shared. One such value is health: for almost all people, other things being equal, it is better not to be ill. It is indeed possible to extend this point. "Health" and "illness" are not purely factual terms; to be ill is to be in a state that is generally disvalued. Our ability to use these terms in an agreed way across cultures reflects the existence of widely shared values. These and other shared values enable us meaningfully to reflect on what constitutes a good life both within and among people. Thus, someone may decide that he is spending too much time on Sudoku or work and too little with his family, or that he really should lose some weight. Similarly, close friends may suggest this to him in the hope that he will see reason.

Hence, we may accept that people take an "all things considered" view of what makes certain behaviour worthwhile, without necessarily accepting that public health professionals should not engage with the value-based element underlying such behaviour. As health is an important and widely shared value, public health professionals are entitled to note where people are making suboptimal health decisions, and encourage reflection and change.

This argument establishes an "in-principle" entitlement for public health professionals to engage with the public. How this engagement takes place must still be governed by the same ethical principles as other healthcare.²⁴ As such, the prevention paradox still presents a challenge for public health. Lay epidemiology can undermine the excessive advocacy of public health. Even if it did not, it is ethically questionable to frame information with a view to getting a desired change in behaviour rather than with a view to informing people. None the less, it seems perfectly possible for public health to engage with the public in a way that does not violate ethical principles (eg, through voluntary screening programmes).

This view can be challenged for at least four reasons.

1. *The role of the state:* Anyone sympathetic to a libertarian view is likely to find it unacceptable for the state to interfere with the values of its citizens; people should make their own decisions and live (and die) by them. Many states participate in the provision of healthcare in a way that is inconsistent with this view. If a state provides healthcare, then this weakens individual choice, particularly about whether we should make our own provision. But, if such state provision by the state is acceptable, there seems no reason in principle why the state may not also endeavour to maintain the health of citizens.

2. *The prevention paradox*: We discussed the argument that the prevention paradox lay at the heart of the "worthy dishonesty" adopted by public health bodies, to which lay epidemiology cottoned on. The implication is that if the public were properly informed about public health injunctions, it would decide not to follow them. For example, from the "all things considered" perspective taken by lay epidemiology, it may not seem worthwhile to reduce fat intake if it offers little chance of personal benefit. Davison *et al*¹ suggest that this implication is based on the assumption that people will change their behaviour only if they anticipate personal benefit, an assumption they question. People may be willing to make behaviour changes for the sake of others, such as family or community, rather than for themselves. A person's belief here may be, say, that he believes that any personal gain is unlikely and certainly not worth the self-sacrifice required. The person may, however, be willing to make that sacrifice for the sake of his or her children. None the less, if public health bodies are unable to persuade people that such changes are worthwhile, then that should be the end of it. In practice however, people's values are changeable and are open to reasoned discussion. Public health bodies are entitled to participate in that discussion. "Worthy dishonesty", however, cannot be justified, even if it were effective.
3. *Cultural intolerance*: As discussed earlier, some communities may have values that run counter to public health aims. The emphasis on strength and independence in one community was part of its resistance to the use of services for coronary heart disease and resulted in avoidable illness.²⁰ Clearly, here it would seem undesirable to undermine such values simply to promote health. Part of the concern is that attempting to change cultural values to accord with the aims of public health represents cultural intolerance, a desire to homogenise people so that they are similar to the currently small number of largely middle-class people who are actively seeking good health.²⁵ The very existence of lay epidemiology, however, may suggest that we should not be too worried about this. For example, despite years of public health information about smoking, the most deprived communities have remained immune to the messages.⁶ Public health professionals need to be aware of the different cultural contexts in which a message operates. In the South Yorkshire communities, they must be aware to provide services in a way that complements the values of that community.²⁶ In terms of making public health measures more effective, engaging with lay epidemiology may be seen as much as an opportunity as a challenge.
4. *Why privilege health?* We have reasoned that health is a widely shared value and have given this as partial justification for the State's interference in people's lives through the medium of health professionals. Could this argument not be used to justify interference in other areas? From the perspective we have defended here, it could. Education and subsidy of the arts are, perhaps, two examples. Once we reject the libertarian view, the question becomes not whether the state can interfere in such areas but to what extent it should.

CONCLUSION

Lay epidemiology is an apparent problem for public health professionals, as it seems to contain a countervailing set of beliefs and values. Its very existence, however, shows that health is of concern to most people. Furthermore, with due respect to post-modernism, most people will want to know

and act on empirical beliefs about health that are true. Epidemiology is far more effective at finding these than is lay epidemiology. As such, public health professionals are correct in presenting their findings to the lay public in ways that are meaningful.

We have also reasoned that people's values are open to rational discussion and that public health professionals are right in participating in this, but they must be honest. They should also be aware of the cultural contexts that mean, for example, that something that is high risk and worth avoiding for one person is not the same for another. Engaging with lay epidemiology is likely to increase the effectiveness of public health work, as well as helping ensure that it is ethically sound.

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Authors' affiliations

P Allmark, A Tod, University of Sheffield, Sheffield, UK

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