

# Different public health geographies of the 2001 foot and mouth disease epidemic: ‘citizen’ versus ‘professional’ epidemiology<sup>☆</sup>

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## Abstract

Recently, there have been calls for health geographers to add critical and theoretical debate to ‘post-medical’ geographies, whilst at the same time informing ‘new’ public health strategies (Soc. Sci. Med. 50(9)1273; Area 33(4) (2002) 361). In this paper we reflect on how, alongside ‘professional epidemiologies’, ‘citizen epidemiologies’ can have credibility in informing public health policy and practice. We do this by drawing on mixed method and participatory research that used a citizens’ panel to articulate the health and social outcomes of the 2001 foot and mouth disease disaster.

We consider the difficulties of creating dialogue between on the one hand, time-limited, discrete, theoretical, visible and by implication legitimate, ‘professional’ knowledge and on the other, ongoing, holistic, experiential and often hidden ‘citizen’ knowledge of the foot and mouth disease epidemic. Despite significant evidence that in disaster and crisis situations, people need to be actively involved in key ‘recovery’ decisions (see for example *At Risk Natural Hazards, People’s Vulnerability, and Disasters*, Routledge, London; *A New Species of Trouble*, Norton, New York), lay accounts, which may in themselves provide valuable evidence about the impact of the disaster, are often ignored. If health geographers are to critically inform ‘new’ public health policy then we need to consider research approaches that give voice to citizens’ understanding of health outcomes as well as those of professionals. If ‘new’ public health is concerned with the material character of health inequalities, with fostering ‘healthy’ living and working environments, the promotion of community participation and individual empowerment (Area 33(4) (2002) 361), then we argue that situated, negotiated, everyday geographies of lay epidemiologies can and should inform public health policy.

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## Introduction

### *Geographies of health*

Since Kearns (1993) call for a ‘post-medical’ geography of health and indeed, Eyles and Woods (1983) text on ‘The social geography of medicine and health’ a decade earlier, there has been a shift in research interests from a dominant biomedical perspective towards a more

cultural/humanistic standpoint. This shift has been outlined in key publications such as reports in ‘Progress in Human Geography’ (Jones and Moon, 1991, 1992, 1993; Kearns, 1995, 1996, 1997; Kearns and Moon, 2002; Hayes, 1999). There have been theoretical developments within a post-medical framework, such as a focus on mental health (Parr, 1998); a consideration of the complex relations between the body, identity, consumption and risk (Brown, 2000); a concern with body/disability (Moss and Dyck, 1996; Butler and Parr, 1999) and a Foucauldian critique of how public health institutions embed education on AIDS/HIV in talk about ‘normal’ and ‘abnormal’ behavioural practices. There has also been a concern with studies where ‘...place matters with regard to health, health care and health policy’ (Moon, 1995, 1; see for example Cummins and Milligan, 2000; Moon et al., 1998) and latterly, a call for a critical geography of public health (Brown and Duncan, 2002).

Simultaneously, there have also been changes within social epidemiology, most notably a move from individual risk factor and disease ecology to greater emphasis on social–structural influences on health. As Macintyre (1997) suggests, the Black report (Townsend and Davidson, 1982) was pivotal in pointing out the relationship between material and health inequalities, a relationship that the UK Government acknowledged (see for example Acheson, 1998; Social Exclusion Unit, 1998; Department of Health, 1999). Questions of area versus individual effects in health difference (see for example, Jones et al., 2000; Popay et al., 1998) and those concerning social and spatial inequalities in health (Shaw et al., 1999; Twigg et al., 2000) are now very much part of geography’s health variation research.

In this paper we endorse ‘the adoption of self-consciously sociocultural theoretical positions, and the quest to develop critical geographies of health’ (Kearns and Moon, 2002, p. 606). We are also aware that there is a discourse of ‘new’ public health, based on paying attention to, ‘prevention rather than cure, to the material character of health inequalities, to the production of healthy living and working environments and to the promotion of community participation and individual empowerment in relation to health.’ (Brown and Duncan, 2002, p. 363). We are also cautious of dualistic thinking, and argue that whilst it is good to move from reductionist, deterministic and essentialist medical-centred understandings of health, it is nevertheless important to recognise ‘socially mediated factors influence individual biology through their effects on the immune, endocrine and central nervous systems (the sociobiological translation)’ (Hayes, 1999, p. 291). We need therefore social and *biomedical* understanding of health.

Our central concern is with questioning how can ‘new’ public health be inclusive, how can it deal with what

Brown and Duncan (2002, p. 376) refer to as ‘health concerns situated in the context of place’? Likewise, how to listen to citizens’ understanding of health, so that a discourse of community participation becomes embedded in public health decision-making? Our starting point is mixed method, participatory research using a citizens’ panel to articulate the health and social outcomes of the UK 2001 foot and mouth disease disaster<sup>1</sup>.

### The UK 2001 foot and mouth disease epidemic

The 2001 UK foot and mouth disease<sup>2</sup> (FMD) epidemic was probably the world’s worst to occur in a previously disease free country (Cumbria FMD Inquiry Report, 2002). From the first case detected on the 20th February to the last confirmed case on the 30th September, 2026 outbreaks were recorded in Britain and 4 in Northern Ireland (The Royal Society, 2002). Government control policy required the slaughter and disposal of susceptible animals from infected farms and from farms considered to have been exposed to infection. This resulted in an estimated 4 million livestock being destroyed (this does not include newborn animals) with a further 2.5 million under related schemes to deal with animal welfare and marketing problems (Cumbria FMD Inquiry Report, 2002).

Cumbria, our study area, suffered by far the greatest number of FMD cases in the UK (893 compared with the next nearest total of 176 for Dumfries and Galloway, representing almost 44% of national FMD cases). The Cumbria Foot and Mouth Disease Inquiry Report outlines three devastating aspects for the county. Firstly, a county rich in natural heritage with an economy dependent on livestock agriculture, outdoor recreation and tourism became crippled by a country wide ban on

<sup>1</sup>This study was undertaken by researchers at the Institute for Health Research, Lancaster University who received funding from the Department of Health. The views expressed in the publication are those of the authors and not necessarily those of the Department of Health.

<sup>2</sup>Foot and Mouth Disease (FMD) is a highly infectious viral disease that mainly affects cloven-hoofed animals, including cattle, sheep, pigs and goats. Fever is typically followed by the development of blisters—chiefly in the animal’s mouth or on the feet. It can spread by direct or indirect contact with infected animals, and whilst the disease is rarely fatal, the effects are serious and debilitating. In dairy cattle these include loss of milk yield, abortion, sterility, chronic mastitis, and chronic lameness. Secondary bacterial infections may also lead to further complications. Advice from the UK Department of Health is that FMD is very rare in humans. There has only been one recorded case of FMD in a human being, in Great Britain in 1966. The general effects of the disease in that case were similar to influenza with some blisters.

livestock movements and widespread restrictions on public access to the countryside. Secondly, the Report notes the massive scale of the slaughter and disposal of livestock and other animals. As well as the 893 infected premises a further 1934 suffered complete or partial animal culls, ‘taken out’ as dangerous contacts or in the cull of contiguous premises. Some 45% of Cumbria’s farm holdings suffered these culls and in the north of the county where the epidemic was most severe, this rose to 70% (Cumbria Foot and Mouth Disease Inquiry, 2002). Lastly the Report notes: ‘there were problems in implementation of disease control, communication and other measures [that] led to an upsurge of public objection and to expressions of public concern, frustration and anger at the way the epidemic was being handled.’ Much of the blame for these problems was directed towards the Department for Environment, Food and Rural Affairs (DEFRA), the government agency responsible for dealing with the disaster. In addition, many of the DEFRA workers recruited or seconded to carry out animal culling or disposal activities reported feeling traumatised by their encounter with sights and sounds and smells that were extraordinary to their common experience (Cumbria Foot and Mouth Disease Inquiry, 2002; Graham, 2002).

### Health and social consequences of the 2001 FMD outbreak in North Cumbria—a critical health geography

#### *The study*

Similar to work on other disasters (Blaikie et al., 1994; Erikson, 1991), we would argue that the people who can best describe the health and social consequences of 2001 FMD outbreak are those who experienced them directly. Indeed, such lived experience, based on local, ongoing knowledge, is essential in terms of informing and sustaining effective recovery policies and initiatives. The study was designed<sup>3</sup> so that participants form a ‘citizen’s panel’ of 54 people from North Cumbria, which reflects a range of local expertise and experience linked to FMD (including farmers, small businesses, slaughter and disposal workers, vets, health workers, the clergy and residents living near disposal sites).

<sup>3</sup>Composition and membership of the panel was shaped by discussions with a multi-disciplinary, multi-agency steering group that reflected concerns about the health impacts of the FMD epidemic on a wide range of people living and working in Cumbria. These discussions produced six occupational groupings each with a detailed profile base on age, sex, sector and location. These profiles were given to an independent professional recruiter who identified individuals to ‘fit’ each one, and who were willing to take part in the study.

The use of citizens’ juries and standing panels as a consultative mechanism is becoming well known in the public services (Coote and Lenaghan, 1997; Kashefi and Mort, 2000). Part of the discourse around the ‘new’ public health concerns involving the public in decision-making, at least from within the provision of health services. For example, ‘Shifting the Balance of Power within the NHS’ (Department of Health, 2001a, b) asserts that ‘patients and the public will be more involved in the NHS’ and ‘Involving Patients and the Public in Healthcare—a Discussion Document’ gives details on how this is to be achieved. Heller et al. (2003, p. 65) suggest that the ‘public should also be involved in decision making about the determinants of health that go beyond the provision of health services, such as individual and community exposures to education, diet, housing, transport and pollution.’

The new public health also endorses, ‘bottom up’ public health networks, such as those created by Local Strategic Partnerships which are claimed to be ‘infused with a sense of public health cutting across all activities, involving a range of agencies from police, education and employment agencies, to local business and community groups’ (MacKian et al., 2003); and by implication, democratic decision making. It has been argued that inclusive/participatory tools such as citizens’ panels/juries may unwittingly reinforce neo-liberal forms of governance (a public consultation ‘5-day exercise’) rather than promote grass roots involvement/activism (Kashefi and Mort, 2000). However, our study is both longitudinal and participatory in the sense that respondents have contributed substantially to the orientation of the project, evolution of project recommendations and have opted to speak alongside project staff at conferences and inquiries.

Between December 2001 and June 2003, respondents wrote weekly diaries (comprising both structured and unstructured sections) and participated in a series of group discussions, the first before diary keeping began and the second to close the data collection. Each member also took part in an in-depth interview at the start of the study. We have also used documentary sources such as evidence from local and national FMD inquiries and a validated ‘Quality of Life’ measure (the EuroQol EQ-5D 1998).

The diary method proved to be remarkably successful, resulting in a dataset of 3071 weekly diaries contributed by a final panel of 51 members. In addition 51 panel members in depth interviews were collected and 12 panel group discussions were held. These data were taped and transcribed for analysis. Drop out rates were low. One respondent, aged 17, left the panel very early, soon after the first group discussion, but was quickly replaced by a respondent from the recruiter’s ‘reserve’ list. Three other respondents left the study at different times, all after they had contributed a significant amount of data

(diaries, interview and first group meeting). For the first, a woman, continuing with the study evoked very distressing memories of implementing the culls on farms, memories which were enduring vividly and this respondent was seeking medical help. The second, a man, initially reported severe feelings of guilt from his time as a front-line worker and withdrew feeling that the process might perpetuate his distress. The third, a woman, found that family difficulties and financial collapse became so overwhelming that diary writing became impossible.

In this way individual, group and longitudinal reflective accounts are included in the data. Mixed methods are best suited to complex studies. As we go on to discuss, these data reveal the distinctiveness of rural/farming communities in Cumbria, their social/economic networks, cultural practices and diverse and complex health and social consequences of the crisis. Early interviews captured recent accounts of living with FMD during 2001. Diaries recorded into Summer 2003, captured the changing and evolving nature of some of these consequences. Study findings should impact on health policy and practice, particularly at the local level.

### Diaries and geography

We would argue here that longitudinal diaries present a hitherto untapped potential for health geography research. A recent paper by Meth (2003, p. 201), for example, has emphasised how diaries offer *'longitudinal personal insight into day-to-day processes... (diaries) provide rich detail on the everyday context of health and illness.'* Perhaps the greatest advantage of diary studies is that they bring the task of data collection into the person's own everyday world (Verbrugge, 1980; Elliot, 1997; Zimmerman and Wieder, 1977). Diaries thus provide the opportunity to study change over time and provide insight, in a very direct manner, into a person's actual experience and how they perceive it (Hayes, 2000).

The 18 months of weekly diaries generated by this study has produced complex, varied and heterogeneous accounts. Three researchers each made monthly visits to approximately 18 panel members over the research period. Visits often took place in the participant's home with other household members present, or, if more convenient, in the workplace. The researcher collected weekly diaries and offered a small payment. During these visits, conversations were wide ranging, from discussing local and national FMD developments and initiatives; to 'everyday talk' about families, paid work, past and future events, hopes and fears; to researcher occasionally seeking clarification from 'diarist', of what

had previously been written or possibly spoken of, during previous telephone calls (to arrange visits).

Visiting households meant that at times, others (e.g. partners, other family members) verbally supplemented the material given in the participant's diary. We absorbed these 'additional stories' but could not use them as 'data' since if they, the participants, do not tell us, we must presume they do not want us to know. The duration and intensity of this 'research process' has led to the development of trusting relationships between researchers and respondents, enabling detailed understandings of the complex socio-cultural health/place nexus inherent in respondents lives.

What follows may seem an unconventional reporting of the study findings with not always a clear differentiation between these and 'established knowledge' of the UK 2001 FMD epidemic. In part this illustrates how indexical recollections of FMD (references to concrete events in time and place), may be framed by local and cultural understandings so that plot, content and context may embody both personally meaningful accounts and the localised, cultural context of experience (and we offer further discussion elsewhere, see Bailey et al., 2003). In part this also raises questions about how and why situated, negotiated, everyday geographies of lay epidemiologies can and should inform public health policy, a central focus of this paper.

### FMD in Cumbria –lifescapes and contingent knowledge

Health concerns need to be 'situated in the context of place' (Kearns and Gesler, 1998, p. 1) and public health should be explored as a "sociocultural practice and a set of contingent knowledge" (Petersen and Lupton, 1996, p. x). Traditional public health impacts were considered – a review of the North Cumbria Health Task Group minutes over the duration of the crisis reveals that health service managers, clinicians and local authority officers perceived the human health risks to be either immediate environmental or zoonotic effects. The latter soon faded as a concern, while and as we outline in Section Three below, the former also dropped from view once large scale pyres were abandoned as the principal disposal method following public protest (North Cumbria Health Task Group, 2001; Longtown Community Centre<sup>4</sup>). While concerns about longer term effects on mental health and well being were occasionally raised at the Task Group and in a number of articles and responses more widely (see for example, Gibson, 2001; Hunter, 2001), little action followed, due to the epistemological

<sup>4</sup>Public Meeting convened to discuss pyre burning with representatives from the Army, Maff, the Environment Agency and local Health Services, 11th April 2001.

problem of how to collect and produce evidence about this. In a crisis situation proof was not available, in the aftermath such evidence cannot easily be recovered.

Thus health and social services did not record any significant increase in demand during the FMD epidemic and subsequent months (Cumbria FMD Inquiry Report, 2002; Carlisle District Council Health Overview and Scrutiny Committee, 2003). This is taken to be a sign that the health and social effects of the disaster were also not significant. We believe that while not surprising, this inference emanates from a service-led perspective and from disease specific, and statistical constructions of, what counts as evidence.

What we have found is that respondents sought community, informal support, practical advice and financial assistance from each other, from voluntary agencies and anonymous, emotional support from rural telephone stress help lines. For some respondents ‘trapped’ inside the epidemic, either surrounded by infected premises or declared such themselves, a visit to the GP was impossible or unthinkable. For others, there was a sense of stoicism, of ‘getting on with it’ as everyone else seemed to be doing. Telephoning the veterinary practice, the auctioneer, the animal feed merchant, the livestock haulier, family, friends and neighbours, people also ‘inside’ the disaster, is what seemed to help. In cases of financial hardship, established rural charities and local church organisations offered assistance, particularly for those not ‘culled out’, but who nevertheless were unable to sell livestock onto markets. Whilst respondents also spoke of social divisions and tensions, some generations old, others created by the disaster; many suggest that informal support was pivotal to their survival.

As illustrated by one respondent, a community nursing sister, routine formal health care did provide an opportunity for emotional support, but support that would not be formally recorded:

This wasn’t because it didn’t happen but because it became the norm. Wound dressing visits that normal took 15 minutes stretched to over an hour as patients sought to off load their concerns for themselves, or more commonly, their loved ones, who were so stressed that they were rapidly losing weight or not sleeping or in tears or not talking or so angry or turning to drink or who were concerned about worsening their already existing ailments. No visit to a house during that period was simple. Emotions were near the surface and every day brought fresh news and concerns. The burdens got heavier and heavier and this picture was repeated among the GPs and the practice nurses too.

Elsewhere (see Convery et al., forthcoming), we have described in detail how we use the concept ‘lifescapes’ to

frame these ‘simultaneously tangible, negotiated and experienced realities of place’ (Kearns and Gesler (1998, p. 4). ‘Lifescapes’ captures what respondents have told us about their everyday lives: work, social life and locality and what living and working in Cumbria means to them. Here we briefly introduce this concept in order to convey localised, social–spatial sensibility of the health impacts of the UK 2001 FMD disaster for a group of people living and working in rural Cumbria. The concept has evolved within social anthropology (Nazaarea et al., 1998; Howorth, 1999; Howorth and O’Keefe, 1999; Convery, 2004) as a way of framing the complex relationship between people, place and production system. *Lifescapes* are necessarily interactive, people and places are intimately interconnected (Howorth, 1999).

Figs. 1 and 2 indicate how FMD disrupted lifescapes in Cumbria. Fig. 1 illustrates how ‘taken for granted’ disruption (events and shows cancelled, weddings postponed) combined with some of the more obvious (stock culls and mart closures) to create a sense that ‘normality has gone’. Fig. 2 presents a teacher’s lifescape during FMD.

The 2001 FMD outbreak was not a human disaster in the sense of a single catastrophic event such as a rail crash or an earthquake which leads to multiple deaths; or in the sense of an ongoing chronic disaster that eventually leads to deaths, such as the outbreak of *Escherichia coli* in Central Scotland in 1996, which killed 18 people over the course of several weeks and which was eventually traced to negligence by a butcher’s company (McLean and Johnes, 2000, p. 88).

However it was a disaster in the sense that those who lived through the epidemic and continue to live with its

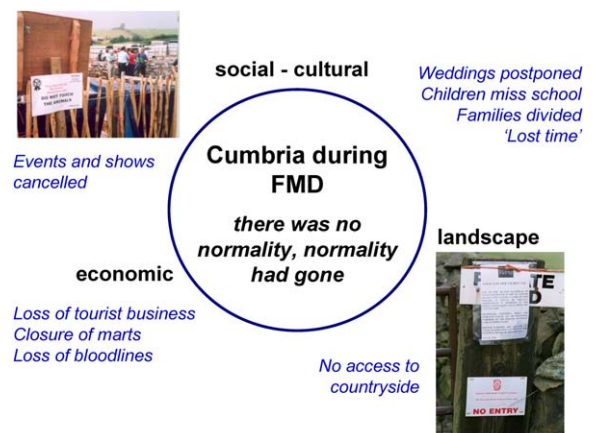


Fig. 1. Altered lifescapes during FMD. The diagram illustrates how the ‘taken for granted’ disruption (events and shows cancelled, weddings postponed) combined with some of the more obvious (stock culls and mart closures) to create a sense that ‘normality has gone’.

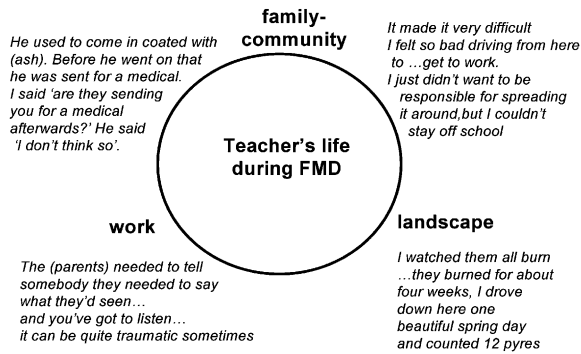


Fig. 2. A teacher's lifescape during FMD, illustrating how different aspects of the lifescape were disrupted during the events of 2001.

consequences, speak of trauma: of flashbacks; of emotional triggers; of life now measured by pre- and post-FMD events; of irretrievable loss; of not 'getting back to normal' because there is now a 'new' normality, lives and communities touched by FMD. Kai Erikson, a sociologist who has been studying the effects of disasters on human communities for the past 30 years, distinguishes between individual and collective trauma. The former he suggests is 'a blow to the psyche that breaks through one's defences suddenly' and the latter, 'a blow to the basic tissues of social life. Trauma damages the texture of community, yet trauma *creates* community, sets the group apart' (Erikson, 1994).

Such individual and collective trauma is spoken of by study respondents:

...there's been bereavement for individuals and communities. You have got to look at a minimum of 2 years to work through it. (Group meeting, February, 2002)

In the next section, we consider how such trauma, fissures in individual and collective lifescapes, may have been exacerbated by a 'clash of knowledge'. On the one hand, time-limited, discrete, theoretical, visible and by implication legitimate, 'professional' knowledge of the 2001 FMD epidemic might suggest that the disaster is over, with little long term, negative health and social impacts. On the other, ongoing, holistic, experiential and often hidden 'citizen' knowledge of the foot and mouth disease epidemic suggests otherwise.

### Everyday geographies of post-disaster processes

Our particular focus here is how our study opened up a 'clash of knowledge', a clash that for many of study respondents, created a 'them and us' scenario between

bureaucratic, authoritative, legislative epidemiology and lay knowledge. A respondent speaks of his understanding of 'knowledge':

Knowledge is passed down generations – it's not learned by somebody coming from nowhere into an office and reading a text book. (diary, June 2003)

Chambers 21st century dictionary definition of knowledge encompasses the experiential and the scientific:

the fact of knowing; awareness; understanding; what one knows; the information one has acquired through learning or experience; learning; the sciences—a branch of knowledge.

..... and somebody has sat down and thought about a logical pattern, which is fine, but biological systems don't work like that. (interview, March 02)

The management, containment and control of the UK 2001 FMD epidemic, seemed to focus upon the disease rather than the local experience of the disease and its management (what was working, where and why?).

It was felt that the Ministry of Agriculture, Fisheries and Food (later to become the Department for Environment, Food and Rural Affairs, DEFRA), the government agency responsible for dealing with the disaster, adopted a centralised, managerial, bureaucratic, rational and utilitarian approach:

... I think I get frustrated with the Ministry's mindset, they have no flexibility, there is no sort of 'what ifs' ... (Interview, March 02)

From a local perspective, this centralised, managerial approach did not appear effective. From early in the epidemic in Cumbria, study respondents suggest that everything was:

...out of control.....

..... Total and absolute confusion.....

I don't think the Ministry knew what they were doing.

I mean the vets that were involved at the time [67 FMD outbreak] are astounded that a lot of the recommendations that were made from the final report in 67 were not adhered to. (Panel Members' interview quotes)

Much of the confusion centred on failure to consult locally:

If somebody from Cumberland had been in charge of the situation they would have known that it wasn't necessary to pay £15 a hour, they could have got somebody for £7. Somebody in London made the decision based on the information they had about London rates of pay. (Group meeting, January 2002)

It was felt that there was lack of communication between central and local operations:

They would speak to somebody connected with the job, but to my knowledge it wasn't anybody in Cumbria, we weren't even told about it, I found out through somebody else.....(interview, March 2002)

and between central and local agencies:

...and they all thought that the [grant aid] money should be there, there and then, and the MPs would say, 'Oh yeah we've released this money', only they hadn't, so it wasn't finalised and we didn't get it, so it took until the end of June...

...we had people ringing in going, "come on where's this money? It said in the papers that there's money and we want it" ... and it was really awkward.

(Group interview with organisation supporting local businesses, February 2002)

The view from the e ground was that there was a lack of contingency planning, exacerbated by a feeling of having no control locally:

....it should have come back to local control, but they wouldn't delegate [...], that should have been devolved down earlier on. The decision should have been made from a local area.

(interview, February 2002, speaking about mapping 'clean' and 'dirty' road routes)

The FMD Cumbria Inquiry suggested that this led to:

There was a strong view that some of the approaches adopted in 2001 had been driven by bureaucratic requirements rather than by common sense. (Cumbria Inquiry Report)

For those experiencing chaos and farce, this led to an erosion of trust in the government handling of the disaster. As Erikson (1991) notes, 'post-disaster, people often come to feel estranged from the rest of society and lose confidence in the structures of government..... voices like those deserve to be listened to carefully'.

A lack of trust was further deepened by the gulf between theoretical and experiential knowledge. Below we offer a brief illustration, in this case the gulf in perception between large pyre disposal operations that were deemed not to pose a public health threat and the everyday view of living with these pyres.

#### *Living the theory*

From the onset of the outbreak, the culling policy led to a huge backlog of carcasses, often left rotting on farms, with subsequent heavy criticism of the government department responsible for managing the crisis. As we have outlined, a conservative estimate of 6 million

livestock were slaughtered. At the peak of the crisis in March 2001, there were 43 outbreaks a day. Each case could present a culling and disposal nightmare. For example on the 28th February the first case was declared in Cumbria, on a farm in the market town of Longtown which had 600 cattle and over 5000 sheep. The disease quickly spread in and around this farming community.

Although not the preferred method of disposing carcasses, pyres were constructed on individual farms. By the 15th March 2001 a local newspaper declared Longtown to be "a smoking, stinking health risk" (News and Star, 2002) and there was much public opposition. The main concerns were the levels of pollution being emitted from the pyres burning for several days, in particular, levels of dioxins being released from both materials used to construct the pyres (e.g. wood, coal, railway sleepers) and the carcasses. Dioxins are naturally occurring chemicals that are formed when biological material is burned and these are known to be carcinogenic (Bell, 2002; Kayajanian, 2001; Olson and Schecter, 1997). There were also concerns about smoke and particulates triggering asthma in susceptible people; the release of prions, the infectious agents that have been linked to BSE and new variant CJD (Roberts, 2002) and creosote from railway sleepers, which releases polycyclic aromatic hydrocarbons (PAH, Allard, et al., 2000) when heated.

Local public health advice and information on potential health impacts of carcass disposal, which was available from the end of March 2001 (North Cumbria District Control of Infection Committee, 2001) suggested that the vast majority of dioxins are ingested via food and that inhalation of additional dioxins via the pyres would be very small. This information also suggested that the risk to public health via prions was likely to be 'remote'. Advice centred on 'keeping windows closed, whilst burning is taking place', and avoiding creosoted materials for pyre construction. As respondents reported, this advice did not seem very practical. How to get to work, to school, to the shops? How to eat in the presence of the acrid smell of putrid and burning flesh? How to carry on with their lives, particularly as an accumulation of several pyres lit over a period of time exacerbated this problem:

I use to wake up in the night and I use to taste that acrid... you didn't seem to be able to get rid of it from the back of your throat. I mean the pyres were suppose to burn for a week and I think they burned for about six to eight weeks. (Interview March 2002)

#### *Professional versus citizen knowledge*

The army under the command of Brigadier Alex Birtwistle, was brought in to organise the ongoing

slaughter and disposal of livestock. On Monday 9th April 2001, the local daily newspaper, 'News and Star' reported that a huge pyre was being constructed on a disused airfield, on the outskirts of Longtown, in North Cumbria, that this was expected to be lit the following day and that 'residents and farmers were shocked by this.' On Thursday 12th April, the same newspaper's front page headline declared: 'People Power Stops The Pyre'. The report continued:

'Longtown fury halts huge fire that would burn all summer. The U-turn came after more than 200 furious local residents attended a public meeting in the town last night to demand that the smoking airfield blaze be extinguished. Up to 1000 animals a day were expected to be burnt all summer on the 500-m pyre, which was lit on Sunday.'

A meeting was called and representatives from the army, MAFF, the Environment Agency and local health services formed an 'expert panel' to respond to the concerns of the public. Residents were angry that they had not been consulted before the plan went ahead (it was suggested that explanatory letters had been sent to local authorities on April 6 and April 10 although this was disputed by a local parish clerk). A member of the 'expert panel' suggested that the risk of dioxins causing harm was just 'one in a million'. A member of the public, described by the 'News and Star' as a 'research scientist and resident' suggested that, 'the fire would belch 60 tonnes of cancer causing sulphur into the atmosphere each day for an estimated 100 days.' The 'expert panel' reported that the burn would consume 1000 tonnes of coal per day—but that they had 'changed' from cheap coal with 25% sulphur content to low sulphur coal of 3%. A member of the public said 30 tonnes of sulphur per day would release 90 tonnes of sulphur dioxide per day. In an area the size of Longtown, this would produce the permitted level in 1 day that is allowed for a maximum of 3 days per annum.

The Government advice on the health impact of pyres which was not forthcoming until the 24th April 2001, suggested that "[o]ptions for involving smaller pyres should be preferred before larger pyres" (Department of Health, 2001b, p. 5).

Study respondents who attended the meeting spoke of a 'them and us' mistrust between the designated 'experts' and members of the public:

And I mean right till the end of the meeting that that carry on was ganna, they weren't going to stop it like. Definitely not till X got up. And he just, he just said, said that Longtown has suffered plenty. ....And all them fires had been burning since March, er beginning of March. ....And they were still burning and er he just, he just says er you he says 'I'm sorry but you know there's no, we've had enough there's going to be no burning'. (interview January 2002)

Another respondent suspects that the 'experts' at Longtown were ill prepared and ill informed because basically:

....they thought Longtown folk were none too intelligent and just expected a load of hysterical housewives banging on about their washing.

As the News and Star article outlines, in this case 'people power' prevailed:

'...a statement was issued by MAFF this morning: "Local residents made clear their strong views about the continuation of the burn. Site activities have been suspended while we pursue the concerns expressed with the parish council."

No further pyres were lit. This then is an illustration of local mobilisation, local expertise and local knowledge forcing its hand. 'Professional expertise' does not always get it right but it may have been easier had there been open dialogue and close partnership decision-making from the beginning. The 'Longtown' resilience, whilst effective arose out of deep mistrust.

## Conclusion

The *Cumbria FMD Inquiry Report* (2002, p. 78) concludes that apart from an increase in subscribing rates for medicines that indicate an increase in respiratory problems (assumed to relate to the smoke from the pyres), that in general, "there does not appear to have been a significant increase in demand on the health services." However, the report does acknowledge that it did find evidence of 'problems with emotional, social and mental health' (78), whilst the then Director of Public Health Medicine in North Cumbria is quoted as saying, that some people 'had too much to bear' (78). Evidence of the scale of this stress was provided by Voluntary Action Cumbria, which, with a team of 8 volunteers manned a 24-hour help-line during the worst of the crisis and by the local offices of the Citizens Advice Bureau (CAB), which provided statistical indicators of the problems experienced by the community. For example in some areas, recorded number of enquiries to CAB was up by 45% on the previous year (78).

As we have discussed, our participatory and longitudinal study also suggests that the 2001 FMD disaster led to a significant amount of trauma at individual and community level; that individuals tended to seek help and support from those 'inside' the disaster, rather than formal health services and that diaries written for the study, some 2 years after the peak of the outbreak, suggest that such trauma may be long lasting. Whilst in some ways diarists write of individual and community



routines and events returning: farms restocking (although this brings a host of problems which we have not space to discuss here, see Convery et al., forthcoming), agricultural shows being resumed, village fetes being organised and people being able to walk the lanes and fields, there is also a sense that this is not so much ‘getting back to normal’ as accepting a ‘new normality’. Every day is now touched by FMD; by a timeline of pre and post-FMD, by what might happen when it strikes again. Such health and social impacts we would thus argue, are now embedded in individual and community lifescapes. It is for this reason that we endorse Brown and Duncan’s (2002, p. 376) view that ‘health needs to be considered in the context of place’. Within rural communities, for new public health to be inclusive, health care needs to be culturally appropriate as recommended in the research report of the Farmers’ Health Project (Burnett and Mort, 2001).

To conclude and addressing our second central concern, ‘how to listen to citizens’ understanding of health?’ we suggest that using participatory methodologies such as citizens’ panels opens up everyday geographies of post-disaster processes and provides rich socio-cultural understandings of health in the context of place. As we have outlined, panel members actively shaped our research findings. Some spoke at a project ‘interim findings’ conference with an audience of government, statutory and voluntary agencies. Some gave written and oral evidence to a local government ‘Overview and Scrutiny Committee’ that is investigating the ongoing environmental and health impacts of FMD in North Cumbria. Others gave media interviews, articulating their understanding of the feasibility of recovery and regeneration policies and their hopes and fears for the future. These ‘voices of experience’ deserve to be heard, alongside those ‘outside’ of the disaster, the professionals who are preparing contingency plans in the event of another similar disaster. In this way critical socio-cultural geographies of health can and should inform ‘new’ public health policy, that which should embrace inclusiveness and partnership, endorse both professional and citizen knowledge of health and situate health concerns in the context of place and more widely, lifescapes.

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