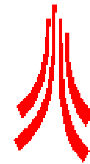
EVIDENCE SUBMITTED TO CUMBRIA FOOT AND MOUTH DISEASE INQUIRY

Submitted by: Institute for Health Research, Lancaster University



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The health and social consequences of the 2001 foot and mouth epidemic in North Cumbria: An action research project

Funded by Dept of Health from November 2001

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1. Summary

The research commissioned independent recruitment of a panel of 54 local citizens, known as the Standing Panel on Foot and Mouth Disease in Cumbria. Evidence is gathered from the panel to generate knowledge of the impact of Foot and Mouth on human health and also help to devise policies that will alleviate potential consequences.

The panel has been recruited to include a broad range of respondents including farmers and their families, workers in related agricultural occupations, those in small businesses including tourism, hotel trades and rural business, health professionals, veterinary practitioners, voluntary organisations and residences living near the disposal sites.

A series of 6 focus groups have been held with panel members meeting in their generic groups to discuss their experiences of the last year. In-depth one-to-one interviews with all panel members have been completed.

Over the course of the project we will be conducting additional interviews with other individuals whose experience will broaden our understanding of the epidemic.

In our longitudinal study, the 54 panel members write weekly diaries, with a combination of structured and unstructured entries. The three researchers make monthly visits to collect the diaries and keep in touch with the respondents. The interview transcripts and diaries collected so far are proving to be a rich source of data and will track the process of recovery over the coming 18 months. The research will last for two years and there will be regular feedback of evidence during the project to practitioners and policymakers.

We are receiving feedback from some respondents about the positive effects of taking part in the research. They have enjoyed the group meetings and they report that keeping the diaries is helping them come to terms with what happened last year. Many of those employed in farming or living in farming communities are going through anniversaries of culls at the moment and this re-experiencing of the crisis will go on for different respondents over the course of the next six months.

We are hearing about frustration, pain and lingering damage caused by the epidemic last year. There are emerging themes that point to the causes of suffering. Within both the farming and business communities there was uncertainty, loss of income, problems with constantly shifting information and advice. A particular distinguishing feature of the crisis is that Cumbrians suffered enduring anxiety from February 2001 through to October.

Diary and interview data, initial findings:

1. **Loss of control over the basic routines of life**
   Severe restrictions put on animal movements
   Changing and conflicting advice from different government departments
   Disruption to the normal calendar of events
   Non-farming businesses radically affected by farming crisis
   Whole population denied recreational use of countryside

2. **Anger and frustration at the way the crisis was handled**
   Sense that local knowledge was ignored, denigrated or misunderstood
   Delays in diagnosis, slaughter and disposal of infected livestock caused deeper crisis
   Failures of communication between local and central agencies
   Erosion of trust in authority

3. **Loss of confidence and self-esteem**
   Rapid declines in business turnover
   Burdens of debt
   Inflexibility and bureaucratic nature of forms of assistance to help business recovery
   Loss of work and income because of location. Businesses in remote and marginal areas suffered more heavily and this was poorly understood

4. **Damage to Social Networks**
   Between farmers who lost stock and those who did not
   Between farming and tourism interests
   Removal of community social activities and contacts
   Many children missed weeks (up to 6 months) of school attendance

5. **Mental Health Indicators**
   Guilt and sadness at not being able to see and support family members (particularly elderly relatives) for most of the year.
   Some respondents show signs of Post Traumatic Stress
   Workers seconded to help on the front line of the crisis now have difficulty coming to terms with the actions they had to take and with reverting to their ordinary role.
   Distraction and loss of concentration
   Mood swings, particularly uncharacteristic anger
   Depression

Through the material collected so far, we already know that Year 1 of the foot and mouth outbreak has caused negative health and social consequences and human suffering. We also know that Year 2 is involving many anniversaries of the culls and other traumas and is proving to be a very disturbing and difficult recovery period. For many Cumbrians, the legacy of Foot and Mouth Disease is set to continue for some time.

2. Ongoing study into the health and social consequences of foot and mouth disease: purpose

The foot-and-mouth epidemic of 2001 has had a major impact on the economic, social and political life of Cumbria[1], and is likely to transform thinking about the structure and organisation of agriculture in Britain. There is a pressing need for an evidence base on the long term social consequences of the epidemic, and in particular the implications for public health, both at individual and community level. The aims of the project are:

- To understand the impact of foot and mouth disease (FMD) on human health and social networks
- To use participatory methods to gather evidence
- To increase awareness of the problems of regeneration
- To facilitate change/new initiatives
- To develop recommendations

3. Context of current study: rural economy

During the last decade, the UK agricultural economy has suffered a significant loss of income. Contributory factors have been the strong pound, an excessive supply of sheep and the B.S.E. beef market crisis. Further, public health scares such as E coli 0157 have undermined public confidence in large scale food production. Rural economies were thus under performing before the onset of FMD. Within Cumbria, the FMD 2001 outbreak has massively damaged livestock farming that was already struggling to survive. This was particularly so in the remoter, upland parts of the county.

Tourism is a key sector of the Cumbrian economy and is often sustained through a close synergy with farming - for example farm accommodation and catering. The virtual closure of the countryside brought much of this tourist industry to a standstill. Distressing media portrayals of burning animal pyres compounded the problem. The real reduction in visitor numbers to rural areas, coupled with predictions of further such losses that become self-fulfilling, has meant hardship and worry for many of those running tourist/visitor oriented businesses. Many village shops and pubs upon which rural communities rely all year round are themselves reliant on visitor trade for their survival. Thus the effects of the FMD outbreak on a 'whole way of life' in Cumbria may have deep and lasting health and social consequences, which need to be understood and monitored in order for policy making to be effective.

4. Context of current study: rural mental health

Walker & Walker (1988) studied the incidence of self-reported symptoms (fatigue, loss of temper, difficulty in relaxing) among Canadian farmers during

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[1] Cumbria 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) and Cumbria County Council has estimated losses to agriculture of about £130 million, and tourism losses of £400 million over one year.

the farm financial crisis in the late 1980s. They found significantly higher incidence among farm women than men, and among younger farmers. In this country, Simkin and others (1988) undertook a questionnaire survey of a random sample of farmers in England and Wales. They found that [the results indicating that - omit]79 per cent had financial worries and 23 per cent reported financial problems. The psychological autopsy approach of Hawton et al (1998) was undertaken in response at that time to concerns about the elevated risk for suicide amongst farmers in England and Wales. Burnett (1992) in a ten-year study of farm accidents in South Lakeland noted an increased rate of accidents during the period of introduction of milk quotas in the mid 1980s and again during the sharp fall in sheep prices in 1989. These difficulties applied particularly to those working small farms. Evidence continues to suggest that rates of psychological morbidity, and suicide and parasuicide, are elevated among farming communities (Watt et al, 1994; Gregoire and Thornicroft, 1998; Booth et al, 2000). The loss of self-esteem and increasing sense of isolation among this group may well contribute to health and social problems. Even before the FMD crisis, the farming press asserted: *Farmers have become isolated, marginalised and misunderstood.* (Farmers' Weekly 1998).

Livestock farmers in particular may be suffering loss of self-esteem as a result of a number of recent agricultural 'shocks' (of which FMD is perhaps the most serious). Their way of life and social identity are called into question. Yet there may be scope for innovative local action, for example as people demand more locally produced food and where local alliances are formed around regeneration initiatives.

The suddenness with which the FMD crisis took hold, and the constant anxiety that one might be 'next in line' for the virus to strike, is likely to have taken a serious toll on the health of farmers and their families. To illustrate graphically what may be involved, one farmer published his daily diary in a regional newspaper (Dumfries Courier), referring to 'an almost physical sensation of a noose tightening', 'an immediate feeling of nausea', and 'the most intense of emotional roller coasters'. Then, when the decision is taken to cull, 'the end of so much and the start of hell', 'the apparatus of death', 'one of the darkest days of my life'. Yet, out of this, some positive thoughts emerge: 'this has been a powerful reminder of how important are family, friends and colleagues…the support we as humans can give to one another has been the one thing that makes any sense and has any value in all this ghastly mess' (Alasdair Houston, Dumfries Courier, April 6th 2001).

5. How our evidence is collected

The project uses a range of methodologies to capture data at both individual and collective levels: diaries, interviews, focus groups and a health assessment questionnaire (EQ – 5D).

Central to the project is a collaborative or participatory style of investigation. This requires those most affected by the issue of concern to help define the issues to be addressed, and to design and assess the action required to mitigate the health and health-related consequences of the FMD crisis.

As a community-based method, we believe that this approach is generating knowledge of these health impacts as well as policies that will help alleviate some of the potential consequences of its aftermath. This style of research contrasts with that of a more conventional epidemiological study that treats its participants as 'objects of study'; instead, it involves a Standing Panel of 54 local people as co-researchers in the project. Within North Cumbria, concerns have been expressed about the health impacts not only on farmers and farm-workers, but also on those affected in a wide range of related occupations. The Standing Panel was thus recruited to reflect both the range of experiences and the spatial dynamics of FMD in North Cumbria (Figures 1 and 2) whilst also achieving a relative demographic balance within the targeted groups, and consists of:

a) farmers, farm-workers and their families;
b) workers in related occupations, including agricultural suppliers, livestock hauliers, auction mart staff, and other groups;
c) those running/working in small businesses, including tourism, hotel trades and other rural businesses;
d) health professionals, including veterinary practitioners;
e) voluntary groups;
f) residents living near disposal sites.

The use of citizens juries and standing panels as a consultative mechanism is well known in health and multi-agency groups[2]. The Standing Panel on FMD addresses these criticisms and it is proposed that the panel also continues to function in some form *beyond* the life of the research project. In this way the research has a developmental role.

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[2] This approach was used by the Principal Investigator and others recently to recruit the Burnley Citizens Jury (Kashefi & Mort 2000) and variations on this procedure have been used by others formulating citizens juries in other contexts (Coote & Lenaghan 1997). But these have been criticised for their lack of 'follow-through' and opportunity for learning (Dowswell et all 1997).

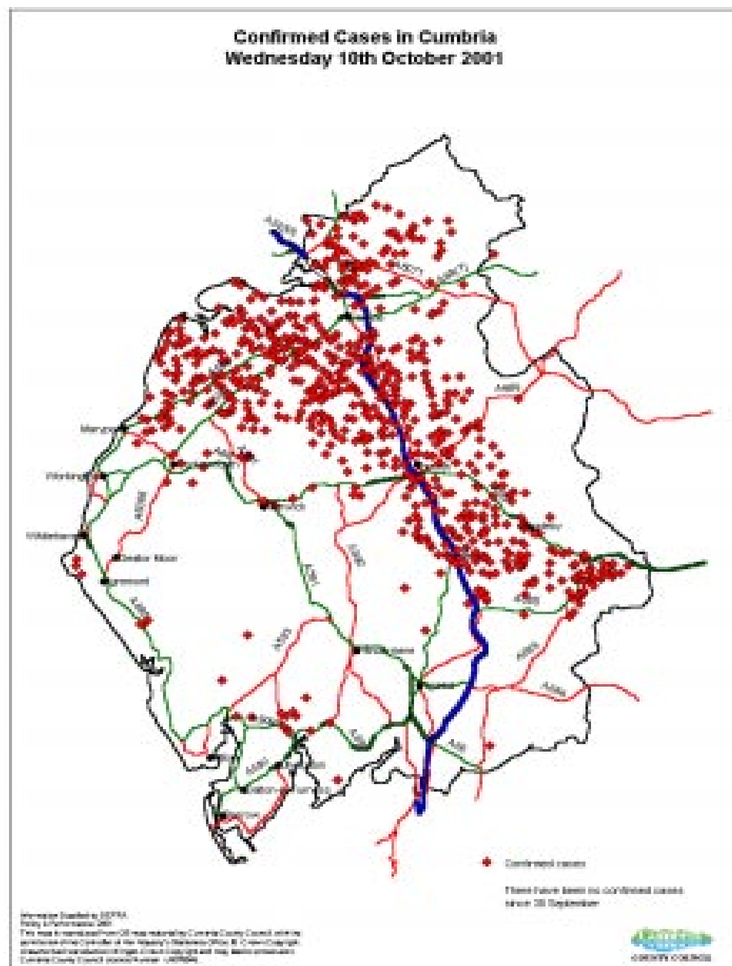

Figure 1

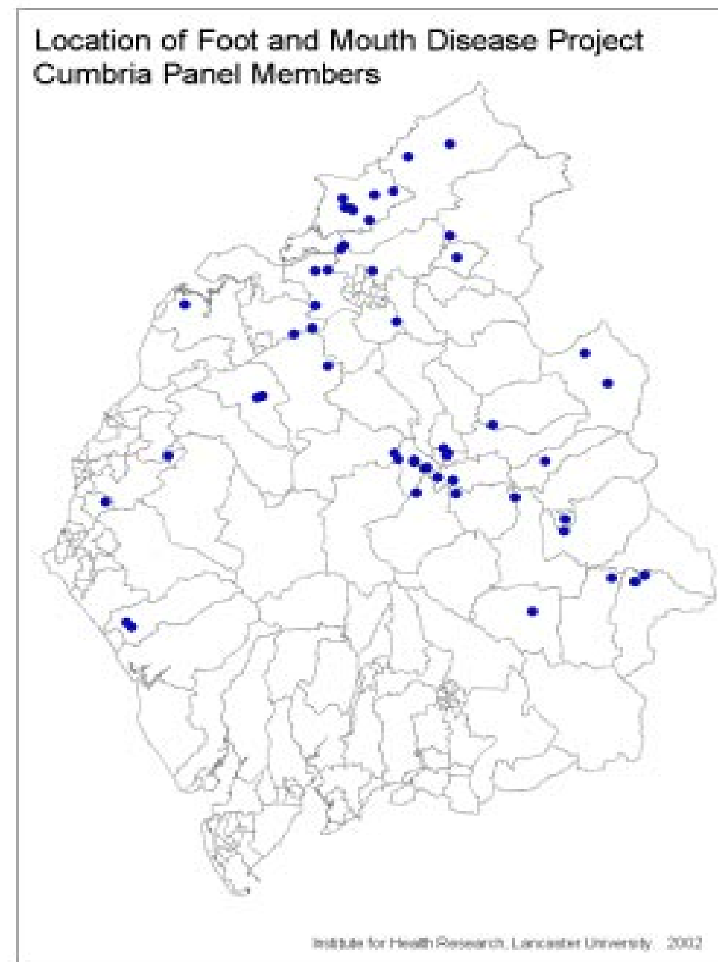

Figure 2

6. Initial Findings

Our research is concerned both with the impact of FMD in 2001 and its ongoing effects and the recovery process through 2002/3. Our findings so far indicate that the scale and severity of the trauma cannot be overestimated. We have conducted more than 54 interviews, held six focus groups and are now reviewing more than 500 weekly diaries. A sample of the human testimonies include:

- The small business set up in farm buildings where the owner was made homeless by the outbreak

- The Defra worker who found his role in the crisis deeply problematic and is now suffering flashbacks from the animal disposal process "…*my reaction was, just thought this is absolute chaos, this is madness, people are …just swimming against the tide here and just jumping into the whole thing without a thought, so I, I firstly became quite detached"*

- The diversified farm which suffered twice, from the cull and the loss of bed & breakfast trade

- The slaughterman who killed 1500 animals per day recalling how best practice had to be sacrificed to the scale of the task *"Like you go to a slaughterhouse everything's set up... You can't make it on a farm eh, not when you're expected to go two minutes, set up, ready, you just can't do it eh?... I dunno. It just sort of got to me like. You used to go to farms and grown men used to come and cry like".*

- The vet who felt that Defra operations were 'top-down' and ignored local veterinary knowledge and expertise

- The vicar counselling farming parishioners by telephone for hours every night as they could not come to church *"In a crisis situation the first thing that you would normally do, as clergy, is go, to be alongside people in their pain and it was the one thing that you couldn't do"*

- The ME sufferer who was effectively 'trapped' in her house near the largest disposal site during the disposal operations.

- The stock valuer/auctioneer who became an informal counsellor to distraught clients, reporting that some are now suffering delayed reactions to events of last year *"We as auctioneers had to learn new skills - we become counsellors as well."*

- The farmer prevented from feeding his condemned sheep for three days.

- The community nurse who felt there was *"a siege mentality in all aspects of life"* (including funerals in the farming community) and who is now

waiting *for "the human health consequences of this animal disease to unfold."*

We are hearing about frustration, pain and lingering damage caused by the epidemic last year. Within both the farming and business communities there was uncertainty, loss of income, problems with constantly shifting information and advice. **Our initial findings indicate that there has been severe and widespread trauma from which recovery, in some cases, may be problematic.**

Psychologically these effects range from unresolved loss and bereavement to **enduring signs of post traumatic stress[3] including nightmares, flashbacks, loss of sleep, anger and guilt feelings**. There is a widespread loss of faith in authority and science, and the emergence of a perceived gulf between central government and local policymakers and practitioners, founded on a sense that **local knowledge was ignored and denigrated by those handling the crisis at the time.** This cultural gap between policy and practice is underpinned by feelings of alienation, loss of dignity and in some cases hopelessness which have accompanied the 'clean-up' following FMD. **A particular distinguishing feature of the crisis is that Cumbrians suffered anxiety from February 2001 through to October**.

While we will publish our work over the course of the next two years, initial findings include:

a) **Loss of control over the basic routines of life**
Severe restrictions put on animal movements
Changing and conflicting advice from different government departments
Disruption to the normal calendar of events
Non-farming businesses radically affected by farming crisis
Whole population denied recreational use of countryside

b) **Anger and frustration at the way the crisis was handled**
Sense that local knowledge was ignored, denigrated or misunderstood
Delays in diagnosis, slaughter and disposal of infected livestock caused deeper crisis *"Heaps of carcasses have laid about for up to a week after slaughter, open to birds and vermin. To see your life's work lying dead in your yards and fields is something no-one can imagine until you see it for yourself."*
Failures of communication between local and central agencies
Erosion of trust in authority

[3] Repetitive, intrusive recollection or re-enactment of the event in memories, daytime imagery or dreams (WHO, 1993)
The development of characteristic symptoms following exposure to an extreme traumatic stressor…including recurrent and intrusive images, thoughts or perceptions about the event... American Psychiatric Association (1994)
Collective trauma is a 'blow to the basic tissues of social life that damages the bonds attaching people together and impairs the prevailing sense of communality
(Turnbull (1998, Traumatic Stress Treatment Unit, Sussex)

c) Loss of confidence and self-esteem

Rapid declines in business turnover
Burdens of debt
Inflexibility and bureaucratic nature of forms of assistance to help business recovery
Loss of work and income because of location. Businesses in remote and marginal areas suffered more heavily and this was poorly understood

d) Damage to social networks

Between farmers who lost stock and those who did not
Between farming and tourism interests
Removal of community social activities and contacts
Whole community affected *"At the time it's so intense…when the cull happened to our neighbours in the village we were all out in the street crying, we were just crying".*
Many children missed weeks (up to 6 months) of school attendance

e) Mental health indicators

Guilt and sadness at not being able to see and support family members (particularly elderly relatives) for most of the year.
Some respondents show signs of Post Traumatic Stress Disorder
Workers seconded to help on the front line of the crisis. now have difficulty coming to terms with the actions they had to take and with reverting to their ordinary role "*it's taken me months to fit back into my job, I still don't feel like I have properly"* and *"I was off work with depression afterwards, I still haven't really fitted back into work."*
Distraction and loss of concentration
Mood swings, particularly uncharacteristic anger
Depression
Feelings of isolation *"…because you were a slaughterman…nobody would want to know you, I didn't want to go back (to a culled farm), I didn't want to go even up the road."*

Through the material collected so far, we already know that year 1 of the FMD outbreak has caused negative health and social consequences and human suffering. We also know that year 2 is involving many anniversaries of the culls and other traumas and is proving to be a very disturbing and difficult recovery period. For many Cumbrians, the legacy of MD is set to continue for some time.

7. Research Team

The team consists of four research staff all of whom are based at the Institute for Health Research: Dr. Maggie Mort (Principal Investigator); Mr. Ian Convery; Ms. Josephine Baxter & Dr. Cathy Bailey, supported by the Institute Director, Prof. Tony Gatrell and Dr. Peter Tiplady, Director of Public Health, North Cumbria Health Authority. For further information about the project please contact Ian Convery (i.convery@lancaster.ac.uk)

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