

The health and social consequences of the 2001 Foot and Mouth Disease epidemic in North Cumbria: an action research project.



(Project 121/7499)

Dr Maggie Mort, Institute for Health Research, Lancaster University

Annual Report 2002

The project commenced in November 2001 and is due to be completed on 31.01.04. As set out in the project bid, the key tasks for Year 1 were:

- recruitment of research staff;
- develop literature review;
- constitute and convene the project Advisory Group
- agree demographic profile of the Standing Panel
- obtain relevant ethical approval
- recruitment of the research panel (54 respondents)
- design the project diary to be completed by respondents
- carry out data collection: first round of 6 focus groups; 54 individual interviews diaries; distribute/collect EQ 5D
- set up regular project newsletter for panel members
- maintain diary keeping
- convene a meeting of the Action Group/ appropriate service responders
- commence data analysis using inductive methods.

1. Recruitment of research staff

The project was fortunate to be able to make an immediate start on the research since one of the bid's co-applicants was already in post, completing an existing project. It required only that a new contract be drawn up for Ian Convery to work full time on the research. Advertisements were placed for the second researcher, or for a job share between two part-time researchers. These generated a high level of interest - the university received 60 applications, so shortlisting and interviewing was time consuming. We were very fortunate to be able to recruit Dr Cathy Bailey and Mrs Josephine Baxter on a job sharing arrangement; both have highly relevant and complementary skills. They took up posts in January 2002.

2. Literature Review

This is ongoing, but was carried out intensively during the first three months of the contract, mostly by Ian Convery. The review is wide ranging and covers a) ongoing review of diary based methodologies in health research; b) history of FMD in the UK; c) all local and government sponsored inquiries; d) disaster studies; e) clinical literature on trauma and PTSD; f) rural health issues. A small sample of the areas of literature reviewed to date is given below:

Methodological Literature

Elliot, (1997) 'The Use of Diaries in Sociological Research on Health Experience'
Sociological Research Online, vol. 2, no. 2.

Rogghmann, K.J. & Haggerty, R.J. (1972). The Diary as a Health Research Instrument in the Study of Health and Illness Behaviour. *Medical Care*, Vol X, No. 3, p143-161.

Disasters literature

Erikson, K. (1976) *In the Wake of the Flood*. George Unwin and Allen, London, UK.

Alexander, D.A. & Wells, A. (1991) Reactions of Police Officers to Body-Handling after a Major Disaster, A Before and After Comparison. *British Journal of Psychiatry*, 159, 547-555.

Clinical literature

Turnbull, G.J. (1998) A review of post-traumatic stress disorder. Part I: Historical development and classification. *Injury*, 9, 87-91.

McFarlane, A.C. (2000). Posttraumatic stress disorder: a model of the longitudinal course and the role of risk factors. *Journal of Clinical Psychiatry*, 61 Supplement 5, 15-20.

3. Project Advisory Group

The project Advisory Group is chaired by Dr Peter Tiplady, former Director of Public Health for North Cumbria Health Authority, now Consultant in Public Health at the Strategic Health Authority (a full set of minutes is available). It meets 3 monthly to review progress and is composed of representatives from key agencies involved both in the management of FMD and post-FMD recovery in Cumbria, including representatives of the agencies listed opposite:

- Cumbria County Council
- Rural Development Service
- Business Link for Cumbria
- Environment Agency
- North Cumbria Health Authority
- Voluntary Action Cumbria
- DEFRA
- Northwest Development Agency
- NFU North West Region
- Primary Care Trusts
- GPs – Health Professionals
- Veterinary practices

Four meetings have been held to date, in November 2001, February 2001, May 2002 and November 2002 all in Penrith. In addition an Action Group was held on 20 March 2002 to discuss ways of developing service (statutory and non-statutory) responses to findings which emerge from the study. Further meetings are planned.

4. Agreeing composition of the standing panel

The task of the first meeting (30.11.01) of the Advisory Group was to agree the demographic profile of the standing panel to be recruited to the study. The panel of 54 citizens was to be composed from 6 groupings, the nature of which were finalised at the meeting.

Group 1	Farmers, farm-workers and their families
Group 2	Small businesses , including tourism, arts and crafts, retail and others.
Group 3	Related agricultural workers including livestock hauliers, agricultural contractors and auction mart staff
Group 4	Front line workers , including DEFRA, Environment Agency, slaughter team
Group 5	Community , including teachers, the clergy, residents near disposal sites
Group 6	Health professionals , including, GPs, community nurses & veterinary practitioners

A more detailed profile for each group was developed, an example of which is given below:

Group 2: Micro businesses¹

	Arts and crafts Riding schools, photographers, film makers, pottery businesses	Hospitality Including hotels, guest houses, public houses, restaurants, taxi firms, coach firms and caravan parks	Retail Tearooms, cycle shops, antique shops, village shops, bookshops, etc.
Age	If possible one member of the group should have been in business during the 1967 FMD outbreak (this may be difficult to achieve). Of the other group members, at least 4 members should have school age children. Composition of the group should reflect the demographic profile of Cumbria in terms of age structure (will advise further)		
Sex	Preferably 4 males and 4 females		
Sector	Three members from each of the sub-sector groups indicated above		
Location	2 from Southern N. Cumbria; 2 from North Cumbria (Longtown area), 2 from Eastern North Cumbria; 2 from Penrith Eden Valley area. It is also important to differentiate in terms of relative location, for example, remote rural (located in very remote area served by limited road network) accessible rural (rural area with good road network, proximity to major roads, etc.) and urban (towns such as Penrith)		

5. Obtaining Ethical Approval

An application was made to East Cumbria Local Research Ethic Committee as soon as funding was agreed, and approval was formally received on 18 January 2002. This LREC notified us that an arrangement was made with the neighbouring West Cumbria LREC that approvals would cover each committee's jurisdiction in North Cumbria. A further approval was later gained for a different aspect of the study related to the EuroQol (see below).

¹ This group profile purposefully did not include the land based sector (nurseries, agricultural engineers, agricultural hauliers, timber hauliers, etc) or agricultural transport sector (livestock hauliers) as these sectors of the economy were included in the Agricultural Related Group 3

6. Recruitment of the Panel

The group profiles were then sent to a professional recruiter, Mrs Irene Evans, whose task was to identify individuals to 'fit' the profiles and thereby make up each of the groups in order, starting with farmers, farm workers and their families. The resulting whole panel profile is below:

Diarist Number	Sex	Age	Occupation	Group Number
54	M	58	Farm owner (stock culled, infected premises) ²	Group 1
53	M	49	Farm owner (stock culled, infected premises)	
52	M	32	Farm owner (<i>form D</i> restricted) ³	
51	F	43	Farmers wife (contiguous cull) ⁴	
50	F	24	Farm labourer (contiguous cull)	
49	F	44	Farmers wife (stock culled, infected premises)	
48	F	53	Farmers wife (<i>form D</i> restricted)	
47	M	45	Farm owner (contiguous cull)	
46	M	51	Farm labourer (stock culled, infected premises)	
45	F	57	Pottery business owner	Group 2
43	F	40	Camping – caravan business owner	
42	M	54	Photographer	
41	M	31	Partner in outdoor shop	
40	M	57	Gift shop owner	
39	F	41	Bed & breakfast business owner	
38	F	58	Bed & breakfast /self-catering accommodation owner	
37	M	36	Crafts business owner	
36	M	61	Dairy tanker driver	Group 3
35	F	42	Agricultural sales assistant	
34	M	37	Agricultural contractor	
33	F	54	Partner in farm supplies business	
32	M	38	Deputy manager, livestock haulage company	
31	F	45	Auction mart worker (non-managerial)	
30	M	37	Livestock manager, auction mart	
29	M	67	General manager, farm supplies business	
28	M	33	Slaughter team worker	
27	F	50	Partner in an A.I company	
44	M	39	Environment Agency (seconded to DEFRA)	Group 4
26	M	30	DEFRA surveillance	
25	F	57	DEFRA field officer	
24	M	42	Environment Agency (seconded to DEFRA)	
23	M	36	DEFRA field officer	
22	F	40	DEFRA field officer	
21	M	30	DEFRA field officer	
20	M	56	Marksman	
19	M	48	Livestock haulage worker	
18	F	47	School secretary	Group 5
17	M	65	Rural vicar	
16	M	50	Rural vicar	

² Infected premises (IP); stock identified as being infected with foot and mouth disease and culled.

³ Stock movements restricted by DEFRA *form D*.

⁴ Stock culled as part of DEFRA contiguous cull programme (farm was bordering an IP).

15	F	52	Infant school teacher	
14	F	37	Disposal site resident	
13	M	54	Disposal site resident	
12	F	42	Disposal site resident	
11	M	58	Disposal site resident	
10	M	64	Disposal site resident	
9	F	20	Disposal site resident	
55	F	41	Disposal site resident	
8	M	38	Veterinary surgeon	Group 6
7	F	37	Veterinary practice manager	
6	F	32	General Practice nurse	
5	F	51	Health visitor	
4	F	49	Health centre manager	
3	F	35	Vet	
2	M	26	Vet	
1	M	36	General Practitioner	
56	F	45	District nursing sister	

7. Data Collection

The project diary is the principal research tool. A pilot diary was previously administered with a small group of volunteers, who were asked for comments on its comprehensibility and usability. Consultations were also held with colleagues including Dr Tiplady and Prof Gatrell over the design of this instrument. The most important issues were a) to achieve the appropriate balance between the structured and the unstructured components of the diary, and b) to encourage those who may not be used to writing diaries, whilst not deterring those more experienced writers. In addition the design should allow the collection of similar material for comparison, whilst allowing for individual expression.

The first focus group, held with Group 1, took place on 21 December 2001 and the discussion was taped and transcribed, marking the formal beginning of data collection. Each panel member signed a formal project consent form at this stage. Diaries were distributed at this meeting, and at all subsequent focus group meetings over the next 6 weeks. Diary writing therefore began for Group 1 in Christmas week 2001.

Each focus group was swiftly followed by semi-structured interviews with those respondents. The table below indicates the total data collected by the project between December 2001 – December 2002. In total 6 focus group meetings were held with each group of the panel between December 2001 and February 2002. To date, a total of 2,637 weekly diaries have been collected. (8 'one-off' interviews have also been conducted with other key informants)

	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6
Focus Groups	1	1	1	1	1	1
Interviews	9	8	10	9	11	9
Weekly diaries	500	408	458	432	425	414
EQ 5D	14	8	12	6	11	7

The EuroQol 5D This instrument was included in the study design to provide a possible comparison with existing EQ 5D returns on the general health status of Cumbria, held by the North Cumbria Public Health Unit. Consent was obtained from each panel member to participate in the EQ 5D. We also obtained additional approval from LREC on 10/07/02 to broaden the sample to include a family member or close friend within the respondent's community. This sample forms the EQ 5D 'FMD Group', about which all relevant demographic data is available, and investigation has started to compare returns with existing population data. Collection of these forms is ongoing.

Maintaining diary keeping - there has been a high level of participation in diary writing (2,637 diaries so far). We believe this level is partly due to the monthly visits made to respondents by the research team, who maintain contact with 18 respondents each. Diaries are collected, the small payments/vouchers agreed are made, and contact with the project is maintained through informal discussion. It is felt that the success of the project depends to a great extent on these regular contacts.

8. Project newsletter

The aim of this is to keep panel members in touch with the project and to give them space to make their own contributions or comments on items they think are relevant to the research, in line with action research philosophy. The newsletter is called 'The Diarist', and 5 issues have been produced so far.

The Diarist

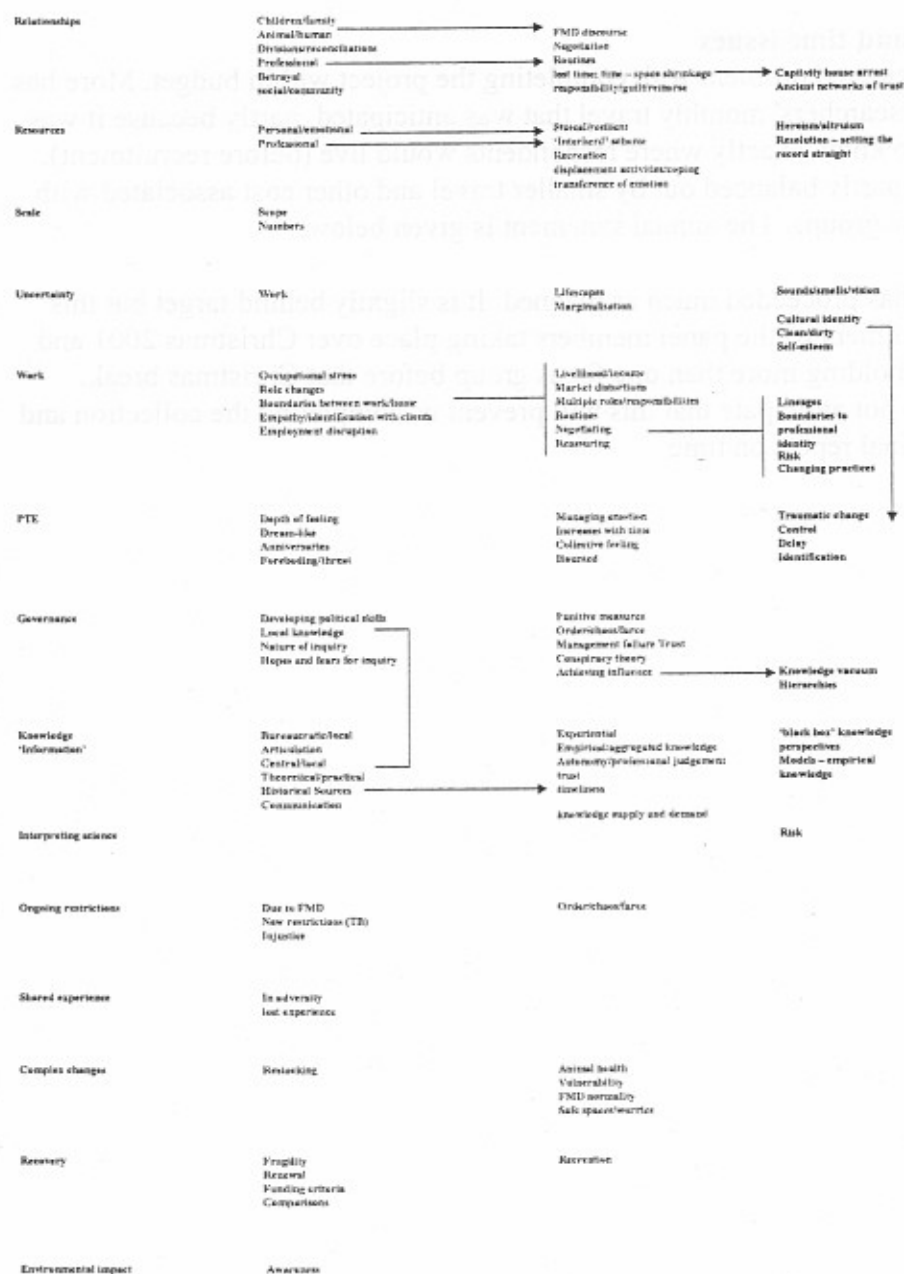
No.3 May 2001

Newsletter of the Standing Panel
on the Health & Social Consequences of Foot & Mouth
Disease

Good News for Milburn School

Last year the children of Milburn Primary School in the East of the county produced a number of large pastel drawings showing how Foot and Mouth affected their lives. They put these beautiful drawings together with poems to produce a book called 'No matter what...' As spring arrived this year, the children produced life-sized sculptures of a ewe and lamb to stand 'sentinel' on the green outside their school...





9. Data Analysis

All interviews and focus group meetings held during Year 1 have been transcribed from audiotape. Diaries have been transcribed from their original (usually hand written) format. In addition to personal reading and initial coding of material 4 all-day 'data clinics' have been held with all 4 members of the team to subject the data to constant comparison and identify emerging themes from the research material. The data is held in ATLAS Ti software, and once the themes are refined following more such clinics, and agreement that 'saturation' has been reached according to the principles of grounded theory, coding using this software will be undertaken. Computer based coding is expected to commence within the next six weeks. NB, the illustration above shows how themes have begun to emerge, which will be subject to further refinement through this process.

10. Budgetary and time issues

There is no anticipated problem with completing the project within budget. More has been spent on researchers' monthly travel that was anticipated, partly because it was never possible to know exactly where respondents would live (before recruitment). However this is partly balanced out by smaller travel and other cost associated with holding the focus groups. The annual statement is given below.

Data collection has proceeded much as planned. It is slightly behind target but this was due to recruitment of the panel members taking place over Christmas 2001 and the difficulty of holding more than one focus group before that Christmas break. However, we do not anticipate that this will prevent us completing the collection and submitting our final report on time.