



VOICES OF EXPERIENCE – Life after FMD Carlisle Racecourse 14/10/03

The Project: The Health and Social Consequences of the 2001 FMD Epidemic

This longitudinal research project has been funded by the Department of Health. It is primarily a diary based study and has resulted in a body of material including 3,800 weekly diaries written by the project's *Standing Panel* of 54 local people. Panel Members are the 'experts' and have told us about the impact that foot and mouth disease has had on their lives. They include farmers and their families, workers in related agricultural occupations, those in small businesses including tourism, rural accommodation and rural business, health professionals, veterinary practitioners, voluntary organisations and residents living near disposal sites. This 28 month study has been guided by an advisory group (see below), and we provide regular feedback to policy makers and service providers in order to contribute to service development. We have also submitted oral and written evidence to the 'Cumbria Foot and Mouth Disease Inquiry' and to the EU Parliamentary Committee on Foot and Mouth Disease.

Project Advisory Group

The group is chaired by Dr Peter Tiplady, formerly Director of Public Health for North Cumbria Health Authority, then Consultant in Public Health at the Strategic Health Authority (he is now retired). 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

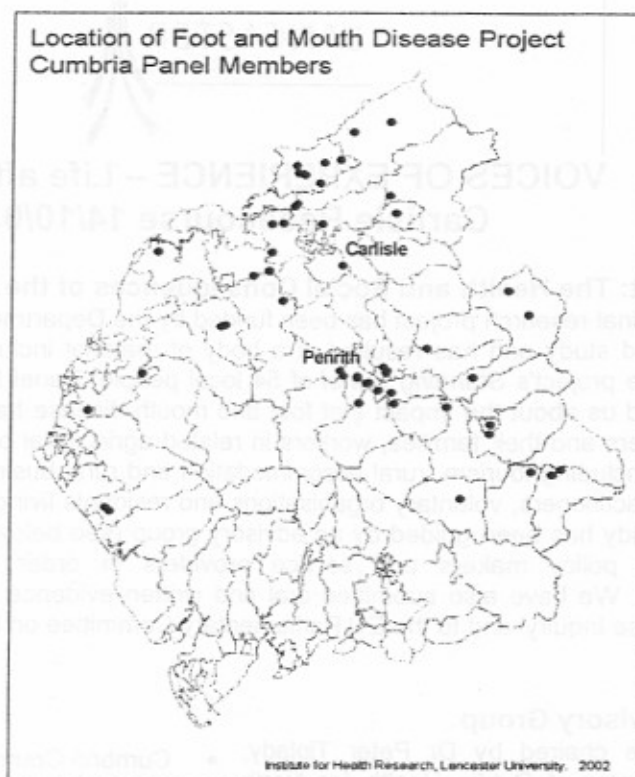
An important function of the Advisory Group was to agree the demographic profile of the Standing Panel (e.g. age, sex, main job, place of residence). An independent professional recruiter then sought individuals who matched this agreed profile.

The Standing Panel

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|---------|--|
| 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, incl GPs, community nurses & veterinary practitioners |

Most of the Standing Panel live in North Cumbria:

Location of Panel Members



Collecting the data

The underlying premise for this was that people who can best describe the health and social consequences of the 2001 FMD epidemic are those who lived through it. We need this understanding of local lived reality of an event in order to inform effective recovery policy and sustain it; so that this may be based on local knowledge, which may grow and change over time.

During 18 months (from late 2001 to early 2003), Panel Members recorded in weekly diaries material about their every day lives, about the impact of the disaster on day to day working, about the recovery process and about their health and well being and that of their families. This required enormous commitment and project researchers' made monthly visits to members to collect the diaries and to maintain contact. Each member also gave us a face-to-face interview at the beginning of the project, so we could capture as far as possible, their view of events before the diary phase started. The whole project was introduced to the members at initial group meetings and later when the diary phase was ending, interim findings were presented at a second round of group meetings. Members also completed a structured health assessment questionnaire (EQ – 5D¹). Systems were put in place to maintain confidentiality.

¹ EQ – 5D is a simple generic measure designed to measure health outcome. The questionnaire generates a health profile which can be compared to existing datasets and used in the clinical and economic evaluation of health

Analysing the material

All material whether sound or written has been transcribed and anonymised. Diaries have been transcribed from their original (usually hand written) format. This forms a very large, unique longitudinal data set which is the basis for the development of analytical themes which we are in the final stages of refining. All the anonymised material has been carefully sifted, compared and discussed in regular 'data clinics', according to structured methods long accepted in social science and is stored in the software programme Atlas Ti for easy retrieval. The result is a 'map' (see attached) of relationships expressed in codes which all come to relate to four major themes:

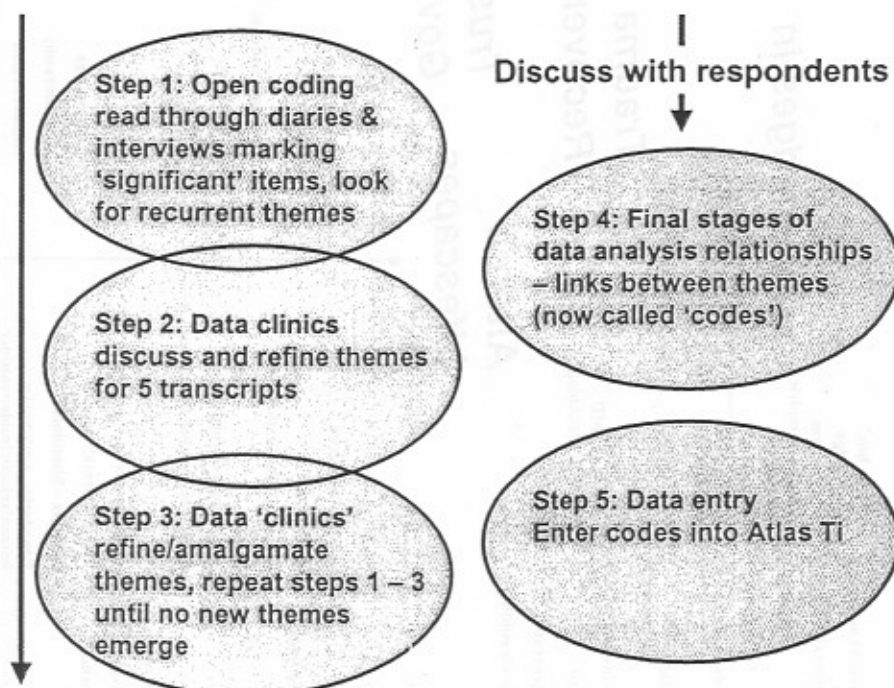
- Altered Lifescapes
- Trauma and Recovery
- Knowledges in Context
- Trust in Governance

For example, the theme 'Knowledges in Context', covers wide ranging aspects of 'knowledge' of foot and mouth:

- 'citizen' and 'expert' knowledge;
- veterinary science and bureaucratic management of the FMD virus;
- the 'distant' aggregated knowledge of epidemiologists and the 'local' particular 'hands-on' knowledge of workers on the ground

It also highlights how failure to bring together many different sorts of knowledge about the FMD outbreaks led to feelings that local knowledge was ignored, denigrated or misunderstood; this theme also includes problems of communication between local and central agencies and a gradual erosion of trust in authority.

The diagram below simplifies our intense process of data analysis.



Throughout the conference we and some of the project respondents will expand on the four major themes, our interim findings. If you would like further information please do not hesitate to contact us at a later stage:

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