Community Experiences of the 2001 Foot and Mouth Disease Epidemic in North Cumbria: An Archiving Story

Cathy Bailey\textsuperscript{a}, Josephine Baxter\textsuperscript{a}, Maggie Mort\textsuperscript{a} and Ian Convery\textsuperscript{b}

\textsuperscript{a}Institute for Health Research, Lancaster University
\textsuperscript{b}School of Natural Resources, Lancaster University

Abstract

This paper recounts our experiences of archiving a large, sensitive, mixed method data set which produced both textual and audio material. In 2001 we began a 30 month, Department of Health funded research project into the health and social consequences of the 2001 Foot and Mouth Disease (FMD) epidemic in North Cumbria. The project generated a large dataset, over 3,000 weekly diaries and 70 recorded interviews. We offer our rationale for archiving this dataset. We describe how we set about seeking respondent consent for archiving. Finally we discuss our archiving process in relation to two overlapping issues that have well debated implications for the broader acceptance and take up of qualitative data sharing and re-use; that of anonymity and defining and capturing data context.

Introduction

‗I think what with my job and where I live, it would be easy for some to identify me‘.

(Study respondent)

‗If you strip out the detail, people, places, events, you‘ll lose the meaning‘.

(Research colleague)

The two opening comments go to the heart of the ethical and practical dilemmas we faced when setting out to archive a large, sensitive, mixed method data set containing both textual and audio material. We wanted to work closely with research respondents, sharing decisions and attempting to solve archiving problems. We wished to adopt a framework for archiving practices that promotes ethical provision and use of data resources. We sought to do this for two reasons. Firstly to address issues about confidentiality, ownership, access, use and collaboration that the provision of data resources for social sciences raises. Secondly, to begin to consider the implications of data sharing for the character and direction of knowledge production from within [the?] social sciences, our work has resonance for the Economic and Social Research Council‘s (ESRC) 2005, ‘Qualitative Archiving and Data Sharing Scheme‘ (QUADS 2006) and its earlier 2001 Research Methods Programme (RMP 2006).
In this paper we reflect upon our archiving experiences. We briefly introduce our study and discuss the impetus for archiving. We reflect upon our approach and detail how we set about seeking consent for archiving from respondents. Finally we discuss our archiving process in relation to two overlapping issues that have well debated implications for the broader acceptance and take up of qualitative data sharing and re-use: that of anonymity and defining and capturing data context.

The Study

In 2001 we began a 30 month, Department of Health (DoH) funded research study into the health and social consequences of the 2001 Foot and Mouth Disease (FMD) epidemic in North Cumbria. The FMD epidemic was probably the biggest rural disaster since the Second World War (‘a traumatic and devastating experience for all those who were affected by it. It was a national crisis and was probably one of the greatest social upheavals since the war’). Government control policy required the slaughter and disposal of susceptible animals from infected farms and from farms considered to have been exposed to infection.

Cumbria, suffered by far the greatest number of FMD cases in the UK. The Cumbria Foot and Mouth Disease Inquiry Report (2002) outlines three devastating impacts on the county. Firstly, a countrywide ban on livestock movements and widespread restrictions on public access to the countryside crippled a county with an economy in which livestock husbandry, outdoor recreation and tourism all play a major role. Secondly, the Report highlights the massive scale of the slaughter and disposal of livestock and other animals. Some 45% of Cumbria’s farm holdings suffered complete or partial culls and in the north of the county where the epidemic was most severe, this rose to 70% (Cumbria Foot and Mouth Disease Inquiry Report, 2002). Lastly the Report captures dissent at the Government’s handling of the epidemic: ‘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.’

The impacts of the UK 2001 FMD disaster thus rippled out beyond farming households, affecting all aspects of rural businesses, rural recreation and rural life. The study was designed in order to reflect this range of local experience and expertise linked to FMD (including farmers, small businesses, slaughter and disposal workers, vets, health workers, the clergy and residents living near disposal sites) and 54 respondents were recruited. Between December 2001 and June 2003, respondents wrote weekly diaries and the free text varies in length from a paragraph to six sides of A4. Respondents also took part in an in-depth interview at the start of the study and participated in a series of group discussions, the first before diary keeping began and the second to close the data collection. We also conducted interviews with personnel from key agencies involved in managing the UK 2001 FMD epidemic. There was low attrition with 50 out of 54 respondents completing 18 months of diary keeping and the study thus generated a large dataset, over 3,000 weekly diaries and 70 recorded interviews.

We could not have predicted either the quantity or the quality of the data we have received. This became a detailed record of recollections of the UK 2001 FMD disaster in Cumbria and of the subsequent 18 months of everyday work and home life. The dataset offers immediacy of contact with this event and eventually should constitute unique, prime and everyday historical evidence. Moreover and echoing the work of the social research organisation, Mass-Observation, it may offer rich insight into Cumbrian rural life at the beginning of the 21st century.

Archiving – the impetus

Our decision to archive was retrospective and not built in to the original study funding. Following an informal research seminar at Lancaster, colleagues expressed a conviction that the data should be archived; subsequent informal discussions with the study’s respondents and advisory group were favourable.
Moreover we found parallels between the invisible aspects of the FMD epidemic and the unseen areas of the research data. For instance, it is known that the north of the county had 893 cases of confirmed infection; it is less well known that there were in addition over 1900 other farms culled collaterally. In terms of our study data, the necessary focus of our final report to the DoH meant that we could not fully reflect the breadth of the huge data set collected. By archiving we could preserve and use the fullest possible collection of the research material.

We were already aware of the ongoing sensitivity of the subject and material collected. Our concerns were reinforced after we attended a meeting in January 2004 convened by a regional arts organisation seeking to bring together a cultural exhibition documenting, through different media (e.g. photographs, video installations, poetry, stories), human experiences of the 2001 FMD epidemic. This took place at ‘Watchtree Nature Reserve’, a disused Cumbrian airfield that became an enormous FMD animal burial site and is now being developed as a nature reserve. The proposed exhibition would tour major cities in order to share with predominantly urban audiences, the events of 2001 that were played out in rural communities throughout the UK. This meeting attracted a wide mix of interested parties, artists, writers, photographers, journalists as well as representatives from the local community, farming unions, farmers and others who had first hand experiences to draw on. A slide presentation revived some of the graphic horrors of culled animals on burning pyres, as well as the sense of invasion that many farms and rural communities suffered as a result of slaughter and disposal policies, ‘clean up’ and bio-security measures.

It quickly became apparent that such images triggered memories of traumatic and personal events for some at the meeting, and during the discussion that followed it was clear that there was some reluctance to sanction the exhibition.

These involuntary responses to external imagery and writing were also evident in diaries throughout our research study: a study respondent refers to an exhibition in Carlisle which included a Damien Hirst calf in formalin:

Work then went to see art exhibition @ Tullie House re livestock. Good exhibition except the calf! Very inappropriate to bring it to Carlisle after FMD. Reminded me of the calves we used to see in their mother’s bodies when their abdomens split open on the pyre. Felt sad.

A respondent who lived near a disposal site records in her diary that she has bought a book collecting together experiences from 2001 in Cumbria (Heart and Soul, ed Caz Graham)

Started reading Heart and Soul last week, I haven’t read much of it, couldn’t see for the tears

Another who lost all her stock in April 2001 records in January 2002

Bought the book “Heart and Soul” from Radio Cumbria. Read a few chapters before bedtime, difficult to put it down but eventually went to bed, could not sleep. All those F&M memories came flooding back.

These extracts help to contextualise the sensitive nature of much of our dataset and why we chose to develop a collaborative and democratic archiving process. Below we reflect on our approach to archiving.

**How to Archive? – Our Approach**

The Economic & Social Research Council’s Green Paper (ESRC 2001) on data policy and data archiving notes that the terms and conditions on which data is made available for deposit and on which it can be accessed and used, are crucial to an effective and responsible archiving provision. There are for example real concerns that
deposition may lead to a breach of confidentiality or that research respondents may not have been given adequate information to give informed consent. This is of particular concern where study respondents have provided highly personal information. There are also the concerns of qualitative researchers, many of these to do with data being ‘re-used’ out of its original context. Paul Thompson (2000) in a personal account of re-using qualitative research data suggests that ‘. . . [t]here is a strange silence close to the heart of the qualitative community. . . ’ (Thompson 2000:1) and that this is to do with a resistance to re-using qualitative data created by other researchers:

Quite often through our work at Qualidata we encounter sociologists who seem almost bonded to their own ethnographic fieldwork notebooks or interviews, feeling that nobody but themselves could interpret them sufficiently well or share the intimate understandings that they have of their informants.

(Thompson 2000: 2)

Qualidata, the ESRC Qualitative Data Archival Resource Centre, was set up in the UK in 1994 at Essex University to, ‘. . . facilitate and document the archiving of qualitative data arising from research, whilst also drawing the research communities' attention to its existence and potential.’ (Corti :1). The present Director of Qualidata, Louie Corti (Corti and Backhouse 2000) suggests that in the early days of Qualidata, there wasn’t a culture of secondary analysis of qualitative data with a concomitant low demand for social science data. However she also highlights that by the late 1990s, there was a notable cultural shift in this respect. In part she attributes this to the work of Qualidata in promoting the preservation, sharing and re-use of qualitative data and in part, to the ESRC Datasets Policy implemented in 1996. This contractually requires all award holders to offer their data for deposit. Corti and Backhouse (2000) also note that other UK research sponsors: the Wellcome Trust, the Joseph Rowntree Foundation and the Nuffield Foundation refer new grant holders to Qualidata for archival advice.

We thus negotiated a computer readable data archive to be held by Qualidata. We also felt that it was crucial to store paper transcripts, paper diaries and audio CDs of interview material, within a local archive in order to ensure their long-term safekeeping and preservation; enable local access and to promote archives as valuable community resources. The Centre for North West Regional Studies, in conjunction with the Rare Book Archive based in Lancaster University Library have accepted this archive. Whilst it is important to develop technologies for sharing distributed and heterogeneous data resources, there should also be scope for the preservation of local and regional archives.

**Seeking consent to archive**

The work of Qualidata and the archiving requirements of research councils made us think of the need for open and honest discussion about the process of seeking informed consent. A search of relevant literature and conversations with the study respondents, researchers, a copyright specialist and archivists, exposed key depositor and user issues including anonymity and confidentiality; immediate access to materials or an embargo; ownership and copyright and use of materials and making copies.

To help us draft terms of agreement with sets of statements that would give the respondents a series of options for how they wished their diaries, copies of their diaries, or portion of their diaries and/or their audio material (CDs) to be archived, we sought expert advice from a copyright specialist. In this way we drafted a depositor consent form for the diary material and a depositor consent form for the audio material. Through a study newsletter, we also gave respondents regular updates of our progress and detailed information on archiving.

Some of the data collected during the study recounts traumatic events at individual and community level (Convery et al 2005). Our longitudinal methodology fostered strong and trusting relationships between research fieldworkers and respondents. Each of the three fieldworkers visited on average 18 households on a monthly
basis, to collect and deliver diaries and to give the small diary keeping payment to the research respondents. Respondents approached the study in different ways, sometimes finding one method of communication suited them better than others. Some who in interview indicated that they had been severely affected by the events of 2001 rarely mentioned these in their diary, one for instance never used the words cull or kill, referring only to ‘that day’; others, living near disposal sites for instance, articulated in their diaries continuing concerns directly related to the long term effects of FMD.

There are ethical considerations relating to intensive longitudinal methods and in particular, repeated visits to diarists. These are well recognised in sociological and health literatures, e.g. how to deal with different degrees of disclosure (Denzin 1989); the insider/outsider dilemma of positioning [a?] fieldworker within the respondent’s household (Gubrium & Holstein 1990); the power relations within the research process (Stanley & Wise 1993) and the difficulties of achieving informed consent (Homan 1991). Overall however, we suggest that the duration and intensity of the research process in this study nurtured trust between researchers and respondents, which we believe lies behind the very high commitment of respondents to the study.

Mindful of this trust, we proposed to discuss consent on an individual basis with research respondents, preferably in their own homes. We ‘piloted’ the consent forms with four respondents. The research team made initial contact via telephone and arranged home visits. The respondents had been sent an ‘Archiving Fact Sheet’ and related information via the study newsletter. Each visit lasted about an hour and covered the following:

- Ensuring that the respondent feels the s/he has been given enough information to make informed choices (referring to the ‘Fact Sheet’ and other sources);
- Emphasising that proposed archives are accessible to the public and that respondents are invited to make direct contact with the archivists if they wish to do so;
- Exploring anonymity and confidentiality issues (what do these mean?; what can we realistically guarantee?);
- Exploring ownership and copyright issues (e.g. whilst respondent assigns ownership of their data to the archive, they retain copyright and hence use of their material is subject to the terms of agreement which are stipulated in the consent form);
- Discussing access issues (e.g. can potential users have immediate access to the archived material or would the respondents request an embargo);
- Asking if respondents would like to retain original, photo-stated or electronic copies of their diaries and interview audio tape;
- Discussing user issues (the consent form states that the archived material will be used by researchers and the public for ‘scholarly and educational purposes’. It cannot be used for commercial or profitable gain);
- Explaining why there are four consent forms which apart from differentiating between the diary and the audio materials are duplicates. There are separate forms for the diary and the audio material in order to give the respondent greater flexibility of choice (so may choose to archive the diary but not the audio tape). There are separate forms for the proposed local and national archive.
- Explaining that audio material includes individual audio taped interview and audio taped group meetings.
- Asking the respondent if they have concerns that the research team has not raised.

The researcher then invited comment on the proposed consent form using the following questions as guidance:

- Is it easy to read?
- Does it make sense?
- Does it give you a good range of choices?

It was also explained why a signature and a witness to that signature was required (it is a legal document).
All four respondents who took part in the pilot stage suggested that the information given and the archiving discussion, made the consent form ‘easy to follow’. We feel that such detailed discussion is crucial if we are to inspire confidence in how our archive is to be stored, managed, retrieved and used.

What we now faced was preparation of the data for archiving and for secondary use. We needed to anonymise, removing identifying information from the data, without stripping context in such a way as to render the telling meaningless. As we have written elsewhere (Bailey et al 2003), such telling, reveals indexical recollections of FMD (references to concrete events in time and place), so that the stories themselves become framed by local and cultural understandings of these events. In this way the context of storytelling may embody both personally meaningful accounts of trauma and recovery and the localised, cultural context of experience. We also needed to consider how best to share the larger story (such as indexical events); to open up particularities (e.g. ‘insider’ language) so that secondary users of the raw materials of our research, might gain both methodologically and substantively rich insights. In the next section we reflect upon the theoretical and methodological challenges of attempting to preserve the data’s rich context while removing information that potentially could identify research respondents.

**Context and Anonymity**

**Anonymity**

Our study respondent consent form clearly sets out an ethical framework for research practice:

> Everything that I tell you will be held in the strictest confidence. Some of the information that I give you may be used in reports and articles, but my identity will remain anonymous (my name will not be given).

Subsequent consent forms for archiving state that ‘anonymised (you will not be named)’ respondent diaries and audio material will be archived. In practice of course it is almost impossible to guarantee lifelong anonymity. A few of the study respondents were not unduly concerned about anonymity:

> Name me and shame them!

(Respondent’s remark during archiving discussion)

The above quote reflects the anger that some respondents felt towards the UK Government’s perceived mishandling of the 2001 epidemic as outlined in the introductory section. An early paper by Shulman (1990) who carried out research in an educational setting contends that researchers need to think about anonymisation in relation to respondent positioning. Being ‘protected’ and ‘hidden’ may render the respondent powerless rather than give them as equal a voice as that of the researcher. Certainly we could say that for some of our respondents, participating in this research was possibly one way of giving voice to their experiences of perceived mishandling and its devastating consequences. Indeed we organised a large public conference to discuss our interim findings wherein some study respondents gave very public and powerful testimonies. This attracted local and national media coverage and some of these respondents later gave press interviews.

For the majority however, there was concern about anonymity and confidentiality, not only for themselves but also for their immediate family, friends, work colleagues and wider community. Many of the study respondents lived within close-knit rural communities. What they do within their jobs, how they live their lives, the geography of where they live may make them easily identifiable. Perhaps surprisingly, in view of the fact that at certain stages of the epidemic people working for Department of Environment, Food and Rural Affairs (DEFRA) had to sign confidentiality agreements, some of the front-line workers who have permanent careers in government agencies were unconcerned about being identified. One wrote beneath his signature on the archiving consent ‘and I am happy to be identified.’ In contrast perhaps, it is a measure of the linear and
The geographical continuity of farming life, that one farming respondent cited as a reason for not archiving, that they wished to protect their children from any future repercussions that might come from criticism of officials in the interview and diary. Health workers in particular were reluctant to archive and were worried about the possibility of their clients being identified even though they had been careful never to name them when they referred to their problems. They explained that in small communities it takes very few clues to establish someone’s identity. It is for reasons such as these that some respondents chose to embargo their diary, their interview, or both, for a period of 20 years.

Using their own experiences of a five year programme that involved the secondary use of qualitative data sets from a range of projects across Canada, Thomson et al (2005) assert that whilst qualitative anonymisation usually centres on ‘telling a story without telling whose story it is’, a plethora of literature also warns of removing identifying details in such a way that the original story becomes distorted (see for example Heaton 2004). Thomson et al (2005) suggest that a key issue here is researcher(s) perspective on what has to be retained and what needs to be anonymized. They also suggest that research team consensus is not always easy to achieve. Certainly for us and as a team of four deciding what to replace, change or in some cases remove, working out a rationale for this was very challenging.

We also had to consider different types of data. We collected handwritten diaries which were word processed for a digitised archive. We also audio recorded interviews, both one to one and in a group discussion. For exhibition purposes, we have also produced an ‘audio montage’, a series of extracts from the individual interviews that illustrate the study findings through the words of several respondents. Whilst anonymising word-processed documents is straightforward, paper sources require erasing or blocking out of text. In terms of audio material, there is the possibility of voice recognition. Our collaborative and democratic process of archiving meant that we could accommodate individual respondent wishes. For example one respondent chose to remove a portion of their diary; another requested her voice to be electronically adjusted.

We then had to reach consensus about how best to anonymize the data set as a whole and in a way that considered respondents’ needs, secondary users’ desires and practical resource constraints. Reading and anonymizing more than 3000 weekly diaries and listening to and editing in excess of 50 interviews and six group discussions is a mammoth task. Our criteria for anonymization centred on removing unwitting identification and that which may be deemed libellous or cause unnecessary distress. Scenarios include where:

- respondent names themselves (surname);
- respondent names another, possibly detrimentally;
- respondent names another respondent (knowingly and unknowingly);
- local people named and associated with local contentious events;
- local companies spoken of detrimentally;
- confidential information given about local person/s/company;
- specific place names coupled with respondent’s job, may make it easy to identify respondent;
- interviewer/s and respondent discuss/es group discussion and other respondents mentioned by Christian name

Such anonymization is complex and very time consuming. Trying to strike a balance between protecting study respondents and retaining useful context, particularly for secondary use, inevitably entailed a struggle between ethical and methodological concerns. Thinking about context involved not only considerations about how not to strip out the story along with potentially identifiable features but also how best to open up the richness of situated ‘insider’ story telling
Making sense

A key question for us was, how does an ‘outsider’ make sense of the particular context of a data set, both shared lexicons and shared linguistic terms around farming and rural language? The language has nuances of difference. For instance, there is a language that is agriculture-specific: ‘holding number’ refers to the unique identification number for all agricultural holdings in the UK. There is also a language that is locally agriculturally specific: a ‘ewe’ becomes a ‘yow’, a ‘ram’ is a ‘tup’ or ‘tip’.

In an early group discussion this ironic exchange illustrates the frustration felt when movement-licensing officials did not understand local terminology:

D. This is what you were up against.

J. There’s no way they’d know what a clouted twinter\(^6\) was.

The study focuses on Cumbrian farming and rural communities and as such is replete with local agricultural terms which, we suggest, give both audio and textual data a localised geography and history. Agricultural terms are often specific to area: a ‘byre’ in north Cumbria would be called a ‘shippon ’ 50 miles further south, a ‘steading’ in the north becomes a ‘yard’ in Furness, even tools and boundaries will have different names according to geography. Whilst such context may seem incidental to larger FMD stories, it nevertheless situates those stories in a landscape and culture that may already have felt itself at some remove from the rest of England and which felt further marginalized by the epidemic of 2001:

It was just like we were in the middle of nowhere, London was miles away

(respondent interview, February 2002)

One way of sharing this language is to offer explanation via footnotes. This raised more questions. Who's going to footnote? Do we do it? Do we ask the respondents to help? Do we note distinctive, very localised differences? We were fortunate in that one of the research team has first hand knowledge of farming and of Cumbrian dialect and thus could tackle this, although we had to be pragmatic about how much footnoting we could realistically accomplish.

We have also written about context in relation to the interplay between what is being told and how it is told, what Gubrium & Holstein (1998) refer to as ‘meaning in practice’ (see Bailey et al 2003). Respondents’ telling of their FMD experiences: their retrospective telling in the in depth interviews and their subsequent 18 months of diary keeping, needs to be understood in the context of shared experiences that are woven into everyday social relations and lifescapes. As Bearman & Stovel (2000: 74) indicate, individuals tend to be embedded in relatively dense clusters of social relations in which the values that they hold and their sense of self are shared by and shaped by others with whom they interact. Thus shared FMD language may be used as a code or shorthand that, when understood, opens up substantive or contextual institutional and cultural conditions that have shaped the experience and lived reality of the storyteller. Our study respondents’ FMD narratives may be an attempt to find meaning, to organise and make sense of extraordinary and, for many, traumatic events. Shared language, perhaps only makes sense to those who have also shared the experiences: experiences that such language attempts to represent. As one respondent commented:

it’s one of these things that nobody can understand what we have been through unless they have been through it with them

(Front line worker, interview, 2002)
We have shown how there is already a dialect tradition in Cumbria which is particularly strong in the farming community where it is part of everyday speech and nomenclature. This ongoing use of occupational language easily adopted the new terminologies associated with FMD.

Just as new language becomes familiar in times of war (‘scud,’ ‘precision bombing’, ‘embedded correspondents’; ‘collateral damage’), so the interviews and diaries testify to an FMD specific vocabulary:

**equipment** – washers, low-loaders, load-alls, bolt-guns;

**places** – Page Street, Rose Hill, Great Orton, Hespin Wood;

**people** – Nick Brown, ‘the Brigadier’, field officer, MAFF, (later) DEFRA, Snowie’s, Armstrongs;

**the process** – washing out, C ‘n D (cleaning and disinfection), going down, taken out, D notice/A notice, signed off, detox, damp down, culling, movement licenses

**new boundaries** – 3 kilometre zone, blue box, Penrith spur, contiguous premises, IP (infected premises), DC (Dangerous contact), ‘still standing’.

These phrases and the way in which they are used as a kind of shorthand become both a form of inclusion: ‘*them that was there knows the crack*’; and of exclusion: the language used to express a defining experience further separates the narrator from the reader.

> a line is drawn around the affected community that makes the people in it feel more different from the people outside the line and the people outside the line to feel more different than the people in

(Kai Erikson, Carlisle 14.10.03)

A sense of insider/out sider language may also, we suggest, reflect what some saw as the core of their frustration, the distance between the policy-makers and those who had to carry out the policy:

> It took until about half past 2, 3 o’clock the following afternoon to convince London we didn’t have foot and mouth. Now how the hell can anybody sat in an office in London be trying to tell this vet his job? I don’t know

(Farm, interview, 2002)

The new FMD vocabulary also captures pivotal events that happened nationally and that are taken for granted, discussed and deliberated upon, within the dataset. In order to open up such events and place them in the context of respondent recollections, we devised a timeline to cross refer between national/international/‘official’ events such as FMD related inquiries with events pertaining to respondents and the study, such as group meetings (Mort et al 2004 p. 24).

We also considered the balance between respondents’ experiences, the macro socio-political context of the 2001 FMD disaster and the implications of sharing that data in terms of not ‘fossilising’ the context, so that its richness may inform and be informed by related, relevant studies. Other regions for example were severely affected by the FMD disaster including North Devon, South Wales and Northumberland. There is also a lot of material that speaks to Disaster Management Studies, and we have worked closely with Professor Kai Erikson from Yale University who has been studying the effects of disasters on human communities for over 20 years. He highlights how their experiences need to be articulated and heard if communities are to maintain confidence in government, in society and in themselves.
We have struggled with the ethical and practical dilemmas that the process of archiving this data set has presented. Nevertheless we suggest that the opportunity to archive such rich material opens up the potential for new understanding and sensitive revisiting that is beyond the scope of more formal data presentation channels such as writing reports for study funders, papers for academic and policy journals and conference proceedings.

**Conclusion**

We have reflected upon how we set out to archive a large, sensitive, mixed method data set and how in so doing; we have tried to develop a collaborative and democratic process. The sensitivity lies not just in the stories that the data conveys but also, we suggest, in the context of the storytelling. The 2001 FMD disaster unfolded within a landscape and culture that may already have felt distanced from the rest of England and which felt further marginalized by the government handling and some public perception of the epidemic.

The statistics which appeared in the press during 2001 represent only the farms where infection was confirmed. Behind them are the huge unpublished numbers of culls which took place because of proximity or dangerous contact. Just as the explicit coverage at the time only told a part of the story so the study’s final research report to the Department of Health could, of necessity, give only an edited view of this massive collection of data.

Archiving may provide some scope for deeper exploration and thus greater understanding of such magnitude. As discussed earlier and illustrated by the work of the Mass Observation organisation, it may also offer a real life tool for further exploration of the everyday. Diary keeping captured 18 months of post FMD ‘recovery’ and generated a huge variety of responses, from those who tended to weave FMD references into their everyday reflections, to those who wrote about everything BUT FMD.

As we have discussed, achieving the balance between protecting respondents, certainly avoiding causing unnecessary harm and sharing the data set so that both content and context are richly available to the secondary user, has been challenging. There is, we contend, a ‘moral space’ beyond the archiving contract. We can’t know of all consequences. However we can strive for an ethically sound archiving contract. We can have ‘honest talk’ with respondents and discuss the limitations of ‘informed consent’. We can thus be morally responsible for being honest about the unknown. We know that trying to achieve democratic and collaborative archiving of qualitative data is a complex and risky process. We hope that in the future, we can look back and say that the rewards are worth the risk.

**Notes**

1. This study was undertaken by 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.

2. 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.

3. Anderson ‘Lessons Learned’ Inquiry secretariat 2002

4. The government agency responsible for dealing with the disaster was the then Ministry for Agriculture, Fisheries and Food (MAFF), now Department for Environment, Food and Rural Affairs (DEFRA).
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.

A maiden sheep that has had a patch of cloth sewn under its tail to prevent mating with a ram.

Towards the end of the study, a local conference was held in order to provide feedback to participants, practitioners and policymakers on the progress of the research. The research team had been reading the work of Professor Kai Erikson (Yale University USA.) on the human impact of disasters and were delighted when he accepted our invitation to speak at this conference. Professor Erikson has been studying the effects of disasters on human communities for over 30 years. He is the author of numerous books including *A New Species of Trouble: Explorations in Disaster, Trauma, and Community* (Erikson 1994).

### References

Anderson Inquiry (2002). ‘Foot and mouth disease 2001: Lessons Learned Inquiry’ Chair, Dr Iain Anderson, Cabinet Office.

Bailey C, Convery I., Baxter J., Mort M. (2003). ‘Narratives of trauma and on-going recovery: the UK 2001 foot and mouth disease epidemic’ *AutoBiography XI* (1&2): pp. 37-46

Bearman, P.S. & Stovel, K. (2000). ‘Becoming a Nazi: A model for narrative networks’ *Poetics*, 27: pp. 69-90

Convery, I., Bailey, C., Mort, M., Baxter, J. (2005). ‘Death in the wrong place? Emotional geographies of the UK 2001 Foot and Mouth Disease Epidemic’. *Journal of Rural Studies*, 21: pp. 99-109

Corti L (2000). Progress and Problems of Preserving and Providing Access to Qualitative Data for Social Research — The International Picture of an Emerging Culture *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* [On-line Journal], 1(3). Available at: [http://www.qualitative-research.net/fqs-texte/3-00/3-00corti-e.htm](http://www.qualitative-research.net/fqs-texte/3-00/3-00corti-e.htm)

Corti L, and Backhouse G (2000). ‘Qualitative Archives: Short Descriptions’

ESRC Qualitative Data Archival Resource Centre (Qualidata), University of Essex, UK *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* [On-line Journal]. Available at [http://www.qualitative-research.net/fqs-texte/3-00/archive/qualidata-e.htm](http://www.qualitative-research.net/fqs-texte/3-00/archive/qualidata-e.htm)

Cumbria FMD Inquiry Report, 2002. Inquiry Report, Cumbria County Council.

Denzin, N. (1989). *Interpretive Interactionism*. London, Sage.

Economic & Social Research Council (2001). *Green Paper on Data Policy and Data Archiving*
Erikson, K. (1994). *A New Species of Trouble*. New York: W.W. Norton & Company

Erikson K (2003). *Voices of Experience: life after foot and mouth disease* Interim findings from the Lancaster University health and social consequences of foot and mouth disease study, Carlisle Racecourse 14th October 2003

Graham, C. (2001). *Foot and Mouth Heart and Soul*. Small Sister.

Gubrium, J., Holstein, J. (1990). *What is family?* London, Mayfield.

Gubrium, J., Holstein, J. (1998). Narrative practice and the Coherence of ‘Personal Stories’. *The Sociological Quarterly* 39(1): pp. 163-187.

Homan, R. (1991). *The Ethics of Social Research* London: Longman.

Mort, M., Convery, I., Bailey, C., Baxter, J., (2004). *The Health and Social Consequences of the 2001 Foot & Mouth Disease Epidemic in North Cumbria*. Report to the Department of Health, Lancaster University. Report Ref: 121|7499.

Mort, M., Convery, I., Baxter, J., Bailey, C (2005). ‘Psychosocial effects of the 2001 UK foot and mouth disease epidemic in a rural population: qualitative diary based study’. *British Medical Journal* 31: p. 1234 (26 November), doi:10.1136/bmj.38603.375856.68 (published 7 October 2005)

QUADS (2006). QUADS Website LINK * [http://quads.esds.ac.uk/](http://quads.esds.ac.uk/)

RMP (2006). RMP Website LINK * [http://www.ccsr.ac.uk/methods/](http://www.ccsr.ac.uk/methods/)

Shulman, Judy H. (1990). ‘Now you see them, now you don't: Anonymity versus visibility in case studies of teachers’. *Educational Researcher, 19*(6):pp 11-15.

Stanley, L. Wise, S. (1993). *Breaking out again: feminist ontology and epistemology*. London, Routledge.

*Thomson D, Bzdel L, Golden-Biddle K, Reay T & Estabrooks C (2005). ‘Central Questions of Anonymization: A Case Study of Secondary Use of Qualitative Data’. Forum Qualitative Sozialforschung / Forum: Qualitative Social Research [On-line Journal] 6(1). Available at [http://www.qualitative-research.net/fqs-texte/1-05/05-1-29-e.pdf](http://www.qualitative-research.net/fqs-texte/1-05/05-1-29-e.pdf)*

Thompson, P (2000). ‘Experiences of Re-analysing Data in Qualitative Research’ [48 paragraphs]. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research* [On-line Journal], 1(3). Available at: [http://www.qualitative-research.net/fqs-texte/3-00/3-00thompson-e.htm](http://www.qualitative-research.net/fqs-texte/3-00/3-00thompson-e.htm)

[I’ve rationalised spacing and quotation marks, using single ones throughout, used indented quotes without quotation marks and indented them on both sides, in line with the other papers]